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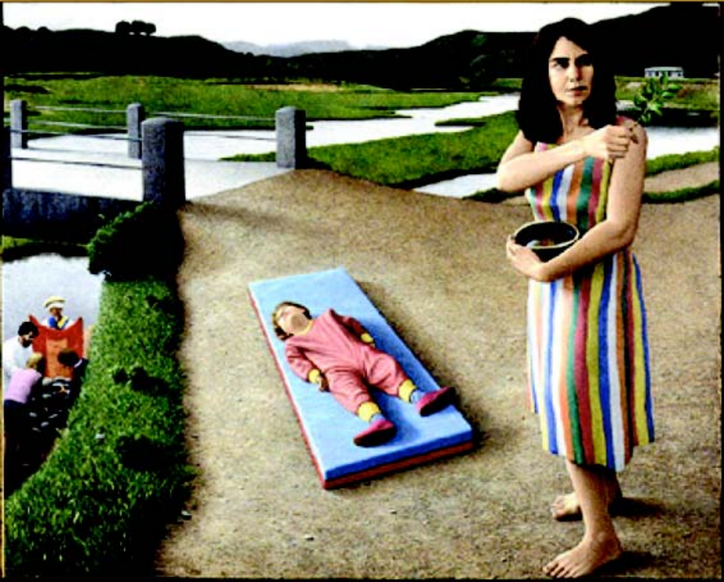
ENCYCLOPEDIA OF DISABILITY



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ENCYCLOPEDIA OF
DISABILITY

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INTRODUCTION

Gary L. Albrecht, General Editor

It has become a commonplace to claim that disability is on the rise in the modern world. Such recognition arrives as we and our families age and modern medicine ensures the viability of children who, only a few decades ago, would not have lived into adulthood. Those who sound this alarm would seek to spoil our attachments to more progressive historical models in which disability, apparently, does not take part. As a marker of our contemporary "decline," one might cite the predictable "nicks and dents" of aging now compounded by the obesity epidemic with concomitant rises in diabetes, osteoporosis, and heart disease. Asthma is often identified as one of the leading disabling conditions resulting from urban growth and environmental pollution. Furthermore, it would be truthful to observe that the upsurge in wars and civil strife around the world has produced millions of men and women who have been permanently injured by land mines, machetes, bullets, bombs, and beatings. Similarly, in developing countries, one might also argue that populations continue to experience the ravages of presumably eradicated diseases such as tuberculosis as well as newer epidemics such as HIV/AIDS. Finally, given the stresses of contemporary life in industrial and developing countries alike, depression has become the number two cause of disability in the world.

Yet this catalogue of contemporary disability sources does not touch on the true significance of disability, particularly with respect to the degree to which people with disabilities exemplify the dynamic variability, vulnerability, and mutability that exist across individuals, populations, cultures, and histories. Perhaps the most surprising observation of all is that disabled people persist in record numbers despite continuing prophecies from medicine, genetics, and rehabilitation about the ultimate eradication of congenital and acquired impairments. In this post-eugenics era, disabilities remain with us but the lived experience of disability has undergone radical changes. Consequently, at its most basic level, the *Encyclopedia of Disability* serves as a reminder that regardless of who we are, where or when we live, disability is with us.

Based on this perspective, the *Encyclopedia of Disability* was conceived as an effort to bring current knowledge of and experience with disability across a wide variety of places, conditions, and cultures to both the general reader and the specialist. An encyclopedia is an introduction to a topic that leads a reader through subjects of interest to greater depth and breadth of understanding and provides the reader with a road map to other sources of information. In this work, the entries, bibliographies, websites, search strategies, cross-references, chronology, visual images, and primary source (original) material will conduct the curious reader along a path to a clear understanding of the definitions, fundamental concepts, basic history, diversity, cultural contexts, experiences, health care issues, environmental constraints, helpful accommodations, social movements, laws and policies, and theories and practices in the disability arena. Furthermore, the encyclopedia seeks to demonstrate that our largely negative view of disability must be challenged by the significant contributions to all cultures made by disabled people and committed allies—in art, in politics, in cultural production, in private and public life. May this encyclopedia improve the reader's understanding and appreciation of the world of disability.

The *Encyclopedia of Disability* was conceived in a broad context. While there has been much research on disability, the research presented in these volumes has usually been approached from an interdisciplinary perspective whenever possible and broken into manageable topics for investigation. For example, the descriptions of public health show how it aims to improve the quality of life by minimizing the effects of diseases, living conditions, work, and the physical and social environments on mortality and disability. The discussion of medicine focuses on diagnosis of disabling conditions, prevention, and treatment. A number of entries describe the multitude of therapies that are designed to operate individually and in concert to return disabled people to as full and complete a life as possible. The overview of rehabilitation engineering concentrates on assistive technologies aimed at accommodating the environment to the individual and the individual to the environment. Disability studies refuses the equation of disability with inferiority and instead aims its analytical lens at the social obstacles that produce disability as a devalued experience. To do so, disability studies examines the definition, meaning, and representation of disability in various social and cultural contexts by incorporating the voices of disabled people and disability communities into the discussion. The history of medicine's contribution is in placing medical conditions and disability into a historical and cultural context to unveil the shifting determinants of disease and difference. Contributors from the fields of sociology, psychology, and anthropology apply analyses that help us better understand disability as a product of interactions between bodies, environments, and belief systems. Economists draw our attention to the monetary and social costs of disability and the benefits of supporting disabled people and helping them reintegrate into society. Lawyers, government officials, and policy makers consider how the modern state can best respond to the reality of variation across populations. Philosophers and ethicists ponder the value of human life, physician-assisted suicide, and human rights to test contemporary culture's commitment to all citizens despite ability levels. The encyclopedia also demonstrates that disabled people and their families are concerned with how they can exercise full citizenship in a society, have a high quality of life, and contribute as active members in a world that often rebuffs such efforts.

The idea for the *Encyclopedia of Disability* was hatched during 1999–2000 in conversations with Rolf Janke of Sage. The intent was to provide a resource that would be available in all of the major libraries of the world to scholars, disabled people, disability advocates and allies, and the general public. To be useful to a wide audience, the encyclopedia needed to have breadth and depth and be written for a general audience. The project was also an opportunity to encourage creative people in different but related fields, all interested in disability, to talk with each other. Another desideratum was to make the encyclopedia as international as possible since disability is an issue that knows no national or cultural boundaries.

After signing the contract for the encyclopedia on September 10, 2001, an international editorial board of 74 editors from the Americas, Europe, Australasia, India, Japan, and China, who were all experts in their own subfields of disability, was constituted. After much discussion, the members of the editorial board and the publisher agreed that the encyclopedia would span five volumes: four consisting of alphabetically listed entries and a fifth composed of primary source materials representing the field of disability broadly defined across history and cultures. Volume V is organized into chronological categories that allow the breadth and depth of cultural thinking about disability to become evident for the first time.

The task of identifying the entries to appear in the encyclopedia was the next exercise in creativity. The major journals, books, government documents, and Web-based disability discussion groups in the world were searched for themes and topics. These were organized into lists and circulated. The editors iteratively added terms and suggested authors. The authors, in turn, often proffered other terms and authors. Great effort was taken to have a considerable number of authors from outside North America to provide balance to the work. Another source of global representation was to include internationally focused entries on most of the key concepts in the encyclopedia and to provide cross-cultural examples wherever possible. Yet, even in the wake of these commitments to achieve an international representation of disability, the encyclopedia cannot claim to be exhaustive to any degree. Because of the global, historical, and conceptual reach of the *Encyclopedia of Disability,* it is virtually impossible to cover every topic, person, and event. This is a mere introduction in many ways to myriad differences that characterize the world of disability. The editors decided to organize the entries hierarchically from large crosscutting concepts such as disability models to smaller entries such as those on individual people. At this point, the editorial board was divided into areas of expertise such as health and medicine, mental illness, cultural studies, rehabilitation, disability studies, rehabilitation engineering and assistive technology, law and social policy, and history, and teams were formed to oversee and deepen these areas and headwords.

A list of suggested authors for all of the terms was then formed and authors were invited to participate. With few exceptions, the editors and authors who were invited to participate in the project eagerly did so; all were experts in their own areas. Each entry is based on the personal expertise of the author, and further readings and websites are listed at the end of most entries. The draft of each entry was reviewed by the editor in charge of that group, by the general editor, and in the case of the more important or contentious entries, by other reviewers as well. Revisions were made based on these comments. At a later stage, entries were cross-referenced with other entries in Volumes I through IV to guide the reader in an exploration of a topic.

The covers of the five volumes were selected to represent disability in various historical periods and cultural settings. The jacket art provides an index to the cultural, historical, and representational diversity of disability imagery. The cover of Volume I, *Tree of Hope—Stand Firm!* (1946), portrays one of Frida Kahlo's many self-portraits as a disabled Mexican woman of color. In the painting, her identity is split. One image proudly holds her back brace while the other image portrays her impairment as if exposed as a medical specimen. The cover of Volume II, by Hieronymus Bosch, *Extraction of the Stone of Madness (The Cure of Folly)* (ca. 1475), depicts a fifteenth-century representation of treatment for mental illness in medieval Europe. The portrait assembles all of the constituent professions of the time—barber, friar, nun—as they treat a patient who looks out anxiously toward the audience as a tulip is extracted from his head. The cover of Volume III depicts the Chinese physician Hua T'o as he seeks to heal necrosis on the arm of the warrior Guan Yu in the fourteenth century. The work, created by the famous Japanese printmaker Utagawa Kuniyoshi in 1853, emphasizes the disparity that exists between social rituals of gaming that continue even as one receives serious medical attention. The cover of Volume IV, showing the early-fifteenth-century Nigerian King Oba being supported by his two personal assistants, captures the king's effort to explain sudden paralysis in his legs. Rather than confessing his incapacity, Oba argues to his subjects that he has become one with the revered mudfish of his day that walks on land and swims in water. At a time when physical, sensory, or cognitive disability in a king could mean expulsion or execution, the bronze demonstrates the necessity of quick thinking that often must accompany disabled persons' ability to fend off violent social tendencies. Finally, the cover of Volume V, *Beacon (Bless the Bastard)* (1991) by contemporary U.S. visual artist Tim Lowly, represents a mother deflecting the discomfort of a society unprepared to accept her disabled daughter in a common public context. In contrast, the multiply disabled daughter appears to revel in the sun while possibly imagining alternative futures for herself yet to be thought by the adults around her.

Taken collectively, the jacket images provide viewers entry into the diversity of cultural responses to, and portrayals of, disability at key moments in history. They become a patchwork of moments in the growing mosaic of our understanding of disability as a historical, cultural, and global phenomenon. In addition, there are more than 100 images related to disability in Volume V. These images illustrate the powerful representation and symbolism of disability in diverse societies.

The use of language and concepts is an issue in an international encyclopedia. Disability is often referred to by different terms and concepts. Rather than forcing each contributor to use the same language, the editors decided to let the authors use the terms and concepts of their culture but to explain them when necessary. This preserves the multicultural flavor of the enterprise. Likewise, when authors were writing about contentious issues, they were encouraged to present the various positions and their rationales. In terms of language, for example, the reader will see "persons with disabilities" and "disabled persons." "Persons with disabilities" is preferred by those who favor "people first" language capturing the importance of the individual in society, and disability as being something *not* inherent in the person. "Disabled persons" is a term used in the United Kingdom and Australia emphasizing minority group identity politics where community and group identity are forces that can be employed to fight oppression experienced in the physical and social environment. Other authors consider disability to be best understood in terms of human differences that should be accepted as such rather than as being seen as regrettable deficits. This position stands against the background where specific disabilities have taken on positive and negative meanings in various cultures. For example, in some societies, blindness has been associated with the characteristics of wisdom and prescience, which are valued, whereas AIDS and leprosy (Hansen's disease) are often stigmatized.

The Reader's Guide classifies entries into twenty-five thematic categories. In addition, the materials in Volume V are listed in the Reader's Guide to enable readers to integrate the content of entries with the primary source documents in Volume V. To put the concept of disability in a historical and cultural context, a chronology maps disability across time, culture, and geography and is repeated at the end of each volume.

"Searching for and Evaluating Websites," by Anne Armstrong, a University of Illinois reference librarian, describes how to use the references at the end of the entries, how to access and use websites related to disability, and how to assess whether websites and their content are credible. This valuable research tool appears at the end of each volume. In addition, throughout the encyclopedia there are listings of print and electronic references to government documents and data that are rich resources to investigate how disability is measured and treated on an international level. There are government documents that can be accessed over the Internet by just entering the keywords "disability" and the name of the country. The International Monetary Fund, World Bank, United Nations, and World Health Organization also are fine sources of data and policy initiatives related to disability, much of which can be accessed over the Internet.

May readers discover that the *Encyclopedia of Disability* provides a fascinating entry into the world of disability where minds are expanded, prejudices shattered, and spirits raised. The range of interrelated resources is designed to stimulate curiosity and encourage readers to move back and forth through the five volumes to pursue their interests. Internet references and search strategies assist the user in entering a larger world of online disability resources that are continually being updated and expanded. The encyclopedia is composed as a multidisciplinary, cross-cultural, and historically grounded resource tool that should lead the reader across fields, theories, debates, and practices. The experience of exploring the encyclopedia should answer the questions: What is disability, and why is it important in my life?

ACKNOWLEDGMENTS

The *Encyclopedia of Disability* is the result of an enormous worldwide, multidisciplinary effort that took six years to conceive and execute, involving 74 editors and more than 500 authors from over twenty countries. The work is the result of lively interactions at conferences, seminars, and editorial board meetings conducted over a cup of tea or a glass of wine, through email, and on conference calls. In many cases, the colleagues, students, and staff of the editors and authors in various parts of the world became support systems and sounding boards for component pieces of the project. Because of the size and complexity of the encyclopedia, it is impossible to recognize everyone who directly or indirectly contributed. Nevertheless, we express our deep gratitude to all of these researchers, colleagues, disabled people, advocates, students, government officials, and policy makers who made this incredible project happen and who stimulated others through their knowledge and resourcefulness.

The idea for the *Encyclopedia of Disability* was conceived during 1999–2000 in conversations with Rolf Janke of Sage Publications, who provided the inspiration, support, and considerable Sage resources that made the project possible. He was ever present to solve problems and enthusiastically support creative ideas. Developmental editor Sara Tauber and project editor Diana E. Axelsen cheerfully kept the production process moving along, Ravi Balasuriya worked his magic on design and layout, and Michelle Kenny helped with the design of the cover and the marketing materials. Kate Peterson led a team of copy editors that included Rachel Hile Bassett, Judy Selhorst, Gillian Dickens, Jenny Withers, and Barbara Ray. Leticia Gutierrez served as reference system coordinator, and Carmel Withers coordinated the marketing campaign and played a key role in shaping the look and feel of the marketing pieces. The index and reader's guide were prepared by Mary Mortensen, Alicia Merritt compiled the chronology, and Sandra Ng Sauvajot assisted with graphics. The C&M Digitals staff produced handsome typeset pages while also meeting the challenge of a tight production schedule.

The senior editors comprised a remarkably productive team that was involved in developing the headword list, generating an international list of authors, inviting authors, reviewing and editing manuscripts, and adding their wisdom and creativity to the project. Their high standards, diversity of background and opinions, broad-ranging circle of international contacts, and insights into the critical issues of the field enriched the final product. Jerome Bickenbach, a philosopher and a lawyer, kept us internationally oriented and focused on the critical legal, governmental, social policy, and moral issues in the disability world. David Mitchell, Sharon Snyder, and their students introduced us to an extensive social network in the arts and humanities and were continual sources of creativity. Sharon Snyder also served as the illustrations editor for the project and compiled a wonderful catalogue of visual images from which the five covers and more than 100 illustrations included in Volume V of the *Encyclopedia* were drawn. Walt Schalick brought the wisdom and insight of a researcher, practicing pediatrician, and medical historian to the group, tempering his standards of excellence with a disarming sense of humor. He organized formidable sets of entries in medicine and history. Scott Brown added a clear understanding of the complex world of national and international government agencies and nongovernmental organizations that deal with disability, especially in the areas of education and employment. Dudley Childress opened up the world of rehabilitation engineering and environmental modifications by organizing the entries and recruiting authors in these areas. Joe Flaherty is a renaissance man who marshaled an interdisciplinary team to address mental health issues related to disability in historical, social, and cultural contexts. His enthusiasm and humor energized the team. Allan Heinemann brought the perspective of a health services researcher to the endeavor, putting disability concerns in the context of health service delivery systems and coordinating these entries. Tamar Heller tapped her extensive international network in aging, intellectual disabilities, and the family to bolster and coordinate the entries in these areas. She also graciously put the resources of the Department of Disability and Human Development at the University of Illinois at Chicago behind the project, which played a major role in making the project feasible. Chris Keys brought the forces of numerous psychologists, community organizers, and advocates to bear to produce a set of entries on disabled people in the community. In Sydney, Trevor Parmenter and his staff offered numerous insights into disability issues in Australasia, coordinated the entries from Australia and New Zealand, and supplied advice in the area of intellectual disability. Tom Shakespeare and Mairian Scott-Hill grounded the encyclopedia in the United Kingdom by bringing their historical and cultural perspectives to the work and adding to the voice of disabled people. They suggested important topics and authors and organized many of the entries from the UK. Henri-Jacques Stiker managed the "Paris Bureau," where he employed his vast knowledge of disability history and representation to develop a set of entries capturing disability issues and figures in the Francophone world.

The sixty International Advisory Editorial Board members from sixteen countries helped add valuable perspectives, diversity, and depth to the work by suggesting entries and authors, reviewing manuscripts, and writing entries. The authors themselves were another source of ideas and perspectives. In addition, many other colleagues eagerly engaged in debates, offered ideas, and reviewed individual manuscripts.

The home base for the encyclopedia was Chicago. At the University of Illinois at Chicago (UIC), the faculty, staff and students of the Department of Disability and Human Development gave unwavering support, advice and intellectual contributions throughout the entire project. Michelle Jarman, Leslie Chapital, and Maitha Abogado provided the office infra-structure that kept the proposals, packages, and images moving and communications clear. Graduate students in the Disability and Cultural Studies Unit at UIC, including Sara Vogt, Mike Gill, Heather Stone, Shilpaa Anand, Carlos Drazen, and Eunjung Kim, oversaw the conversion of textual documents into electronic files and collated many of the materials, particularly for Volume V. Both Sara Vogt (UIC) and Ingrid Hoffmann (University of Minnesota) applied their expertise and linguistic knowledge to the translations of many international entries. Mike Gill and Heather Stone provided integral support to the illustrations editor in compiling and reproducing visuals for the project. Finally, we would like to extend a special acknowledgement to Chicago-based visual artists Riva Lehrer and Tim Lowly, who have generously donated the use of their art work and expertise in the formation of the encyclopedia.

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In Paris, Jean-François Ravaud and Catherine Barral assisted Henri-Jacques Stiker in organizing the

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Over the years, Arthur Falek showed us how human genetics influence disability discussions, John Basmajian pioneered our understanding of biofeedback, J. Richard Udry and Naomi Morris demonstrated how biology and behavior are intimately related, and Henry Betts provided countless opportunities for people in the disability world. Each in their own way, Colin Barnes, Vic Finkelstein, Mike Oliver, Ed Roberts, and Irv Zola were pioneers who influenced us and helped shape the development of Disability Studies as a field. David Braddock founded the Department of Disability and Human Development and Ph.D. program in Disability Studies at the University of Illinois at UIC, which formed the environment that made this work possible. Disability experience was infused into the encyclopedia through the editors and authors who were themselves disabled or who were parents, children, and family members of disabled people. Members of disability organizations and advocacy and self-help groups provided another source of input for the disability voice. As the work was being conceived, focus groups of disabled people who were neither activists nor academics were also conducted to ascertain what they considered the critical concerns of the disabled to be. Sadly, five major figures in the disability movement passed away during the course of the project: Peter Abberley, Tanis Doe, Ron Mace, David Pfeiffer, and Mairian Scott-Hill. Each energetically contributed to the planning and creativity of the work before their untimely deaths. We express our gratitude to these members of the disability community who contributed in their own special ways to this project.

Sabbatical leave to Nuffield College, The University of Oxford and to Maison des Science de l'Homme, (MSH), Centre de Recherche Medicine Sciences Santé et Société (CERMES), and Centre Techniques National d'Etudes et de Recherches sur les Handicaps et les Inadaptations (CTNERHI) in Paris gave Gary Albrecht the time and scholarly environment to imagine the project, engage colleagues, and explore ideas. At Nuffield College, Anthony Atkinson, Ray Fitzpatrick, David Cox, Richard Breen, John Goldthorpe, and Christopher Wlezien set a scholarly example and encouraged creativity. Steve Winyard showed how to bridge the gap between research and policy. In Paris, Jean-Luc Lory and colleagues at MSH again offered a stimulating environment in which to think and write. Martine Bungener, Isabelle Baszanger, Henri-Jacques Stiker, Jean-François Ravaud, Catherine Barral, Isabelle Ville, Michel Fardeau, Janine Pierret, and Sebastien Dourteligne were colleagues who opened the door to French history and work in disability. The Robert Wood Johnson Foundation provided funding to one of our Senior Editors, Walt Schalick, for historical research on disabilities.

In sum, an enthusiastic team of researchers, disabled people, activists, and policy makers representing global social networks in multiple fields made this work possible. We dedicate the *Encyclopedia of Disability* to those people around the world whose lives have been or will be touched by disability. Finally, we thank our families and colleagues who provided their steadfast encouragement and heartfelt support during this difficult but rewarding project.

ABOUT THE ENCYCLOPEDIA COVERS: VISUALIZING VARIATION

Sharon L. Snyder

The five covers for the *Encyclopedia of Disability* represent a selection of artistic impressions across a range of cultures, time periods, and multiple disabilities. They also render some of the unique orbits for the complex relationships that disability experiences provoke. Each is purposively nontragic and discourages pathos or too easy sentiment. Instead, the covers emphasize the creative and self-inventive side of disability experience. All make disability a window onto diverse landscapes for the body different.

Taken collectively, they may even suggest an odd refuge in disability—the degree to which incapacities can be viewed as protecting us, and motivating creative agency, even as they may render us most vulnerable. Perhaps someone such as Frida Kahlo, who lived so intensely in her body, could identify the lure of incapacity to this extent. She wrote in her diaries:

> We take refuge in, we take flight into irrationality, magic, abnormality, in fear of the extraordinary beauty of truth of matter and dialectics, of whatever is healthy and strong—we like being sick to protect ourselves. Someone—something—always protects us from the truth—Our own ignorance and fear. (*The Diary* 1995:248–249)

Thought about in such a way, disability no longer means a condition, an incapacity, or lack that belongs to a body, but rather a product of the interactions between self, society, body, and the variety of interactions (from political economies to personal commitments) that they engender. Disabled bodies, then, are artifacts—found or experienced while saturated with the meaning of our own investments, concerns, hopes, and insignificance in the world.

That the relations precipitated by human differences so often become detrimental to people with disabilities, turning even families or institutions devoted to their care into warehouses or danger zones, does not lessen their significance. Analysis of disability from a social perspective reveals the extent to which cultures prove creative at inventing endless varieties of human diminishment. In response, one finds counter-creativity demanded of disabled people. Their own livelihood, and sometimes their very lives, can rely on an ability to subvert supernatural views held about their conditions, contest medical fascination with their corporeality as "specimens," or spend years finding the means to escape confinement from back wards, closets, and institutions. The art depicted on the covers of this five-volume set, then, present us with this multisided nature of disability experience. Each portrays individuals both marked as undeniably different and actively transforming of the social terms of their reception.

The bronze sculpture of the Nigerian King Oba (cover of Volume IV) speaks directly to this idea of disability as urgently necessary renegotiation of the terms by which the nondisabled may see us. The king stands between the dual supports of his personal assistants with his mudfish legs on full display to the viewer. Rather than a story of personal diminishment by paralysis, the king explains his condition, contrariwise, as a deepening of his power. Mudfish represented a revered species in Nigerian culture at the time of this event. A king who awakens to discover himself immobile—particularly when the appearance of physical or cognitive disability in a ruler results, by law, in exile or execution from his subjects—can avert certain catastrophe only by such inventive quick thinking. Instead of concealing his paralysis, the king parades his body transformation before more lethal rumors can begin to circulate.

The Oba's explanation for his sudden mobility impairment draws directly upon insider understanding: Difference of form does not equate with absence of kingly capacity. Legs bow out and gradually modify into the heads and forelegs of the mudfish as the product of a powerful formulation of the meaning of body changes. The king tells his subjects that he can now pass between earthly and spiritual realms just as the mudfish navigate land and sea as half-reptile and half-fish. Circling the human figures, a series of four amphibian heads stare out as totemic sentries. The artist admires the flexibility of such an in-between space occupied by the Oba in his claimed role as a mediator now between human assistants and animal protectors.

Both Oba and artist participate in the recognition that variation exists across species and hence offers to us a rich array of explanations for the value of bodily configurations that might otherwise be cast out as undesirable. The sculpture posits continuity to natures, creatures, cohabitants, in a portrayal of paralysis: mudfish legs, human assistants with partially truncated torsos, pineapples, elephant trunk, snake, and swamp tangle. All life forms mesh in a symbiotic system of mutual belonging despite intense differences of capacity. Diversity teems across the bronze figure's vertical and horizontal axes. A celebration of varying capacities from human to animal culminates in the exhibition of Oba's bowing legs in order that variations across bodies in nature can provide context for a human body with paralyzed legs without a lessening of value.

The nineteenth-century Japanese triptych *Hua T'o Treating an Instance of Necrosis on the Arm of the Warrior Guan Yu* (cover of Volume III, 1853) by the famous printmaker Utagawa Kuniyoshi, depicts a historical event from fourteenth-century China. To the far left of the work we witness a surgeon, dwarfed in the presence of the massive body of Guan Yu, plying his trade in spite of the recreational distractions taking place around him. The physician, Hua T'o, meaning "miracle working doctor" (or "divine physician" based on the Japanese word *shenyi*), concentrates on a lesion eating away at the general's right arm. His localized treatment effort contrasts with the social frivolity portrayed in the rest of the painting. Medicine pursues its healing art as the world continues on indifferent to the work of bodily salvage. In this reading, we could situate ourselves as admirers of precise medical application as the "patient" stubbornly pursues other desires with a reckless lack of concern: Medicine works against time and gross inattention to attend to human vulnerability. We are situated as admirers of medical technique; the physician's perseverance is sustained in spite of activities that might prove distracting to the treatment effort.

Likewise, a viewer of the painting may also contemplate the work as a commentary on war. Bodies are wantonly exposed to violence and disability, disease, and death. Human wreckage is exposed as the primary product of militarized clashes between individuals, tribes, and nations. The painting depicts Guan Yu calmly receiving treatment following a battle wound caused by a poison arrow. The warrior ignores the cleaning of the wound down to the bone as an example of the power of the first administration of anesthetic. He has adopted an attitude that places his body as fully secondary to more immediate concerns, whether the task at hand is a battle or gamesmanship. In the unfinished disability play *The Deformed Transformed* (1822), the renowned Romantic poet Lord Byron, argued that masculine able-bodiedness seemed to require that men put their healthy bodies at risk of violation, as if they could not feel their lives as "real" enough without exposing themselves to the potential of disability. The thrill of physical threats pursued and then evaded. The painting of Hua T'o suggests a similar reading in that the development of necrosis suggests a near-gangrenous wound progressing to the point of a serious medical condition. A poor result might yield the loss of a limb or disuse of his arm because the general has refused to attend to the initial laceration in a timely manner. This patient inattention to the poisoning produces an even graver medical predicament. From this vantage point, a viewer might choose to indict the warrior's indifference to his own health concerns or grow further weary of war's destruction.

Alternatively, one may also glimpse a cultivated demeanor in Guan Yu's laissez-faire attitude toward medical attention. We might draw an interesting parallel to the experience of medicalization by disabled persons—particularly in the case of individuals who have spent significant time "under the knife." While medicine demands the full attention of the patient to participate in its own healing mission, those exposed to continuous medical care often refuse this singular attention paid to their bodies. Undergoing medical care requires a multitasking mission, or the rest of one's life comes to a full stop. In this view, we might think of medicine as the disruptive event against which the rest of one's life must be experienced. A certain capacity develops among disabled people to handle their other "business" as the medical industry rages around them. In fact, there's a form of patient *cool* where one refuses to allow a medical event to eclipse the myriad other demands on one's life—such an attitude can be found on display in the Kuniyoshi print as the game of Go continues in the face of surgery. In fact, the medical activity is reduced to a mere third of the triptych while the game occupies the remainder of the artist's interest. The social interaction requires as much seriousness as the presence of necrosis itself.

Likewise, Tim Lowly's *Beacon (Bless the Bastard)* (cover of Volume V, 1991) emphasizes independent coexistence among bodies occupying shared space. Rocks, river, grass, and other earthly elements populate the scene with an adult care provider and a disabled child positioned a few feet away. The two female figures, out of doors and beyond the traditional confines of domesticity, do not show shame or efforts to hide from the world's discomfort with disability. The caregiver looks off in the distance responding to some unknown force with a stem wielded over her shoulder in the gesture of a blessing. Behind and below the caregiver, a child (the artist's daughter Temma) lies on a bright blue pallet that cushions her from the ground—the same ground on which her mother's bare feet are firmly planted. The disabled girl's body, illuminated in the landscape and sprawled beneath the sky, wears a one-piece playsuit with socks and shoes, carefully swaddled despite the apparent warmth of the day. The relationship between the two figures, emphasized by the colors in the child's garment and repeated in the mother's striped dress, openly proclaims their identification. This is Temma's consciously placed residence in the world; she might be lying there contemplating a future yet to be articulated by the adults around her. The daughter's figure, aimed like a magnetic compass arrow toward the bridge in the upper left canvas, serves as a beacon to the artist, and, in this landscape, literally could be cast in a red outfit as if a signal translated from one location to another. The way a painter selects and places a subject onto a canvas in a highly self-conscious act parallels how Temma's caregiver has consciously situated her in this setting. In other works, Temma lies near a muddy puddle, a pond, on a day bed, across a desert floor, near a wooded river stream; her figure a geographic nomad yet without apparent mobility. These portraits capture Temma's vantage point as contemplative of universes unrevealed in ordinary landscapes—and strangely altered by the insertion of a disabled body. The historical absence of disabled people in routine places makes every appearance potentially transgress audience expectations. Conversely, every insertion undermines the belief that there are some places disabled persons should not go.

Just below the bridge, a small group clusters around a makeshift stone altar and, in a rather ritualistic manner, evokes a history of atonement practices. These ritualistic acts often occur in response to a mystery disability seems to evoke. Why me? Or what did I do to deserve this fate? Or what does this difference mean for the community? Are we culpable in some way? Piled stones reference all the hard things humans negotiate, arrange, and work with, just as the allegorical landscape offers hugely divergent elements, from spongy riverbed to wooden platform, to inhabit. Each formation seems to be selected for its yielding principles. Fjords—irregular land and water masses—remind us of the nonstandard geometries of embodiment and mirror the daughter's figure akimbo on land. Bodies of water and of land encroach on and define each other—clearly etched by nonregimented and unpredictable shorelines. The work on the makeshift altar occurs while the determined "blessing" of the mother above also redoubles as a fending off of outside forces and even our gaze, as viewers prying into a private scene. As if we must first fathom the precision of the mother's expression and gesture in the foreground before gaining access to the proceedings beyond her, she stands as a cautious gatekeeper before the rest of the painting.

The subtitle, *Bless the Bastard,* refers not to the child but to the concept of flinging back insults with a shield of mercy. The artist explains the idea as a matter of how one might bless those who curse one with additional punch. The mother's determined motions, her turning outward and her gesture toward the past, and her daughter's resident outside location, present them as participants in a fully parallel existence. The story of disability unveils that even the most ordinary outing requires a variety of self-conscious placements and protective gestures.

Finally, a white building perched near the skyline in the upper-right-hand corner recalls, as well, the Olson house on the upper horizon of Andrew Wyeth's famous painting *Christina's World.* As in the Lowly work, the house in Wyeth's painting also makes a young disabled woman's predicament into an allegory. The disabled figure in each work lies in the foreground staring off into the distance—relatively immobile or alternatively mobile in body but imaginatively engaged in future prospects unknown to, and unimagined by, viewers. In *Beacon,* the far-off residence appears like a temple amid a landscape that is filled with objects that catch a viewer's eye. Each item serves as a potential enhancement or barrier to navigation across it. Certainly, both disability paintings place a demand on the viewer to acknowledge these scenes as complete worlds. In them an ordinary morning scene, the forthrightly mundane world, is lent a hue of studied complexity toward a disability's self-conscious placement therein. *Beacon* offers Temma's figure as a guidepost rather than repulsion. The disability-wise gestures of the figures themselves are understood to occur in the face of a modern hyperrational clarity that would dispense with disability experience as some all-too-obvious tragedy. The paintings provide a lesson in how to live in the world with severe disability. Both ask us to reexamine this premise by requiring that we look closely enough to discern the disability coordinates of lives that might at first glance appear wasted.

Whereas Lowly and Wyeth represent intimate works about disability by nondisabled artists, Frida Kahlo's work supplies an example of artistic traditions spawned by disabled artists themselves (cover of Volume I). Responses to the disability context of Kahlo's work and life have ranged from incredulity to simple disability disavowal: "Frida Kahlo—she's a national treasure. How could she be a disabled woman?" Contrariwise, the complex disability perspectives that inform her subject matter and the terms of her artistic exploration can become so central that disability interests may overwhelm all else in her work. Certainly, few artists since the Middle Ages made the topic of personal suffering such a wellspring for creative figuration. For disability critics, one must note the inventiveness that informs Kahlo's access to artistic practices, from painting on canvasses suspended over her bed to laptop easels to the elaborate journal she kept detailing her pain, confinement, and multiple surgeries (including the amputation of her right leg in 1955). Such investments in the ability of art to provide her with immense joy "in spite of my long illness" led her to have her four-poster bed dismantled and reconstructed in the national museum of Mexico City. The unusual accommodation occurred on an evening prior to the one exhibition during her lifetime in her home country for the purpose of being able to view the exhibit herself in comfort.

Kahlo's life, whether conceived as utterly conditioned by disability or as having disability merely incidental to it, has served as the topic of children's books and films. Controversies rage over the terms and origins of her multiple impairments. Some have identified her disability as resulting from a bus accident when she was 16 years old in 1926; others with the effects of polio contracted at the age of 6; and still others, such as Philip Sandblom author of *Creativity and Disease* (1997), propose that she was born with the congenital condition of spina bifida, which she spent her life concealing. We may be discussing some combination of all of these events in one body as well. These discussions are as interesting for the fears and concerns interpreters express about the meanings of congenital (as opposed to acquired) disabilities for stories of artistic achievement. Acquired disability makes one a hapless victim of circumstances while congenital disability signifies a status as metaphysical pawn.

Nevertheless, the latter attribution of spina bifida as an initial source of her disabilities becomes most provocative given her preoccupation with the spinal column in her work. Her paintings commonly depict Mexico as an ionic column with wings. In addition, she also uses duality or twinning such as in her work, *The Two Fridas* (1939), where we see her heart beating and a circulatory system that feeds the nearby identical body image with which she clasps hands. The work depicted here, painted in 1946 amid a flurry of surgeries and hospital stays, *Arbol de la Esperanza Mantente Firme* (*Tree of Hope—Stand Firm!*), associates an ironic meaning to the figure holding a back brace in one half and wounds along the supine figure's spine in the other. The sense of strength that Kahlo must have felt in herself—particularly through her political commitments to Communist revolution—resound as both a plea (make me strong in the face of pain) and a command to others (stand firm in your political convictions). These words, *"arbol de la esperanza mantente firme,"* which one of her biographers, Hayden Herrera, identified as the lyrics to a song she knew, would also appear a year later in a diary entry celebrating the 30th anniversary of the Bolshevik revolution. For Kahlo, debilitating physical anguish could be offset to some degree with a merger of disability and political images in that both coexist without eclipsing the other: The most disabled also embody the fiercest commitments for social justice. The two often become a self-referencing system in the body of her works.

Compositionally, the contrasted backgrounds of night and day suggest a confluence of binary associations between light and dark, health and illness, passive hospital patient and active revolutionary. Yet the painting throws such easy oppositions into question in that all coexist, and enlightenment may come from either source. The more medical image appears in the day where one might expect to find her more "public"—that is, less vulnerable—self. Thus, the work is an emblem of Kahlo's artistic *oeuvre* in that these versions of the self do not simply balance the subject but rather serve as wellsprings for creative vision in their own right. The pink brace grasped securely in the hands of the formally dressed figure who waves a small flag contrasts with the night and small moon on the right side of the canvas. The body of the fully draped figure situated at a perfect right angle to the reposed figure on the wheeled operating table function as two supports along the canvas's vertical and horizontal planes. The figure on the left displays open seeping wounds across a back that is exposed between pulled-apart sheets as if to unveil her body in a surgical cut-away.

Likewise, spinal lesions echo across both halves of the painting. They duplicate cracks and ridges that split dry earth across which the stretcher seems precariously perched. This yawning crevasse is exactly the same size as the wheeled bed. A surreal glittery ball stands for the sun, and her flowery headdress hovers suspended in this cosmic stratosphere. The velvet dress suggests a more formal version of the Aztec clothing that she wore throughout her adult life. It's also a chosen legacy rescued from a colonized past. Hence the more surreal aspect of this painting: The body left behind, ruptured, and lying across night and day is juxtaposed to the upright, dressed red figure who gazes at the viewer while holding the brace in full display. It also appears that the seated figure wears a similar corset-like apparatus beneath the dress because the bulbous endings appear around her chest and match the same design of the brace in her hands. In a *Time* magazine article of April 27, 1953, Kahlo insisted that "I never painted dreams. I painted my own reality" (p. 90). The painting may most of all render homage to her prosthetic back brace and her investments in it. Today, one can find the same pink back brace with personal decorations in a visit to her home, now a national museum. In either case, both portraits echo with Kahlo's disability markers that worked to flaunt, as opposed to mask them, from the viewer.

Kahlo's work has been often attributed to the influence of northern Dutch painters such as Pieter Brueghel the Elder, and particularly, Hieronymus Bosch (Jeroen Van Aken: 1450–1516). While Brueghel painted mimetic images of everyday northern peasant life, Bosch's impact on Kahlo is often identified through his portrayals of bizarre imaginings such as the events captured in his work *Extraction of the Stone of Madness (The Cure of Folly)* (ca. 1475) (cover of Volume II). Whereas Kahlo followed Vincent van Gogh in portraying her physicians in respectful portraits as a sign of appreciation, Bosch participates in a less reverent approach. In this painting, Bosch satirizes the medieval medical practice of removing stones from the head as a treatment for madness, traumatic brain injury, and insanity. In addition, the other two onlookers—a friar and a nun—represent alternative religious domains where madness was commonly addressed with alms and prayer. Thus, Bosch assembles the surgery's audience carefully in his effort to draw the three figures into the net of this parody—as if every charlatan, barber, and pious practitioner of his day comes together in this unholy gathering to witness someone else's suffering. Their own moral stature in the community depends on catering to those residing among the "less fortunate."

The subject of the surgery—a patient drawn in the guise of various "fools" of the day—undergoes a risky intervention. Hopes for release from such conditions as insanity resulted in a willingness to expose oneself to disastrous—and often life-threatening—efforts to alleviate symptoms. Similar practices for the treatment of mental illness were widespread in Bosch's day. Evidence also suggests that in spite of critiques such as this one, the practice continued into the Renaissance where similar procedures are documented as late as the sixteenth century. Like Kahlo, Bosch rarely ventured far from home, and his works include details of familiar scenes within a tightly circumscribed area. Yet, as in this work, Bosch's paintings place the rituals of life in question by unveiling the violence that often resides just beneath the surface. Consequently, *Extraction of the Stone of Madness* suggests that "deviant" behavior may be found on both sides of the treatment divide.

Bosch's painting, inspired by various folk tales and critiques of the physicians' guilds of his time, appears fairytale-like in its allegorical assemblage of medical and religious personnel. In each figure, the primary treatment tools come on display—from the barber's scalpel to the friar's chalice-like vessel to the nun who balances a book on her head. The physician applies his effort directly to the body, the male priest talks and gestures toward the patient during the ordeal as if performing an exorcism of demons, and the nun looks on in contemplation as if patiently awaiting inspiration from the text above. Each intervention strategy seems poised to encourage equal levels of suspicion. Rather than a stone, the surgery results in the extraction of a flower from the man's head. This is a curious object in that the flower appears much more at home in the naturalistic setting while the human practitioners seem out of place. The town situated off in the distance further emphasizes their displacement. As one commentator puts it:

> Moreover, this work of art bears the inscription 'Master, take away the stone, my name is Lubbert Das." It is worth pointing out that Lubbert Das was a comical character that originates in the Dutch literature of that time. The stone is represented as a flower (tulip) on the head of the patient near the surgeon's knife, because of the similarity between the words tulip (*tulp*) and madness in Dutch. (Babiloni et al. 2003:1)

This direct parallel between organic life and insanity may suggest Bosch's effort to equate both objects with the forces of nature that ultimately evade human control.

While madness may be commonly represented as severe distraction from the applications of daily living, only the patient's gaze breaks the painting's plane as he looks out uncertainly toward the artist capturing the event and/or the hapless viewer consuming the event. His look of personal concern contrasts with the concentrated efforts of the others as they attend directly to the site of conflict—namely, his brain as resident location for the "disorder"—and thus the "patient's" objectification turns out to be at least threefold on behalf of the barber, artist, and viewer. We participate as consumers of the discomforting scene. Bosch captures the worst kind of medical theater, one that not only subjects one to painful procedures of dubious merit but also is witnessed by others to further deepen the stigma.

The painting also comments on a long-standing belief in medicine that the body functions as symptomatic surface for otherwise ephemeral "cognitive" phenomena (i.e., madness in this case). Without a tangible bodily location, medicine would prove at a loss as to how to proceed in its material correctives. The concept of a "stone" of madness then takes an abstract matter of behavior perceived as deviant and objectifies it in physical terms. Thus, various bodily zones get targeted as the seat/source of intangible phenomena. In the eugenics period (1840–1940), "idiocy" was theorized as a lack of control of the will, and "docile" bodies were targeted through physical exercises, concentration rituals (e.g., standing in one place for minutes at a time), and hygienic grooming practices—a presentable body represents a compliant citizen. In each instance, exerting force on the physical body provided a route through which to impose control over minds.

In sum, these artistic works demonstrate that disability is both a product of specific local contexts *and* shared, even global, disability perspectives. Africa, Japan, the United States, Mexico, and the Netherlands all contribute to a multinational mosaic of disability representation; in doing so, disability transcends geography, culture, and history in its situation as a metaphorical and pragmatic device of social meaning making. The question "What do we do with our disabled people?" resonates in most cultures and across historical moments. In the midst of its invocation as perpetual crisis, disability can expose ruses to the control and mastery of human variation, give expression to individual assertions of difference and group identity, portray indifference or excruciating investment in the denial of deviance, resignify incapacity into unexpected ability, or provide opportunities of interdependency among human vulnerabilities in search of mutual support. On each cover of Volumes I through V, disability serves as the medium through which artists—and, consequently, the viewers of their art—may ponder cultural responses to the persistence of human heterogeneity. Difference prompts myriad social schemes of suppression in futile efforts to contain variation within a narrower range of expression. Artists of disability are not in any way immune to the homogenizing projects of cultures, but their work gives us perspective on how we might improve the future by contemplating the limitations of tolerance in our past.

Further Readings

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ABOUT THE GENERAL EDITOR

Gary L. Albrecht is Professor of Public Health and of Disability and Human Development at the University of Illinois at Chicago. His current work focuses on the quality of life of disabled people based on National Institutes of Health (NIH)–funded studies of disabled women experiencing the menopausal transition and a study of disability risk in the United Kingdom, France, and the United States. Complementary work on the experience of disability in the inner city has been funded by the National Institute on Disability and Rehabilitation Research (NIDRR). He is past Chair of the Medical Sociology Section of the American Sociological Association, a member of the Executive Committee of the Disability Forum of the American Public Health Association, an early member of the Society for Disability Studies, and an elected member of the Society for Research in Rehabilitation (UK). He has received the Award for the Promotion of Human Welfare and the Eliot Freidson Award for the book *The Disability Business: Rehabilitation in America.* He also has received a Switzer Distinguished Research Fellowship, Schmidt Fellowship, New York State Supreme Court Fellowship, Kellogg Fellowship, National Library of Medicine Fellowship, World Health Organization Fellowship, the Lee Founders Award from the Society for the Study of Social Problems, the Licht Award from the American Congress of Rehabilitation Medicine, and the University of Illinois at Chicago Award for Excellence in Teaching.

He has been elected Fellow of the American Association for the Advancement of Science (AAAS) and is a frequent Visiting Fellow at the University of Oxford and Scholar in Residence at the Maison des Sciences de l'Homme, Paris. He has led scientific delegations in rehabilitation medicine to the Soviet Union and the People's Republic of China and served on study sections, grant review panels, and strategic planning committees on disability in Australia, Canada, the European Community, France, Ireland, Poland, Sweden, South Africa, the United States, and the World Health Organization, Geneva. His most recent books are *The Handbook of Social Studies in Health and Medicine* (Sage, 2000, edited with Ray Fitzpatrick and Susan Scrimshaw) and the *Handbook of Disability Studies* (Sage, 2001, edited with Katherine D. Seelman and Michael Bury).

ABOUT THE ASSOCIATE EDITORS

Jerome Bickenbach is a full Professor in the Department of Philosophy and the Faculties of Law and Medicine at Queens University, Kingston, Ontario. He currently holds a Queen's Research Chair, and he was a previous holder of a Killam Fellowship, working on the law and policy of health systems performance assessment, including the legal and ethical aspects of summary measures of population health. His research is in disability studies, using qualitative and quantitative research techniques within the paradigm of participatory action research. Most recently, his research includes disability quality of life and the disability critique, disability epidemiology, universal design and inclusion, modeling disability statistics for population health surveys, the relationship between disability and health, and the ethics and policy implications of summary health measures.

As a lawyer, Dr. Bickenbach was a human rights litigator, specializing in antidiscrimination for persons with intellectual impairments and mental illness. Since 1995, he has been a consultant with the World Health Organization (WHO) working on the revision of the ICIDH, from alpha and the beta drafts, to the final draft leading to the ICF. He has participated in nearly all revision activities, and continues to consult with WHO on ICF dissemination and international disability social policy.

He is author of *Physical Disability and Social Policy* (1993) and coeditor of *Introduction to Disability* (1998), *Disability and Culture: Universalism and Diversity* (2000), *A Seat at the Table: Persons with Disabilities and Policy Making* (2001), *Quality of Life and Human Difference* (2004), and numerous articles and chapters in disability studies, focusing on the nature of disability and disability law and policy.

David T. Mitchell is Associate Professor of Disability Studies at the University of Illinois at Chicago. From 2000 to 2004, he served as Director of the first Ph.D. program in disability studies. He has also served as president of the Society for Disability Studies and as Chair and founding member of the Modern Language Association's Committee on Disability Issues. He has served on the Board of Directors for Chicago's Independent Living Center, Progress Center, and as an editor on numerous editorial boards including that of the journal *Disability & Society*. He earned his Ph.D. from the Program in American Culture at the University of Michigan, Ann Arbor.

Most recently, Dr. Mitchell has been concerned with the inclusion and advancement of students with disabilities in higher education. Disability studies takes as its charge the goal of making classrooms and the university more accessible. Similarly, fields of inquiry need to become more answerable for their embedded assumptions about disability. Part of this work involves querying the role that disabled persons play as objects for different kinds of knowledge acquisition about them. Consequently, he directed the first National Endowment for the Humanities Summer Institute in Disability Studies for Educators. In addition, he has traveled and lectured extensively on these and other disability studies topics, in the United States, Canada, Germany, Ireland, Russia, Britain, and Costa Rica. In 2004, he codirected a seminar project team that researched euthanasia murder files and original documentation from psychiatric institutions in National Socialist Germany. This commission remains committed to making the history of disability genocide more known, studied about, and understood.

He is coauthor of *Cultural Locations: Discourses of Disability* (2005), coeditor of *Eugenics in America: A History in Primary Sources* (2005), coauthor of *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), coeditor of *The Body in Physical Difference: Discourses of Disability* (1998), coeditor of a special issue of *Disability Studies Quarterly* on disability studies in the humanities, and coeditor of a special issue on disability issues in writing by the American author Herman Melville for the journal *Leviathan*.

Walton O. Schalick III is Assistant Professor of Pediatrics and of History at Washington University in St. Louis. He is a practicing pediatrician and physiatrist in the Division of Newborn Medicine at St. Louis Children's Hospital, where he works with children with disabilities and does clinical research, a portion of which involves practical ethics and children with chronic conditions. He is an award-winning teacher of medical students and residents, and, in the Faculty of Arts & Sciences, an award-winning teacher of undergraduate and graduate students in history, history of medicine, and disability studies.

He holds M.D. and Ph.D. (History of Medicine) degrees from the Johns Hopkins University. His Ph.D. included work in nineteenth-century European and modern American medicine, but focused on medieval European medicine. He completed two residencies, one in Pediatrics (Children's Hospital, Boston) and one in Physical Medicine & Rehabilitation (PM&R or physiatry) (Spaulding Rehabilitation Hospital) at Harvard University, and a Chief Residency in PM&R. Since that time, he has been on the faculty in both the School of Medicine and the Faculty of Arts & Sciences at Washington University in St. Louis.

Professor Schalick's historical work encompasses a study of children with physical disabilities from 1800 to 1950 in France, Germany, the United Kingdom, and the United States, funded in part through the Robert Wood Johnson Foundation's Generalist Faculty Award Scholars. His first book manuscript, *Marketing Medicine,* traces the origins of academic medicine and marketplace dynamics in medieval France. He has published widely on pediatrics, medieval history, and history of disabilities in both the clinical and the scholarly literature and is the recipient of numerous awards for history, including the Shryock Medal of the American Association for the History of Medicine.

Sharon L. Snyder is Assistant Professor in the Department of Disability and Human Development at the University of Illinois at Chicago. She is a founding member of the Modern Language Association's Committee on Disability Issues and of the Disability Studies Discussion Group. As a faculty member in the first Ph.D. program in disability studies in the United States, she has developed graduate courses including disability in film, the history of eugenics, representational history, globalization and political economies, and curriculum development for disability studies. In 2004, she directed the Legacies of Eugenics, a DAAD (German Academic Exchange Service) seminar for U.S. and Canadian faculty at the Einstein Forum, Potsdam, Germany. She has codirected a National Endowment for the Humanities Summer Institute and served as a faculty lecturer at the University of Costa Rica.

Dr. Snyder is coauthor of *Cultural Locations of Disability* (2005), coeditor of *Eugenics in America* (2005), coeditor of *Disability Studies: Enabling the Humanities* (2003), coauthor of *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), and coeditor of the first collection of essays on disability studies in the humanities, *The Body and Physical Difference: Discourses of Disability* (1997). As the series editor for Corporealities: Discourses of Disability, she has been instrumental in encouraging scholarly work in the new analytical field of disability studies. Her essays on disability theory, disability culture, and representational history have been published widely and translated for many international professional journals.

The founder of the independent production company Brace Yourselves Productions, she is also a documentary filmmaker whose work includes *Self-Preservation: the Art of Riva Lehrer, Disability Takes on the Arts, A World without Bodies*, and *Vital Signs: Crip Culture Talks Back*. Awards for her films include the Festival Grand Prize at Rehabilitation International's Film Festival, Achievement and Merit Awards at Superfest, and Best of the Festival at Moscow's Breaking Down Barriers.

ABOUT THE SENIOR ADVISORY BOARD

Scott Campbell Brown is an Education Research Analyst with the U.S. Department of Education, Office of Special Education and Rehabilitation Services, Office of Special Education Programs. His major focus is early childhood, with a long-term interest in promoting use of the World Health Organization's International Classification of Functioning, Disability and Health. He has served as a consultant to the United Nations on disability policy and to the International Labour Organization on disability statistics. His education includes a Ph.D. in demography from the University of Pennsylvania.

Dudley S. Childress is Senior Rehabilitation Research Scientist in the Jesse Brown VA Medical Center, Professor of Biomedical Engineering in the McCormick School of Engineering at Northwestern University, and Professor of Physical Medicine and Rehabilitation in the Feinberg School of Medicine in Chicago. He directs the Prosthetics Research Laboratory and the NIDRR Rehabilitation Engineering Research Center in Prosthetics and Orthotics, and is Executive Director for the Prosthetics & Orthotics Education Program.

He joined Northwestern's Department of Orthopaedic Surgery in 1966. In addition to limb prosthetics and orthotics, his experience includes almost 20 years of research and development (R&D) work in the general area of assistive technology for persons with disability, which include wheelchair controllers, communication aids, environmental controllers, computer systems, and other appropriate technology for activities of daily living. He holds an M.S. degree in electrical engineering from the University of Missouri (Columbia) and a Ph.D. degree in electrical engineering from Northwestern University.

He is currently engaged in scientific studies of human movement (particularly walking) and in the development of engineering systems that assist people with walking (e.g., artificial feet). He remains interested in control systems for artificial hand/arm replacements and with computer-aided engineering for fabrication of prosthetics and orthotics. He is a member of the Institute of Medicine of the National Academy of Sciences.

Joseph Flaherty is Dean of the School of Medicine and former Professor and Head of the Department of Psychiatry, as well as chief of the psychiatry service at the University of Illinois at Chicago, where he received his medical training and his psychiatric research training. He had additional research training in sociology at London University. Over the past 15 years, Dr. Flaherty has examined the effects of gender on the development of symptoms and illness as well as health-seeking behavior and treatments in alcoholism and depression. He also has been involved in psychometric testing of new instruments and their cross-cultural adaptation through research conducted in Peru, Panama, Israel, and the USSR. For more than 20 years, his research has been funded by branches of the National Institutes of Health, including the National Institute on Alcohol and Alcoholism and the National Institute of Mental Health, as well as the MacArthur Foundation, the Chicago Community Trust, and other governmental and private agencies. He is currently involved in a large-sample longitudinal study on the effects of occupational stressors on heavy drinking. He is also developing models of health care delivery for high-risk children in state care with the aim of early intervention and prevention.

Dr. Flaherty has published more than 180 professional papers, books, and chapters. He is an editorial member or reviewer for a variety of professional journals and consults with a number of agencies including the World Health Organization and the Falk Institute in Jerusalem.

Allen W. Heinemann directs the Center for Rehabilitation Outcomes Research, a rehabilitation-focused health services research unit at the Rehabilitation Institute of Chicago (RIC) where he has worked since 1985. He is also Associate Director of Research at RIC and Professor in the Department of Physical Medicine and Rehabilitation at the Feinberg School of Medicine, Northwestern University. He serves on the Coordinating Committee for Northwestern University's Institute for Health Services Research and Policy Studies. Research interests focus on health services research, psychosocial aspects of rehabilitation including substance abuse, and measurement issues in rehabilitation.

He is the recipient of funding by the National Institute on Disability and Rehabilitation Research (Switzer Fellowship, Field Initiated Projects, Innovation Award, DRRP on Health Services Research, RRTC components), the National Institute on Alcohol Abuse and Alcoholism, Centers for Disease Control, the Social Security Administration, the Substance Abuse and Mental Health Services Administration, the J. M. Foundation, the Paralyzed Veterans of America–Spinal Cord Research Foundation, and the American Occupational Therapy Foundation and Association. He is a Fellow of the American Psychological Association (Division 22) and a diplomate in Rehabilitation Psychology (ABPP). He serves as the president elect of the American Congress of Physical Medicine and Rehabilitation and the Rehabilitation Psychology division of the American Psychological Association. He serves as a study section member for the National Institutes of Health's Center for Scientific Review, on the editorial board of the *Archives of Physical Medicine and Rehabilitation, NeuroRehabilitation, International Journal of Rehabilitation and Health, Journal of Outcome Measurement, Journal of Head Trauma Rehabilitation, Rehabilitation Psychology,* and *Rehabilitation Counseling Bulletin.* He is the recipient of the Division 22 (Rehabilitation Psychology, of the American Psychological Association) Roger Barker Distinguished Career Award.

He is author of more than 100 articles in peer-reviewed publications and is editor of *Substance Abuse and Physical Disability*. He earned a doctoral degree in clinical psychology at the University of Kansas with a specialty focus in rehabilitation.

Tamar Heller is Professor and Chair of the Department of Disability and Human Development, University of Illinois at Chicago. She also directs the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, the Advanced Training for Disability and Rehabilitation Scholars program, and projects on support interventions for individuals with disabilities and their families. In addition, she is Director of the University Center of Excellence in Developmental Disabilities for the State of Illinois. Previously, Dr. Heller directed the Family Studies and Services Program, which included an interdisciplinary diagnostic clinic serving nearly 1,000 families per year from the inner city, a family support program, and studies on lifespan family support. Dr. Heller has served on the boards of the American Association on Mental Retardation, the European Course on Mental Retardation, and several leading national and international journals on disability issues.

Dr. Heller has written more than 100 publications and presented nearly 200 papers at major conferences on disability policies and interventions. She has coedited two books (*Health of Women with Disabilities* and *Older Adults with Developmental Disabilities: Optimizing Choice and Change*) and edited special issues of *Technology and Disability, American Journal on Mental Retardation, Journal of Policy and Practice in Intellectual Disabilities,* and *Family Relations.*

Christopher B. Keys is Professor and Chair of the Psychology Department at DePaul University and Professor Emeritus of Psychology and of Disability and Human Development at the University of Illinois at Chicago. Professor Keys's current research and interventions focus on the empowerment of people with disabilities and their families, the promotion of success in education and in life by youths and young adults with disabilities, and attitudes toward people with intellectual disabilities and disability rights. He is also conducting intervention research concerning the development of the program evaluation capacity of organizations that serve people of color with disabilities. He is particularly interested in the intersections of disability, ethnicity, and social class.

A Fellow of the American Psychological Association and the Society for Community Research and Action, Dr. Keys was one of the first to serve as president of the Society for Community Research and Action and Chair of the Council of Community Psychology Program Directors. His work has been recognized by awards, appointments, and honors from the American Psychological Association, the World Bank, the American Institutes of Architects, and the National Government of Australia. He has been invited to present his research in Asia, Australia, Europe, and Latin America.

With his colleagues, Dr. Keys has coauthored more than 100 journal articles, book chapters, and reports concerning people with disabilities, empowerment, disabilities, organization development, community research methods, and related topics. He has also coauthored more than 250 conference presentations and has been responsible for training more than 10,000 staff serving people with disabilities and working in other human services, education, and justice systems. Recently, he coedited *People with Disabilities: Empowerment and Community Action* and *Participatory Community Research: Theory and Method in Action.*

Trevor R. Parmenter holds a joint appointment of Foundation Professor of Developmental Disability in the Faculty of Medicine at the University of Sydney and Director of the Centre for Developmental Disability Studies (CDDS). He also holds the position of Adjunct Professor in the School of Education and Social Work at the University of Sydney. Prior to his appointment at CDDS in 1997, Professor Parmenter, Ph.D., FACE, FAAMR, FIASSID, held the position of Professorial Fellow in the School of Education, Macquarie University and Director of the Unit for Community Integration Studies. Previous to his appointment to Macquarie University in 1974, he held teaching and administrative positions with the New South Wales Department of Education (1953–1973).

Areas of research and publication include research into behavioral and emotional problems of people with disabilities; quality-of-life assessment; program evaluation; policy development; community living and employment for people with disabilities; assessment of cognitive processes; brain injury; family studies; transition from school to further study, work, and adult living; and aging and disability. He is a member of the editorial boards of eight international journals and a Fellow of the Australian College of Educators, the American Association on Mental Retardation, and the International Association for the Scientific Study of Intellectual Disabilities.

His international activities have included work in association with the World Health Organization and the International Labour Organization, presidency of the International Association for the Scientific Study of Intellectual Disabilities, and vice presidency of the International Sports Federation for Persons with Intellectual Disability. At the national level, he chairs the Advisory Committee on Australian and International Disability Data for the Australian Institute of Health and Welfare and is a member of the Institute's Burden of Disease Advisory Committee. He was a member of the Disability Council of New South Wales for several years.

Mairian Scott-Hill (who also published as Mairian Corker) earned a B.Sc. in biological sciences from the University of East Anglia as a mature student. She had previously been working in the hematology department at St. Thomas' Hospital in London after leaving school. Her employers recognized her outstanding intellectual abilities and sent her off on day-release classes to obtain an H.N.D. in science, after which she took her degree and then an M.Phil. on the subject of deafness. She then worked for the Deaf Children's Society, before returning to the field of education in a post at the City Lit institution. Subsequently, she was a senior research Fellow attached to several universities—including University of Central Lancashire, University of Leeds, and King's College London—although she never took up a full-time academic position. Mairian was a very original thinker, and a prolific writer. Her books include *Counselling—The Deaf Challenge* (1994), *Deaf Transitions* (1996), *Deaf and Disabled or Deafness Disabled* (1998), and two edited books, *Disability Discourse* (with Sally French, 1999) and *Disability and Postmodernity* (with Tom Shakespeare, 2002). Mairian's research interests centered in deaf studies and disability studies included linguistics, discourse, identity, childhood, law, and culture. She led the way in applying the insights of poststructuralism and postmodernism to British disability studies, and she was very active in online debates about disability theory, particularly in supporting new generations of scholars. Mairian died on January 22, 2004, and will be missed by the whole disability studies community.

Tom Shakespeare is currently Director of Outreach for the Policy, Ethics and Life Sciences Research Institute at the University of Newcastle, a project exploring bioethics and science engagement (www.peals.ncl.ac.uk). He earned his B.A. in Social and Political Science, M.Phil. in Social and Political Theory, and Ph.D. in Sociology from the University of

Cambridge. He did research and taught sociology at the Universities of Sunderland, Leeds, and Newcastle. He has been involved in the UK disability movement since 1986 and instrumental in founding Disability Action North East and the Northern Disability Arts Forum. He has experience as a performer and a writer, has given keynote speeches at academic and activist conferences throughout the world, and regularly contributes to UK print and broadcast media. He was awarded the UK Award for furtherance of the human rights of disabled people at the 2003 RADAR People of the Year Awards and delivered the Lister Prize Lecture at the 2003 British Association for the Advancement of Science Festival. His research interests in disability studies concern models of disability, disabled childhood, disability and genetics, disability and sexuality, disability and social care, and cultural representation of disability. He has many publications in the field of disability studies and bioethics and is coauthor of *The Sexual Politics of Disability* (1996), *Exploring Disability* (1999), and *Genetic Politics: From Eugenics to Genome* (2002).

A

AAATE

See Association for the Advancement of Assistive Technology in Europe

ABLEISM

Ableism describes prejudicial attitudes and discriminatory behaviors toward persons with a disability. Definitions of ableism hinge on one's understanding of normal ability and the rights and benefits afforded to persons deemed normal. Some persons believe it is ableism that prevents disabled people from participating in the social fabric of their communities, rather than impairments in physical, mental, or emotional ability. Ableism includes attitudes and behaviors emanating from individuals, communities, and institutions as well as from physical and social environments.

HISTORY

The term *ableism* evolved from the civil rights movements in the United States and Britain during the 1960s and 1970s, but prejudice and discrimination against persons with a disability has existed across the globe and throughout history. During the civil rights era, disability activists transformed religious and scientific understandings of disability into a political paradigm. In religious and scientific paradigms, disability is an individual characteristic. The disabled individual bears primary responsibility for enduring or remedying the disability through prayer in the religious paradigm or through medical intervention in the scientific paradigm. Although disabled persons are sometimes isolated from nondisabled persons, the dominant theme in both religious and scientific traditions is that nondisabled persons should behave compassionately toward disabled persons. From the civil rights perspective, often called a minority oppression model, society creates disability by creating physical and social environments hostile to persons different from the majority or "abled" culture. *Ableism* has become a term used to describe "the set of assumptions and practices that promote unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences" (Terry 1996:4–5).

MANIFESTATIONS OF ABLEISM

Discriminatory attitudes and practices that promote unequal treatment of disabled persons share many similarities with the discrimination against other minority groups. Discrimination may be direct or indirect, legally or culturally encoded, based on scientific norms or based on false assumptions. Stereotyped notions of the minority group, whether chosen by an individual or ascribed to an individual by others, may prevent members of the majority group from even perceiving individual characteristics. Common components of ableism include lowered expectations, normalization as beneficence, limitations in self-determination, labeling, and eugenics.

Lowered Expectations

Expectations refer to beliefs about probable future occurrences based on current observations. Expectations of parents, teachers, employers, and others often influence one's self-concept and one's achievement. Research demonstrates correlations between high expectation and high achievement among students in elementary through higher educational settings, as well as correlations between low expectation and low achievement. Moreover, research demonstrates that the younger the person, the stronger the influence of expectations held by others. The consequences of low expectation are particularly pernicious when those forming expectations erroneously evaluate ability and when they assume that low achievement in one performance domain automatically transfers to low achievement in other performance domains. For example, children with speaking impairments are often erroneously assumed to have more difficulty learning than those who are easily understood.

Two areas of lowered expectations receive special attention in the disability literature and in public policy: education and employment. Across continents, many nations prohibit certain forms of discrimination in educational and employment opportunity. In the United States, the Individuals with Disabilities Education Act (1975, 1997) requires schools to provide "free and appropriate education" for all students, and the Americans with Disabilities Act (ADA; 1990) provides employment protections for qualifying persons with disability. In Australia, the Disability Discrimination Act (1992) supports nondiscrimination in education and training and the Disability Services Act (1986) provides that a person with disability has a right to achieve his or her individual capacity for physical, social, emotional, and intellectual development. In the United Kingdom, the Disability Discrimination Act (1995) prohibits employer discrimination against disabled persons in recruitment, employment conditions, training, and promotion. One limitation of these and similar acts in other nations is that they cannot adequately protect persons from unspoken judgments of inadequacy that follow a person throughout childhood and adulthood.

Ableism manifested by lowered expectations in education may be remedied in several ways. Hehir (2002) wrote at length about policies to reduce ableism in schools. He asserted that children with learning disabilities should have access to the rest of the curriculum even if evidence suggests that reading and writing will always be weak. He proposes the elimination of policies in which schools are allowed to a priori exclude the performance of children with disabilities from overall school performance. Laws with this type of exclusion reinforce lower expectations, and consequently lower achievement, of children with disability.

Ableism causing lowered expectation in employment is also pervasive across cultures. Especially in capitalist economies, persons with disability are viewed as expensive labor or not suited for labor at all. The inordinate focus on the characteristics of the disability to the exclusion of that which a person can do exacerbates lower expectations and produces discrimination.

Normalization as Beneficence

Ableism is manifest whenever people assume that normal physical, mental, and emotional behavior is beneficial regardless of a person's actual physical, mental, and emotional attributes. Especially when strong research evidence supports alternate conclusions, the equating of normal with desirable may be harmful to disabled persons. For example, educators and parents may assume that deaf children will better negotiate the hearing world with oral language than with manual language (e.g., sign language). A large body of research, however, demonstrates that deaf children make greater educational achievements when manual, rather than verbal, language skills are emphasized. Language provides organization for the acquisition and utilization of knowledge. It is therefore logical that an emphasis of oral language over manual language would be detrimental to most deaf children. Normalization may be particularly noxious when persons without disability assume positions of power over persons with disability.

Limitations in Self-Determination

Self-determination describes the right and the responsibility of people to make decisions for themselves. Self-determination includes freedom to associate with whomever one chooses, authority to control money owned by or used to purchase services for oneself, autonomy to be the boss of one's own life, and assuming responsibility for the consequences of one's decisions. Self-determination is an internationally endorsed value. The United Nations General Assembly adopted the "Universal Declaration of Human Rights" in 1948. This document affirms that the "recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world." A problem is that these inalienable rights have often been denied to disabled person. Ableism occurs whenever a group of persons endorses self-determination among most group members but restrict or inhibit disabled persons from making basic life choices. Even when legal codes establish the rights of disabled persons to exercise the same rights of self determination that are afforded to abled persons, disabled persons often are not able to exercise their rights to self-determination in education, employment, transportation, housing, medical decision making, and social interchange. These rights may remain inaccessible to disabled persons due to inaccessibility of physical and social spaces, limited financial resources, and disabling attitudes.

Labeling

Labeling a person as "disabled" requires a judgment, usually by a professional, that an individual's behaviors are somehow inadequate, based on that professional's understanding of community expectations about how a given activity should be accomplished. Professionals typically consider methods used by "abled" person of the same age, sex, and cultural and social environment to accomplish a task to be normal, and all other methods to be abnormal. A problem with this interpretation of disability is the duality of categorization. People are either "disabled" or "abled." "Abled" persons set the criteria for the categorization, and "abled" persons make the judgments that assign people to one of the two categories. The label "disabled" implies inadequacy as a person. The social meaning of a classification often more strongly influences the daily life of a labeled person than the characteristics that cause the person to meet the classification criteria. When a label carries positive social meaning, the labeled individual may experience expanded opportunities. When the label carries negative social meaning, opportunities often contract. The label "disabled" carries negative social meaning. In the United States, the authors of the ADA recognized the seriousness of the negative consequences of being thought of as "disabled." The ADA protects persons thought of as "disabled" equally to persons who otherwise meet the criteria for disability under the act. Few other countries have enacted laws to address disadvantage that results from simply being called "disabled."

Eugenics

Eugenics may be defined as development and improvement of the human race. Eugenic methods include preventing persons deemed deviant and defective from being born, preventing persons born deviant or defective from reproducing, and isolating persons deemed deviant and defective through institutionalization or murder. The systematic killing of disabled children by the Nazi regime in Germany during World War II illustrates an extreme form of ableist behavior. The identification of the human genome (entire genetic makeup of human beings) facilitates selective abortion based on ableism. Selective abortion is a contemporary form of eugenics. Societies that permit abortion for fetuses likely to be born disabled, but do not permit abortion for those likely to be born abled, invalidate the lives of disabled persons.

—Sandra J. Levi

See also Americans with Disabilities Act of 1990 (United States); Disability Discrimination Act of 1995 (United Kingdom); Eugenics; Individuals with Disabilities Education Act of 1990 (United States); Stigma; Stigma, International.

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(973–1057)

Arab poet and freethinker

The renowned Arab poet and philologist Abu 'l-`Ala lost most of his sight to smallpox in his fourth year and was blind as a youth. His memory developed well, and he retained huge amounts of Arabic literature. Abu 'l-`Ala took up the role of blind poet, having a tiny pension for himself and his sighted attendant. When that income failed, he moved to Baghdad and joined literary circles there, managing briefly to earn a precarious living from writing and public recitation of verses. While his talents were appreciated, they did not save him from some quarrels and humiliations. Within two years, he had returned to Ma`arrat and resumed his life there, in 1010. Extant correspondence shows him active in literary affairs and teaching. As his teeth began to drop out, he complained of his own mispronunciation, leading to his amanuensis writing mistakenly. Abu 'l-`Ala actively courted controversy with unorthodox religious views, even writing a book that could be considered as attempting to rival the Qur'an.

—Kumur B. Selim

See also Abu 'l Aswad ad-Duwali; `Ata ibn Abi Rabah; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

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ABU 'L ASWAD AD-DUWALI

(603–688)

Arab scholar

The scholar and innovative grammarian Abu 'l Aswad ad-Duwali lived in Basra, Iraq, and for a short period may have been city governor, under the caliphate of `Ali. In later life, Abu 'l Aswad suffered paralysis and could hardly walk, yet insisted on going to market in person, though he was wealthy. An acquaintance remarked that there was no reason to put himself to this trouble, so Abu 'l Aswad explained why he would continue to appear in public as long as he could: "I go in and out, and the eunuch says: 'He is coming,' and the boy says: 'He is coming,' whereas, were I to continue sitting in the house, the sheep might urine upon me without anyone preventing them" (*Ibn Khallikan's Biographical Dictionary*, 1842–1871). Another reason was that Abu 'l Aswad had lost all real influence after the murder of his patron `Ali, but in public he was still recognized as a man who had been of some consequence.

—Kumur B. Selim

See also Abu 'l-`Ala al-Ma`arri; `Ata ibn Abi Rabah; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

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ABUSE AND HATE CRIMES

Abuse and hate crimes are serious problems in the lives of many disabled people. Abuse can take many forms, including: physical, sexual, emotional, medical, and financial abuse, as well as maltreatment and neglect. Physical abuse can include hitting, slapping, and pushing; sexual abuse can involve unwanted touching, sexual contact, or rape; emotional abuse can including bullying, threatening, and intimidating a person; medical abuse can involve overmedicating a person or denying them appropriate medications; financial abuse involves wrongfully using someone else's finances; and neglect may range from failure to provide basic necessities to putting someone at risk through unsafe practices.

Many studies show that disabled people are far more likely than nondisabled people of the same age and gender to be the victims of abuse. However, the studies that have been carried out on disability abuse have often been conducted on small populations of people with specific impairments. For instance, Sullivan, Vernon, and Scanlan (1987) and Elder (1993) reported sexual abuse among Deaf youths at rates higher than 50 percent. Jacobson and Richardson (1987) found that 81 percent of psychiatric inpatients with multiple disabilities had been abused. Pava (1994) studied the vulnerability of vision-impaired people to sexual and physical assault, concluding that one in three of her sample had been targets of either attempted or actual assault. In an Australian study, Wilson and Brewer (1992) reported that people with an intellectual disability were 10 times more likely to experience violent crime victimization than other adults. McCabe, Cummins, and Reid (cited in Chenoweth 1999) found that 20.5 percent of people with an intellectual disability had been raped, compared to 5.7 percent of a control group of nondisabled people.

There is an abundance of literature suggesting that disabled children experience far higher rates of abuse than nondisabled children. Ammerman and Baladerian (1993) concluded that the rate of maltreatment of disabled children is 4 to 10 times higher than nondisabled children. Sullivan and Knutson (1998) examined nearly 40,000 hospital records and reported rates of maltreatment among children with disabilities that were 1.7 times higher than nondisabled children. A later review of school records by Sullivan and Knutson (2000) indicated maltreatment among 31 percent of disabled children compared to 11 percent of the overall school population. A number of studies suggest that abuse is often carried out by people who are known to the victim—family, friends, other disabled people, and even paid caregivers. However, many cases of abuse are not reported to authorities because of the victim's shame, fear of retaliation, fear of not being believed, or reliance on third parties to report the abuse.

Sobsey, Randall, and Parrila (1997) suggested that there may be different patterns of abuse for disabled boys than disabled girls. They reviewed the case files of 1,834 children and found that 62 percent of girls with disabilities and 38 percent of boys with disabilities experienced sexual abuse, 59 percent of girls with disabilities and 41 percent of boys with disabilities had been emotionally abused, and 56 percent of disabled boys were neglected, compared to 44 percent of disabled girls.

Dick Sobsey's (1994) major study, *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* suggested that disabled people are more likely than nondisabled people of the same age and gender to experience abuse and that this abuse is more likely to be prolonged and severe. Sobsey also suggested that a "culture of abuse" often existed in certain institutions. This argument is supported by Furey, Nielsen, and Strauch (1994), who reviewed cases of substantiated abuse and neglect of mentally retarded adults in Connecticut. They found that such abuse and neglect is far more likely to occur in group homes and institutional settings than in private residences. Chenoweth (1996) acknowledged that there may be a "culture of cover-up" in institutions and group homes. However, she emphasizes the importance of other social factors in creating environments where abuses take place, including the dehumanization of residents in institutions, a "paradox of care and abuse within the one system," and the enormous power differentials between people and the system.

The rates of abuse experienced by disabled women are particularly high. Nosek et al. (2001) also stated that 62 percent of physically disabled women in their study reported experiences of sexual abuse. The Disabled Women's Network of Canada surveyed 245 women with disabilities in 1989 and found that 40 percent had experienced abuse, and 12 percent had been raped (Riddington 1989). The most frequent perpetrators in these cases were spouses and former spouses. Less than half of these cases of abuse and rape were reported.

A number of studies suggest that the vast majority of perpetrators of abuse are male and are known to the victim (National Center for Injury Prevention and Control 1998). Perpetrators of abuse include caregivers, family members, other disabled people, health care providers, and acquaintances. The fact that many disabled people have a number of caregivers in their lives, whose work often involves rather intimate tasks, may be one of the factors that puts them at increased risk of abuse. Social and personal boundaries are often at risk of being blurred in the provision of personal assistance (Saxton et al. 2001).

Some of the responses that have been developed to prevent abuse include the following: training programs for both potential victims and caregivers to increase awareness of abuse issues; sex education programs that emphasize choice making, personal rights, and assertiveness training; and staff screening programs involving reference and police checks to weed out convicted sex offenders from caregiving positions (Sobsey and Mansell 1990). It is essential that child protection workers, law enforcement personnel, and educators (particularly in special education settings) be provided with sufficient training to appropriately respond to cases of disability abuse.

Unfortunately, many child protection workers lack knowledge about disability issues. This lack of confidence in dealing with disability issues has led to the situation where disabled children are overrepresented among victims of abuse but underrepresented among the caseloads of child protection workers (Orelove, Hollahan, and Myles 2000). As a result, disabled victims of abuse often experience significant difficulty in accessing appropriate services. Over 50 percent of the services studied by Sobsey and Doe (1991) did not provide any accommodations to meet the needs of their disabled clients. Many professionals also report a lack of training in dealing with abuse histories of male clients, which may compound these problems (Lab, Feigenbaum, and De Silva 2000).

DISABILITY HATE CRIMES

Disability hate crimes are criminal acts aimed at people because of their disability identity, or because of their connection with someone who is disabled. To prove that a crime is actually a hate crime, there must be evidence to demonstrate conclusively that the perpetrator discriminated in the selection of the victim. There are two victims in hate crimes: individuals and communities. Hate crimes not only represent an attack on the rights and freedoms of individuals, they indicate a lack of physical safety for anyone in the community that has been attacked. Because hate crimes have two victims (both individuals and communities), offenders are often given extra penalties for these crimes.

The unique aspect of hate crimes is that they involve "parallel crimes" (Jenness and Grattet 2001:130). That is, there are two crimes embedded in a single act: a crime such as vandalism, theft, arson, murder, or assault, and another crime, a bias crime. To prove that a bias crime has occurred, it is necessary to demonstrate that the offender discriminates in the selection of his or her victim. To prove a disability hate crime exists, discrimination on the basis of real or perceived disability must be a substantial reason for discriminating against this particular individual. Evidence of hate can include words or symbols associated with hate, demeaning jokes about a particular group, the destruction of that group's symbols, a history of crimes against a group, a history of hate crimes in the community, and the presence of hate group literature.

Hate crime legislation typically outlines specific identity categories that are protected from bias crimes. This has led some critics to suggest that there is a hierarchy of protected categories, with race, religion, and ethnicity being the least controversial categories and gender, sexual orientation, and disability being the most controversial (McPhail 2000). In *Hate Crimes: Criminal Law and Identity Politics,* James Jacobs and Kimberly Potter (1998) argued that protecting certain categories of identity generates political conflict, produces an overly negative picture of intergroup relations, and creates recurrent occasions for intergroup conflict. The proponents of hate crimes legislation counter these arguments by arguing that the legislation responds to, rather than creates, intergroup conflict—particularly the violent suppression of marginalized identities and the violent defense of hegemonic identities.

Hate crimes tend to be associated with high levels of violence. Compared to other forms of crime, hate crimes are far more likely to involve physical threat and harm to individuals, rather than property. Victims of a hate crime are three times more likely to require hospitalization than victims of a nonbias assault (Bodinger-DeUriate and Sancho 1992). In one study, half the victims of hate crimes were assaulted. This is a significantly higher rate than the national crime average, where only 7 percent of crimes involve assault (Levin and McDevitt 2002:17). The psychological consequences of hate crimes also seem to be more significant than those for nonbias crimes, in terms of depression, anger, anxiety, and posttraumatic stress (Herek, Gillis, and Cogan 1999; Herek et al., 1997).

Many hate crimes are committed by complete strangers—people who do not know the victim at all. Hate crimes are also often unprovoked (McPhail 2000). This aspect of the crime reinforces the sense that it is not something about the particular individual, but simply the person's shared identity with a collective group, that is the source of the victimization. In fact, this aspect of the crime is often seen as pivotal in establishing that the act was a hate crime rather than another form of crime.

Only a very small minority of disability hate crimes involve organized hate groups. However, it is important to acknowledge that some organized hate groups also overtly display their hostility to disabled people. Some neo-Nazi groups rely on eugenic ideas to debase disabled people and deny the right of disabled people to live. For instance, the white supremacist group Stormfront often discusses the need to "eliminate bad genes" and rid the world of disabled people.

Hate crimes often involve multiple perpetrators (whereas most assaults usually involve two mutual combatants), and often the victims are unarmed while the perpetrators are armed (Bodinger-DeUriate and Sancho 1992). Also, perpetrators of hate crimes often do not live in the area where they commit the crimes. They frequently spend time and money in traveling to unfamiliar areas in order to perpetrate the crime (Medoff 1999). And in most property crimes, something of value is stolen, but hate crimes that involve property are more likely to entail the destruction rather than the theft of that property (Medoff 1999).

Few countries retain national data on disability hate crimes. Often these crimes are not reported to police, or not recorded even if they are reported. Even when crimes against disabled people are neither random nor circumstantial, they are almost never acknowledged as "hate crimes." However, the FBI has published some data on disability hate crimes in America, suggesting that the most common forms of disability hate crimes are assault, intimidation, destruction of property, and vandalism. FBI data on American disability hate crimes from 1997 to 2001 indicate that the most common forms of disability bias crime are simple assault and intimidation, both of which comprise 29 percent of all disability bias crimes. The next most common form of disability bias crime is destruction, damage, or vandalism, which comprised 14 percent of all disability bias crimes.

For a range of bureaucratic reasons, those agencies responsible for reporting hate crimes may not have reported all crimes in their jurisdictions. This is a problem generally with hate crime statistics, and not just disability hate crimes. One of the serious misgivings that has to be voiced about these data is that less than 2,000 of the eligible 17,000 law enforcement agencies have ever filed a report of any sort of hate crime—whether by racial, religious, gender, sexuality, nationality, disability, or other bias (Center for Criminal Justice Policy Research and Justice Research and Statistics Association 2000).

The problems with these data stem from the fact that submitting hate crimes reports is voluntary, not all jurisdictions within states submit reports, and time frames for reporting are uneven—ranging from one month to one year (American Psychological Association 1998). Another problem is that there is a great deal of inconsistency in the location of hate crime units, the nature and amount of training received by responsible officers, procedures for screening and handling cases, and record-keeping systems (Martin 1996). Balboni and McDevitt (2001) suggested that lack of departmental infrastructure, lack of training and supervision, and communication breakdowns between line officers and those responsible for reporting the crimes may inhibit accurate reporting of hate crimes. Green et al. (2001:295) commented, "One cannot compare jurisdictions that use different reporting standards or have different levels of commitment to the monitoring of hate crime." Potok (2001) argued that the process is riddled with errors, failures to pass along information, misunderstanding of what constitutes a hate crime, and even falsification of data. Despite these misgivings, it must be acknowledged that many police departments are making significant efforts to implement hate crime policies and to monitor the incidence of hate crimes in their jurisdiction. Other factors may contribute to the failure to report hate crimes in such circumstances (Haider-Markel 2001).

—Mark Sherry

See also Child Abuse; Violence.

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▣ ACCESSIBILITY

Accessibility is a term with no precise definition. In the disability field, the concept of accessible environments is used to describe environments that are approachable, obtainable, or attainable. Often this means that the environment can be altered to enhance the individual's probability to participate in that environment in a way that is meaningful to the individual. Such environments are thus viewed as accessible. In this sense, issues of access and accessibility are usually not discussed in isolation, but rather in terms of specific environments to which access is desired. Examples of environments where accessibility is discussed are communication systems, education, employment, health care, housing, information technology, medical offices, polling places, public transportation, and websites. This list is by no means exhaustive. Any environment can be deemed as one to which accessibility is desirable.

Accessibility is a distinct characteristic from both participation and the environment. By its nature, *participation* refers either to an act of taking part or to a state of being related to a large whole. *Accessibility* is not an act or a state but a liberty to enter, to approach, to communicate with, to pass to and from, or to make use of a situation. The *environment* is either that large whole or parts thereof or that situation which is accessed. From these distinctions, it is clear then that the elements of accessibility are characteristics of an environment's availability but not characteristics of the environment itself.

By its nature, accessibility is interactive. An environment that is accessible to one person may not be accessible to another. As such, accessibility references issues to the interaction of persons and their environment. Hence, questions can be raised as to whether an environment has been formed or designed in such a way that a person can approach, obtain, or attain some aspect that is desired by that individual. Yet some enhancement of the individual's ability to obtain such access may be desirable. For instance, Braille can make linguistic communication that is usually obtained through sight attainable to persons who are blind, but those persons must know how to use the sense of touch to access Braille. Thus, written communication will not be accessible to persons who are blind if both of these conditions do not obtain—(a) written works must be available in Braille and (b) individuals who are blind must know how to read Braille. However, even the second part raises an issue of accessibility—the access of individuals who are blind to training in Braille. In this sense, accessibility is not a static phenomenon but can occur across different planes.

For more than 30 years in the United States, the concept of accessibility has been legally codified in Section 502 of the Rehabilitation Act of 1973, which created the Access Board. The work of this board interfaces not only with the Rehabilitation Act but also with the Architectural Barriers Act, the Americans with Disabilities Act, and Section 255 of the Telecommunications Act. The board grew out of the creation by Congress in September of 1965 of the

National Commission on Architectural Barriers to Rehabilitation of the Handicapped. As a result of the commission's June 1968 report, Congress enacted the Architectural Barriers Act (ABA) on August 12, 1968. The ABA requires access to facilities designed, built, altered, or leased with federal funds. However, there were no design standards to determine the accessibility of facilities.

To address this lack of standards, Congress established the Access Board, originally named the Architectural and Transportation Barriers Compliance Board in Section 502 of the Rehabilitation Act. The board's mandate was to ensure federal agency compliance with the ABA, and it was constituted of representatives from several different agencies. In the Rehabilitation Act Amendments of 1978, Congress authorized the board to establish minimum accessibility standards under the ABA, to ensure compliance with the requirements and to provide technical assistance. In 1984, the board issued the "Minimum Guidelines and Requirements for Accessible Design," which now served as the basis for enforceable design standards. The 1990 Americans with Disabilities Act (ADA) expanded the board's mandate to include developing the accessibility guidelines for facilities and transit vehicles. Facilities covered by these guidelines are restaurants and cafeterias; medical care facilities; mercantile establishments; libraries; hotels, motels, and transient lodging; and transportation facilities and vehicles. Under the Telecommunications Act of 1996, Congress authorized the board to develop guidelines for the accessibility of telecommunications products. The board issued its guidelines in 1998. The Rehabilitation Act Amendments of 1998 give the Access Board additional responsibility to developing accessibility standards for electronic and information technology. The Access Board has established ongoing committees to develop and update its accessibility guidelines and standards, which include those representing designers, industry, and people with disabilities.

Beyond the United States, the concept of accessibility has been a critical element in international disability policy for more than 20 years. Access and accessibility are concepts that are addressed several times throughout the World Programme of Action Concerning Disabled Persons, passed by the United Nations General Assembly in 1983. The World Programme references a concern with cultural, physical, or social barriers that prevent the access of individuals with disabilities to the various systems of society available to other citizens. The concept of accessibility is discussed in conjunction with the definition of equalization of opportunities as the process through which the general systems of society are made accessible to all people. Although addressed several times in the World Programme, accessibility is mainly discussed in terms of those societal elements that should be made accessible to all, such as community services.

Passed by the General Assembly in 1993, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities uses the term *available* instead of *accessible* in the context of defining equalization, perhaps because one of the rules, Rule 5, employs the term *accessibility* a little more narrowly. Accessibility is divided in two main areas: the physical environment and the communication environment. In terms of the physical environment, the Standard Rules offer the possibility of legislation, standards, and guidelines to ensure accessibility to housing, buildings, public transport services, and other means of transportation and outdoor environments. Those designing these environments, such as architects and construction engineers, would, hence, have the means to acquire information on measures to achieve accessibility. The rules urge such consideration at the beginning of the design process.

For information and communication, the importance of access to information about rights, services, programs, and diagnosis is considered of paramount importance. The issue of alternative formats for persons with vision and hearing and other communication issues is raised, along with media and computer accessibility. To ensure such accessibility, the role of persons with disabilities and their organizations is stressed. If the more broad term of *availability* is considered as the concept of accessibility, then the rules offer guidance for accessibility in all the designated target areas for equal participation—education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion.

Somewhat more complicated than issues related to accessibility of the physical or built environment is addressing the issue of accessibility to programs, such as access to education. Prior to passage of the Individuals with Disabilities Education Act (IDEA) in the United States, individuals with disabilities were not in school until the idea of access to school as a civil right emerged. Upon passage of the act, progress was made in gaining access to school, in a physical sense. Then, accessibility involved the concepts of mainstreaming and least restrictive environment. The emphasis in each of these approaches to access was the setting, in particular the classroom setting.

While setting remains important, attention is increasingly focusing on curriculum access. To that end, the U.S. Department of Education's Office of Special Education Programs has provided funding to the American Institutes for Research to house a national technical assistance (TA) center called the Access Center. The center strives to improve educational outcomes for elementary and middle school students with disabilities by building the capacity of TA systems, states, districts, and schools, to help students with disabilities learn from the general education curriculum. The center's goals are as follows:

1. Increase awareness of research-based programs, practices, and tools.
2. Strengthen the ability of educators to be informed consumers of programs, practices, and tools.
3. Assist educators to implement and evaluate programs, practices, and tools.

The Access Center has developed a framework for thinking about access to the general education curriculum. It views access as a multidimensional and dynamic process that involves a combination of instructional practices and supports. Under this approach, the general education curriculum is operationalized in terms of appropriate instructional and learning goals for individual students with disabilities, including appropriate scope and sequence. Appropriate research-based instructional methods and practices that have a track record of helping students with disabilities learn general education content and skills would then be employed alongside appropriate research-based materials and media, as well as supports and accommodations. Finally, appropriate tools and procedures would be used to assess and document whether students with disabilities are meeting high standards and achieving their instructional goals. The center has noted the importance of universal design in providing accessibility.

Whether the discussion focuses on access to programs or to the physical environment, the two approaches for achieving accessibility have been considered to comprise accommodation and universal design. Whereas accommodation involves changing existing environments to enhance accessibility, universal design occurs at the environmental design stage, where products and environments are created to the greatest extent possible to be accessible to persons of all ages and abilities. Often one or both of these approaches are implemented based on practical considerations. When institutions are well established and cannot be redesigned, accommodation solutions may be chosen. When institutions need to be designed or redesigned, principles of universal design may be employed to enhance accessibility.

Accessibility can be viewed as a multidimensional phenomenon. At this time, at least four models attempt to more fully explain the concept of accessibility. The first is the World Health Assembly's adoption in 2001 of the International Classification of Functioning, Disability, and Health (ICF). (The World Health Organization's [WHO] classification systems must be approved by the World Health Assembly, which consists of the member states that belong to the WHO.) The ICF incorporates for the first time in a health taxonomy the systematic consideration of environments whose accessibility can be evaluated. Broad categories include products and technology, as well as the natural environment and human-made changes to the environment. These encompass many of the areas previously discussed. Also considered, however, are elements of a more sociological nature, such as attitudes and support and relationships. Finally, services, systems, and policies are included. These environments can be characterized as barriers or facilitators. Though it does not employ the concept of accessibility in a systematic way, the ICF does note that accessibility can be dependable or variable, as well as of good or poor quality. Not only that, but environmental access may be limited due to the presence of a certain phenomenon, such as stairs, or the absence of a phenomenon, such as a ramp.

The multidimensionality of accessibility has led to attempts to systematically define access and describe its dimensions. Some of the earliest work in this area was conducted not in the disability field, but in the area of access to health care. In 1981, Pechansky and Thomas defined *access* as a concept representing the degree of "fit" between the clients and the system. Recognizing the multidimensionality of access, Pechansky and Thomas proposed that five dimensions be considered:

1. Availability—Type and extent of services, supports, and resources relative to personal needs
2. Accessibility—Location of the environment
3. Accommodation—The way services and resources are provided relative to persons' abilities to make use of them
4. Affordability—The cost vis-à-vis the resources of individuals
5. Acceptability—The match in attributes and attitudes between providers and clients

This health care model of accessibility has been applied by Simeonnson and colleagues (Simeonnson et al. 1999) to persons with disabilities. They argue that the notion of "fit" is compatible with person-environment interaction. In this manner, accessibility is not only the location of the environment, but it also may refer to interaction with the environmental barriers, such as stairs, referenced earlier.

In a similar vein, Whiteneck and colleagues (Whiteneck, Fougeyrollas, and Gerhart 1997) have proposed five general characteristics of environments that influence how poorly or how well an individual becomes an active, productive member of society. Three terms (accessibility, accommodation, and availability) are used in both models and appear to correspond with each other. Their five dimensions are the following:

1. Accessibility: Can you get to where you want to go?
2. Accommodation: Can you do what you want to do?
3. Resource availability: Are your special needs met?
4. Social support: Are you accepted by those around you?
5. Equality: Are you treated equally with others?

The five characteristics do not constitute a classification of the environment or a ranking of the environment but a classification of different kinds of interactions that the environment has with individuals, with the environment as a reference point. Despite the use of the term *accessibility* for one of the interactions, this taxonomy of interactions can be viewed as an attempt to understand the dimensions of how environments interact with individuals or how such environments are accessible to individuals. In this case, the unit of analysis is the environment, rather than the fit interaction of the Pechansky and Thomas model.

A fourth model derives from the Handicap dimension of the International Classification of Impairments, Disabilities, and Handicaps (World Health Organization 1980) and classifies the dimension of access across planes of interaction, such as who, what, where and when. This system is more like the Pechansky and Thomas approach in that the unit of analysis may be individuals or the environment. The seven dimensions in this model are the following:

1. Orientation: Who—do you have information you wish?
2. Independence: What—do you choose what you wish to do?
3. Mobility: Where—do you go where you wish?
4. Occupation of time: When—do you engage when you wish?
5. Social integration: With whom—are you accepted by others?
6. Economic self-sufficiency: With what—do you have the resources you need?
7. Transition: Change—are you prepared for change?

This model attempts to meet the criteria of universality attempted in the ICF, but would constitute a dimension currently not distinct in it, although some elements may be present.

The dimensions of accessibility as elaborated in the four models have been proposed as potential elements for human rights frameworks relating to disability. However, their theoretical nature and the complexity of performing analyses at the level of interaction may inhibit their use in the short run.

—Scott Campbell Brown

See also Americans with Disabilities Act of 1990 (United States); Communication; Handicap; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Models; Participation; Rehabilitation Act of 1973 (United States); United Nations Disability Convention; United Nations Standard Rules; World Health Organization.

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ACCESSIBILITY CODES AND STANDARDS

There are many standards and codes that apply to building design. Accessibility is only one issue that codes address. Accessibility standards and codes have been developed to provide architects and other designers with clear guidance about how to implement accessible design. Accessibility codes are regulations promulgated by governments to implement laws that mandate accessibility. The term *guidelines* is also associated with accessible design, for example, Americans with Disabilities Act Accessibility Guidelines or Fair Housing Accessibility Guidelines. In some cases, guidelines may be more general than standards and codes. For example, a guideline might read, "Provide a space for turning a wheelchair" as opposed to a standard that could read, "Provide a space with a five foot turning diameter."

Accessibility standards that are developed in the United States by the American National Standards Institute (ANSI) A117 Committee are consensus-based documents developed for use as criteria in the design of buildings and facilities. The ANSI A117 Committee is an independent professional organization that oversees the process of developing standards. In Europe, accessibility standards are developed by the International Standards Organization and various public agencies. The European Manual for an Accessible Built Environment was developed to promote standardization in access across Europe. Yet it uses the more general form of a guideline. But in other cases, such as the Americans with Disabilities Act (ADA) and the Fair Housing Act, the term *guidelines* is sometimes used in place of the term *standards*.

While standards and guidelines are often voluntary and nonbinding, regulations and codes are always legal mandates. Standards and guidelines usually focus on the technical criteria for providing accessibility, for example, how much space is needed and the configuration of the space. Regulations, on the other hand, usually have technical criteria but also include rules defining the scope of accessibility—what types of buildings and facilities are covered, how many accessible elements are required, and when exceptions can be made. Regulations can reference standards. On the other hand, regulations do not have to reference standards. In fact, some U.S. state laws require the detailed technical criteria to appear directly in their regulations.

The content, form, and intent of accessibility standards and codes vary significantly from one society to the next. This variation is caused by differences in cultural attitudes toward accessibility, building technologies available, the local built and natural environment, the legal system, and the process for developing standards. Since the regulatory process is political, different interest groups can influence regulations while under development or revision. Consumer advocacy groups work to ensure that the scoping and technical criteria will satisfy the needs of their constituencies, while representatives of the building industry strive to make sure that the codes will not negatively affect their businesses. Design professionals and building officials seek to ensure that the codes will be understandable and enforceable. This process may be more democratic in some societies than others.

In general, accessibility regulations improve the level of accessibility in a jurisdiction. In places where accessibility codes are first being introduced, goals may be modest, whereas in places with a long history of accessibility codes, the goals may be much broader and the criteria much more inclusive and restrictive. The differences in goals can apply within a jurisdiction due to differences across sectors of the building industry or across types of construction. Thus, in the United States, new efforts to mandate accessibility to detached single-family homes are focused primarily on homes built with public funding because there is much political opposition to regulating the design of privately built homes. As another example, the ADA Standards for Accessible Design apply only to new construction and those portions of buildings undergoing renovation. In existing buildings, only "readily achievable" modifications to remove barriers to use need to be provided. Readily achievable modifications are a far lower standard.

Accessibility standards may be organized together in one document or dispersed among several. Most accessibility standards are independent stand-alone documents that include criteria for general design issues and specific criteria for many built elements. In some countries, such as in Sweden, criteria for accessibility to different parts of buildings have been incorporated into standards for those elements. The advantage of having an independent inclusive document is that the human and economic resources needed to develop, monitor, interpret, and improve the standards are easier to assemble and organize. When accessibility standards are dispersed in many different documents, each developed by a different industry, expertise is diffused among many different committees. Moreover, the coordination of criteria can be an overwhelming task.

Accessibility standards are generally organized into several parts. The first part is an introductory section that explains the purpose of the document, describes how it should be applied, and provides definitions of technical terms used in the document. The second is often a technical section that covers the main issues of accessibility, for example, wheelchair sizes, clearances for wheelchair maneuvers, and reach limits. Other sections of the document follow with provisions for specific parts of buildings and facilities, for example, parking lots, entrances, interior circulation, and toilet rooms. These sections include technical criteria and usually include any exceptions to the rules.

In the United States, the legal implications of misinterpreting the detailed technical criteria are great, and as a result there is a tendency to provide extensive text and great detail, referred to as the “prescriptive” approach to standards writing. Some U.S. experts feel that the more flexible “performance” standards approach is desirable, leaving room for new and innovative ideas to emerge, and encouraging the development and use of new products. The European Union’s guidelines are much more “performance oriented,” specifying the objectives to be reached rather than the means. This performance approach is clearly appropriate in Europe where the guidelines have to be used in a very diverse set of legal and built contexts—an approach that works in Italy, for example, may be totally inappropriate in Denmark.

Accessibility codes may include the scope of application, the method by which the code will be implemented, a process for design review and appeal, referenced standards, exceptions, penalties for noncompliance, and other administrative issues. If the accessibility code is a part of a general building code, most of this material will be covered by general sections of that building code. In other cases, there may be a separate administrative process. Many of the states in the United States have a separate accessibility code committee that works independently of the general building code process.

Exceptions and variances are an important part of any standard and code. They define the specific situations where the rule may be waived or altered. There are many examples where the provision of full accessibility, as defined by a standard or code, may be infeasible. For example, historic buildings sometimes cannot be made fully accessible without destroying their cultural value. Building codes usually include provisions that allow some flexibility in renovation of such buildings. Other reasons for exceptions and variances include unusual topography, geological conditions, climate factors, very small size, uninhabited structures, and short-term or temporary structures. In general, blanket exceptions are not usually needed or allowed.

Accessibility standards and codes in the more industrially developed countries are often complex and highly technical. They often represent a significant change in the practice of building design, especially for certain types of buildings such as civic buildings where monumental stairs are traditional. Many countries have experienced difficulties actually implementing accessibility standards, even those with highly educated professional designers and extensive building regulatory apparatus. These countries are gradually adopting new approaches, often modeled on the experience of the United States, Canada, or Western European countries.

At an international level, there are certainly many factors that suggest that there should be differences in standards across countries and within regions of a country. The use of Imperial units of measurement in the United States is clearly an important difference that cannot be ignored. Another factor that encourages differences in standards is attitudes toward disability and rehabilitation practice. Northern European experts criticize U.S. standards for toilet stall sizes because, in the United States, space on either side of a toilet with fold-down bars is neither provided nor allowed. On one hand, the Northern Europeans believe that a toilet stall should be usable for a transfer from either side, whereas the U.S. experts believe that it is important to have the side grab bar mounted on a wall to provide additional stability and support, thus eliminating the possibility of transfer from that side. U.S. code groups have also not been willing to accept the fold-down grab bar that is needed for this type of design as an alternative to the fixed wall mounted bar, believing that many people with severe disabilities will have difficulty moving the bar.

In spite of the need for national or regional differences in standards and codes, consistency of standards around the world would be very useful, especially as international travel and tourism become increasingly popular. To participate in our global culture, people with disabilities need to be able to find facilities that they can use wherever they may travel. Moreover, international standards could be adopted by international agencies and multinational corporations for application to their facilities around the world. International standards would make it easier for less developed countries to make progress in accessibility more rapidly. However, it is important to consider the implications of such a development. There is a tendency to adopt the standards and codes of countries where accessibility laws are more advanced as models.

But this may not be the most appropriate approach for places in the world where accessibility to the built environment is a new idea. The adoption of an unrealistic standard or code could easily lead to widespread lack of compliance and therefore no progress at all. Countries that do not have an educational and regulatory infrastructure developed to ensure that standards and codes will be implemented should consider a different approach, one that is more realistic, easy to communicate, and easy to enforce. Thus, at this point in time, international standards should probably include a minimal set of "must have" requirements. They could have more extensive optional requirements. But they should be performance oriented and designed for flexible application to different local conditions.

—Edward Steinfeld and John P. S. Salmen

See also Fair Housing Act Amendments of 1988 (United States); Home Modification; Housing: Law and Policy.

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ACCESSIBLE INTERNET

Accessible Internet is the manner of creating websites that are as usable as possible by web surfers with disabilities. To access a website, individuals with disabilities rely on assistive devices, such as screen reader software, which translates information on a computer screen into automated audible output, and refreshable Braille displays. However, there has been continuous concern surrounding the issue that the information that disabled persons receive from a website may not be equivalent to the information that individuals without disabilities get. With rapid advances in Internet technology, assistive technology has had considerable difficulty in keeping up with web browsers with special features: electronic forms, HTML tables, style sheets, multimedia presentations, applets and plug-ins, scripting language, and more. Therefore, the designer of the website needs to provide the information carried by the special features in the formats/methods that assistive devices can easily use. For example, a screen reader cannot describe a picture, but it can convey the text information to the user who has visual impairments. Thus, the provision of special feature information by web designers is imperative for the most efficient use of assistive technology within Internet technology.

Section 508 of federal law has established design standards for federal websites to be compatible with existing and future assistive devices. However, these standards do not apply to private sector websites, which might not be prepared for products of assistive technology. The proposal of Section 508 was first initiated in 1996, when the U.S. Department of Justice asserted that the Americans with Disabilities Act (ADA) would apply to the coverage of websites. Two years later, former President Bill Clinton signed into law the Rehabilitation Act Amendments of 1998, which included the legislation component of Section 508. According to Section 508, federal websites must be made accessible to individuals with disabilities (federal employees and the general public), unless an "undue burden" is imposed on the department or agency. In addition, the Architectural and Transportation Barriers Compliance Board (Access Board) was required to establish and publish technical standards, among others, for federal websites to ascertain compliance with Section 508. In December of 2000, the Access Board published final rules, and the enforcement provisions of Section 508 took effect in June 2001. Many state governments are following the federal example. Nearly every state now has some sort of web accessibility policy, and more than 20 states have accessibility laws modeled on Section 508.

The Access Board's standards are based on access guidelines developed by the Web Accessibility Initiative of the World Wide Web Consortium. Issues such as the usability of multimedia presentations, image maps, style sheets, scripting languages, applets and plug-ins, and electronic forms are addressed within these standards. The provisions do allow the use of such advanced web technology or enhancement technology but require that equivalent information be provided in a format compatible with assistive technology.

A website required to be accessible by Section 508 would be in complete compliance if it met the standards of paragraphs (a) through (p) of the final rules' Section 1194.22. Most of these provisions ensure access for people with vision impairments, although some provisions address the needs of individuals with both visual and hearing impairments. Paragraph (a) requires that a text equivalent for every non-text element, such as photographs, images, and audio presentations, be provided. For example, when audio presentations are exhibited on a web page, text, in the form of captioning, must accompany the audio, to allow people who are deaf or hearing impaired to comprehend the content. Furthermore, when an arrow image is used to indicate a navigational action such as "move to the next screen" the image must be accompanied by actual text that states the purpose of the image. Similar to audio presentations, when an image is used to represent page content, the image must have a text description accompanying it that explains the meaning of the image.

Paragraph (c) does not prohibit the use of color to enhance identification of important features, but it does prohibit its use as the single method for indicating important information on a web page.

Moreover, paragraph (d) does not prohibit the use of style sheets that allows website designers to create consistent appearing web pages that can be easily updated. Instead, it requires that these web pages employing style sheets can be read accurately by browsers that do not support style sheets, as well as browsers that have disabled the support for style sheets.

Paragraphs (e) and (f) address image maps that provide different "links" to other web pages, depending on where a user clicks on the map. Client-side image maps, as opposed to server-side maps, can display links related to the map in a text format that can be read with the use of assistive technology. By contrast, a server-side map cannot. Therefore, when only a server-side map is available, a web page designer must add the equivalent text link.

Paragraphs (g) and (h) permit the use of tables but require that the tables be coded according to the rules for developing tables of the markup language used. If row and column headers are not identified for data tables, some assistive technology cannot accurately read the content. HTML table codes must be used to associate data cells and header cells for data tables that have two or more logical levels of row or column headers.

Paragraph (i) addresses the use of frames, a common technique used by web designers to create different "portions" or "frames" of their screen that serve different functions. This provision requires that frames be titled with text to identify and assist in navigating the frames by labeling them as "navigation bar" or "main content."

Paragraph (l) handles the use of special programming instructions called "scripts." When pages use scripting languages to display content, or to create interface elements, the provision requires web page authors to ensure that all the information placed on a screen by a script shall be available in text format for assistive technology.

Paragraph (n) requires that people with disabilities have access to interactive electronic forms. When electronic forms are designed to be completed online, the form must allow people using assistive technology to access the information, field elements, and functionality required for completion and submission of the form, including all directions, feedback, alerts, and cues.

Some provisions apply to individuals with hearing impairments or to overall individuals. Paragraph (b) provides that real-time captioning of an audio be provided. However, providing captioning does not preclude posting a transcript of the speech for people to search or download, although the real-time captioning is usually preferred over the delay in providing a transcript. In addition, paragraph (j) sets limits on the blinker or flicker rate of screen elements (a frequency greater than 2 Hz and lower than 55 Hz). Furthermore, paragraph (m) requires that web pages that provide content, such as Real Audio or PDF files, also provide a link to a plug-in that will meet the software provisions. Moreover, paragraph (o) mandates that a method be used to facilitate the easy tracking of page content that provides users of assistive technology the option to skip repetitive navigation links. Finally, paragraph (p) dictates that when a timed response is required, the user be alerted and given sufficient time to indicate more time is necessary in order to respond.

Congress established the Compliance Office to monitor federal law relating to employment of and access to public services and accommodations by disabled persons. One compliance case illustrates a growing demand for accessible websites for people with disabilities. In October 2002, the Atlanta-area people with disabilities complained about numerous problems they experienced with accessibility in the Metropolitan Atlanta Rapid Transit Authority (MARTA) website, including difficulties in obtaining schedule and route information in an accessible format. This information was available on the MARTA website, but people who used screen readers to access the site could not get complete access to schedule and route information. It was ruled that although MARTA provided information to people with visual impairments over the telephone, this service was not equivalent to that provided over the Internet to nondisabled passengers.

Web pages accessible to individuals with disabilities offer practical advantages that go beyond simple access. On March 13, 1998, President Clinton issued an executive order ensuring that the federal government assume the role of a model employer of adults with disabilities. The order addressed the concern that people with disabilities are markedly less likely to be employed, even though they received comparable levels of education to people without disabilities. For example, less than half of the people with significant disabilities who have a college education are employed. In the same year, Congress passed the 1998 Government Paperwork Elimination Act, which required that federal agencies make electronic versions of their forms available online when practicable, and allow individuals and businesses to use electronic signatures to file these forms. Electronic forms are a popular method used by many agencies to gather information or to permit a person to apply for services, benefits, or employment. Because Section 508 requires all electronic forms to be made available to individuals with disabilities, accessible web pages may have enhanced employment opportunities for disabled persons. Furthermore, accessible Internet may also have enhanced the productivity of federal employees with disabilities.

Advantages offered by accessible web pages are not limited to federal employees or federal job seekers with disabilities. Because accessible format often means better structured code that follows the standards of the World Wide Web Consortium, the compliant code can give better search engine rankings by separating the content of pages from the code required to style or present the pages. The ratio of information to overall code on the page increases, which becomes more attractive to search engines. The code also makes atypical web browser devices, such as Internet-able cell phones or PDAs (personal digital assistants), to assist in more effectively using the site. Again, this is due to the separation of content. In addition, the site is more effective as a communications tool. Accessible Internet makes its site more available to dial-up Internet users, since accessible standardized code is often smaller in size. Being accessible can also help increase customer base. Currently, there are 30 million Americans ages 21–64 with disabilities, comprising almost 20 percent of the U.S. population. The disabled are the country's largest minority group and collectively possess a disposable annual income of more than $175 billion. Although the Section 508 requirement does not apply to private sector websites, they will soon follow suit to address the growing trend of use of Internet and the diversity of Internet users.

Section 508 does not require that assistive technologies be provided universally. The standards of Section 508 focus only on compatibility with existing and future assistive devices. Provision of assistive technologies is still governed by the reasonable accommodation requirements contained in Sections 501 and 504 of the Rehabilitation Act. However, Section 508 does not require that assistive devices be purchased, although it does require that covered electronic and information technology be capable of having such devices added at some later time as necessary. Therefore, Section 508—accessible web page design—is insufficient to ensure accessible Internet. Access to a computer is a prerequisite for the use of the Internet. But unlike persons without disabilities, they need alternative computer access tools for physical reasons. Examples of input methods include alternate keyboards, interface devices, joysticks, keyboard modifications, keyboard additions, optical pointing devices, pointing and typing aids, switches with scanning, scanners, and optical character recognition, trackballs, touch screens, voice recognition, and arm and wrist supports. Examples of output assistive devices include Braille embossers and translators, refreshable Braille displays, monitor additions, screen enlargement programs, and talking and large-print word processors in addition to screen readers and speech synthesizers mentioned earlier.

A recent study suggests that Internet use among persons with disabilities has beneficial impacts on health-related quality of life. It has been found that, after controlling for sociodemographic factors (e.g., race and education), a higher level of Internet use, among persons with spinal cord injuries, was associated with a higher quality of life, such as a higher self-perceived health status, a better health status compared to 1 year ago, less severe depression, a higher social integration score, a higher occupation score, more frequent contacts with friends, more business contacts, and higher levels of satisfaction with life. The study also found that there were significant differences in Internet access among specific subgroups, indicating more barriers among persons with less education and among African Americans and Hispanics.

In conclusion, accessible web page design enables people with disabilities to use the Internet—and assists in the better overall utilization of the Internet for everyone. However, accessible Internet cannot be completed without the availability of assistive technology. The finding of disparity in Internet use among specific groups may indicate the need for assistive devices. Moreover, accessible Internet is important because it can be related to better quality of life among persons with disabilities, in addition to practical matters such as better employment opportunities. Research commissioned by Microsoft and conducted by Forrester Research of Cambridge, Massachusetts, suggest that 60 percent of U.S. adults ages 18–64 and 57 percent of working-age computer users could benefit from accessible technology for vision, hearing, dexterity, or other impairments.

—Kyusuk Chung

See also Assistive Technology; Communication: Law and Policy; Computer Software Accessibility; Computer Technology; Information Technology; Rehabilitation Act of 1973 (United States).

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ACCIDENTS

Accidents occur everywhere and have always been a common feature of the human experience. Every year, large numbers of people across the world are injured and permanently disabled in accidents. Others are temporarily disabled and have to spend months, sometimes years, in therapy to regain their previous function. Despite the best intentions, accidents can occur anywhere: in the home, during transportation, in the hospital, on the sports field, and at work.

Road accidents are one of the largest contributors, in both the first and developing worlds, to the numbers of disabled people. The number of cars on the road increased steadily over the twentieth century and continues to rise in the twenty-first century. Despite ever improving safety features, large numbers of people are disabled in road accidents each year. Speeding is often the cause of accidents. This is not a recent phenomenon; before the Road Traffic Act of 1930, which abolished the speed limit, the courts and the police in Britain tried to cope with the hundreds of thousands of speeding cases each year as drivers exceeded the limit of 20 miles per hour. The Royal Society for the Prevention of Accidents was formed in 1916 as a response to the number of road accidents from the increasing numbers of cars on the road. A speed limit was reintroduced in Britain in 1934.

Besides vehicular speed, the nature of the vehicle can alter accidents. Motorcycles are particularly dangerous, and in the United Kingdom alone 28,000 motorcyclists per year are currently injured as a result of accidents. During World War II, 23,000 British servicemen were injured in motorcycle accidents. Other users of the road—bicyclists, horse riders, and pedestrians—are all regularly involved in accidents. In New York City in 1992, there were 3,250 bicycle-motor vehicle collisions, of which 17 were fatal. In the same year, there were 13,599 pedestrian-motor vehicle collisions, of which 294 were fatal, and 298 pedestrian-bicycle collisions, leading to 2 fatalities.

As well as the incidence of death, such accidents result in a wide range of injuries and often permanent disability. In an attempt to limit some of this damage, in some countries such as Australia, it is mandatory for children riding bicycles to wear protective helmets. Accidents involving buses are also responsible for large numbers of people becoming injured, although many countries are making seat belt use in buses mandatory to reduce the injury rate. Equally, safety features on cars including seat belts, side-impact reinforcement, and airbags have contributed to fewer injuries that result in permanent disability. Externally, cars have been fitted with bumpers that cause less damage to pedestrians who may be hit. Preventive measures such as campaigns on the dangers of drunk driving, enforcing speed limits and using cameras to catch traffic law violators, and educating children about road safety have raised awareness but seem to have little effect on the numbers of people disabled in car accidents. The World Health Organization has estimated that by 2020 road accidents will be one of the top three causes of death and disability.

Accidents on the sports field have long been the cause of disabilities. Since the rise of modern organized sports in the latter half of the nineteenth century, all sports, especially those involving contact, such as American football or U.K. rugby, have witnessed crippling injuries, disability, and death. One well-known person disabled in a sports accident was actor Christopher Reeve (1952–2004), star of the *Superman* films, who in 1995 fell off his horse in a jumping competition and was rendered tetraplegic. Sports such as horse riding are by their very nature dangerous and account for a high number of disabling injuries in any national statistics, as do traditionally dangerous outdoor sports such as mountain climbing, rappelling, and alpine sports. Since the 1970s, the number of sports that deliberately court danger, the so-called extreme sports, has grown rapidly and resulted in a concomitant number of injuries.

Sports accidents are not limited to adults; many children are injured in sports accidents, often causing disability. Contact sports are often more likely to be the sports in which people are injured, so rules have been changed and safety equipment introduced to reduce the incidence of accidents and severity of injuries on the sports field. However, such action does not eradicate injury. In ice hockey, for example, a 1994 survey found that 12 percent of players suffered accidents resulting in shoulder injury and 11 percent in knee injury, which can cause temporary disability and often result later in replacement surgery. In Ontario alone, 79 players had accidents that led to permanent disability or death, although with better safety regulations and improved on-site medical treatment, this number was reduced to 26 by 1992.

The home is a site for many accidents, and falls in particular are the cause of many disabling injuries. The success of home improvement programs on television has resulted in many people doing their own home maintenance, which has resulted in many accidents and permanent disability. In the United Kingdom, each year 3,900 people require hospital treatment as a result of accidents relating to home improvement activities, while 70 people are killed (50 alone from ladder-related accidents) and nearly 250,000 are hospitalized. Accidental fire caused by poor wiring or malfunction of electrical items in the home can cause disabling burns. For example, poorly wired or old electric blankets cause 5,000 house fires in the United Kingdom every year, which leads to 20 deaths and 200 disabling injuries.

Children can be disabled in the home by falls or from burns from boiling water, for example. In Britain, children celebrating Guy Fawkes Night on November 5 have become blind through accidents involving fireworks. In 2001, fireworks were responsible for 1,362 injuries, of which 469 required hospital treatment and 73 resulted in permanent injury.

Accidents involving procedures or medication can occur in hospitals, and these can cause permanent disability. These include brain damage caused by problems during birth, or in some cases people are given the wrong medication while in a hospital. It was estimated in 2002 that 2,610 American children died from infections caught while staying in hospital, while between 44,000 and 98,000 Americans died from preventable medical accidents.

Accidents involving ordnance left over from war or accidents involving noncombatants such as children occur every day. Since the end of the twentieth century, the focus of this problem has been land mine accidents. Land mines can be hidden in most types of ground, and they are designed to disable as opposed to kill. Unfortunately, they are difficult to clear and many civilians, particularly children, have been disabled by land mines. At present, it is estimated that there are 110 million active land mines buried across the globe. As a result of this huge number of active mines, more than 70 people are killed each day, and 300,000 children under the age of 16 are disabled each year. In less developed nations, where land mines are often located, problems of disability are exacerbated because there is little money for artificial limbs and aids to assist those who have lost limbs as a result of land mines.

Work is hazardous. In some occupations, the threat of accidents is very real, particularly in industries such as construction and mining where heavy equipment is used. Industrial accidents are associated with the modern age of factories, mines, and foundries. In the twentieth century, work was still dangerous and many people were still disabled as a result of accidents at work. Some disablement, such as “beat knee” or later “vibration white finger,” was caused by constant and repetitive work with machinery in the mining industry, or long-term exposure to dangerous materials such as asbestos. There was little in the way of safety equipment to prevent accidents, and long-term exposure to dangerous chemicals could cause severe disablement and death. Before factory owners were called on to make their workplaces safer, many workers were injured in accidents. When permanent disability was the result, often that worker was doomed to a life of poverty as there was often little in the way of compensation for their injury. In Britain, while the National Insurance Act of 1911 allowed workers to insure themselves against injury, the 1937 Workers Compensation Act was a more beneficial piece of legislation for those with permanent disabling conditions. In some cases, disabled people were seen as perfect for certain types of work. In World War II in factories in Britain, deaf people were employed in the very noisy occupation of shell filling because it was believed that no further damage could be done to their hearing. In less active occupations, the risk of falling, strains, or even stress can cause debilitating conditions that can mean that a person is unable to work and has to rely on state support.

Safer work environments and better compensation for workers were an aspect of the twentieth century. Despite that, there is still a potential for accidents whether it be in the home, as a result of a fall, or in some countries at war with each other, from the lurking and ever present threat of land mines. Accidents also continue to happen because of the natural fallibility of both technology and humans.

—Julie Anderson

See also Burns; Spinal Cord Injury; Sports and Disability; Traumatic Brain Injury.

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ACCOUNTABILITY

Persons with disabilities, as well as the general public, are increasingly demanding greater accountability from politicians, government bureaucracies, teachers, public school systems, physicians, and health care organizations. The term *accountability* is widely used by the public in diverse and changing contexts, which conveys different meanings of the term at various times and places. Although there are numerous definitions of accountability, in general, it is commonly understood to mean the giving of an explanation for the discharge of responsibilities entrusted to individuals or organizations. In short, accountability is a reckoning, or a justification of conduct.

To have accountability, three mechanisms are required: the identification of the specific responsibilities given to an individual or organization, the provision of information about the actions that were or were not taken, and the availability of appropriate sanctions. Accountability provides a set of constraints on actions or omissions because someone or some organization is held responsible. Accountability also implies an implicit or explicit set of criteria against which comparisons are made, and then penalties or rewards are applied.

Individuals and organizations frequently deal with multiple, overlapping, and sometimes conflicting accountability systems. Some of the more common types of accountability systems include political, legal, bureaucratic, economic, moral and ethical, and professional accountability.

Political accountability refers to the democratic process by which national, state, and locally elected officials periodically submit their past actions to an electorate. Democratic control is based on ballot counts and the overall preferences of the voters. If a political official is viewed as having increased the public's well-being through appropriate actions and services, he or she will be elected to office again, if not, the person will be voted out of office.

Legal accountability systems are generally based on the relationships between an individual or organization and an outside controlling party. The outside party may be an individual or group in a position to impose legal sanctions or assert formal contractual obligations. Typically, these outsiders make the laws and other policy mandates, which the individual or organization is obligated to enforce or implement. Legal accountability relationships emphasize compliance and external oversight of performance. These systems typically use contracts, audits, inspector generals, oversight hearings, and court proceedings.

Bureaucratic accountability refers to large government and private sector organizations that require subordinates to both formally and informally answer to their superiors. The functioning of bureaucratic accountability systems requires an organized and legitimate relationship between superiors and subordinates in which the need to follow "orders" is unquestioned. Subordinates are under close supervision for meeting standards of performance, and they must follow explicit organizational directives, rules, regulations, and standard operating procedures. In these systems, the relationship is hierarchical and based on the ability of supervisors to reward and punish subordinates.

Economic accountability refers to the market relationship of consumers and providers. The marketplace operates on a supply-and-demand basis, with both consumers and providers expected to economize if buying and to maximize profits if selling. One type of economic accountability is corporate accountability. This type of accountability requires managers and board members of for-profit corporations to prudently and wisely use the human and capital resources of the firm to return a profit to the corporation's owners and stockholders.

Moral and ethical accountability systems are standards of good behavior that arise from conscience, religious beliefs and norms, and concerns for the general welfare of society. These systems reflect concerns with the concepts of how or by what means individuals and organizations choose a course of action and how they subsequently defend it.

Professional accountability refers to the relationships among peers with similar training and expertise. This type of accountability employs peer group pressure almost exclusively to discipline and reward its members, although licensing is the formal device for entry and expulsion from the profession. It relies on specific performance standards derived from professional norms and prevailing practices of peers. Because professionals have special knowledge and expertise, they are generally given much discretion, have a high degree of job autonomy, and are self-regulated.

Professions such as medicine, law, clergy, and university teaching are self-regulated for a number of reasons. Members of these professions tend to be carefully recruited and supervised. To be in good standing within the profession, members are required to follow and adhere to codes of ethics and practice standards (e.g., the American College of Physicians–American Society of Internal Medicine requires its members to advocate and assist medically disabled patients to obtain their appropriate disability status and to complete all disability evaluation forms factually, honestly, and promptly). To enforce their standards, these professions have their own review boards, which police individual members. Last, members of these professions have a fiduciary responsibility to place their clients' needs ahead of their own self-interest.

Professionals tend to have high prestige and power in society because of indeterminacy and uncertainty. Many of the tasks performed by professionals cannot be easily broken down or otherwise routinized (indeterminacy). Similarly, many professionals deal with areas of high uncertainty or risk for their clients.

Professional accountability in medicine is particularly difficult to determine. Accountability is problematic because of asymmetric information, difficulty in evaluating the outcomes of care provided to patients, and the ever-changing complex nature of health care medical errors that tend to frequently occur. Asymmetric information exists when one party to a transaction possesses more information than the other. Because of their years of training and experience, physicians have a much greater knowledge of health care and health than patients do. It is very difficult for patients to judge whether they received appropriate and efficacious care from their physicians. Some medical conditions are self-limited and patients will get well regardless of what physicians do or do not do. Conversely, other medical conditions are incurable and physicians can do nothing to stop them from progressing. Last, because of increasingly new and complex medical technologies, drugs, and treatments, and the sheer volume of care provided, medical errors commonly occur.

Attempts to hold physicians accountable for the care they provide are probably as old as the medical profession itself. For example, the 4,000-year-old Babylonian Code of Hammurabi, one of the world's oldest known collections of laws, contains several statutes that set fees for surgical operations and establish penalties for surgical errors. Specifically, a physician was held liable when a patient died as a result of an operation or lost an eye because of his surgical intervention. Penalties varied according to the social status of the patient. The penalty for death or loss of an eye in the instance of an upper-class person was having the physician's hand cut off, but only compensation was required from the physician in the cases of commoners or slaves. This is the earliest recorded instance in history of the legal consequences for medical malpractice.

The Hippocratic Oath, written more than 2,000 years ago, presents the first known ethical standards for physicians. In the oath, the Greek physician Hippocrates, the father of Western medicine, outlines the physician's duties and responsibilities. The oath is divided into two parts. The first part specifies the duties of the physician toward his teacher and his obligations to transmit medical knowledge; the second part gives a short summary of medical ethics. Some of the ethical duties of the physician include keeping patients from harm and injustice, not dispensing deadly drugs, not giving a woman an abortive remedy, not indulging in sexual contact with patients, and not divulging confidential patient information. To this day, many physicians graduating from medical schools throughout the world recite the oath or some modification of it.

An important figure in modern professional accountability in medicine was Ernest A. Codman. In the early 1900s, Codman, an eminent Boston surgeon, was one of the first to apply outcomes management concepts to medical care. Specifically, he developed a system of tracking the long-term outcomes of hospital patients to identify clinical success and failure (e.g., medical complications and preventable deaths) to improve the care of future patients. He also believed that this information should be made public so that patients could be guided in their choices of physicians and hospitals. Unfortunately, his ideas were not accepted by the medical community of the time. And his work was forgotten for decades.

Since the 1980s, there has been a large movement in the United States to measure and improve the quality of health care and increase the accountability of physicians, health care plans, and health care institutions. A number of factors were responsible for this movement. Large computer systems became widely available, which could cheaply and quickly analyze millions of individual patient insurance claim records. Government and business groups were increasingly concerned with the rising costs of health care, and they believed that improving the quality of care would help keep costs down. And many managed care organizations wanted to closely monitor the costs and quality of care provided by the physicians they employed, and to hold them directly accountable for it.

As a result of these efforts, a number of medical quality indicators have been developed including various measures of clinical outcomes, operational performance, and patient satisfaction with care. Today, the federal government, many state governments, and several private sector firms compile and publish printed reports, and post on the Internet medical quality indicators of individual physicians, hospitals, managed care organizations, and nursing homes.

—Ross M. Mullner

See also Consumer Satisfaction; Health Management Systems; Hippocrates.

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ACTIVISM

Activism is a term used to characterize the activities of people with disabilities who are engaged in advocacy actions intended to advance their policy agenda at the local, state, or national levels. Activism refers to the active participation of people with disabilities in visible efforts to address the issues that concern them. Activism in the disability community can be distinguished from other forms of advocacy because it includes direct action and confrontational tactics. Conceptually, advocacy goals and strategic tactics can be placed along a continuum ranging from those that emphasize a high degree of confrontation and visibility to those that rely on them minimally. For example, acts of peaceful civil disobedience in which people with disabilities block traffic in a street or the entrance to an inaccessible store involve a high degree of confrontation and visibility. In the middle of the continuum would be less confrontational tactics, such as town meetings or rallies. Tactics such as signing petitions or building coalitions have a low degree of confrontation.

Activists in the disability community often refer to a sense of urgency for increasing the level of confrontation necessary to achieve their goals, as "time to escalate." Most disabled activists try to use tactics that generate media attention for their cause, which increases public sympathy for their predicament. However, using more confrontational actions also increases the likelihood of police repression and legal action against the group members. These are risks that advocates consider as they engage in the advocacy process.

The history and development of disability services and policies have been significantly marked by the critical role that a number of individual activists have played in promoting change. Of course, the actions of the leaders are almost always accompanied by the actions of many others who remain unknown but whose involvement is critical to the success in achieving a particular aim. The history of activism associated with the advancement of policies and services for individuals with disabilities in the United States can be categorized in two distinct periods.

The first period was led by professionals and other well-intended individuals who took upon themselves the task of starting institutions or services to help individuals with disabilities. Examples of leading activists of this time in history include Thomas Gallaudet, who opened the first American asylum for the education of the deaf in 1918 in Hartford, Connecticut; Francis Fauquier, who opened the first facility for mentally disabled individuals in Virginia in 1773; and Dorothea Dix, who advocated for the creation or expansion of asylum facilities for the mentally disabled from 1840 to 1870. With few exceptions (e.g., Helen Keller, Clifford Beers), individuals with disabilities themselves did not lead the efforts for reform during this period, being considered for the most part incapable of such a task.

The role of individuals with disabilities in charting their own destiny became the most important change during the second period of activism in the United States. Inspired in part by the civil rights movement during this period, individuals with disabilities themselves took the lead in organizing and leading the fight for reform. Examples include Ed Roberts, who was one of the founders of the independent living movement, and Judy Heumann, who founded Disabled in Action in 1970 to address barriers faced by people with disabilities. A vanguard of leaders with disabilities took direct action in several forms at historic moments thereby helping to create, energize, and sustain the disability rights movement. More recently, people with intellectual disabilities established a national organization called Self Advocates Becoming Empowered (SABE) to promote the closure of state-operated mental retardation institutions in the United States.

In this second period of activism, the broadness and complexity of social and policy changes gave rise to a variety of advocacy and social activist groups. During the 1970s, people with disabilities organized themselves to establish the first center for independent living in Berkeley, California. Federal funds for these community-based organizations were later expanded. This expansion was a direct result of disabled activists confronting the political unwillingness and perhaps even the ineptitude of the federal government that delayed, for several years, the enactment of the rules and regulations for the implementation of the Rehabilitation Act of 1973. On April 1, 1977, in various cities across the United States, disabled activists organized protests at the federal offices of the Department of Health and Human Services. The confrontational protest that occurred in San Francisco, California, stands out in history due to its length and the impact it had on social and political change. Wheelchair users, people who were deaf or blind, and people with developmental and other disabilities organized themselves to exercise their collective power and political might. The protesters held the regional offices hostage for 28 days, gaining national attention and resulting in an agreement with federal officials for the rapid establishment of the rules and regulations to implement Section 504 of the 1973 Rehabilitation Act.

Disability rights activists usually learn and practice direct action as part of single-issue, grassroots community organizing. For example, during the 1980s in the United States, many grassroots activists organized to gain access to accessible mainline public transportation through a group called ADAPT (American Disabled for Accessible Public Transit, now also called American Disabled for Attendant Programs Today). Their struggle for "lifts on buses" at both the national and local levels emphasized that disabled people had a civil right to access public transportation. By the end of the decade, these disabled activists had won a victory in the courts and access to mainline buses on the streets. They helped drastically change public opinion about civil rights for people with disabilities. They used the media effectively to portray the images of disabled individuals being arrested or being pushed to the ground by the police. They also chained themselves to buses and often engaged in civil disobedience. ADAPT developed a reputation across the country as the radical wing of the disabled movement that actually helped change the perception of people with disabilities as uninvolved and apathetic to their issues. These were people who were willing to die for their cause.

Activism is a cornerstone of democracy and, as such, epitomizes the role of the citizen as willing and entitled to act in benefit of the common good. Critical characteristics of a first-rate citizen are being informed in order to make sound decisions and being willing to join with others to act on relevant issues. In many ways, good citizenship is associated with social activism as a commitment for improving society for all its members. Typically, grassroots activism occurs within members of the educated middle class who have a sense of entitlement and are savvy about lobbying and advocating for their rights. Unfortunately, poor people with disabilities have been denied full citizenship rights for many years and have been segregated and marginalized from the decision-making forums of society.

A long history of oppression and discrimination against a particular group of people can lead to negative societal beliefs and low expectations about the group's capacity to transform the group's social reality. Individuals with disabilities have to overcome such a history, as well as self-defeating perceptions of their own inferiority and inadequacy, to become activists. It is precisely through active involvement in community change efforts that most people with disabilities develop their critical awareness and some radicalize themselves. In some cases, the fight for justice and equality becomes the reason to be, the reason to overcome barriers and discrimination. There is an obvious parallel with the perceived conditions that led to the civil rights movement in the United States.

Effective social change requires both critical reflection and understanding of the issues affecting a particular group, as well as careful planning of actions intended to generate the most impact with the least cost to the groups involved. Activism is focused on producing shock and getting attention to the issues. Good activists are always reviewing the impact of their actions and planning their next step accordingly. Typically, the activists' actions prepare the context for negotiations and compromises, and the actual agreements are usually reached in private meetings and with only a few representatives.

The members of the coalition or group leading the change effort have to be prepared to overcome unanticipated challenges, delays, attacks, setbacks, or diminishing resources. The strengths of the activists lie on their numbers, their resilience, and the fact that often their conditions are so desperate that they have nothing more to lose and a lot to gain by engaging in a particular struggle. In many developing countries, this kind of activism is leading to gradual improvements in services and policy changes to protect the rights of people with disabilities. Disabled organizers have learned effective strategies for social activism from community organizing, labor movements, civil rights movements, and other national efforts intended to promote social justice and political change. These models indicate that to achieve desired change, people with disabilities have to become actively and visibly involved in the struggle and that they should be ready to take some risks.

—Fabricio Balcazar and Rene Luna

See also ADAPT; Advocacy; Citizenship and Civil Rights; Consumer Control; Justin Dart; Empowerment and Emancipation; Independent Living; Ed Roberts.

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ACTIVITIES OF DAILY LIVING

Activities of daily living (ADLs) are most broadly described as those tasks that are commonly completed by most persons in a culture, often habitually or done repeatedly at regular intervals, and often serve as prerequisites for other activities (e.g., laundering clothes or taking them to the dry cleaners in order to have clean clothes to wear to work or for leisure activities). ADLs may be perceived as routine, but they may in fact be quite creative endeavors (e.g., choosing clothes to wear to create a certain "look," or cooking a meal in which ingredients are selected for complementary flavors and color). In particular, ADLs are important for the roles they serve in maintaining social life and connections with other persons.

ADLs are distinguished from productive activities such as paid employment, volunteerism, and education and also from leisure, recreational, and social activities. ADLs are sometimes divided into basic or personal activities of daily living (BADLs or PADLs) and instrumental activities of daily living (IADLs). The distinction may be somewhat vague and academic, although ADLs (or PADLs or BADLs) are more often activities that are related to taking care of one's own body while IADLs are more often activities that support others in addition to self and are often thought to be more "complex" in nature. Whether ADLs are distinct categories or simply two ends of a continuum remains open to debate, particularly among those involved in development of instruments that measure a person's performance on these activities.

ADLs (or BADLs or PADLS) include, but are not limited to, activities such as washing oneself, bathing and showering, bowel and bladder management, caring for one's own well-being and comfort, communication and communication device use, dressing, eating, feeding, functional mobility, personal devise care, personal hygiene and grooming, sexual activity, sleep/rest, and toilet hygiene. IADLs include activities such as caregiving, care of pets, child rearing, community mobility, financial management, health management, procuring and caring for necessities, procuring and maintaining a home, meal preparation and cleanup, and safety procedures.

It should be clear from the preceding lists that deciding whether an activity is an ADL or IADL can be quite arbitrary. For example, meal preparation could be regarded as part of self-maintenance, and communication and communication device use are just as often considered as ADLs as IADLs. In addition, while the concept of ADLs is distinct from productive, educational, and leisure activities, the categorization of particular activities is less clear. For example, some ADLs and IADLs may be performed for remuneration (such as grooming, home maintenance, child care) or for leisure (such as cooking, shopping). While activities may be broadly categorized as ADLs and IADLs, whether a particular activity is considered as such for a particular individual is much more dependent on the context and meaning of that activity for that individual.

Society often has expectations of how ADLs should be performed, and they are often used to describe what a person can or cannot do, what they need assistance with. These culturally accepted forms of performance are often based on how able-bodied persons might complete the task. This is of particular consequence because unacceptable performances of ADLs and IADLs are all too frequently invoked as indicators of disability. Particularly in Western cultures, inability to perform ADLs, particularly self-care activities, without assistance is a strong indication of disability.

The social disability model challenges this view. Social disability theory helps us to recognize that in the same way able-bodied persons may use a computer to order and have groceries delivered to their homes, or may choose to drive to work instead of taking public transportation to have more time and energy for work, a person with a disability may choose to have a personal assistant help with morning self-care activities to have more time and energy to be gainfully employed. Typically, however, the latter example is viewed as an indication of dependence while the former example is viewed as independence, even though all of these "time and energy saving" strategies require the assistance of other individuals.

Determining independence in ADLs is often narrowly defined as completing a task completely by oneself, which ignores the often highly social components to ADLs such as asking someone to stir a pot while more ingredients are added by another, having someone set the table while another finishes preparing the meal, receiving assistance with bringing groceries into one's home, or assistance with folding sheets after being laundered. Defining what "basic" components of ADLs should be completed alone, by an individual, in order to be considered independent are quite arbitrary and reflect goals and values of both the individual and the larger society. Often task completion is related not to independence but rather to notions of intimacy.

ADLs have also become linked to definitions of disability and dependence through the development of a wide, and ever-growing, range of assessments that rate a person's ability to perform ADLs independently or how much assistance they require to complete an ADL. In general, the items on assessment tools, which reflect only a small and rather impoverished number of ADLs, are commonly referred to as limited data sets. Often for reasons of time, cost, and efficiency, the number of items included is kept to a minimum and focus only on those activities that are not influenced by societal gender roles. For example, IADLs such as home maintenance and shopping are often thought to be more closely associated with women's roles. In addition, the ADLs selected for use within medical systems may be more a reflection of service delivery concerns rather than what is most important to the person and his or her family. Thus, the activities that have come to most commonly define ADL assessments (PADL or BADL) include eating, bathing, dressing, toileting, bowel and bladder control, functional mobility (transfers, walking, stair climbing), and sometimes grooming, and IADL assessments generally include telephone use, shopping, laundry, meal preparation, housework, and sometimes reading, driving, finances, and medication management.

ADL and IADL instruments are frequently designed to meet pragmatic goals, such as assessing the outcomes of treatment programs; to predict successful living in a home or community setting, need for assistance, or the need for nursing home care; and to evaluate the impact of impairments on daily life. Observational or self-reported scores of performance of ADLs are often used as a description of an individual's "functional status," or as a measure of "disability." ADLs are even used as a large component of, or even as a substitute for, quality of life, sometimes referred to as health-related quality of life. However, disability scholars have pointed out that "disability" is essentially a political term, connoting a status that arises from discriminatory actions of an able-bodied society that fails to take full account of the rights of all citizens and creates barriers to full inclusion.

A broader way of thinking about ADLs is as a person-task-environment transaction. A person-task-environment (PTE) transaction approach does not consider whether a person is dependent in ADL but under what conditions can a person successfully complete ADLs in a manner that he or she finds personally acceptable and satisfying. By viewing performance of ADLs as PTE transactions, the strengths and limitations of a particular individual, the specific components and requirements of the particular task, and the supports and barriers within the physical and social environment in which the person is performing the task are all considered of equivalent status in determining how successful and satisfying any particular ADL performance is. From this perspective, there are not prescribed or generally acceptable ways to perform or complete ADLs, but rather ways that are unique and personally acceptable. Instead of asking, "Can a person dress independently?" or "How much assistance does he or she need with cooking?" the question becomes, "Under what circumstances can or does this person get dressed or cook in a way that he or she finds most satisfying?" Thus, one person may choose to employ a personal care attendant to complete ADLs that are viewed as laborious in order to have enough time and energy to do the things that are most important, while another person chooses to adapt the environment, methods, or use assistive devises to complete the same tasks.

—Trudy R. Mallinson

See also Aids for Activities of Daily Living; Self-Sufficiency.

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ACUPUNCTURE

Acupuncture has been practiced in China for at least 2,500 years and is an essential component of traditional Chinese medicine (TCM). This practice involves the insertion of fine needles just beneath the skin's surface at specific points along clearly defined paths to treat a variety of different medical conditions. These paths, which are usually called channels or meridians, pass through every organ and are interconnected through a network of branches and collaterals. They all carry intrinsic life energy called *qi* (pronounced chee). Because of its emphasis on interconnectedness, acupuncture takes a holistic and nonlinear approach to treating health problems. In the past four decades, acupuncture has gained increasing acceptance in the United States and other Western nations and is now used increasingly by itself or as a complementary therapy in combination with Western medicine. Acupuncture is generally used to treat disability in two ways: to alleviate disabling symptoms (e.g., treating nausea in people undergoing chemotherapy) and to strengthen the body overall (e.g., creating an appropriate immune response in people living with HIV/AIDS or lupus).

TCM views the body as an integrated whole, with mind, body, and spirit as one indivisible entity. This medical system stresses finding and healing the underlying cause of ill health rather than treating individual symptoms. For example, while a Western doctor may prescribe the same medication for all of his or her patients complaining of chronic indigestion, an acupuncturist would first seek to discern the distinct energy imbalance in each patient and treat that accordingly. As a result, acupuncture treatment is unique and specific to each individual patient. Many believe that this holistic, patient-centered approach makes acupuncture particularly useful for treating the complex, chronic medical conditions associated with disability.

Fundamental to acupuncture and TCM is the concept of yin-yang. According to this theory, we find the opposing forces of yin and yang in all of nature. Yin energy is dark, damp, cool, earthy, and female, while yang energy is light, dry, warm, celestial, and male. Yin cannot exist without yang and vice versa. In addition to being interdependent, they are also the source of each other's genesis. Yin and yang are often described as “divisible but inseparable.”

Qi arises from the interplay and interdependence of yin and yang. It travels along an interconnected series of 12 major meridians and eight related collaterals called vessels to nourish every part of the body. On the skin, at least 350 points exist that allow an acupuncturist direct access to these meridians.

When yin and yang are in balance in the human body, an individual will be in good health, adaptable to many stresses, and able to fight off most pathogens. When yin and yang are unbalanced as a result of environmental, physical, spiritual, mental, or emotional stress, *qi* can become unbalanced, weak, and/or blocked. As a result, ill health occurs. According to TCM, people with chronic illness and/or disability are particularly vulnerable because they often face a multiplicity of stressors. For example, the stresses caused by multiple sclerosis, HIV, and type II diabetes typically result in a yin deficiency along one or more vital meridians in most individuals.

When an individual goes to an acupuncturist, he or she will be diagnosed through a process called the four examinations: (1) observation of the patient's overall demeanor and appearance with specific emphasis placed on the condition of the tongue; (2) inquiry about health including questions about pain, sleep, dizziness, appetite, thirst, and elimination; (3) listening to the patient's voice and breathing and checking for abnormal or strong body odors; and (4) palpation of the patient's body with specific emphasis placed on the pulse. In acupuncture, 12 different types of wrist pulses are observed that correspond with each of the 12 meridians. Acupuncturists have 28 different descriptive terms to accurately describe each pulse.

From the four examinations, the acupuncturist determines which energy channels and corresponding organ systems have unbalanced, blocked, or deficient *qi* and then inserts acupuncture needles into appropriate points along the appropriate channels in the patient's body. Sometimes an acupuncturist may also pass a small electric current through the needle in a process called electroacupuncture. The acupuncturist may also use other elements of TCM including *moxibustion* (the burning of the herb moxa close to the skin), herbs, dietary suggestions, and massage.

Although archeological evidence suggests that acupuncture has existed for at least 4,000 years, its recorded history begins with *The Yellow Emperor's Internal Classic,* the first text to outline acupuncture practice, compiled around 300 BCE. Two other texts form the backbone of acupuncture's early development and dissemination. In about 282 CE, Huang-fu Mi described the major acupuncture points, many of which are still in use today in *The Systematic Classic of Acupuncture and Moxibustion.* Last, around 1000 CE, Wang Wei-Yi compiled all existing knowledge of acupuncture, accurately charted the energy meridians, and described them in *The Manual of Illustrated Points for Acupuncture or Moxibustion.* He also commissioned two bronze figures with acupuncture points clearly marked and named, making it possible for acupuncture to be widely taught, researched, and disseminated for the first time. As a result, the practice of acupuncture traveled to other Asian countries, including Korean and Japan. The term *acupuncture* (*acu* = with a needle + *puncture*) was actually coined by Dutch physician Willem Ten Rhyne when he visited Nagasaki, Japan, in 1684.

Although some Western awareness of acupuncture has existed for centuries, it did not capture the Western imagination until 1971 when *New York Times* journalist James Reston was stricken with acute appendicitis while in China, covering Henry Kissinger's work toward normalization of that country's relationship with the United States. Chinese doctors operated on Reston using acupuncture instead of Western methods of anesthesia. When he returned to the United States, he wrote of his experience, piquing the interest of the American public.

Western medicine has been cautious in acknowledging the effectiveness of acupuncture, because *qi* and energy meridians cannot be detected through its methods. Much research has been devoted to finding a way to prove the mechanisms of acupuncture through Western methods. Current theories suggest that acupuncture works by directly altering the body's biochemical, bioelectrical, and/or neurological systems. While acupuncturists do not dispute these findings, they interpret them differently: They perceive these measurable changes as a manifestation of the correct flow of *qi* rather than a beginning and end result.

With increasing acceptance has come broader acknowledgment from government organizations. The World Health Organization compiled a list in 1979 of more than 40 medical conditions that lent themselves to acupuncture treatment. In 1996, the U.S. Food and Drug Administration shifted the classification of acupuncture needles from experimental to standard medical devices and approved their use by licensed practitioners. In 1997, the National Institutes of Health used stringent guidelines to create a consensus statement based on a review of all existing literature on acupuncture and clinical trials. The statement deemed acupuncture an effective therapy for treating postoperative and chemotherapy-based nausea and alleviating postoperative dental pain. The statement also noted that acupuncture could be an effective complementary therapy to Western medicine for certain types of pain, addiction, stroke rehabilitation, and asthma.

Acupuncture is used for people living with disability to relieve disabling symptoms and to strengthen an individual's overall body and immune response. Acupuncture's common uses for symptom relief fall into at least five categories. First, it can relieve nausea in people undergoing drug treatments such as cancer or HIV/AIDS chemotherapy. Second, it is used to alleviate dizziness characteristic of people with Meniere's disease, anemia, and other chronic conditions. Third, acupuncture is used as treatment for peripheral neuropathy in people with HIV/AIDS and type II diabetes. Fourth, acupuncture is often employed to treat symptoms and cravings associated with nicotine, cocaine, or heroin withdrawal. Fifth, acupuncture is used to alleviate chronic pain for many disabling conditions including fibromyalgia, osteoarthritis, and carpal tunnel syndrome.

Use of acupuncture to strengthen the overall well-being of an individual tends to require a systematic long-term series of approaches and techniques. It is often used in three ways. First, it may be used in conjunction with Western medicine to treat the energy imbalances that TCM believes exist in certain mental illnesses such as major depression and bipolar disorder. Second, it may be used to strengthen specific organs that are severely taxed by specific pathogens, for example, treatment of the liver and related meridians for people with hepatitis C. Finally, it can be used to strengthen and/or balance the overall immune system for people facing HIV/AIDS and autoimmune diseases such as lupus or multiple sclerosis.

—Martha E. Lang

See also Complementary and Alternative Medicine; Disability in Contemporary China; Experience of Disability: China.

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ACUTE AND CHRONIC CONDITIONS

This entry discusses acute and chronic conditions in the context of ability and disability. The focus of the discussion is the nature of different conditions and how they affect function. Clinical or case examples illustrate acute and chronic conditions that affect people and how they interact with their environment. Other entries in this encyclopedia elucidate many issues that directly relate to specific conditions and their functional impact; therefore, the examples found herein are for illustration only.

A *condition* in the context of ability and disability can be described in terms of physical, cognitive, or behavioral changes that affect one's ability to participate in functional activities. For example, osteoarthritis of the knee results in anatomic and physiological changes to the joint that render it less capable of bearing an axial load such as when bearing weight. The resultant loss of mobility renders the person less able to walk long distances or remain standing. The functional outcome of this limitation is less mobility independence. If this limitation is concurrent with other limitations (such as shortness of breath due to cardiovascular disease), then the person's independence might be impaired such that he or she would be considered disabled using standard societal definitions.

Using this definition, an acute condition is one that has an immediate effect on the individual. The type, degree, and severity of the condition may then produce functional limitations. The time course for an acute condition is generally short in duration, with most authorities such as the Centers for Disease Control and Prevention in the United States considering an acute medical condition as one lasting three months or less. Such definitions are predicated, however, on the immediate and accurate identification of the condition. For example, an individual with buttock pain present for 11 months that multiple physicians have failed to identify and treat adequately is evaluated by a consulting expert and found to have specific pathology affecting the piriformis muscle in the buttock. Shortly after the initiation of a treatment program for the specific problem, the condition completely resolved, rendering her fully functional. The condition cannot therefore be considered chronic in nature, but rather the result of inadequate identification of the acute condition.

It is for this reason that purely time-based considerations relating to acute conditions must be considered in their context. Some conditions will present themselves immediately or, with rapid progression, affect the individual, then abate, leaving the person fully functional at the conclusion of the condition. Others will affect the individual at the outset, with residual impairments that extend beyond the period of illness or injury. Polio would serve as an example of an acute illness that produces limitations that persist beyond the period of the infection.

In the United States, disability resulting from an acute condition can be measured in terms using temporary partial disability, temporary total disability, permanent partial disability, or permanent total disability based on the degree and severity of the impairment and its affect on the person's employability during the period of acute illness or injury. European systems offer a similar approach to temporary incapacity, with most systems considering the transition from acute to chronic disability occurring on or around the first anniversary of the onset of the disabling condition. Differing systems exist for the determination of income replacement when substantive improvement cannot be expected beyond the 360-day period of temporary disability. Most programs will use some formula for the determination of benefits at the determination of maximum improvement but may differ widely from state to state (as in the United States) or from country to country (as in the European Union).

From a biopsychosocial perspective, a more appropriate definition of an acute condition is one that manifests itself rapidly with demonstrable changes in function and one that in most circumstances will improve with appropriate identification and treatment. Some conditions, such as pneumonia or meningitis, will manifest themselves rapidly and result in either death or recovery with appropriate treatment. Other conditions represent the more immediate manifestations of a chronic condition (see below). Defining disability in acute conditions revolves around the duration that the impairment results in functional limitation.

A chronic condition can therefore be considered one for which there may be neither rapid onset nor rapid resolution. Some chronic conditions, such as spinal cord injuries, manifest different limitations during their acute and chronic phases. With many other conditions, chronic manifestations can be present even during the acute phase of the condition. For example, suffering behaviors can be identified in some individuals who are experiencing acute low back pain. This likely relates to that person's pain threshold and any other psychosocial factors or life stressors that might exist concurrent to the acute episode. Similarly, an acute psychosis may demonstrate features that represent an underlying and more chronic psychiatric condition. The goal of treatment of the acute condition is to reduce or eliminate the potential conversion to a chronic condition with resultant functional impairments.

Other conditions progress gradually over months or years and only become manifest or clinically evident when functional ability begins to decline. Various neurodegenerative conditions manifest themselves slowly over time, with functional limitations dependent on where in the course of the condition that person might be. Some chronic conditions have an exacerbating-remitting course, with acute phases interspersed with more chronic manifestations. Malaria, once considered virtually eradicated but increasingly evident in developing countries, is a good example of a condition with an exacerbating-remitting course superimposed on chronic disease-related manifestations. Therefore, as with acute conditions, chronic conditions do not require a specific time interval before being manifest, nor are they necessarily predictable in how they impair the individual. Nor does a chronic condition necessarily impair function. There are many chronic conditions, such as psoriasis, for which there are no specific functional limitations. The goal of treatment and rehabilitation of chronic conditions is to minimize the impairments that are due to the condition and when necessary to establish compensatory strategies (through the use of assistive devices, prostheses, or alternate methods to subsume the same activity).

The physical and functional manifestations of acute and chronic conditions can help differentiate their respective impact on the individual. Acute mycoplasma pneumonia will result in fatigue, lethargy, and respiratory manifestations. These acute changes will result in an immediate loss of endurance and strength, and they may result in shortness of breath that limits the individual's function. Once treatment is initiated, the condition will generally improve such that the functional limitations abate. In contrast, chronic obstructive pulmonary disease (COPD) results in similar feelings of fatigue, lethargy, and shortness of breath. Treatment for this condition is directed toward minimizing the impact of the condition and resultant impairments but generally does not change the underlying condition. With chronic conditions, there is a higher likelihood that treatment is more commonly directed toward palliative measures or treatments directed toward minimizing the impact of the condition rather than its elimination.

Other conditions, such as spinal cord injury, will manifest different functional impacts at different phases of the condition. Acute spinal cord injury results in significant hypotension that limits a person's ability to go from lying to sitting. This substantially limits rehabilitative efforts, necessitating aggressive measures to maintain blood pressure. In chronic spinal cord injury, a condition termed *autonomic dysreflexia* can occur (depending on the type and level of the paralysis) that results in overactivity of the autonomic nervous system. This overactivity causes severe increases in blood pressure that can be life threatening if left untreated. Aggressive measures must be taken to ensure that blood pressure does not rise uncontrolled. This example illustrates how treatments can differ substantially during the acute and chronic phases of the same condition.

Behavioral as well as physical manifestations can also be differentiated between acute and chronic conditions. Acute pain is most often associated with tissue trauma. As the tissues become traumatized, inflammatory mediators are released, initiating transmission by peripheral pain fibers to the central nervous system. After modulation at the spinal cord, the signal is then transmitted to the brain where pain is sensed. A simple example of this would be spraining one's ankle. Acute pain is usually described as local or regional in nature (i.e., the hip does not hurt if the ankle has been injured) and can be identified by appropriate diagnostic testing. The pain response associated with the acute event results in protective reactions that reduce function to an even greater degree. In the circumstance of an ankle sprain, weight bearing is limited both due to the original injury and as a protective mechanism to reduce further injury. Once the acute condition has either resolved or been treated, the functional limitation resolves. Chronic pain by contrast results from multimodal changes that occur both at the site of injury and more centrally. Additional behavioral changes are commonly associated with chronic pain. Due to the neurochemical and behavioral changes manifest in chronic pain, the same protective mechanisms fail to apply to the injured area or the whole person, resulting in continuing and persistent limitations.

The resultant physical or cognitive limitations of acute and chronic conditions impair the individual's ability to interact with his or her environment. Using the framework of the International Classification of Functioning, Disability, and Health (ICF), acute and chronic conditions represent only one of three dimensions that result in disablement. Specifically, an acute or chronic condition impairs body functions and structures. The result of that condition is the restriction of personal activities (dimension 2) that limits the person's ability to participate (dimension 3) in his or her environment.

Traumatic brain injury (TBI) is an example of a condition that manifests acute and chronic features and for which the functional limitations result in a loss of ability to participate in the environment. The acute phase of the condition is often manifested with spastic paralysis and profound cognitive impairment (dependent on the severity of the TBI). As a result, there is an immediate loss of bodily functions that include mobility impairments as well as cognitive alterations that limit the injured person's ability to interact with the environment.

In the chronic phase, there is some improvement of bodily and cognitive function such that the limitations experienced in the acute phase are less profound, or where compensatory strategies have been found for lost bodily functions. For example, a person with TBI would manifest limitations at the level of the person that consisted of right upper and lower limb weakness, speech limitations, and slowed cognitive processing and memory. This would result in activity-specific limitations (previously considered as an "impairment") including dressing, grooming, and toileting. As a result of these person-level limitations, the individual with a TBI would be less able to participate in activities requiring his direct involvement, such as driving a motor vehicle. Other functions, such as using an adapted computer for access to educational resources or memory augmentation, would not be impaired and could partially ameliorate other person-level limitations. The societal context of the person and activity level impairments relate to the external implications of the limitations. Using the ICF as the framework, these society-imposed "limitations" relate to access to public spaces, social service resources, and vocational opportunities. Exposure to negative societal attitudes and pity among "able-bodied" persons represent additional external factors that impair the ability of the person with TBI to interact within a social context.

It is therefore evident that acute and chronic conditions represent powerful contributors to the occurrence of disability. Acute conditions impair an individual's ability to engage in functional tasks during the period of incapacity. Some acute conditions produce long-term residual impairments that affect the individual well beyond the acute episode of illness or injury. Chronic conditions may represent the continuum of a condition from the acute to the chronic state, or may gradually affect function as the condition progresses. Both acute and chronic conditions result in limitations that can be defined at the tissue or organ level. These physiological or cognitive limitations will result in either temporary or longer-lasting activity deficits that can be expressed in functional terms. The disability that results from acute and chronic conditions results from internal and external factors that contribute to that person's ability to participate fully in his or her environment.

—Anthony Margherita

See also Accidents; Health; Pain; Spinal Cord Injury; Traumatic Brain Injury.

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ADAPT

ADAPT, the American Disabled for Attendant Programs Today, also called American Disabled for Accessible Public Transit, is a grassroots network of disability rights activists within the United States. Unlike many advocacy organizations, there are no monetary dues or membership cards. Individuals "join" ADAPT by becoming active within the ADAPT community. While the overall structure of ADAPT is informal, activities function at both local and national levels. There are more than 40 active local groups within 25 states and the District of Columbia. Each local ADAPT group develops its own style and structure, with decisions typically made through group consensus at meetings. Local groups often take on particular local issues but are united in a shared vision at the national level. For over the past decade, ADAPT's mission has focused on expansion of community-based attendant services and supports.

The origins of ADAPT trace back to Atlantis Community, located in Denver, Colorado. Atlantis Community was founded in 1975 as the second independent living center, following the establishment of the first in 1972 by Ed Roberts and fellow disabled students at the University of California, Berkeley. Simultaneous struggles for community-based independent living services and social justice prompted Wade Blank to found Atlantis Community. Blank was working in a nursing facility known as Heritage House with young disabled residents. After being fired for his advocacy to integrate the youths back into the community, Blank "freed" nine young disabled individuals from Heritage House, initially providing personal assistance services himself at no cost. Access to public transportation became an essential issue for this group in order to live independently in the community. On July 5–6, 1978, Wade and 19 disabled activists, using tactics of civil disobedience in the tradition of other civil rights movements, blocked buses with their wheelchairs and bodies and brought traffic to a standstill on the corner of Broadway and Colfax in Denver: American Disabled for Accessible Public Transit was born (this was the original name for the acronym ADAPT).

Demonstrations branched out nationally and intensified. Between 1983 and 1990 alone, ADAPT organized more than 20 protest actions in nearly every major U.S. city. The American Public Transit Association (APTA) and the Urban Mass Transit Administration (UMTA), now the Federal Transit Administration (FTA), were the targets. "We Will Ride!" was the rallying cry. The Urban Mass Transit law, passed in 1970, required wheelchair-accessible lifts on public buses, but regulations for implementation were delayed by the transit industry for more than 20 years.

ADAPT continued to gain public awareness through tactics of civil disobedience until regulations were finally issued in 1990 with the passage of the Americans with Disabilities Act (ADA). ADAPT played a key role in applying pressure within Washington to pass the ADA. In one of the largest disability rights protests to date, the "Wheels of Justice March" brought more than 600 demonstrators to the Capitol in March of 1990. ADAPT national leader Mike Auberger addressed the crowd, "We will not permit these steps to continue to be a barrier to prevent us from the equality that is rightfully ours. The preamble of the Constitution does not say 'We the able-bodied people.' It says, 'We the People'" (Shapiro 1993:133). With those remarks, dozens of protesters threw themselves out of their wheelchairs and began crawling up the 83 marble steps to the Capitol to deliver a scroll of the Declaration of Independence. The following day, 150 ADAPT protesters gathered in the center of the Capitol rotunda. Locking their wheelchairs together, they engaged in a sit-in until police carried away the protesters one by one. With the combined efforts of many individuals and organizations, the ADA moved quickly through Congress and was signed into law by President George H. W. Bush on July 26, 1990. On the second anniversary of the ADA, a plaque was dedicated by the city of Denver at the intersection of Broadway and Colfax, honoring the names of "The Gang of Nineteen"; a large mural on the inside wall of the transit station now memorializes the legacy of Wade Blank.

Following the victory around accessible transportation in 1990, ADAPT refocused its political objectives. Returning to foundational roots, ADAPT decided to tackle the issue of community-based personal assistance services. The acronym ADAPT was creatively reconfigured to stand for American Disabled for Attendant Programs Today. Many individuals active within ADAPT have lived, or still live, in nursing homes or other institutions. The struggle for community-based personal assistance services lies at the heart of the independent living movement. ADAPT has raised awareness concerning the "institutional bias" that exists within the United States long-term care system. Medicaid is the primary funding source of long-term care services within the United

States. Approximately 75 percent of Medicaid spending on long-term care funds services in nursing homes and other institutions. Nursing home services are mandatory for states participating in the Medicaid program, while community-based attendant supports and services are optional.

To correct the institutional bias in the delivery of long-term care, ADAPT has worked with legislators at the national level to introduce a number of pieces of legislation. The first bill (H.R. 2020 of the 105th U.S. Congress) was introduced on June 24, 1997, in the House of Representatives by Newt Gingrich. The bill was titled the Medicaid Community Attendant Services Act, commonly referred to as MiCASA. The MiCASA proposal required states to provide the option of community-based attendant services for individuals entitled to nursing facility or intermediate care facility services under the Medicaid program. Cost-effectiveness limits were embedded, so that aggregate spending on community-based services did not exceed what would have been spent on institutional services. Also, transitional money was proposed for states to change their systems of delivery. MiCASA was referred to the House Subcommittee on Health and Environment and garnered bipartisan support from 77 cosponsors. Congressional hearings were held in March 1998; however, the bill did not make it out of committee.

Subsequent versions of the legislation were reintroduced in the 106th, 107th, 108th, and 109th U.S. Congresses in both the Senate and House of Representatives. These versions became known as the Medicaid Community-Based Attendant Services and Supports Act, or MiCASSA. Senators Tom Harkin (D-IA) and Arlen Specter (R-PA) and Representative Danny Davis (D-IL) were among the members of Congress instrumental in developing MiCASSA with ADAPT. While each version has become more politically savvy, using federal reimbursement incentives, the general goals of the original version have not drastically changed. However, later versions of MiCASSA have embraced a more cross-disability perspective of disability, for example, incorporating mechanisms to address the needs of individuals who may require more support. In addition to MiCASSA, ADAPT has also been successful in getting another piece of legislation introduced known as "Money Follows the Person." This legislation also aims to rebalance the institutional bias in long-term care through demonstration projects that would allow individuals to move from institutional to community-based settings of their choice. While MiCASSA and Money Follows the Person have obtained administration and bipartisan support, they have not passed through Congress.

ADAPT continues to use tactics of civil disobedience to raise awareness of MiCASSA. Since 1990, more than 45 major actions have been organized by ADAPT around issues of community-based attendant services and supports. Examples of recent actions include the "Stolen Lives Campaign," in which more than 500 demonstrators converged on the White House to demand a presidential apology for individuals who have been forced to live in institutional settings due to lack of available community-based supports, and the 144-mile "Free Our People March" from Philadelphia to Washington, D.C., on the 20th anniversary of the Civil Rights March of 1963. Under the leadership of Bob Kafka and ADAPT at the national level, individuals with diverse disabilities and ages have united in solidarity. Hundreds of individuals have participated in direct actions at the national level, and hundreds of disability-related organizations at the local, state, and national level have signed on in support of MiCASSA. ADAPT's efforts have successfully led to some enactment of principles within MiCASSA through systems change grants under the Clinton and Bush administrations. As a single-issue grassroots organization, ADAPT has been extremely successful in uniting the disability community; and if the history of ADAPT is telling, the fight will continue until the rallying cry of "Free Our People!" is heard.

—Joe Caldwell and Larry Biondi

See also Advocacy; Americans with Disabilities Act of 1990 (United States); Independent Living; Ed Roberts.

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ADLs

See Activities of Daily Living

ADOPTION AND FOSTER CARE

Most children with disabilities are raised in the homes of one or both of their biological parents, but some grow up in other environments including adoptive and foster care homes. Although historically children with disabilities were considered not to be adoptable, by the end of the twentieth century that had changed. Greater recognition of the rights of persons with disabilities combined with the decreased adoption availability of healthy infants helped public attitudes to become more favorable toward adoption of special-needs children—those who were older, of minority race or ethnicity, who were members of sibling groups of three or more, or who had disabilities. These more favorable attitudes were reflected in federal laws in the United States such as the Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 and the Adoption Assistance and Child Welfare Act of 1980. This legislation expedited the adoption process by establishing adoption exchanges, training adoption workers, and offering financial subsidies for adoptive families, all of which promoted the adoption of children with special needs, including disabilities. In 2000 in the United States, 11.8 percent of all adopted children ages 5 to 17 had at least one disability, in contrast to only 5.2 percent of biological children.

Children with many types of disabilities have been adopted. Some disabilities are mild and correctable, whereas others are severe and life threatening. Although severity of disability and prognosis for a very limited lifespan are deterrents for some potential adopters, at least one-third of women currently seeking to adopt consider adopting a child with a severe physical or mental disability, and approximately 5 percent actually prefer to adopt this kind of special-needs child. As an example, in the 1980s and 1990s in the United States, the AIDS pandemic began to orphan children, some of whom were HIV-positive and therefore at high risk for both disability and early death. Many of these children were placed with foster families, became available for adoption, and were adopted. Although the number of pediatric AIDS cases in the United States is declining, worldwide it is increasing rapidly, and U.S. families who adopt internationally are at some risk for unknowingly adopting an HIV-infected child.

Children with disabilities become available for adoption in two ways. Some are relinquished voluntarily by their birth parents with the disability as a contributing factor, and others are removed involuntarily because of abuse and/or neglect. For example, several studies have yielded estimates that approximately 20 percent of children with Down syndrome are voluntarily relinquished for adoption by their birth parents, almost always immediately after diagnosis. This relatively high percentage results in a fairly large number of children with Down syndrome available for adoption, and some individuals and agencies have specialized in finding homes for them. Nonetheless, infants with Down syndrome are much in demand and agencies frequently report that potential adoptive families may need to wait for several years before one becomes available.

Many children with disabilities are adopted by their foster families, especially since 1997 in the United States when Public Law 105–89, the Adoption and Safe Families Act, was enacted. This legislation is quite complex, but it and state regulations and policies related to it have resulted in a number of improvements in children's welfare: The amount of time that children spend in foster care waiting for reunification with birth parents has decreased and the number of adoptions from foster care has increased, in some states by as much as 50 percent or more in just one year. Nationally, foster care adoptions grew from approximately 31,000 children in 1997 to 50,000 in 2001. Because many children in foster care have disabilities, it is anticipated that increasing the number of adoptions from foster care will also increase the number of adoptions of children with disabilities.

From the adoptive parent perspective, the rewards of adopting children with disabilities seem to far outweigh the difficulties. Many parents speak of the life-changing experiences of their adoptions and report positive changes in their marriages, their other children, and their understanding of life meaning. Parents also describe that they are proud of their child's achievements and that they delight in their child's positive characteristics such as an affectionate nature, a contagious sense of humor, and an optimistic outlook on life. One indication of the success of adoptions is that many families choose to do it again. It is not unusual for families to have adopted more than one child with a disability, and some families described in published research studies have, over their lifetimes, adopted more than 20 children with disabilities.

Nonetheless, there are also challenges in adopting children with disabilities. Along with rewards, many parents report problems, including a variety of negative child characteristics; worry, anxiety, or guilt relating to the child; an increase in family disharmony as a result of the child's adoption; and lack of emotional bonding to and from the child. Medical emergencies may be a common occurrence, and dealing with service providers can be a chronic source of stress.

Because many adopted children with disabilities have suffered neglect and physical and/or sexual abuse in their families of origin, psychological and behavioral issues related to these experiences arise and can cause problems such as oversexualized behaviors or a victim mentality. Identity issues also arise, sometimes exacerbated if the adoption is transracial or transethnic. However, there is no indication that disability, in general, is related to adoption disruption (termination before finalization) or dissolution (termination after finalization). Many studies, however, do confirm that both adoption dissatisfaction and disruption or dissolution are predicted by the children's behavioral disorders. Externalizing or acting-out behavior, in particular, is linked to adoption breakdown.

The adoption process consists of several phases. Family recruitment is often the first step because there are more children with disabilities waiting to be adopted than potential adoptive families for them. Children who are older and have emotional or behavioral problems in addition to other disabilities are particularly hard to place. Photo books and media presentations of waiting children are useful strategies, as are national recruitment efforts with children frequently adopted across state lines. Many potential adoptive families have initial preferences for the type of child they would like to adopt, but to expedite placements, agency workers may encourage parents to consider children who do not match those preferences, a practice called "stretching." Many successful adoptions result from some stretching, but disrupted and dissolved adoptions are likely to be poor matches between child and family.

Although there is no typical or ideal family for a child with disabilities, some characteristics are usually found in successful adoptive families. These include familiarity with child rearing and with disability; a family-centered approach, including high cohesiveness; and flexible parenting style. Neither higher parental education nor greater family income appears to be positively related to good outcomes, and some studies have actually found that families with lower incomes and less education are more successful, perhaps because their expectations for child achievement are less likely to be unrealistically high.

The adoption process is not complete even after placement and finalization. Postadoption services are essential for families adopting children with disabilities, and use of these services is known to be associated with low disruption. Postadoption service providers can help families identify, locate, and obtain assistance of a financial, educational, therapeutic, or medical nature. Issues related to child and family adjustment change as the child and the family enter different life stages, and access to ongoing or periodic treatment is important.

Although a permanent placement is the ultimate goal for all children, including those with disabilities, it is not always achievable. At the beginning of the twenty-first century in the United States, more than a half million children are in foster care, with an average stay of almost three years. Although some of these children will return to their families of origin, and some will be adopted, others will remain in the foster care system throughout their childhood. Years in foster care usually result in multiple placements, which put the child at additional risk for emotional and behavioral problems.

Research has shown that a majority of foster children have developmental delays and a variety of disability conditions. For children with extensive special needs including psychiatric care, treatment or therapeutic foster care has emerged as a viable option to residential care. Therapeutic foster parents are experienced and mature, and they are trained to be responsive to many of the difficulties that the children require. Typically, there are consultant clinical/psychiatric services available and utilized. Although the majority of children in foster care have multiple risk factors for poor outcomes, an enduring relationship with at least one supportive adult is protective. Thus, it is important that children in foster care be returned to biological homes if possible or be placed for adoption as soon as is feasible. If they remain in foster care until the age of majority, the transition to adulthood, including coordination with agencies serving adults with disabilities, needs to be managed.

—Laraine Masters Glidden

See also Behavioral Disorders; Childhood, Youth, and Adolescence; Developmental Disabilities; Down Syndrome; Early Childhood Intervention; Parenting.

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ADVERTISING

Advertising is defined as a paid, mass media-driven attempt to persuade selected audiences. Advertising messages, whether carried on traditional media (television, radio, newspaper and magazines) or nontraditional channels (e.g., Internet, kiosks in malls, signs in malls), are designed to provide the public with brand information, change their perception about a particular product, or motivate them to take action.

Although the definition seems simple, advertising is anything but simple. In the United States alone, more than $300 billion is spent each year on advertising campaigns targeted to various market segments. According to the National Organization on Disability (NOD) (Cheng 2002), the disability community is a market segment worth $220 billion in collective spending power each year. The 54 million people making up this segment represent 20 percent of the U.S. population. It is not surprising therefore that advertising and disability are linked. According to a 1999 report (Farnall and Smith 1999), more than 100 corporations producing general consumer goods were including people with disabilities in their television advertising campaigns. *Advertising Age,* a major trade publication in the advertising industry, addressed the connection between people with disabilities and major corporations by claiming it is just "good business sense" to use ability-integrated advertising. While these facts might be interpreted as an acceptance of people with disabilities in advertising executions, it is important to remember the percentage of people with disabilities in advertising is approximately 2–3 percent, well below the population percentage.

The debate over the social impact of advertising is particularly appropriate to this discussion. Advertising is first and foremost a business activity designed to improve the bottom line for companies, yet some research on advertising featuring people with disabilities supports the idea that there can be societal benefits to positive portrayal in advertising. Other social science studies have found either no effect or negative impact such as when the portrayal included physically disabled females interacting with nondisabled males.

The history of advertising targeting people with disabilities is fraught with many of the same ethical issues (stereotypical representations, absence from the media) other minorities have encountered. And the power of a message that is intended to persuade cannot be overlooked in a discussion of that history.

HISTORICAL DEVELOPMENT

The association between advertising and the disability community can be segmented into two major periods approximately separated by passage of the 1990 Americans with Disabilities Act (ADA). Prior to the ADA, advertising featuring people with disabilities was either promoting a product developed specifically for that target and placed in disability media or designed to raise money for various causes. About the time Congress was considering passage of the ADA, marketers began to acknowledge the economic potential of the disabled community. Consequently, the appearance of disabled characters in consumer goods advertising mushroomed and ability-integrated advertising became much more commonplace.

Examples of Early Advertising

A search of the archives of the National Museum of Advertising History at the Smithsonian Institution uncovered a limited number of examples of early-twentieth-century advertising containing images of people with disabilities. The examples that were found fit into one of two groups. The first group of ads dates back to the 1920s and is the most unflattering portrayal of people with disabilities. It is characterized by line drawings of disfigured bodies just waiting for replacement limbs and raucous posters of sideshow attractions such as General Tom Thumb and the Fiji Mermaid. Often these same posters exaggerated the physical differences of the celebrity, such as one poster that enlarged the head of the famous general to make his body appear even smaller than his 3-foot frame.

The other group of ads could be labeled as charity advertising. Typical of this group are the “poster child” print ads for nonprofit organizations and the heart-breaking TV spots aired during the telethons of the 1970s. In these advertising executions, the visuals usually featured a child in a wheelchair or with braces and crutches. The voice-over copy was usually dramatic and poignant. In its most bold form, the copy portrayed a person whose life needed to be changed and who was condemned to a pitiful existence without contributions.

Fortunately, the trend in charity advertising shifted away from that approach to a more positive theme in the 1990s. For example, in 1995 the National Easter Seals fund-raising event moved away from the old-style “telethon” to a 20-hour televised program featuring more entertainment and theme segments on acceptance of children and family members with disabilities. In 1998, the marathon event was dropped completely by the group.

Transition to Ability-Integrated Advertising

The phrase “ability-integrated advertising” refers to the practice of including roles for people with disabilities in advertising for products that are not exclusively intended for the disability community. There is some disagreement among experts about which national company was the first to recognize the potential of including people with disabilities in its overall promotional efforts. Some researchers claim that discount retailer Target Stores was the first major marketer to insert people with disabilities in its print ads. Others point to a 1983 CBS television promotional spot featuring a paraplegic wheelchair racer.

No matter who led the charge, the number of print ads and television commercials with disabled roles increased to the point of being noticed in the late 1980s and early 1990s. Major manufacturers including Levi’s Jeans, McDonald’s, Kodak, Kellogg’s, Mattel, and Plymouth were including representations of people with disabilities in their advertising campaigns. Marketers were beginning to recognize and address a market estimated in 1985 to be 43 million strong. The use of disabled actors and actresses in the ads also suggested that society might be ready to start to look at people with disabilities as individuals able to lead normal lives and as promoters and consumers of products.

MARKETING STRATEGIES FOR ABILITY-INTEGRATED ADVERTISING

The inclusion of people with disabilities in advertising has not occurred without some pitfalls in both execution and strategy. Organizations such as the Media Access Office (MAO) and NOD provide advertising strategies and guidance to producers, directors, agency creative directors, and talent. In addition, organizations such as the National Easter Seals Society (NESS) have stressed the need to portray people with disabilities in positive, yet realistic, situations.

Examples of advertising from general products companies that successfully communicated the positive, realistic approach focused on normal characters in daily life experiences. The executions were emotional, but not too emotional. Plot lines included such things as one child learning sign language from his computer so that he could communicate with the "new kid" on a school bus who happened to be deaf or two brothers who wake up to the smell or sound of their mother preparing sausage (one brother was deaf), or the famous Nike ad portraying a man with an artificial limb getting knocked around in a street basketball game. Of course, humor was also used, as in the campaign for Airtouch Cellular featuring blind actor Rick Boggs. In all these examples, the ad worked because it did not pity the person with the disability or depict that person as achieving unrealistic feats.

Execution Pitfalls

It is not surprising that advertising executions do not always succeed in the area of positive portrayal for the disabled. Even with the best of intentions, it is easy to fall into one of the negative stereotypical portrayals of people with disabilities such as the "supercrip" or "one to be cared for." When writers, producers, and directors include characters with disabilities only to make sure that the group is represented, there is a greater chance the ad will actually alienate disabled consumers instead of embracing them.

In the relatively short history of disability-integrated advertising, the faux pas most often cited is the use of nondisabled actors to play disabled roles. Many have been guilty of that error, but no case better illustrates how easily it can happen than the Maryland Planning Council on Developmental Disabilities campaign. In 1988, a Baltimore agency produced a set of 30- and 60-second TV spots for the council featuring a nondisabled actor portraying a man in a wheelchair. The agency said a last-minute rewrite at the request of the council changed the script from one in which the actor got up from the wheelchair to one in which the actor did not reveal his ability to walk. The casting had already been done. The spots brought an avalanche of letters to professional publications and the council from activist groups and individuals who were aware of the production.

Examples of other campaigns that used disabled actors but still failed to capture the desired effect include a series of actor Christopher Reeve ads for an investment company, a retailer that showed a disabled shopper receiving help from the store's staff, and a shoe manufacturer's use of insensitive language about people with mobility impairment in its shoe ads.

ORGANIZATIONS SUPPORTING ADVERTISING EFFORTS

There are a number of private companies and consultancies that have experience in helping companies target consumers with disabilities. But on a national scale, three not-for-profit organizations lead the way.

National Organization on Disability

The NOD has a much broader mission, but it also provides support through its website for marketers interested in reaching people with disabilities. NOD efforts in this area include articles offering marketing strategy tips, information, and resource lists, and even partnership programs with corporate sponsors interested in the disability community. One recent example of sponsorship programs was the 2004 special advertising section in *Motor Trend* magazine. The 15-page spread was the largest mass-market effort to publicize automotive industry achievements in the field of mobility equipment.

Media Access Office

The purpose of the MAO is "to actively promote the employment and accurate portrayal of persons with disabilities in all areas of the media and entertainment industry, ensuring that the industry recognizes people with disabilities as part of cultural diversity" (California Governor's Committee 2004). The California Governor's Committee on Employment of People with Disabilities and entertainment and media industry professionals established the MAO in 1980. In addition to promoting ability-integrated advertising, this group works with writers, producers, and directors to advocate the use of actors with disabilities in disabled roles and promote a more positive portrayal of people with disabilities in the entertainment industry. Programs and services of the MAO include casting, talent development, talent support, project development, community education, and awards.

NESS Equality, Dignity, and Independence Awards

The emergence of ability-integrated advertising was a positive step toward gaining respect for the disability community. For 10 years, a primary force in supporting this role was the NESS. From 1989 to 2000, NESS recognized and encouraged realistic media portrayals of people with disabilities by presenting EDI Awards to members of the media, entertainment, and advertising industry. In the advertising category, both print and broadcast executions were judged with the best receiving recognition. In 1989, only five entries were received in the advertising category. By 1992, the number of entries had increased by 300 percent.

—Olan F. Farnall

See also Easter Seals; Poster Child; Telethon.

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ADVOCACY

Advocacy refers to actions taken to express one's view, to further a cause or belief, and/or to exercise rights. Advocacy is used by people with disabilities (as individuals or organized groups) to increase their influence and obtain their rights. Advocates, people who take advocacy actions, may focus their actions on themselves, other individuals, families, organizations, communities, and/or public policies. Self-advocacy activities are those practices that involve individuals taking the initiative to request, pursue, obtain, and, if necessary, demand particular things they need in their daily lives to attain and exercise their rights. Community-based or other systems-level advocacy efforts target larger shared concerns that individuals may have with organizations or social movement building. Examples of advocacy of this nature include community outreach and education, community organizing, and public policy initiatives. Systems-directed advocacy can cover a wide range of disability-related issues such as education and youth services, transportation and housing, health care and personal assistance, and human and civil rights.

Within the disability rights movement (DRM), self-advocacy has been a key strategy in changing social conditions. In the context of the DRM, the term *self-advocacy* has sometimes been used as synonymous with the movement through which people with disabilities seek human, civil, and legal rights. In using self-advocacy as synonymous with the DRM, it becomes difficult to differentiate among other terms such as *advocacy, community movement,* and *self-help organization.* This entry will consider *self-advocacy* as advocacy that entails those individual actions directed at attaining better conditions for the self and *advocacy* as actions often taken by groups directed at improving conditions for others, groups, communities, and larger social systems. Advocacy and self-advocacy have become important means by which people with disabilities (along with their allies and families) have been able to gain rights. Another meaning of self-advocacy that is common in the DRM, especially among individuals with intellectual disabilities, is advocacy done by people with disabilities themselves.

A *social or community movement* occurs when a number of individuals work together to address important social problems with the purpose of producing social change. These efforts often involve increasing access to opportunities, civil rights, and stronger government support for exercising group member civil rights. Social movements rely on collective efforts by individuals, groups, and/or organizations that share similar values and common goals. Community movements are considered "bottom up" efforts that can produce changes in the structure and mindset of societies. Five defining elements of social movements include that they are joint efforts, have a common goal to produce change, are organized, continue across time, and use a combination of actions both within and external to existing institutions.

Within the DRM, structured settings in which people with disabilities meet and discuss common issues as well as plan advocacy actions are organizations known as *self-help organizations.* The primary goal of self-help organizations is to provide members with a supportive social network that can offer both instrumental and emotional support. Self-help organizations also tend to have a defined mission of change and strategies to obtain that change. The group's purpose may range from personal change to social change, or it may include both approaches to advocacy, self and system, as part of its change agenda. Members of self-help groups are often trying to address a particular issue and may join the group in an effort to gain personal control. Self-help groups operate within informal settings in which marginalized individuals who have similar concerns, experiences, or living conditions can give and receive support. Self-help organizations are often organized in a nonhierarchical manner with group members leading the group; professionals rarely have an active role in the group unless they participate as members or nondirective advisers. Membership is usually open to anyone who has the focal problem, situation, or identity in common with other group members.

Across time, self-help organizations have served diverse purposes and taken a variety of forms to achieve their goals. Different types of self-help organizations include local self-help groups, local advocacy and program centers, local single-issue advocacy groups, public policy groups, single-issue national advocacy groups, national membership organizations, national coalitions, federations of groups, national single-disability organizations, regional organizations, and international organizations.

Self-help organizations can be viewed along two dimensions, political and personal, with high and low gradations of foci on either dimension. Successful self-help organizations can take at least three forms: (1) a primary emphasis on political issues, (2) a prominent emphasis on personal issues, or (3) a significant dual emphasis on both. Organizations that reflect this latter dual focus on personal and political issues include centers for independent living, which have both national and local agencies; each branch of the organization may differ on its emphasis depending on whether it is a national or a local organization. Members of these organizations are both highly involved in political advocacy as well as seek and provide individual assistance and support through the organization.

Other organizations have a high political component and a moderate to low individual element such as Self-Advocates Becoming Empowered, the national federation of statewide advocacy organizations of, by, and for people with intellectual disabilities. Organizations such as these tend to be more focused on policy issues and engage in actions such as lobbying of policy makers. Other organizations have a strong personal component with a less active political agenda. These types of organizations tend to focus on individual needs. For example, a local chapter of People First for people with intellectual disabilities or another single-disability organization (i.e., an organization dedicated to only one form of disability) may focus exclusively on personal issues such as social support and interpersonal relationships. Within this high-low two-dimensional framework, there might be organizations that have both low political and individual agendas.

These organizations might be starting up, dying down, or in transition. Given the nature of grassroots organizing, it is typical for self-help organizations to be in this stage briefly at certain points in their development. Self-help organizations may shift their emphasis throughout time. The high-low two-dimensional framework includes all combinations of emphasis on the political and the personal and recognizes that today's personal concern may become tomorrow's political issue. It is dynamic in that the mix of personal and political can vary at different times in the life cycle of a self-help organization.

It may be that self-help organizations that recognize the personal as political and vice versa are most successful. For example, an individual who participates in self-help organizations might engage in political activities because it becomes personally rewarding to speak on behalf of others. In this context, the personal experience is affirmed because it has broader implications. Thus, when individuals in a self-help organization integrate the personal and political, the self-help organization may become stronger and serve multiple purposes.

All self-help organizations provide environments in which people have the opportunity to organize, develop self-advocacy skills, and receive support. These environments allow individuals to obtain public (e.g., taking a political stand) and private (e.g., establishing friendships) goals.

THREE INTERRELATED CONCEPTS

The focus of advocacy actions by advocacy, social movement, or self-help organizations can be placed on a continuum of different levels or units of analysis. This continuum includes actions that are directed at the self to actions directed at society. Examples of advocacy at the individual or family end of this "levels of analysis" continuum of advocacy include a parent who advocates at a school to obtain needed supports for his or her child and a disabled person who advocates at a rehabilitation services center for better service provision. In the middle of the continuum, at the community level, a group of residents may advocate for accessible parking. On the other end, actions taken to change legislation or public policy such as building codes or services are considered advocacy at a systems level. It is critical to note that placing advocacy actions on this continuum does not mean that advocacy efforts do not overlap or flow between these levels. Indeed, advocates and their organizations often move along this continuum. For example, a person with a disability may advocate for himself or herself as a self-advocate; however, while the person can advocate on an individual level (e.g., for adequate personal attendant care) he or she can also advocate at a systems level (e.g., lobbying legislators).

Advocacy serves as an empowering force through which people with disabilities obtain social change. In the 1970s, an international disability social movement emerged based on self-advocacy and advocacy efforts. The social movement known as the DRM began when people with disabilities started organizing themselves with the intent of speaking out and demanding their rights. For people with disabilities, the process of forming self-help organizations provided an infrastructure for self-advocacy development by providing a setting in which people could share their experiences and knowledge and receive support.

As part of the empowerment and self-determination movement, different organizations and groups of individuals drafted their own definitions of self-advocacy. For example, in 1991 People First, an advocacy organization of and for people with intellectual disabilities, defined self-advocacy as

> independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination. It teaches us how to make decisions and choices that

> affect our lives so we can be more independent. It teaches us about our rights, but along with learning about our rights, we learn about our responsibilities. The way we learn about advocating for ourselves is supporting each other and helping each other gain confidence in themselves to speak out for what they believe in. (Dybwad 1996:2)

Definitions of self-advocacy reference common factors such as empowerment, self-determination, self-help, independence, and integration. In addition, they call for a reconceptualization of what it is to be a person with a disability by pushing for a change in society's view of disability from a medical and individual impairment to a socially created experience. The advocacy and self-advocacy efforts that have occurred over time across disabilities and specific historical developments led to the community movement known as the DRM.

HISTORY

Early Origins

People with disabilities have organized for centuries. Historians have been able to trace the existence of self-help organizations to medieval China and Europe. There, people with disabilities, especially those who were blind, were marginalized by society and then organized for self-protection and economic support. In China, informal organizations became guilds and associations composed exclusively of blind people. In at least one guild, members earned a living by singing and entertaining. The guild was self-governed, and all the members of the board were blind except the secretary. Board members decided on all issues including recruitment of new members and discipline of members. Children who entered the guild learned skills for specific trades. As members acquired skills, they ascended the hierarchy of the guild.

During the Middle Ages in Europe, blind people also formed guilds for the purpose of self-protection. Group membership provided status and a means of expression, participation in the community, and demonstration of self-sufficiency. Guilds were known as "free brotherhoods of the blind." In Paris, a group called the "Congregation and House of the Three Hundred" was formed composed of blind men and women. These early associations provided members emotional support and sometimes access to economic self-sufficiency. Despite these early associations, later historical events impeded the further development of these organizations. Nonetheless, the existence of these associations is important to be noted; men and women with disabilities who participated in these organizations were self-advocates of their time.

In the 1800s in the United States, advocates spoke out and demanded changes, particularly in laws and education. One of the first organizations to promote collective advocacy was the National Association of the Deaf, which advocated for the right to include sign language as part of education for people with hearing disabilities at a time when mainstream society opposed sign language. Similarly, in the nineteenth and first half of the twentieth centuries, there was an increase in the population of psychiatric hospitals. Initially, mental institutions were conceptualized as places to care for mentally ill individuals. However, they quickly became a means for social control. Mental institutions were often used as means to discipline and alienate those who were different.

Fortunately, successful advocacy strategies brought the problem of institutionalization to the public's attention. In 1866, Elizabeth Packard was committed to a psychiatric hospital against her will. She wrote a book on her experience and advocated for the creation of the Packard Law, which stipulated that a jury must decide whether to commit a person to a psychiatric hospital against his or her will. In the early 1900s Clifford Beers, a former inmate at a psychiatric hospital, authored a book on his experience. His book, *A Mind That Found Itself,* made public the experience of abuse while committed to a mental hospital. These instances of advocacy through written experiences reflect early efforts and success in changing public views towards mental illness.

Modern Advocacy Organizations

The first modern advocacy organization for the blind, the National Federation of the Blind, was founded in 1940. Around this time, parents of people with intellectual disabilities also began to organize to advocate for services for their children. After World War II, as the population increased, there was an increase in the number of children with disabilities. Other single-disability organizations arose such as the National Association for Retarded Children (formerly named the National Association of Parents and Friends of Mentally Retarded Children; *Children* was later replaced with *Citizen* and now the organization's name is the acronym ARC.). The ARC pushed forward the concerns of parents of children with intellectual disabilities including their children's exclusion from public education, the dearth of community and residential services, and dissatisfaction with extant conditions for employment of people with intellectual disabilities. The ARC has served as a leader in advancing public policy for people with intellectual disabilities including steps toward deinstitutionalization. Its success may be linked to the high social status of its members and effective, grassroots social action strategies.

During this same time period, a group of ex-patients publicly criticized institutions by bringing attention to issues of human rights violations in mental institutions. In doing so, ex-patients formed self-help groups and demanded changes in policy. In the mid-1960s, the mental health patients' movement slowly emerged. Simultaneously, the population of psychiatric hospitals was dropping due largely to the availability of medications that helped people live in the community, literature that improved social beliefs about mental illness, and concomitant shifts in public policy. Interplay among science, culture, society, and government began to produce changes that remain today. Literary examples that worked to induce these changes include Thomas Szasz's *The Manufacture of Madness* (1970) and Ken Kesey's *One Flew over the Cuckoo's Nest* (1962).Within the policy arena, President John F. Kennedy signed laws regarding mental health issues. For example, the 1963 Community Mental Health Act contributed to having people live and receive treatment in the community. In addition, the Kennedy administration contributed to setting the stage for attention to intellectual disabilities. Influenced by a sister with intellectual disabilities, Kennedy advanced the cause of providing public school services for people with disabilities by commissioning a presidential panel on mental retardation and creating a bureau for special education.

A group of parents filed a lawsuit to get their children with disabilities educated. Their advocacy efforts led to the passing of the federal law known as The Education for All Handicapped Children in 1975. Signed by President Gerald Ford, it guaranteed education in "the least restrictive environment" for children with disabilities. The original law has been revised over the years and has since been renamed the Individuals with Disabilities Education Act or IDEA.

The independent living movement was one of the first movements that provided tangible gains for people with disabilities by demonstrating that people with disabilities were capable of living and being leaders in their communities. In the early 1970s, the Berkeley Center for Independent Living opened. Centers for independent living (CILs) are nonresidential, not-for-profit organizations that do advocacy, service, and educational activities. CILs are cross disability, and the majority of the members on the board of directors are people with disabilities.

Similarly, in the 1970s, a group of individuals with intellectual disabilities founded People First, the first self-advocacy group for people with intellectual disabilities. The name was developed as an initial step in speaking out and demonstrating a sense of identity defined first by their humanity and second by their disability. The purpose of People First is to help members learn to advocate for themselves. The 1974 convention of People First in Oregon provided a setting to discuss issues in self-advocacy and served as a propelling force for the self-advocacy movement. As a result, many organizations flourished. By 1994, approximately 11,600 people with intellectual disabilities were involved in self-advocacy groups. Early issues addressed by advocates centered on public transportation, lack of accessible and affordable housing, institutionalizing of the poor, inclusion of students with disabilities in the classroom, and changing the understanding of disabilities.

In the mid-1970s, diverse advocacy groups led by ex-patients and mental health consumers were formed. These groups used strategies such as awareness raising, organizing, and political action techniques to effect change. The most radical of the groups viewed psychiatry as the oppressor and were suspicious of professional advocates. Others viewed some professionals who supported change as valued collaborators. The differences of opinion were often strongly held, which sometimes made it difficult to establish synergy among mental health advocacy groups.

Mental health advocates championed changes in policies through a variety of approaches, and various advocacy groups were created such as the National Alliance for the Mentally Ill (NAMI), founded in 1979. NAMI originated as a network of mutual support groups and expanded to include national public education efforts as well as legislative lobbying at the local, state, and federal levels. NAMI is an advocacy and education organization that now has hundreds of affiliates and represents thousands of families. Advocacy organizations such as NAMI have increased awareness of mental health issues and affected policy and legislation. Early impacts on legislation resulted in the right of a person with a mental disability to receive treatment, in the least restrictive environment, protected from intrusive procedures and from involuntary commitment without appropriate procedures.

ADVOCATE DEVELOPMENT AND ADVISORY

Since the initiation of the DRM, people with disabilities have obtained and been more able to exercise their rights through advocacy efforts. Many have initiated their advocacy activities as a result of personal experiences with disability whether as a person with a disability or as a family member or other loved one of a person with a disability. Other individuals have initiated advocacy activities from a shared interest in promoting equality. Some researchers have suggested stages of advocate development ranging from starting to be involved to being highly involved. Balcazar, Keys, Bertram, and Rizzo (1996) identified three developmental stages: beginner, involved, and activist. At the beginner stage, a person belongs to an organization and acts as a relatively passive member, receiving few services and taking few advocacy actions. In the involved stage, a person is a more active member of at least one organization, obtains services as needed, and takes more advocacy actions to address personal needs. An activist, however, likely belongs to several organizations, including those at the state and/or national levels, and has taken leadership roles in at least one advocacy organization. An activist also works to obtain services for local group members and takes a significant number of advocacy actions on a regular basis. By understanding advocate development, advocacy actions can be tailored according to the expertise, interests, and activity level of advocates. Advocacy training can be developed that is appropriate to participants' present level of involvement.

Many recognize a need to enhance and support advocate development in order to affect policy and society. Advocacy training programs have been designed to enhance the skills of advocates with the intention of maximizing the roles of people with disabilities and family members. Many advocacy training programs have been developed. One example is Partners in Policy Making. Partners is a training program designed to empower people with developmental disabilities and their families to pursue their cause. By introducing trainees to disability policy, advocacy skills, and state-of-the-art services, Partners in Policy Making promotes involvement in positive and progressive advocacy activities by program graduates. The program has been very successful in developing advocacy leaders in many states in the United States.

Advocacy training programs offer participants intensive training in advocacy skills and provide an opportunity for diverse people to become advocates. In a study with participants of different levels of advocacy activity, researchers found that advocates that already had a high level of participation in advocacy activity increased their participation the most and their family members with disabilities received three times more services when compared to people with medium or low levels of participation. In addition, researchers found that people can move beyond personal interest to address the needs of others similar to themselves. Results from this study shed light on the benefits of advocacy involvement and training.

In one program, participants in advocacy training programs delineated supports and barriers to successful advocacy. Participants identified elements such as empowered voices, networking, courage, and leadership as essential factors for successful advocacy efforts. Participants also outlined barriers to advocacy including lack of time, lack of financial resources, and the interference of emotions. By identifying and sharing the supports and barriers that advocates encounter, advocacy development trainings can build a sense of universality among advocates. That is, these training programs can increase participants' awareness that others share struggles and benefit from supports similar to their own. Universality can lead to greater solidarity among disability advocates. It can motivate participants to enhance their skills and collaborate to develop and share strategies to combat barriers to effective advocacy.

In general, individuals who participate in self-advocacy efforts become empowered, or gain greater control over things that affect their lives. Models of empowerment suggest that self-advocacy and advocacy provides a setting for people to become empowered by gaining awareness of society and self, emphasizing one's strengths, taking action, engaging in collaborative relationships, and effecting social change. Through participation in advocacy activities, including advocacy trainings, individuals gain a sense of awareness of their roles as advocates. For example, people with intellectual disabilities who participate in self-advocacy activities learn that social and physical structures are often discriminatory. They see that changes to systems must occur to meet and integrate individuals with disabilities to society. Once individuals become aware of barriers that impede the integration of people with disabilities, individuals are often more able to acknowledge that people with disabilities are persons with strengths and capable of contributing to society. In addition, individuals who participate in advocacy efforts are able to take action and gain greater control over their lives. Furthermore, members of self-advocacy groups gain peer and public support and a sense of self-confidence.

ADVOCATE ADVISERS

The DRM pushes for a shift from a traditional deficit model of disabilities to a social model that is strengths based, supportive, and collaborative. Collaboration occurs when members of different groups work together for a common cause or bring in nonmembers as consultants to provide specific expertise or guidance. For example, many self-advocacy groups of people with intellectual disabilities include a nondisabled member as an adviser. Advisers are usually community members or professionals who work in the disabilities field. The role of the adviser is to facilitate and provide assistance in various areas. Advisers are not experts but rather collaborators. It is important to note that advisers are not necessary for a self-advocacy organization and that there are advantages and disadvantages of having an adviser. One advantage of having an adviser is that it permits groups to access knowledge or expertise that may be less available within their current membership. One disadvantage is that some advisers can act beyond their advisory role and counteract members' advocacy by promoting disempowering relationships between the adviser and organization members.

To facilitate collaboration between an advocacy organization and advisers, it is important for advisers to be committed to the philosophy and realization of empowerment and self-determination. Effective advisers work to facilitate personal and collective changes, incorporate creative ideas, and recognize individual worth, equality, and skills of organization members. The role of advisers and nondisabled advocates is not without controversy: There is the potential for many to not fully understand their role within the DRM and to not fully appreciate the social role of people with disabilities.

CHALLENGES TO ADVOCACY MOVEMENTS

In addition to controversy over the role of advisers and participation of able-bodied individuals, there are several other challenges to the success of advocacy efforts. Many times, advocacy efforts have had difficulty finding a common cause given the broad scope of disabilities and individual needs related to this diversity. A second barrier might be that different models of disability are used as a basis for action and change. Differences among these approaches can present a barrier for a successful advocacy. For example, some people may incorporate the medical model and work within this framework to increase access to traditional services. However, others may feel that the legal rights model is a more adequate framework and work within this framework to change the services available and how they are delivered. Thus, those following the more traditional approach would ask for individual student services offices in universities to provide more readers or individual supports to make texts more readily available to blind college students in a timely manner. Others, noting the inadequacy for print access through these offices on campus, might focus instead on developing a policy with publishers or a law for them. For example, all publishers would make computer-readable versions of texts and journals available to blind students at a reasonable cost. These variations in perspectives on disability can affect the tactics and strategies used for advocating as well as present a challenge if consensus is not reached.

ADVOCACY TACTICS AND STRATEGIES

There are diverse tactics and strategies that advocates adopt to pursue change. As mentioned earlier, differences in these strategies might present challenges in pushing forward any particular agenda. However, many agree that the milestones reached in the contemporary DRM were obtained through the use of multiple advocacy strategies including the most action oriented of all, activism. Advocacy practices are geared toward changing services, promoting inclusion in society, and influencing legislation and policy. Advocacy efforts can be speaking out in the community, serving on boards and committees, communicating with decision makers, lobbying, writing letters, and participating in the development and implementation of programs, among many other tactics. There are also many tactics available to advocates such as peer advocacy, parent advocacy, professional advocacy, and self-advocacy.

An illustrative example of using multiple advocacy strategies occurred in 1973 when Section 504 of the Rehabilitation Act was passed. This act prohibited discrimination against disabled individuals from organizations receiving federal financial assistance. Regulations were passed thanks to cross-disability advocacy efforts. Multiple advocacy tactics were used ranging from single phone calls to a sit-in at federal buildings. Different advocacy approaches such as writing letters, lobbying, and media appearances made the promulgation possible. Another example of the success of multiple advocacy tactics is that of individuals with psychiatric disabilities issuing a public statement, called the “Highlander Statement of Concern and Call for Action on March 25, 2000.” In this statement, a call for a mental health system founded on self-determination, respect, ethical behavior, and humane services and supports was made. Similar cross-disabilities, multifaceted advocacy efforts helped pass the Americans with Disabilities Act of 1990 (ADA). There are fundamental elements necessary to obtain a successful advocacy effort: Set goals, develop a strategy, gather information including asking questions, and use other support to establish your place in the process. Using these advocacy elements can bolster the effectiveness of the effort.

CONCLUSION

Overall, anecdotal accounts and research have established that appropriate advocacy strategies are effective in implementing change and can provide benefits at many levels, including to individuals, communities, and societies. Through advocacy, empowered groups have greater potential to have an impact on society and terminate the long history of unequal treatment against individual with disabilities. Advocacy, self-help, and social movement activities will continue to be integral to attaining social justice for people with disabilities in the twenty-first century.

—Yari Colon, Christopher B. Keys, and Katherine E. McDonald

See also Advocacy, International; Advocacy Movements: France; Advocacy Movements: Germany; Empowerment and Emancipation; Individuals with Disabilities Education Act of 1990 (United States); Lobbying; Parental Advocacy; People First.

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▣ ADVOCACY, INTERNATIONAL

Advocacy refers to actions taken to express one's view, to further a cause or belief, and/or to exercise rights. Advocacy is the practice, in this context, by people with disabilities (as individuals or groups), to increase their influence and independence. Self-advocacy activities are those practices that involve individuals taking the initiative to demand and pursue particular things they need in their daily life. Community-based or systemic advocacy efforts dovetail with organization and movement building. These efforts may include community outreach and education, community organizing, and public policy. They can cover a wide range of disability-related issues such as education and youth services, transportation and housing, health care and personal assistance, and human and civil rights. It is with the latter notion of advocacy and its connection to organization and movement building that this entry is concerned, although there are many connections between self-advocacy and community-based advocacy.

PHILOSOPHY AND PRACTICE

The philosophy and practice of advocacy, self-help, and social movement building have evolved out of an emerging consciousness of political activists worldwide that is informed both by their own particular local experiences and the reach of the international disability movement. They incorporate the interconnected principles of empowerment and human rights, integration and independence, self-help and self-determination. The meaning of these concepts and where they programmatically lead can, not surprisingly, be different and, more noticeably, can have different strategic movement or organizational importance. This reflects the divergent and often conflictual politics of the movement's activists.

DISABILITY RIGHTS AS A NEW SOCIAL MOVEMENT

The building of a disability movement rooted in self-help organization and advocacy reflects many of the traits of other new social movements that emphasize identity. These social movements focus on new forms of social and collective action, involve personal intimate needs, and are not centralized but loose and diffuse. There has been much debate among activists and scholars about how similar the disability movement(s) is to other new social movements such as women's, human rights, landless peoples', and environmental movements. In arguing that the disability rights movement is a new social movement, two British disability rights scholars, Mike Oliver and Gerry Zarb, argued that the critical traits of new social movements mirror those of the disability rights/advocacy movement: "To varying degrees and in varying ways the new movements also seek to connect the personal (or cultural) and political realms, or at least they raise psychological issues that were often submerged or ignored." Oliver and Zarb (1989:237) go so far as to make the assertion, "Hence, the disability movement will come to have a central role in counter-hegemonic politics and the social transformation upon which this will eventually be based." This assertion contrasts with the lack of interest most sociologists who study social movements have shown in the advocacy, community movement, and self-organization of people with disabilities.

CONTEXT OF ADVOCACY, MOVEMENT, ORGANIZATION

Out of the different and often hard realities of everyday life, advocacy organizations of people with disabilities have appeared in virtually every country in the world. These organizations form the core of the international disability rights movement. Although this development touches only a relatively small portion of people with disabilities, it nevertheless parallels the process of consciousness and organization that has given rise to many kinds of community-based advocacy and self-help organizations and social movements.

Many of these organizations started as a response to the simple need for survival—food, shelter, and work—and their goals were limited to economic self-help and self-sufficiency. Others started as political groups that wished to mobilize people with disabilities in their communities, cities, countries, or regions. These groups and purposes have gradually merged. All seek to link their work with the struggle for self-determination and human rights. With few exceptions, this struggle is their common denominator.

Although the development of disabled persons advocacy and self-help organizations has been uneven, it is undeniable. Within the past 25 years, self-help groups have formed in leprosy communities in southern Africa, in refugee camps in Kampuchea and Mexico, and on remote islands in the Philippines, Palau, and Fiji. A village in the mountains of Mexico has become the center of a self-organization of and by people disabled from drug-related violence and has attracted hundreds of people with disabilities from throughout the country.

Advocacy activists have made different choices over the years on how and what to organize around. In southern Africa, activists took a perspective that national and regional federations had to be organized that would in turn promote locally based economic development projects. For example, the National Council of Disabled Persons Zimbabwe fostered the establishment of a supermarket in a township outside Bulawayo and collective gardens outside Harare. In Southeast Asia, various individuals who had returned from international conferences banded together to form chapters of Disabled Peoples' International because they understood all policy and services were mandated by a number of connected politicians in their countries' capitals. Indeed, Disabled Peoples' International–Thailand quickly established a national presence by staging demonstrations criticizing the Thai government for dismissing a deputy cabinet member who used a wheelchair. In many places in the third world, the lack of rehabilitation services and mobility aids for those with physical disabilities created both an impetus to organize and goals of newly formed groups. In Nicaragua, one of the first things the Organization of Disabled Revolutionaries (ORD) did after the Sandinista revolution was to set up a wheelchair production and distribution system using locally available materials in their wheelchair design. Other activists, especially in the United States and Japan, out of a perceived overarching need to create community and employment, opted to concentrate on establishing centers for independent living.

HISTORY

Most of these groups are relatively new, small, and fragile. Most exist with little or no funding. As indicated, the 1980s were the first time people with disabilities and their supporters founded a large number of advocacy organizations. The National Council of Disabled Persons Zimbabwe, initially registered as a welfare organization, became a national disability rights group in 1981. The Organization of Disabled Revolutionaries was set up in the wake of the Sandinista victory in 1979. The Self Help Association of Paraplegics of Soweto was started in 1981 as an economic development project. The Program of Rehabilitation Organized by Disabled Youth of Western Mexico also began in 1981 as a rural community-based rehabilitation program. DPI-Thailand was established in 1983, and the Southern Africa Federation of the Disabled was formed in 1986 as a federation of nongovernmental organizations (NGOs) of disabled persons. It was during this time that many disability rights and advocacy groups were established including the Disability Rights and Education Defense Fund, ADAPT (American Disabled for Accessible Public Transit, also called American Disabled for Attendant Programs Today), and France's Groupement Francais de Personnes Handicapees. Also begun during this period were England's British Council of Disabled People (BCODP), Greater London Action on Disability, and Disability Awareness in Action; Cuba's Asociacion Cubana de Limitados Fisicos Motores; and many European advocacy groups.

Often these organizations have reached across borders to establish similar groups in neighboring countries. For example, members of DPI-Thailand, based in Bangkok, made numerous trips to Vietnam, Laos, and Kampuchea to spread the philosophy of disability rights and to initiate activities. There have been international exchanges between Hong Kong and the People's Republic of China. Some of these NGOs have very close connections to the governing party. Close connections have historically been the case in Vietnam, Mozambique, Angola, Cuba, Indonesia, Nicaragua, and the People's Republic of China among other countries, particularly in the third world. In other instances, disability rights and advocacy-oriented NGOs have been allied with opposition forces in their countries such as in Brazil (with the Workers Party), South Africa (with the African National Congress), and Japan. In most cases, disability rights and advocacy-oriented groups have stayed out of national politics, focusing instead on narrow disability issues.

A TYPOLOGY OF ORGANIZATION

Reviewing the various structures and strategies of international advocacy groups, we could group them by the following typology: (1) local self-help and advocacy groups, (2) national advocacy organizations and coalitions/federations, and (3) worldwide organizations.

Local Self-Help Groups

Local self-help groups vary from small collectives of people providing peer counseling and moral support to small plot gardening and agricultural ventures to larger projects involving a significant level of support, production, and revenue. Some are cross disability, cutting across many different kinds of disabilities, and others focus more on persons with a single disability or cluster of similar disabilities. The experiences and lessons from the hundreds of self-help groups are diverse. The peer relationships and friendships, material aid and support, and sense of control they engender have significantly contributed to the health and sustenance of hundreds of thousands of people. These groups are the easiest to establish but the hardest to maintain. In South Africa, for example, there are more than 175 revenue-generating self-help projects, most associated with Disabled People South Africa. Most employ fewer than 30 people and yield little revenue. However, the projects generate a minimal level of food or income for their members, which often is the margin between life and death. The largest and best known is the Self Help Association of Paraplegics (SHAP) established in 1981 by a group of Soweto paraplegics (primarily spinal cord injured).

Probably the most important local advocacy groups are centers for independent living (CILs). The first CILs appeared in the United States in the early 1970s, and there was a large increase in the number of CILs in the 1980s and early 1990s in the United States (now more than 400) as well as Japan (now exceeding 100) and Europe (where there are dozens in Northern Europe and England). Activists in Brazil set up Latin America's first CIL in Rio de Janeiro (Centro de Vida Independente). Later, in the late 1990s, CILs spread to a number of cities throughout Latin America. Efforts to establish CILs in Africa and Asia have been sporadic and less successful.

National and Regional Advocacy Organizations

National and regional advocacy organizations have local chapters throughout or across countries, and their membership participates in advocacy and program activities as well as in organizational business.

Most of the national advocacy groups are quite democratic, although there is a strong tendency to follow the same leadership over extended periods of time. Most countries have such organizations, although examples offer divergent pictures. For example, the constitution of the National Council of Disabled Persons Zimbabwe (NCDPZ) spells out the organization's mission: "[to] promote full integration into Zimbabwean society of all disabled persons and active participation by the disabled in the planning and decision-making processes that affect their own lives." The work of NCDPZ involves advocacy, grassroots organizing, services, and leadership development training. NCDPZ has been able to obtain funding from foundations located in Northern Europe. These foundations support specific programs or purchases, such as personal computers or agency vans. Another national organization is the BCOPD, the United Kingdom's national organization of disabled people. BCOPD was set up in 1981 by disabled people to promote their full equality and participation in UK society. By 2003, BCOPD included 126 groups run by disabled people in the UK. Between them, their member groups have a total membership of around 350,000 disabled people throughout England, Wales, and Scotland and is affiliated with Disabled Peoples' International.

An example of a regional organization is the Southern Africa Federation of the Disabled (SAFOD), which represents disability rights groups from a number of countries in southern Africa including Angola, Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Zambia, and Zimbabwe. The aims of SAFOD are to provide a forum for disability rights activists to meet, share common concerns, and coordinate regional projects. SAFOD has a secretariat in Bulawayo, Zimbabwe, with a small staff headed by a secretary general. SAFOD is a member organization of Disabled Peoples' International. SAFOD is governed by an executive committee, elected at each biannual general assembly and drawn from the national organizations. It also widely circulates its newsletter, *Disability Frontline*. The creation of SAFOD eventually led to the founding of the Pan-African Federation of the Disabled for the entire continent more than a decade later.

International Advocacy Efforts

There are a growing number of disability rights organizations that do international exchange work. Some, such as Mobility International, based in Eugene, Oregon, provide opportunities for advocacy activists to visit other countries. These exchanges have been successful in spreading the experiences of independent living, peer counseling, self-help projects, and an awareness of the politics of disability across many cultures. Worldwide organizations such as Disabled Peoples' International and the World Institute on Disability (WID) focus on international advocacy, networking, public policy, research, and training. WID has developed educational and leadership training programs throughout the world from Latin America to the former Soviet Republics. Many of WID's staff have spent considerable time outside the United States promoting disability rights. WID has convened international forums and foreign exchanges on personal assistance, leadership training, and disability rights philosophy. Other important international organizations in Europe include the Institute on Independent Living in Stockholm and Disability Awareness in Action based in London, which has established contacts in 158 countries, most of which are in underdeveloped countries and whose newsletter, *Disability Tribune*, reaches readers throughout the world. There has been a great deal written about Disabled Peoples' International, the most important of these organizations.

FUTURE DIRECTIONS IN ADVOCACY AND COMMUNITY ORGANIZATION

The disability rights movement has always situated self-control and community control at the center of its agenda. The history of the movement has been the growing consciousness and activism of greater numbers of people with disabilities. For the first time in history, millions of people with disabilities have seen or heard about other people with disabilities who are struggling for a better life. This is a beacon of hope for many. The practice of empowerment means and has meant creating, increasing, and improving the options available to people with disabilities in their everyday lives.

There is an abundance of challenges and a scarcity of choices. The dilemma most people with disabilities throughout the world face is how to use their meager resources to attend to this condition. So the most obvious challenge is the most elementary: how people with disabilities secure the basic needs to survive. For the vast majority of the 375 million people with disabilities living in the third world, meeting basic needs can be a matter of life and death. For those of us living in the developed world, achieving a level of self-sufficiency goes directly to the question of quality of life. In the course of grappling with an array of complex and burdensome issues, the fundamental challenge is how the movement develops politically. What kind of analysis and political program will its leaders and activists bring to their struggle? What is the strategic goal of the disability rights movement? Is it strictly human rights, or is it liberation and freedom? There are many questions with many answers. The answers will strongly inform the future of disability advocacy and community organization.

—*James Charlton*

See also Advocacy; Disability in Contemporary Africa; Disabled Peoples' International.

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ADVOCACY MOVEMENTS: FRANCE

The topic of French advocacy movements for the disabled is explored in this entry from two perspectives: first, the chronology and history of movements that have emerged from the disabled world and, second, the political and social situation of these movements. The phrase "disabled world" is justified by the fact that in recent times the representation of disabled persons and the effort to enhance their visibility in society were, with some few exceptions, more the work of parents and support circles than of the people who were directly concerned. *Movements* is an intentionally broad term even though most of the initiatives that have been and are being taken fall within the framework created by the French law of 1901 concerning associations.

Three historical waves can be identified. The earliest goes back in part to the first appearance of large numbers of work-related accidents in the nineteenth century and stimulated the creation in 1921 of the National Federation of Injured Workers (the French acronym is FNAT) and also others such as the National Union of the Disabled and Injured Workers (UNIAT), focused essentially on the protection of rights. Another contributing factor was the wounded veterans of World War I (1914–1918). These veterans founded dozens of organizations with a generally similar mission, for example, the National Union of the War-Wounded and Rehabilitated, but were also committed to the defense of very specific categories of the injured such as those with lung trauma, those with head injuries requiring surgery, and wounded agricultural workers.

These two great losses of life, marginalizing the economic activity of thousands of people, caused disability to be transformed from purely natural status to a form of socialization, in which society was seen as the agent that produced this multitude of injured persons. As a consequence, there emerged the idea that relief from, and compensation for, these prejudices was a collective responsibility, requiring a solidarity organized through the medium of social security. This right to compensation and the desire to recover a place in community life would form the basis for the claims of FNAT, of the *gueules casées* (a nickname that referred to severe facial injury), and with a similar thrust, of tuberculosis patients, who considered themselves the victims of a blight that was social in nature and not simply a health issue.

Numerous groups of disabled people, or the "diminished" as they called themselves at the time, were created, although in quantitative terms relatively small numbers of people were involved. Along with FNAT and federations and unions for war veterans, there appeared Auxilia (1924), dedicated to the retraining of the hospitalized disabled; Ladapt, or League for the Rehabilitation for Work of the Physically Disabled (1929), whose name spells out its program; and Clair-Vivre, a residential village for the rehabilitation of tuberculosis patients (1924), soon followed in the mid-1930s by the Association of the Paralyzed of France (APF) and the Marine Cross associations (which would become the Marine Cross Federation for Assistance in Mental Health in 1952).

This is not an exhaustive list. To be emphasized is the degree to which these movements and organizations were principally concerned with physical disability, except for the Marine Crosses. These movements were more the achievement of those affected than would be the case in the period that followed. It should also be noted that institutions that went back to the French Revolution and were not the creations of disabled people themselves continued their work, but they were fundamentally concerned with children and therefore addressed chiefly disabled children with prominent distinguishing features such as blindness, deafness, or mental retardation.

The second wave dates from the period after World War II. The great majority of the initiatives were the work of families and addressed the mentally disabled or "handicapped" as they were then known, or at least disabilities that caused difficulties or slow progress at school. In the face of the inertia of the public school system and the scarcity of appropriate institutions, parent groups formed, initially less to constitute a lobby than to create schools and training facilities, supplemented, as required, by lifelong vocational support structures. The families became the administrators. This is the case with the White Butterflies, regional or local associations that in 1960 joined to form the national Union of Associations of Parents of Maladjusted Children (UNAPEI).

Between 1950 and 1970, initiatives multiplied and it would be fruitless to attempt an enumeration. An exemplary case is the APAJH, initially created as the Association for Assistance and Vocational Placement for Disabled Adolescents (AAPAJH, 1962), then renamed Association for Vocational Placement and Assistance for Disabled Youth (APAJH, 1963), and last, Association for Disabled Adults and Youth (APAJH, 1981). This evolution illustrates that the connection between disabled adults and youngsters is a recent development. It also shows that two years after UNAPEI (1962), the French term *inadapté* (maladjusted) was dropped in favor of *handicapé* (handicapped or, more currently in English, disabled). The FNAT would become the FNATH and, last, the associations would become increasingly polyvalent and ambitious, tending to take the form of large national entities, powerful in the face of the authorities, rich in endowments and staff numbers.

This was also the path followed by associations that were formed between the wars (Ladapt, APF). Today, a group called the Committee of Understanding encompasses upwards of 50 national associations, and it is politics that effectively determines the dozen or so that are counted as heavyweights, such as those named above. In the course of this period, roughly the 30 years after World War II—three glorious decades for France because of economic expansion, full employment, implementation of far-reaching social policies, and the importance of the government's economic advisory committee—the overwhelming majority of associations wished (UNAPEI) or were obliged (APAJH) to manage their own operations. There were some exceptions such as the National Federation of the Ill, Disabled and Paralyzed (FNMIP, 1945), which engaged in the protection of rights, training, and advocacy but administered no facilities or services of its own.

In chronological terms, we may speak of a third wave of newly established movements or organizations concerned with disabled people. Here it is not so much a flood of new creations as a gradual emergence in the sense that antiestablishment groups coalesced, opposed both to existing institutional and legislative arrangements, and to earlier associations. These groups in general count fewer members in comparison with the others, adopt theoretical stands, and are inspired by movements already under way outside France. This rather heterogeneous assembly ranges from highly politicized movements such as the "mean crips" (*handicaps méchants*) of the mid-1970s to associations of disabled researchers (GIHP), which would eventually become an association of services, in particular as concerns adaptive transportation for the disabled. In the central range of the spectrum is the move toward emancipation from specialized institutions, such as Living Upright (*Vivre Debout*), which would lead to the creation of the association's first group living facility in 1977, and the initial establishment in France of Disabled Peoples' International (DPI).

From this hasty overview, reference may be made to the typology proposed by Catherine Barral (1998):

> The French association landscape has taken shape around three broad tendencies: associations that administer specialized facilities dominate the picture in terms of number, reputation, and representativity; a second group is made up of associations of the trade union kind, such as FNATH . . . ; the third type is represented by user-advocate associations on the model of consumer rights movements.

But to this typology, which readily permits each of the groups of associations to be situated in social and political terms, should be added an analysis that identifies the relationship between this nebula of associations and the authorities. In the case of every association that administers any kind of service or facility, financing comes in very large part from public funds or at least nonprivate sources. In fact, there is a near equilibrium today between state funding and, increasingly, funding by regional collectivities and funding from social security agencies. Self-generated funding or independent revenues are of only marginal importance. These associations thereby assume a public mission, what in France is called "subsidiarity": What is normally considered a responsibility of the state is delegated by it to private organizations.

This situation has very specific features in France. What is less specific is the degree to which the authorities respect but also restrain these agencies: They are partners; they cannot oppose the establishment, or can do so only to a limited degree. One example will suffice, the drafting of new legislation to replace that of 1975, in which associations that ran their own operations played the primary role, silencing the voices of those that refused any special legislation. In the reform of 2004, there was a moment when the government's approach to disability satisfied no one. The associations gathered under the heading Committee of Understanding could have required the lawmakers to rewrite the legislation completely but they preferred, as in the past, to settle for amendments.

But it would be wrong to give the impression that the organizations administering their own operations were incapable of evolution and innovation. They have developed a number of alternatives to the single route of specialized establishments. They do, however, remain hegemonistic when confronted with movements and associations that seek to position themselves differently, preferring to play on the generalized principle of nondiscrimination and a strengthened desire for democratic recognition.

In conclusion, all French organizations are today confronted by what comes from beyond, in particular European developments and recommendations that will become more constraining as Europe refashions itself into a tighter union. The European constitution, if adopted, will further this process.

—Henri-Jacques Stiker

See also Advocacy; Disability Law: Europe.

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ADVOCACY MOVEMENTS: GERMANY

The German disabled people’s disability rights movement began at the end of the 1970s in West Germany. Disabled people in East Germany (then German Democratic Republic) had to wait until the reunification of Germany in 1989 before they could be actively involved. After the catastrophe of national socialism and the horrible experiences of compulsory sterilization and euthanasia earlier in the twentieth century, followed by decades of silence about these atrocities and also decades of being put away in institutions and homes, German people with disabilities started to set up their own groups. The time seemed to be ripe: Disabled people profited from the political, societal, and cultural changes that had been initiated by student revolutions at the end of the 1960s. Ever since, Germany has been gradually turning into a more liberal, pluralistic, and individualistic society. “Self help” was the key concept of these and the following years.

Undoubtedly, when the disability rights movement started, disabled people in Germany could look back on a long tradition of self-help organization, which can be traced back to the beginning of the twentieth century. Blind and deaf people as well as war victims of World War I (1914–1918) were among the first who had their own interest groups. An early self-help organization of the physically disabled was founded by Otto Perl (1882–1951) in 1919. After World War II (1939–1945), organizations of war victims grew even bigger and were quite successful in political lobbying. Since the end of the 1950s, parents of disabled children began to build up their own disability-related organizations and services. The Bundesvereinigung Lebenshilfe (Confederation Help to Life) for mentally disabled children, founded in 1958 in Marburg, is one prominent example of a parent group.

Despite these activities, until the late 1970s a cross-disability rights movement did not exist in Germany. But the end of that decade saw the emergence of something new: So-called cripples’ groups sprang up in several places. Their members came together solely because of their disabilities, but their specific impairments did not matter. Principally, the meetings were open for all people who defined themselves as being disabled. In contrast to the already existing organizations, the new groups excluded nondisabled people from their ranks. These new groups founded the “Krüppelzeitung” (“cripples’ newsletter”) and adopted a radical position: the “cripples’ standpoint,” which had been formulated by Franz Christoph (1953–1996), a major activist of the new movement. This philosophy was directed against professionals and experts, who took charge of and oppressed disabled people, and against do-gooders and what was viewed as their denigrating compassion. The new disability standpoint was full of angry protest against the ideologies of partnership and integration propagated by the traditional disability organizations. Instead, the new disability rights movement followed the example set by the women’s liberation movement and women’s consciousness-raising groups. Its aim was to accept and value disability as a specific form of life. Radical changes in living conditions were demanded as political rights and not as charity.

After that first phase in which angry young men and women with disabilities protested, for example, against the charity approach officially adopted in Germany for the 1981 International Year of Disabled Persons, a more pragmatic period followed. During the 1980s, German activists in the disability rights movement were busy organizing peer counseling services, giving each other legal advice and psychosocial support, protesting against inadequate public transport, and political lobbying. They built up their own infrastructure, consisting of counseling and advocacy facilities as well as job creation programs all over the country.

Gradually, the "cripples' movement" turned into the independent living movement in which the principle of self-representation continued to play an important role. The magazine *die randschau* (*from the margin*) became the new mouthpiece. Inspired by the American philosophy of independent living, German disabled people started their own independent living centers. Consequently, personal assistance became an important issue. In 1990, the nationwide umbrella organization Interessenvertretung Selbstbestimmt Leben (Independent Living Interest Group) was founded. A further field of intensive campaigning were bioethics and the effects of genetic engineering and reproductive technologies on the lives of disabled people. Female activists especially were involved in this issue. Disabled women also managed to build up their own feminist networks, and they gained a self-confident voice within the movement. Furthermore, the 1990s saw people with learning difficulties starting their own networks. A new phase began when the issue of equal rights and opportunities was put on the agenda.

Since the beginnings of the 1990s, the legal approach has dominated and both old and new disability organizations have started to work more closely together instead of competing against each other. In 1994, the disability rights movement was successful in using for its own aims the reform of the German constitution, which had been made necessary by the reunification of Germany. Since that year, an amendment to the constitution forbids discrimination on the ground of disability. Other laws, such as the Rehabilitation and Participation Law (2001) and the Federal Equal Rights Law (2002), have been formulated with the active contribution of disability rights activists. In 2003, the official German program of the European Year of People with Disabilities was organized by a prominent activist of the disability rights movement, and a summer school on critical disability studies took place. It seems as if disabled people finally have taken their place in German society, but at the same time discrimination continues and new issues arise on the disability agenda requiring new approaches and policies.

—Anne Waldschmidt

See also Advocacy; Franz Christoph; *Cripple*; Independent Living.

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▣ AESOP

(Seventh- or sixth-century BCE; possibly legendary) Greek fabulist

Although the fables attributed to Aesop, such as "The Ant and the Grasshopper" and "The Tortoise and the Hare," are as well known as any of Hans Christian Andersen's tales, little is known of this early poet or even whether he existed. Aesop was connected with the Greek island of Samos in some way, either by birth or later residence. The sources for Aesop's life are very late, written many centuries later, thus unreliable. One tale tells us that he was born mute but granted not only speech but also eloquence by the goddess Isis. Another dubious piece of information—dubious because it was recorded so many centuries later—is that Aesop was lame or hunchbacked. Robert Garland, in *The Eye of the Beholder* (1995:11), tenuously identified as Aesop a disfigured man in conversation with a fox on a charming red-figure drinking cup from the classical Greek period.

—M. Lynn Rose

See also Folk Belief.

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AESTHETIC SURGERY

From the close of the nineteenth century to the present, aesthetic surgery has come to be ever more widely practiced. It has also become the focus of ongoing criticism of what limits society and the individual can or should set, with respect to control over our own bodies and the bodies of others. These debates are often undertaken in complete ignorance of the history of aesthetic surgery, which is seen as being an American (read: Hollywood), patriarchal form of the oppression that women were (and are) subject to. The reality is that aesthetic surgery is a classic product of the modern world, with all of its advantages and disadvantages, including our claim to control our bodies. It is the test case for all of the claims about human autonomy that the Enlightenment defined as "modernity."

The technology of aesthetic surgery, in its modern form, arose out of the anxiety about the visibility of the diseased and damaged body that forms its common history with reconstructive surgery. Wounds of war, lesions of diseases from syphilis to smallpox, and congenital malformations all formed the background to the beginning of aesthetic surgery at the close of the nineteenth century. The Berlin surgeon Johann Friedrich Dieffenbach (1792–1847), a central figure in nineteenth-century facial surgery, wrote in 1834 that

> a man without a nose arouses horror and loathing and people are apt to regard the deformity as a just punishment for his sins. This division of diseases, or even more their consequences, into blameworthy and blameless is strange. . . . As if all people with noses were always guiltless! No one ever asks whether the nose was lost because a beam fell on it, or whether it was destroyed by scrofula or syphilis. (Dieffenbach 1829–1834: Vol. 3, p. 39)

Disability was the product of the physical malformation and (equally important) the stigma associated with it. This the surgeon could remedy.

Here there was little question of the nature of the disability associated with the body. For early "reconstructive" surgeons, disability was defined as lack of function coupled with the stigma associated with perceived deformity. With the introduction of the technologies of anesthetics and antisepsis, the potential of a human being, through surgical intervention, to change his or her body became both imaginable and practicable. Yet the idea of a perceived difference from an implicit norm remains central to this new aesthetic surgery. From the first patients in the 1870s and 1880s to the millions (perhaps billions) having aesthetic surgery across the world today, the idea of surgical manipulation of the body has become commonplace. But at its center is the sense of our desire (through the agency of medicine) to give us the bodies that we want rather than those that we have in order to combat the stigma we associate with those aspects of our bodies that we wish to change.

Given the predilections of our desire to control our bodies, the history of aesthetic surgery can be rather neatly divided into the world before the end of the nineteenth century and the world afterwards. It is between 1870 and 1900 that virtually all of the present procedures for the aesthetic alternation of the body are introduced. They build, of course, on earlier developments in surgery. The initial patients, with few exceptions, were men, a fact seemingly lost in the history of aesthetic surgery. But why was there an explosion of both patient interest and surgical innovation at that specific time? Such surgery prior to the nineteenth century, before the introduction of antisepsis (no infection) and anesthesia (no pain), was undertaken only when it was truly a functional necessity. Aesthetic surgery demanded something in addition.

Anesthesia became generally accepted and central to the practice of surgery after the discovery of ether anesthesia by William Thomas Green Morton (1819–1868) in 1846. The further development by the 1880s of local anesthesia, in the form of cocaine for surgery of the eye as well as spinal (subarachnoid) anesthesia and epidural anesthesia, meant that the greater risk of dying under general anesthesia could be avoided. Local anesthesia has played a central part in the development of aesthetic surgery as a widely practiced specialty. It is one of the primary factors in the successful outcome of the patient, who can follow the procedure and, unlike the patient under general anesthesia, does not morbidly fantasize about the opening of the body while unconscious. Under local anesthesia, aesthetic surgery can be experienced as a procedure a patient actively chooses, not a cure to which he or she passively submits under general anesthesia, giving up all control of the self. The patient's perception of autonomy is central to the popularity of aesthetic surgery.

The movement toward antisepsis paralleled the development of anesthesia. In 1867, Joseph Lister (1827–1912) provided a model for antisepsis, which became generally accepted by the end of the century. The potential avoidance of infection meant that patients' anxiety about cutting the skin was lessened. The acceptance of antisepsis for all surgery was relatively slow but was strongly encouraged by aesthetic surgeons. On November 26, 1877, Robert F. Weir (1838–1894), one of the major figures in the creation of American aesthetic surgery, said in a talk before the New York Medical Association that the British and German acceptance of this procedure had outpaced that of the United States. He urged that the smallest detail of the cleansing of patient, surgeon, instruments, and surgical theater be carried out so as not to place the patient at needless risk. Once this was done, the risks attendant on aesthetic surgery decreased sharply because of the reduction in the high incidence of infection.

With pain and infection removed or reduced, aesthetic surgery came into its own. Yet anesthesia and antisepsis were necessary but not sufficient to mark the beginning of the modern history of aesthetic surgery. It was the Enlightenment ideology that each individual could remake himself or herself in the pursuit of happiness that provided the basis for the modern culture of aesthetic surgery. Indeed it is remarkable how often aesthetic surgeons describe "happiness" as the goal of the surgery. "Happiness" for aesthetic surgeons is a utilitarian notion of happiness, such as that espoused by John Stuart Mill (1806–1873), who placed the idea of happiness within the definition of individual autonomy. You can make yourself happy by being able to actively participate in the world. This was mirrored in the rise of modern notions of the citizen as well as the revolutionary potential of the individual.

Autonomy stands as the central principle in the shaping of aesthetic surgery. "'Dare to use your own reason,'" wrote Immanuel Kant (1724–1804), "is the motto of the Enlightenment" (1963:3). And it is the ability to remake one's self that is the heart of the matter. Aesthetic surgery is therefore a truly modern phenomenon that demanded not only a set of specific technical innovations in surgery but also a cultural presupposition that you have the inalienable right to alter, reshape, control, augment, or diminish your body (with, of course, the help of the surgeon). The autonomy that aesthetic surgery represents is truly a modern one: You can act as you desire to become happy, but only with the aid of and comfort provided by the technocrats whose expertise you can employ.

In the course of the nineteenth century and the movement from a functional to a transformative model of aesthetic surgery, the stigma of race had its impact. Some male Jews in Germany wished to vanish into the nonracial world of unracialized men. And in Berlin in the 1890s, there was Jacques Joseph (1865–1934). Joseph had been a highly acculturated young German Jewish surgeon practicing in fin-de-siècle Berlin. Born Jakob Joseph, he had altered his too-Jewish name when he studied medicine in Berlin and Leipzig. Joseph was a typical acculturated Jew of the period. He developed the first procedure of reducing the size and shape of the "Jewish" nose at the moment when political anti-Semitism first became a potent force in Germany.

In January 1898, a 28-year-old man came to him, having heard of a successful operation on a child's ears. He complained that

> his nose was the source of considerable annoyance. Wherever he went, everybody stared at him; often, he was the target of remarks or ridiculing gestures. On account of this he became melancholic, withdrew almost completely from social life, and had the earnest desire to be relieved of this deformity. (Joseph 1898 in Aufricht 1970:178)

The psychological symptoms were analogous to those of the young boy whose ears Joseph had repaired.

Joseph took the young man's case and proceeded to perform his first reduction rhinoplasty, cutting through the skin of the nose to reduce its size and alter its shape by chipping away the bone and removing the cartilage. On May 11, 1898, he reported on this operation before the Berlin Medical Society. In that report, Joseph provided a detailed "scientific" rationale for performing a medical procedure on an otherwise completely healthy individual:

> The psychological effect of the operation is of utmost importance. The depressed attitude of the patient subsided completely. He is happy to move around unnoticed. His happiness in life has increased, his wife was glad to report; the patient who formerly avoided social contact now wishes to attend and give parties. In other words, he is happy over the results. (Joseph 1898 in Aufricht 1970:178)

The patient no longer felt himself marked by the form of his nose. He was cured of the "disease" of "nostrility." In his own eyes, he looked less different from the group he desired to join—the non-Jews. Joseph had undertaken a surgical procedure that had cured his patient's psychological disorder. Yet he had left scars, which pointed to the procedure itself, and this became a major concern of Joseph's. He warned his colleagues that "disclosure to the patient on the problem of scarring is very important. Many patients, however, will consider even simple scars too conspicuous." He raised the specter of a court case in which the "unsightly scar might represent a greater degree of disfigurement than the enlarged cartilage of the nose presented previously." More centrally though, surgical scars, unlike scars obtained through socially acceptable and manly activities such as dueling, reveal the inauthencity of the body and the effort to "pass" via medical intervention.

The general claim that the surgery creates some form of happiness remains central to aesthetic surgery. In the nineteenth century, surgeons claimed that they were altering the body to change the psyche. In 1887, John Orlando Roe in Rochester, New York, developed a procedure to alter the shape of the "pug nose." Roe did not only claim to cure the pug nose, he claimed to be also curing his patient's unhappiness. His comprehension of the relationship between mind and body was clear:

> We are able to relieve patients of a condition which would remain a lifelong mark of disfigurement, constantly observed, forming a never ceasing source of embarrassment and mental distress to themselves, amounting, in many cases, to a positive torture, as well as often causing them to be objects of greater or lesser aversion to others. . . . The effect upon the mind of such physical defects is readily seen reflected in the face, which invariably conforms to the mental attitude, and leads after a time to a permanent distortion of the countenance. (quoted in McDowell 1977:114)

The surgeon in curing the deformity makes the patient happy, which in turn alters the physiognomy of sadness.

At the beginning of the twenty-first century, we have a resurgence in the idea that men (too) desire to shape their bodes through surgery to provide them with new, younger bodies. It is not actually much of a change. The bodybuilding culture for men that stressed the muscular, shaped body arose in the 1890s at the same time as the origin of modern aesthetic surgical procedures. Shaping or cutting can reform the male body by the desire of the individual in concert with the professional (either bodybuilder or surgeon).

Today, we have come not much further in the popular understanding of aesthetic surgery. Columnist Anne Duggan in Australia wrote in 2002:

> What man or woman is ever truly happy with every part of their face or body? Even if you are quite comfortable with your appearance, you probably think there is room for improvement. Cosmetic surgery can be a great adjunct to your health and fitness regime, improving those areas that diet and exercise won't. According to cosmetic surgery specialists, having a nip or a tuck is catching on in Australia, as the procedures become more acceptable and accessible for all Australians. Whether you'd like a smaller nose, fewer

> wrinkles or bigger breasts, there is a cosmetic surgery procedure that can help. (p. A7)

Can we truly become happy? And what does that happiness come to mean for us when we achieve it through surgery? Is happiness an appropriate goal for life or does it demand too much?

—Sander L. Gilman

See also Body, Theories of; Deformity; Identity.

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AESTHETICS

Disability aesthetics is a critical approach to thinking and making of art through a disability perspective. It is an approach that revises and resists the ways in which mainstream society has marginalized the disabled person as well as disability art. In part, this work has centered on the efforts of arts scholars to critique traditional notions of aesthetics that emphasize an ideal body and simultaneously discount, minimize, or erase disability. Cultural assumptions about disability inform many artistic artifacts and performance, and the analysis of these assumptions helps us to understand how disability has been historically and socially construed as well as how these parameters on disability limit the possibilities for new artistic practices. Consequently, a disability perspective foregrounds the value and power of human variegation, and it challenges the ways in which disability has typically been viewed as a deficit.

It is important to grapple with how art reinscribes and helps maintain traditional societal frames for disability, work that has been undertaken by such scholars as Lennard Davis, David Mitchell and Sharon Snyder, and Rosemarie Garland Thomson. This work helps us understand how disability and its figures have worked as the hidden partners in supporting what are deemed important cultural messages that are disseminated through art. Davis's work on the deafened moment looks at "deafness as a critical modality"—more specifically at the sites and ways in which the emphasis on hearing and sound falls out and there is a reliance on nonverbal signs. There are, as he demonstrates, cultural and artistic practices that emphasize moments of deafness without fully acknowledging the ways in which the practice rests on deafness itself. Mitchell and Snyder show the ways in which disability is used as a narrative prosthesis in literature, how images of disability act to jumpstart engagement with the text through a problem or crisis. It sets in motion the storyline, but by the end of the narrative, the disability most often gives way to some triumph of the able-bodiedness or the normal. Thomson has addressed how freak shows, photographs of the disabled, and other cultural evidence rely on the audience response of staring and thus communicate a set of coded messages about disability and its place in society.

The representation of disability is, of course, not new. Historically, a number of performing artists, as a result of their investment in challenging traditional modes of representation, have incorporated the presence of the disabled in their works. These numerous approaches include disabled characters in plays, sensory frames of reference from a position of "as if" disabled (such as Robert Wilson's early work, *Deafman Glance,* with African American deaf-mute Raymond Andrews), the use of sign language in modern dance works, or an entire aesthetic of modernity based on what could be called a disability perspective, such as the work of Antonin Artaud. In fact modernist (as well as postmodernist) aesthetics has often drawn on the seemingly unstable and often unclassifiable bodies of the disabled to bring new life to art practices. While a number of these examples open up new aesthetic frames, they also have worked to reinscribe the abnormal phenomena back within the regime of normalcy.

All too often the disabled person has fallen out of the picture. This maneuver reflects the larger sociocultural malaise toward dealing with disability—of disappearing or marginalizing the disabled—as well as the ways in which art claims to rest on the position of the ideal body. The disabled person, in these cases, does not play the disabled character. Robert Wilson, for instance, continues his work with its complex visual textures and "deafened" tones without his counterpart, and we still go to see modern dance that uses sign language but does not include deaf dancers.

More recently, disability aesthetics has also begun to account for how disability itself produces art, what those art practices are, and how those endeavors lead to a new aesthetics—revising what we have typically and traditionally considered aesthetics with its emphasis on the beautiful. This account can help us understand how the incidents of the anomalous body in a vast amount of art history are not simply always an effort to discount the lives of the disabled and the ways in which the unusual reinvigorates artistic practice. But, even more significantly, disability art today bypasses traditional modes of representation and demands new practices of engagement.

Artistic practice relies on the manipulation of sensory frames of reference, and these sensory amalgamations carry with them emotional and conceptual implications. Consequently, disability aesthetics as practice provides a rich frame for articulating different ways of existing as persons in the world.

The disabled are privy to all sorts of sensory experience not accessible to the able-bodied. Disability art is one way of providing access to this unfamiliar territory and of creating space for the emergence of new concepts and experiences of artistic creation. This pattern not only challenges traditional representations of the body, but it also unsettles conventional ways of knowing and communicating. And the increasing number of arts organizations, dance companies, and performance companies that generate work giving direct voice to the disabled gives witness to the growing interest in disability arts.

There are a number of challenges regarding the disability perspective. Feminist disability theorist Thomson (1997b) noted: "Disability, perhaps more than other forms of alterity, demands a reckoning with the messiness of bodily variegation, with literal individuation run amok. . . . [D]isability foregrounds embodiment's specificity" (p. 283). The question of "embodiment's specificity" finds particular cogency in disability arts with its emphasis on corporeal particularity and the unpredictable and unfamiliar. In performances of various sorts, disability invites the audience to engage with art and performance in new ways as they provide us with what Petra Kuppers, following dance choreographer Deborah Hay, calls "perceptual challenges." Examples include, but are not limited to, the inclusion of dancers in wheelchairs (AXIS and Infinity USA, CandoCo Britain), dancers with cerebral palsy and cognitive differences in Restless Dance (Australia), performers with sensory and physical impairments in Graeae Theater (Britain), deaf dancers in Common Ground Sign Dancer Theater (Britain), or the recent inclusion of deaf dancers in Nancy Hauser's Company (United States), as well as a choreographer and dancer who has dystonia, Neil Marcus (United States). This variety not only changes the look of what's staged but also the feel, as these perceptual challenges often create an emergent space of experience and understanding. Consequently, we engage with disability as difference rather than deficit as it bypasses the usual representational circuitry.

Contact improvisation, a dance form where the participants rely on the exchange of energies between a variety of physical contact points and shifts in body weight both individually and shared, has a well-developed history in including disabled performers. Part of the reason for this occurrence is that the form itself does not rely on the typical cultural expectations of upright physicality and presentational qualities; it relies on the feel of the dancing rather than its look.

This radical, liminal space unsettles expected transactions between performer and audience, and it creates an arena of instability. In this arena, previous assumptions and significations become unmoored; new possibilities emerge. Confronted with the material world of disabled performers, the present and palpable bodies of physical difference the audience also faces its own phantasms of disability—questions of illness or weakness, physical appearance, or suffering that are often dismissed or rejected by society at large. This body is unpredictable, unstable. Unleashing ourselves from the proclivity of bracketing the anomalous body helps to generate space not only of visibility for the disabled but also a space for grappling with the inherent hybridity of our physicality—its concomitant sensory and emotional variety.

In the National Theatre of the Deaf, for example, the deaf performers use sign language, which is a visual-kinetic mode of language and often referred to as "silent poetry," but voicing actors also interpret their performances. This work challenges the traditional limits of language, poetry, and the use of voice; deaf individuals speak visually and kinesthetically in ways that the hearing population is not accustomed to hearing. The location of deaf poetry—and by implication deaf poetry as it occurs in theatrical performance—within the larger discussion of the ways we have moved from a textually based model of communication to a performance-based model of communication indicates an emphasis on a visual-spatial field rather than that of sound. Consequently, the use of American Sign Language (ASL) in performance is a valuable site for grappling with an aesthetic that valorizes the position of deafness.

It is important, furthermore, to note that several well-known ASL poets, such as Clayton Valli and Ella Mae Lentz, have chosen not to have their work sound-interpreted as a matter of a political statement to the hearing community. This work invites a consideration of how "think-hearing" is what Michael Davidson has called "a subject of aesthetic critique while utilizing ASL as a powerful discourse to phonocentric models for literature." Davidson has addressed the ways in which the work of Flying Circus, with deaf performer Peter Cook and hearing performer Kenny Lerner, use speech as well as vocalization in their performances to challenge and revise the ways in which the use of speech tends to signal specific meanings for the hearing. Davidson also critiques the work of Deaf performance artist Aaron Williamson and the ways in which he uses the visual channels to render the in-between status and states of a late-deafened adult—the ways in which meaning slides between image, object, body, and voice. For Williamson, Davidson concluded that he critiques the organizing cultural metaphor for meaning as the ear rather than the voice. Work of this sort serves to locate disability artists within the nexus of a broad range of concerns that provides a powerful critique of how the construct of disability operates across a range of questions about human experience.

Street performer Bill Shannon, aka "Crutchmaster," with strong ties to both the hip-hop dance scene and the disability arts scene, has developed an entire dance aesthetic out of his need to use crutches to move around. In his street improvisations, Shannon uses both his crutches and a skateboard to maneuver in and around people passing by on the streets. This approach plays off of and with people's discomfort and confusion about how to deal with someone moving through public space in unfamiliar ways. Consequently, Shannon's prowess in moving invites spectators to revise their expectations about how disabled individuals can navigate public spaces. It also inserts the generation of a new movement aesthetic into the experience of everyday life.

In addition to innovative engagement with how mainstream notions of aesthetics can be changed through the development of new practices for staging the moving body and various sensory frames, the use of storytelling has also helped to further disability aesthetics by investigating new ways to look at narrative. For example, Anne Basting's TimeSlips (U.S. based) is an interactive project on storytelling for Alzheimer's patients. Bastings has developed a process for doing storytelling circles with these patients that centers on telling a story in the present through the impetus of a visual stimulus. The stories that emerge out of these workshops emphasize the power of image rather than the linearity of traditional storytelling. This work has led to the development of an interactive component on the TimeSlips website, installation work, and a TimeSlips play, as well as growing interest in the creative possibilities of dementia.

There are a number of other groups that have used storytelling in innovative ways. Artistic director Ruth Collett's project Stalking Histories (Britain based) explores lost stories from the disability culture, in relationship to such events as the Holocaust in Germany or the impact of Mendel (1822–1884; a botanist and monk who developed the study of genetics) and integrates the use of new technologies and nontraditional sites for the sharing of the stories. As they continue to explore the implications of new technology for disability performance and storytelling, they are making progressive use of their website as a gallery space for the sharing of stories.

Other disability artists exploring how the new technologies make the production and access to artwork more available for disabled artists include Bilderwerfer's (Austria) web-based collaboration area and Petra Kuppers, director of Olimpias Performance Research Project. She explores the connections between story, mental health system survivors, disability arts, and the new media. The projects take a variety of forms: installations, film, and CD-ROM. Each of these examples develops an alternative venue to the traditional structures of the presentational stage, allowing a more mobile approach to be taken to the making and sharing of art. In addition, cultural expectations about looking at a performance are disrupted or challenged and the audience members must adopt a more participatory and nonlinear approach to experiencing the artwork.

These unfamiliar moments are not easy to analyze or to live through with complete lucidity, yet, as new spaces of exchange open up, new identities and geographies can unfold. Consequently, as we attend to the embodied traces of disabled identity in the mobile landscape of the everyday, performance provides a medium par excellence for mapping new identities. The fixities of personal and social identity, the traumas of history, and the obsessively repeated stories give way to the possibilities of other narratives, new viewpoints. The body shape-shifts, and as it responds to the creative charges and unexpected changes it is suddenly engaged in a new storyline, a different angle in the aesthetic trajectory brought on by the mobilizing of communal energies.

—Kanta Kochhar-Lindgren

See also Body, Theories of; Culture; Dance; Deaf Culture; Drama and Performance; National Theatre of the Deaf; Sign Poetry.

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TimeSlips, http://www.timeslips.org/outreach/play.html
World Institute on Disability, http://www.wid.org

AFFIRMATIVE ACTION

See Quota Hiring Policy

AFFIRMATIVE BUSINESSES

Affirmative businesses provide employment opportunities for people with disabilities. They operate as regular businesses, producing goods and services for sale within the broader community. Affirmative businesses have typically emerged from nonprofit organizations and have developed through a collaboration between people with disabilities, vocational rehabilitation professionals, and businesspeople. This collaboration is directed toward the creation of a business organization that is sensitive to the needs and aspirations of persons with disabilities, constructs a working environment that can meet diverse needs for training and job accommodations, and operates using sound business principles and practices. In this way, affirmative businesses are structured to neutralize the individualism and competition that disadvantage individuals with disabilities in the open labor market.

The exact nature of an affirmative business will depend on the interests and skills of the potential workforce and on the market prospects in the local community. Examples include businesses that have focused on industrial subcontracting, cafés and catering, desktop publishing and video production, car washes, greenhouses, laundry services, and retail convenience and gift outlets. Since they are designed as true businesses, they provide workers with either the opportunity for long-term employment or a place to develop their work capacities before they move on to other jobs in the open labor market.

The effectiveness of the affirmative business is measured by its commercial success. A primary objective is to reduce reliance on funding from government or philanthropic organizations. They are also expected to offer wages that are consistent with standards in the open labor market and opportunities for advancement. Effectiveness is also measured by the extent to which the working environment facilitates participation and ownership by individuals with disabilities.

The affirmative business approach to job development has been applied broadly to people who are disadvantaged with respect to employment. John Durand is widely credited for its application to persons with disabilities in the 1960s. The approach is one of many commercially oriented ventures that attempt to develop business practices that promote a socially responsible and sustainable economy.

Community integration in this employment approach is realized at the level of the business. Employees connect with the broader community in the day-to-day context of offering goods and services to the public, ordering supplies, and participating in local business networks. It is expected that the financial rewards and personal connections made in the context of work will facilitate opportunities for community participation outside of the business.

Critics of the approach have argued that this is segregated employment and is minimized as a credible business model in the open labor market. There are also concerns that these businesses typically provide only entry-level jobs with poor prospects for financial compensation and opportunities for advancement. Finally, it has been argued that the structure of the organization will favor employment of professionals from the human services sectors in key management positions, undermining full ownership by persons with disabilities.

—*Terry Krupa*

See also Consumer-Run Businesses; Employment; Sheltered Workshop.

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AFRICA

See Deaf People in African Histories;
Disability in Contemporary Africa;
Experience of Disability: Sub-Saharan Africa

AFRICANS, DEAF

See Deaf People in African Histories

AGASSIZ, (JEAN) LOUIS (RODOLPHE) (1807–1873)

American (Swiss-born) naturalist

The naturalist Louis Agassiz began his career working on fish fossils and studying under Georges Cuvier (1831). In 1847, he became a professor at Harvard University where he founded and directed the Museum of Comparative Zoology until his death in 1873. Furthering Cuvier’s work on geological catastrophism and classification of animals, Agassiz developed the glacial theory of the Ice Age (1840) and a classification of biological life forms (1851–1855). Similar work on biological order led Charles Darwin and Ernst Haeckel to theories of evolution and natural selection. Agassiz rejected these theories and, instead, adhered to natural science as a combination of empirical methodology and natural theology. In 1847, he advocated polygenesis, basing his support on new geological evidence. Polygenesis, the theory that at least some races had separate origins, was also employed as a defense of Christianity and eventually as a social doctrine (1850). He advocated the permanence of different races and worried about the “tenacious influences of physical disability” if races were mixed (1863). While his teaching and early research brought unprecedented national and international recognition for the field of natural science, his antievolution position and support of polygenesis were controversial throughout his life and contributed to his marginalization in subsequent years.

—*Jee Yoon Lee*

See also Race and Ethnicity.

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AGING

Conceptions and definitions of *old age* and *disability* vary in different cultures. These include chronological age, functional limitations (activities of daily living and instrumental activities of daily living), social performance, or work capacity. One approach is to define aging as an ongoing process that includes age-related changes related to physiological processes occurring at certain stages in life (e.g., puberty and menopause) and age-related conditions that occur as individuals age (e.g., hypertension and coronary artery disease). Criticism of these definitions of aging and disability center on their failure to measure the impact of social, political, economic, and cultural factors on a person's ability to perform or engage in social roles. Common barriers to participating in social roles include architectural barriers and attitudinal barriers that can impede active community participation. The Americans with Disabilities Act of 1990 (ADA) acknowledges that people with impairments (even in the absence of any limitation) may face discrimination due to social forces, such as stigmatization, fears, or myths regarding disability. According to the ADA, a person with a disability is someone who meets at least one of the following criteria: (1) has a physical or mental impairment that substantially limits one or more major life activities, such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, or working; (2) has a history or record of such an impairment; or (3) is perceived by others as having such an impairment.

The onset of disability for most people occurs at older ages and the duration is short. These individuals experience disability with aging. Adults who acquire their disability in childhood, before the age of 20 (about 7–9 percent in the United States), experience aging with a disability. The terms *disability with aging* and *aging with a disability* have generated stereotypical views about aging and disability in that the onsets of disability is an issue for older persons and "aging" is an issue for younger adults with permanent disabilities.

GLOBAL AGING AND AGING IN THE UNITED STATES

Human longevity climbed in the twentieth century due to changes in public health policies (e.g., improved sanitation and food and water safety), advances in medical practice (e.g., antibiotics and insulin), and greater emphasis on health promotion and disease preventive. The older population of persons aged 60 years or older is growing faster than the total population in almost every region of the world.

Data from the United Nations Department of Economic and Social Affairs (2002) indicate that over the past 50 years, the number of older persons has tripled from 205 million persons in 1950 to 606 million in 2000 and is projected to triple again by 2050 to approximately 2 billion persons aged 60 or older. People who are 80 years or older are the fastest-growing group of older individuals; this cohort is projected to increase five-fold from 69 million in 2000 to 379 million in 2050.

In the United States, according to the U.S. Bureau of Census (2002), 35.1 million persons are over the age of 65 years (12.4 percent of the total population). Of these, 21 million are women and 14 million are men. The 2003 "American Community Survey (ACS) Data Profile" (U.S. Bureau of the Census 2003) reported that 20 million (12 percent) people 21–64 years old have a disability and 14 million (40 percent) persons age 65 and older have a disability. The likelihood of acquiring a disability increases as people live longer. Age-associated disabilities include impairments in mobility, hearing, vision, cognition, and loss of function due to medical conditions such as congestive heart failure, stroke, and chronic obstructive pulmonary disease. In the United States, the number of people aging with a disability also is increasing. Today, the population over age 60 years includes more than half the persons with disabilities in the United States.

LIFE EXPECTANCY

The average life expectancy in the United States for infant girls is now 79.7 years and 74.1 years for boys. While the life expectancy for persons with disabilities acquired early in life has increased significantly, in general, disabled people have a life expectancy that is 15 to 20 years less than the rest of the population. With advances in medical treatment and living conditions, life expectancy for some people with disabilities (e.g., people with developmental disabilities and spinal cord injury) has risen dramatically and is only slightly lower than that of the general population. Individuals with spinal cord injuries have the highest mortality rate in the first year after injury, and those who have greater neurological deficits tend to die earlier. For people with Down syndrome, cerebral palsy (particularly individuals with lower functional levels), and severe intellectual disabilities, life expectancy is significantly lower than for the general population. In addition, life expectancy for persons with intellectual and developmental disabilities is significantly lower than that of the general population in the presence of the following impairments: severe mobility impairment (requiring a wheelchair and assistance for propulsion), severe manual dexterity impairment (unable to feed and dress without assistance), and severe intellectual disability (IQ < 50).

VIEWS OF AGING AND DISABILITY

Perceptions of aging and disability in any era and culture are influenced by lifespan, economic conditions, social expectations, and images presented in contemporary media, arts, and literature. During the past several centuries in the United States, the religious and secular movements have transformed our views of aging and disability. In the seventeenth century, Puritans revered people who were aged and saw aging as a sacred pilgrimage to God. Similarly, reformers motivated by religious principles worked to help people with disabilities, as they helped children and heathens. During the Victorian age, youth became a symbol of growth and expansion, and people with disabilities, who were increasingly sent to live in mental asylums, state schools, and homes for the feebleminded, had little control over their lives. As the need to provide for a rapidly growing population increased, youthful energy, westward migration, and technological advances made the elderly seem out touch and their traditions seemed cumbersome and a hindrance to progress. In addition, medical advances during the twentieth century promised to eliminate much disability. Though this promise was overstated, people with disabilities were less visible in our communities as many people continued to be placed in institutions or special schools or kept out of sight at home.

In the past 20 years, portrayals of aging have shifted from viewing aged individuals as victims or those to be pitied, shunned, or ridiculed to seeing robust images of aging adults maintaining active lifestyles within their communities. Images of people with disabilities have also transformed from depicting them as broken people who need fixing to people who want the right to live, work, and engage in recreational activities within their communities. Increasingly, we are recognizing and confronting the negative assumptions and values our culture has held about old age and disability.

As more persons are living longer with a disability, whether the disability onset is earlier or later in life, the intersection of the fields of disability and gerontology is greater. Biological, sociological, and psychological theories seek to understand the determinants of mortality, morbidity, and well-being in later life. These determinants include individual biological and lifestyle issues as well as environmental aspects, including support services and the physical environment.

THEORIES OF AGING

Historical Perspectives

The concept of aging represents a phenomenon of populations and individuals. On a *population* level, aging represents the success of a society based on the outcome of human discoveries and developments in hygiene, nutrition, biomedical technology, and sociopsychological and political advancements. Aging also reflects societal challenges, given the costs required of social and health programs in modern societies. On an *individual* level, aging takes into account three main aspects: biomedical, psychological, and social well-being, though throughout the history of the study of aging, the biomedical discipline has predominated, compared with psychology or any of the other social sciences.

Theories related to the universal human phenomenon of aging have been debated since early philosopher-scientists. According to Ebersole, Hess, and Luggen (2004), Aristotle believed that aging was a period of disengagement and interiority, whereas Cicero and Montaigne saw aging as a period of self-discovery, pursuit of gentility, and complexity. Plato viewed aging as the development of wisdom and a metamorphosis of the soul. Leonardo da Vinci saw aging as a time of coping with the reality of physical decline, and Charcot viewed aging as a latency period of diseases that appeared only in old age. While Galen asserted that old age is not a "disease," Benjamin Rush stressed the importance of heredity and behavior on aging and Louis Cornaro believed that restricted diet and moderation were necessary for a long life. Alasdair Fothergill linked the effects of mind on body by recommending the benefits of positive attitudes on aging. Arnald of Villanova thought that moderation and humoral balance were critical to vitality.

Contemporary Theories on Aging

As scientists expanded their knowledge, improved their research methods, and discovered more about aging, they came to view aging as a complex and variable process. During the twentieth century, biologists, sociologists, and psychologists developed theories to explain the phenomenon of aging. These theories fall into several broad categories such as biological (encompassing measures of functional capacities of vital or life-limiting organ systems), sociological (involving the roles and age-graded behaviors of people in response to the society of which they are a part), and psychological (referring to the behavioral capacities of people to adapt to changing environmental demands).

Biological Theories

Although aging and disease are independent processes, aging clearly includes increased vulnerability to disease. Early medical theories focused on the relationship between disease and aging. More recent medical theory focuses on assessing and improving the functional health of aging individuals. Evolving theories addressing not only longevity but also active life expectancy and functional health explain the recent emphasis on health promotion interventions and provide goals for healthy aging.

All organ systems undergo a gradual decrease in reserve capacity, although at different rates. This rate depends on the genetic composition, such as the presence of genetic syndromes or disease-resistant genes, and on "wear and tear" brought on by a stressful lifestyle and environmental factors (e.g., smoking, poor diet, alcohol abuse, muscular strain). Diminished immunity increases susceptibility to chronic conditions such as cancer, infections, lupus, and rheumatoid arthritis. When little reserve capacity remains, the likelihood of developing a disease increases. People with disabilities may have less reserve capacity remaining. For example, a person who had polio is unlikely to reach the same peak pulmonary capacity as a nondisabled person. Persons who have been nonambulatory for many years are unlikely to reach the same peak bone density as other persons.

Sociological Theories

Early sociological theories of aging (in the 1960s) focused on the adjustment of older people to losses within the context of their roles in society. Examples of these theories are the disengagement and activity theories. In the 1970s, the perspective broadened to also examine the complex interrelationships between older persons and their physical, political, and socioeconomic environments.

The premise of the disengagement theory proposed by Cumming and Henry is that aging is a time of mutual withdrawal and gradual reduction of roles and responsibilities so that the older person could be replaced. This view depicted the older person as preoccupied with himself or herself and with decreasing emotional involvement with others. Criticism of this theory posits that such disengagement is neither natural nor inevitable and presents a one-sided view of older persons, as many persons remain active throughout old age.

Robert Havighurst's activity theory conceptualized aging in terms of the developmental tasks of later life. Using a lifespan perspective, he suggested that these developmental tasks include (1) coping with physical changes; (2) redirecting energy to new roles and activities such as grandparenting, retirement, and widowhood; (3) accepting one's own life; and (4) developing a point of view about death. The premise is that to maintain a positive sense of self, elderly persons must substitute new roles for those lost in old age.

Lawton proposed the concept of the person-environment fit that examines the interrelationship between personal competence and environment; for each level of competence, there is an optimal level of environmental demand (environmental press) that is most advantageous to a person's function. Those persons with a low level of competence can tolerate only a low-level press, and those with higher levels of competence can tolerate increased demands. This paradigm is useful in planning suitable interventions for older adults with disabilities who reside in private homes and institutional settings.

Psychological Theories

Psychological theories of aging address old age within the context of a person's life cycle, wherein one moves through stages in certain patterns. Successful aging occurs when people fulfill life tasks that they consider important despite reduced energy in later life.

Erik Erickson's original theory in the 1960s described the last life stages as ego integrity (vs. despair) followed by life review activities that result in wisdom. He believed that mastery in an earlier stage laid the groundwork for success in the next stage. In the 1980s, Paul Baltes distinguished between normal, pathological, and optimal-developmental enhancing and age-friendly environments. He viewed aging as (1) a lifelong process that influences and in turn is influenced by social processes and (2) that is perceived differently by each age cohort. Among individuals, latent reserve capacity is highly variable. Individual and social knowledge can help compensate for age-related decline in fluid intelligence. Aging is a lifelong process of selective optimization with compensation allowing people to age successfully and to engage in life tasks that are important to them.

Successful Aging

For years, gerontology promulgated the "decline and loss" paradigm: that aging encompasses a series of decrements or losses in the individual to which elders and society needed to adapt. Rowe and Kahn's notion of *successful aging* used the concept of physiological reserve to make a distinction between "usual" aging and "successful" aging. People who age *successfully* have a great amount of physiological reserve. Successful aging outcomes include (1) low probability of disease and disease-related disability, (2) high cognitive and physical functioning, and (3) active engagement with life through involvement in close relationships and in meaningful activities (paid or unpaid). It stresses that much of the feared losses with aging are preventable and that many functional losses can be regained. This perspective attributes many of the problems associated with "normal" aging to a high-risk lifestyle. Hence, health promotion activities are seen as a way to lower the risk for disease and disability in later life.

Although this perspective offers a more positive image of aging than do the models focusing on decline and losses, this conceptualization does not take into account early-onset disabilities. People with disabilities can age well. The successful aging model also pays scant attention to (1) aging over the life course; (2) race, class, and gender inequities; (3) implications of losses and gains in later life to older persons with disabilities; (4) stigma associated with disability when viewed as a failure; and (5) limitations of the concept when applied to people with disabilities.

This model fails to adequately address heterogeneity of experiences for people with long-term disabilities whose views of effective functioning may differ from that of other people. People with disabilities may view success as the degree to which the environment changes to accommodate their changing bodies and needs. Hence, stigma is shifted from the old to the disabled, who may be more likely to experience lower adaptive functioning and may be less able to fully participate in community life.

A need exists for a broader environmental approach that stresses environmental accommodations, societal attitudes, and policy changes. People with disabilities have low employment rates (less than one-third in the United States) according to the 1994 "Survey of Income and Program Participation" (McNeil 1994; Yamaki and Fujiura 2002). They are also twice as likely to live alone (19.6 vs. 8.4 percent). Lower income is associated with poorer diet and less exercise. Consequently, people with disabilities need access to programs and policies that promote a higher standard of living, greater participation in society, improved health behaviors, and decreases in inaccessible environments and poverty.

AGING AND AGING WITH A DISABILITY

Age-Related Changes

A common misconception is that age changes indicate illness or disease. Universal changes occur for all people, but the rates of change are different depending on individual circumstances. The gradual wearing down of essential organs and systems is largely related to unmodifiable changes that lead to anatomic and physiological changes. The Baltimore Longitudinal Study (Shock et al. 1984) identified the following normal changes of aging that were not associated with disease:

- Loss of height (1 cm for every 20 years of aging) and weight (peaks in mid-50s for men and mid-60s for women and then declines)
- Reduced cerebral blood flow (20 percent), cardiac reserve (decrease from 4.6 to 3.3 times resting cardiac output), and lung vital capacity (17 percent)
- Decreased muscle mass (30 percent decrease) and bone density
- Diminished smell and taste receptors (smoking, dental problems, medications, or illnesses may contribute to the loss)
- Diminished pain and tactile perception
- Decreased vision (amount of light reaching the retina decreases by 70 percent) and hearing (environmental noise, genetic disease, ototoxic agents contribute to the loss)
- Increased susceptibility to disease

Age-related changes can be categorized as *usual aging* (e.g., combined effects related to the aging process, disease, adverse environmental and lifestyle factors) and *successful aging* (e.g., changes from the aging process uncomplicated by damage from environment, lifestyle, or disease). Individual variations across the lifespan and in every bodily system are tremendous. Moreover, lifelong use and abuse of the body through diet and physical and psychological trauma through accidents and injuries are thought to be related to wear-and-tear changes. Significant changes in structure, function, and biochemistry, along with genetics and lifestyle, are responsible for changes in tissue elasticity, subcutaneous fat, gastrointestinal function and motility, muscle, bone, immunity, and the senses.

Aging with a Disability

A majority of persons aging with a disability will experience a multitude of premature medical, functional, and psychosocial problems as they age. Chronic disability is not stable over the lifespan, and an *aging gap* is becoming evident as many persons with disabilities present with functional changes that are customarily not seen in nondisabled persons until much later in life. Recent studies have documented higher rates of morbidity and mortality for adults aging with disabilities in comparison with the general population for a number of health conditions, such as dental disease, gastroesophageal reflux, esophagitis, and constipation. Several chronic conditions seem to be more prevalent among individuals with disabilities than in the general population, including non-atherosclerotic heart disease, hypertension, hypercholesteremia, obesity, heart disease, diabetes, respiratory illness, osteoporosis, and pressure sores. Also, obesity, mobility impairment, thyroid disease, psychotropic drug polypharmacy, and deaths due to pneumonia, gastrointestinal cancer, bowel obstruction, and intestinal perforation have a higher prevalence among groups of people with various disabilities.

Individuals with disabilities have a higher risk of developing chronic health compromises at younger ages than other adults, due to the confluence of biological factors related to syndromes and associated developmental disabilities, access to adequate health care, and lifestyle and environmental issues. Although people aging with early-onset disabilities (including developmental disabilities, spinal cord injury, polio, diabetes, and rheumatoid arthritis) can now expect to live late in life along with their nondisabled peers, many experience major changes in health, function, and psychosocial status at much earlier ages. The new problems reported by people aging with a disability as early as in their 30s and 40s include the onset of age-related chronic health conditions, pain, loss of endurance, changes in employment, discouragement, and worry. These changes, suggestive of *premature aging,* have a major impact on family and friends.

Age-related health problems of women are often overlooked though they have higher rates of osteoporosis (for people with Down syndrome, epilepsy, and cerebral palsy), earlier onset of menopause for women with Down syndrome, and inadequate screening for breast, cervical cancer, and heart disease. People with Down syndrome have an earlier onset of Alzheimer's disease.

People aging with spinal cord injury (SCI) have a greater risk for pressure ulcers, decreased muscular strength, decline in immune system function/increase in incidence of infection, decreased flexibility of soft tissues (e.g., skin, ligaments, tendons, joint capsules), osteoarthritis, osteoporosis (related to immobility), diminished sensation, and spasticity. Individuals with SCI may also experience overuse and degenerative changes in the shoulder and lower extremities due to repetitive use of these joints and nerve entrapment due to repetitive use from wheeling their wheelchairs.

An estimated 25–50 percent of polio survivors are developing post-polio syndrome (PPS), which is a condition affecting polio survivors anywhere from 10 to 40 years after recovery from an initial paralytic attack of the poliomyelitis virus. PPS may affect more than 300,000 polio survivors in the United States according to the National Institute of Neurological Disorders and Stroke (NINDS). While the cause is unknown, new research is starting to clarify the mechanisms of this complex syndrome. With PPS, some of the initial problems that polio survivors had with polio are reappearing. Increasing numbers of polio survivors are reporting the onset of new symptoms, including increased muscle weakness, fatigue, swallowing difficulties (dysphagia), breathing difficulty (breathing capacity declines twice as fast compared to their nondisabled peers), and muscle joint pain, after years of stable functioning. Polio survivors are also reporting functional difficulties related to climbing stairs, making transfers, and dressing.

Persons aging with cerebral palsy may experience earlier-onset arthritis related to excessive joint wear and tear, chronic pain, gastroesophageal reflux (heartburn), contractures, and bowel and bladder problems. Women with cerebral palsy are three times more likely to die from breast cancer than nondisabled women. Adults with cerebral palsy are more likely to die from brain cancer, trauma, and diseases of the circulatory and digestive systems than their nondisabled peers. Health care services for these adults are often inadequate in addressing the need for accessible examination tables, increased time for communication, and primary care providers knowledgeable about their health conditions.

Syndrome-specific effects (e.g., Down syndrome, Williams syndrome, autism spectrum disorders, PKU, Smith-Lemli-Opitz syndrome, Prader-Willi syndrome) link to special risk factors. For example, among adults with cerebral palsy, later-life morbidity and functional declines seem to be related to the long-standing effect of movement patterns on the musculoskeletal system. Also, recent studies of older persons with autism spectrum disorders suggest that at least some threats to health maintenance and social isolation respond to health promotion approaches.

SUPPORTS TO MAINTAIN COMMUNITY PARTICIPATION

People with long-term disabilities or those who acquire a disability later in life can experience a severe sense of personal loss if they lack adequate family and community resources that allow them to maintain the degree of independence and community participation they desire. Age-related declines in health and functioning and psychosocial losses necessitate accessing an array of potential supportive services. As one ages and has more difficulties with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), it becomes more difficult to maintain a household or employment and there are greater needs for assistive technologies, environmental accommodations, therapeutic and nursing services, and respite and other housing and vocational supports. In addition to care provided by families, a range of public programs can provide these types of support. In comparison with other older adults, older adults with long-term disabilities are more likely to have received some type of housing supports, to have been unemployed or underemployed, and to have lived in poverty most of their lives with little retirement pensions. Some adults with disability, such as those with polio or Down syndrome, may experience earlier age-related physical decline and may experience loss of function, fatigue, and pain, which could result in leaving one's job or current residence, if adequate supports are not in place.

Families

Families have a pivotal role in meeting the increased needs for care by persons with disability as they age. In the United States, up to 80 percent of care, including physical, emotional, psychological, and financial, is provided by family caregivers. Over three-quarters of adults with intellectual and developmental disabilities live with families.

As function changes with age, families are called on even more frequently. With longer life expectancy, parents of persons with a long-term disability have a longer period of responsibility. There is also a greater likelihood of the disabled member outliving his or her parents. These parents are more likely to face dealing with their own aging in addition to the aging of their adult children. Another challenge is planning for future caregiving. Earlier aging of the family member with disabilities has implications for family caregiving. For spouses and parents, the changing roles can be stressful as one of the members develops a disability with aging resulting in increased needs for assistance from family members.

Caregiving can affect the nature of a relationship. For example, a spouse providing personal care can result in a change in the intimate relationship. Caregivers are the main providers of support, including instrumental support (e.g., personal care, transportation, and money) and socioemotional support. Caregivers are mostly women, who often give up, cut back, or lose job opportunities. The consequences can be stressful. The incidence of psychological disturbances among spouses of stroke survivors and of brain injury survivors is high. Cognitive changes (such as in Alzheimer's disease) are particularly difficult for families, who often lack adequate services and experience the loss of shared activities and their own independence.

Public Programs

Strong traditions of public support programs serving for both elderly and disabled persons exist in the United States. In colonial times, almshouses provided care jointly to persons who were elderly, poor, disabled, and mentally impaired. Over time, separate systems of care developed for each of these groups. More recent ongoing efforts seek to build bridges between the aging and disability networks.

The aging and disability programs differ in their philosophical approaches, systems of care, and histories of political lobbying. This divergence can serve as a barrier to merging the two programs. The elderly services focus on retirement and dealing with age-related losses, whereas the disability programs tend to focus on development of skills and rehabilitation. Rather than referring to older persons as *disabled*, they are often described as *frail* or *impaired*. *Caregivers* provide care to elderly persons, while *attendants* provide assistance to people with disabilities. Frequently, elderly persons do not want to associate with disabled and younger adults who do not share many common interests with them.

Aging Programs

Aging programs aim to assist and compensate elderly persons who experience age-related declines in function. Services tend to focus on financial support, disease management, assistance with adaptive functioning, and promoting social well-being. These programs are typically age based rather than need based.

In the United States, Social Security and Supplemental Security Income (1972) provide financial support to elderly, disabled, and poor persons. These programs were also expanded to cover spouses, widows, children of deceased or disabled workers, and parents of children with disabilities. The Older Americans Acts (1965) offers service delivery and support including compensatory services, in-home assistance, and congregate services such as recreation and meals delivered through senior centers. Medicare and Medicaid (established in 1965) provide national health insurance for both elderly (over age 65 years) and disabled persons. It includes hospital, nursing home, and home health care, hence covering both acute and long-term services.

Disability Programs

Disability programs focus on education, job training, and residential services. The emphasis tends to be on rehabilitation and vocational training. In the United States, the Rehabilitation Act (1973) laid the foundation for the disability rights movement. Its Section 504 asserted that people with disabilities had equal rights that prevented discrimination based on their disability. The civil rights of persons with a disability were further protected with the landmark American with Disabilities Act (ADA) (1990). It established equal access for people with disabilities through accommodation in the workplace and in the community. It has helped decrease environmental barriers for both disabled and elderly persons experiencing age-related functional losses. In 1999, the U.S. Supreme Court issued a ruling in the case of *Olmstead v L.C.* that under Title II of the ADA unjustified institutionalization of persons with disabilities is discrimination. This ruling is likely to give momentum to the expansion of community-based care.

BUILDING A COALITION

As more people live longer and potentially develop disabilities and more persons with long-term disabilities live into older age, greater attention is being given to the overlapping needs and constituencies of elderly persons and those with disabilities. Commonalities exist in the needs for long-term care, housing, medical care, and home and attendant care services. Aging is now more likely to adopt the language of the disability rights movement in regard to consumer-directed home- and community-based services. In 1994, the two networks joined together to form the U.S. National Coalition on Aging and Disability in order to hold a series of state conferences in preparation for the White House Conference on Aging in 1995. More recently, policy makers and advocates have begun to see the benefits of some merging of services. Examples of commonalities in needs and services include the Medicaid/Medicare services, assistive technology and environmental accommodations, housing, and health care policies.

Medicaid/Medicare

In the United States as of 2001, more than 40 million people receive health insurance from Medicare and nearly as many receive Medicaid services for their acute and long-term care needs. Over 75 percent of Medicaid expenditures are for institutional care. The trend over the past couple decades has been to reduce institutional spending and to increase community spending. The program has expanded to include the Personal Care (PC) program and the Home and Community-Based Services (HCBS) waiver program in most states. The PC program includes home health care and assistance with personal care, ADLs, IADLs, and housekeeping chores. The HCBS program services include home modification, case management, and habilitation (pre-vocational, educational, and supported employment). Now both of these programs cover not only elderly people but also younger people with intellectual and developmental disabilities. Though this program has grown significantly since the 1990s, states can still limit the number enrolled.

Assistive Technology and Environmental Interventions

As individuals with long-term disabilities and other older adults face declines in health and function, there is a greater need for assistive technology (AT) and environmental interventions (EI) to help them maintain their independence and community participation. With earlier discharge from hospitals and greater emphasis on community living, there is a greater need for AT/EI approaches to help the older adult and the family caregiver.

New and highly personalized devices and technological advances can now aid aging individuals with disabilities in maintaining or increasing their independence, productivity, and quality of life. AT/EI innovations reduce their dependencies on others for assistance, lower their risk of secondary conditions, allow caregivers to provide assistance more easily, and forestall the need for nursing home care. Advances in microelectronics, computer science, communications, bioengineering, and health and rehabilitation sciences have led to the development of a host of physical and cognitive aids. These aids can help older adults function in work, home, recreational, and other community settings as they encounter age-related changes. Examples of the uses of such technologies include the following:

- Helping with planning, execution, attention, and memory (cognitive prosthetics and orthotics)
- Monitoring health and safety (tele-care, tele-health, alert systems)

- Assisting with ADLs and IADLs (robotics, personal digital assistants, adapted eating devices, handrails)
- Controlling the physical environmental in the home (environmental controls, ramps)
- Facilitating greater community participation (navigational systems, recreational aids, communication devices for social interaction)
- Improving mobility (wheelchairs)
- Providing communication and learning aids for educational and employment settings (augmentative communication devices)
- Using information technology (Internet, computers, adapted web browsers)
- Helping to improve vision (glasses) and hearing (hearing aids)

While many older individuals and their caregivers could benefit from such advances, often they are unaware or unable to access or pay for them. This is particularly true for individuals with intellectual disabilities who lag behind other disability groups in their use of technology. Older people and people with disabilities are less likely than other people to own or use computer technology. Barriers to use include lack of proper equipment, poor fit of mobility devices, lack of training in use of equipment, poor communication of needs, and reluctance to accept need for devices.

In the United States, the Technology Act (Technology-Related Assistance for Individuals with Disabilities Act of 1988, and 1994 amendments) provides financial assistance to the states to support programs of technology-related assistance for individuals with disabilities of all ages. These programs provide technical assistance, information, training, and public awareness activities relating to the provision of AT/EI devices and services. They also promote initiatives to increase the availability of funding for, access to, and provision of AT devices and AT/EI services.

Health Promotion and Health Care

Now that people are living longer with a disability, whether the disability occurs early or later in life, health promotion and disease prevention increase in importance. Key components of health promotion include adequate health care, diet and nutrition, and physical activities.

Although persons with a disability have a significant need for routine primary care screenings as they age, in general, for them surveillance and early detection of chronic health conditions is poor. Screening activities such as breast, pelvic, and prostrate examinations; blood pressure and cholesterol checks; urinalysis; and bowel analysis can lead to enhanced functioning, prevention of secondary conditions, and an increased quality of life for persons with disabilities. To provide people with disabilities more resources to age well across the lifespan, better diagnostic tools are needed, along with greater understanding of the physiological changes that occur as people age with disabilities.

Adults with disabilities are often disadvantaged when attempting to access social and health services. Much of this is due to several factors: (1) inadequate services capable of addressing their aging-related needs; (2) a need for supportive services, health surveillance and provision, and family assistance; (3) special problems facing women who often find themselves a disadvantaged class; (4) and health practitioners who generally fail to recognize special problems experienced by persons with lifelong disabilities who are aging.

Physical barriers often constitute a problem for many persons with disabilities. Older women with cerebral palsy report difficulties obtaining dental and gynecologic care because of accessibility problems. Health care facilities often are not accessible to individuals with disabilities who may have physical and sensory impairments. In addition, persons with disabilities often experience difficulties with examinations and procedures. For many people, the most important barrier to effective medical care is case complexity. They encounter a variety of medical subspecialists, dentists, mental health providers, and other health care professionals, often without sufficient guidance.

Because of age-related changes, the presence of chronic diseases that are prevalent in the aging population, feeding problems, multiple concurrent medications, cognitive and functional declines, and syndrome-specific morbidity and comorbidities, older persons with disabilities are a nutritionally vulnerable group. Adults with disabilities also have low fitness levels, a high incidence of obesity, and tend to lead sedentary lives. Hence, they are also at a higher risk than the general population of developing secondary conditions and age-related declines at an earlier age.

With the scant attention given to health promotion strategies for people with disabilities, there is a need for prevention strategies that account for their specific impairments and potential risks for developing new conditions for adults living with long-term disability. Specific guidelines pertaining to the types of exercises, nutritional requirements, and use of medications for various types of conditions or syndromes may be necessary. For example, for people with cerebral palsy, exercise prescriptions need to consider the potential for overuse resulting in pain, injury, and fatigue. Adults with Down syndrome are more prone to osteoporosis and are more likely than other people to require calcium and vitamin D supplements as they age. Coordination between various health care providers, patients, and families is critical. Many primary care physicians have little training in disability or geriatrics, and even fewer have training that crosses both of these areas. They may lack training in dealing with multiple conditions, interacting medicines, and unique aspects of various disabilities.

To improve the fitness capacity and psychosocial well-being of adults with intellectual or developmental disabilities, Heller and her colleagues (Heller, Hsieh, and Rimmer 2004; Rimmer et al. 2004) developed and demonstrated the effectiveness of an innovative fitness and health education program. Results of this program demonstrated improved physical fitness and psychosocial well-being for participants, including more positive attitudes toward exercise, higher life satisfaction, and less depression. The next challenge is to develop and test methods of delivering health promotion interventions within the individual's natural settings, such as where they live, work, or recreate. This would require developing methods of training staff and setting up on-site health promotion programs as well as using fitness and recreation centers in the community.

FUTURE NEEDS

According to the U.S. National Long-Term Care Survey, the proportion of older adults who report certain activity limitations has decreased. However, the absolute number of older Americans living with disabilities and chronic illness will likely grow, particularly as the baby-boom generation enters old age and life expectancy continues to increase. The aging and disability service systems will need to build more capacity to provide services to a growing number of persons with lifelong disabilities who are aging and to other older individuals with disabilities who will increasingly need more services and supports to maintain their health and independence. Communities will need to adapt to this population by designing environments that accommodate elders of diverse abilities and functional limits. This includes developing more accessible transportation, recreational facilities, and businesses. In addition, there is a need for better and more training of health care professionals on age-related changes in disability.

Finally, family caregivers, who provide the greatest amount of care—physically, emotionally, psychologically, and financially—themselves need supportive services.

—Tamar Heller and Beth Marks

See also Aging, International; Alzheimer's Disease; Cerebral Palsy; Down Syndrome; Family; Frailty; Mobility Aids.

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AGING, INTERNATIONAL

The term *aging* is broad and implies various concepts and dimensions including chronological, biological, and mental aging, which are applicable to persons with and without disabilities. The aging process occurs in the context of historical age. Chronological age is the lived time from birth, and administrative age is the age cutoff used by administrators, statisticians, and epidemiologists. Biological aging refers to the physical state of the body in its relation with biological processes of growth, ripening, disease, and decay of organ functioning and body functioning. Social, psychological, cognitive, and social ability also affect aging, and aging may be strongly influenced by legal, ethical, religious, and historical considerations. For instance, under the notion of legal age (categorization based on political considerations), the age category of 55 to 65 years reflects the period when some societies legislate or allow individuals to stop work and become pensioners.

Under the notion of social age, aging may be characterized as a period of changing lifestyle, preretirement, or other social determinants of growing older. As members of the greater society, older adults are more underprivileged when they are long-term disabled. They are often unemployed or underemployed; underprivileged in income and social status; segregated in a special system of work or activity, housing or leisure; and often dependent on the help of others. Scientific data about the impact on social aging of those indicators of low social economic status, segregation, and dependency on health and on the use of health services are very scarce.

Mental or cognitive age refers to intellectual and maturational capabilities. It can be very important in the analysis and interpretation of behavior. When a 2-year-old child repeatedly throws a drinking cup on the floor, it is usually interpreted as a sensory-motor game played by that child and his or her parents. The same behavior, exhibited by an older adult, is likely to be viewed as destructive, or even as psychopathological. Cohort effects require the researcher to consider the dimension of historical age in psychological, social, and epidemiological studies. One needs to analyse the impact of cohort effects in all aspects of human life of today's adults who are elderly. To explain today's behavior, adaptations, complaints, functioning, and health problems, one needs to take into account the different opportunity structures and socializing systems available to them when they were young. For example, as a group, young adults with disabilities of today will know much more about their heart, its function, irregularities, and heart failure when they are 60 years old compared to those adults who have already reached this age. In countries such as Germany and Austria, there are very few survivors with severe disabilities of the Nazi regime. Persons from the birth cohorts before the year 1945 are almost nonexistent in the disability statistics of those countries. In all countries, but especially in the developing countries, older adults are healthy survivors from limited opportunity structures in the past. This is the case for persons without lifelong disability, but is especially evident for persons with lifelong disabilities. For example, many of the children with Down syndrome born in the 1950s and 1960s with congenital heart disorder had a very limited life expectancy, whereas those from later birth cohorts were operated on successfully and have joined the ranks of today's adults.

COMMON TERMINOLOGY OF DISABILITY

Within and between countries the term *disability* has very different connotations. The World Health Organization (WHO 2001) has provided one common terminology by developing the International Classification of Impairments, Activities, and Participation (ICIDH-2). The WHO defines impairment as a "loss or abnormality of body structure or of a physiological or psychological function." This (physiological, psychological) impairment can lead to limitations in activities, which in turn can lead to restrictions in participation in society. An individual with an impairment may not experience any disability; alternatively, an individual may have a disability as a direct consequence of an impairment; or a disability may be a psychological response to an impairment.

The original ICIDH was based on a model where impairment, disability, and handicap were causally linked as consequences of diseases or disorders at the levels of the body, person, or society, respectively. The ICIDH-2 uses the human functioning approach. In this approach, there are no assumptions related to causality. The key components are body functions and structures, activities and participation, environmental factors, and personal factors. In this new classification, disability is a negative aspect of body functions and structures as well as activities, while impairment is defined as a negative aspect of body functions and structures only (but not of activities). The term *disability* is also used as a generic term for impairments, activity limitations, and participation restrictions.

NUMBER OF PERSONS WITH DISABILITY IN THE EUROPEAN UNION

In a report of the European Commission (EC) (2001), it is estimated that the number of people in the European Union with a disability varies from 8 to 14 percent. The group consists of disabled people with congenital and acquired impairments, with different degrees of disability, and with mental and physical, permanent and temporary disabilities. Among them are those who are able to work and those who are not; in most countries, a significant proportion of people with disabilities report a combination of impairments.

Labor Market Participation and Age

Disability has a reverse effect on labor market participation and on unemployment. Differences in sociodemographic characteristics such as age and education account for the relatively weak labor market position of people with disabilities. The report of the EC (2001) shows that their probability of being in employment is lower for almost all age categories and for all educational levels than for nondisabled persons. These effects reinforce each other. The labor market position of older people with disabilities is worse than the sum of the effects of being old and being disabled. Compared to other people with disabilities, working disabled people are younger and more likely to be male and better educated (EC 2001). However, compared with nondisabled people in employment, the pattern is reversed: Working disabled are older and slightly more likely to be female and less well educated than nondisabled workers. Employment rates vary greatly between types of disability. People with mental illnesses, learning disabilities, or psychological impairments are less likely to be employed than are people with physical impairments

(EC 2001). The majority of adults and older adults with intellectual disability in the EU have found employment in sheltered work settings.

AGE AND DISABILITY

There is a strong relationship between age and disability. Disability is much more prevalent among older people: 63 percent of people with disabilities are older than 45 years (EC 2001). For nondisabled people, the corresponding percentage is only 34 percent. Hence, the disabled population is relatively old. This is particularly so in Germany, Greece, Italy, and Spain. This pattern is mainly due to individuals' health conditioning deteriorating with age. Furthermore, many impairments leading to disability are acquired during a person's life. There may, in addition, be a generation factor or cohort effect insofar as younger age groups experience better health, education, and working conditions in their early life and better health care and rehabilitation provision than their predecessors in older generations. Also, the rising life expectancy for people in general and especially for persons with lifelong disabilities affects strongly the number, distribution, and level of participation in society of older adults with disabilities.

LIFE EXPECTANCY AND NUMBER OF OLDER PERSONS

Life expectancy has risen sharply in the past 100 years and is expected to continue to rise in virtually all populations throughout the world. The number of people reaching old age is therefore increasing. At the end of the twentieth century, there were about 580 million people in the world who were aged 60 years or older. This figure is expected to rise to 1,000 million by 2020—a 75 percent increase compared with 50 percent for the population as a whole (WHO 1999). Health is vital to maintain well-being and quality of life in older age, and it is essential if older citizens are to continue making active contributions to society. The vast majority of older people enjoy sound health and lead active lives. It is expected that from the 1,000 million older people in 2020, more than 700 million will live in the developing world. The reason for the increase of life expectancy is the sharp decline in premature mortality from many infections and chronic diseases. Improvements in sanitation, housing, nutrition, and medical innovations, including vaccinations and the discovery of antibiotics, have all contributed to the steep increase in the number of people reaching older age.

Health Status of Older People

As more people reach a "ripe old age," however, they also enter a period in their lives when they are at a higher risk of developing chronic diseases, which in turn may result in disability. In fact, chronic diseases, including cardiovascular diseases, diabetes, and cancer, are the main contributors to disease in older persons. However, there is mounting evidence from developed countries that people are maintaining better health in later life than ever before. It is estimated that in 1996, there were 1.4 million fewer disabled older persons in the United States than would have been expected if the health status of older people had not improved since the early 1980s (WHO 1999). The increase in life expectancy was most spectacular for persons with lifelong disabilities.

Effect of Incidence and Life Expectancy

The high proportion of older adults with lifelong disabilities in the population of countries is a function of incidence and life expectancy. Even when in Western countries the birth rates are declining in more recent years, the overall prevalence is increasing because of longer life expectancies of persons with disabilities born in the large birth cohorts after World War II. In developing countries, the prevalence rates as well as the number of elderly persons with disabilities have been increasing significantly during the past decades by the combined effect of high incidence rates of disability and of a longer life expectancy of affected persons.

DIVERSITY OF DISABILITY AT OLD AGE

"Older people" constitute a very diverse group. Many older people lead active and healthy lives, while some much younger adults are more passive and unhealthy. People age in unique ways, depending on a large variety of environmental and genetic factors.

Environmental Factors

Climate and geographic location can be a significant factor determining the incidence of disability, life expectancy and the process of aging.

Whereas iodine deficiency disorders are a major cause of disability, little is known about the life expectancy and the process of aging of persons with this condition in their community. As a consequence, iodine deficiency disorder can result in intellectual disability, deaf-mutism, spastic-diplegia, and squint. Between 600 and 1,000 million people are at risk of iodine deficiency in various regions of the world, mostly in developing countries. According to Dund and van der Haar (1990) about 710 million persons in Asia, 227 million in Africa, 60 million in Latin America, and 20–30 million in Europe are at risk of developing iodine deficiency disorder. At least 200–300 million of them have goiter or some other demonstrable consequence of iodine deficiency, and at least 6 million suffer from severe consequences of iodine deficiency. The most severe iodine deficiency occurs in inland mountainous areas, far from the sea, such as the Alps, the Andes, or the Himalayas. However, iodine deficiency is not confined to mountainous regions; it has also been associated with areas exposed to frequent flooding. In areas of iodine deficiency, 1 in 10 neonates has intellectual disability caused by the deficiency, and there are small pockets where the figure reaches 1 in 4.

Many young persons, especially those living in developing countries, have vision, hearing, speech, mobility, and/or intellectual functioning impairments. From the start of their life, these are not at all homogeneous groups of disabled persons. These individuals differ widely in genotype and phenotype, severity, and treatability of their impairment. Many of those persons have multiple disabilities, with various and different consequences.

Genetic Factors

For persons with intellectual disabilities, there are over 200 monogenetic causes. An increasing number of specific chromosomal and molecular-generic syndromes are associated with intellectual disability. For example, there are more than 60 chromosome-linked disorders. The interaction of genotype and phenotype is much more complex and shows much more variation between individuals than was expected.

Whereas the aging process is relatively well documented for persons with Down syndrome, there is scarce or nonexistent information about older adults with other causes of intellectual disability such as fragile-X syndrome and fetal alcohol syndrome (FAS). FAS is one of the most common causes of intellectual disability, ranking worldwide ahead of Down syndrome and spina bifida, and is characterized by intellectual disability, abnormalities in the central nervous system, growth retardation, and craniofacial and cardiac abnormalities. Abel and Sokol (1987), basing their estimate on 20 studies from Australia, Europe, and North America, which covered a total of more than 88,000 births, found a rate of 1.9 cases of FAS per 1,000 live births; rates were higher in the United States (2.2 per 1,000) than in Europe (1.8 per 1,000). This European rate will change with the extension of the EU.

AGING IN A LIFESPAN PERSPECTIVE

In his work, Plato (fourth century BC) emphasized the personal and lifespan experience of aging. His concepts have a strong educational and social basis. The feeling of "being old," as an aspect of psychological aging, is very much dependent on the person's view of young and old people. In Plato's view, to age "wisely" and peacefully, it is necessary to live a righteous life. For this reason, youths should be educated to live with a sense of duty in order to enjoy old age. The Platonist view of healthy aging is reflected in the modern conception of geroprophylaxis, as proposed by J. E. Birren and J. J. F. Schroots, which emphasizes educating people in healthy lifestyles, management of stress, the need for adequate exercise and nutrition, and the prevention of loss of autonomy as well as prevention of disease. This process must begin in young adulthood to be fully effective.

Life Course Development

Genetic components and early disabilities may contribute to how long persons live. However, health and activity in older age are largely an accumulation of the experiences, exposures, and actions of an individual during the whole span of life. The life course begins before birth. There is evidence that when fetuses are undernourished in the womb, they grow up to be adults more likely to suffer from a variety of diseases, including coronary heart disease and diabetes; they also seem to age faster than people who receive good nutrition during early life. Although aging begins in the womb, changes attributed to senescence usually begin in the postpubertal years. From age 20 years and older, cognitive functions such as fluid working memory and speed of processing show steady decline with each decade. However, crystallized knowledge does not. In fact, domain-specific knowledge among the intact elderly may exceed that for younger persons. There are differences in rate of decline between some physiological systems. For example, pulmonary function declines more rapidly than physical strength.

Aging is also associated with multiple changes wrought by illness. Some of these changes are gradual (e.g., the onset of osteoarthritis) and others are abrupt (e.g., diagnosis of life-threatening illness). Some have instant disabling consequences for the life of the individual; others will show symptoms in older years. Previous accidents and injuries make chronic and sometimes disabling diseases more likely in adult life. Lifestyle factors in adolescence and adulthood, such as smoking, excessive alcohol consumption, lack of exercise, and inadequate nutrition or obesity, greatly add to disease and disability at any age in adulthood.

Differences in education level, income, and social roles and expectations during all stages of a person's life increase the diversity of aging. Throughout the world, the average education of older people is below that of younger people, and this is especially the case for older adults with lifelong disabilities. Higher levels of education are important, because they are associated with better health and less social handicap. People with higher education levels at all ages tend to adopt and maintain healthier lifestyles and have better access to health care and health information.

Healthy Aging

Since the beginning of the 1980s, Paul B. Baltes and colleagues have conducted studies on the psychological processes of development and aging from a lifespan perspective. Their work resulted in a psychological model, called "selective optimization with compensation." The central focus of this lifespan model is the management of the dynamics between gains and losses (i.e., a general process of adaptation), consisting of three interacting elements: selection, optimization, and compensation. It is expected that the lifelong process of selective optimization with compensation allows people to age successfully (i.e., to engage in life tasks that are important to them despite a reduction in energy). This model does not fit well for persons with lifelong disabilities, because the three major components for healthy aging, low probability of disease or disease-related decline, high cognitive and physical function capacity, and active engagement with life, are valid only for a well-functioning minority. Lifelong disability need not impede healthy or successful aging of persons with lifelong disabilities if there are no significant medical aspects of the disability and if the person has productive coping and compensatory mechanisms during adulthood and has maintained control over his or her life activities.

AGING, DISABILITY, AND PLANNING OF SERVICES

Person-Centered Planning

Aging is a lifelong process of learning in taking responsibilities and making choices that can be optimized in the concept of person-centered planning. In Western countries, adequate planning of services for the older generation of people with lifelong disabilities is increasingly based on person-centered planning. Person-centered planning values the customer's views and preferences when defining which services to offer, the manner in which they should be offered, and the personnel providing them. To fulfill such requirements, rigorous changes are needed in the planning of services for older persons with disabilities—changes of goals and values as well as changes in the structure of service delivery and the distribution of financial means. With regard to goals and values, today's living situation of older persons with lifelong disabilities can still be characterized in many countries as dependent, segregated, custodial, patient-like, and without dignity.

UN PRINCIPLES FOR OLDER PERSONS

The UN Principles for Older Persons (United Nations 1992) offer a useful opportunity to stimulate alternative and more human goals and values not only in the field of general aging but also in the field of aging with lifelong disabilities. The UN resolution lists in this respect five principles: independence, participation, care, self-fulfillment, and dignity. Two other basic principles are least restrictive environment and self-determination. The independence principle calls for living in environments that are safe and suited to personal preferences and changing capacities. The participation principle requires that older adults remain integrated in society, participating actively in the formulation and implementation of policies that directly affect their well-being.

Under the principle of care, the United Nations urges that older adults should have the benefits and protection of family and community care. The principle of self-fulfillment promotes the ability of older people to pursue opportunities to develop their personhood through access to educational, cultural, spiritual, and recreational resources. The principle of dignity states that older people should be able to live with dignity and security, free of exploitation and physical or mental abuse. The principle of least restrictive alternative stimulates the reduction of unnecessary restriction in the lives of older adults with and without disabilities. The principle of self-determination enhances the wish of growth and autonomy for older adults with disabilities.

Based on these principles, the following structural changes in policy are recommended:

- Build up a developmental-oriented care system with stimulating but safe environments in which all facets of aging from childhood through senescence are addressed.
- Enhance service capacity for older adults with disabilities because of longevity and the demographic bulges due to the high birth rates in the 1950s and 1960s.
- Define an agenda for planning for the needs of an aging population considering demographics, changing ideologies and practicalities, and the changing needs of older adults with disabilities as they age.
- Develop a professional support system that is sensitive and directed toward personal goals, wishes, and choices of older adults with disabilities, a support system that works with realistic yet safe self- determined plans.
- Plan policies and programs for housing and physical infrastructure, health and hygiene, income security, education and training, social welfare, and family support.

It is still an open question whether the model of person-centered planning for older adults with disabilities can be and should be expanded to non-Western countries and cultures. It needs extensive adaptations when applied to countries with low-income economies or to cultures where identity primarily is defined by being member of a family, clan, or community. For successful implementation of a model of person-centered planning, it will be essential that aging and disability be viewed within the context of the local community, its values, priorities, and social and financial resources.

—Meindert Haveman

See also Aging; Family, International; Frailty.

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AGORAPHOBIA

Agoraphobia is a disabling complication of panic disorder. Although originally conceptualized as separate disorders, research suggests that panic disorder and agoraphobia actually represent a single illness. In fact, agoraphobia in the absence of panic is unusual. The term *agoraphobia* translates literally from Greek as "fear of the marketplace." Although many patients with agoraphobia are uncomfortable in shops and markets, their true fear is to be separated from their source of security. Agoraphobic patients often fear having a panic attack in a public place and embarrassing themselves or having a panic attack and not being near their physician or medical clinic. They tend to avoid crowded places, such as shops, restaurants, theaters, and churches, because they feel trapped. Many have difficulty driving long distances (because they fear being away from help should a panic attack occur), crossing bridges, and driving through tunnels. Many agoraphobic patients insist on being accompanied to places they might otherwise avoid. At its most severe, agoraphobia leads many patients to become housebound. Common situations that provoke people with agoraphobia are public transport, crowding, and shopping malls. Panic disorder is prevalent among the general population between 1.5 and 3 percent. The prevalence of agoraphobia is slightly higher. Many patients, however, will report that panic attacks began after an illness, an accident, or the breakup of a relationship; developed postpartum; or occurred after taking mind-altering drugs such as lysergic acid diethylamide (LSD) or marijuana.

Panic disorder generally is treated with a combination of specific medication and individual psychotherapy. Cognitive-behavioral therapy (CBT), a form of individual psychotherapy, also appears to be effective in the treatment of panic disorder; its combination with medication may be even more powerful. CBT usually involves distraction and breathing exercises, along with education to help the patient make more appropriate attributions for distressing somatic symptoms. Patients with agoraphobia, with or without panic attacks, should receive behavior therapy. Exposure in vivo is the most effective intervention and in its most basic form may consist of gentle encouragement for patients to enter feared situations, such as shopping in a grocery store.

—Ahmed Okasha

See also Behavior Therapy; Panic Disorder.

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AIDS FOR ACTIVITIES OF DAILY LIVING

Aids for activities of daily living (AADLs) are products, devices, and equipment used within everyday functional activities. They are commonly included as a category of assistive technology. Other common terms for AADLs include adaptive equipment, ADL equipment, self-care equipment/aids, basic assistive technology, rehabilitation equipment or technology, and low technology.

The focus and purpose of these technologies are to adapt the environment, rather than the person, to support identified needs, choice, and control. These products may be used to compensate for impairments and functional limitations or to augment or assist in task performance, such as enabling quicker, safer, or more efficient performance of everyday activities. Products may address vision, hearing, fine and gross motor, sensory, proprioceptive, cognitive, communication, safety, and learning needs.

AADLs include a wide range of devices. Potential categories of equipment may span, but are not limited to, eating and meal preparation, grooming, bathing and showering, dressing, transferring, mobility, writing and basic communication, environmental control, home management, phone use, time management, organization and scheduling, money management, shopping, leisure/recreation/play, community living, and school and work activities. Common examples include tub benches, reachers, large-print or talking devices, and adapted utensils or utensil/tool holders that can be used across many activities.

AADLs are often distinguished from other assistive technologies as low, simple, or basic technology. However, this conceptualization can be misleading in that there is an increasing, rapidly changing pool of products and features from which to choose; many involve electronic components (e.g., phone systems); some involve custom fabrication or fitting to meet the specific person-task-environment demands (e.g., fabrication of a custom orthotic to hold a variety of everyday utensils); and in most cases, AADLs need to be considered as part of an accommodation package involving complex integration and environmental fit issues. For instance, AADLs are often combined with physical and social environment adaptations and strategies. An example is that commonly used ADL equipment in the bathroom includes tub benches/seats, long-handled reachers, raised toilet seats, and extended shower controls. These products are often used in combination with environmental modifications such as grab bars, roll-in or seated shower stall modifications, nonglare lighting, nonslip flooring, and offset temperature controls and sensors, which are then coupled with a set of individually customized strategies to manage and troubleshoot bathroom activities on a routine basis, such as strategies for transferring safely and efficiently.

Previously, AADLs were available only through medical or rehabilitation professionals, most commonly occupational and physical therapists, and required a physician's prescription to obtain and fund them through third-party reimbursement sources such as Medicare, Medicaid, or private insurance. Although rehabilitation remains a primary source for AADLs in the United States, particularly if third-party reimbursement is sought, the market for and availability of this equipment has broadened significantly. Given the functionality of these devices, many are now built into new homes and community environments and are widely available in department stores, consumer product catalogs, and Internet-based vendor sites. With the universal design movement, AADLs are being constantly redesigned and updated to increase their ease of use, efficiency, and ergonomics in response to the growing disability and aging consumer markets. As an example, the line of Good Grip products by OXO International, and other similar product lines on the market, represent a growing line of AADLs that not only support everyday activity but also look and feel good when using them, thus increasing their appeal and lowering their cost given the widespread market base. Thus, many types of AADLs are no longer considered "assistive," but rather are perceived as common tools and are available to the general public.

Research examining the effectiveness of assistive technologies, much of which would be categorized as AADLs, has shown the supportive role this equipment can play in maintaining, increasing, or delaying declines in everyday function for people with disabilities and older adults, particularly as they and significant others in their social world experience age-related issues. AADLs may also support the function and safety of family, personal attendants, and others who may work interdependently with people with disabilities during everyday activities. At the same time, however, research has shown that AADLs are often abandoned at rates from 20 to 50 percent. Reasons for abandonment include that the technology did not do what it was intended to do or did not match the person's needs, the consumer and important others' were not included in the decision-making process, the technology was not accepted due to aesthetics and issues surrounding being labeled as "disabled," a change in needs occurred that was not considered, and the technology was broken or needed to be updated.

These findings point to the critical need for consumer involvement in AADL decisions and to the complexity of factors influencing the fit between the person, the task, the AADL, the physical and social environment in which it will be used, and societal systems and policies involved in obtaining it. Despite the growing need, one of the primary barriers to obtaining needed or wanted AADLs is economic; that is, a large number of people with disabilities cannot afford AADLs and are not able to get reimbursed for them through existing funding systems. As an example, although tub benches have been found to support function and safety, they are typically not funded through third-party reimbursement systems as they are considered "optional," do not qualify as durable medical equipment (DME), and therefore do not meet eligibility criteria.

In response, a number of systems change initiatives have occurred to increase access to AADLs. In the United States, a national network of alternative financing programs offers a consumer-directed program and range of alternative financing strategies to increase access to funding for AADLs and other technologies. Several countries, such as Canada and Sweden, have implemented delivery systems that offer more extensive access to AADLs as part of integrated community living plans across the lifespan. In the United States, several states are using Home and Community-Based Waiver (HCBW) programs to provide needed AADLs as part of an integrated community support package, complying with the 1999 *Olmstead* decision that mandated the right to live in the least restrictive setting with reasonable accommodations.

—Joy Hammel

See also Assistive Technology; Home Modification.

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AIDS/HIV

See HIV/AIDS

AIR CARRIER ACCESS

While there is much in common between different countries' approaches in disability antidiscrimination legislation to employment and goods and services, there is considerable variation in approach to air carrier access throughout the world.

In the United States, for example, access is dealt with primarily by means of the Air Carrier Access Act (ACAA; 1986). The act provided for the U.S. Department of Transportation (DOT) to develop new regulations that ensure that disabled people would be treated without discrimination in a way consistent with the safe carriage of all passengers. The relevant regulations (the Air Carrier Access rules) were published in March 1990. The legislation and rules prohibit discrimination in air transportation by domestic and foreign air carriers against qualified individuals with physical or mental impairments. It applies only to air carriers that provide regularly scheduled services for hire to the public. Requirements address a wide range of issues including boarding assistance and certain accessibility features in newly built aircraft and new or altered airport facilities. People may enforce rights under the ACAA by filing a complaint with the DOT or by bringing a lawsuit in federal court (although recent decisions have cast doubt on the ability of individuals to bring a lawsuit under the ACAA—see *Love v. Delta Air Lines,* 310F 3d. 1347 11th Cir [2002], and the National Disability Council Position Paper on Amending the ACAA to Allow for Private Right of Action, July 8, 2004).

In January 2004, the DOT produced a report on the implementation of the ACAA, in which it detailed some of the ways it had dealt with a failure to comply with the act: "For example, the Enforcement Office has instituted an in-depth investigation of eight major air carriers for violations of the ACAA relating to boarding and wheelchair assistance based on formal and informal complaints. These investigations have resulted in separate consent orders under which a number of airlines were directed to cease and desist from further violations of the ACAA and Department regulations prohibiting discrimination against air travelers with a disability. These investigations also assessed civil penalties to $1.35 million" (*Implementing* 2004:1).

In Australia, the Australian Disability Discrimination Act (1992) makes it unlawful to discriminate in relation to access to premises, including public transportation. In addition—and perhaps as regards transport, more important—specific provision is made in the act for disability standards to be drawn up in relation to the provision of public transportation services and facilities. Failure to comply with these standards is made unlawful. Such standards have now been drawn up, although this has taken 10 years since passage of the ADA. The Disability Standards for Accessible Public Transport (2002) apply to public transport vehicles, conveyances, premises, and infrastructure and set out a timetable for adjustment by public transport operators over 30 years, with fixed milestones every 5 years. They list detailed accessibility requirements including access paths, ramps, boarding devices, allocated spaces, handrails, doorways, controls, signage, information provision, and much more. Given the late passage of the regulations, it is likely to be some time before significant improvements are seen in disability access to air carriers in Australia.

In Canada, provisions relating to accessible air transport are contained primarily in the Canada Transportation Act 1996, which covers, among other methods of transport, air travel. The act created the Canadian Transportation Agency (CTA), which has the power to remove "undue obstacles" from Canada's transportation network. The CTA also attempts to resolve passenger complaints regarding access to air travel. The Air Transportation Regulations make provision for services and information that air carriers are required to provide in relation to disabled people where they are Canadian air carriers operating services within Canada with aircraft of 30 or more passenger seats; while the Regulations on Personnel Training for the Assistance of Persons with Disabilities cover the training of staff—a vital aspect of ensuring accessible transport. There is also the Aircraft Code of Practice, which covers physical accessibility of equipment used in air transportation, although it applies in general only to fixed-wing aircraft with 30 or more passenger seats and only those areas of an aircraft that may be used by the general public.

According to the Council of Canadians with Disabilities, it is generally believed that the CTA has not been successful at tackling systemic issues through either its complaints mechanisms or its other work, although its response to individual complaints has in general been fairly good. Unlike the approach to air carrier access considered above, the European approach to air carrier access has been extremely limited. Very few European countries have antidiscrimination legislation dealing with goods and services at all, and those that do tend not to have addressed air travel. Disabled passengers have had to rely primarily on the International Air Transport Association Resolution 700 (Acceptance and Carriage of Incapacitated Persons) and the Airport Voluntary Commitment on Air Passenger Service—neither of which is based on any rights perspective or indeed has the force of law. However, on February 16, 2005, the European Commission tabled a proposal for a Regulation on the Rights of Passengers with Reduced Mobility When Travelling by Air, which will prohibit discrimination against disabled air passengers. This proposal, once it is adopted by the European Parliament and the Council of the European Union, will apply to all airlines, all airports (public and private), and all passengers. The regulation will prohibit refusal of booking or refusal of carriage to disabled persons because of their disability; prohibit charging disabled passengers for assistance needed; ensure provision of assistance for disabled passengers and establish a centralized charging system (the managing body of an airport will provide assistance free of charge to disabled passengers; costs of the centralized system will be covered by airlines, which will pay an amount proportional to the number of passengers they carry [based on all passengers, not just disabled passengers]); and quality standards will be set by the managing body of the airport in conjunction with airport users' committees. The regulation proposal contains mechanisms for complaints, sanctions, and enforcement in the regulation.

In the United Kingdom, which has had disability discrimination legislation since the 1995 Disability Discrimination Act was passed, anything consisting of the use of a means of transport is specifically excluded from the goods and services provisions of the act, although the infrastructure—such as stations and airports—is still covered by the act (and this exemption will be removed by the Disability Discrimination Act 2005 and regulations made under it, although it will not be covering aircraft for the foreseeable future). Although there are regulations governing the accessibility of trains, buses, and coaches, no such provision exists for air travel. There has, however, been a significant legal case involving assistance at an airport for a passenger. In the case of *Ross v. Ryanair and Stansted Airport Ltd.* (EWCA Civ 1751 [2004]), Mr. Ross—a disabled person with a mobility impairment who was not a wheelchair user—brought a claim relating to a charge of £18 that he had to pay for the provision of a wheelchair to get him from the check-in point at Stansted Airport to the departure gate. Mr. Ross succeeded in his case, with the court holding that Ryanair was responsible for providing the assistance and that it should have done so at no charge. It was particularly interesting that the court held that—despite the low cost of Mr. Ross's flights—it was nevertheless reasonable for Ryanair to provide the assistance required at no charge. Ryanair appealed against the decision, on the basis, and the Court of Appeal upheld the appeal purely in relation to who was responsible for providing the free assistance, holding that because of the particular circumstances of the case both Ryanair and the airport were 100 percent liable for ensuring that Mr. Ross and others in his position had access to wheelchair assistance free of charge.

As can be seen from the brief overview above, access to air travel for disabled people, and specifically the legislation and guidance that govern it, is extremely piecemeal. As with antidiscrimination legislation on disability more generally, the United States appears to lead the way in terms of both the comprehensiveness of its legislation and the activity of its enforcement agency—although this is, of course, no guarantee that disabled people as a whole can actually access flights more easily. Such an approach is perhaps a reflection of the reliance in countries such as the United States and Canada, which cover such vast geographic areas, on internal flights to ensure any degree of travel within the country—something that in Europe remains less prominent. Australia, though, has been slow to catch up, with its regulations being promulgated only as recently as 2002. Nevertheless, European countries will have significant ground to make up to ensure that their disabled citizens have the same rights of access as those in the United States, Canada, and Australia.

—Catherine Casserley

See also Disability in Contemporary Australia; Disability Discrimination Act of 1995 (United Kingdom); Disability Law: Canada.

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▣ ALIENATION

Alienation is the act of withdrawing a person's affections from something else. One can alienate another person, a group of persons, an idea or social reality, or even aspects of their own body or behaviors. Alienation often results in an indifference or outright aversion by an individual or group of individuals toward some aspect of life that might otherwise be attractive and significant. Ignoring others or treating them in a way that causes the other person or group discomfort or excludes them from participating in social aspects of life is an example of alienation. Some ethnic minorities in the United States, women, and people with disabilities have a history of being excluded from full participation in social life by others in power, and are examples of how groups in power can alienate those not in power. People can be alienated, or indifferent, to the products they make or promote in their work. Another example of alienation is when an individual withdraws emotional connection from aspects of themselves, such as a part of their body that has an impairment or illness. Often they consider that the impaired body part no longer is a part of them and is indifferently or negatively perceived by the disabled individual.

Alienation is a process that develops in an ongoing relationship between an individual and another person or group of people, or in an individual as he or she negotiates the emotional terrain of dealing with an unwanted aspect of the person's physical or psychological state. It involves an unexpected deterioration in the quality of interactions and outcomes between individual players, and it continues until the alienated individual or aspect of the individual remains spatially or psychologically separate from others or to the whole person. Alienation is the experience of being disconnected with one's self, with others, with one's gods, nature, or a transcendent realm of being. While alienation is not considered to be a mental disorder, it is recognized as an element of a condition called antisocial personality disorder. Often alienation overlaps with other major psychological symptoms such as boredom, depression, and loss of locus of control.

HISTORICAL ORIGINS

In its early intellectual roots in ancient philosophy and medieval theology, the concept of alienation originally contained a fullness of positive, neutral, and negative connotations. The term was first used by Hegel, who stated that human life easily becomes estranged from the natural world unless validated by the divine. It was a force of development, a mode of conciousness used to signify stepping outside oneself; as Hegel put it, "Alienation is the fundamental feature of consciousness throughout its history" and was considered a necessary precondition for man to realize the true self.

Alienation can be applied to different social circumstances. Judeo-Christian texts find the concept of alienation from one's source of transcendant being in both Old and New Testamants: "My God, my God, why hast thou forsaken me?" In its original Marxist sense, alienation referred to the process of labor whereby workers became estranged from the products they produced. Marx understood alienation in terms of social and historical forces that resulted in spritual disillusionment and the physical separation of labor from its products. Marx noted in his famous "alienation of labor" treatise that conditions in a capitalist society make it impossible for workers to live meaningfully in relation to each other, to the products of their labor, or even to themselves. Simone de Beauvoir and other feminist thinkers point out that women in a patriarchal culture undergo additional forms of alienation when they are pervasively treated as the objects of male sexual desire and effectively coerced into submitting to male-biased political, social, and intellectual norms. Goffman (1968) noted that alienation can also occur when people with disabilities feel stigmatized by their surrounding society as a result of their impairment.

PSYCHOLOGICAL PROCESS OF ALIENATION

The psychological component of alienation is a process of self-estrangement and is considered a failure of self-realization. Alienation causes an altered relationship with the self that takes three forms:

1. The “despised” self, a negatively evaluated discrepancy between the person’s preferred ideal and the perceived actual self
2. The “disguised” self, a false consciousness that is out of touch with one’s feelings
3. The “detached” self, a disjunction between activity and affect (i.e., the individual’s engagements in activities that are not rewarding in themselves)

Alienation involves feelings of meaninglessness, powerlessness, being manipulated, social and self-isolation—a major theme in all of these feelings is a person’s feeling of lack of power to eliminate the gap between the definition of the role he or she is playing and the one the person feels he or she should be playing in a situation. The intensity of the individual’s feelings of powerlessness to achieve the rightful life role he or she has claimed also contributes to the degree of alienation realized. Other feelings of helplessness, loss of community, lack of understanding, and the opposite of commitment can also be present in alienation. Common symptoms of alienation may include the following:

- Loss of a sense of humor
- The conviction that life is without meaning
- Need to withdraw from social and familial circles
- Emotional disconnectivity or numbness
- Belief that one doesn’t belong to formerly intimate groups
- Inability to care for others

Alienation is usually thought of in terms of an individual’s emotional distance from social groups. However, alienation can also be thought of in terms of an individual’s emotional distance from himself or herself—a term called *self-alienation*. This facet is closely associated with an individual’s sense of identity. When self-alienation occurs, individuals may be confused about their identity and the role they are “supposed” to play in the context of their life. This disconnectedness serves to depersonalize events, interactions with others, feelings, and interpretations.

ALIENATION AND DISABILITY

In terms of disability, alienation occurs when the state of disability or impairment causes the individual to develop a state of disconnectedness with his or her personal identity, relating to the adaptation to the impairment within the framework of reconciling relations between mind and body expectations and realities. For instance, an athletic person loses his leg in an accident. While the reality is that he is now an amputee, he refuses to go to recommended therapy, stops going to the gym to work out, and drops completely out of his social society. He feels angry that his leg “betrayed him,” that it makes him “less of a man,” and he eventually considers his impaired leg as something that does not belong to him but is unfortunately attached and therefore must be accommodated. In this example, the man has alienated himself from his community, and he has alienated the impaired part of his body from his personal identity.

While there is research of alienation and how it manifests in the disabled population, it has primarily focused on physical illness or impairment. There is little known about alienation as it relates to individuals with cognitive impairments or mental illness, or whether the concept of alienation operates within impairment categories of this kind.

Individuals may ignore or minimize illness or impairment when they choose not to acknowledge its effects on their lives or their lack of control over those effects; by doing so, they hope to preserve the sense of unity between body and self that they had before disablement. The disabling condition, or impairment, is separated from the primary essence of the individual as it is perceived by the individual to “cause” the events and feelings of disconnect. Placing the disability or impairment “outside” of the individual identity and removing it from one’s inner essence makes the disabling condition something external and foreign to the essential core being of the individual.

—*Ann Cameron Williams*

See also Depression; Isolation.

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ALTERNATIVE MEDICINE

See Complementary and Alternative Medicine

ALZHEIMER'S DISEASE

Alzheimer's disease is considered to be the commonest form of a group of illnesses that predominantly occur in later life and are referred to as "the dementias." These illnesses have in common a progressive loss of brain function leading to the development of impairments in a number of cognitive and functional abilities such as memory, the use and understanding of spoken language, and the ability to undertake complex tasks. As dementia progresses, these impairments become increasingly severe with the eventual loss of everyday living skills, resulting in an inability to care for oneself. Changes in personality and behavior are also apparent. The exact course and characteristics of the dementia in an individual varies depending on the cause for the dementia and also because of individual differences. The majority of the dementias are rare before the age of 60, but the prevalence rates increase steadily in older age groups. The general consensus is that the occurrence of Alzheimer's disease should not be considered inevitable with increasing age, but rather it is an illness that is age related and affects a proportion of people. Summarized below is a compilation of prevalence data published in the Alzheimer's Disease International (1999) "Factsheet 3." These figures are a conservative estimate with some studies suggesting that nearly 50 percent of people over the age of 85 have dementia.

Age group	*Prevalence rates (%)*
65–69	1.4
70–74	2.8
75–79	5.6
80–84	11.1

Alzheimer's disease was named after Alois Alzheimer, who in 1906 described the clinical features and postmortem findings of the brain from an elderly person who had suffered from particular mental experiences prior to her death. On postmortem, she had a significant loss of brain tissue and many microscopic *plaques* and *tangles* in her brain. Later research established that the plaques, containing beta amyloid, and the neurofibrillary tangles, containing aggregations of a modified form of another protein called tau, are together the characteristic brain changes of what is now called Alzheimer's disease. It was later established that there was a relationship between the severity of the symptoms of dementia prior to death and the extent to which these plaques and tangles were present in the brain at postmortem. While among Caucasians Alzheimer's disease is considered to be the cause of over half of the cases of dementia, this may not be so across all cultures. Globally, Alzheimer's disease is of increasing concern because the number of people over age 65 years, and therefore at risk of dementia, is increasing. For developed countries, mean life expectancy is now in the late 70s. It has been estimated in the United States that 4.5 million people have Alzheimer's disease at present and, if trends continue, it is estimated that 13.2 million will have Alzheimer's disease by 2050 (see Herbert et al. 2003).

PRESENTATION AND COURSE OF ALZHEIMER'S DISEASE

The clinical presentation and course of Alzheimer's disease reflect the progression of the underlying brain pathology. It has three stages. An early sign is memory loss for recent events. This goes beyond what would be considered normal for that person's age and is a result of the brain pathology starting in an area of the brain called the hippocampus. The person may be unable to remember how to get around, and disorientation becomes a serious problem. In the second stage, involvement of the surfaces (cortex) of the two lateral lobes (cerebral hemispheres) of the brain results in further problems, such as a deterioration in the understanding and use of language, an inability to recognize commonplace objects, and/or an inability to undertake complex tasks (such as brushing one's hair) even though the physical ability to move the necessary parts of the body remains intact. The person's personality may change during the course of the illness, and he or she may engaged in inappropriate and difficult behavior or suffer from frightening experiences more characteristic of major mental illnesses, such as experiencing auditory or visual hallucinations or paranoid ideas. In the final, third stage complete care is necessary as the person is unable to feed or care for himself or herself and to undertake the basic necessities of life. The average length of illness from diagnosis to death is between eight and ten years but can be longer.

DIAGNOSIS OF ALZHEIMER'S DISEASE

The diagnosis of dementia, and specifically of Alzheimer's disease, depends on evidence of the progressive development of the above clinical characteristics as set out in established diagnostic guidance, such as the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) or the International Classification of Diseases (ICD-10). Other causes of dementia (e.g., multi-infarct dementia) and also conditions that might mimic dementia (e.g., profound depression, endocrine disorders) are excluded on the basis of the clinical picture and as a result of clinical investigations, such as brain scans and specific blood tests. This process of *differential diagnosis* is crucial as it identifies possible treatable disorders mimicking dementia and guides subsequent interventions. Specific psychological tests are available to enable the systematic assessment of those areas of cognitive ability that are known to decline with dementia, such as memory, orientation, and language. The best known of these is the Mini Mental State Examination developed by Folstein and colleagues. Such established assessments can screen for and monitor the disorder's progression.

CAUSE OF ALZHEIMER'S DISEASE

The cause of Alzheimer's disease remains unknown. Research has focused on investigating the brain changes and also on identifying those factors that might affect the risk of developing the illness or modify its course. One very striking feature is that it is predominantly an illness of later life, increasing age being the most significant risk factor. Both the plaques and the tangles in the brain have been the focus for intensive study. There are those who argue that a protein called amyloid is central to the pathological process. The large amyloid precursor protein (APP) is found across the cell membrane of the brain cells (neurons), with parts inside and outside of these cells. It is a smaller extracellular part of this protein (beta amyloid) that appears to be the basis for the development of the microscopic plaques characteristic of Alzheimer's disease that subsequently accumulate in the brain in the space outside of the neurons. In contrast, there are those who see the formation of the abnormal neurofibrillary tangles (consisting of modified tau protein) inside of the nerve cells as being the crucial pathological event. These two processes must in some way relate to each other, leading to the accelerated atrophy of brain tissue and therefore the progressive course of the illness. The main, but not exclusive, brain neurotransmitter system affected is that of acetyl choline, and it is this observation that has been the focus for treatment developments.

In the rare cases of people developing Alzheimer's disease in middle age, genetic factors are important. In these families, subtle changes (mutations) in specific genes (amyloid precursor and presenilin genes) develop. People with Down syndrome also develop the brain changes and the clinical features of Alzheimer's disease relatively early in life. The gene that codes for the APP is located on chromosome 21, the chromosome that is inherited in triplicate rather than in duplicate in those with Down syndrome. Having the abnormal number of three copies of the APP gene and therefore too much of the protein amyloid is the possible process that leads ultimately to plaque and tangle formation in those with Down syndrome. Other genetic risk factors for Alzheimer's disease are not causative but either protect against or increase the risk of developing the disorder with increasing age. One example is the normal variation in the type of ApoE gene inherited by individuals. One variant (number 2) protects against and one (number 4) increases the risk. Lifestyle factors may also have some influence, such as level of past educational achievements and present activity, or the occurrence of previous serious head injuries.

TREATMENT OF ALZHEIMER'S DISEASE

An accurate diagnosis is the starting point for the development of an individualized package of care for the affected person, together with support for carers. The fact that at present there are no treatments that arrest or reverse the progressive brain atrophy can lead to a feeling of hopelessness. However, despite the absence of curative treatments much can be done to maintain the quality of life of the person concerned. Medications developed to date have a temporary modifying effect on the course. Their action is primarily to temporarily restore activity of the neurotransmitter acetyl choline, and by doing so temporarily improve cognitive and functional abilities. Other medication approaches have included the use of antioxidants such as vitamin E, anti-inflammatory medications, and hormone replacement therapy. None of these permanently arrest the course of the illness.

The main approaches to providing support for people with Alzheimer's disease remain maintaining good physical health; trying to ensure a consistent, predictable, and safe environment; and using strategies that help maximize memory and other cognitive functions. Nighttime can be a particular problem with erratic sleep patterns and the increased likelihood of confusion that darkness brings. Thus, changes to lighting and nighttime support are often crucial. Medications may be needed with the development of epilepsy or psychotic phenomena but should be used with care as they can add to a person's disorientation and state of confusion. Guidance from national Alzheimer's disease organizations is available.

—Anthony Holland

See also Aging; Dementia; Down Syndrome.

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AMERICAN DISABLED FOR ACCESSIBLE PUBLIC TRANSIT

See ADAPT

AMERICAN DISABLED FOR ATTENDANT PROGRAMS TODAY

See ADAPT

AMERICANS WITH DISABILITIES ACT OF 1990 (UNITED STATES)

The Americans with Disabilities Act of 1990 (ADA) is the most prominent and comprehensive law prohibiting discrimination on the basis of disability in the United States. Passed by the 101st Congress of the United States and signed into law by President George H. W. Bush on July 26, 1990, the statute prohibits disability discrimination by a wide range of private employers, businesses, and state and local government agencies.

ORIGINS AND ENACTMENT OF THE ADA

A shift in focus from asking for charity to demanding civil rights for people with disabilities in the United States in the late 1960s and 1970s prompted calls for federal statutory protection of the civil rights of individuals with disabilities. The Civil Rights Act of 1964, which prohibited discrimination on the basis of race, color, religion, or national origin, was a major inspiration for the concept of similar protection for people with disabilities. Bills to add disability or "handicap" to the grounds of discrimination prohibited by the

1964 act were periodically introduced in Congress, but most of them died in congressional committees. A partial success of such efforts occurred in 1973 with the enactment of Section 504 of the Rehabilitation Act; this provision, patterned on Title VI of the Civil Rights Act of 1964, prohibited discrimination on the basis of "handicap" in programs or activities that receive federal funding.

The first proposal in U.S. legal literature of a more comprehensive federal statute that would prohibit discrimination based on disability, other than by simply adding "handicap" to the Civil Rights Act of 1964, occurred in a 1984 article published in the American Bar Association's *Mental and Physical Disability Law Reporter* (Burgdorf and Bell 1984). The article presented a "statutory blueprint" for such a law, suggesting that it should provide a definition of discrimination on the basis of disability and should explicitly impose obligations to make reasonable accommodations; to remove architectural, transportation, and communication barriers; and to eliminate discriminatory qualification standards. It also advocated broad coverage of such a law, arguing that Congress should prohibit discrimination on the basis of disability in all contexts in which it had prohibited other types of discrimination and should broadly cover all entities whose activities affect interstate commerce.

These theoretical concepts took a major step toward realization when the National Council on the Handicapped, an independent federal agency comprised of 15 presidential appointees, published its 1986 report to the president and Congress, titled *Toward Independence.* Under the leadership of the Council's executive director, Lex Frieden, and informed by the input received in a nationwide series of consumer forums conducted by its vice chair, Justin Dart, the Council advanced 45 legislative recommendations in ten broad topic areas. The first recommendation in the report was that "Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap." Subsequent recommendations in the report described in detail what should be included in such a statute and suggested that the law should be called "the Americans with Disabilities Act."

In its 1988 follow-up report, *On the Threshold of Independence* (Farbman 1988), the council took the somewhat unusual step—at the insistent urging of the report's editor, Andrea Farbman—of publishing its own draft ADA bill, written for the council by its attorney staff member Robert L. Burgdorf Jr. With a few changes, the council's draft bill was introduced in the Senate by Senator Lowell Weicker (R-Conn.) on April 28, 1988, and in the House of Representatives by Representative Tony Coelho (D-Cal.) on April 29, 1988. After joint congressional hearings on the bills had been held on September 27, 1988, the 100th Congress expired without either house of Congress taking action on the proposed legislation.

Before reintroducing the ADA legislation in the 101st Congress, congressional supporters revised the proposal in consultation with national disability consumer organizations, adding specificity and some policy compromises. The revised ADA bills were introduced in the new Congress on May 9, 1989, with Senator Tom Harkin (D-Iowa) as the sponsor in the Senate and Representative Coelho in the House of Representatives. On August 2, 1989, the Senate Committee on Labor and Human Resources approved a substitute bill reflecting certain compromises and clarifications arrived at through negotiations between the Bush administration and Senate sponsors of the bill. The Senate passed the bill, with a few floor amendments, by a vote of 76 to 8 on September 7, 1989.

In the House of Representatives, the House Committee on Education and Labor reported out the House's version of the Senate bill, with some additional clarifying language, on November 14, 1989. After approval by the three other House committees to which the legislation was assigned, the full House passed the ADA bill on May 22, 1990, by a vote of 403 to 20. Two separate conference committees were required to work out final differences between the Senate and House versions, after which the House approved the final version of the bill on July 12, 1990, and the Senate followed suit on July 13, 1990.

In his remarks before the more than 3,000 people, predominantly individuals with disabilities, who gathered on the South Lawn of the White House for the signing ceremony, President George H. W. Bush described the act as a "historic new civil rights Act . . . the world's first comprehensive declaration of equality for people with disabilities." The president added that "with today's signing of the landmark Americans with Disabilities Act, every man, woman, and child with a disability can now pass through once-closed doors into a bright new era of equality, independence, and freedom" (Bush 1990:1–2). He also noted that other countries, including Sweden, Japan, the Soviet Union, and each of the 12 member nations of the European Economic Community, had announced their desire to enact similar legislation (p. 2).

CONTENT OF THE ADA

The long title of the ADA describes it as "an Act to establish a clear and comprehensive prohibition of discrimination on the basis of disability." The act is divided into five titles: I—Employment; II—Public Services; III—Public Accommodations and Services Operated by Private Entities; IV—Telecommunications Relay Services; and V—Miscellaneous Provisions. The substantive titles are preceded by preliminary sections providing the short title of the act, a table of contents, congressional findings and purposes, and certain definitions.

Title I applies to employers having 15 or more employees, and to employment agencies, labor organizations, and joint labor-management committees. It establishes a "general rule" that "no covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual." This applies broadly to various aspects of applying for, getting, retaining, and benefiting from employment, including compensation, promotion, and "other terms, conditions, and privileges of employment." Title I goes on to specify several forms of discrimination that are contained in the general prohibition, including such things as segregation; using standards, criteria, or methods of administration that have a discriminatory effect or perpetuate discrimination; discriminating against a person because of that individual's relationship to another individual who has a disability; not making "reasonable accommodations" to known limitations of a qualified individual with a disability; and using discriminatory standards, tests, or other selection criteria.

Title II of the ADA, styled "Public Services," prohibits discrimination by any "public entity," a term defined to include states, local governments, or departments, agencies, or instrumentalities of states or local governments; and Amtrak and entities providing commuter transportation services. Title II subjects all the activities, programs, and services of such entities to a prohibition of discrimination on the basis of disability, requiring that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of public entities." Previously, such a nondiscrimination requirement had been applicable pursuant to Section 504 of the Rehabilitation Act only to those activities, programs, and services of such entities that received federal financial assistance. Pursuant to Title II, all state and local government facilities, services, and communications are made subject to accessibility requirements established under Section 504 and to other requirements consistent with other parts of the act, including, specifically, obligations to make "reasonable modifications to rules, policies, or practices"; to achieve "the removal of architectural, communication, or transportation barriers"; and to ensure "the provision of auxiliary aids and services."

Title II also includes detailed provisions applicable to public transportation systems, Amtrak, and commuter transit authorities. These provisions resolved some of the controversial, contentious issues that had arisen from the ambiguity and inconsistency in prior statutes regarding the extent of accessibility obligations for public transportation systems, and had led to considerable litigation. Among other things, these provisions of Title II impose requirements and set standards for accessibility of new or refurbished buses and trains, for bus and train stations, and for paratransit services for people with disabilities unable to use fixed-route bus services.

Title III addresses "public accommodations," defined very broadly to encompass most types of privately owned businesses, including places of lodging, establishments serving food or drink, places of exhibition or entertainment, places of public gathering, sales or rental establishments, service establishments, transportation terminals and stations, places of public display or collection, parks and other places of recreation, schools and other places of education, social service establishments, and places of exercise or recreation. Title III contains a sweeping "general rule" that prohibits discrimination "on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation." Subsequent provisions identify forms of discrimination encompassed in the general prohibition; these include such things as imposing discriminatory eligibility criteria, failing to make reasonable modifications, failing to provide "auxiliary aids and services" necessary for equal participation of an individual with a disability, not providing opportunities in "the most integrated setting appropriate to the needs of the individual," and denying a person equal treatment because of that individual's relationship with an individual with a disability.

Title III also imposes certain requirements regarding architectural and communication accessibility. One provision requires public accommodations to remove architectural barriers and communication barriers from existing facilities, where doing so is "readily achievable." The act defines "readily achievable" to mean "easily accomplishable and able to be carried out without much difficulty or expense." One of the most far-reaching provisions of Title III is the requirement that newly constructed facilities or altered portions of facilities of "commercial facilities" must be accessible, except where it is "structurally impracticable." The term "commercial facilities" is defined extremely broadly as facilities "intended for nonresidential use . . . whose operations will affect commerce." Title III also prohibits discrimination by private companies that provide transportation services, other than by air, to the general public. In general, public accommodations that offer transportation must provide service to individuals with disabilities equivalent to that available to others. New fixed-route vehicles seating more than 16 passengers must be accessible.

Title IV establishes requirements regarding two types of telecommunications services: telephone transmissions and television public service announcements. Companies offering telephone services to the public must provide telephone relay services to individuals who use telecommunications devices for the deaf (TDDs) or similar devices throughout the areas that they serve. Any television public service announcement that is produced or funded in whole or in part by any agency or instrumentality of the federal government is required to "include closed captioning of the verbal content of such announcement." "Closed captioning" refers to a system that allows only viewers with a decoder to view the captions.

Title V of the ADA contains various provisions relating to procedural and enforcement issues. Among other matters, it addresses the coverage of Congress and legislative branch agencies by the act; the application of the act to the insurance industry; the availability of attorney's fees under the act; states' liability for being sued under the act; the process for issuing accessibility standards; and liability for acts of retaliation, interference, coercion, or intimidation against a person for exercising rights under the act.

INTERPRETATION AND APPLICATION OF THE ADA

The various titles of the ADA direct that implementing regulations be issued by the federal agencies with enforcement responsibilities under the respective titles. The Equal Employment Opportunity Commission (EEOC) was directed to issue regulations for implementing Title I, the employment provisions of the ADA. As the head of the Department of Justice (DOJ), the attorney general was charged with issuing regulations both for carrying out Title II's requirements regarding state and local government entities and for implementing the requirements Title III places on public accommodations. The secretary of transportation was made responsible for issuing regulations for the implementation of the ADA's transportation requirements both for state and local government entities under Title II and public accommodations under Title III. The Federal Communications Commission (FCC) was directed to issue and enforce regulations for carrying out Title IV's requirements regarding telephone relay services. These regulations and additional regulatory guidance issued by the federal agencies provide considerable guidance regarding the scope and substance of ADA provisions.

Despite the enforcement activities of the federal agencies and the guidance they have provided, many claims under the ADA have wound up in courts. The passage of the ADA provoked a great deal of litigation. In the lower courts, the results were disproportionately unfavorable (90 percent or higher in some studies) to those filing employment discrimination lawsuits, generally on the grounds that they had not adequately proven that they had a disability under the law.

Eventually, the cases began to make their way to the higher courts. By the end of its summer 2004 term, the Supreme Court of the United States had decided 19 cases interpreting and applying the ADA. It is difficult to draw many firm conclusions from these decisions, but they suggest some general patterns or trends. Examining the results according to which title of the ADA was at issue reveals that the Court decided cases under Title III (public accommodations) in favor of litigants with disabilities, ruled about evenly for and against litigants with disabilities in cases under Title II (activities of state and local governments), and came down against litigants with disabilities in a significant majority of the cases under Title I (employment).

The Supreme Court's decisions can also be classified according to types of legal issues raised. Thus, the decisions addressing the language of the ADA in terms of what things it covers—*Pennsylvania Department of Corrections v. Yeskey* (prisons); *Olmstead v. L.C.* (residential treatment facilities); *PGA Tour, Inc. v. Martin* (PGA Tour golf tournaments); *Clackamas Gastroenterology Associates, P. C. v. Wells* (medical clinic owned by physician director-shareholders); *Tennessee v. Lane* (state courthouse facilities)—have produced results generally favorable to litigants with disabilities. Decisions interpreting the substantive requirements of the ADA—*Olmstead v. L.C.* (prohibiting segregation); *U.S. Airways, Inc. v. Barnett* (reasonable accommodation)—have produced mixed results. The Court's rulings on the scope of defenses available under the act—*Bragdon v. Abbott* (direct threat to health or safety of others); *Albertson's, Inc. v. Kirkingburg* (application of a federal transportation safety regulation); *PGA Tour, Inc. v. Martin* (fundamental alteration); *Chevron U.S.A. Inc. v. Echazabal* (direct threat to the employee's health or safety); *Raytheon Co. v. Hernandez* (non-disability-based misconduct rules)—have also been mixed, although, in numerical terms at least, slightly more adverse than favorable to litigants with disabilities.

The decisions of the Court addressing procedural issues, such as attorney's fees—*Buckhannon Board and Care Home, Inc. v. West Virginia Department of Health and Human Resources* (applicability of "catalyst theory")—and availability of punitive damages—*Barnes v. Gorman* (under Title II and Section 504)—that disability rights law shares with other civil rights constituencies, have mainly been restrictive of the interests of litigants with disabilities. Decisions addressing the scope of congressional authority to enact the ADA (and other civil rights laws)—*Board of Trustees of University of Alabama v. Garrett* (state liability for monetary damages under Title I); *Tennessee v. Lane* (right of access to state courts under ADA Title II upheld as exercise of congressional authority under Fourteenth Amendment)—have produced mixed results but have not resolved some fundamental questions. Finally, cases addressing who can invoke the ADA's protection have been mixed, but increasingly limiting as time has gone on; some have taken an inclusive view of the definition of disability—*Bragdon v. Abbott* (asymptomatic HIV infection)—and who is "qualified"—*Cleveland v. Policy Management Systems Corp.* (extent of inconsistency between application or receipt of disability benefits and pursuing ADA action)—but some very significant decisions—*Sutton v. United Airlines* (consideration of mitigating measures in determining disability of individuals with severe myopia); *Murphy v. United Parcel Service* (consideration of mitigating measures in determining disability of a person with high blood pressure); *Albertson's, Inc. v. Kirkingburg* (whether monocular vision is automatically a disability); *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams* (whether carpal tunnel syndrome and painful condition of wrists, elbow, and shoulders substantially limited major life activity of performing manual tasks)—have taken a highly restrictive view of what it takes to demonstrate a disability under the ADA.

One of the most influential of the Supreme Court's ADA rulings occurred in the case of *Olmstead v. L.C.,* in which a six-justice plurality agreed that the integration provision of Title II of the ADA requires states to place individuals with mental disabilities in community-based facilities in appropriate circumstances. To the central issue in the case of whether the prohibition of discrimination in the ADA may require placement of persons with mental disabilities in community settings rather than in institutions, the Supreme Court answered with “a qualified yes.” The Court concluded that “unjustified isolation,” for example, institutionalization when consulting physicians deem community treatment equally beneficial, “is properly regarded as discrimination based on disability.” No single opinion in its entirety, however, garnered the votes of a majority.

The effect of this ruling was magnified when President George W. Bush made the ADA’s integration requirement a cornerstone of his administration’s “New Freedom Initiative.” In February 2001, the president formally announced the “New Freedom Initiative” and committed the administration to ensuring the rights and inclusion of persons with disabilities in all aspects of American life. By Executive Order No. 13217, issued on June 18, 2001, the president declared the commitment of the United States to community-based alternatives for individuals with disabilities, and required the attorney general, the secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, and the commissioner of the Social Security Administration to work cooperatively with the states to ensure that the *Olmstead v. L.C.* decision is implemented in a timely manner, including providing services to individuals with disabilities in community-based settings, whenever appropriate to the needs of the individuals. The executive order directed federal agencies to work together to tear down the barriers to community living. As a result, various federal departments entered into joint efforts with states and others to provide elderly persons and people with disabilities the necessary supports to participate more fully in community life.

A significant issue only partially resolved by the U.S. Supreme Court’s ADA decisions through the end of 2004 is that of constitutional limits on congressional authority in relation to the ADA. In *Board of Trustees of University of Alabama v. Garrett* in 2001, the Supreme Court ruled that suits by employees of a state to recover money damages from a state for violations of Title I of the ADA were barred by the Eleventh Amendment to the U.S. Constitution. This followed the Court’s decision in 2000 in *Kimel v. Florida Bd. of Regents,* in which the Court had ruled that another federal law, the Age Discrimination in Employment Act, did not validly abrogate states’ Eleventh Amendment immunity from suits by private individuals. In *Garrett,* the Court indicated that in evaluating congressional authority to enact ADA provisions as part of its power to enforce the Fourteenth Amendment, the Court would require that legislation reaching beyond the scope of the Fourteenth Amendment’s guarantees must exhibit “congruence and proportionality” between the constitutional injury being addressed and the means adopted to address it. Applying such standards to Title I of the ADA as it applies to state employment, the Court found that the evidence Congress assembled of unconstitutional state discrimination in employment was inadequate and that Congress had not imposed a remedy that was congruent and proportional to the targeted constitutional violation.

The scope of the Court’s ruling in *Garrett* was relatively narrow; the ruling did not prevent lawsuits against state employers for injunctive relief, did not preclude suits initiated by the federal government for monetary damages, and did not bar suits for money damages against private employers or local governments. And despite the *Garrett* decision, most state workers still retained rights to sue for money damages under Title II of the ADA and under Section 504 of the Rehabilitation Act of 1973. The Court also expressly made clear in its *Garrett* decision that the same analysis might not apply to cases brought under Title II of the ADA. But the Court’s ruling in *Garrett* raised substantial fears that the analytical standards applied to Title I would subsequently be applied to bar private suits for monetary damages against states under Title II, and fueled concerns that the *Garrett* decision was but a stepping-stone toward a broader effort by the Court to restrict congressional authority and to expand the rights of states.

Such concerns were allayed to some degree when the Supreme Court issued its decision in the case of *Tennessee v. Lane* in 2004. In the *Lane* ruling, the Court upheld provisions of Title II of the ADA as applied to create a right of access to the courts for individuals with disabilities. The state of Tennessee had raised questions regarding the authority of Congress to place accessibility obligations on states and state entities under Title II and to authorize monetary damages when they fail to comply with these obligations. The Court rejected these challenges and held that Title II of the ADA, as applied to cases implicating the fundamental right of access to the courts, constituted a valid exercise of Congress's enforcement power under the Fourteenth Amendment. The Court found that "Congress enacted Title II against a backdrop of pervasive unequal treatment in the administration of state services and programs, including systematic deprivations of fundamental rights." The Court ruled that the congressional finding in the ADA of persisting discrimination against individuals with disabilities in critical areas, including access to public services, "together with the extensive record of disability discrimination that underlies it, makes clear beyond peradventure that inadequate provision of public services and access to public facilities was an appropriate subject for prophylactic legislation." While recognizing a solid constitutional foundation for the basic thrust of Title II of the ADA, particularly in its application to access to state courts, the *Lane* decision does not fully resolve all questions about the legitimacy of congressional authorization of private lawsuits against states in situations where access to the courts or other "fundamental rights" may not be at issue.

PROBLEMS AND CHALLENGES

The National Council on Disability, which originally proposed the enactment of the ADA, has monitored progress under the law on an ongoing basis. In June 2000, the council issued a report addressing federal compliance, enforcement, technical assistance, and public information activities for Titles I through IV of the ADA. The report, *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act,* examined ADA enforcement activities of DOJ, the EEOC, the Department of Transportation (DOT), and the FCC. The National Council on Disability found that, although the executive branch had consistently asserted its strong support for the civil rights of people with disabilities, "the federal agencies charged with enforcement and policy development under the ADA, to varying degrees, had been overly cautious, reactive, and lacking any coherent and unifying national strategy." The report was critical of case-by-case enforcement efforts in lieu of ongoing compliance monitoring and cohesive, proactive enforcement strategies. It also criticized the federal agencies for not having taken leadership roles in clarifying frontier or emergent issues. Underlying causes of enforcement deficiencies were identified as including the "cultures" of particular agencies, their reluctance to expand their views of their missions and to take strong stands on issues, and, critically, chronic underfunding and understaffing of the responsible agencies. Such factors, according to the council, had undermined federal enforcement of the ADA in its first decade, allowing the destructive effects of discrimination to continue without sufficient challenge in some areas and contributing to problematic federal court ADA decisions unnecessarily narrowing the scope of the law's protections. The report included 104 specific recommendations for improvements to the ADA enforcement effort.

In addition to its oversight of federal agency ADA enforcement efforts, the National Council on Disability has monitored ADA cases in the courts. In 2002, the council inaugurated a major initiative to address serious problems created by court decisions interpreting and applying the ADA. Spurred by concerns expressed at a series of meetings with ADA stakeholders, the National Council on Disability had become increasingly troubled by decisions in which the U.S. Supreme Court took restrictive and antagonistic approaches to the ADA, resulting in significant diminishment of the civil rights of people with disabilities. Initially, the council developed a series of policy briefing papers explaining the problematic aspects of the decisions of the Supreme Court and describing their negative implications. Such papers were issued under the title *Policy Brief Series: Righting the ADA Papers,* and were published on the council's website.

On December 1, 2004, the National Council on Disability issued a final summary report, titled *Righting the ADA,* highlighting key material derived from the various specific topic papers and offering legislative proposals for addressing the problematic implications of the Supreme Court's ADA decisions. The report presented legislative proposals in a combined form to produce a draft "ADA Restoration Act of 2004." It explained that such drastic action was necessary to address "a series of negative court decisions [that] is returning [Americans with disabilities] to 'second-class citizen' status that the Americans with Disabilities Act (ADA) was supposed to remedy forever": "Like a boat that has been blown off course or has tipped over on its side, the ADA needs to be 'righted' so that it can proceed toward the accomplishment of the lofty and laudable objectives that led Congress to enact it." The ADA Restoration Act was designed to (1) reinstate the scope of protection the act affords, (2) restore certain previously available remedies to successful ADA claimants, and (3) repudiate or curtail certain inappropriate and harmful defenses that have been grafted onto the carefully crafted standards of the ADA.

Despite its concerns about some judicial interpretations and executive agency enforcement of the ADA, the council expressed in both its *Promises to Keep* and *Righting the ADA* reports its belief that the law has had numerous positive effects and has "begun to transform the social fabric of [the] nation":

> It has brought the principle of disability civil rights into the mainstream of public policy. The law, coupled with the disability rights movement that produced a climate where such legislation could be enacted, has impacted fundamentally the way Americans perceive disability. The placement of disability discrimination on a par with race or gender discrimination exposed the common experiences of prejudice and segregation and provided clear rationale for the elimination of disability discrimination in this country. The ADA has become a symbol, internationally, of the promise of human and civil rights, and a blueprint for policy development in other countries. It has changed permanently the architectural and telecommunications landscape of the United States. It has created increased recognition and understanding of the manner in which the physical and social environment can pose discriminatory barriers to people with disabilities. It is a vehicle through which people with disabilities have made their political influence felt, and it continues to be a unifying focus for the disability rights movement. (National Council on Disability 2000:1; 2004b:37–38)

These rosy sentiments are tempered with the observation that "implementation has been far from universal and much still remains to be done."

—Robert L. Burgdorf Jr.

See also ADAPT; Antidiscrimination Law: Judicial Interpretations; Communication: Law and Policy; Family: Law and Policy; Health Care and Disability; Housing: Law and Policy; Rehabilitation Act of 1973 (United States).

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AMOR HEREOS (LOVESICKNESS)

The term *amor hereos,* meaning lovesickness, stems from a twelfth-century Latin medical text by Constantine the African, a translator of Arabic treatises: "Amor qui et eros dicitur morbus est"—"The love, which is called 'eros,' is a disease." Lovesickness, as a concept, dates at least from ancient Greece and later Byzantium, continuing in academic medical treatises until the early modern period. Texts on *amor hereos* are found in Greek, Arabic, Latin, French, English, Italian, and many other vulgar languages (languages of the common people). Its life in popular culture continues today.

Amor hereos is a curious cultural condition; it had no social class basis in its early medical descriptions, but by the end of the thirteenth century became an illness of the elite, a transition characterized by modern scholars as one from *amor eros* to *amor heroicus.* This transition occurred in concert with the rise of chivalry; Geoffrey Chaucer refers to it thus in the *Knight's Tale.* Lovesickness was so important in this courtly context that later texts suggested ways of simulating its symptoms.

In its more classic evocation, the image of the loved one entered through the victim's eyes, causing a humoral alteration, particularly the two hot humors, blood and black bile. The disabling symptoms of lovesickness were variable, sudden, and chronic (lasting six months or more). Insomnia, pain, anxiety, a jaundiced color, and wasting were some of its symptoms. In one early modern case, a shoemaker fell limp and lost speech for a week, assuming a form of paralysis. Severe melancholy and even death were other potential outcomes.

Some treated the condition with wine, conversations with close friends, walks in nature, music, and observing the faces of beautiful women. Others recommended playing games and doing delightful things, and also fattening and moistening foods, jokes, intercourse with a woman who was not the cause of the condition (often a prostitute), or a purgation of the humors.

Initially, men were the typical victims of lovesickness, though Galen treated at least one woman with the condition in the second century. During the Renaissance, as chivalric culture declined, lovesickness became increasingly a condition of women. With its shifting gender, lovesickness's pathologic etiology changed from psychological to sexual, while therapy changed to regimenal and dietary interventions.

—Walton O. Schalick III

See also Galen; Hippocrates; Melancholy.

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AMPUTATION

To *amputate* is to cut off (e.g., a limb, arm) by a surgical operation (*American College Dictionary*). The term sometimes is used to refer to a traumatic event such as to have a leg or foot amputated by a land mine where salvage is impossible.

SOME CAUSES OF LIMB AMPUTATION

About 90 percent of lower-limb amputations in Western countries of the world are due to peripheral vascular disease (PVD), which is often connected with diabetes mellitus. Surgical attempts to salvage limbs (e.g., where there is PVD) may later have to go on to amputation. Not uncommonly, salvage failure causes patients and even some surgeons to feel that amputation signifies a failure. However, experienced clinicians look upon necessary amputation positively as a new opportunity for successful rehabilitation if the surgical amputation is handled expertly and if good pre- and postmanagement procedures are followed. Therefore, they believe that special attention should be placed on the techniques associated with amputation and that amputation should be thought of as a high art.

Elective amputation may be necessary following infections of various kinds. Infections frequently occur in the foot when that area has sensory deficits caused by diabetes or other medical conditions. Many amputations due to infections can be avoided if there is good patient compliance with foot management regimens (e.g., proper shoes, foot hygiene, skin care, proper nutrition, and periodic medical observation). Infections such as bacterial meningococcemia are particularly pernicious and may result in loss of multiple limbs or death even in healthy young persons.

Elective amputations can also result from tumors or from failure of limb salvage attempts during tumor removal. Under ordinary conditions, tumor-related amputations are not as common as amputations due to PVD or infection.

The general population probably thinks first of amputation caused by trauma. Leading trauma causes of amputation are farm machinery accidents, car accidents, industrial accidents, burns from high-voltage electrical accidents, frostbite, and military combat.

A small number of children are born with limb deficiencies. Years ago, before the fetus could be viewed in utero by ultrasonic methods, the birth of a child with a limb deficiency was often a shock to parents. This shock can now be ameliorated with counseling and preparations before the child's birth.

DEVELOPMENT OF AMPUTATION SURGERY AND ARTIFICIAL LIMBS

Amputation of body parts and their artificial replacements can be traced to antiquity. Ambroise Paré, a French Army surgeon of the sixteenth century, is often regarded as the father of amputation surgery, partly because of his development of the ligature, his selection of sites for amputations, and his interest in prostheses and outcomes. Development of the ligature and later the tourniquet, aseptic techniques, and anesthesia has been key to successful amputation surgery. With these techniques, amputation procedures developed rapidly during and following World War I, particularly by German surgeons exemplified by Krukenberg and Sauerbruch. In a number of countries, the end of World War II in 1945 ushered in the first organized research and development efforts in the field of amputation and prosthetics. Scientists, engineers, and prosthetists were brought together with surgeons to advance the field of amputation and prosthetics, as admonished by Sauerbruch around 1916.

This interdisciplinary approach has been productive, and significant advances are being made, but adequate replacement of human limbs remains a daunting task. It seems clear that technology is not enough. Surgeons need to be important members of research teams in this field, not only to perform amputations but also sometimes to reorganize body tissues in ways that make it possible to design and build completely new kinds of limb replacements that may be superior to what has been known previously.

PEOPLE WITH AMPUTATIONS

People who have had amputations, like many other persons with disabilities, are not sick. Whether famous or infamous, many people who have had amputations have been achievers throughout history. The Netherlands'

Peter Stuyvesant wore a wooden leg and was governor of New York. England's Admiral Horatio Nelson was a right-arm amputee. Blind in his right eye, Nelson ended his naval career—and life—with a spinal cord injury from a sniper's shot in 1805. Look carefully at Nelson's statue on the tall column in Trafalgar Square in London and you will be able to see that his right sleeve is empty. Confederate General Thomas J. "Stonewall" Jackson was accidentally shot in the left arm by his own troops as evening fell at Chancellorsville. When he died from blood poisoning a few days after amputation of his arm, General Robert E. Lee, leader of the Confederate forces in the American Civil War said, "Jackson has lost his left arm, and I have lost my right arm."

French actress Sarah Bernhardt, "the Divine Sarah," had a leg amputation. John Wesley Powell was an intrepid explorer of the Colorado River without a right arm. Bernhard Schmidt was not inhibited by amputation of his arm when he was 15 years old. Known in Germany as "the optician," his famous telescope design and his ability to make mirrors and lenses to high accuracy is legendary. "Peg Leg" Bates was a dancer in New York City, even though he had lost part of his left leg in an auger accident. He became a star tap dancer using an artificial leg. Harold Russell, who lost both hands in a military training accident, received two Academy Awards—one for Best Supporting Actor and a second, honorary, award for "bringing hope and courage to his fellow veterans"—for his acting role in the 1946 movie *The Best Years of Our Lives*. That event led him to become an important American advocate for persons with a disability.

Two unlikely amputations occurred in 2003. A young woman, Bethany Hamilton, lost her left arm in a shark attack while surfing. A hiker/climber, Aron Ralston, 27, had to amputate his own arm below the elbow using his pocketknife to escape death when he became caught by a boulder in a remote area of Utah.

The previous paragraphs illustrate how the lives of some widely known people have been altered by amputation of limbs. Their stories are compelling but really no more compelling than the stories of many others with amputations who are just less well known.

—Dudley Childress

See also Accidents; Biomechanics; Burns; Diabetes; Phantom Limb Pain; Harold Russell; Surgery; Veterans.

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AMPUTEES AT PERSEPOLIS

As Alexander the Great advanced to take Persepolis in southwestern Persia in January 330 BCE, he met a large, desperate group of released Greek prisoners whose hands, feet, ears, or noses had been cut off by their captors. In one account, there were 800 men who had been trained in various skills or crafts, "then their other extremities had been amputated and they were left only those which were vital to their profession." In another version, nearly 4,000 men had had parts amputated and then were "branded with letters from the Persian alphabet" to amuse their captors: "They looked more like outlandish phantoms than men."

The group begged Alexander to save them from their tormentors. Shaken by the spectacle, Alexander promised help. The men withdrew to discuss what to ask. The key issue was whether to return to Greece and disperse to their villages, facing an uncertain reception because of their appearance, or to remain as a mutually supportive group in the Persian lands conquered by Alexander. The debate is framed in the mouths of two orators. One states that public and private reactions back home will be adverse, and they know this because they themselves would find each other's appearance intolerable if they were not all in the same boat. They should stay in Persia, keeping their misfortune hidden from those who had known them earlier. The second speaker suggests that decent people do not think like this, and the group should certainly return to breathe the sweet air of their homeland and enjoy their freedom, their own gods and culture.

A few of the men wanted to return to Greece, but the great majority voted to ask for land and benefits in Persia. When their delegates met Alexander again, he had already decided that they would opt to go home, and he had made arrangements for transport and cash in hand. When the men explained what they really wanted, Alexander changed his plan, granting them land, livestock, clothing, food, and money.

The incident has undergone much skeptical review by classical scholars, as many curious myths and legends are attached to Alexander's life. The earliest extant manuscript record of the story dates from about 1,200 years later. It may have been rooted in contemporary records, but it could have been fabricated centuries later. However, no evidence actually disproves the story. The mutilations, the anticipated public reactions, and other details are consistent with other data from Persia in that period. It appears as the world's earliest record of a recognizable debate among a large group of people with significant disabilities, and also the first record of such a group advocating their case with a ruler and causing him to change his plan for their welfare.

—Kumur B. Selim

See also History of Disability: Ancient West.

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▣ ANTHROPOLOGY

Cultural anthropology is an especially well-suited disciplinary perspective to use in considerations of impairment and disability. This is partly evident in the number of nonanthropologists who have applied anthropology's methods and core concept of culture in their research. The central concern of cultural anthropology has always been the understanding of difference: how various forms of difference are defined, constructed, and managed in different times and places. This preoccupation with difference and the discrimination that is often attached to devalued differences reveal why anthropology can be of vital importance to the study of disability.

Particular dimensions of this work have produced questions that are especially salient for impairment. Some examples illustrate the connections: In what ways are the negative cultural constructions of subgroups based on their differences contributing to and rationalizing their marginalization and oppression? Parallel issues faced by many indigenous peoples are elaborated in ethnographic research. How do questions of power, resistance, voice, representation, and self-determination get worked out for cultural subgroups? We look at how both these processes also hold the potential for positive group identity and emancipation. Anthropologists interrogate medicalized, individualizing responses to what are fundamentally sociopolitical or economic justice problems in a way that echoes concerns in disability studies. Beyond its conceptual concerns, anthropological research methods and critical reflection on them offer potentially fruitful avenues for research in this field. This is especially true for new areas that require an exploratory approach because not enough is known to undertake standard survey research.

Although for various reasons anthropologists have been slow to engage more deeply in disability studies, original and controversial research in the past decade suggests that the tide is turning. Anthropology offers salient insights and practical tools for sharpening core disability studies debates, partly because it has already been over isomorphic terrain in relation to issues faced by indigenous people and minority groups around power, voice, intra-movement fragmentation, insider-outsider (emic/etic) debates, and how to stake claims for recognition and accommodation with a dominant group that uses different measures of value. Anthropological experience with cross-cultural comparison and its conundrums will also be instructive.

Anthropology would grow from greater attention to advances in critical disability studies where the aforementioned issues combine with sensitive cultural norms and ethical/medical taboos to reveal the limits of some theories' usefulness. For excellent examinations of how anthropology and disability are linked, see especially Kasnitz and Shuttleworth (1999), Linton (1998), and Stiker (1992).

DEFINITION OF TERMS

This entry uses the Union of the Physically Impaired against Segregation (UPIAS) definition of *impairment* as a physical or cognitive lack or abnormality a person has and *disability* as a restriction or disadvantage accruing to the person due to physical and social environments not being designed to support that impairment. The term *developmental disability* will be used to encompass intellectual disability (mental retardation) as well as autistic spectrum disorder, cerebral palsy, and other conditions that can result in substantial restriction of cognitive function or the expression thereof.

Anthropology and *culture* have no single, agreed-on definitions. This reflects both their breadth of subjects and theories and the discipline's tradition of self-critique. Minimally, anthropology is the study of human cultures that comprise human beliefs and behaviors. Culture, then, is what we think and feel, how we make sense of the world, and what that can lead us to do (action) and produce (artifacts). Anthropologists do not *create* meaning, but rather use their analytical writing (ethnography) to evoke and render intelligible (to others) a way of life that is already meaningful to those living it, as Clifford Geertz put it. While the audience used to be those "outside" the culture under study, increasingly, ethnographies are written with inside audiences in mind, through new articulations and analyses of their experiences.

For instance, Pamela Cushing's (2003b) ethnographic research of L'Arche, a residential support organization for people with developmental disabilities, sought to elucidate how that subculture worked against stigma to promote mutuality in caregiving relations. Her research aimed to inform and influence state policy makers and other providers who are currently struggling with how to improve relations and social inclusion in the mainstream. Esther Ignani's research (2005) with youths with disabilities seeks to work against misinformed but common notions of what life with impairment is like, as they co-create autobiographical films. This is part of what Cushing calls reshaping the public's moral imagination regarding disability, and what anthropologists Rayna Rapp and Faye Ginsburg (2001) call rewriting disability narratives.

Although anthropologists study all aspects of culture, current research focuses more on everyday life than grand, ritual events. Second, its methodological core is the grounded, long-term research of participant observation, which includes extended periods of sharing and participating in everyday life with those you are studying as well as in-depth qualitative methods such as individual and group interviews, or narrative analysis. Combined, these make anthropology well suited to identify gaps between stated beliefs and actual lived behavior. Rather than judge such gaps from their own worldview, anthropologists use the gaps as a starting point to begin asking critical questions about the culture: What purposes or whose interests might such a gap serve? What tensions or uses of power does it reveal? This perspective could help to explore the gap between the positive hopes of disability rights and the daily forms of exclusion faced by many individuals and families living with developmental disability.

Culture is often defined through its traits. Culture is not inherited but learned both consciously and inadvertently, and shared among a group. Although shared differential access to cultural knowledge is inevitable, subgroups develop specialized cultural norms and knowledge, or, alternatively, status differences can restrict one's access. For example, within disability culture, subgroups such as wheelchair users or Deaf people have their own nuances, jokes, and language based on shared experience. An understanding of culture as dynamic (changing), heterogeneous (having different, even disparate elements), and syncretic (many influences) has replaced the previous view of culture as static (unchanging), homogeneous, and bounded (closed). Since many disability scholars use culture as a core concept, the definition is important: The term is often diluted or misused outside the discipline. The idea of a "disability culture," for example, has been widely debated with little reference to anthropological theory, as discussed below.

Another important development in cultural theory is the recognition of how power is at work in cultures and of a need for greater critical examination of those processes. Feminist and postmodern scholars have shown that since cultures have multiple subject positions within them, cultural knowledge is always partial, positioned, and embedded in such power relationships. This does not mean that all perspectives are invalid or solipsistic, but rather that multiple views need to be gathered and consulted to establish an empirical sense of the whole. In terms of disability studies, such theories indicate that better evocation of the worldviews of people with anomalous bodies and minds will contribute to widening the scope of human understanding.

Finally, anthropologists have also identified common pitfalls in how the concept of culture is applied that are relevant to disability. Wikan (1992) argued that the very notion of "a culture" lures people to overemphasize differences, especially exotic ones, that tend to separate us as humans, over the commonalities that could bring us together. Roeher Institute (1996) and Trent (1994) have shown how detrimental a fixation on (devalued) difference has been for people with impairments whose identity becomes conflated with the impairment.

Others argue that the culture concept tends toward generalizations that gloss or flatten intragroup differences. For instance, the idea of promoting a coherent front for the disability movement or culture is a form of strategic essentialism and can be effective for rhetorical and activist purposes. The pan-impairment solutions that get proposed, however, do not necessarily meet the particular needs of all members. This has arguably been the case for people with developmental disabilities within the broader disability movement. They remain burdened with significant stigmas; ongoing resistance to their inclusion in schools and workplaces and rising rates of selective abortion of fetuses with impairments are two cultural indicators of this attitude.

HISTORICAL CONTRIBUTIONS

Anthropologists studying impairment such as Stiker ([1982] 1999), Kasnitz and Shuttleworth (1999), and Rapp and Ginsburg (2001) have variously lamented that no adequate anthropology of disability had yet emerged. Just 15 years ago, Oliver (1990) noted that most anthropologists still considered disability (unlike gender or race) to be an unproblematic category, and like many writers, consigned nontypical or so-called deviant people to footnotes. Anthropologists' lack of engagement can be traced to manifold factors. Goffman's (1963) "courtesy stigma" (avoidance of deviance) could play some role in our field site choices, and perhaps disability was not as visible a "social issue" for the mainly preindustrialized peoples we have classically worked with. It is not true, however, that impairment was absent in past ethnography because disabled people did not survive in tribal societies (Linton 1998).

Two theoretical explanations for our absence are also plausible. For many years, the ethnographic optic was predominantly *across* cultural groups; an interest in *intra*cultural heterogeneity or theorizing exceptionality (such as impairment) is only of recent interest. Marxist and feminist approaches have since added much-needed correction to this interpretive bias. Furthermore, prior to the 1970s, ethnographies aimed for a "snapshot" of a coherent, homogeneous tribe or cultural group, which did not leave much room for inclusion of anomalous characters or unusual scenarios. Corrective research has emerged such as those that explicitly consider exceptional circumstances of families with a child with an impairment.

Interestingly, Oliver noted that the analyses of certain anthropologists who did venture into disability contained prescient insight akin to the future social model. Benedict (1934) made an impressively early attempt to argue for conceptualizing epilepsy and other abnormalities as cultural constructs. Farber (1968) wrote that disability is a "social imposition," not a personal limitation, and that the negative effects of labeling were equal to those due to actual "incompetence." Based on Mexican research, Gwaltney (1970) perceptively concluded that the meaning of blindness is variable and thus must be culturally contextualized. These insights hint at an idea of the *social* status of handicap historically and cross-culturally.

When Edgerton did his now famous longitudinal ethnographic study (1967) of deinstitutionalization of the "mentally handicapped," however, he chose to use Goffman's concepts of stigma and institutional effect, as well as labeling and symbolic interactionism. Edgerton's portrayal was evocative and was widely read across the social sciences, helping identify significant transition challenges. He described how people tried to pass (as normal) in society through coping tactics, relationships, and harmless ruses. Klotz (2004) argued that Edgerton's conceptual framework biased the course of ethnography toward concepts implying deficit or lack, and away from cultural construction or direct subject/worldview elaboration. Still, such vintage ethnographies offer useful perspectives on cultural norms of the period, and they drew much-needed attention to deinstitutionalization as a social concern.

CONTEMPORARY RESEARCH

Disability studies as a critical field of study based in human and social sciences (outside medical, rehabilitation, and education) has grown rapidly since the mid-1970s with the founding of the Society for Disability Studies (United States) in the early 1980s. While the use of anthropological theory and methods by other scholars has been an important part of that growth, engaged anthropologists remain few and, as Kasnitz and Shuttleworth (1999) noted, they often write for anthropological audiences without sufficient reference to disability studies developments, although this is changing.

Categories of Anthropological Research

Grouping the existing ethnographic research in impairment/disability helps to highlight the relevance of anthropology to impairment and disability studies, whether undertaken by anthropologists or not. There is no set typology for this formative area of research. The categories below reflect recent anthropological activity. See the final section of this entry for areas of strong potential. Cultural constructionism, cross-cultural comparison, and insider methods and perspectives are the three categories, and the risks of disability studies interdisciplinarity are also addressed.

The most effective of these works take disability seriously as an analytic category within the culture, rather than beginning from a traditional biological, individual perspective. While the latter is also useful, it can hide or distort other important cultural processes and beliefs at work. Groce's (1988) ethnography of Martha's Vineyard, an island off the New England coastline, is notable in this vein. She shows how the meaning of deafness, an impairment that was generally perceived in American culture to be a deficit and a "personal tragedy," was socioculturally contingent. Since hereditary patterns made deafness pervasive on the island, most locals learned to sign, thereby greatly reducing the stigma and "disabling effects" of the environment.

Another example of taking disability seriously as an analytic category comes from emerging attention to impairment in medical anthropology. Rapp and Ginsburg (2001) explore how parents' experience of having and raising a child with an impairment is interwoven with cultural expectations and taboos regarding perfection and health in individuals and families. Along with Gail Landsman (1998), they examine how the private narratives and experiences of American parents expecting or raising an anomalous baby interact with the mainly negative public narratives of disability. Their work builds from literature, such as Kenzaburo Oe's (1995) biography and novels about his family's transformation through the birth of their son.

Cultural Construction and History

A common approach to impairment/disability among anthropologists and others is to show how it is a socially and culturally constructed category, contingent on values and ideology as much as physical/mental conditions. Acknowledging this contingency helps to provide the analytical framework for understanding the powerful negative effects that labeling, segregating, and devaluing have had. Those effects are largely ascribed to the negative assumptions of the biomedical and functional models of impairment (although these should not be seen as separate from the moral fabric of the society that produces them). This critical cultural history approach examines the shifting meanings that disability has had over time in a culture.

It works from the postmodern assumptions that truth is partial, contingent, and interested. Four examples of this approach demonstrate its power and breadth.

Trent (1994) used archival research and document analysis of early- to mid-twentieth-century U.S. institutional records, correspondence, and government policy shifts. He teased out a set of cultural metanarratives that successively guided policy, welfare support, IQ testing, rehabilitation, and institutional life for "the mentally retarded." He shows how these conceptual changes had less to do with scientific advances than with broader sociocultural or economic changes. For example, he noted the impact on people with intellectual disabilities of changes in social organization due to industrialization, in notions of contagion due to rise of germ theory, and in systems of moral and social control that arose with eugenics. Trent outlined the public and professional shift from narratives of compassion and protection *of* "the handicapped" to that of suspicion and protecting society *from* them. Anthropologists have long examined how such metanarratives interweave cultures, effectively permeating public perspectives about a subgroup such as indigenous peoples.

Stiker ([1982] 1999) also situates impairment/disability in its cultural and historical context using cultural symbolism. He examined the emergence of state governance of the "invalid body" in France, as many war veterans acquired physical impairments. Stiker critiqued disability scholars for too smugly accepting the medical and social models as theoretical end points. Like Foucault's studies of madness and institutions, Stiker used enduring cultural problematics such as limits and boundaries (here, normal and abnormal) as his optic for exploring such social changes.

An anthropological perspective should, he argues, alter the reductive emphasis of considering disability simply in terms of oppression (rights, minority group politics) and economic systems (exclusion/poverty). That disabilities operate as powerful emotional triggers suggests deeper social conflicts than just material oppression in a particular social structure (Western, capitalist, medical). Disability discrimination also originates in our abiding collective cultural fantasies about perfect bodies, health, and minds and the converse fears of infirmity, deformity, and unreason.

Indeed Stiker suggested that the specificity and fundamental symbolic significance of disability can be clouded or drowned by those other emphases. For example, he applauded Murphy's use of cultural liminality as a heuristic with specific symbolic meanings for impairment related to modernist social order. Research into broader symbolic and cultural meanings could offer more thorough understanding of the bases for exclusion that would feed more creative ways of imagining impairment back into the social fabric.

Two anthropologists use this symbolic approach. Desjardins (2002) conducted research into the emic (insider) perspective of people with developmental disabilities on their experience of daily social life in relation to the mainstream, which he described as simulacra or parallel worlds. He uses his findings to undermine mainstream assumptions about what kind of inclusion people want and to explore what the symbolic meaning and function of the inaccurate assumptions were. He points to modern society's intolerance of real difference, but also to the potential richness of life on the margins. Michalko (2002) begins from personal experience of blindness and usefully generalized to cross-impairment issues with a range of theoretical perspectives. He insisted that disability is a difference that matters symbolically and practically and should not be elided with other differences.

Cross-Cultural Comparison

Anthropology's locus classicus has been preindustrial, non-Western societies and thematic cross-cultural comparisons using those findings. Some anthropologists, and other scholars using ethnography, are beginning to answer the call for greater ethnographic description and theorizing of anomalous bodies and minds in those settings. This work has helped substantiate further that impairment and disability as conceived in the West are culturally located notions, but improvement is still needed. The disability specialists Kasnitz and Shuttleworth (1999) and Linton (1998) argue that more cross-cultural studies are needed. Specifically, they call for studies designed for this purpose, not ones that mine old data for signs of (Western-defined) impairment, which makes for thin data and risks layering etic interpretations on local perceptions. Phenomenological studies are needed that do not begin from Western categories and that assess local understanding and management of perceived challenging, anomalous conditions.

Devlieger's (1995) ethnography of the African Songye people's worldview is a good model. His goal is to understand whether the concepts of impairment or disability hold any meaning in the Songye symbolic systems. He found that they have three categories of "abnormal" kids, none of which is equivalent to the U.S. term *disability*. He showed that Songye are more concerned with the existential and familial (the social meaning of anomalous children) than the technical (rehabilitation, cure, medicine). This leads them to think more about causes, especially social ones, and how to rebalance those social wrongs, rather than how to "fix" the child directly. This notion curiously echoes earlier Christian notions of disability as punishment, which may have been imported via missionaries. Furthermore, social consequences of impairment are variable.

Ingstad and Whyte's (1995) widely read collection of cross-cultural research introduced useful new perspectives, and the critiques of it are also instructive. Kasnitz and Shuttleworth (1999) noted inconsistent use of the terms disability and impairment across contributors, and various authors begin from an etic/outsider understanding of an impairment (e.g., blindness). Finally, these and other cross-cultural researchers often neglect to acknowledge, use, or challenge existing disability studies theory, hence omitting key disciplinary concerns. Still, this and other cross-cultural texts are necessary first steps.

Oliver (1990) noted that the paucity of existing material and its tendency toward a medical or individual model makes it difficult to develop either an empirical or theoretical account of disability cross-culturally. More research is needed both on specific impairments and on pan-impairment conceptions, and both need to draw on and evoke the emic point of view more extensively. While Devlieger cautioned that greater state involvement does not necessarily signal better quality of life, there is also an unhelpful tendency for some authors to romanticize the non-Western societies' approaches, assuming that the *lack* of an elaborate medical labeling system indicates de facto greater support or acceptance. For example, the lack of state or medical support for people with developmental disabilities in Ukraine reflects rejection and lack of political will or resources, not acceptance. Greater anthropological attention to these concerns should aid in creating a basis for cross-cultural comparison even without common terms. Oliver reviewed research that begins to name common factors that effect perception and treatment.

Insider's Perspective and Methods

Disability studies scholars continue to call for greater inclusion of the active voices of people with disabilities in research and less emphasis on the perspectives of nondisabled peoples' *response to* disability. Insider (emic) writing has expanded in the past two decades. These tend to be by or about people with physical impairments, often late-onset or acquired ones. They are mainly autobiographical and only occasionally analytical (e.g., Murphy 1990). People with developmental disabilities often need special supports or alternative media forms to tell their story. College and university access centers and disability studies programs are beginning to develop creative solutions for increasing disabled students' access to social science education.

The qualitative, intimate research methods of anthropologists and some sociologists have begun to yield more representative accounts. Qualitative research can be especially fruitful when exploring new areas or emic worldviews such as the views of people with intellectual impairment. Klotz (2004) discusses anthropologists who have used participant observation and naturalistic phenomenology for this purpose to good effect. This research emphasized the centrality of interactions and relationships to understanding what a person with profound intellectual impairments is experiencing, and the meaning of certain behaviors. Such research can expand anthropological paradigms and contribute to better social care policy.

The anthropologist Gelya Frank (2000) undertook long-term collaboration with a social sciences student who had complex physical impairments. Both wrote about the student's life story, one as an autobiography, and one as a reflexive ethnobiography that critically explored what could be learned about the student's cultural environment from events, themes, and structures in her life story and how she narrates them. Narrative theory continues to flourish in the field.

The anthropologist Murphy (1990) wrote a combination ethnography and autobiography, which "anthropologized" his personal experience of acquiring a degenerative disability. This widely read book attempts to situate processes such as stigma in specific cultural values and personal interactions. He also explored, with some disdain, the direct relationship between his physical and mental decline and the quality or willingness of others to interact with him. He theorized his experience that when a person with impairments cannot fully "recover normalcy," he or she is socially positioned in what anthropologists term a "liminal" or "in-between" state: not ill but not well, neither sidelined fully nor integrated, and perceived somehow as at fault for being a disturbance to modernist order.

Challenges for Interdisciplinarity

Murphy's (1990) insightful book was critically acclaimed and widely read by anthropologists and activists, but it has also been critiqued in ways that illustrate the challenges of doing research in an interdisciplinary field. It is difficult to keep abreast of developments in theory across all the fields whilst also maintaining depth in one's own discipline.

Murphy chose to write within anthropological and sociological frameworks rather than within the emergent disability studies sociocultural model. While some, such as Stiker, praised his innovative application of those frameworks, others critiqued his insensitivity to disability studies theory. For instance, Arthur Frank identified common themes in acquired disability narratives such as restitution (cure/getting well again), chaos (confusion), and quest (illness as route to transformation). Kasnitz and Shuttleworth contended that Murphy sustained a restitution narrative through much of the book emphasizing only negative aspects of his impairment: loss, depression, and exclusion. Furthermore, his story often conflates identity and impairment in contrast to the disability studies theorists' attempt to show that impairment is neither deterministic nor universalizing. Many anthropologists and other authors have similarly either ignored disability studies and even accused it of analytical omissions that it did not have, presumably due to inadequate knowledge of that literature.

Anthropologists must better situate their research both in anthropology and emergent disability studies theory to avoid a merely add-on treatment of disability. This theory is increasingly sophisticated and offers insights around difference, power, and exclusion, which will also refine anthropological theory. For instance, classic ethnographic categories such as kinship and reproduction are problematized and enriched by considerations of the exceptional family, while still avoiding exotification or overemphasis on role of difference. Disability studies theorists must also become more familiar with fundamental advances in relevant anthropological theorizing such as cultural analysis and change, difference, positionality, representation, voice, narrative, and interpretivism.

FUTURE RESEARCH DIRECTIONS

Anthropological theory and approaches are especially well suited for illuminating disability as a social, cultural, and symbolic process. Greater attention to questions raised by impairment-disability will also sharpen and inform that theory. What follows are a few suggestions for future research directions for anthropology and impairment-disability.

Symbolism and Cultural Analysis

Anthropological theories of voice, power, difference, and representation can illuminate underlying cultural tropes and values that impairment and disability trigger. Theorizing exceptionality, anomaly, and marginality may provide one fruitful avenue. More nuanced studies of disability symbolism in Western and other cultural stories, idioms, and events are needed. Further examination of the role of religion and spirituality as symbolic systems of meaning in relation to impairment fits well into this category.

Medical Anthropology

Medical anthropology involves reflexive analysis of the construction of knowledge of health, illness idioms, and social injustice. It can reintroduce disability studies to questions of embodiment, the role of medical technologies in people with disabilities' lives, and issues with health care systems. Anthropologists have recently turned greater attention toward the sensory, somatic, and biological aspects of life, after years of neglect. Sterilization, euthanasia, reproduction, caregiving, and abuse are all potential disability studies topics. One question is, how does neo-eugenics come to make cultural sense amid the inclusive discourses of disability rights? What are the roots of the countervailing discourses of perfection and mastery?

Disability Culture Debate

The scholarly and popular disability communities continue to debate whether or not there is a disability culture, its politics and cohesiveness, and boundaries (who is in or out of it). Anthropologically informed voices could help articulate the characteristics and evolution of the social movement and support it to consider its options, for example, to sound a caution about how strategic essentialism (pan-disability arguments) is used for rhetorical/activist purposes, since it can leave people out, render inadequately considered solutions, and ultimately fragment the group.

Policy: Social Inclusion

Social inclusion and exclusion policy provide a good starting point for bringing cultural and disability questions together (Cushing 2003a). The challenge is, what alternatives are we giving people with disabilities? Social inclusion is not either/or; it is an ongoing process involving many important cultural variables alongside the economics. Anthropology could provide subtle insight around the negative or fearful attitudes toward disability in our culture that act as barriers to greater social acceptance along with the physical integration. It can also illuminate the diverse, culturally contingent meanings of inclusion from an emic (disability) standpoint. Considerations of quality of life, belonging, and spirituality are all salient.

Methodology

Participant observation and creative forms of personal interviews hold the possibility of greater phenomenological understanding of insiders' everyday life experience of impairment-disability, and of generating more positive narratives of this experience as grist for the social mill. The long-term nature of fieldwork lends itself well to studies of impairment and the life course, adult-onset changes, and shifts in self-understanding. Participatory action research offers a route to include the voice and agency of more people with disabilities; however, such work must carefully balance activist aims with research standards of empiricism.

—Pamela Cushing

See also Autobiography; Citizenship and Civil Rights; Cultural Context of Disability; Deafness, on Martha's Vineyard; Developmental Disabilities; Disability in Contemporary Africa; Inclusion and Exclusion; Sociology.

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ANTIDISCRIMINATION LAW: JUDICIAL INTERPRETATIONS

The U.S. Congress took a comprehensive approach to disability discrimination in the Americans with Disabilities Act of 1990 (ADA), defining the covered class broadly, providing flexible, individualized requirements, and authorizing various remedies. Congress's approach reflected a civil rights approach to disability. Under this model, people with disabilities are recognized as a minority that traditionally has been unnecessarily excluded from full participation in society. This modern approach to disability contrasts with traditional models that saw disability as an automatic and necessary basis for exempting people from both the benefits and responsibilities of full community participation. The traditional model addressed disability as either a medical issue to be cured or a justification for charity and segregations. While Congress intentionally used the civil rights model in drafting the ADA, the courts, and most notably, the U.S. Supreme Court, often have continued to rely on the traditional models in interpreting the law. This has led to severe, and sometimes inconsistent, restrictions on disability law.

LIMITATIONS ON WHO IS PROTECTED

Mitigating Measures

The ADA defines a disability as a physical or mental impairment that substantially limits a major life activity. Congress took a broad view of disability when enacting the ADA. The U.S. Supreme Court, in its first case analyzing that definition, appeared to adhere to that definition. The Supreme Court in *Bragdon v. Abbott* took up the issue of when an impairment's limiting effect is substantial. The divided Court found that Ms. Abbott's asymptomatic HIV substantially limited the major life activity of reproduction. The Court concluded that the risk of transmitting the disease to a fetus or sexual partner constitutes a limitation on the ability to reproduce.

Thus, the *Bragdon* Court indicated that limitations external to the disabled individual may be taken into consideration. The Court also made clear that the impairment need not completely prevent the major life activity. In this case, the 8–25 percent risk of HIV transmission to a fetus was substantial enough.

The Court considered whether the "substantial" inquiry should take into consideration personal choices as well as objective limitations. Because of the divisions within the majority, the Court did not provide a clear answer. The Court noted that Ms. Abbott had testified that the risk of transmission controlled her decision not to have a child, thus implying that the decision might have turned out differently if she had made the decision for other reasons or if she had chosen to ignore the risk and have a child. However, the majority drew back from giving dispositive weight to the personal choice factor, stating that "in the end, the disability definition does not turn on personal choice."

However, in a subsequent series of cases interpreting the definition of disability, the U.S. Supreme Court has severely restricted the scope of the statute's protection. The Supreme Court imposed significant restrictions in *Sutton v. United Air Lines, Inc.* and its companion cases, *Albertson's Inc. v. Kirkingburg,* and *Murphy v. United Parcel Service, Inc.*

In *Sutton,* twin sisters had vision worse than 20/200 in both eyes, but corrective lenses gave them 20/20 vision. United rejected them for positions as pilots based on a company requirement that pilots must have uncorrected vision of at least 20/100. In *Albertson's,* Mr. Kirkingburg was a truck driver who was blind in one eye. When the company discovered that he did not meet a federal vision guideline, it fired him without exploring the possibility of a waiver of the federal guideline. In *Murphy,* the plaintiff was a mechanic with high blood pressure that was near normal when he took medication. His job required him to drive commercial vehicles, and he was fired because the employer believed his high blood pressure would not meet a federal requirement.

Together, this trilogy of cases raised the issue of whether mitigating measures should be taken into consideration when assessing whether a person's impairment is substantially limiting. Mitigating measures are measures, such as medication, equipment, or internal coping mechanisms, that reduce the effects of an impairment. The Supreme Court made clear that, when judging whether an individual is substantially limited for purposes of ADA protection, the individual's mitigating measures must be considered.

Thus, the Sutton sisters are not covered by the ADA because their eyeglasses improve their vision to 20/20. Mr. Murphy is not protected because, when medicated, his high blood pressure does not prevent him from functioning normally. Mr. Kirkingburg may not be protected, despite having vision in only one eye, because his brain has developed subconscious adjustments to compensate for reduced depth perception. The Court made clear that the side effects of medications and other mitigating measures should also be taken into account and could weigh in favor of finding a substantial limitation.

The Court relied on three parts of the statute to support its conclusion: (1) the fact that the statute is written in the present indicative verb tense ("limits"), thus "requiring that a person be presently—not potentially or hypothetically—substantially limited"; (2) the requirement of an individualized inquiry focusing on the actual effects on the particular individual, rather than general or speculative effects; and (3) the statute's findings stating that there were approximately 43 million people with disabilities in the United States and the Court's belief that covering everyone who wears glasses would far exceed that number. The Court's conclusion rejected the opposite analysis adopted by the U.S. Department of Justice and the Equal Employment Opportunity Commission and supported by the ADA's legislative history.

The Court's approach in the *Sutton* trilogy demonstrates a particular view of disability and discrimination protections. The Court views people with disabilities as fundamentally different from the general population, rather than as part of the spectrum of ability levels within society. The Court treats disability rights protections not as a check on unfairness, justified by a history of prejudice, but as a type of affirmative action or charity intended only for a small group of individuals whose disabilities set them apart from the Court's view of the general population.

The Court's analysis will prevent individuals with minor impairments from receiving accommodations, such as equipment or policy changes, in the workplace. It will allow a defendant to refuse to hire an individual solely because of his or her impairment, such as diabetes, but escape liability by arguing that the impairment does not arise to the level of a disability because the individual takes medication. It creates a gap in which individuals are considered (quite possibly unfairly) too impaired to work but not impaired enough to be protected from discrimination.

As a result of the analysis in the *Sutton* trilogy, courts are frequently called on to analyze whether a plaintiff's impairment significantly restricts him or her from engaging in a major life activity. Because the plaintiff bears the burden of proof on this issue, impairments that respond to medication, such as diabetes, depression, and epilepsy, are difficult to establish as disabilities, often being ruled out on summary judgment without reaching the merits of the case. However, mitigated impairments still may be "regarded as" disabilities, and entitled to coverage under another prong of the ADA definition of disability.

Major Life Activity

To be covered under the ADA, a person's impairment must substantially limit one or more major life activities. Major life activities include "functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working." The Supreme Court in *Bragdon v. Abbott* provided that major life activities are not restricted to those that have "a public, economic, or daily character." Thus, purely personal activities, such as reproduction, can be major life activities. However, the activity must be of "comparative importance." In *Toyota Motor Mfg., Kentucky, Inc. v. Williams,* the Supreme Court emphasized the need to assess work-related and non-work-related activities in determining whether a limitation is substantial.

In *Toyota,* the plaintiff, Ms. Williams, had carpal tunnel syndrome, which prevented her from lifting more than 20 pounds, working with her arms raised, and doing repetitive wrist or elbow movements. She worked doing paint inspection and assembly inspection at a Toyota factory. Toyota added body auditing and surface repair to Williams's job. To do these tasks, Williams had to hold her arms at shoulder height for several hours at a time. Because her carpal tunnel syndrome bothered her, she requested to be reassigned to do only paint inspection and assembly inspection. Toyota refused. Williams was, therefore, placed under a no-work restriction and fired.

In that case, the Court addressed the boundaries of the major life activity of performing manual tasks. A unanimous Court found that major life activities are those "activities that are of central importance to most people's daily life." The Court went on to decide that performing manual tasks could be a major life activity only if the tasks included were centrally important to most people's daily lives. The Court recognized that "the manual tasks unique to any particular job are not necessarily important parts of most people's lives." Instead, "household chores, bathing, and brushing one's teeth are among the types of manual tasks of central importance to people's daily lives."

The *Toyota* Court, therefore, required a weighing of the objectively important manual tasks Ms. Williams could and could not do. No special weight or emphasis is to be placed on whether the impairment actually affects the job from which the plaintiff is being excluded. While the *Toyota* decision is arguably limited to the major activity of performing manual tasks, some courts that have addressed the issue have applied the requirement of "central importance to most people's daily lives" to other types of major life activities as well.

Direct Threat to Self

The U.S. Supreme Court has narrowed the protection of the ADA by excluding from coverage anyone whose disability would be aggravated by the job or activity in which they seek to participate. Thus, in

Chevron v. Echazabal, Mr. Echazabal was denied employment by Chevron because Chevron believed the job would exacerbate his hepatitis. Although the statute only allows employers to exclude disabled employees who pose a direct threat to the health or safety of others, the Court ruled that Title I, as interpreted by the Equal Employment Opportunity Commission, allows employers to exclude qualified people with disabilities from the workplace because they pose a direct threat of harm solely to themselves. Therefore, people whose disabilities do not prevent them from doing the job and do not pose any risk to other employees or customers may be excluded from jobs because the job might aggravate their disabilities. Disability advocates oppose this approach as allowing paternalistic attitudes of employers to override their own choices.

LIMITATIONS ON RIGHTS CONFERRED

The Supreme Court has not only narrowly interpreted the size of the class of individuals protected by the ADA, it also has interpreted the scope of the rights conferred by the act narrowly. In general, Title I does not require an employer to violate legitimate seniority provisions to accommodate an employee with a disability. The Supreme Court, in *U.S. Airways v. Barnett,* held such an accommodation to be presumed unreasonable where the seniority policy or collective bargaining agreement contains bona fide seniority provisions. The Court held that reassignment to another job in direct violation of a company seniority system is unreasonable as a matter of law, absent a special showing by plaintiff to the contrary.

A showing that reassignment would violate the rules of a seniority system therefore typically warrants summary judgment for the employer, "unless there is more." According to the Court, the plaintiff bears the burden of showing that special circumstances demonstrate the assignment is reasonable. Once the plaintiff has made this showing, the employer then must show evidence of case-specific circumstances that demonstrate undue hardship.

In *Hernandez v. Hughes Missile Systems Co.,* the plaintiff worked as a technician for Hughes. During his employment, he was addicted to drugs and alcohol, and he eventually tested positive for cocaine. The plaintiff was given the option to resign in lieu of termination, which he chose to do. Two years later, the plaintiff applied to be rehired with Hughes, attaching a letter from his counselor to his application. His counselor indicated that Hernandez had been attending Alcoholics Anonymous and staying sober. Hughes declined to rehire the plaintiff based on an unwritten policy of not rehiring former employees whose employment had ended due to termination or resignation in lieu of termination.

The Ninth Circuit Court of Appeals had found this facially neutral policy could be discriminatory if Hughes regarded the plaintiff as being disabled—by virtue of being a previous drug and alcohol user—at the time it failed to rehire him. The appeals court applied a disparate impact analysis to the plaintiff's claim, finding that the facially neutral no-rehire policy violated the ADA because it excluded former drug addicts based on their disabilities. The Supreme Court used this case as an opportunity to focus on a distinction between disparate treatment and disparate impact theories of disability discrimination, a distinction that had not played a large role in previous disability rights case law. A disparate impact claim challenges a facially neutral rule that has an undue effect on a protected population. A disparate treatment claim challenges a rule that treats people with disabilities differently from nondisabled people. The Supreme Court found that Hernandez's argument that Hughes's policy was discriminatory toward former drug addicts was a claim of "disparate impact," rather than a claim of disparate treatment. However, because Mr. Hernandez had not specified such a claim in his complaint, he was precluded from relying on disparate impact as a basis for liability. This approach requires courts and claimants to be specific about the bases for ADA claims, at the risk of losing them.

LIMITATIONS ON ENTITIES COVERED BY THE LAW

In *Board of Trustees of the University of Alabama v. Garrett,* the Supreme Court held that an individual state is immune, pursuant to the Eleventh Amendment to the U.S. Constitution, to suits for money damages under the employment provisions of the ADA. The

Court's reasoning in *Garrett* can be summarized as follows: To abrogate the states' Eleventh Amendment sovereign immunity pursuant to Section 5 of the Fourteenth Amendment, Congress needed to find sufficient proof of a pattern of unconstitutional discrimination against people with disabilities in the area of state employment. The unconstitutionality of this state behavior must be judged by a rational basis standard, because people with disabilities do not receive heightened scrutiny under the Equal Protection Clause. The Court held that Congress failed to meet the requisite standard of proof and that the means it employed to remedy ADA violations were not a congruent and proportional remedy to the harms it did find.

In *Tennessee v. Lane*, the Court faced the issue of whether states are immune from suits for money damages under Title II of the ADA. The plaintiff in *Lane* sued the state of Tennessee for failure to make a state courthouse accessible. The Court held that because access to courts is a "fundamental" constitutional right under the Due Process Clause, Congress validly abrogated states' sovereign immunity insofar as Title II applies to this category of claims. The Court's decision was a narrow one, and left unclear whether states can be sued for damages for ADA violations of other fundamental rights or in cases that do not involve fundamental rights.

There has been a separate question regarding the application of ADA Title III to foreign-flagged cruise ships that enter U.S. waters. The courts of appeals have split on the issue. In *Stevens v. Premier Cruises, Inc.*, the Eleventh Circuit Court of Appeals held that Title III applies to those aspects of cruise ships that qualify as public accommodations in themselves (e.g., lodging, restaurants, shops, and spas), at least while the ships are in domestic waters. The Eleventh Circuit found that foreign-flagged ships were not, in themselves, extraterritorial when they were in U.S. waters. The Fifth Circuit Court of Appeals disagreed, and in *Spector v. Norwegian Cruise Line Ltd.* applied a presumption against extraterritoriality absent a clear expression of intent by Congress. The Fifth Circuit believed that Title III enforcement in U.S. waters would necessarily result in extraterritoriality, because the architectural changes would be permanent and would be carried into foreign waters by the ships. The Fifth Circuit relied on *EEOC v. Arabian American Oil Co.*, in which the Supreme Court held that Title VII of the Civil Rights Act does not apply to American employees of American companies abroad. The Supreme Court granted *certiorari* to review the question, and a decision is expected in mid-2005.

—Eve Hill, Charles D. Siegal, Michael Waterstone, and Peter Blanck

See also Americans with Disabilities Act of 1990 (United States).

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ANTIPSYCHIATRY MOVEMENT

The antipsychiatry movement is lacking a clear definition, and the name itself was not totally accepted by its supporters. Nonetheless, one could say that it is characterized by its diversity, both theoretical and geographic. The effort to offer a synthetic, global image risks reducing this important dimension. Developed in Great Britain, it spread to several European countries, including Italy, and also had proponents in the United States. The movement was built up around forceful personalities from the psychiatric profession, who elaborated an important critique both of the ideas at the heart both of theories of the mind and of associated practices. Its exponents have drawn on contributions from outside the profession, in particular from philosophy, and social criticism, the latter deriving in part from the context of the political and social confrontations of the 1960s. Their philosophical inspiration is based as much on existentialism as on phenomenology, Marxism, and certain libertarian currents.

The physicians D. Cooper, R. Laing, F. Basaglia, and J. Foudraine have by and large challenged the validity, even the necessity, of existing institutions for treatment of psychiatric disorders. They fault these institutions for their violence against patients, for example, through the use of electroshock treatments. They also blame them for being the more-or-less voluntary instruments of social repression, in which the sick person is the exemplary victim. Psychiatrists of the antipsychiatry movement react against the excesses of the old hereditary determinism and the nosography that had become a finality rather than a stage in the understanding of the patient's suffering. The various exponents of the movement have not limited their criticism to the notions and concepts at the heart of psychiatric reasoning; they have been equally active in the sphere of praxis. Kingsley Hall in Great Britain, Trieste with the Italian Basaglia, and the Bonneuil Center in France represent some of the efforts to create real alternatives to the psychiatric hospital and have quickly become sites of pilgrimage for caregivers and intellectuals, who have placed a great deal of hope in the realization of these alternatives.

But the critical spirit of antipsychiatry practitioners and the hope that it raised have not been widely diffused. The antipsychiatry movement has remained a collection of individuals rather than a true school of treatment. Its probable legacy is, then, difficult to assess. On the one hand, the radical nature of its critique has engendered lively resistance. Without necessarily associating antipsychiatry with the left-leaning political and intellectual movements of the 1960s and 1970s, it must be stated that the psychiatric community has, on the whole, not been favorably disposed toward antipsychiatry. It has interpreted the antipsychiatry project as a denial of mental illness, which is a considerable exaggeration. On the other hand, antipsychiatry has renewed the critique of a medical discipline that, by the admission of its own representatives, cannot meet its own costs. Nonetheless, such criticisms have necessarily been generated from a common base: the utility and necessity of a science of the human psyche that produces facts and norms. The most fruitful lesson of antipsychiatry is doubtless to have reminded us that psychiatric knowledge is a tributary in the link between the production of medical facts and social norms. From this perspective, the Italian law on mental health inspired by Basaglia and passed in 1978 bears witness to the way in which a society can renew its relationship with exclusion and alterity. This is what antipsychiatry, however awkwardly but sincerely, wished to point out.

—Jean-Christophe Coffin

See also Mental Illness; Psychiatry.

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ANTISOCIAL PERSONALITY DISORDER

Antisocial personality disorder (APD) is characterized by a pervasive pattern of disregard for the feelings of others often accompanied by violation of the rights of others through negligence or overt actions. This disorder is believed to occur in 3 percent of adult males and 1 percent of women. In the past, this disorder was often called "psychopathic" or "sociopathic," though these terms are misleading as in the past they have been identified too closely with serial killers and other extreme and violent forms of this disorder. While it has a lifelong course, many patients with this disorder "burn out" in later life and become less problematic.

These behaviors usually begin in childhood and are often marked by early problems with the law. The most common childhood diagnosis is conduct disorder. People with APD usually lack empathy and often do not have the capacity to engage in close relationships. They may experience odd beliefs and behaviors as well as distorted and paranoid thinking. Such individuals have great difficulty conforming to social norms and rules, making it very difficult for them to maintain employment and function within a family. Although individuals with APD are most commonly seen as a problem to society, they are also disabled. Many individuals with APD engage in high-risk, novelty-seeking behavior often associated with substance use. Because of these behaviors, they are much more likely to die prematurely or have morbidity associated with disease, vehicular accidents, and homicide or suicide attempts.

—Joseph A. Flaherty

See also Psychiatric Disorders.

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▣ ANXIETY DISORDERS

Anxiety is an innate emotion and an adaptive mechanism that signals a potentially harmful internal or external change and enables us to avoid harm. When anxiety occurs for seemingly no reason, or in an exaggerated manner, to relatively innocuous stimuli and disrupts a person's life, an anxiety disorder (AD) is diagnosed. ADs are the most common psychiatric disorders in the world. Despite effective treatments, most ADs are not diagnosed or treated adequately. ADs are often chronic and disabling conditions associated with enormous emotional and monetary costs. Surprisingly, very little research has been done on the quality of life, functional impairment, and disability associated with ADs.

DISABILITY ASSOCIATED WITH ANXIETY DISORDERS

People with ADs experience significant emotional distress due to anxiety symptoms associated with an abnormally increased expectation of harm and overestimation of danger. This leads to a pattern of progressive avoidance of situations that may trigger symptoms, which, over time, envelops all aspects of life. They have an increased risk of developing depression, substance abuse, suicidal thoughts, and an excessive use of medical services. Anxiety also complicates the manifestation and treatment of other illnesses such as schizophrenia, depression, and heart disease. Severe ADs can be as disabling as other disorders associated with increased disability such as heart disease and depression. The seriousness and public health relevance of ADs is highlighted by a U.S. study that estimated the annual cost (for 1990) associated with ADs, to be $42 billion, accounting for almost a third of costs due to all mental disorders. More than 50 percent of those costs resulted from repeated use of nonpsychiatric health services.

Specific Anxiety Disorders

Panic Disorder

Panic disorder (PD) is characterized by sudden, sometimes spontaneous attacks of terrifying anxiety accompanied by mental and bodily symptoms such as the experience of terror, heart palpitations, and sweating. Fear of the attacks themselves generates a pattern of avoidance that can severely constrict the person's life. During attacks, fear that the symptoms may signal a heart attack, stroke, or other medical problem leads to repeated emergency room visits and expensive workups. People with PD report poor emotional and physical health and significant impairment of family life, and they have increased work absenteeism and decreased productivity. They are more likely to be financially dependent, attempt suicide, and have extremely high rates of using medical care compared to people without PD. PD patients are equally or more impaired on ratings of mental health and role functioning as people with depression or diabetes. They have higher rates of other ADs and depression, the presence of which increases the severity of the disability.

Social Anxiety Disorder and Specific Phobias

Social anxiety disorder (SAD) typically develops in adolescence, is more common in women, and usually runs a chronic course. SAD and phobias involve an exaggerated, irrational fear of usually nonthreatening objects or situations. Symptoms of anticipatory anxiety, distress when in the presence of the feared object or situation, and active avoidance of triggering situations are characteristic. SAD is often accompanied by depression and a higher risk of alcohol abuse. Persons with SAD are more likely to rate themselves as low functioning, to be impaired in their social relationships, and have a specifically increased risk of dropping out of school and college. They are more likely to have lower incomes, greater rates of unemployment, and financial dependency compared to those without SAD. Persons with SAD report significant subjective distress comparable to other ADs (such as PD). Even subthreshold SAD symptoms have been shown to be associated with significant disability, which increases with concurrent depression.

Generalized Anxiety Disorder

People with generalized anxiety disorder (GAD) have persistent worry and anxiety symptoms for at least a six-month period. GAD affects women more than men. Prevalence rates are higher in midlife, and it tends to run a chronic course. GAD is often accompanied by other disorders such as depression, PD, SAD, and substance abuse. Indices of disability in GAD such as impairment in social and role functioning and reduced work productivity have been reported to be comparable in severity with those for major depressive disorder. GAD is more prevalent in primary care patients compared to the general population and possibly the most common AD in this group. GAD patients in primary care have worse emotional and physical health perceptions than those with other ADs, increased unexplained physical symptoms, and high rates of use of medical care. People with GAD have also been shown to have significantly more impairment in social and role function compared to medical disorders such as diabetes and congestive heart failure, despite less physical impairment. The presence of depression (which is common), and other conditions, increases the burden of disability as well as economic costs (due to absenteeism, increased health care use, and hospitalizations).

Posttraumatic Stress Disorder

Persons exposed to a life-threatening trauma (sexual abuse, combat, natural disasters) may, as a sequel, have troubling symptoms including recurrent intrusive thoughts and dreams of the trauma, abnormally increased alertness and anxiety, and emotional numbing, as well as avoidance of situations that remind them of their trauma. Posttraumatic stress disorder (PTSD) is highly prevalent, tends to run a chronic course, and is often associated with other anxiety disorders, depression, and substance abuse. Patients have significant problems with anger and trust, leading to difficulty in interpersonal relationships. Follow-up studies of PTSD in war veterans reveal significantly diminished subjective well-being as well as increased physical limitations, unemployment, and increased work absenteeism and early medical retirement in firefighters. Veterans with war-related PTSD have high rates of health complaints, medical conditions, and health care use. Similar impairments of subjective distress, poor physical and emotional health, and impaired social and role functioning are also experienced by nonveteran PTSD patients (e.g., rape victims). PTSD often co-occurs with chronic pain and other medical conditions (such as HIV) and is associated with intensified pain, greater disability, and worse medical outcomes. PTSD is associated with higher rates of suicide attempts compared to other ADs and the general population.

Obsessive-Compulsive Disorder

Obsessive-compulsive disorder (OCD) is characterized by the presence of repetitive, highly intrusive, anxiety-provoking thoughts and images known as obsessions, leading to mental and motor compulsions (repetitive ritualized thoughts or acts) to reduce the anxiety. People with OCD often spend several hours a day engaged in compulsions, to the exclusion of normal life activities. OCD usually manifests in children or young adults, tends to run a chronic waxing-and-waning course, and is associated with significant disability in many life areas. Many OCD patients report low self-esteem, tend to seek help very late, have an increased chance of being unmarried, and have high rates of major depression during their lifetime. People with severe OCD have seriously impaired independent living skills and social functioning, and they tend to be financially dependent, similar to people with schizophrenia. OCD is one of the most disabling (10th) of all medical illnesses in the world according to a World Health Organization study. Family members of the patient are often caught up in the compulsions, which reduce quality of life for the entire family and is a significant obstacle to treatment success.

ASSESSMENT, ADVOCACY, AND LEGISLATION

ADs are clearly and severely disabling, but surprisingly, assessment of functional disability in persons with anxiety and depression in primary care and specialty clinics is still not routine practice. Specifically targeting functional gains rather than just symptom reduction with treatments could greatly improve functional outcomes. Routine use of simple validated rating scales can objectively document functional impairment, aid in evaluating the true efficacy of treatments, and assist patients in their application for disability benefits or appropriate workplace accommodations. This is extremely relevant to persons with ADs, who often experience shame, ridicule, and stigmatization. The Americans with Disabilities Act (ADA) prohibits discrimination against an individual with a mental or physical disability in employment and other life areas and is of great potential value in efforts to improve functional capacities and reduce stigma of those with ADs. However, actual application of this legislation to patients with ADs is far from optimal. Though participation in family support groups has not been systematically studied, clinical observations suggest that such groups could provide useful information and support to people with ADs and their families.

THE EFFECTS OF TREATMENT

Several options for treating people with ADs exist, including cognitive-behavioral therapy and medications. Obstacles to treatment include frequent failure of the health system to detect disorders and the shame, fear, and stigma that often accompany diagnoses. Even when treated, many patients are left with residual symptoms and disability. However, there is also clear evidence that both effective psychotherapeutic and medical treatment can improve personal and occupational functioning, raise quality of life, and reduce unnecessary medical use costs in most ADs.

—Brian Martis

See also Behavior Therapy; Obsessive-Compulsive Disorder; Panic Disorder; Posttraumatic Stress Disorder; Psychiatric Disorders.

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APHASIA

Aphasia is an acquired disorder of linguistic processing that disturbs translating thoughts into language. Aphasia does not arise from loss of memory for words as associated with dementia, or loss of organs of speech production as occurs after laryngectomy or muscles weakened by motor neuron diseases (e.g., ALS). All patients with aphasia suffer from the inability to precisely name objects on confrontation. Aphasia disturbs the syntax of language, the rules of organizing language, lexicon, and the meaning of the sounds.

Aphasia can be caused by stroke, head trauma, and primary or secondary brain tumors that destroy or disconnect portions of the speech-related centers of persons that are located in the left hemisphere of almost 90 percent of all humans. Two-thirds of left-handed persons have speech facility localized to their left cerebral hemisphere.

Nonfluent aphasia causes decreased rate of word production. Broca's aphasia causes mispronunciation, decreased fluency, loss of grammatical structure, and inability to repeat verbatim phrases that contain conjunctive, or conditional, words. These patients retain understanding and appropriate speech content and are angered by inability to communicate. The lesions of Broca's aphasia involves Brodmann's areas 44, 45, and 46, but also areas 8, 9, 10. (See an illustration of Brodmann's areas online at http://spot.colorado.edu/~dubin/talks/brodmann/brodmann.html.) Transcortical nonfluent aphasia is diagnosed when patients can repeat, but have impaired ability to name and to speak fluently. The lesion for this disorder lies in the frontal lobe of the speech-dominant hemisphere anterior to the locus for Broca's aphasia.

The fluent aphasias include Wernicke's and transcortical fluent aphasia. Persons speaking fluently but displaying faulty repetition and loss of meaningful content, who are unable to understand written or spoken words and unaware of meaningless utterances, are diagnosed with Wernicke's aphasia. Damage to posterior portions of left auditory association cortex (Brodman's area 22) and Brodman's areas 37, 39, and 40 produces Wernicke's aphasia. Persons repeating accurately but speaking or reading out loud with paraphrastic words, due to erroneous substitution of a letter or a concept, are diagnosed with transcortical fluent (sensory) aphasia.

Conduction aphasia (CA) is distinguished from other aphasias by inability to repeat accurately, intrusion of paraphrastic words, and normal fluency and understanding. CA is caused by damage to area 40, the supramarginal gyrus and the left auditory cortices (areas 41 and 42).

Global aphasia patients manifest nearly complete loss of ability to comprehend language and formulate speech, with right hemiparesis. Damage to the terminal branches of the left middle cerebral artery produces this disorder, or multifocal infarctions from emboli can damage Wernicke's and Broca's areas, sparing intervening basal ganglia and internal capsule. Speech output is greatly reduced due to damage to the head of the caudate nucleus and subjacent internal capsule. Loss of speech function cannot be attributed solely to an isolated area of the brain, but rather disconnection of working units within the brain.

Recovery from global aphasia depends on permanence of hemiparesis. If there is damage to Broca's and Wernicke's areas and sparing of the intervening tissue, recovery from global aphasia can occur. Treatment directed at the physiological defect will hasten recovery. Melodic intonation therapy ameliorates patients with loss of word production; visual communication therapy improves global and Wernicke aphasia.

—Edward J. Fine

See also Apraxia; Paul Broca; Speech and Language Pathology; Traumatic Brain Injury.

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APRAXIA

Apraxia has been defined as a disorder of voluntary actions that can neither be referred to as elementary motor disorders, such as paresis or tremor, nor general cognitive problems, such as dementia or aphasia. Symptoms can be observed in a variety of settings, from traumatic brain injuries to cerebral infections to congenital disorders. Notions about apraxia have been important in our developing understanding of the workings of the human brain.

The concept of apraxia arose from the debate over cerebral localization of function in the late nineteenth century. In particular, it was linked to another condition, aphasia, a complete or incomplete inability to comprehend or use language (often because of brain injury, infection, or stroke). A central issue of this debate was whether language is an isolated function of the human mind, the neural substrate of which can be localized within the brain. Opponents of this compartmentalization of the human mind into localizable functions emphasized that aphasia is regularly accompanied by disturbances of nonverbal intellectual capacities. The German psychiatrist Carl Maria Finkelnburg observed that communicative gestures of aphasic patients are frequently clumsy and incomprehensible. In a very influential paper published in 1870, he posited that they suffer from a general "asymbolia" preventing the use and comprehension of any communicative signs. Ten years later, the linguist Heymann Steinthal used the term *apraxia* to denote the faulty use of everyday life objects, such as a fork and knife or a penholder, by patients with aphasia. He considered their errors an "augmentation" of aphasia.

Modern theories of apraxia have been shaped in the early twentieth century by the German psychiatrist Hugo Karl Liepmann. By systematic group studies, he confirmed the frequent occurrence of disturbed communicative gestures and aberrant use of tools and objects in patients with left-hemisphere brain damage and aphasia. To this confirmation, he added the new observation that these patients commit errors also when imitating gestures, an observation central to his conception of apraxia. He reasoned that in imitation the model of the intended movement is unequivocally provided by the demonstration and that errors thus testify to insufficient motor execution. He concluded that apraxia is a disorder of motor control that frequently accompanies aphasia but is itself a distinct and localizable symptom of circumscribed brain damage rather than indicating the augmentation of aphasia to general mental deterioration. For explaining the frequent co-occurrence of aphasia and apraxia after left-hemisphere brain damage, Liepmann speculated that the left hemisphere has a dominance for motor control beyond and perhaps above its dominance for speech.

The dependence of apraxia on left-hemisphere damage has since then been largely, although not completely, confirmed. Whereas the production of communicative gestures on command seems to be very tightly bound to left-hemisphere integrity, imitation of gestures and the use of tools and objects may be sensitive to right-hemisphere brain damage too depending on the exact nature of the task used to assess them. Liepmann's proposal that apraxia is a disorder of motor control fares less well in the light of contemporary research. His idea that faulty imitation implies deficient motor execution of a correctly conceived gesture was challenged by studies showing that patients who cannot imitate gestures have similar difficulties when asked to replicate them on a manikin or to select them from an array of pictures, and by reports of single patients in whom severely defective imitation of gestures contrasted with flawless execution of communicative gestures on command.

After more than 100 years of research, the existence of apraxia in many patients with left-hemisphere brain damage is firmly established, but its nature and its relationship to aphasia and to hemisphere dominance remain subject to debate and inquiry.

—Georg Goldenberg

See also Aphasia; Speech and Language Pathology; Traumatic Brain Injury.

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ARATA

See Australian Rehabilitation and Assistive Technology Association (ARATA)

ARCHAEOLOGY

The consideration of disability in archaeology is a recent development. It has emerged in response to challenges to the discipline, particularly to those critiques that question archaeology’s relevance in the contemporary world. Archaeological reactions to these concerns have included the development of both public archaeologies and community-based archaeologies. These ways of doing archaeology represent some archaeologists’ attempts to frame archaeology outside its traditional niche as a private, professional, and academic pursuit. This is accomplished through collaborative projects formulated through the cooperation of archaeologists and communities from outside the discipline. Through these community-based methods, archaeologists hope to increase diverse communities’ engagement with the past.

Public and community-based strategies ultimately allow archaeologists to forge connections with audiences and participants traditionally alienated from professional and academic circles. One such group of audiences and participants includes persons with disabilities. To create relationships with new audiences and participants, including persons with disabilities, archaeologists must address research questions related to the experiences and interests of these individuals. This has been enacted in two distinct ways.

First, archaeologists strive to understand disability in past human populations by placing disability at the center of their research questions. In so doing, they attempt to develop knowledge that is relevant to individuals concerned with experiences of disability across both time and place. To interpret disability in the context of past peoples, archaeologists make interpretations based on the consideration of various types of data. These data include, but are not limited to, the remains of structures, material objects, and human remains.

Archaeologists have traditionally based their interpretations of disability on medical models. Owing to the influence of larger sociopolitical movements, such as the disability movement, social models are becoming more common in archaeological interpretations related to disability. This trend builds on the use of social models to interpret and understand how humans have both constructed and experienced ideologies of gender, sexuality, age, and race across time and place.

Second, archaeologists have begun to recognize how ideas about ability, disability, and the body are connected with the practice of archaeology. This has occurred as a result of sociopolitical movements that have raised awareness about disability across communities and experiences. Media institutions present archaeology as a very physical pursuit. Moreover, these institutions portray archaeologists as nondisabled individuals. For instance, images of archaeologists with disabilities rarely grace the covers of glossy science magazines or show up on prime-time television specials. As a result of observations such as these, archaeologists have begun to develop research that looks at the ways in which ideas about ability and disability affect the accessibility of archaeology and archaeological programming. Some current research addresses these issues by focusing on the involvement or lack of involvement of people with disabilities in archaeology. In addition, following work that explores the theoretical issues connected to these relationships, more and more archaeologists are attempting to create practical, grounded solutions by archaeological programming that is accessible to a diverse range of embodiments and experiences.

—Meredith A. Fraser

See also History of Disability: Pleistocene Period.

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ARISTOTLE (384–322 BCE)

Greek philosopher and scientist

Student of Plato, tutor to Alexander the Great, Aristotle is one of the most influential ancient figures in Western thought. A scientist and philosopher, Aristotle was interested in categorizing and systematizing all phenomena. Aristotle is important to disability studies for several reasons. His writings rest on careful observation; some observations are strikingly modern; others, such as his speculations in *Generation of Animals* that a female is technically a deformed male or that children sometimes inherit from their parents such characteristics as scars and brands, seem quaint at best. Aristotle considers the ideal state and proposes several highly regulated components of human organization in the *Politics*. These regulations, within a detailed caste system, include his recommendation for the elimination of deformed infants. "As to exposing or rearing the children born, let there be a law that no deformed child shall be reared" (1335b). Ironically, according to later biographers, Aristotle's own physical characteristics were far from perfect. In addition to being bald and having thin legs, he lisped. Paul Cartledge (2000:199–200) provided a succinct overview of Aristotle's life in *The Greeks: Crucible of Civilization*.

—M. Lynn Rose

See also Euthanasia.

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ARNOLD, IVAN KARLOVICH (1805–1891)

Russian school administrator

Ivan Karlovich Arnold, who was deaf, was the founder of the first Moscow school for the deaf (1860). The school was later named after him—Arnoldo-Tretyakov School. He was educated in the St. Petersburg School for the Deaf and then in Berlin, Germany. He graduated from the Art Academy in Dresden, Germany. Arnold was the director of the Moscow School for the Deaf from 1860 to 1866.

—Anna Komarova and Victor Palenny

See also Deaf, History of the.

ART THERAPY

Art therapies allow individuals to express themselves through creative means. Often the process of making art is the core of the process of art therapy: Through the work, individuals can experience themselves as empowered, valued, able to achieve, and able to deal with a task. Art can articulate deep feelings and can bring unconscious issues to the fore. Group art therapy approaches can also foster sociality and find forms of being with others not usually sanctioned by everyday life.

Dance, music, drama, drawing, photography, sculpture, creative writing—most art practices have specialized art therapy approaches associated with them. One significant difference between "mainstream" art practices and art therapy is the status of the final product: Concepts such as mastery, control, and commercial value are either not important or much less important than self-expression. Also, public consumption is not necessarily an aim of art therapy. Public display can have therapeutic effects on individuals, in particular, people who have seen themselves as being devalued, invalid, for a long time, but the processes and products of art therapy are also private and often remain so.

Against both mainstream practice and art therapy approaches stands community or participatory art practice. Here, training is also often unimportant, and process is often stressed over product as a value in its own right. Different from art therapy, though, community and participatory practices often stress the community as the focus of the work practices. Doing something together and finding ways of expressing a shared vision become important concepts in this art practice, and public display is often seen as effective in community transformations.

Within disability culture, art therapies have a dual standing. On the one hand, art therapy approaches can be useful in allowing people to work through the social stigma or personal problems associated with impairment and disability issues. Art therapy is also often the first place where institutionalized people encounter the alternative expressive means of art, enabling them to find new perspectives on their life experiences.

On the other hand, the potential emphasis of art therapies on the individual as the locus of intervention can be seen to hinder political processes. For many disability activists, the "problem" of disability is not the individual and his or her acceptance or adjustment, but the wider social world and its exclusionary practices. The "medical" framing of art therapy, and the professional status of art therapists, many of whom are licensed or part of professional bodies that control training, can here be seen as extensions of the oppressive regime of normalization. For this reason, many disability activists resist the wider connotations of "therapy" and instead investigate other forms of art making, both inside and outside the mainstream.

—*Petra Kuppers*

See also Dance; Drama and Performance; Music; Poetry.

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ARTHRITIS AND CARTILAGE DISEASES AND INJURIES

Musculoskeletal diseases are the most prevalent causes of chronic medical disability, due to painful and/or restricted mobility of any joints, weakness, and potentially, associated predisposition to visceral impairments. Of the diseases that have been separated from "rheumatism," this entry briefly describes osteoarthritis (OA), gout, rheumatoid arthritis (RA), ankylosing spondylitis, and juvenile polyarthritis.

OA is by far the most common arthropathy. Its actual prevalence in relation to disability has been difficult to establish because surveys have usually based the diagnosis on radiographic findings and, except in advanced cases, the correlation between the radiographic findings and symptoms of pain and/or restricted motion is poor. OA primarily is a disease of articular cartilage, but not necessarily a consequence of aging. It is not a sufficiently specific diagnosis since cartilage may deteriorate for a variety of reasons. The disease may be an isolated result of injury to the affected joint or adjacent bone, or be due to asymmetric weight bearing, as results from unequal leg length. It can be attributed to a heritable predisposition affecting only the finger joints, or be the end result of cartilage damage from RA or gout. It may be multi-articular and resemble RA. Joint infection, mainly due to tuberculosis or gonorrhea, once was an important cause, but this has become rare since the advent of effective antibiotic therapy.

Treatment of OA has continued to depend mainly on analgesics with some anti-inflammatory potency. These numerous nonsteroidal anti-inflammatory drugs (NSAIDs) have largely replaced aspirin. The principal potentially serious side effect from the older "COX-1" medications is gastrointestinal bleeding, and from the "COX-2" medications, cardiovascular injuries.

Advanced disease in individual joints is treated orthopedically. Joint replacements were first performed in the hips and now in many joints. These procedures are performed more frequently in cases of OA than RA. All require postoperative physical therapy to maximize range of motion and/or improve the strength of adjacent muscles.

Gout, which had frequently been a synonym for rheumatism in the mid-nineteenth century, was the first to be differentiated by the new science of biochemistry. While it remained uncertain how an excess of uric acid in the blood causes gout, this substance became accepted as etiologically critical. As the diagnosis became dependent on the detection of uric acid, gout became recognized less frequently, and again increased as the sensitivity of uric acid determinations improved, achieving its present level in the 1960s. Gout also was the only musculoskeletal disease for which a fairly specific and effective medication became available in the nineteenth century. While colchicine can abort acute joint inflammation, it has no effect on the production or elimination of uric acid. Thus, the development of chronic disability due to the accumulation of tophi (uric acid nodules) was not diminished. Subcutaneous tophi may be disfiguring, but usually are not disabling. However, accumulation of urate in joints causes destruction of articular cartilage as well as bone, resulting in loss of motion, contractures, cutaneous ulcers from which urate extrudes, and chronic pain. These manifestations were first ameliorated by the discovery of drugs that stimulate increased elimination of uric acid by the kidneys (probenecid in 1952 first), and a drug that inhibits the synthesis of uric acid (allopurinol in 1963).

Numerous terms were coined for both rheumatoid arthritis (RA) and osteoarthritis (OA), and, indeed, RA was called OA at one time. *Rheumatoid arthritis* was proposed in 1859 because it did not imply "any necessary relation between it and either gout or rheumatism [i.e., rheumatic fever]" (Garrod 1859:542). The first objective differentiation was made radiologically, based on excess bone formation adjacent to joints (hypertrophy) in OA and loss of bone (atrophy) in RA. This soon was followed by description of a fundamental pathologic difference: OA begins with deterioration of articular cartilage, and RA begins with inflammation of the synovial tissue that lines joints and only secondarily affects the cartilage.

The discovery of *rheumatoid factor* in the blood of patients with RA in the 1950s was hoped to overcome diagnostic uncertainties. However, it has proven to develop in no more than three-fourths of cases of RA and often only develops after clinical findings have made the diagnosis likely; furthermore, positive tests are not limited to RA. Overdependence on this test has led to many misdiagnoses. It, however, has prognostic value. The presence of rheumatoid factor tends to be associated with the eventual development of extra-articular manifestations and a more aggressive course of RA than is typical of cases that remain rheumatoid factor-negative.

The simplest of numerous sets of criteria to classify the severity of RA and response to treatment is the Steinbrocker Functional Classification:

I. Unrestricted in all activities
II. Normal activities can be performed, but with discomfort and/or some limitation of joint motions
III. Activities are limited mainly to self-care
IV. Incapacitated with little or no self-care capability

Salicylates, and soon thereafter synthetic analgesic drugs, became available about 1880, aspirin in 1898. Aspirin became accepted as the drug of choice for rheumatic fever, but pessimism prevailed for any drug therapy for RA. Physical therapy, mainly hydrotherapy and massage, was recommended with guarded hopes until the 1930s, when aspirin in larger doses became the choice for analgesia and gold salt injections to retard disease progression. Because of their potent anti-inflammatory effect, corticosteroid drugs, beginning with cortisone in 1950, were for some years believed to be the solution to the treatment of RA. However, the recognition of serious side effects with chronic use dashed this hope after a decade. These drugs are still employed in small doses in combination with other agents. The breakthrough for advanced disease began in the 1950s with orthopedic surgery: osteotomies (realignment of a joint) and insertion of prosthetic joints. In the 1980s, immunologically based therapy that endeavors to interrupt the inflammatory process before joints are seriously damaged began and is now the forefront of research.

Two-thirds of patients with RA are women, and nine-tenths of patients with pain and stiffness usually progressing from the pelvis up the vertebral column are men. Nevertheless, whether the latter is a variant of RA, rheumatoid spondylitis, or a separate disease, ankylosing spondylitis, was not resolved until the 1970s. This resulted from the discovery of a class of antigens inherited from both parents (HLA) and that specific immunologic types of these could be distinguished. The presence of some of these types appeared to predispose to the development of or resistance to certain diseases. The presence of HLA-B27 was found to be present about 12 times as frequently in cases of ankylosing spondylitis than in the general Caucasian population, but no more frequent in cases of RA. The same technique demonstrated that most cases of polyarthritis in children are not RA.

The primary therapy of ankylosing spondylitis, contrary to other arthropathies, from the 1920s to 1950s was roentgen irradiation. For unknown reasons, this had a significant analgesic effect on the inflammation of the spinal column, but not on peripheral joints. It was discontinued not because a more effective drug had been found, but because of evidence that it may induce myelogenous leukemia. Courses of physical therapy are more important in this disease than in other arthropathies. There still is no therapy to prevent adjacent vertebrae from fusing, and there is a strong tendency for anteflexion to develop. Therefore, the goal of the physiatrist is for erect posture to be maintained. A severely flexed back, even with unaffected extremity joints, can be totally disabling.

Juvenile polyarthritides occur less than 5 percent as frequently as RA. The eponym of Still's disease resulted from a description in 1897, which distinguished it from the then common disease of rheumatic fever. It remains uncertain how many diseases are included within childhood arthritis. The syndrome described by Still is the most acute, with fever and potentially multiorgan involvement, but the least common. Cases with few affected joints (*pauci-articular*) are the most frequent and most likely to undergo cessation of symptoms but most prone to ocular inflammation and permanent impairment of vision. In the third category (*oligo-articular*), many joints are affected without visceral involvement. These cases most closely resemble adult RA, but they differ in their HLA type. No doubt, a few children do develop adult RA or ankylosing spondylitis and some adults develop juvenile chronic polyarthritis. Skeletal disability depends greatly on the age of onset. The earlier the disease begins the more growth centers are likely to be affected. This may result, for example, in arrested growth of the jaw or, most often, small stature. The principal modes of treatment have until recently been physical and aspirin or NSAID because of apprehension of untoward effects from the more potent immunosuppressive agents.

—Thomas G. Benedek

See also Orthopedics; Pain; Physical Therapy.

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ASPERGER SYNDROME

HISTORY

Asperger syndrome is an eponymous neurodevelopmental disorder on the autistic spectrum, named after the Viennese pediatrician Hans Asperger (1906–1980). In 1944, he described a group of children with difficulties in affective contact, a lack of "practical intelligence," academic failure, motor clumsiness, and less frequently, obsessions or stereotypies, using the term *autistic psychopathy* (*Die Autistischen Psychopathen im Kindesalter*). The publication was largely ignored by contemporaries, appearing first in translation in 1991. In 74 of Asperger's case records, 68 percent fulfilled current criteria for Asperger syndrome while 25 percent fulfilled criteria for autism. Asperger's original descriptions were similar to those of childhood autism published in English by Leo Kanner in 1943.

EARLY LITERATURE

A number of early case descriptions have been provided for individuals who may have had Asperger syndrome, most notably in the Scottish case of Hugh Blair of Borgue. Many famous individuals may have been affected. These include L. S. Lowry, Ludwig Wittgenstein, Sir Keith Joseph, Eric Satie, Albert Einstein, and Isaac Newton.

DIAGNOSTIC CRITERIA

Asperger syndrome first appears as a clinical disorder in both the World Health Organization's International Classification of Disease (ICD-10) in 1993 and in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) in 1994.

On both the ICD and *DSM* systems, the core features of Asperger syndrome are as follows:

Impairment in social interaction

Restricted, repetitive behavior and interests

No "clinically significant" delay in language

No "clinically significant" cognitive impairment;

Does not meet criteria for other problems such as schizophrenia

Current nomenclature in the area of autism, including Asperger syndrome, is in a state of flux. Much of the published literature has used varied criteria not matching those in the current diagnostic systems. Less restrictive criteria have often been used, sometimes including those with communication problems, learning difficulties, and comorbid schizophrenia.

Physical Correlates

There are no consistently reported physical features. There are reports of excessive joint flexibility, dermatological abnormalities, and muscular dystrophy. Metabolic abnormalities, particularly of prefrontal cortical function, and of mitochondrial dysfunction are reported. No data have been collected indicating the extent of such associations.

Differential Diagnosis

DSM or ICD criteria do not clearly distinguish between Asperger syndrome and "high functioning autism." The distinction is supposedly on exclusion of clinically significant communication problems, learning delay, or schizophrenia. Autism can be diagnosed in individuals without such problems. Any difference would, therefore, need to be on the basis of factors additional to the current diagnostic criteria. Some reviews and research studies conclude there is no basis on which to differentiate.

Neuropsychological Differentiation

The neuropsychological profile in Asperger syndrome may discriminate the condition from other autistic spectrum disorders on the basis of a nonverbal learning disability (NVLD) profile. Similar differences have been reported in several studies analyzing Asperger cases. Others, however, have failed to replicate the findings across reported groups or consistently within the reported population. A subgroup of individuals with a diagnosis of Asperger syndrome shows an NVLD profile; a further subgroup does not.

—Kenneth J. Aitken

See also Autism.

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▣ ASSISTIVE TECHNOLOGY

The Technology-Related Assistance for Individuals with Disabilities Act of 1988 defined *assistive* *technology* (AT) as “any item, piece of equipment or product system, whether acquired commercially off the shelf, modified or customized, that is used to increase, maintain or improve the functional capabilities of individuals with disabilities.” Conceptually, this definition encompasses not only the device but also the applied nature of how the device is used and who uses the device. Fundamental to this definition is the concept that assistive technologies enhance the ability of a person with a disability to participate in major life activities, actions, and tasks that would be difficult or impossible to perform without technologies that are used as a consequence of the individual’s impairment-related limitations. This principle of enhanced ability includes an increased level of independent action, a reduction of time spent in activities of daily living, more choices of activities, and greater satisfaction in participating in activities. In short, the technology included under the rubric of assistive technology has to assist the user to participate in activities.

The other essential inclusion criterion for defining AT is setting the rules for who is or is not included as disabled. Who is considered disabled varies by the type and severity of impairment (mild arthritis to near total paralysis), functional capacity (reduced vision or hearing to deaf or blind), or type of activity (work tasks or personal care). Well over 50 definitions of disability are in use in the United State alone. Most of these definitions are based on the idea that the inability to do an activity is caused by the person’s physical or cognitive impairment. Recent models and classifications of disability portray disability as the outcome of interactions of people and their environments. The expression of disability changes with nature of the environment. AT devices are a part of the environment that can reduce the expression of disability. AT is used to improve building accessibility, augment communication, afford computer access, allow environmental control over electronic devices, modify homes for access, assist with personal care activities and family activities, enhance mobility, stabilize seating, and modify workplaces and schools. The impact AT has on individuals’ ability to interact effectively and independently in their environment has been established, and millions of people with disabilities rely on numerous AT devices daily.

The International Classification of Functioning, Disability, and Health (ICF) uses *disability* as a term that covers problems in organ structures and functioning, activity limitations, and restriction in participation. Improvement in any of these three components reduces disability and improves function. This new ICF classification framework allows for AT to be applied to reducing an individual’s impairments, improving tasks performance in activities, and promoting full participation in major life activities. This framework is important because devices that improve structure and their functions (e.g., prosthetic legs, cochlear implants, implanted electronic control of bladder); devices that improve activity performance (e.g., voice entry, stair-climbing wheelchairs, communication boards); and environmental modifications (e.g., automatic door openers, level entrances, accessible bathroom) that reduce or eliminate restriction to participation can all fit the definition of AT.

AT SERVICES

A model for assessing the component interactions of the service delivery system has been developed to provide a framework for understanding how AT and the services often needed for acquiring AT can change performance of people with disabilities. This model, the human activity assistive technology model (HAAT), postulates four components: human, activity, assistive technology, and context. All components must be considered when selecting an AT device.

For simple, inexpensive AT, consumers require little if any help in acquiring devices. However, when the AT device is complex, costly, or paid for by a third party, the process of obtaining the device can require the help of individuals trained in providing AT services. The services needed may include evaluations for the types of AT that are needed to enhance physical, sensory, and cognitive functions; improve performance in activities; and increase participation in major life activities. The evaluation may involve an interdisciplinary team of people who have training in engineering, therapy, medicine, and device use. The introduction of AT into the life of a person with a disability requires an analysis of the existing capacities of the consumer, the settings where the AT will be used, the features included in the AT device, and the goals of the consumer and his or her family, employer, and educator.

After the AT device is selected that best fits the consumer's situation, the device is purchased. If the device is inexpensive or the consumer has the necessary funds, the acquisition is relatively straightforward. However, if other organizations provide the funds for the AT purchase (third-party payers), then the consumer may find the process difficult, lengthy, and frustrating. For example, when the AT is paid for by health insurance, the rules for what may be purchased and the forms required for reimbursement are very complex. This part of AT services requires that competent, experienced individuals assist the AT consumer in providing the information required by the reimbursement entity. For AT deemed to be medically necessary, a physician must sign and send in a letter that describes the individual's diagnosis, prognosis, and the functions that will be improved or maintained by the requested device. If the first request for reimbursement is denied, then a lengthy process of appeals ensues.

Once a device is acquired, services may be needed to fit, customize, maintain, or repair the AT device. These services are provided at durable medical equipment companies, rehabilitation facilities, or volunteer organizations. An additional important but often neglected service is the training or technical assistance provided to the consumer and his or her family in the use of the AT. For example, communication boards that allow individuals with no or poorly understood speech to make their needs and views known take a significant amount of time to learn. To offer this full array of services, people need to be trained in the wide variety of skills required to match the individual's needs and capabilities with the features of the AT.

AT CLASSIFICATION AND CHARACTERIZATION

Well over 20,000 AT devices are listed in computer databases (http://www.abledata.com/) and in sales catalogs. A device can be located using any of several strategies including product name, company, or key word, which helps when searching for a device. In the United States, the following categories are used to provide a structure for organizing AT: architectural elements, sensory elements, computers, controls, independent living, mobility, orthotics/prosthetics, recreation/leisure/sports, and modified furniture/furnishings. Each general category has a numeric code, as do the subdivisions of the categories. In Europe, AT devices used by individuals with disabilities are classified by the 2002 ISO 9999 "Technical aids for persons with disabilities—Classification and terminology." The classification uses a three-tiered hierarchical organization with the highest level describing a broad set of functions such as devices for housekeeping. The second level, subclass, includes a great degree of specificity in the use of the device (e.g., AT for meal preparation). The specific devices are classified at the third, or division, level, which could include devices such as special knives and cutting boards. These classifications allow for rapid information retrieval, tracking product inventories, and matching devices to impairment, activities, and participation.

AT devices that help people do activities can be characterized in many ways. Some devices are technologically complex, involving sophisticated materials and requiring precise operations and are referred to as *high tech*. Examples include prosthetic limbs that have joints that can move in several planes, powered mobility devices that balance on two wheels, communication devices that are programmed to output speech, and computer screen readers for graphic displays. Simple, inexpensive, and easy-to-obtain devices are commonly referred to as *low tech*. Finger extenders, large-handled eating utensils, canes, and large-print reading materials are examples of low-tech devices.

Another distinguishing characteristic is *hard technologies* and *soft technologies*. Hard technologies are tangible components that can be purchased and assembled into AT systems. This includes everything from simple mouth sticks to computers and software. Soft technologies are much harder to obtain because they are the human areas of decision making, strategy development, training, and concept formation. They may be available in one of three forms: (1) people (e.g., a teacher or therapist, effective strategies), (2) written (e.g., an instruction manual), and (3) computer (e.g., help screens). Hard technologies cannot be successful without the corresponding soft technologies, which are difficult to acquire because they are depend so much on human knowledge that is obtained slowly through formal training, experience, and textbooks.

Another distinction is between commercially available devices—those that are mass produced for the general population or for individuals with disabilities—and those that are custom made for an individual person. Often commercial products are designed according to the principles of universal design so that they are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

Some AT devices are used in many different applications across a wide range of applications (general purpose) and others are intended for a specific application (special purpose). The first type includes (1) positioning systems for body support, (2) control interfaces (e.g., keyboards, switches, and joysticks), and (3) computers. Specific applications include devices for communication, manual and powered wheelchairs, feeding devices, hearing aids, and mobility aids for persons with visual impairments. Due to the unique needs of people with disabilities in each of these areas, the assistive devices must be specifically designed to meet those needs.

An assistive device may function as an appliance or a tool. The distinction is based on whether skill is required to operate the device. If there is skill required, the device is referred to as a tool and soft technologies become important. If no skill is required, then the device functions as an appliance. Examples of appliances are eyeglasses, splints, a wheelchair seating system designed for support, and a keyguard for a computer keyboard. Since a powered wheelchair requires skill to maneuver it and success depends on the skill of the user, the wheelchair is classified as a tool. Other examples are augmentative communication devices, electronic aids to daily living (EADLs), and reading devices for individuals who are blind.

AT USERS

In 1990, more than 13.1 million Americans, about 5 percent of the population, were using AT devices to accommodate physical impairments, and 7.1 million persons, nearly 3 percent of the population, were living in homes specially adapted to accommodate impairments. The majority of persons who use AT are elderly. They primarily use low-tech devices for maintaining their capacity to do their personal care (e.g., grab bars in the bathroom, special kitchen utensils, brighter lighting, canes, and walkers). Children and young adults use a significant proportion of the devices, such as foot braces, artificial arms or hands, adapted typewriters or computers, and leg braces. By 2000, approximately 10 percent of the U.S. population (25 million people) used AT devices and/or modifications to their home, work, or school that allow them to participate in major life activities.

Several studies have reported that the most frequently used AT is mobility devices, 60 to 70 percent of all devices reported. Hearing devices, personal care devices, information technologies, and anatomical devices were reported by less than 10 percent of the people in these U.S. national surveys. The sources for payment of these devices included personal pay, health insurance, Medicare, Medicaid, vocational rehabilitation, employers, Department of Veterans Affairs, charitable organizations, and several others. The consumer most often pays for mobility devices (canes, crutches, walkers, specialized recreational wheelchairs), hearing devices, and home modifications. To offset those who pay for their own AT, deductions from earned income are allowed for most medically necessary devices, businesses that make their buildings accessible, and some modifications to vehicles. Many charitable organizations raise funds that are used to provide AT for children whose families cannot afford to pay for the devices the child needs.

High-tech devices for mobility (electric powered wheelchairs), voice recognition systems, and prosthetic limbs were most often paid for by third-party payers (e.g., private insurance, Medicare, Department of Veterans Affairs, schools, and vocational rehabilitation). Medicare and Medicaid (Centers for Medicare and Medicaid, CMS) use a list (*Coverage Issues Manual*) of devices (termed *durable medical equipment*) to guide the purchase of about $7.7 billion of medically necessarily equipment. However, third-party payers such as private insurance companies, Medicare, Medicaid, and the vocational rehabilitation system have no consistent or compatible payment formulas across geographic regions, by types of impairment or disability, or by eligibility criteria.

BENEFITS OF AT USE

With the introduction of AT, some people with disabilities can do activities without the help of family members or paid assistants, participate in parenting, improve their work productivity, avoid being institutionalized, and join in active recreational activities. Although many people with disabilities report that the use of AT greatly improves their quality of life, measurement of the change in their choice, satisfaction, self-esteem, adaptability, safety, and competence have been little studied. Several new assessments are beginning to be used to assess how individuals feel about their devices, how they use their devices, and the quality of their participation in major life activities.

The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) is a measure of satisfaction with device features and service provision. The QUEST includes a broad range of variables reflecting that user satisfaction is a multidimensional phenomenon involving three types of variables: those involving the environment, pertinent features of the person's personality, and the characteristics of the AT itself. The QUEST allows the user to determine the relative importance of the satisfaction variable. The Psychosocial Impact of Assistive Devices Scale (PIADS) is a self-report measure that provides a measure of the psychological response to using AT devices. Three components of the PIADS are adaptability, competence, and self-esteem. The PIADS has been applied to measurement of outcomes with a variety of AT devices from eyeglass and contact lens wearers to users of EADLs. The PIADS and QUEST are reliable and valid measures of the consumer perspective in conjunction with assessments of functional status.

AT USE AND DISUSE

Most of the literature on AT is focused around the issues of design; consumer preferences; use, disuse, and abandonment; and costs and policy. Phillips and Zhao (1993) surveyed more than 200 users of AT devices and identified four factors that were significantly related to the abandonment of AT devices: (1) failure of providers to take consumer opinions into account, (2) easy device procurement, (3) poor device performance, and (4) changes in consumer needs or priorities. Consumers may abandon devices when their opinion is not considered. An essential component of the assistive device delivery system is an effective process that ensures that the needs and goals of the individual are accurately identified. Easy device procurement refers to the situation in which a consumer obtains a device from a supplier without an evaluation by a professional provider. This most often occurs with simple devices such as crutches, canes, or reachers. Poor device performance may be the result of inaccurate or inappropriate expectations on the part of the user, a mismatch between consumer skills and device characteristics, or actual device failure.

AT LEGISLATION

In addition to defining AT and AT services, U.S. federal legislation influences many aspects of AT from basic research to mandating provision to providing funds for purchase. The Rehabilitation Act of 1973 (P.L. 93–112), as amended, requires that programs receiving federal funds to provide reasonable accommodations (Section 504), make electronic equipment accessible to people with disabilities (Section 508), and include AT in vocational rehabilitation plans. The Individuals with Disabilities Education Act (IDEA) of 1990 (P.L. 101–476) and 1997 (P.L. 105–17) states that a child's need for AT must be determined on a case-by-case basis, made part of the individualized education program (IEP), and paid for by the public school system. The Technology-Related Assistance for Individuals with Disabilities Act of 1988 (Technology Act) and the Assistive Technology Act of 1998 (AT Act) provide funds for state programs to support increased AT services, advocacy for AT, information on AT, and alternative financing for AT. The Americans with Disabilities Act of 1990 (ADA) (P.L. 101–336) prohibits discrimination against people with disabilities in employment, public institutions, commercial facilities, transportation, and telecommunications. The impact of the ADA on AT and AT service provision has been enormous because nearly all buildings have had to make accessible entrances, bathrooms, program areas, and parking spaces. In addition, the provision of interpreters for the deaf, Braille, and large-print materials for the blind are required for effective communication. The Telecommunications Act of 1996 (P.L. 104–104) requires the telecommunication industry to make equipment that will support transmission of information in forms accessible to people with disabilities including broadband and television program captioning.

FUTURE DIRECTIONS

Advancements in AT will occur in the technology itself, the services associated with the technology, and in the government policies and programs relative to AT. There will more widespread use of universal design, with less special-purpose AT required. People who have disabilities must continue to have access to the Internet to participate in the knowledge-based economy. This is a challenge since the Internet is becoming more and more dependent on multimedia representations involving complex graphics, animation, and audible sources of information; people who have disabilities have greater challenges in the retrieval of information. This creates barriers for those who are blind or deaf. Complicated websites that may include flashing pictures, complicated charts, and large amounts of audio and video data will be difficult for people who have learning disabilities and dyslexia to use.

AT needs to take advantage of advances in handheld, portable, and satellite-based communication and computing technologies to allow greater capability for persons with disabilities. Control interfaces that directly sense signals from the brain or nerves need to be further developed to allow greater control of devices by people with severe physical disabilities. Intelligent interfaces are required to adapt to the needs of persons with disabilities to allow greater participation in work, recreation, and self-care. Devices that can transmit messages from the brain to activate target muscles (e.g., finger, arms, feet, legs) without having to pass through the spinal cord need to move from basic research laboratories to clinical trials. Devices based on direct stimulation of the brain for those with visual and hearing loss need further development. Technology advances will also occur in materials (lighter, stronger, and more durable) used to make devices such as wheelchairs and the cases for portable electronic devices.

In the area of service delivery, community centers are needed where people with impairments can try different types of AT without first having to purchase a device. To avoid device abandonment, consumers of AT devices need a greater say in what is recommended for and provided to them and greater control over the resources to purchase AT.

In the area of government policy and programs, longitudinal studies are needed to assess the effects of AT interventions on the lives of consumers. Tax reforms are needed to reduce the cost of purchase for the individual and to encourage investment in new AT. Justification for government programs and health insurance purchase of AT needs to expand beyond medical necessity and in-home use to include activities that are important for community participation by people with impairments, including employment, recreation, education, volunteer services, and many others.

—David B. Gray and Albert M. Cook

See also Accessible Internet; Americans with Disabilities Act of 1990 (United States); Communication; Computer Technology; Educational Assistive Technology; Individuals with Disabilities Education Act of 1990 (United States); Information Technology; Mobility Aids; Rehabilitation Act of 1973 (United States).

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ASSOCIATION FOR THE ADVANCEMENT OF ASSISTIVE TECHNOLOGY IN EUROPE (AAATE)

The Association for the Advancement of Assistive Technology in Europe (AAATE) is an interdisciplinary association devoted to increasing awareness, promoting research and development, and facilitating the exchange of information. AAATE is composed of more than 250 members from 19 countries. It was founded in 1995.

AAATE activities include a biannual conference, special interest groups, the scientific journal *Technology and Disability*, seminars, and workshops. Current special interest group topic areas include Robotics and Education.

AAATE interacts with sister organizations the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation Assistive Technology Association (ARATA) to advance assistive technology use worldwide. On August 26, 2000, the leaders of the four organizations signed the Tokushima Agreement to promote exchange of information and collaboration.

—Glenn Hedman

See also Assistive Technology; Australian Rehabilitation Assistive Technology Association (ARATA); Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) (United States); Rehabilitation Engineering Society of Japan (RESJA) (Japan).

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ASTHMA

Asthma is an ancient condition and a modern chronic disease. Wheezing, struggling for breath, awakening every night with a cough that will not stop—these signs of an acute asthma attack, accompanied by a feeling of suffocation, form the central experience of asthma. Descriptions of wheezing, heavy breath, and desperate suffocation can be found in the earliest medical texts. The term had its origin in the ancient Greek, ασθμα, which described gasping or breathlessness, and first appeared in the *Iliad* of Homer to describe a hero out of breath after battle.

Before 1800, *asthma* was generally used as a generic term. Depending on the context and the author, it could describe the symptom of shortness of breath in anyone from any cause. By the 1820s, asthma was a disease we would recognize as much like our own ideas about the disease, a chronic illness characterized by wheezing and shortness of breath with its origins in pathological changes in the lungs. Other disorders that caused shortness of breath, most notably heart and kidney disease, no longer carried the label "asthma." Indeed, after early autopsies of "asthmatics" in the 1810s showed that most had heart disease, emphysema, or tuberculosis, asthma became defined as a chronic lung disease with no specific pathological findings at autopsy. Despite changes in diagnosis and treatment, asthma remained an entity without clear boundaries. The symptoms of asthma—coughing, shortness of breath, the flush of exertion, pain in the chest from the use of accessory breathing muscles—are shared by many respiratory disorders, infectious and noninfectious, chronic and acute. In the nineteenth century, a cough or wheeze could be the first sign of a cold, asthma, bronchitis, tuberculosis, or a dozen other diseases. As stethoscopes, x-rays, and other tools and techniques became available, asthma was increasingly viewed as a distinct disease.

Because there has not been a single test, gene, lesion, sensitivity, antibody, or other biological or chemical marker of asthma, the disease has been defined by its symptoms. Several physicians in the eighteenth and nineteenth centuries who wrote about asthma also suffered from it. These doctors worked to convince their colleagues that asthma had a physical mechanism and was not simply a reflection of nervousness or emotional imbalance. Their dual status as experts and sufferers gave them credibility to challenge their colleagues' more stigmatizing perspective.

Because of changes in diagnosis, treatment, theory, and practice, every generation has its particular "asthma." The patient who suffered from asthma in 1850 would have been advised to visit Saratoga Springs or consider a trip to the Swiss mountains or the Mediterranean coast. In 1900, the same patient might have been offered adrenaline, cocaine, or one of a variety of patent remedies to inhale or smoke. In 1950, the same person's asthma might have been treated with steroids or an intensive analysis by an émigré disciple of Freud to work through suppressed emotions or a smothering maternal relationship. By 2000, the standard treatments for asthma were inhaled medications, symptom-relieving β-2-agonist inhalers such as albuterol and preventive treatments such as inhaled corticosteroids and inhaled sodium cromoglycate. Some patients also pursued allergy treatments including antihistamines and allergen immunotherapy—receiving weekly or monthly injections of purified pollens, venoms, and other allergens to modify their bodies' reactions to these substances.

The early 1900s saw improvements in available drugs for asthma, with the debut of adrenaline in 1900, theophylline in 1922, and ephedrine in 1924, all drugs with stimulant properties used to treat the acute asthmatic crisis. Cortisone, available in 1949, was established as a treatment for asthma within the first years of its use. Definitions of asthma have changed repeatedly as new treatments altered the way the disease was understood. In the era of stimulant therapy, bronchial spasm, hyperresponsiveness, or "twitchy airways" defined the disease. In an era of steroid treatment, the emphasis shifted to inflammation. Current treatments combine aspects of allergen avoidance in sensitive individuals with bronchodilating inhalers for both acute symptoms (chemically related to adrenaline) and anti-inflammatory inhalers to reduce the chronic reactivity of the lungs that can lead to chronic shortness of breath and severe attacks.

Since the 1960s, asthma prevalence, hospitalizations, and mortality have been rising in most of the industrialized world. In the United States from 1982 to 1994, asthma prevalence rates increased 61 percent, rising from 3.1 percent of the U.S. population to 5.4 percent, and by 2002 the national average asthma prevalence was over 10 percent. In some urban areas in the United States, up to 30 percent of children are reported to be asthmatic. These changes appear to be happening at both ends of the severity spectrum, with severe asthma and mortality worsening at the same time that there is expansion of the diagnosis toward milder cases of wheezing and shortness of breath with exercise or in the setting of upper respiratory infections that a generation ago would likely not have been diagnosed at all.

From 1970 to 1995, asthma hospitalization rates almost tripled in the United States. Asthma hospitalization rates among children under age 15 rose faster than in any other age group with 5.8 hospitalizations for asthma per 10,000 members of the U.S. population under age 15 in 1970 and 36.7 hospitalizations per 10,000 in 1995, a six-fold increase. By the mid-1990s, hospitalization rates for asthma in the United States began to level off, attributed more to the efforts of insurance companies to limit hospital stays than to decreases in population morbidity.

There has been a persistent linkage in the epidemiological literature around the world between asthma and measures of increasing Westernization, urbanization, and industrialization. The narrative of asthma as a "disease of civilization" is almost irresistible, inspiring images of the dirty, diseased city and the healthy countryside.

The epidemiology of asthma in the United States points to greater prevalence and severity of asthma (measured as rates of mortality and hospitalization) in inner-city areas with large poor and minority populations. Living in inner-city areas appears to confer special risk, but it is unclear whether the most important features of inner-city asthma severity and mortality are driven by poverty, environmental conditions (including allergens and atmospheric pollutants), housing conditions, health habits, access to health care, or other factors.

Asthma deaths, though terrifying, are rare, occurring in a tiny fraction of severe asthmatics, amounting to approximately 5,000 deaths per year for the past 10 years in the United States, out of an estimated population of 14 to 28 million asthmatics. These severe asthmatics typically have multiple risk factors for death, often including severe disease, poverty, and poor access to health care. In the United States from 1979 to 1998, asthma mortality rates doubled from approximately 1 per 100,000 to 2 per 100,000. While this increase was concerning, it took place against a background decline since the 1950s, when asthma mortality peaked at 4.4 per 100,000. In fact, the most obvious feature of the trends in asthma mortality in the United States is that in some years there are sharp discontinuities—increases, decreases, or inflections in the curve. These reflect changes in the coding of deaths under the International Classification of Diseases (World Health Organization 1992). Changes in classification have frequently shifted deaths between the categories of asthma, chronic bronchitis, and more recently chronic obstructive pulmonary disease (COPD). And while the sum of mortality from all of these disorders continues to climb, in part because of the continued impact of tobacco on population health, the significance of rising then falling asthma mortality in the past 25 years is not completely clear.

Is asthma truly rising in prevalence, or do more people now label their shortness of breath as asthma and seek treatment for the condition? It is possible that on the mild end of the asthma spectrum the prevalence rates can be partially explained as an increase in patients considering themselves sick and more physicians willingly prescribing the safer new generation of asthma drugs? The long-distance runner who is asthmatic according to specific criteria of bronchial hyperreactivity, and therefore seeks treatment, is quite a different asthmatic than the frail wheezing child of the past. This element of choice for the individual, visible in asthma, is seen throughout health and illness. People choose when to seek help, how, and what advice to accept or reject. What some label noncompliance others see as autonomy. Asthma is a disease without a cure, a diagnosis that an individual carries forever, and one that despite improved treatments can still force a change of occupation, residence, and lifestyle like so many other disabilities.

—Carla Keirns

See also Acute and Chronic Conditions.

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ASYLUMS

See Brigham, Amariah; Dix, Dorothea; Fernald, Walter; Fuller, Margaret

`ATA IBN ABI RABAH (645–733)

Nubian teacher

`Ata ibn Abi Rabah was a highly respected legal adviser and teacher at Mecca (Makkah) during the first century of Islam. He may have specialized in the rites of pilgrimage, a practice incumbent on all Muslims. Of Nubian descent, he was described as "black in colour, blind of an eye, flat-nosed, having the use of only one arm, lame of a leg, and woolly-haired; when advanced in life he lost the use of his sight" (*Ibn Khallikan's Biographical Dictionary* 1842–1871). These features would have been socially disadvantageous in Arabia, yet they were outweighed by the fact that his knowledge of law, and of the traditions of the prophet Muhammad, came directly from several of the companions of Muhammad.

—*Kumur B. Selim*

See also Abu 'l-`Ala al-Ma`arri; Abu 'l Aswad ad-Duwali; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

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ATTITUDES

Attitudes are evaluations that help decide how an individual will respond to the individual, group, object, or idea that is evaluated. When applied to persons with disabilities, attitude theories have concerned the content of attitudes, applicability of attitude content across cultures, formation of attitudes, and attitude change. In recent years, attitudes have become an important component of a social definition of disability. A key aspect of the social definition is that an individual's disability may be as much or more a function of negative attitudes and misconceptions of others in society than it is a function of the individual's particular limitations or conditions. Attitudes can create or remove barriers to full life for persons with disabilities. For example, attitudes can play a crucial role in facilitating or hindering implementation of legislation to counteract prejudice against people with disabilities. Understanding attitudes toward people with disabilities and learning how they can be changed may be a key factor in improving the lives of people with disabilities.

L. L. Thurstone (1946) defined an *attitude* as "the intensity of positive and negative affect for or against a psychological object" (p. 39). As the role of thought processes came under growing scrutiny by psychologists, definitions of attitudes shifted from being centered on responses to being seen as mechanisms influencing behavior, and increasingly included components of thought processes and behavioral intentions in addition to emotional responses. The shift from affective response to behavioral formation is reflected in the evolution of measures of attitudes toward persons with disabilities. Attitude measures developed in the 1960s and 1970s tapped general evaluations, beliefs, and intentions, with items containing general statements of beliefs about persons with disabilities, such as "Disabled people are often unfriendly" and items measuring affective responses, such as "The way disabled people act is irritating." By the 1980s, measures of attitudes included behavioral intentions, such as willingness to socialize with persons with disabilities. By the 1990s, attitudes began to be conceptualized according to their relevance to community inclusion efforts and implementation of the Americans with Disabilities Act.

Another aspect of the definition of attitudes is what is meant by the concept of evaluation. Once limited in scope to general positive or negative feelings about an object, evaluations involved in attitudes are now seen as having multiple dimensions. Charles Osgood suggested that all attitudes may be reduced to positions on three dimensions. An object may be evaluated as to whether it is good or bad (moral dimension), strong or weak (potency dimension) and active or passive (activity dimension). A similar categorization has been used in classifying historical and societal attitudes toward persons with disabilities. This viewpoint suggests that in times and societies when persons with disabilities were regarded as good, strong, and active, they were deified, that is, believed to have special divine gifts. For example, the great astronomer Tycho Brahe (1546–1601) had a man with mental retardation as a close companion. Brahe wrote down the words spoken by the man, and then endeavored to put them together in order to form divine prophecies. However, in times when persons with disabilities were regarded as bad, strong, and active, social norms and policies would favor their destruction, as was the case during the height of the eugenics movement at the beginning of the twentieth century.

STRUCTURE OF ATTITUDES

Recent measures of attitudes toward persons with disabilities usually assess different types or facets of attitudes. For instance, the Community Living Attitudes Scale, a contemporary measure of attitudes toward inclusion of persons with intellectual disabilities, assesses contradictory and specific aspects of more general questions regarding community inclusion and participation. The Empowerment subscale asks about the extent to which persons with intellectual disabilities should make their own decisions even in the face of opposition by family members and professionals. In contrast, the Sheltering subscale assesses attitudes toward the protection of persons with intellectual disabilities from harm. Likewise, the Similarity subscale measures the extent to which respondents believe people with disabilities are similar to other people, while the Exclusion subscale assesses attitudes toward separating people with disabilities from the rest of society.

The shift from general evaluations to multiple facets of specific attitudes has occurred as philosophies of service and support for persons with disabilities have moved toward community inclusion. Increased inclusion efforts have revealed numerous specific instances when attitudes create barriers. For example, a person may hold the general belief that persons with disabilities should have job opportunities, but be reluctant to hire a person with a disability for a specific job. Because general positive evaluations may mask more negative specific attitudes, measures of attitudes have moved toward assessing behavioral intentions on specific issues. This movement is reflected in recent measures of attitudes toward mental retardation and eugenics, attitudes toward specific educational practices for children with disabilities, attitudes towards inclusion in education, disability rights, and the Americans with Disabilities Act.

A final issue in the structure of attitudes is the extent to which the attitude structures found in U.S. studies generalize to other populations. Much of the disability attitude research has been conducted in the United States, and some has been done in other nations. Recent research suggests that dimensions of community inclusion attitudes generalize to samples in Japan, Korea, Israel, and Australia. However, these other nations emphasize these dimensions to different degrees than do samples in the United States. For example, a study of Israeli staff serving people with intellectual disabilities found that they emphasize protecting persons with disabilities from harm to a greater extent than they emphasize individual rights and self-determination, whereas the reverse was true of staff in the United States. It has also been suggested that in cultures characterized more by collectivism than individualism, measures assessing the effects of an individual's disability on families and communities may need to be developed to assess attitudes more accurately and completely.

ATTITUDE CHANGE

Another important aspect of attitude research is studying attitude change. Social psychologists have conducted substantial research into methods for changing attitudes, much of which applies well to attitudes toward persons with disabilities. The oldest theory of attitude change is the idea that attitudes change when the rewards for maintaining them change, an idea based in early learning theories. According to this theory, attitude formation is dependent on the incentives that are offered. Cognitive consistency theories, on the other hand, suggest that people strive to maintain consistency in their attitudes, and between their attitudes and their actions. Inconsistency is a painful state, which motivates a person to change either attitudes or behavior. Other theories of attitude change focus on the individual's conformity to others' attitudes or pressure to change from peer groups.

Another theory of attitude change draws both on cognitive consistency theories and on social psychological experiments demonstrating that hostility between groups can be reduced if common interests can be found and emphasized. If people come to see persons with disabilities as like themselves and not as different, the desire for consistency in their attitudes will motivate change in other disability-related attitudes. Thus, the more persons with disabilities are constructively included in normal community life, the more negative attitudes toward them should decline. In fact, several literature reviews have found prior positive contact with people with disabilities to be related to positive attitudes. Positive contact can also be an effective method of improving attitudes, especially when combined with information about people with disabilities. Recent research has shown that including disability-related course work, rationales for inclusion, and rotations or practicum experiences in the training of teachers, social workers, and health care providers can strengthen attitudes about the similarity of persons with disabilities to others, which may then lead to other attitude improvements.

An area of particular concern for attitude change interventionists is the persistence of a preferential hierarchy based on disability type. Several researchers have found that people with intellectual or psychiatric disabilities are viewed more negatively than people with physical disabilities.

Attitudes toward persons with disabilities play a key role in the inclusion of children with disabilities in education and the employment of persons with disabilities. Educational inclusion has become common, yet not universal, practice in North America, Europe, and other continents. Attitude research has contributed to the success of educational inclusion efforts. Researchers have explored the attitudes of students with and without disabilities, teachers, and administrators and pointed out the necessity of providing appropriate supports for educational inclusion to succeed. Research on attitudes toward employment of persons with disabilities has found that global attitudes toward the employment of persons with disabilities tended to be positive. However, more specific behavioral intentions of employers were conflicted or negative when the costs of accommodation, training, supervisory demand, absenteeism, and other factors were considered.

More needs to be understood about attitudes toward persons with disabilities in the workplace and other contexts, and how such attitudes can be changed. Attitudes toward persons with disabilities are likely to be related to quality of services and acceptance in community life. As a marginalized group, persons with disabilities often face discrimination and exclusion. Public attitudes influence public policy and its implementation. Knowledge of attitudes of service providers and community members can identify areas in which persons with disabilities are most likely to encounter resistance, as well as highlight concerns which need to be addressed in education and advocacy.

—David B. Henry

See also Employment; Inclusion and Exclusion; Stigma.

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AUDIO DESCRIPTION

Audio description renders visual images into spoken word for people who are blind or visually impaired. It is the process of narrating visual aspects of theater, museum exhibits, films, television programs, parades, and other public venues in such a way that a partially sighted or blind recipient may access the presentation more comprehensively. It provides descriptions of key visual elements such as actions, scene changes, text captions, wardrobe, sets, scenery, facial expressions, colors, textures, and composition.

Gregory Frazier is credited with developing the concept of audio description in the 1970s. In 1981, Margaret Rockwell Pfanstiehl, visually impaired, and her husband, Cody Pfanstiehl, were the first to provide audio description to theater audiences at the Arena Stage Theater in Washington, D.C. In addition, they founded Audio Description Services, which promoted theater descriptions throughout the United States.

In the mid 1980s, WGBH in Boston became the first public television station to provide audio description. Using the secondary audio program (SAP), viewers can hear the regular sound track as well as a prerecorded audio description. The United Kingdom's Broadcasting Act of 1996 requires a minimum proportion of audio-described programming. Japan, Spain, and other countries voluntarily provide some audio-described television programming, and the United States provides up to 10 hours of audio-described programming per week.

Theater performances are narrated live, while playbill information can be prerecorded. A trained audio describer speaks into a microphone, which is transmitted directly to visually impaired patrons through an earpiece. In this way, the description is heard individually and does not disturb other patrons. Description of Hollywood films at cinemas, available on a limited basis, is provided with similar equipment, while video/DVD films use the SAP capability of the video player. Similarly, prerecorded material can be provided via personal headsets to patrons of museums, art galleries, nature walks, and other exhibits.

It is important for audio descriptions to be precise and concise to fit the short spaces between dialogues, and to be objective and specific to allow the audience members to draw their own conclusions. Audio descriptions should maintain the artistic integrity of the work without qualification or interpretation. For example, instead of stating, "She looks upset," the describer should translate her facial expression or action, such as "She is crying with her face in her hands."

Television audio description is currently under debate in the United States. In 2000, the Federal Communications Commission (FCC) passed regulations requiring 50 hours of described programming per quarter by each major broadcasting company. These regulations were overturned in 2002. While many U.S. blindness groups fought strongly to get these regulations in place, the National Federation of the Blind (NFB) and the Motion Picture Association of America (MPAA) led its opposition. The NFB advocated that an easier and more straightforward version be mandated, which includes on-screen text, especially for broadcast alerts, weather reports, and advertisements. The MPAA claimed First Amendment violations because of significant changes in the creative work required for audio description.

—Terri Thrower

See also Assistive Technology; Blindness and Visual Impairment; Television.

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▣ AUDISM

The term *audism* was coined in 1975 by Tom Humphries to name the discrimination against persons who are Deaf. According to Humphries, *audism* would appear in a dictionary as the following:

> **audism** (o diz m) *n.* The notion that one is superior based on one's ability to hear or behave in the manner of one who hears.

The primary manifestations of audism, Humphries (1975) noted, is "in the form of people who continually judge deaf people's intelligence and success on the basis of their ability in the language of the hearing culture." It also appears when deaf people themselves "actively participate in the oppression of other deaf people by demanding of them the same set of standards, behavior, and values that they demand of hearing people" (n.p.).

As Humphries defines it, *audism* is a set of beliefs held by individuals (either hearing or deaf) that stem from the common assumption of the superiority of hearing over deafness. People who hold and practice these beliefs could be labeled "audists." At this level of analysis, Humphries's definition of audism would be roughly analogous to the notion of "individual racism" in which an individual holds beliefs and exhibits racist behaviors, ranging from assumptions about the intelligence of speakers of ebonics to racist jokes to the most obvious act of hate crimes. Thus, the initial discourse of audism came in the form of identifying "individual audism" as it manifests in the beliefs of individuals, whether hearing or deaf themselves.

It was not until the 1990s that the term *audism* appeared in several publications, beginning with Harlan Lane's 1992 *Mask of Benevolence,* where Lane defined *audism* as "the corporate institution for dealing with deaf people . . . [it] is the hearing way of dominating, restructuring, and exercising authority over the deaf community" (p. 43). Lane draws on the work of French philosopher Michel Foucault and others to interrogate the organizations that attempt to care for the Deaf but actually perpetuate the conditions of disability. Since the beginnings of deaf education and the science of audiology, Lane demonstrates, educational and medical institutions have assumed authority over deaf persons, claiming to act in their best interests while not allowing them to have a say in the matters that concern them the most. From the crude and tortuous methods of French doctor Jean Marc Gaspard Itard to the surgical procedure of cochlear implants, and from the strict oralism of Johann Conrad Amman to the current trend of mainstreaming, Deaf people have been physically and pedagogically coerced into adopting hearing norms, whether they wanted to or not.

Lane's analysis has added this important historical and systemic perspective to the notion of audism. This systemic perspective coincides with definitions of structural or systematic racism. Borrowing from David Wellman, Beverly Daniel Tatum (1997) defined racism as "a system of advantage based on race." "This definition of racism is useful," Tatum wrote, "because it allows us to see that racism, like other forms of oppression, is not only a personal ideology based on racial prejudice, but a system involving cultural messages and institutional policies and practices as well as the beliefs and actions of individuals" (p. 7). The implications of this definition are far reaching, for it brings the notion of "privilege" to the fore, which allows us to grasp the benefits allotted to white individuals within a white system of advantage. Such advantages range from the ease with which many white people get housing to the availability of "skin color" Band-Aids (McIntosh 1988). Hearing privilege may come in the form of unfettered access to information, for which they cannot be faulted; however, settings that are designed to cater to deaf persons (i.e., schools) famously create barriers to communication by denying deaf persons access to a sign language and a visually rich learning environment. Therefore, there is a whole system that still favors hearing persons in environments designed for deaf people. Thus, we may succinctly use this definition to articulate the definition of *institutional audism* as a system of advantage based on hearing ability (Bauman 2004).

In this vein, Humphries's and Lane's contributions to the concept of audism have helped to make previously hidden structures of thought and beliefs visible. Institutional oppression is inherently difficult to detect, for it often masks itself as practices that follow common sense. The production of common sense—that is, the hegemony of hearing-as-norm—has roots that extend to fundamental metaphysical questions of human identity.

Thus, the discourse on audism has extended from the individual and institutional sites to include the metaphysical site. Thus, *metaphysical audism* refers to the orientation that links human identity and being with language defined as speech (Bauman 2004:242). Historically, humans have been identified as the speaking animal; those who cannot speak are seen as akin to humans in body but animals in mind. In this orientation, we see ourselves as becoming human *through* speech. Brenda Brueggemann (1999) summed up this condition of audism in the form of a syllogism: "Language is human; speech is language; therefore deaf people are inhuman and deafness is a problem" (p. 11).

It is within this orientation (language is human/speech is language) that deaf people have frequently been described as animals, especially by those who have taught them. One of the earliest practitioners of audism, Johann Conrad Amman (1873) wrote in 1700 about deaf persons: "How dull they are in general. How little do they differ from animals" (p. 2). A century and a half later, an American oralist, Lewis Dudley, wrote that the deaf students are "human in shape, but only half-human in attributes" (quoted in Baynton 1996:52). The metaphorics of deaf-as-animal became especially widespread in the aftermath of Darwin's theory of evolution. For many educators of the deaf in the late nineteenth and early twentieth centuries, Doug Baynton explained, "To be human was to speak. To sign was a step downward in the scale of being" (p. 55). Yet it was not only the oralists who constructed their deaf pupils as animals. The famous successor of the Abbé de l'Épée in France, Abbé Roch-Ambrose Sicard (1984), asserted even more vehemently that the deaf were even lower than animals prior to education. He referred to the uneducated deaf pupil as "a perfect nonentity, a living automaton . . . the deaf person lacks even that unfailing instinct directing animals destined only to have that as their guide" (p. 84).

If "deaf people are inhuman," then the logical consequence is that deafness becomes a problem of immense proportions. If poor deaf creatures are to be included in the human family, they must be made to be more fully human, that is, a speaking animal. At this point, the metaphysics of audism gives way to the systemic level where institutions of education, medicine, and law work to make the deaf creature a more normal, fully speaking human being.

Since the revelation of the grammatical nature of sign languages, and the recent work in neurolinguistics, we know that all humans (whether hearing or deaf) are born with the equal capacity to receive and produce a manual as well as a spoken language. Indeed, if this is true of humans born today, then we must assume that we have always had the potential to be the signing as well as the speaking animal. This insight now enables us to assert that Western traditions have been operating with an incomplete definition of language and hence of human identity. A theory of audism, then, may work toward the deconstruction of this presumed natural status of speech in the Western metaphysical heritage so that speech may be seen not as *the only,* but as *one of* the modalities of human language. In this vein, a critique of the Western audist orientation dovetails with a critique of *phonocentrism,* a project set under way in Jacques Derrida's *Of Grammatology* (1974). Thus, the discourse of audism has implications, not only for those most directly affected by it but also for those who have critiqued, for one reason or another, the predominance of speech and phonetic writing as the sole means of human language modalities.

Now that these three levels of audism—individual, institutional, metaphysical—have become defined and published, a more thorough dictionary definition may be offered:

audism (o diz m) *n.*

1. The notion that one is superior based on one's ability to hear or behave in the manner of one who hears.
2. A system of advantage based on hearing ability.
3. A phonocentric orientation that links human identity with speech.

Now that the term is rapidly becoming more common in the Deaf community, it may function much like a lens that brings into focus what was previously obscured behind trappings of institutionalized procedure and protocol. Foregrounding these aspects of the oppression of deaf and hard-of-hearing persons allows resistance to be articulated as struggle for human rights and dignity for a linguistic minority to have access to a fully human language that best fits their visual learning needs. Thus, the discourse around audism allows its users to perceive the overarching drive to normalize Deaf persons into hearing persons as a severe instance of discrimination and oppression at the hands of a ruling majority.

—H-Dirksen L. Bauman

See also Alexander Graham Bell; Deaf Culture; Sign Language; Speech and Language Pathology.

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AUGMENTATIVE COMMUNICATION

Augmentative communication comprises methods of communicating without speech. It includes the use of communication aids such as alphabet boards and electronic communication devices that speak as well as unaided communication methods such as sign language and gestures. People who are unable to speak or speak clearly rely on augmentative and alternative communication (AAC) methods to exchange information, express needs, maintain relationships, and participate in the activities of their community. People typically use multiple AAC methods and may use different methods with different people. For example, a child with dysarthric speech may be understood by his parents; however, for classroom participation and phone conversations he may need to augment his communication with an electronic communication device.

AAC methods are typically differentiated as aided or unaided. Unaided communication methods include vocalizations and speech attempts as well as gestures and body movements. It includes those communication methods used and understood by most people, such as facial expressions, looking (eye gaze), pointing, and other common gestures as well as methods and individualized signals that may only be understood by familiar people. For example, a child may raise her arm to talk about someone who is tall and look toward a kitchen to talk about food, hunger, or the person who cooks. In addition, people with limited ability to move may use subtle finger movements or eye blinks as codes for answering "yes" or "no" questions.

Sign language is also considered an unaided communication method. There are many different sign languages, specific to different cultures, such as American Sign Language and British Sign Language. Elements of sign language may be used by people who are unable to physically produce all the hand shapes and coordinated two-handed movements typical of sign languages. Individuals with limited speech and multiple impairments may be taught to use individual signs or adapted signs from a sign language. For example, a child with cerebral palsy may learn to use sign positions to quickly communicate needs or wants, such as touching a fist to his forehead to indicate "father" and touching his mouth to indicate "eat."

Aided communication methods include use of electronic and nonelectronic communication aids. Nonelectronic aids include writing tools, as well as boards and books with letters, words, pictures, and/or other symbols. There are many types of communication symbols; however, Blissymbolics, a language composed of more than 2,000 graphic symbols, is currently used in 33 countries. Also, Boardmaker, a graphics database for making communication aids, contains more than 3,000 picture communication symbols translated into 24 languages. People may communicate by eye-pointing or directly touching symbols with their fingers or other body parts. If someone cannot point, a communication partner may point to symbols until the person indicates which symbols he or she wants.

The category of electronic communication aids includes more than 100 dedicated communication devices, as well as computer-based communication systems and AAC software. The selection of devices is based on individual needs and capabilities of the person in his or her environment. For example, people who can spell typically choose devices that have synthesized speech to speak messages that are typed. Most devices allow people to sequence words/symbols to create messages or recall pre-stored phrases. People who cannot operate devices by touching symbols or letters may use alternate access methods such as scanning, joystick, and mouse emulation.

—Patricia A. Politano

See also Assistive Technology; Autobiography; Communication; Computer Technology; Sign Language; Speech and Language Pathology.

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AUGUSTINE, SAINT

(354–430 CE)

Roman philosopher and Christian reformer

One of the four fathers of the Catholic Church, Saint Augustine of Hippo was born in Tagaste (Algeria) and died in Hippos (Annaba), his life spanning the formal collapse of Antiquity and the rise of the Middle Ages, with the fall of Rome (410). In between, he wrote approximately 5 million words, which substantially reshaped the early Church and the nature of its subsequent development; in particular he helped to reform the newly Christianized Rome and to unify the concepts of salvation and faith. His principal works include the *Confessions* (ca. 397–400), *On Christian Doctrine* (ca. 397), and *The City of God* (413–426).

At least two Augustinian aspects relate to disabilities: his life and works. The man himself endured a mysterious, painful chest condition in his 32nd year, impairing his teaching and cutting short his meteoric rise in Roman academics. His convalescence, however, allowed his baptism by (Saint) Ambrose and his eventual elevation to the bishopric of Hippo. As he entered old age, Augustine was plagued by recurrences of this condition and by many debilities of aging. Both experiences notably affected his faith and his writings.

In his works we find numerous connections with disability, two of which are mentioned here. Critically, Augustine formulated the core of the evolving ecclesiastical precept of Christian charity with its far-flung impact on disability. In addition, Augustine's neoplatonic dualism offers tantalizing insights into the Christian supremacy of the soul and yet the author's profound dependence on experiences of the body to interpret the soul. Much work remains to be done to integrate Augustinian precepts with modern disability theory.

—Walton O. Schalick III

See also Charity.

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AUSTIN, MARY HUNTER

(1868–1934)

American author

Raised in Illinois by a disabled Civil War veteran and a mother who was a nurse and temperance activist, Austin's youth involved an early awareness of the familial impact of disability. After college, Mary Hunter moved to California, where she soon married Stafford Wallace Austin and gave birth to their only child, Ruth Austin (1892–1918). Ruth's developmental disability (possibly autism) soon became apparent; Mary Austin struggled to provide or arrange adequate care for her daughter, and in 1904 placed the girl in a private hospital in Santa Clara, where she would remain until her death. Mary Austin's disappointment, guilt, and sadness about her daughter inspired her to work for marriage reforms and sex education. In her Western short stories, disabled characters appear often, and themes of "nature versus nurture" are common. Austin's 1932 autobiography, *Earth Horizon,* was frank about the isolation Mary experienced as a young mother, the blame she placed on her husband, and the pressure she felt in her career: "Caring for a hopelessly invalid child is an expensive business. I had to write to make money," she explained, in a 1927 essay.

—Penny L. Richards

See also Family.

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AUSTRALIA

See Disability in Contemporary Australia; Disability Studies: Australia

AUSTRALIAN REHABILITATION ASSISTIVE TECHNOLOGY ASSOCIATION (ARATA)

The Australian Rehabilitation Assistive Technology Association (ARATA) provides a forum for exchange of information between professionals and consumers involved in assistive technology. ARATA achieves this through conferences, regional chapters, and a quarterly newsletter.

Special interest groups (SIGs) also give ARATA members a means of sharing ideas on specific areas of assistive technology. SIGs exist in augmentative and alternative communication, manufacturers and suppliers of communication/computer assistive technology, computer users and environmental control systems, service delivery and government policy, wheeled mobility and seating, and human perspectives of technology.

ARATA interacts with sister organizations—the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), the Association for the Advancement of Assistive Technology in Europe (AAATE), and the Rehabilitation Engineering Society of Japan (RESJA)—to advance assistive technology use worldwide. On August 26, 2000, the leaders of the four organizations signed the Tokushima Agreement to promote exchange of information and collaboration.

—Glenn Hedman

See also Assistive Technology; Association for the Advancement of Assistive Technology in Europe (AAATE) (Europe); Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) (United States); Rehabilitation Engineering Society of Japan (RESJA) (Japan).

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Australian Rehabilitation and Assistive Technology Association, http://www.e-bility.com/arata/index.php

AUTISM

Autism is one of the most controversial and provocative disability topics. From diagnostic methods to questions of origin, autism maintains an ambiguous existence. Autism evades classification; depending on perspective and discipline, autism appears under many classificatory rubrics. Autism is often defined as a neurological condition, psychiatric/psychosocial profile, pervasive developmental disorder, comprehensive communication disorder, or disintegrative sensory pathology. Researchers in medicine, hard sciences, social sciences, and the humanities, as well as parents, teachers, and professionals, actively contest the meaning, cause, and implications of autism. In any case, neither theory nor statistics exhausts the full scope of autism. Furthermore, any accurate account of autism necessitates the voices, thoughts, and experiences of autistic individuals.

AUTISM SPECTRUM

Autism constitutes a continuum of impairment. Hence, contemporary autism specialists articulate a spectrum of autism variations. The autism spectrum ranges from highly verbal, high-functioning individuals with superior intelligence, to nonverbal persons with low IQs. These impairments may or may not be disabling depending on their location along the autism continuum and environmental barriers. About 10 percent of people with autism have some form of savant skills—special limited gifts such as skill in memorizing lists or calculating calendar dates, drawing ability, or musical skills. Many people with autism have unusual sensory perceptions.

HISTORICAL CONTEXT

Leo Kanner, a child psychiatrist at Johns Hopkins University, first recognized autism as a syndrome in 1943. Kanner described a social impairment characterized by some of the following traits: aloofness; lack of social reciprocity; absence of eye contact; an inability to effectively communicate; repetitious, stereotyped behavior such as rocking, hand flapping, or preoccupation with seemingly arbitrary facts like types of vacuum cleaners; and strong resistance to changes in environment or routines.

Part of the controversy surrounding autism derives from Bruno Bettelheim's archaic theories. After being interned in German concentration camps at Dachau and Buchenwald from 1938 to 1939, Bettelheim immigrated to the United States. As the head of the Orthogenic School at the University of Chicago, he employed a controversial theory of autism, which blamed mothers' emotional indifference. Bettelheim claimed these so-called refrigerator mothers were to blame for their child's autism. Many autistic children institutionalized in his school were isolated and abused under the auspices of therapy. Ultimately, the research community discredited and renounced Bettelheim's theory of autism. In 1990, Bettelheim committed suicide.

MODERN DIAGNOSTICS

The fourth *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) of the American Psychiatric Association constitutes the dominant diagnostic tool. The Autism Diagnostic Interview-Revised (ADI-R) operationalizes the American Psychiatric Association's *DSM-IV* criteria for diagnosing autism. Both the ADI-R and *DSM-IV* consider effects in three main areas: communication, social development, and restricted, repetitive behaviors. Furthermore, the *DSM-IV* corroborates diagnostic practices used by the World Health Organization's International Classification of Functioning, Disability, and Health (ICF). According to the *DSM-IV*, autism is a type of pervasive developmental disorder. It interferes with a person's ability to communicate with and relate to others. Autism is a lifelong condition. Autism affects how a person perceives and processes sensory information. Signs of autism almost always develop before a child is three years old, although the condition is frequently undiagnosed until later. Typically, parents first become concerned when they notice their toddler does not respond or interact like other children of the same age. Toddlers with autism do not usually babble or talk normally, and they may seem to have hearing problems. Early diagnosis and treatment helps young children with autism develop to their full potential. However, standard treatment guidelines to achieve this goal have not yet been established by the pediatric community.

Autism is often difficult to diagnose. Unlike fragile X or Down syndrome, autism cannot be located in any chromosomal structure. Most research suggests that people with autism have irregular brain structures. More study is needed to determine the cause of these irregularities, but current research indicates they are inherited. While there is some evidence that suggests neurological or physiological differences in the brains of autistic people, medical authorities still rely on behavioral characteristics to assert an autism diagnosis. Parents who have had one child with autism are more likely than other couples to have a second child with autism. There is no way yet identified to prevent autism, but experts agree that early educational intervention, often in conjunction with medicine or therapy, increases an autistic individual's chances for social success and a high quality of life.

—Heather Stone

See also Asperger Syndrome.

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AUTOBIOGRAPHY

Insofar as it is regarded as a departure from a norm, disability, especially visible disability, seems to demand or provoke autobiographical narrative: What happened to you? In fact, a collection of autobiographical narratives edited by Lois Keith has been published under that title. Yet, until very recently, autobiographical narrative of disability has been rare. Instead, third-person narrative has dominated the representation of disability—in various literary genres, such as drama and fiction; in mass media; and in tacit cultural scripts. Disability has loomed large in myth, legend, and drama from the classical Greeks onward and in the novel from its more recent origins. Historically, then, disability has been represented primarily by nondisabled writers and almost exclusively in fictive or imaginative genres.

Such representation, moreover, has typically been hostile or, at best, patronizing toward people with disabilities. Disability has largely been represented as a trope for a moral or spiritual condition (usually, but not always with a negative valence), rather than as a lived condition of interest and value in itself. The most prejudicial "explanations" for disability have been divine disfavor or moral flaw in the individual (which are variants of a single trope). Many conventional rhetorics of disability—for example, those of triumph or spiritual compensation—tend to devalue it, portraying it as a problem for an individual to overcome through force of will or for God to offset through force of grace.

Before 1900, autobiographical representation of disability was sporadic. In the latter half of the nineteenth century, a small number of American women produced narratives of institutionalization in mental asylums. And from the mid-nineteenth to the mid-twentieth centuries, tuberculosis patients produced numerous written (but not always published) accounts of illness and invalidism. In the second half of the twentieth century, personal narrative of disability grew significantly. For his classic study *Stigma: Notes on the Management of Spoiled Identity* (1962), Erving Goffman surveyed the extant autobiographical literature; his bibliography is thus a good resource for early narratives, most of which concern physical or sensory impairments and appeared before World War II. (One of these, Katharine Butler Hathaway's *The Little Locksmith,* was recently rediscovered and reprinted.) The return of disabled veterans after the war gave a new visibility to disability autobiographies such as Harold Russell's *Victory in My Hands;* while exceptional, insofar as circumstances associated disability with patriotic duty, sacrifice, and heroic masculinity, these narratives may constitute a market breakthrough.

The next waves of narratives had to do with disability caused by disease rather than war. The spread of polio (and its middle-class demographics) gave rise to a significant number of narratives; polio was thus perhaps the first disabling condition to generate a significant number of autobiographical narratives over a short period of time. Decades later, HIV/AIDS, an epidemic with very different demographics and politics, also generated a considerable literature. In the early years of that epidemic, however, when AIDS was tantamount to a death sentence, it was typically represented biographically, by surviving partners or relatives; only after the development of drugs that made it possible to live with AIDS as a chronic illness did autobiographical accounts proliferate. The autobiographical literatures of polio and AIDS (and breast cancer) suggest, then, that one important factor in the development of disability autobiography has been medical advances that have enabled individuals to survive serious illnesses. This is true of the growing autobiographical literature of paraplegia and quadriplegia as well; only in an era when people can live indefinitely with significant paralysis can these conditions generate much in the way of autobiographical literature.

A different phenomenon was the sudden proliferation in the 1990s of narratives devoted to a large range of conditions, some relatively obscure, some of recent cultural (read medical) creation, hence hitherto absent from autobiographical literature. Such conditions include (in alphabetical order) amnesia (Robinson), amyotrophic lateral sclerosis or Lou Gehrig's disease (Robillard), Asperger syndrome (Willey), asthma (Brookes, DeSalvo), cystic fibrosis (Rothenberg), deformity of the legs (Fries), depression (Styron), diabetes (Roney), disfigurement (Grealy), epilepsy (McLean, Robinson), locked-in syndrome (Bauby), multiple sclerosis (Mairs), obsessive-compulsive disorder (Wilensky), stroke (McCrum and Robinson), stuttering (Jezer), Tourette syndrome (Handler and Wilensky). More remarkable, conditions that might seem to preclude verbal self-representation have recently been given autobiographical treatment: autism (Grandin, Williams), Down syndrome (Kingsley and Levitz), and early-stage Alzheimer's disease (DeBaggio, McGowin). Conditions that preclude writing in conventional (i.e., manual) modalities have been represented by way of collaborative mediation. For example, Ruth Sienkiewicz-Mercer, who has cerebral palsy so severe that she cannot walk or talk, wrote *I Raise My Eyes to Say Yes* with the assistance of Steven B. Kaplan and through the mediation of customized word boards.

Autobiography is a particularly valuable and liberatory medium for the representation of disability because by definition it involves *self*-representation; the growing number of disability autobiographies is encouraging insofar as it suggests that the marketplace is opening up to the voices of disabled people. Autobiography is increasingly living up to its potential as the most democratic, most catholic (i.e., inclusive), and most accessible of literary genres. Indeed, this phenomenon seems to parallel the increasing inclusion of disabled people in public life in the United States in the wake of the Americans with Disabilities Act (1990). As legislation mandates their inclusion in public institutions, and as such individuals are revalued in the body politic, people with disabilities have felt encouraged to represent themselves—in the political as well as mimetic sense—in autobiography. They become more visible, more audible, more assertive. The relation between civil rights legislation and autobiographical discourse is a recursive one: Each at once reflects and advances the other.

Numbers are not everything, however, and self-representation is not necessarily advocacy. Even contemporary disability autobiography sometimes recycles and thus perpetuates prejudicial rhetorics. One such rhetoric is that of spiritual compensation; in this schema, the disabled individual finds compensation in the spiritual realm for a physical or sensory impairment. The formula can be found in contemporary narratives such as Reynolds Price's *A Whole New Life,* which has to do with paralysis caused by spinal tumor in midlife, and Ruth Cameron Webb's *A Journey into Personhood,* which has to do with cerebral palsy. Webb, a Ph.D. and counselor to people with disabilities, resolves her sense that God "gave" her cerebral palsy only through a transfiguring visitation in which a voice tells her to give up her anger and accept God's love. Though it is clear to the reader that Webb has suffered primarily from discrimination, she seeks solace not in political action or disabled identity but in a sense of divine sanction. In her view, disability is her problem—a challenge given her by God for inscrutable reasons—not a social or political issue.

A more common script in disability narrative, including autobiography, is that of triumph over adversity. This emplotment of disability, like other culturally preferred scenarios, is consistent with the medical paradigm, which locates disability entirely within a "defective" or "abnormal" body. Disability is presented primarily as a "problem" that individuals must overcome by way of individual will and determination rather than political action. This formula, however, is susceptible to a progressive variant: that of triumph over *discrimination.* It matters, then, whether adversity is defined as *impairment* and located in the body or as *disability* and located at the interface between individual and culture.

A subgenre that embraces the latter approach is the increasingly popular "coming out" narrative. Narrators in this vein are typically people with congenital or early-acquired disabilities; in adulthood, they undergo a change, not in their condition, but in their relation to it, such that they self-identify as disabled. They are newly assertive and proud of that identity. Their narratives may either retrace the emergence of a disabled identity, in the manner of Stephen Kuusisto's *Planet of the Blind* (in which his acquisition of a guide dog marks him as blind in a new way), or explore it more self-reflexively and in an essayistic manner, such as Georgina Kleege's *Sight Unseen,* which begins, "Writing this book made me blind." (In the case of Irving Zola, his coming out was a product of his residence, as a researcher, in a community of disabled people in the Netherlands.)

When the focus is on overcoming discrimination—that is, oppression—we move toward a rhetoric of emancipation, as is the case in the aforementioned narrative by Sienkiewicz-Mercer. In her case, collaborative self-inscription—the use of word boards to narrate her life—is integral to the project of releasing herself from the custody of state hospitals in which she was placed as a girl; personal narrative is thus crucial to her physical and psychological emancipation. While she does not achieve physical independence, Sienkiewicz-Mercer moves to a position of greater power and mobility. The narrative is not a story of overcoming her cerebral palsy. It is thus not what Arthur Frank calls a "narrative of restitution"—a narrative in which a physician would play a transformative role. Nor is it even primarily a narrative of rehabilitation. Though she does learn to use various assistive technology devices to communicate, Sienkiewicz-Mercer never manages to walk or talk; she will always require care. The comic resolution of her narrative is not a function of removing or correcting her impairment, but of getting the world to accommodate her irreparable impairments, of removing the physical, social, and cultural obstacles to her integration into mainstream society.

Indeed, *I Raise My Eyes to Say Yes* has interesting affinities with slave narratives. The narrative is reminiscent of a slave narrative both in the sense that, on the level of plot, it traces a movement from virtual imprisonment to relative freedom, and in the sense that her emancipation is a function of a broader movement to deinstitutionalize disabled people. Like many, if not all, slave narratives, it defies the ascription of mental deficiency to the body of the Other and exposes the confinement of those bodies as a contingent social phenomenon rather than a "natural" one. It has particular affinities, then, with those slave narratives elicited by sympathetic abolitionists, for Sienkiewicz-Mercer's account is in effect promoted and sponsored by individuals seeking to liberate people with disabilities and even to abolish their "institutionalization." And in this regard, it represents a distinctly new, implicitly political, self-narrative of disability. Even more important, then, than the quantitative uptick in the autobiographical literature of disability, then, is a qualitative change: Disabled authors are increasingly departing from or challenging conventional formulas, tropes, and rhetorics.

Another significant aspect of *I Raise My Eyes to Say Yes* is that it represents, by implication, many lives that generally go unrepresented, uninscribed because of disability. In that sense, it suggests not the limitations of people with disabilities but those of autobiography as an accessible medium of self-representation. The book communicates both the liberation of access to language and the limitations of it. That is, it suggests that autobiography as traditionally conceived, with its inherent valorization of individualism and autonomy, presents its own barriers to people with disabilities.

It may also be considered a form of *autoethnography*, as Mary Louise Pratt (1992:7) defined the term: "instances in which colonized subjects undertake to represent themselves in ways that *engage with* the colonizer's own terms. If . . . ethnographic texts are a means by which Europeans represent to themselves their (usually subjugated) others, autoethnographic texts are those the others construct in response to or in dialogue with those metropolitan representations." (It is autoethnography, too, in that it is an inmate's view of the asylum.) As this narrative suggests, then, contemporary disability autobiography may display a postcolonial impulse—the impulse to define oneself in resistance to the dehumanizing categories of the medical and health service institutions. Both as individual and institutional history, *I Raise My Eyes* supplements, challenges, and indicts official discourse, which assumes that standardized testing can adequately indicate the inner life of the subject in question.

To characterize it as standing in for other unwritten, perhaps unwritable, accounts is to suggest its affinity with a more current first-person genre: *testimonio.* John Beverley (1992:103) has distinguished testimonio from autobiography as follows: "*Testimonio* represents an affirmation of the individual subject, even of individual growth and transformation, but in connection with a group or class situation marked by marginalization, oppression, and struggle. If it loses this connection, it ceases to be *testimonio* and becomes autobiography, that is, an account of, and also a means of access to, middle- or upper-class status, a sort of documentary *bildungsroman.*" In *I Raise My Eyes,* we have a disability memoir that moves toward, though it may not fully occupy, the position with regard to the disability rights movement that testimonio occupies with regard to the movement for the rights of indigenous peoples. *I Raise My Eyes to Say Yes* is testimonio to the (considerable) extent to which its narrator speaks not as a unique individual but for a class of marginalized individuals, in ways already suggested.

One of the arguments made against *narrating* disability would seem to apply to all forms of life writing, including autobiography: that presenting disability in narrative form serves to reinforce the individual paradigm of disability. First-person discourse cannot be exempted summarily from this critique. Indeed, much autobiographical literature individualizes (and sometimes medicalizes or pathologizes) disability. Thus, although autobiography may offer a degree of access that other literary genres do not, and although it may offer a degree of control over representation that other media may not, cultural constraints continue to limit the counterhegemonic potential of disability memoir. Culture filters and manipulates even seemingly "self-generated" texts in various ways, protecting its interest in marginalizing and ignoring disabled lives.

At the same time, there are signs of promise in some recent texts—narratives from hidden corners, some of which may connect with each other in ways that challenge and undermine the limited medical paradigm of disability. Such narratives not only attest to but advance the work of the disability rights movement; in their consciousness of their own condition as culturally constructed and as shared by others, their authors move beyond the familiar formulas of disability memoir and point the way to broader critiques of the construction of disability today.

—G. Thomas Couser

See also Augmentative Communication; Blindness and Visual Impairment; Katharine Butler Hathaway; Novel, The; Harold Russell.

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AVERSIVE THERAPIES

In the education and human services fields associated with developmental disabilities, *aversives* are programmatically designed and systematically induced punishments sanctioned by professionals and directed at people with disabilities to directly control their actions and hypothetically shape their behaviors toward what are determined to be appropriate ends. Over the past two decades, numerous disability-related organizations and panels have called for an end to the use of aversives because they are abusive, dehumanizing, and psychologically and physically dangerous (see, e.g., Autism National Committee 1999; National Council on Disability 1995; TASH 2004; International Association for the Right to Effective Treatment 2003).

The National Council on Disability (1995), a federal agency making recommendations to the president and Congress on disability issues, noted:

> Prisoners [in the United States] are afforded protection under the law from [harsh and abusive] treatment. . . . Students with severe behavioral disabilities are not criminals, and yet present law allows them to be subjected to procedures which cannot be used on the most hardened criminals, or, in some cases, even on animals.
>
> Public funds intended to provide positive educational experiences and results for children should not be expended to have these children subjected to unproven, experimental, dangerous, or violent program procedures which—by design—result in pain, physical injuries, psychological damage, hunger, social deprivation, or other such negative experiences. In any other context, the use of these procedures would be considered child (or dependent) abuse or neglect. They should not be viewed as "treatment" just because a student has a disability. Through its support of these procedures used on children with disabilities, the United States could be cited for human rights violations against people with disabilities under its own Country Reports on Human Rights published annually by the Department of State.

While the proclamation of the National Council on Disability has been available for more than a decade, use of aversives on people with significant disabilities continues to be widespread. As documented by the disability-advocacy organization TASH (formerly the Association for Persons with Severe Disabilities), current, common aversive practices used to control behavior include electric shock applied to the body (e.g., arm, leg, or hand) for the purpose of discouraging the specific behavior it follows by causing pain; extremely loud white noise or other auditory stimuli not uncommonly delivered through a mask-like device; forced exercise; shaving cream to the mouth; lemon juice, vinegar, or jalapeño pepper to the mouth; water spray to the face; placement in a tub of cold water or cold showers; placement in a small room, closet, or box; slapping or pinching with hand or implement; pulling the hair; ammonia capsule to the nose; blindfolding or other forms of visual blocking; placement in a dark isolated box or other methods of prolonged physical isolation; ice to the cheeks or chin; teeth brushed or face washed with caustic solutions; prolonged restraint through manual or mechanical techniques (e.g., face-down four- or five-point restraint using mechanical tie-downs or several staff applying physical pressure); and withholding of multiple meals/denial of adequate nutrition.

HISTORY OF AVERSIVES

Harsh treatment and daily punishment have been a consistent part of the disability experience in Western cultures for centuries. Wrote Aristotle in his *Politics* (1997), "As to the exposure and rearing of children, let there be a law that no deformed child shall live" (p. 543). Such overt hostilities, often guised as benevolence, continued unabated into the eugenics era in the United States during the first half of the twentieth century. In 1942, the American Psychiatric Association developed a position statement in favor of the euthanasia of children classified as *idiots* and *imbeciles:* "Those hopeless ones who should never have been born–nature's mistakes" (p. 14).

Though euthanasia was never widespread in the United States, the use of systematic aversives gained scientific legitimacy with the early-twentieth-century emergence of the field of psychology and its predominant paradigm of behaviorism. Edward Thorndike (1914), an early psychological behaviorist, claimed that *learning,* as opposed to reasoning, rationalism, motivation, goal seeking, and higher-level emotions, was the singular explanation for all human behavior. Learning, according to Thorndike, was the trial-and-error process of forming bonds between physical events (i.e., environmental stimuli and an individual's immediate response) and mental events (described merely as things perceived by the senses). Education was the process of stamping in what were deemed to be correct perceptions and responses to stimuli through pleasurable consequences and stamping out incorrect perceptions and responses through the use of aversives.

At the same time that Thorndike's learning theory came to dominate American behaviorism, state legislatures across the United States were passing compulsory education laws. These resulted in increasingly larger, far more rigid schools and the emergence of the first special education classrooms. The use of aversives, central to the fledgling science of learning, quickly became acceptable practice in these classes made up of struggling students segregated from the mainstream but forced by law to remain in school.

Thorndike's behaviorism focused on the individual's response to recognized stimuli, but what about individuals considered to have more severe intellectual disabilities, who, it was believed, could not meaningfully perceive or respond to stimuli? Compulsory education laws specifically excluded individuals with significant disabilities, but parents of children categorized as severely disabled were beginning in the mid-twentieth century to organize educational opportunities for their children. As professionals began to take over these new schools, they began to implement versions of the learning theory developed by psychologist B. F. Skinner in laboratories using pigeons, rats, and mice.

Beginning in the 1940s, Skinner (1974) identified classes of behavior called operants that individuals emit, but whose initial stimuli are unknowable in any absolute sense. Instead, professional focus is firmly placed on stimuli that follow the behavior. Reinforcers are stimuli that increase the probability of the operants reoccurring. Aversives are punishing consequences said to decrease the probability of the behavior's reoccurrence.

In 1949, researchers at Indiana University were the first to tie Skinnerian psychology to people with significant disabilities. In the introduction to the study appearing in the *American Journal of Psychology,* Fuller (1949) first described rather mixed results of stimulus-response (i.e., Thorndikian and classical) conditioning using people with disabilities as subjects. He noted, for instance, that while one experiment showed "subnormal children formed conditional responses to shock faster than normal children," another experiment failed in its "attempt to condition a salivary response to an 18-yr.-old idiot, probably due in part to [subject's] refusal to have a saliometer attached" (p. 587).

In contrast, the Indiana University experiment was an operant conditioning (i.e., Skinnerian) effort using an 18-year-old "vegetative idiot" (p. 588). The researchers deemed desirable the subject's movement of his right arm. To increase this operant, they withheld his food for 15 hours, then waited for the behavior to be emitted. When the subject's arm moved, they injected sweetened milk into his mouth. The experiment was hailed as a success as the subject increased his right arm movements considerably. Fuller (1949) concluded:

> According to the attending physicians, Subject had not learned anything in the 18 years of his life—yet, by using the operant conditioning technique, an addition was made to his behavior which, at his level, could be termed appreciable. . . . For years many psychologists have experimented exclusively with infrahuman subjects. Perhaps by beginning at the bottom of the human scale the transfer from rat to man can be effected. (p. 590)

The Fuller (1949) experiment served as the genesis for the mass implementation of operant conditioning in programs for individuals with significant disabilities and initiated the scientific justification for the use of aversives on this population. Sobsey and Dreimanis (1993) noted:

> To apply the laboratory science of behaviorism to special education, it was necessary to model the special education classroom after the laboratory rather than the regular classroom. The highly controlled conditions that were considered to be necessary for teaching students with special needs were alien to and incompatible with the regular classrooms. The results have been catastrophic for students with disabilities. (p. 6)

Most recently, accumulated research demonstrates that a wide range of instructional methods are available that not only are more effective than use of aversives and behavior modification in general but also do not inflict pain on, humiliate, dehumanize, or overly control or manipulate individuals with disabilities. Alternative approaches that are proven to be effective attempt to identify the individual's purposes in behaving as he or she does and offer support and education to replace dangerous or disruptive behaviors with alternative behaviors that are positive and will achieve the individual's needs.

The international disability advocacy organization, TASH (2004), has publicly called for an end to all use of aversives:

> Be it resolved, that TASH, an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field, affirms the right of all persons with disabilities to freedom from overly restrictive procedures and from aversive or coercive procedures of any kind. TASH is unequivocally opposed to the inappropriate use of restraint and to the use of overly restrictive and aversive procedures under any circumstance and calls for the cessation of the use of all such procedures.

—Christopher Kleiwer

See also Euthanasia.

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AYRES, A. JEAN (1920-1988)

American occupational therapist and scholar

A. Jean Ayres, an occupational therapist and a clinical psychologist, pioneered development of therapy for children who have subtle neurological impairments. Her work with children with cerebral palsy and learning disabilities led to the development of the sensory integration theory. This theory attempts to explain how certain learning or behavioral problems can be based in difficulties of processing sensations, such as touch, movement, sight, and sound. Children with sensory integration problems exhibit insecurity or fear of movement and consequently can have difficulty with ordinary activities such as playing with toys and doing self-care.

During her 35-year career, Ayres wrote several books and published multiple scholarly articles addressing her theory and techniques for clinical application. In 1976, she founded the Ayres Clinic where she evaluated and treated children using the approach she developed. Sensory integration therapy stresses detailed evaluation and understanding of each child's unique sensory style and challenges as a basis for providing the child appropriate opportunities to learn how to process and use sensory information to enhance skill in performance.

Today, sensory integration theory continues to evolve and is one of the most extensively researched and developed models of practice in occupational therapy. The approach has evolved away from a more exclusive focus on remediation of the underlying sensory processing impairment to emphasize environmental adaptation, self-understanding, and personal management of sensory challenges.

—Eynat Shevil

See also Occupational Therapy.

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B

▣ BABY BOLLINGER (1915–1915)

American victim of infanticide

"Baby Bollinger" (first name: Allen) was born to Anna and Allen Bollinger at the German-American Hospital in Chicago, Illinois. The seven-pound Baby Bollinger was diagnosed with multiple physical anomalies and became the first victim in a string of public infanticides of disabled babies committed by the head of staff at the hospital, Dr. Harry Haiselden. The doctor declared Baby Bollinger a "monster," a "pitiful bundle of semi-life." Anna Bollinger was encouraged to allow her baby to die by withholding life-saving surgery. "I want my baby. But the doctor has told me . . . I want him to live—but I couldn't bear to think of how he would suffer . . . how he would so often curse the day he was born. So I agreed with the doctor." On the day of Baby Bollinger's death, a Chicago newspaper printed the following description of him: "A pink bit of humanity lay upon the white cloth. Its blue eyes were wide open. Its hair was brown and silky, it dug at its face with little fists. It cried lustily as it drew up chubby legs and kicked out. It seemed quite vigorously informed with life."

—Sharon Lamp

See also Eugenics; Infanticide.

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▣ BANK-MIKKELSEN, NIELS ERIK (1919–1990)

Danish reformer

Niels Erik Bank-Mikkelsen, an early champion of normalization, was born in Denmark in 1919 and received a degree in law in 1944 from the University of Copenhagen. During World War II, he joined the Danish resistance movement, was captured, and interned in a Nazi concentration camp. He developed the concept of normalization in response to his perception that institutionalized people with disabilities were treated only slightly better than concentration camp inmates. Following the war, he entered the Danish Ministry of Social Affairs. In 1950, he moved to the Danish Service for the Mentally Retarded, becoming departmental head in 1959.

He introduced the concept of normalization in a piece of Danish legislation called the 1959 Mental Retardation Act. He described normalization as a means to ensure people with this diagnosis the right to the same community-based existence as their peers without disabilities, including clothing, housing, education, work, and leisure. Normalization was seen as a way to ensure that this population received the same legal and human rights given to other citizens. In 1968, Bank-Mikkelsen received the Kennedy Foundation

Award in recognition of his work. In 1971, he became the Director of the Department of Care and Rehabilitation of the Handicapped, Danish National Board of Social Welfare, and was instrumental to the 1980 formation of Denmark's Central Committee on the Handicapped.

—Pamela Block

See also Bengt Nirje; Normalization.

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▣ BARBELLION, W. N. P.

(1889–1919)

English naturalist and author

The fledgling scientist and writer W. N. P. Barbellion, born Bruce Frederick Cummings, kept a journal from the age of 13 almost to his death. Earlier parts show the lad's abilities as a naturalist, a largely self-taught thinker, and voracious reader. When he learned in 1915 that the ailments long plaguing him arose from "disseminated sclerosis" (multiple sclerosis), the journal recorded a race against time to achieve some large ambitions before his body collapsed. He was by then married, had had scientific papers published, and held a minor post at the British Museum of Natural History. Barbellion (1984) continued "tinkering about in the Museum," though he found it "excoriating to be thus wasting the last few precious days of my life in such mummery merely to get bread to eat" (pp. 282–283), against a background of the Great War across Europe. A bowdlerized edition of his journal, published in 1919, impressed most of the critics with its freshness and lively acumen. Barbellion died knowing that he had made his mark in the world of human self-knowledge. Ironically, despite republication in the late twentieth century, his work remains practically unknown and unused by the disability movement.

—Kumur B. Selim

See also Autobiography; Multiple Sclerosis.

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▣ BARKER, ROGER GARLOCK

(1903–1990)

American scholar and author

Just after World War II, Roger Barker, while on the faculty in psychology at Stanford University, was asked by the Social Science Research Council to conduct a comprehensive review of the psychological literature on physical disability to help meet the needs of returning war veterans with injuries. Not content with an annotated bibliography of the literature, Barker, in collaboration with Beatrice A. Wright, Lee Meyerson, and Mollie Gonick, published an extensive theoretical and research monograph dealing with the social psychology of physique, disability, and illness. The monograph was revised in 1953.

In this work, Barker applied Kurt Lewin's field theoretical concepts of new and overlapping psychological situations to problems of physique, physical disability, and illness. He coined the term *somatopsychological relation* to refer to the question of how variations in physique affect the psychological situation of a person by influencing the effectiveness of the person's body as a tool for actions or by serving as a stimulus to the person or others. This pioneering monograph helped to establish the psychology of physical disability and rehabilitation as a research and professional discipline and to the launching of the division on Rehabilitation Psychology of the American Psychological Association.

—Phil Schoggen

See also Kurt Lewin; Psychology.

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BASHSHAR IBN BURD

(714/715–783/784)

Arab poet and critic

The renowned blind poet Bashshar ibn Burd spent much of his life at Baghdad. He was probably born blind, though some writers argue that he lost his sight later. Efforts have been made to elucidate the question from his verses. Of the poetry of Al-A'sha and Bashshar, the celebrated critic Al-Jahiz wrote that these two blind men succeeded in catching truths that sighted people failed to discern, and Bashshar in particular excelled in doing so. Bashshar's self-reflexive wit gave rise to anecdotes, as when he broke wind in company and dismissed it as "merely a noise. Don't believe anything unless you see it!" Sometimes the joke turned against Bashshar. He publicly teased another savant, Said the Philologer, for academic fraud, by asking him the meaning of the word *jaranful* among the Bedouin. Said, who had himself invented this bogus word, was briefly silent, then came back, "The *jaranful* is one who has commerce with blind men's wives," causing hilarity among those present.

—Kumur B. Selim

See also Abu 'l-`Ala al-Ma`arri; Abu 'l Aswad ad-Duwali; `Ata ibn Abi Rabah; Jahiz, Al- (Abu Othman Amr bin Bahr); Khalil, Al-; Middle East and the Rise of Islam.

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BEECHER, HENRY KNOWLES

(1904–1976)

American anesthesiologist and researcher

Henry Knowles Beecher was an outspoken advocate of ethical standards in human subjects research and a pioneer in the study of pain, analgesia, and the placebo effect. He was also influential in the growth of anesthesiology as an independent medical specialty. Born in Kansas in 1904, Beecher earned his medical degree from Harvard Medical School in 1932. After early surgical training, Beecher was appointed Chief of Anesthesia at the Massachusetts General Hospital, despite having no formal education in anesthesia. In 1941, Beecher was named the Dorr Professor of Research in Anaesthesia at Harvard University, the first endowed chair of anesthesia in the world. Beecher's career was interrupted by service in World War II, when he observed pain responses of battle-wounded soldiers to be quantitatively different from those of surgical patients. Later, Beecher compared morphine and placebo to investigate psychological context in the physiology of pain control. This work has led to Beecher's appellation, "father of the prospective, double-blind, placebo-controlled clinical trial."

Beecher will be remembered most for his stance on human experimentation. He argued for informed consent by research subjects, and he condemned research that did not demonstrate potential benefit to patients as ethically unjustifiable. His landmark 1966 article in the *New England Journal of Medicine* chronicled 22 published studies with ethical infractions and consequently stimulated U.S. researchers to obtain informed consent prior to experiments.

In 1970, Beecher retired and received the Distinguished Service Award from the American Society of Anesthesiologists. Beecher died in 1976.

—Hugh M. Smith

See also Consent to Treatment; Ethics; Pain.

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BEERS, CLIFFORD WHITTINGHAM (1876–1943)

American advocate

Clifford Whittingham Beers developed the concept of mental hygiene, the precursor of our term *mental health* and the basis of much of prevention emphasis.

A Yale graduate who shared his struggles with mental illness openly in his autobiography, *A Mind That Found Itself* (1908), Beers garnered the support of mental health professionals and the public alike in an effort to advance the fledgling sciences of psychiatry and psychology. As founder of the Connecticut Society for Mental Hygiene (1908) and the National Committee for Mental Hygiene (1909), these groups picked up the term *mental hygiene* coined by Adolf Meyer, and developed an educational and reform movement for care of the mentally ill.

Beers's emphasis on prevention and his own example of recovery from a severe illness in his early adult life could be likened to the abolitionist efforts against slavery. As an articulate insider of Yale intelligentsia and some of the best-known private and public asylums of his day, Beers crafted a vision of recovery that engaged others and caught the attention of mental health professionals. His autobiography provided a balanced, substantive view into mental illness, allowing others to view compassionately and realistically the struggle of the human mind to come back from this loss. As a businessman and a communicator, he played a major role in formulating mental health policy by establishing a database on mental institutions, counting the number of individuals served by these institutions, and the psychiatrists serving there. Among the legacies of Beers's courage is the National Mental Health Association, formed in 1950. This organization's mission is to continue Beers's goals of "spreading tolerance and awareness, improving mental health services, preventing mental illness, and promoting mental health."

—Patrick H. Tolan
and Karen Taylor-Crawford

See also Advocacy; Autobiography; Mental Illness.

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BEGGING

People with disabilities have begged throughout history and across the world. They have asked for money and other kinds of charity. Peddling, the selling of typically inexpensive items, can be similar to begging. Begging is done by individuals and in more organized ways. Societies have supported and opposed begging by those with disabilities. Begging by those with disabilities reflects their subordinate position in society.

People with disabilities have begged for thousands of years. In ancient Egyptian and Hebrew societies, blind people often begged. The Bible records that Jesus encountered blind people who begged. While individuals born with disabilities in ancient Greece were often killed, those who became disabled later in life were spared. Some who were spared turned to begging, often near well-traveled places such as temples. During the Middle Ages, begging by those with disabilities was widespread. Many works of art have associated disability with begging.

Begging continues today, though it may be more prevalent in developing countries. Most people with disabilities live in developing countries, where opportunities for them to earn a living without begging are often few. Begging becomes a means for survival. It may be the most common employment worldwide for those with disabilities.

Similar to begging is peddling. For example, some deaf people sell cards printed with the manual alphabet and other small items at airports and other public places. They may ask the recipients to "spend" whatever they wish. The unskilled playing of a musical instrument by a blind person in order to receive donations from passers-by is comparable to begging.

Begging by those with disabilities has been an individual and an organized enterprise. Adults have enlisted disabled children to beg. They have even maimed children in order for them to beg more successfully. During the Middle Ages as competition among beggars occurred, guilds and brotherhoods were established, including ones for blind beggars. Pensions have been provided to beggars, as they were to elderly, blind beggars in Italy in the fourteenth century. Some deaf peddlers, at times illegal immigrants who do not know well the language of their host country and have little education, have been organized into peddling rings under the control of deaf or hearing bosses.

Communities have supported begging by those with disabilities. Disabled people have often been viewed as the deserving poor. They deserved the charity of those more fortunate. Religions such as Christianity, Hinduism, and Islam teach their followers to show charity toward those in need, including those with disabilities. In the ancient world, blind people were assigned the role of beggar. Statutes in France from the mid-fourteenth century governed the begging by blind residents for the benefit of their entire community. During the Middle Ages, the church at times supported begging by those who were blind by allowing them to beg near their entrances or on church grounds. Laws restricting begging by nondisabled people sometimes made exceptions for those with disabilities, as did statutes in more than a dozen states in America in the early part of the twentieth century that made exceptions for blind people who begged.

Societies have also discouraged or prohibited begging by those with disabilities. Begging became so widespread during some eras that disabled beggars were viewed with contempt, as dangerous rascals, with suspicion and hate. Laws were enacted to limit begging.

As societies industrialized, begging may have become less accepted. Industrialization emphasized paid work as the way to contribute to society. Work increasingly became a measure of a person's worth. Begging was not paid work that contributed to society. Furthermore, with the development of the Enlightenment, the view spread that people with disabilities could be, should be, educated in order to be productive members of society. Begging was contrary to this understanding of those with disabilities.

Begging expresses a complex relation between people with and without disabilities. It relies on the sympathy, pity, perhaps relief, and maybe fear of the nondisabled donor. It enacts interpersonally the larger social relation of inequality between those with and without disabilities. Yet when people with disabilities beg, they also assert themselves. They make themselves visible instead of hidden and ask, even demand, to be compensated for the inferior position the nondisabled world puts them in. Begging may help reproduce the subordinate position of those with disabilities, but it is also a rational response to limited opportunities. Until societies enable all members to sustain themselves through paid work or other means, some people with disabilities will beg.

—*Paul Higgins*

See also Charity; Poverty.

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BEHAVIOR THERAPY

Behavior therapy refers to a broad range of theories (hypotheses about factors that contribute to the prediction and control of behavior) and a set of treatments that derive from these theories designed to change behavior that is disruptive to patients' lives and functioning. In 1919, John Watson published *Psychology from the Standpoint of a Behaviorist,* and in his preface he states:

> The present volume does some violence to the traditional classification of psychological topics and to their conventional treatment. For example, the reader will find no discussion of consciousness and no reference to such terms as sensation, perception, attention, will, image, and the like. These terms are in good repute, but I have found that I can get along without them. (p. viii)

Watson proposed that the aims of psychology were the prediction and control of behavior. It is reputed that a major newspaper of the day ran an article with the headline "Psychology Loses Its Mind." Other early contributors to the theory and practice of behavior therapy were Ivan Pavlov (respondent conditioning), B. F. Skinner (operant conditioning), Joseph Wolpe (desensitization), Albert Bandura (social learning theory), and Aaron Beck's and Albert Ellis's independent development of cognitive behavior therapy. What characterized these diverse thinkers and their paradigms was an adherence to the scientific method for establishing principles of learning and functioning that formed the basis of their theories and therapeutic methods.

There are three major disabling conditions from a psychiatric perspective: developmental disability, autism, and schizophrenia. Behavior therapy has developed effective treatment strategies for each of these conditions primarily using the operant paradigm, or contingency management, going back more than 40 years.

Before the 1960s, developmentally disabled people were largely warehoused in residential and hospital settings with very little hope for any other life. With the advent of behavior modification programs focusing on verbal behavior, social skills, and independent living skills, most of this population can live more normal lives working in lower-level jobs or sheltered workshops and living in independent or semi-independent (supervised) settings.

Similarly, Ivar Lovas's pioneering work, starting back in the 1960s, with autistic children using intensive operant conditioning procedures on acquisition of verbal behavior, communication skills, social skills, self-care, and independent living skills has increased substantially the proportion of this population able to live more normal lives (some entirely normal) outside of institutional settings.

Schizophrenia is another area in which major contributions have been made by behavior therapy since the 1960s. Gordon Paul's seminal research showed clear superiority for a token economy treatment program over milieu and standard state mental hospital care. Patients were more functional in terms of symptom reduction, social/communication skills, and independent living skills, as indicated by higher discharge rates and lower relapse rates (ability to function and maintain themselves in the community). Even more impressive is the fact that these results were achieved without the use of medication. More recently, cognitive therapy and behavioral systems therapy are being used effectively with patients and their families to further enhance the patient's ability to live in the community.

In addition to the above three conditions, the crippling effects of severe depression and anxiety can result in disability. Disorders such as major depressive disorder, bipolar disorder, panic disorder with agoraphobia, posttraumatic stress disorder, obsessive-compulsive disorder, as well as other anxiety disorders, have been the focus of a great deal of research resulting in the development of effective treatment protocols. For more than 30 years, Beck and his colleagues have been developing cognitive therapy as a treatment of choice for depression. During the same time frame, Peter Lewinsohn and, more recently, Neil Jacobsen with his behavioral activation therapy, have effectively approached depression from an operant perspective. Exposure and response prevention (ERP), which was pioneered by Edna Foa with obsessive-compulsive disorder, and later by David Barlow with panic disorder with and without agoraphobia, has become the treatment of choice for anxiety disorders, producing significant improvement rates of between 70 and 80 percent.

Other potentially disabling conditions such as attention deficit disorder with or without hyperactivity (ADD and ADHD), substance abuse, and borderline personality disorder have also been the focus of attention from behavioral researchers and clinicians. ADD and ADHD have been treated for many years with incentive programs focusing on academic performance and prosocial behavior, as well as parent training programs. More recently, Joel Lubar pioneered the development of neurofeedback therapy, a form of conditioning therapy focusing on brain wave patterns as a promising treatment for, in particular, ADD. Sophisticated behavioral approaches to substance abuse using a wide variety of behavioral techniques to target the multifaceted problems of this population (e.g., functional analysis of drinking behavior, self-management strategies, social skills, self-soothing and emotional regulation skills training, cognitive therapy, couples' therapy, and relapse prevention strategies) have been developed. Marcia Linehan's dialectical behavior therapy (DBT) and Jeffrey Young's schema therapy are the only psychosocial treatments for borderline personality disorder that have demonstrated efficacy.

Over the past 80 years, major contributions to the treatment of diverse disabling conditions have come from the operant, respondent, social learning, and cognitive paradigms. And over those same years, as might be expected, controversies have arisen. An early controversy involved the symptom substitution hypothesis;

that is, behavior therapy targets superficial symptoms rather than deeply rooted causes, and thus new symptoms will emerge. Another controversy involved the coercive nature of behavior modification programs in hospital and prison settings. The movie *A Clockwork Orange* raised a controversy about the use of aversive conditioning. In actuality, however, the goal was to create a stable disability of sorts (inhibited libido and erectile dysfunction), but if Alec's demonic smile at the movie's end is any indication, the goal was not achieved. Many technologies can be abused (e.g., cars result in a high number of injuries, disabilities, and deaths, as do guns, industrial waste, nuclear energy, and even food). The key here is in ensuring the knowledgeable, compassionate, and ethical use of an effective technology through well-conceived and comprehensive research, training, and monitoring of practice.

—*Michael B. Evans*

See also Agoraphobia; Anxiety Disorders; Autism; Developmental Disabilities; Obsessive-Compulsive Disorder; Panic Disorder; Posttraumatic Stress Disorder; Psychiatric Disorders; Schizophrenia

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BEHAVIORAL DISORDERS

Behavioral disorders can be defined as the state in which youths under age 18 behave persistently and repetitively in ways that violate the basic rights of others or major age-appropriate cultural, or ethnic norms. The person is more sick than wicked. When behavioral disorders occur after the age of 18, they are considered to be personality disorders.

There are four criteria to diagnose behavioral disorders. To make the diagnosis, at least three should be present during the past 12 months, and at least one should be present for six months:

1. *Physical aggression:* This includes physically cruel behavior toward people and animals, initiating physical fights, using dangerous weapons such as a knife or a gun against others, robbing, or forcing someone into sexual activity.

2. *Deliberate destruction of others' property,* with or without fire setting, to cause serious damage.

3. *Deceitfulness or theft:* This includes breaking into another's home, building, or vehicle; lying; and stealing (including shoplifting).

4. *Serious violations of rules:* This includes often staying out at night despite parental prohibitions (before the age of 13); running away from home overnight at least twice; frequent truancy from school before the age of 13. In many Eastern countries, however, truancy at any age is considered as a behavioral disorder—an example of how differences in traditions lead to different diagnostic criteria.

To fit the diagnosis, these behaviors must also significantly affect performance (academic, social, vocational, or personal skills); hence behavioral disorders are considered to be disabilities. Patients who suffer from behavioral disabilities also are unable to learn or work, and these disabilities are not due to intellectual, sensory, or health factors. These patients also lack the ability to build or maintain satisfactory interpersonal relationships.

Because the diagnostic criteria of behavioral disorder vary widely, its manifestations at different stages differ, and because of differences in the adopted methodology, it is impossible to determine precisely its prevalence. However, it is considered to be a common problem in children and adolescents. In the United States, the condition is more prevalent among boys (6–10 percent) than among girls (2–9 percent). The prevalence is more in urban and suburban than rural settings, and even greater in overcrowded cities.

Behavioral disorders can be present with, or derive from, biopsychiatric disease (mood disorders, psychosis, attention-deficit hyperactivity disorder), organic impairment, and mental retardation. Although some of these children and adolescents have family history of behavioral disorders (which might indicate a genetic role), in most cases family, socio-economic, and environmental factors contribute heavily to the genesis of behavioral disorders. Conduct disorders can be complicated by drug abuse, alcoholism, AIDS, dropping out of school, and criminal behavior.

Only a fraction of children with this disorder are treated. Family and school intervention, psychotherapy, cognitive-behavioral therapy, and medications (psychostimulants, antidepressants, antipsychotic, anticonvulsants) have been successful.

The most important preventive measure is the establishment of a strong and cohesive family, with a clear policy of child-rearing practices, stressing the importance of religious and social factors.

—Marwan M. Al-Sharbati

See also Crime and Delinquency; Parenting and Disability.

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BELL, ALEXANDER GRAHAM (1847–1922)

American (Scottish-born) inventor and scientist

Alexander Graham Bell, inventor of the telephone, was one of the foremost proponents of a nineteenth-century oralist movement in Deaf education. Bell used his international fame to promote a philosophy that American deaf children should be taught to speak and taught only through articulation and speech-reading, with no use of sign language. The oralist ideology was very much a product of its times, riding the late-nineteenth-century wave of nativism and social Darwinism to promote a view that Deaf people should be linguistically and socially assimilated into a monolingual, auditory, speaking society.

Bell was one of a number of scientists interested in questions of heredity who would go on to found the American eugenics movement. Among his publications was the 1883 *Memoir on the Formation of a Deaf Variety of the Human Race* in which he claimed the intermarriage of Deaf people would invariably lead to a Deaf subset of humanity. This claim proved false, but would recur periodically among scientists and the general public over the next decades.

Bell was born to a Scottish elocutionist and his deaf wife in Edinburgh on March 3, 1847. His marriage to one of his first deaf pupils, Mabel Hubbard, was by all accounts a happy one, lasting 45 years. Both his mother and his wife did not use sign language. Bell died on August 2, 1922, in Nova Scotia, Canada.

—Joseph J. Murray

See also Audism; Deaf Culture; Eugenics; Sign Language; Speech and Language Pathology.

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BELL'S PALSY

Bell's palsy was named in honor of, but not by, the Scottish surgeon-anatomist (1774–1842) who discovered in 1821 the difference between the fifth cranial nerve that gives the face sensation (trigeminal nerve) and the seventh cranial nerve that gives the face expression (facial nerve).

Bell's palsy refers to a specific type of sudden, unexpected onset of facial paralysis on one side of the face and is the most common cause of facial paralysis in all age groups. It is a diagnosis of exclusion (idiopathic), meaning that all other causes of facial paralysis have been sought and excluded. This distinction is important because there are definable other causes of sudden facial paralysis that should be detected and treated differently; some of these may be quite dangerous, such as cancer, nonmalignant tumors, infections, and trauma.

Recently, herpes simplex virus, type 1, the common cause of fever blisters, has been implicated as a cause of some cases of Bell's palsy. Because of this, antiviral medications have begun to be used in conjunction with orally administered corticosteroids, such as prednisone, a commonly used treatment for Bell's palsy. However, there is little scientific evidence to prove these treatments are helpful.

The physical impairment from Bell's palsy falls in two time domains, immediate and late. Immediate impairment is the dysfunction of the facial nerve (seventh cranial nerve), resulting in complete paralysis or partial paralysis (also known as paresis). The resulting disability from this impairment is the inability to close the eyelids, thus failing to lubricate and protect the eye; the inability to express emotions or produce voluntary movements, such as smiling, on that side; and difficulty eating with the mouth fully closed. Because all cases of Bell's palsy recover to some degree, but not necessarily to normal, late impairments are common. Late impairments are permanent paresis, synkinesis, and contracture. Synkinesis is the concurrent movement of a portion of the face in a region other than the one voluntarily or emotionally moved, for example, winking when trying to smile. Contracture is the increased resting tone of the side of the face, which leaves the patient with an eye more closed than normal and a mouth with a permanent smirk. Disabilities from these late impairments are the inability to express oneself completely, especially smiling and softening of the eyes in the smiling process, and the inadvertent transmission of incorrect nonverbal facial messages, such as winking while eating or permanently smirking. Excessive tearing while eating, known as “crocodile” tears, may occur and impair or distort communication, such as tearing in one eye during a romantic dinner.

Facial expressions in human communications are important in both the receptive and the expressive modes. Because Bell's palsy is more common during the teenage and early adult years, times of important social development, the disabilities may be especially socially traumatic. Similarly, infants learn to detect facially expressed emotions and develop accordingly. Facial disfigurement may be distressing to the receptive infant and to the expressive sibling, parent, or grandparent who may look quite different with Bell's palsy.

—*J. Gail Neely*

See also Neurological Impairments and Nervous Disorders; Paralysis.

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BIESALSKI, KONRAD (1868–1930)

German pediatrician and reformer

Konrad Biesalski was a pediatrician, orthopedic specialist, and the founder of the rehabilitation policy for the physically disabled (“cripples’ care”) in Germany. He was born in Osterode/Prussia and studied medicine in Halle and Berlin. In 1894, he passed his Boards, after which he got his Ph.D. in medicine and became an assistant doctor in Berlin and Würzburg. Biesalski initiated the first census of physically disabled youths, or “cripples” as they were officially known, in 1906. Through cure, education, and employment of the affected persons, he wanted to prevent the economical harm caused by the social needs of the physically disabled. His motto was “Vom Almosenempfänger zum Steuerzahler” (“From alms recipient to taxpayer”). In addition, in 1906 Biesalski opened a small institution in Berlin. After he had founded the *Zeitschrift für Krüppelfürsorge* (*Journal for the Care of Cripples*) in 1908, the Deutsche Vereinigung für Krüppelfürsorge (German Organization for the Care of Cripples) was created on April 14, 1909, as an umbrella organization for the care of the physically disabled.

In 1911, with the *Leitfaden der Krüppelfürsorge* (*Manual for the Care of Cripples*), Biesalski published a standard work for this new field of social policy. On May 27, 1914, he opened the Oskar-Helene-Heim für Heilung und Erziehung gebrechlicher Kinder (Oskar-Helene-Home for the Cure and Education of Frail Children) in Berlin, which soon became internationally known as a model facility. With the Kriegskrüppelfürsorge (care of war cripples) initiated by him during World War I, Biesalski laid the foundation for establishing specialized medical treatment for the first time, along with special institutions, and the prospect of social and professional rehabilitation. The Preußische Krüppelfürsorgegesetz (Prussian Cripples’ Care Law) of 1920 enacted, for the first time, a right to medical care, and scholarly and occupational education for the physically disabled. In 1928, the Museum der Deutschen Krüppelfürsorge (German Cripples’ Care Museum) opened in the Oskar-Helene-Home. Biesalski died two years later on January 28, 1930, of a cardiac infarction.

—Petra Fuchs

See also Advocacy Movements: Germany; *Cripple*.

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BINET, ALFRED (1857–1911)

French psychologist

Universally known as the developer of the *quotient d’intelligence*, Alfred Binet was most of all an innovative psychologist. Initially, he undertook legal studies, receiving a law degree in 1878, but he also expressed interest in natural science. In 1883, he began work in Jean-Martin Charcot’s laboratory at Salpêtrière Hospital in Paris. The birth of his two daughters provided him the opportunity to study child psychology, more particularly analysis of individual differences in connection with genetic inheritance and education. In 1892, he had his first contact with Theodore Simon, who solicited his counsel for the education of the abnormal children for whom he was in charge.

His question about abnormal children is capital: What distinguishes them from “normal” children; is it a difference of degree or nature? And how to define, in a general way, this concept of difference, and how to evaluate it? In 1904, he and Simon brought about the creation of a departmental committee, whose objective was the examination of two problems: the diagnosis of the states of mental retardation and the education of abnormal children.

Six months later, he presented his test of diagnosis at the International Congress Psychology (Rome, 1905), which was first version of the future "metric scale of the intelligence." In a clinical approach of epistemology, Binet transformed the diagnosis into numbers representing the intellectual level to make measurement an effective instrument of backwardness. The next few years were devoted mainly to the development of the famous test known as the Binet-Simon Test, whose centenary was celebrated during 2004. Binet died on October 28, 1911, at age 54.

—Henri-Jacques Stiker

See also IQ.

▣ BIOETHICS

This entry reviews the major intersections of disability studies and bioethics, describing the principal issues that have sparked controversy between disability rights activists and scholars and mainstream bioethicists. The discussion lays out key arenas of struggle between those with a disability rights perspective and those within bioethics; it also comments on issues that have received less attention from within disability rights but that could benefit from a dialogue.

CONVERGENCE AND CONTRAST WITH DISABILITY RIGHTS

What characterizes the field of bioethics is its concern with fundamental questions of health and illness; life and death; autonomy, dignity, personhood, and humanity; the relationship of medicine to nature; the relationship of health to well-being. Both bioethics and the disability rights movement have appeared only in the past half-century, and each has emerged in reaction to a dominant paradigm in the medical and helping professions. Recognition of bioethical issues first arose when the public learned that physicians and scientists all over the world in the first half of the twentieth century engaged in widespread abuse of many classes of vulnerable citizens by failing to obtain their consent to serve as subjects in dangerous medical research. Prisoners, concentration camp inmates, residents of institutions for the psychiatrically and cognitively disabled, and African American sharecroppers had all been victims of government and professional research interests. Discovery of these abuses spurred demands for regulation, reform, and new oversight of governmental and professional behavior.

The early U.S. independent living and disability rights movements exemplified much the same challenge to professional domination and demands for self-determination and autonomy. Adults with disabilities and advocates for disabled children protested abuses by powerful government and philanthropic institutions that historically had usurped the decision-making authority of parents and guardians, using the same language as physicians, lawyers, philosophers, and theologians who questioned the power and paternalism of medicine in conducting medical research and using new life-sustaining technologies.

If disability and bioethics began with similar concerns, they have also broadened their focus in similar ways. As disability scholarship and activism have moved from demands for individual control and self-determination to calls for sweeping societal change, bioethics has recognized that the complex life-and-death decisions made by individuals and families cannot remain its only concern. Recent debate also focuses on the implications of life-creating and life-changing technologies, on questions of what constitutes a just distribution of resources for medical care, and on which life situations should properly come under the purview of medicine.

But if bioethics resembles the disability rights movement in its commitment to patient autonomy, its skepticism about professional authority and paternalism, and its support of consumer rights, it has never shared its understanding of disability or its valuation of lives with disabilities. The dominant bioethics voices have argued that human life has to be respected and valued, but not necessarily at any cost or in any state of impairment. Now that human mastery over nature permits lives to be sustained despite significant illnesses and disabilities, it is incumbent on individuals and societies to set limits on which medicine and technology should be used for these purposes. Instead of the medical question, "Can this life be saved?" bioethics invites the question, "Should this life be saved?" Bioethics challenges the disability community by asking whether it is appropriate to use medical technology to sustain the life of someone who would be left with a severe disability.

For disability scholars, these very questions, and the haste with which bioethicists have answered them negatively, reveal a fundamental misunderstanding of the nature of disability. Bioethics has presumed that impaired mobility, physical deformity, sensory deficits, or atypical learning style or speed explain why people with disabilities are less likely than their fellow citizens to be educated or employed, and more likely to live in poverty and isolation. Most bioethicists uncritically adopt what Gliedman and Roth (1980) and Bickenbach (1998) termed the medical model of disability, as contrasted with the social or minority group models. Disability critics of standard bioethics reject the medical model, with its assumption that functional impairment is the sole or primary cause of what is presumed to be an unacceptable, unsatisfying life.

HEALTH, NORMALITY, DISABILITY, AND QUALITY OF LIFE

Those who embrace either the social or the minority group model of disability contend that prevailing bioethics understandings of impairment rest on two erroneous assumptions. First, the life of someone with a chronic illness or disability is permanently disrupted, in the way one's life can be temporarily disrupted by the flu or a back spasm. Second, if a disabled person experiences isolation, powerlessness, poverty, unemployment, or low social status, these are inevitable consequences of biological limitation. Many bioethicists generalize from the problems and disorientation that some people experience at the onset of a disability and assume the disruption is unchanged by rehabilitation, adaptation, mastery of new means to accomplish desired ends, or changes in the life plans one pursues. Many bioethicists also fail to recognize the extent to which disadvantages experienced by people with disabilities arise through society's lack of accommodation to the different methods of performing valued activities such as learning, communicating, moving, or taking in the world. Disability scholars counter, first, that life with disability is not the unremitting tragedy portrayed in medical and bioethics literature and, second, that the culprit is not biological, psychic, or cognitive equipment but the social, institutional, and physical environment in which people with impairments must function—a world designed with the characteristics and needs of the nondisabled majority in mind. For the past three decades, disability scholars and activists have argued that the main problem of disability is, indeed, the denial of civil, social, and economic rights, not the lack of health or functioning.

A substantial body of literature reveals that even before legal and political advances in the United States and other nations, but certainly since then, many people with disabilities have found satisfaction in their lives that was far greater than anything expected of them by members of the health and rehabilitation professions. When people with disabilities report unhappiness or dissatisfaction (a minority in every study), the sources resemble those in the lives of nondisabled people—inadequacies in financial security, work, or social and personal relationships. While impairment-related factors, such as pain or fatigue, sometimes contribute to unsatisfying relationships or employment difficulties, the greater frustrations come from barriers to incorporating the impairment into existing interpersonal and institutional life.

There are several plausible explanations for the gap in understanding between bioethicists and disability scholars. Few bioethicists identify as people with impairments or as members of the disability rights movement. The emphasis on self-sufficiency of many bioethicists leads them to doubt that anyone who cannot execute "normal" life tasks of eating, walking, or managing personal hygiene could live as well as someone who performs these tasks without human assistance. And their focus on individual cases, often to the exclusion of social and economic background conditions, reinforces the impression that even satisfied people with disabilities are a burden to their families and society.

In one area, cognitive impairment, disability scholarship often displays the same limitations of experience and understanding as bioethics. Like bioethicists, disability scholars are typically highly educated individuals who prize rationality and intellect, place a premium on "autonomy," and tend to denigrate, or ignore, the interests and rights of people deficient in those characteristics. But this bias and oversight have not gone unnoticed. From within the disability rights and bioethics communities, researchers have complained that the esteem given to intellect, rationality, and self-awareness leads some scholars to question the moral status or life quality of people with cognitive impairments.

The gap in understanding about life with disability has surfaced in two controversial areas of health care policy: (1) deciding whether to initiate, maintain, or withdraw life-sustaining treatment for impaired patients, particularly newborns, who cannot decide for themselves or communicate their preferences; and (2) deciding whether to test for impairments prenatally, and whether to abort, or decline to initiate pregnancy, if they are detected.

EXTENDING AND CREATING LIVES WITH DISABILITIES

Extending Lives: Newborns with Impairments

In the early and mid-1980s, U.S. disability rights adherents first challenged bioethics over decisions about standards of care for infants with significant disabling conditions who required immediate medical treatment. Should physicians counsel parents of children with Down syndrome who also had heart problems to let the infant die rather than treat the heart condition, leaving the infant with Down syndrome? Should parents of a child with spina bifida be permitted to refuse surgery to close the child's spine and reduce the risk of infection? Should parents of a child with bowel obstruction consent to surgery to remove a necrotic bowel to save the child's life, although long-term survival of a child with such obstruction is estimated at less than 1 in 10,000? Should a severely premature baby be placed on a respirator against the wishes of the baby's parents if chances of survival are negligible?

Rationales for withholding treatment focused on the suffering caused by potential treatments and the impairments themselves; on the suspicion that technology was being used to sustain children who would have short, painful, and miserable lives regardless of what was done for them; on the reluctance to impose further anguish on parents who might have to watch their child die slowly after fruitless medical procedures; on concern for the disappointment of parents who would not have the healthy child they expected and would instead have to raise one never free of disabling conditions; and on the conviction that the millions of dollars spent for such treatments could be better spent in other ways.

Disability critics rejected these rationales as both mistaken and unjust—mistaken in their assumptions about the quality of life possible for impaired infants and the burden they imposed on their families; unjust in denying treatment to one class of human beings. Concentrating on infants with treatable medical conditions, they maintained that denials of beneficial treatment represented discrimination against people with disabilities by the medical profession and frightened parents. If denying beneficial medical treatment to a nondisabled infant constitutes child neglect or abuse, so does denial of that same treatment to one with a disability. These discrimination claims appear to have changed prevailing practice. In 2000, most infants with Down syndrome and spina bifida born in the United States received medically indicated treatments, as did premature and low-birth-weight infants who—if they survived—became part of the disabled population. Most U.S. bioethics literature now concentrates on other topics, although there are no public retractions of the views that enraged the disability rights movement.

Creating Lives: Prenatal Testing and Selective Abortion

By the 1990s, bioethicists, health professionals, and the public generally accepted the claim that a live-born infant should get medical treatment to provide a chance at life. However, the vast majority of theorists and health professionals still held that prenatal testing, followed by pregnancy termination if a potentially disabling condition was detected, promoted family well-being and public health—it was simply one more legitimate method of reducing disability in the world. Disability rights scholars and activists raised the question of how the increasing use of prenatal testing and selective abortion affected the place of people with disabilities in the world. Opposition to prenatal testing has led to no highly publicized court cases, but the themes in the prenatal testing debate echo those in the earlier debate about disabled newborns.

Standard justifications for prenatal testing and selective abortion invoke the suffering or hardships of both the disabled child and his or her parents, although most disabled children are manifestly happy to be alive, and the burdens on their parents appear to differ from those facing the parents of nondisabled children mainly in degree, if at all. Disability scholars have challenged the empirical and moral assumptions that lie behind such conventional views. Parens and Asch (1999) described the disability rights critique of prenatal testing as follows:

> Rather than improving the medical or social situation of today's or tomorrow's disabled citizens, prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved. . . . In rejecting an otherwise desired child because they believe that the child's disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child's characteristics might occasion. (p. S12)

This disability critique, and the response from bioethicists, are discussed at greater length in the entry on reproductive rights. The debate illustrates the extent to which bioethics and disability scholars and activists continue to differ in their assessment of the quality of life with disability, a difference that recurs in two other contexts we will examine: life-and-death decision making by people with disabilities, and the relevance of disability to the allocation of scarce health care resources.

LIFE AND DEATH: DECISION MAKING

Most bioethicists oppose the medical treatment of patients against their expressed wishes, insisting on the right of competent adults to stop treatment, even if by doing so they ended their lives. The recognition of a right to self-determination concerning medical treatment has been partially extended to adults with cognitive impairments.

Most cognitive impairment leaves individuals with some means of understanding their situations and expressing preferences about how they are treated and who should decide for them when they cannot decide for themselves. It should be possible for people with nearly any disabling conditions to communicate about whether they find life and medical treatments worthwhile and acceptable to them. The bioethicists Buchanan and Brock (1989) recognized that persons unable to examine all long-range implications of a decision may nonetheless be able to provide valuable information to ultimate decision makers about their preferences and thus meaningfully participate in decisions about their lives and well-being. Several recent discussions by professionals familiar with people who have cognitive disabilities favor methods that would enable people who fall short of legal "competence" to reveal their decisional capacities, express their preferences, and, if possible, make choices about their medical treatment.

Many bioethicists, though, contend that difficulties in communicating preferences and making decisions can largely be preempted by using "advance directives" to express the prior choices of individuals who can no longer make their own wishes known. They also recommend the appointment of health care proxies to act on their behalf. Such legal devices might assist families and health professionals in dealing with treatment decisions for the millions of people who lose some of their cognitive and communicative abilities through stroke, Alzheimer's disease, or the like. However, they would be of no help to the lifelong disabled. Moreover, "living wills" or advance directives do not encourage people to think critically about which capacities and activities are essential components of an acceptable or good life.

From the standpoint of disability rights, the most serious flaw of advance directives is that noted by the bioethicists Dresser and Robertson (1989), who criticized the "orthodox" reliance on any advance statement of preferences. People who are not living with disabilities and cannot imagine that their lives as disabled would be satisfying make such statements in profound ignorance of relevant information and experience. Dresser and Robertson urged that nondisabled people evaluate treatment decision making from the perspective of the now-disabled individual. Their point is an important corrective to snap assessments that "Mom would hate living like this" or "my brother's advance directive was explicit about stopping life support if he could not hear or speak"—despite the fact that the mother or brother appears to take great pleasure in the activities and experiences that remain possible for them. Admittedly, as Buchanan and Brock and others argue, people care about more than their current experiences. Even an apparently content person with severe dementia might prefer that his or her wish not to live in a disoriented, demented state be honored by following a validly executed advance directive. In general, bioethicists are more inclined than disability scholars and activists to let clear, emphatic pre-impairment directives override post-impairments preferences, especially if the latter are uncertain or ambiguous.

Furthermore, most case law has concerned individuals very likely to die without treatment. More problematic, and more revealing of the continuing chasm of perception between bioethicists and disability scholars, are those cases where apparently competent patients with disabilities seek withdrawal of treatment or physician assistance in suicide for conditions that are not terminal in this sense; conditions with which they could live for decades with technological support, for example, with spinal cord injury or multiple sclerosis. Bioethicists often equate requests to die in such conditions as equivalent to the requests of imminently dying people who wanted to avoid prolonging their lives by a matter of days, weeks, or months.

Most disability theorists and activists, however, construe these decisions to stop treatment entirely differently. They agree that people with disabilities deserve to have their views respected. However, they argue that such decisions are often made because people with disabilities have experienced constant discrimination, denials of information about life possibilities, inability to obtain legally available services and supports, and abandonment by family and friends.

Key to the differing appraisal of these cases is the different understanding of concepts of dependence, independence, and interdependence. Like the newly disabled people themselves, professionals construe the inability to execute life tasks such as dressing, toileting, or moving from place to place as demeaning dependence and as leading to inevitable feelings of embarrassment and humiliation. Disability rights adherents contend that independence need not be viewed in physical terms; rather, self-direction, self-determination, and participation in decision making about one's life are more genuine, authentic measures of independence or, better, universal interdependence.

These themes play out in the broader physician-assisted suicide (PAS) debate of the past two decades. As the bioethics debate shifted from terminating life-prolonging treatment to PAS, the disability rights community sounded a cautionary note with some influence on the mainstream bioethics literature and the case law. But that community does not speak with one voice. Two ideological strands of the disability rights movement offer divergent responses to PAS. The strand of the disability rights movement that stresses self-determination argues that disabled people are no more vulnerable in general to coercion, pressure from family, or victimization by society than anyone else and may benefit from legalized assistance in dying. These theorists are offended by what they see as the paternalism that leads some prominent members of the disability rights community to oppose PAS.

In contrast, the ideological strand that stresses biased social arrangements for people with disabilities holds that the legalization of PAS in a world of harsh prejudice, inadequate health care, unreliable social services, and frequent familial rejection would inevitably lead to its widespread abuse to hasten the death of vulnerable patients seen by society, and often by their families, as burdens.

While recognizing the legitimacy of both perspectives within the disability community, the fact remains that support for PAS among bioethicists reflects troubling assumptions about the quality of life with disability. As Bickenbach (1998) noted:

> It is telling that . . . there is never any suggestion that the right to physician-assisted suicide should extend to people who do not have a severe disability. Implicit in the judgments themselves . . . is precisely the prevailing prejudicial social attitude that having a disability is a sensible reason for committing suicide. (p. 130)

JUSTICE IN HEALTH CARE ALLOCATION

The sharpest conflicts between disability rights and bioethics have occurred in life-and-death situations. But the stigma and devaluation of lives with disability can take subtler, or less explicit, forms than the outright denial of treatment or "assisted" suicide, and these other forms need closer attention from bioethicists. One historically freighted example is the recurrent medical abuse of people with cognitive impairments, who often become research subjects without informed consent. At present, however, people with disabilities are more likely to suffer from medical neglect than unwanted attention. This is apparent both in the provision of reproductive services and in the allocation of scarce health care resources more generally.

Bioethicists who consider reproductive liberty as a fundamental human right have largely neglected the obstacles facing people with disabilities in pursuing parenthood. Sterilization is still forced on people with many impairments, especially with cognitive or psychiatric impairments, in nations such as Australia, Spain, and Japan. But even in societies that have rejected involuntary sterilization, people who need assistance with household and daily activities face obstacles to parenthood if they cannot acquire any additional services for child care. Neither bioethics nor the disability rights movement has undertaken a sustained discussion of what social accommodations are owed to those people who can experience the rewards of parenthood only with some assistance or supervision. The lack of attention to reproductive and parenting support reflects a broader devaluation of the health care needs of people with disabilities.

A chief concern for the disability community arises in the context of access to health care itself and whether—if at all—an individual's existing impairments should influence the types of services he or she receives. Disability has sometimes been used invidiously to deny people available treatments from which they could benefit. For example, someone with Down syndrome may be denied a kidney transplant, based on the assumption that he or she could not comply with treatment requirements, or on an evaluation that rated life with Down syndrome as less worthy of scarce organs because of its presumptively low quality.

Several different methods have been proposed to allocate health care based on its presumed effect on the recipient's "quality of life," as Dan Brock argued in 1993. Should priority be given to those considered "worst off," or to those whose presumed quality of life after treatment would be high? Different allocation schemes would have vastly different results for the world's disabled population. If societies choose to provide care to improve the conditions of the worst off, people with disabilities could receive care based on being considered worst off. However, if they choose to provide care to those expected to derive the most benefit in terms of maximal quality of life, stereotypes about disability and life quality could severely limit the care received.

Even if experts or nations achieved consensus on the version of social justice that should guide allocation decisions, there would be conceptual and empirical difficulties in ascertaining quality of life. From whose perspective should life quality be judged? If people with disabilities consistently indicate that their lives—even with problems—are more satisfactory to them than nondisabled people or health professionals believe, should their judgments be used in measuring life quality? If, instead, health professionals and nondisabled people become the judges of future life quality with impairments, people with disabilities will fare badly in allocation decisions based on expected quality of life.

MEDICAL INTERVENTIONS AND "CORRECTION" OF IMPAIRMENT

What about possible efforts to "cure" disability by cochlear implants, spinal cord regeneration, fetal tissue transplants, or gene therapy? Such actual or potential medical interventions to reduce functional impairment or restore species-typical function raise the issue of what makes something an "impairment" that one ought to correct, as opposed to a characteristic that one has no reason to change. Is being "short" a biological impairment or exclusively a socially constructed disability in a society that prizes height? The new paradigm of disability must play a role in deciding when growth hormone is a legitimate medical therapy and when it is an inappropriate enhancement. If individuals can gain hearing from cochlear implants, are they morally obliged to have them, and should they lose access to interpreter services if they decline, as Tucker (1998) asserted? Are people morally obliged to obtain any therapy that reduces impairment or restores species-typical functioning? If the disability rights movement would endorse surgery for an infant with spina bifida to increase mobility, is it equally acceptable to support parental interests in providing some hearing by virtue of a cochlear implant? Is deafness properly considered a culture, not an impairment? If somatic cell or germ-line therapy could safely correct detectable impairments in eggs, sperm, or embryos, should they become standard parts of medical care? Should people with disabilities support or oppose such measures, which do not exclude or select against individual lives but reduce the incidence of disabilities? Is having an impairment just one desirable or inconsequential form of human variation, or, even with just or optimal accommodation, is impairment always undesirable? Bioethics and disability studies must work together to understand the apparent importance of health and normal functioning and to explore the meaning of impairment and disability.

It seems fitting to close this discussion of the intersections of disability studies with bioethics by affirming what bioethics can learn from disability studies. Paul Longmore's (1995) description of the values needed for people to accept the disabled are values that, he says, would change orientations toward another regardless of disability. They would change bioethics and society in ways that could surely promote human rights for everyone: "not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community" (p. 9).

—Adrienne Asch and
David Wasserman

See also Death; Ethics; Euthanasia; Family: Law and Policy; Health; Health Management Systems; Impairment; Normality; Physician-Assisted Suicide; Quality of Life; Reproductive Rights.

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BIOLOGICAL DETERMINISM

The term *biological determinism* refers to claims that most human characteristics—physical, mental, and personality based—are determined at conception by hereditary factors passed from parent to offspring during reproduction. Of course, all human traits are ultimately based in the material nature of our being organisms (e.g., memorizing a poem involves changing molecular configurations at synapses, where nerve cells interact), but the term *biological determinism* has come to imply a rigid causation largely unaffected by environmental factors. Prior to the turn of the twentieth century and the rediscovery in 1990 of Gregor Mendel's work on heredity, a wide variety of hereditary causes were postulated (such as direct environmental effects acting on the mother's or father's germ cells or indirectly on the fetus via the mother during pregnancy). After the rediscovery of Mendel, theories of biological determinism came more and more to be formulated in terms of the new science of genetics, so that today *biological* and *genetic determinism* are virtually synonymous.

In the eighteenth and nineteenth centuries, theories of biological determinism were based on vague, often highly controversial ideas about of the nature of heredity. Since the concepts and tools were not available during that period to study heredity directly, biologists and anthropologists measured physical features of humans, trying to associate mental and personality traits with some anatomical (occasionally a physiological) feature, such as facial angle (angle of slope of the face from chin to forehead) or cranial index (ratio of lateral to vertical circumference of the head). Certain physical features, such as high cheekbones or a prominent eyebrow ridge, were often said to be indicative of criminal tendencies. With the growing acceptance of Mendelian genetics in the first half of the twentieth century, most theories of biological determinism came to locate the causal element in defective genes. With the revolution in molecular genetics during the second half of the century, defective genes became identified with altered sequences of the molecule of heredity, deoxyribonucleic acid (DNA).

Throughout its history, theories of biological determinism have been particularly applied to what were conceived of at the time as negative physical traits such as cleft palate, clubfoot, dwarfism, gigantism, foreshortened appendages, and social traits such as criminality, feeblemindedness, pauperism, shiftlessness, promiscuity, "feeble inhibition," manic depression, and hyperkinesis (hyperactivity). Many of these later conditions or traits we would refer to as disabilities today, and the claim that most or all of them are inherited was, and is, highly controversial. This is partly a result of the difficulty in obtaining rigorous data about the genetics of such traits, especially when there is no established definition on which all investigators can agree. (What *is* criminality or alcoholism, or when does exuberance become hyperkinesis?) It is also a result of the fact that so many other factors interact with whatever genetic elements are present that it is difficult to tease them apart. Thus, throughout recent history, attempts to show that certain disabilities were genetic have had little success.

One of the most prominent movements to apply genetics to understanding social and personality traits emerged early in the twentieth century as the eugenics movement. *Eugenics* was a term coined by British geographer, statistician, and general polymath Francis Galton (1822–1911), first cousin of Charles Darwin. By "eugenics," Galton meant "well" or "purely born," and he argued for planned breeding among the "best stock" of the human population, along with various methods to discourage or prevent breeding among the "worst stock." It was the belief of eugenicists such as Galton, his student Karl Pearson (1857–1936), and their American convert Charles B. Davenport (1866–1944) that most social problems were due to the accumulation of genetic defects, producing an increasingly disabled, or "degenerate," population. Society was deteriorating through the increased reproduction of the disabled—particularly the mentally disabled. Various forms of inherited mental disability were said to be the root cause of social problems as varied as crime, alcoholism, and pauperism (in all cases, it was claimed that low mental ability led to inability to cope in a complex society, and hence the turn to antisocial behaviors).

Using the newly developed IQ tests in the 1920s and 1930s, eugenicists proceeded to rank people into categories based on quantitative scores (normal = 90–110, high-grade moron = 70–90; idiot = > 50; imbecile = no ranking). In most cases, especially in the largest categories, those individuals with scores between 70 and 90, who were claimed to be genetically disabled were not disabled at all, simply disadvantaged (the poor, the uneducated, the immigrant who could not adequately interpret test questions). Nor was there much sound evidence that such cases were in any way genetically determined.

The eugenics movement in the United States, and especially Germany after the National Socialist takeover in 1933, carried through legislation specifically aimed at taking action against the disabled of all sorts, but again the mentally disabled in particular. In the United States, laws were passed in more than 30 states by 1935 allowing for the compulsory sterilization of those deemed to be genetically unfit in state and federal institutions such as mental hospitals, asylums, and prisons. Overall, in the United States more than 60,000 people had been sterilized under these laws by 1963. In Germany, similar laws (actually based on ones in existence in the United States) led to the sterilization of more than 400,000 people by the early 1940s. Sweden and Canada had similar laws allowing for sterilization of the supposedly genetically disabled.

One of the major consequences of widespread belief in biological (genetic) determinism is the underlying assumption that if a trait or condition is genetic, it cannot be changed: "Genes are destiny," genetic determinists have claimed. However, the relationship between what geneticists call the genotype (the actual genes an individual inherits) and phenotype (what traits they actually show) has turned out to be far more complex and unpredictable than previously thought. For example, cystic fibrosis (CF) is a multifaceted disease that is present in about 1:2500 Caucasians and can be severely debilitating. It is due to a recessive Mendelian gene (meaning that for it to show up phenotypically, the individual has to inherit the defective gene from both parents), and it has now been completely sequenced (meaning that every base-pair in the sequence of nucleotides that make up the DNA of the gene has been determined). Moreover, more than 1,000 mutation sites are known, and most have been related to different manifestations of the disease. However, one of the startling findings has been that even with the same mutated site within the gene, different individuals will show remarkably different phenotypes. Some will show early onset, others, later onset; in some, the kidney is most afflicted, while in others, it is the lungs. In some individuals even with the most common mutation, the effects are severe, while in others they are mild to nonexistent. Although the reasons for these differences are not understood, it is clear that both genetic background and environmental factors (such as diet) must play an important role. In other words, genes are not destiny even in cases where the genetic basis of a disability can be well understood. It is certainly not destiny when the genetic basis is unclear or circumstantial.

With modern genomics, the science of understanding complex genetic interactions at the molecular and biochemical levels, the possibility exists of treating such genetically based disabilities, such as diabetes type I, cystic fibrosis, or sickle-cell anemia (a genetic defect in the hemoglobin molecule) either with gene therapy (much more difficult at present) or pharmacologically, prescribing drugs that can perform and carry out the normal biochemical function of the defective gene. Social attitudes about what constitutes a disability, and how economic and social resources are to be allocated to deal with disabilities, change over time. In hard economic times, the disabled tend to be written off as "too expensive," often justified on the basis of "genetic determinism" (whether scientifically valid or not). Throughout its history, arguments for biological determinism have been employed more to restrict than to expand human potential.

—Garland E. Allen

See also Eugenics; Eugenics: Germany; Feeblemindedness; Walter Fernald; Henry Herbert Goddard; IQ; Sterilization.

BIOMECHANICS

Biomechanics is the study of the structure and function of biological systems using the methods of mechanics. Although the ideas and investigations that can be classified as biomechanics go back to Giovanni Borelli (1608–1679), who first described the basis of muscular and skeletal dynamics, the term *biomechanics* and research performed in this field have became well known only in the past several decades.

Contemporary biomechanics is a multidisciplinary field of science that combines physical and engineering expertise with knowledge from the biological and medical sciences. Biomechanics includes several main directions of research, for example, cardiovascular biomechanics, cell biomechanics, human movement biomechanics, in particular orthopedic biomechanics, occupational biomechanics, and sport biomechanics. As an example, sport biomechanics deals with performance improvement and injury prevention in athletes. In occupational biomechanics, biomechanical analysis is used to understand and optimize mechanical interaction of workers with the environment. Development of the biomechanics of labor focused on increasing worker efficiency without sacrificing labor safety. It resulted in the design of new tools, furniture, and other elements of a working environment that minimize load on the worker's body. Another development was clinical biomechanics, which employs mechanical facts, methodologies, and mathematics to interpret and analyze typical and atypical human anatomy and physiology.

Beginning during and after World War I and especially World War II, the focus on development of prosthetic limbs for management of the many wartime amputations led to major progress in rehabilitation medicine as a result of the application of biomechanics. Work in this area focused on increasing the mechanical efficiency of orthopedic implants that, for example, allowed those undergoing hip or knee replacement surgery to walk again. A biomechanics-research-based approach generated a major step toward improving walking for individuals with lower-leg amputation and children with cerebral palsy. As an example, development of a new class of prosthetic feet that store and return mechanical energy during walking allowed for reduction of the metabolic expenditure in amputees and made it possible for individuals with amputation to participate in athletic activities. The biomechanically based design of assistive devices, such as wheelchairs, and the optimization of the elements of the environment allow individuals with disabilities to improve their lives.

Application of biomechanics is wide-ranging as its diverse topics include everything from human gait to blood-flow dynamics. During the past decade, growing public opinion favoring investment in medical and health care research contributed to opening of new avenues in biomechanics. Among these are the use of biomechanical analysis in artificial prosthesis design (e.g., artificial heart and small-diameter blood vessels), the engineering of living tissues and organs (e.g., heart valves and intervertebral discs), biomechanics of injury prevention related to labor safety and vehicle accidents (from low-speed collisions with minor soft-tissue injuries to high-speed collisions with severe and fatal injuries), and biomechanical aspects of disability with the ultimate goal of improving the lives of individuals with functional impairments.

—Alexander S. Aruin

See also Amputation; Veterans.

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BIPOLAR DISORDER

Bipolar disorder (BPD) is a chronic, recurrent, disabling illness characterized by mood instability and associated with significant morbidity and mortality. Both biological and environmental factors are critical to its development. BPD is frequently complicated by other comorbid conditions that can impede proper diagnosis and treatment. Optimal strategies to manage bipolar disorders require medication, psychotherapy, and attention to concurrent psychiatric disorders.

BPD includes symptoms of mania/hypomania, depression, or their combination (i.e., mixed states). While the defining characteristic of BPD is mania (i.e., elevated, expansive, or irritable mood state) or hypomania (a less severe form of full mania), depression is often the heralding symptom, and patients usually experience more time depressed than manic over the course of their illness. More severe episodes can also present with psychotic features (e.g., delusions of grandiosity) and impulsive destructive behavior (e.g., suicide). The suicide rate for BPD is about 10 percent in untreated patients and about 25 percent will attempt suicide at some point in the course of their illness. The risk for suicide is greatest during a depressed or mixed episode. Lack of treatment is also a major risk factor, since mood stabilizers appear to protect against suicide.

Classic *bipolar I* patients experience *full mania* and depression, while *bipolar II* patients experience *hypomania* and full depression. Associated symptoms may include hyperactivity, pressured speech, flight of ideas, inflated self-esteem, decreased need for sleep, distractibility, and excessive involvement in activities that have a high potential for painful consequences. The course of illness can vary from only few episodes to a more virulent pattern characterized by multiple episodes over short periods of time. One example is *rapid cycling* (i.e., four or more episodes per year), which is more common in females with bipolar II disorder; has a higher suicide risk; and may be precipitated by antidepressant use or thyroid dysfunction. The U.S. lifetime prevalence rate of bipolar I disorder is estimated to be 1.3 percent. When bipolar II and other more subtle forms of the illness (e.g., cyclothymic disorder) are also considered, the prevalence rate has been estimated to be about 3.7 percent. There is an equal distribution among ethnic groups and between men and women.

While BPD can occur at any time, the onset of this disorder is usually before the age of 20, with the peak period between 15 to 19 years. Initially, BPD may present as one or more depressed episodes, have psychosis as a prominent feature, or mimic disorders characterized by hyperactivity. As a result, it is often mistaken for other conditions (e.g., unipolar depression; schizophrenia; attention deficit hyperactivity disorder [ADHD]). This, in turn, can delay accurate diagnosis and implementation of appropriate treatment. In most individuals, BPD produces substantial disability and functional impairment in work, leisure and interpersonal activities, both during and between mood episodes.

Secondary mania is a condition separate from BPD that can be precipitated by a variety of medical conditions (e.g., hyperthyroidism and complex partial seizure); medications (e.g., steroids, tricyclic antidepressants); or drug use or withdrawal (e.g., amphetamines, cocaine). Further, substance and alcohol abuse or dependence frequently co-occur in this population, make accurate diagnosis more difficult, worsen the long-term course and compromise otherwise effective treatments. Other comorbid conditions frequently associated with BPD include obsessive-compulsive disorder, panic disorder, bulimia nervosa, impulse control disorder, ADHD, conduct disorder, and certain personality disorders. Recognition of the high rates of comorbidity in BPD is critical to developing treatment strategies that will address all existing disorders. For example, unless alcohol-related complications are adequately managed, it is unlikely that adequate mood stabilization can be achieved or sustained.

ETIOLOGY

As with most complex major psychiatric disorders, the cause of this condition is thought to involve both biological predisposition and environmental influences. Several hypotheses have been proposed to help elucidate the biological basis for BPD. They include abnormalities in: relevant neurotransmitter activity (e.g., norepinephrine, serotonin); second messenger systems (e.g., phosphoinositide cycle); biological rhythms (e.g., sleep-wake cycle); neuroendocrine function (e.g., thyroid system); neuroanatomy; neurophysiological activity (e.g., kindling phenomenon); and the immune system. The support for a genetic basis comes from family studies that establish a pattern of aggregation, linkage studies that can identify specific genomic regions associated with the disorder, and twin studies that estimate concordance rates to be 14 percent for dizygotic twins and 57 percent for monozygotic twins (whether raised together or separately). The absence of 100 percent concordance rate in monozygotic twins, however, indicates a role for other factors. Thus, a genetic-environmental interaction has been proposed in which a number of small susceptibility genes establish a gradient of liability that may trigger BPD in the context of various stressors. Other important risk factors include a family history of mood disorders, females who are postpartum, or a history of cyclothymic disorder (symptoms similar to but less severe than full bipolar disorder). Of note, linkage studies report a number of genomic regions that may represent susceptibility loci for both BPD and schizophrenia. This is also consistent with a number of observed characteristics that these two disorders have in common. They include a similar lifetime prevalence; onset in early adulthood; tendency to run a chronic, episodic course; high suicide risk; substantial overlap in symptom presentations; and response to antipsychotics. Such data speak to the possibility of greater commonalities between these two disorders than our present diagnostic system would indicate.

TREATMENT

The management of BPD is complicated, must encompass effective treatments for acute episodes of mania and depression, appropriately manage comorbid disorders, and should ensure long-term mood stabilization. In addition, education of patients and their families is crucial to long-term success. Since there is no ideal therapy, BPD often requires complicated strategies to achieve the optimal outcome. While *medication* has been the primary approach, various *psychotherapeutic interventions* (e.g., cognitive behavioral therapy [CBT] and interpersonal therapy [IPT]) may substantially enhance the beneficial effects of drugs. Group, family, marital, and other forms of individual psychotherapy may also be useful. For example, psychosocial interventions combined with pharmacotherapy have been found to significantly reduce any episode recurrence, hypomanic relapse, and depressive relapse when compared to drug treatment alone. *Somatic treatments,* particularly electroconvulsive therapy (ECT), may also be effective for both the manic and depressed phases in patients who are in an acute crisis or who are poorly responsive to or intolerant of medications.

Several classes of medications have been used, including mood stabilizers, antipsychotics, antidepressants, anticonvulsants, and anti-anxiety/sedative hypnotics. The exact definition of a mood stabilizer is still a matter of debate. However, most experts agree that such a drug should be effective for acute mania and depression, stabilize mood over the long term, decrease the impulsive suicidal propensity of bipolar patients, not cause a switch from one mood state to the other, and not worsen the course of BPD (e.g., induce rapid cycling). Mood stabilizers include lithium; divalproex sodium and lamotrigine, which are anticonvulsants; and second-generation antipsychotics (SGAs) such as olanzapine and risperidone. Until recently, most trials with these agents have involved treatment of the manic phase of bipolar disorder.

The ideal approach is to manage BPD with a single agent usually combined with some form of psychotherapy. Unfortunately, this is rarely possible. Thus, if adequate trials for *bipolar mania* with one of the two most commonly prescribed mood stabilizers (i.e., lithium *or* divalproex sodium) are insufficient, then various drug combinations are usually required.

This may include combining the primary mood stabilizer with an anti-anxiety sedative-hypnotic agent, an antipsychotic, or another mood stabilizer (e.g., lithium *plus* divalproex sodium). More recently, the newer generation antipsychotics (i.e., olanzapine, clozapine, risperidone, quetiapine, ziprasidone, and aripiprazole) have demonstrated antimanic properties separate from their antipsychotic effects. Thus, they may represent another strategy when used in combination with other agents or as a monotherapy for acute mania.

Unfortunately, much less data is available to guide treatment of *bipolar depression.* Antidepressant monotherapy is not recommended due to the high risk of mood destabilization. The best evidence to date supports monotherapy with lithium, lamotrigine, or carbamazepine. Other approaches include combining mood stabilizers (e.g., lithium plus lamotrigine); a traditional mood stabilizer plus antidepressant; or an SGA plus antidepressant (e.g., olanzapine plus fluoxetine). Potential biological, nonpharmacological alternatives for bipolar depression include ECT, bright light therapy, and possibly such investigational therapies as vagal nerve stimulation and transcranial magnetic stimulation.

Given the recurrent nature of BPD, *relapse* prevention and *prophylaxis* to prevent future episodes are critical. In this context, the best data support lithium, divalproex sodium, and lamotrigine. Other strategies include combining mood stabilizers, a mood stabilizer plus SGA, or a mood stabilizer with cognitive therapy.

—Philip G. Janicak

See also Depression; Psychiatric Disorders.

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National Alliance for the Mentally Ill, http://www.nami.org/

BLACK REPORT

The Black report is the popular title given to the *Report of the Working Group on Inequalities in Health*, published in 1980 in the United Kingdom. The working group had been appointed by the Labour government in 1977 under the chairmanship of Sir Douglas Black.

The report brought together information about difference in health status between different social classes and examined the causal factors. It also suggested implications for policy and made recommendations for further research. The 30 recommendations for action, which can be summarized under the following four broad themes:

- Development of a comprehensive antipoverty strategy
- Development of policies aimed at giving children a better start in life
- Encouragement of good health among a larger proportion of the population
- Reduction of the risk of early death among disabled people in order to improve their quality of life, and to reduce the need for institutions as far as possible

This entry examines the link between social inequality and individual health, as outlined by the Black report.

BACKGROUND TO THE HEALTH AND DEPRIVATION DEBATE

Much previous research has sought to identify the links between social class and ill health. Indeed, differences in health and economic status have been noted as far back as the twelfth century. Prior to the Black report (1980), there had been a long tradition of health inequalities research in the United Kingdom, one of the earlier examples of which is Frederick Engels's *The Condition of the Working Class in England* published in 1845.

In this text, Engels presented evidence for widespread inequalities in health based on social class. He argued that the industrialized urban poor suffered much higher mortality rates than the wealthy. Engels attributed this inequality to, among other things, poor housing, ventilation, sanitation, environmental pollution, clothing, and working conditions. Contemporaneously with Engels, the early "modern" public health movement was emerging in Britain, with Edwin Chadwick as its leader. Unlike Engels, capitalism was the driving philosophy behind Chadwick and his followers: It was feared that ill health and premature death led to loss of worker productivity and lower profits. The public health movement argued that tackling social causes of ill health, such as poverty, poor sanitation, and poor housing, would eventually pay for itself. Public support for public health measures soon followed, and Britain embarked on a range of measures aimed at improving the living conditions of the urban poor.

These arguments around improvement of the public health resurfaced in Beveridge's 1942 *Report on Social Insurance and Allied Service.* This laid the foundations for the British Welfare State and the National Health Service, the first socialized health care system in the world. The Beveridge report claimed that "want" could be eliminated via the provision of a state-run insurance scheme to guard against interruption or loss of earning power and the provision of child benefits. Coupled with a new Health Service, this would eventually lead to an improvement in the public health and a reduction in expenditure. Inequalities in health would also be eradicated.

Conventional wisdom was that the establishment of the welfare state, despite soaring costs of health care, had at least gone some way to removing health inequalities. These beliefs started to be called into question in the mid-1970s: Britain was slipping behind some other countries in health improvement, despite 30 years of the welfare state. There were differences in mortality rates across social classes, and speculation that these persisting health inequalities were to blame for the lack of improvement in mortality rates. This led to the setting up by the government of the Research Working Group on Inequalities in Health in 1977, chaired by Sir Douglas Black.

THE BLACK REPORT AND ITS FINDINGS

The resulting Black report was the first time any government had attempted to explain trends in inequalities in health and relate these to policies intended to promote as well as restore health. The main findings of the report were as follows:

1. Men and women in social class V had a two-and-a-half times greater chance of dying before retirement age than class 1.
2. Inequalities existed throughout life and at all stages of the life course.
3. Risk of death for men was twice that for women.
4. There were major regional differences, both on a macro and a micro scale.
5. Mortality varied by housing tenure, owner occupiers having a lower mortality rate than local authority tenants.

The report noted the following trends:

1. Morbidity follows same general pattern as mortality.
2. Pre-1950s there was a long-term decline in death rate for males in all occupations.
3. Post-1960 social class V's health declined both relatively, when compared to social class 1, and absolutely.
4. A long-term decline in infant mortality.

EXPLAINING INEQUALITIES

The Black report identified four possible explanations for inequalities in health: that the findings were an artifact, that they arose because of natural or social selection, that cultural/behavioral reasons were to blame, or that they were due to materialist explanations.

Artifact

This explanation implies that there are no actual inequalities: The observed effect is the result of the way in which class and health are measured. It suggests that changes in social class and classification of occupations over time make such comparisons impossible. This explanation is confounded by work that found difference in mortality dependent on salary.

Natural or Social Selection

This explanation suggests that it is not class that determines health but health that determines class: The healthy experience upward mobility, and the ill slip down the social scale. There is some evidence to support this explanation, particularly for disabled people. Disabled people are more likely to be living on or below the poverty line. The Black report recognized this and argued for the implementation of a comprehensive disability allowance to pull disabled people out of poverty. More recent work has also highlighted this cause of inequality. However, the extent of social mobility in Britain is not sufficient to account for the large variations in health.

Cultural or Behavioral Explanations

This approach argues that people in lower social classes adopt a more risky lifestyle. These people adopt what are seen as reckless, irresponsible, or unthinking behaviors and place themselves at greater risk of ill health. Lifestyle explanations have considerable appeal to governments that may want to reduce public expenditure. If individuals are seen as responsible for their own health, then government inactivity is legitimized. It adopts what is termed a "victim blaming" approach in which individuals are seen as being responsible for factors that disadvantage them but over which they have little or no control. Victim blaming is applied both to individuals and to whole groups.

Material Disadvantage

In this explanation, inequalities reflect unequal distribution of resources in society. Those who experience ill health are those who have the least money, are lower in social hierarchy, are the least educated, and experience the most unemployment. These social factors make it difficult for them to implement what they know to be healthy choices. Social and health care provision also varies inversely with the need for it in the population served—known as the inverse care law.

The material disadvantage explanation was the one favored by the Black report. However, it did not find favor with the Conservative government of Prime Minister Margaret Thatcher, to which the working party reported in 1980, and for that reason the whole report was largely ignored. However, with the election of a Labour government in 1997, it could be argued that the agenda of the Black report finally began to be implemented in the United Kingdom.

THE BLACK REPORT AND DISABILITY

The Black report recommended that the government must take into account the material conditions of poorer groups, and it called for a reorientation of health and personal social services. Disabled people were one of the target groups identified by the authors. In addition to calling for the funding of a comprehensive allowance for disabled people, the report examined the inequalities in health and social care experienced by disabled people. It argued that class differences existed in the provision of care to disabled people. Disabled people who had been non-manual workers often lived in different accommodations than did manual workers. More often than not, non-manual workers who were disabled lived in their own homes while manual workers who were disabled were found in institutions. Those living in their own homes had better care and better rehabilitation. They were also more likely to be employed and have better social relations and experience greater privacy. The report argued strongly for a reduction of the number of people in residential care and called for the implementation of what is now termed *community care*. To enable this policy, the report also urged the government to increase home help services and expand the number of accessible private and public houses for disabled people.

Although there is little evidence that the recommendations of this report influenced government policy in Britain throughout the 1980s and early 1990s, its wider impact was widespread through public health debates in many countries. The report played a central role in the shaping of the Common Health Strategy of European Region of the World Health Organization; in particular, it located equity as a central theme in that document and a reduction in inequalities was the first of the 38 targets set as part of Health for All 2000.

—Nick Watson

See also Health; Poverty.

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BLADDER CONTROL

Urinary incontinence (UI) refers to a loss of bladder control. UI is considered a symptom rather than a disease. Causes are many and include infections of the urinary tract or vagina, weak or overactive bladder muscles, enlarged prostate, neurological diseases, pelvic or spinal injuries, aging-related degenerative changes, and problems resulting from pregnancy or childbirth. UI is categorized into the following types:

- *Stress* (damage to the sphincter or pelvic muscles results in leaking when the bladder is under pressure)
- *Urge* (sudden and uncontrollable bladder contractions due to illness or neurological damage result in an urgent need to pass urine)
- *Overflow* (blockages or injuries produce a situation where the quantity of urine exceeds the holding capacity of the bladder, causing leakage)
- *Functional* (bladder control is normal but medical disorders or disabilities, such as restricted mobility, make it difficult to get to an appropriate place for urination prior to loss of control)
- *Mixed* (two or more types)

UI is a dynamic condition, with continence status fluctuating throughout the life course. Treatments include behavior therapy (bladder control training, pelvic muscle exercises, biofeedback, and timed and prompted voiding); pharmacological therapy; and surgery. In addition, management techniques may be used such as implants, urethral plugs, and various absorbent devices.

UI appears to be highly prevalent worldwide, especially among women, with stress incontinence predominating and incidence increasing with age. Across cultures, quality of life has been found to decrease as UI becomes more severe. In the United States, up to 25 million people are estimated to be affected, including approximately 1 in 10 of those 65 years of age or older. In addition, 10 percent of children over age 5 have problems with bedwetting.

The meaning and significance of UI are linked to that of urination in general; these meanings vary by culture. Very little scientific or scholarly literature exists on how urination and UI are understood cross-culturally. That which does exist focuses primarily on urination, for example, practices related to urinary hygiene (such as where it is appropriate to urinate in a particular culture), attitudes toward urination (which range from nonchalance to humor to extreme shame), and painful/difficult urination and traditional treatments for these conditions. Discussions of incontinence in the ethnographic literature concentrate on its management among infants and young children, its role as a symptom of culturally specific illnesses, and ideas about behaviors that may cause or prevent the problem. As examples of the latter, the Iroquois traditionally believed that the use of clamshells as spoons could cause UI, while the Yakutat Tlingit reportedly thought that rotten wood under the toilet in the menstrual house would protect a teenager from incontinence in old age.

Despite variation in beliefs and knowledge about UI, in many cultures it remains underreported and undertreated, in part because affected individuals do not seek help. Hesitation with respect to seeking professional attention may be related to embarrassment, lack of resources, and doubts about the effectiveness of available treatments.

—Lori L. Jervis

See also Aging; Bowel Control.

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BLIND, HISTORY OF THE

The history of the blind is difficult to chart. There are few examples before the nineteenth century of sustained, organized efforts by the blind to act in concert to achieve collective goals. Rather what is left to the historian is a collection of biographies of "extraordinary" individuals, from Homer to Helen Keller, Louis Braille to Jorge Luis Borges, which provides little in the way of a narrative thread that one can pull together to create a tapestry of blind history. Prior to the eighteenth century, the history of the blind is atomistic, a collection of biographies, protagonists in religious and secular stories, weaving in and out of popular consciousness, serving as object lessons, or providing inspiration to the sighted. The negative historical assumption is of the blind as objects of charity rather than active agents in history. Occasionally, the blind could be found clustered in certain state- or church-sanctioned professions or guilds such as massage, minstrelism, and mendicancy, but in large part blindness is assumed to be a ticket to misery, a curse, a sentence to second-class status.

The blind, in truth, occupy no greater or lesser a place in history commensurate to their numbers in the general population. There are historical examples of blind teachers, soldiers, religious and secular leaders, scientists, philosophers, mathematicians, historians, and a variety of other professions. There are, as with the sighted, countless blind who lived out their lives in quiet obscurity. Thus, it can be said that while history offers a pantheon of blind characters, there exists nothing unique to blind people that is unknown to the sighted. Even so, the past 200 years have seen efforts by the blind to come together to improve their situation, share strategies of success, and have a voice in society, rather than to be objects of curiosity and speculation.

THE BLIND IN THE ANCIENT WORLD

In the preindustrialized world, it has long been assumed that the blind enjoyed few opportunities and lived out their days in penury as beggars, or wards of their families in the absence of any systematic state or government assistance. Historical knowledge of the lives of blind people in the premodern Western world is extremely limited, and it is strongly influenced by literary or religious texts. Traditional interpretations of classical literary representations hold that blindness is a punishment for social or religious transgressions or, alternatively, is the price one pays to gain spiritual vision and insight. Oedipus is often cited as an example of the former, while Tiresias may be seen as an example of the latter. There are 79 references to blind persons in classical Greek literature, all of which describe blindness as occurring through accident, through warfare, or as punishment for social or religious transgressions. Today, 2.9 percent of cases of blindness result from accidents, and there is no evidence to support the idea that the situation would be any different for those living in Greece or Rome. With so few examples to draw on, most of which falsely portray blindness as occurring from accident, literary sources do not provide good evidence on which to base broad assumptions about either how the blind lived or how the blind were popularly perceived as a class by their contemporaries.

Religious texts similarly provide little knowledge of actual blind people in the early centuries prior and subsequent to the Christian era. Biblical scholars debate whether blindness is to be interpreted in either spiritual or corporeal terms. Some New Testament scholars, for example, believed that depictions of Jesus healing the blind is meant to be seen as curing spiritual blindness, not physical blindness. Nonetheless, ancient and medieval depictions of the blind as either sinners or saints persisted into the modern era and continued to be the subjects of religious and philosophical inquiry.

While the Greek poet Homer is often assumed to be blind, there is no evidence of whether or not he could see, although Homer's *Odyssey* features the blind poet Demodocus. The names of a handful of other blind storytellers survive, such as Ossian, blinded warrior and son of the third-century BCE Caledonian King Fingal; and Torlogh O'Carolan, Gaelic poet (b. 1607). Better known are the blind scholars of the premodern era. Best known of these in the early Christian era is Didymus, born ca. 313 CE in Alexandria. Didymus used carved wooden letters and was the teacher of St. Jerome. St. Herve (b. 539) established a monastery in Brittany, which today is a shrine for blind musicians. In Japan, Prince Hitoyasu (b. 853), son of the emperor of Japan, established music and massage as designated professions for the blind and established the role of court historians as the purview of the blind. Abdul al Moiré (b. 973 CE near Aleppo) became a preeminent poet. His poetry transcended the mundane topics of love and war and reflected a skeptical view of the world. Prospero Faghani (ca. 1590–1671) was a canonical scholar who refuted the medieval Catholic Church's dispensation to the blind as outside the obligations of the church. Faghani asserted that the New Testament was more concerned with blindness of spirit rather than the body, and he brought the blind into the fold of the church. John Milton (b. 1608) is perhaps the best-known blind author of the late Renaissance/early Enlightenment. He was a well-known poet before going blind at age 44, although he wrote his masterpiece of epic poetry, *Paradise Lost,* after losing his sight.

THE BLIND IN THE AGE OF PHILOSOPHERS

The Enlightenment-era philosophers introduced new questions about blindness and the nature of the blind, moving the conversation away from strictly spiritual questions toward rational interpretations of understanding and knowledge. Enlightenment scholars debated whether or not the blind were more likely to be atheists due to their presumed bitterness against God over their condition. Others argued that the blind were closer to God, as they were spared the burden of earthly distractions owing to their blindness. John Locke, in *An Essay Concerning Human Understanding* (1690), considered the question of whether a person born blind who became sighted would be able to recognize objects previously known only by touch. Locke asserted that newly sighted people would not be able to understand the world using their new vision. Bishop Berkeley in 1709 disagreed with Locke, arguing that what one saw with the eye was merely the inference, not the essence, of a thing. The question was a favorite among philosophers long after Locke, as the rhetorical scenario allowed speculation as to the nature of learning and understanding.

The debate was not merely rhetorical to the blind, however, as there were direct implications as to whether or not the blind could or should be educated in reading and writing and the classics. If sight was required to understand the essence of a thing, as Locke argued, then educating the blind was a futile enterprise. If understanding was generated from within, as Berkeley argued, then there was no reason a blind person could not learn as well as the sighted.

Nicholas Saunderson (1682–1739) lost his sight at the age of one from smallpox. Saunderson went to Cambridge University to study mathematics, but he was not allowed to matriculate as a student. He was given access to the library, where he used a tactile ciphering board to work out mathematical formulas. Saunderson's advanced mathematical acumen gained him the attention of Sir Isaac Newton, then at the height of his fame. Newton personally lobbied to have Saunderson given a chair at Cambridge, despite the lack of formal credentials, as he was one of the few who Newton felt truly understood the ideas expressed in *Principia Mathematica.* Saunderson became one of the Enlightenment's foremost mathematicians and philosophers.

EDUCATION AND THE BLIND

Denis Diderot penned one of the most influential treatises on the blind and education in 1749 with his "Letter on the Blind," which he revised in the course of his lifetime. Diderot met and was deeply impressed by the Parisian music sensation, Melanie de Salignac, who had devised a tactile form of print to both read music and correspond with friends. Diderot saw de Salignac as an example of what was possible, and he argued that the blind could be educated so long as the educator focused on what skills the blind person possessed and not on the lack of sight. As one of the most influential philosophers of the French Enlightenment, Diderot provided a philosophical foundation for the education of the blind.

It was Valentin Haüy (1745–1822), however, who opened the first school for the blind in Paris in 1784. Haüy had been influenced by the Abbé de l'Épée, who had opened the first school for the deaf in the 1770s. Haüy, like Diderot, was inspired by a talented blind pianist, Maria Theresa von Paradis (b. 1759). Von Paradis showed Haüy the tactile alphabet she had developed, which she used to read and write. Von Paradis had been corresponding with a German man, George Weissenbourg, who in turn had taught other blind students the finger alphabet the two used to write one another. Haüy appreciated that the blind could learn by reading with their fingers. The school for the blind in Paris soon had more than 50 students. Haüy developed a raised alphabet system to teach his students. Haüy's methods would become the standard and the model adopted by educators of the blind for the next half century. Unfortunately, reading raised roman letters was a very inefficient system of reading. Haüy wanted a system that looked attractive to the sighted as much as he was interested in what actually worked for the blind.

This conflict between what the sighted educators asserted the blind needed and what the blind themselves insisted really worked became the central organizing force of blind people in the coming two centuries. By the early nineteenth century, several schools appeared in Britain: Liverpool (1791), Edinburgh (1793), and Bristol (1793), among others. These schools were developed along English trade school models, where students were taught a trade rather than to read and write. Johann Wilhelm Klein founded a school in Vienna in 1804. Klein believed that blind students should be integrated into the classroom with their sighted peers. These three models—Haüy, English trade schools, and Klein in Vienna—drove the debate for the next century about what blind children should learn. Some educators believed it was better to teach a trade in order that the blind could support themselves as adults, while others asserted that a classical education would propel the blind into more esteemed professions, as well as provide examples of the potential of the human capacity for learning.

Just as the blind sparked a debate among Enlightenment philosophers over the nature of understanding in the seventeenth and eighteenth centuries, social reformers of the nineteenth century argued over the degree to which the blind could be "rehabilitated" or trained to take their place in the broader community as contributing citizens. Samuel Gridley Howe (1801–1876), who opened the Perkins School for the Blind in Boston in 1831 (the second school of its kind in the United States), argued that the blind could be educated and trained to become independent members of society, earning their own way in the world. The education of the blind for these reformers was akin to an experiment in human engineering to prove broader philosophical points about the redemptive powers of social programs.

Howe's School for the Blind in Massachusetts became a model for schools all around the United States. In part, Howe's success derived from his famous pupils. Laura Bridgman, a deaf-blind girl, arrived at the Perkins school in 1832 and would become one of the most famous women in the world by the 1840s. Howe wanted to prove that anyone could learn to read and write, and he set out to teach Bridgman language through finger spelling and raised type. Bridgman would live her life out at the school and would in 1876 meet the next century's most famous deaf-blind girl, Helen Keller, who would also go to Perkins to study.

In 1837, Ohio established the first state-sponsored school for the blind. By the time of Howe's death in 1876, there were 23 schools for the blind, most of which were state funded, marking a change from the education of the blind as a charitable enterprise to an entitlement paid for with tax dollars. Blind children would continue to be educated at residential schools, apart from sighted children, until well into the twentieth century. By the 1920s, educators and blind advocates began to argue forcibly that the blind ought to attend school with their sighted peers. By 1970, this idea would become a movement known as mainstreaming. With the passage of the Education for All Handicapped Children Act in 1975 (now known as the Individuals with Disabilities Education Act [IDEA]), the mainstreaming of blind children became a right, not a trend. Schools for the blind diminished in importance in favor of integration of the blind with the sighted.

THE BLIND ORGANIZE

Much of the debate about the abilities of the blind in the years from Diderot to Howe occurred among the sighted. The actual voices of the blind were not part of this debate. However, the advent of schools and institutes for the blind afforded the blind an opportunity to organize as a group for their own interests. The blind were able to talk to one another and learn strategies of success for living as a blind person. Schools and institutes served as hothouses for the development of and experimentation with new devices and systems of writing.

Louis Braille (1809–1852), a student at the Royal Institute for the Blind in Paris in the 1820s, took a raised-dot system of code brought to the school in 1821 and turned it into the most important advancement in blind education. Charles Barbier, a sighted military officer, had invented a raised-dot system intended to allow officers to communicate with one another in the dark. The French army never adopted the system, nor did the Paris School for the Blind at first. However, Louis Braille took the eight-dot system proposed by Barbier, reduced it to six dots, which was easier to read with the fingertips, and created a system of abbreviations and shorthand symbols that would allow the blind to read at a much faster rate. The dots looked nothing like the roman letters they replaced, but the system was much easier for the blind to read. The school rejected Braille's system, in part because school administrators were reluctant to replace all the raised-alphabet volumes created at great expense under Haüy and his successors. Braille was a teacher at the school, however, and taught his system to his blind students. By the time of Braille's death in 1852, the school finally accepted the superior Braille method of transcription.

Braille's system also made it possible for the blind to be teachers of the blind, further strengthening resistance to the raised-dot system by sighted teachers. The introduction of Braille not only revolutionized education for the blind, it allowed the blind to communicate with one another without sighted intervention, creating a community of blind alumni. In addition, the blind began to publish their own stories in the form of memoirs intended to capture the interest of a sighted readership. Such narratives were a combination of religious inspiration and titillating details about the life of blind people.

By the end of the nineteenth century, the blind were organizing into professional associations, such as the American Association of Workers for the Blind (AAWB), and began to agitate for more overtly political objectives in such publications as *The Problem* and *The Outlook for the Blind*. Advocacy groups organized by blind activists flowered in the 1920s and 1930s in a number of states. Blind activists in Wisconsin, Pennsylvania, Colorado, and California were successful in agitating for pensions for the blind and public awareness efforts to inform their communities about the needs and interests of the blind. These state affiliates came together in 1940 to charter the National Federation of the Blind (NFB). The NFB would organize affiliates across the United States to become the largest advocacy group of blind people. The NFB began publishing the *Braille Monitor* in 1957, and it is still in print today. The NFB produced a number of leaders in what would be called the "blind movement" by those who advanced the objectives of the NFB and its supporters. Jacobus tenBroek, president of the NFB from 1940 to 1960, and Kenneth Jernigan, president of the NFB from 1968 to 1986, were galvanizing figures in the blind movement. TenBroek was a constitutional law professor who agitated on behalf of a blind pension divorced from the social security system, and Jernigan was a teacher, who transformed rehabilitation services for the blind as the director of the Iowa Commission for the Blind from 1958 to 1978. In 1960, the American Council of the Blind (ACB) was established by former members of the NFB who disagreed with the direction and leadership of that organization. The ACB publishes the *Braille Forum.*

World War I prompted the rise of national efforts to provide services to blinded veterans, which would eventually morph into the dense network of state rehabilitation and private welfare programs for the blind in the twentieth century. The Smith-Fess Act of 1920 expanded the range and scope of rehabilitation services available through the states to the blind. In 1948, the Hines Training Center was opened outside of Chicago. Named after Frank Hines, Secretary of Veterans Affairs, the Hines Center was an innovative program that sought to train blinded vets to transition back into their communities. Students at the center were given long white canes, known as Hoover canes—named for their inventor, Richard Hoover in 1944. The Blinded Veterans Association (BVA)—founded in 1945—was active at Hines and in progressive politics for many decades. Rehabilitation programs became increasingly important to all blind Americans and would become the focus of advocacy groups such as the NFB, BVA, and ACB, which agitated for better services from the agencies that were charged with providing help to the nation's blind.

—Brian R. Miller

See also Advocacy; Blindness and Visual Impairment; Louis Braille; Laura Dewey Bridgman; Denis Diderot; Valentin Haüy; History of Disability: Ancient West; History of Disability: Early Modern West; Visibility and Invisibility.

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BLINDNESS AND VISUAL IMPAIRMENT

Throughout recorded history, the eyes—the sense of sight, of looking and seeing, of vision and blindness—have been a fascination for artists and scientists alike. Writings about blindness as symbolic of human traits and action or as a sign of divine intervention are found across many cultures and societies, and they date back to ancient times. Science and medicine developed specializations in eye diseases as far back as the Ebers papyrus, an Egyptian medical textbook dating from the Eighteenth Dynasty (ca. 1500 BCE), which has an entire chapter devoted to eye diseases (Monbeck 1973). Blindness and visual impairment have important socioeconomic implications for blind people and for the societal structures in which they live. Blind people are treated differently because of their blindness—they face environmental, economic, social, attitudinal, and educational barriers. Nowadays, blindness is thought to be a major public health problem, which is being addressed by governments, health, economic, and charitable organizations at international, national, state, and local levels. The costs of rehabilitation and care may be the most apparent, with indirect costs resulting from loss of productivity. Modern medicine has developed specific definitions of blindness and visual impairment within which they frame data collection, research findings, and public policy.

DEFINITIONS OF BLINDNESS AND VISUAL IMPAIRMENT

The World Health Organization's (WHO) International Statistical Classification of Diseases and Related Health Problems (ICD-10) defines blindness as visual acuity of "less than 3/60 (0.05) or corresponding visual field loss in the better eye with best possible correction" (visual impairment categories 3, 4, and 5 in ICD-10). This corresponds to loss of walkabout vision. "Low vision is classified as visual acuity of less than 6/18 (0.3) but equal to or better than 3/60 (0.05) in the better eye with the best possible correction" (visual impairment categories 1 and 2 in ICD-10). The international medical community generally accepts the ICD definitions of disease and uses it to describe and diagnose medical conditions, diseases, and disabilities.

Almost all U.S. government agencies have adopted medical measurements broken down into three categories of visual impairment, which are used to determine eligibility for services and financial compensation:

1. Totally blind
2. Legally blind (20/200 or less visual acuity in the best corrected eye [20/200 visual acuity means that what a fully sighted person sees from 200 feet away, a person with 20/200 vision sees from 20 feet away], and/or 20 degrees or less in the visual field)
3. Partially sighted (20/70 visual acuity in the best-corrected eye or 20 degrees or less in the visual field); the U.S. Bureau of the Census simplifies its definition into lay terms (unable to see regular-size newsprint)

All of these definitions of blindness and visual impairment determine eligibility for financial support, social services, and government-funded medical services, including research studies, treatment, cure, ocular prosthetics, rehabilitation training, and job placement. Given these governmental definitions of blindness, it is commonly assumed (particularly by sighted people) that someone would only identify as "blind" if they had no vision at all. However, many people categorized as "legally blind" actually identify as blind. These people challenge traditional notions of blindness because they retain some usable vision, demonstrating that blindness, like sight, is a continuum. Many people identified as "legally blind" or "partially sighted" greatly benefit from standard accommodations for blindness, such as audio description of environments, access devices and technology, books on audiotape or compact disk, and universal design.

Even though the degree of blindness is calculated in a very functional way by government agencies and many other institutions, it cannot be assumed that there is a simple relationship between the difficulties individuals face in their lives and their level of blindness. Many other factors intervene in this process, such as the accessibility of their environment, the degree of support they have, and their financial resources. While magnifiers; monoculars; talking watches, personal digital assistants (PDAs), and portable global positioning systems; and large-print and speech output software can significantly facilitate blind people's inclusion into everyday activities of living, costs are often prohibitive, even for those who are working. In addition, many technological and optical devices are largely unheard of, and certainly unaffordable, in developing nations where 90 percent of all blindness and visual impairment occur.

COMMON CAUSES OF BLINDNESS

The most common causes of blindness vary according to geographic location, socioeconomic status, and age. Largely preventable and treatable, bacterial diseases such as onchocerciasis, otherwise known as river blindness, and trachoma are leading causes of blindness in the developing world. Many international health-promoting organizations have blindness prevention programs. They work in rural, poverty-ridden communities to improve hygiene education, sanitation conditions, and access to health care.

The U.S. Centers for Disease Control and Prevention (CDC) reports that many causes of blindness occur before birth, although some conditions clear up over time. Older children (between 3 and 10 years old) have more vision impairments than do children younger than 3 years old. Nearly two-thirds of visually impaired children also have at least one other impairment. This may, in part, be due to the fact that some diseases have visual impairment as secondary effects. Diabetes, glaucoma, and cataracts are the most common causes of blindness among adults in Western nations. Because more people are living longer than did earlier generations, age-related macular degeneration is becoming more prevalent.

PREVALENCE OF BLINDNESS

The World Health Organization estimates that there are about 148 million blind or visually impaired people around the world, with 9 of 10 cases occurring in developing nations. There is a strong link between poverty and blindness. Of the more than 100 million blind children around the world, more than 80 percent live in underdeveloped countries. The majority of cases are preventable, but adequate financial commitment to prevention and treatment programs, healthier agricultural practices, and more attention paid to nutritional deficits is needed (World Bank 2003b). Current available studies estimate that there are, at minimum, 1.5 million blind children in the world; 72,000 of them live in Europe, the United States, and Japan (Kocur and Resnikoff 2002). The level of ophthalmic health care is shaped by each country's political system. For example, countries that were part of the USSR are currently grappling with shifting their socialist (free) health care to non-government-subsidized health care systems, for example, private health insurance; hence, health care, including ophthalmic care, is in transition and so is not always adequate (Kocur and Resnikoff 2002). In North America, there are between 10 and 11 million blind or visually impaired people (American Foundation for the Blind [AFB] 2001; U.S. Bureau of the Census 1996) with the large majority having some residual vision.

The Royal National Institute for the Blind (RNIB) in the United Kingdom reports that it is difficult to know exactly how many blind and visually impaired people there are in European Union countries, but the most widely used estimate is 7.4 million out of a general population of 385 million. In the United States, approximately 1 million people over age 40 are blind (National Eye Institute and Prevent Blindness America [NEI] 2001). One problem gathering accurate data is that people who begin to lose their vision as part of the aging process often do not register for social or rehabilitation services (RNIB 2003). In addition, different countries have different data collection methods, which makes it difficult to estimate total numbers of blind and visually impaired people.

EMPLOYMENT DATA

Employment figures as well as prospects for future employment of blind and visually impaired people are dismal in every country across the globe. Public policy toward blindness is measured in terms of economics—cost-benefit ratios. Statistics are gathered about how much blindness prevention, treatment, and rehabilitation costs, and then are analyzed in comparison with productivity levels to determine if governments are making a good capital investment. Blindness and blind people are characterized as "financial burdens."

No other socioeconomic group in the Unites States has more unemployment than do blind people (AFB 2001). Less than 50 percent of all blind/visually impaired Americans are employed. More than one-third of those who are employed report being underemployed (U.S. Bureau of the Census 1996).

ATTITUDES TOWARD BLINDNESS AND BLIND PEOPLE

The World Health Organization (WHO) began its fact sheet on blindness, "The loss of eyesight is one of the most serious misfortunes that can befall a person" (WHO 1997a). The World Bank uses "suffering" and "overcoming" in its reports about projects "fighting blindness." Many medical, humanitarian, and philanthropic organizations describe blindness as a "tragedy." The idea that blindness is a horrific fate is long-standing and well documented. Blind people are often portrayed within such negative stereotypes as "deserving of pity and sympathy; miserable; in a world of darkness; helpless; fools; useless; beggars; unable to function; compensated for their lack of sight; being punished for some past sin; to be feared, avoided and rejected; maladjusted; immoral and evil; better than sighted people (idealized); mysterious" (Monbeck 1973:25). Writers of ancient biblical texts used metaphors of illness and impairment to dramatize moral, ethical, and religious lessons as well as to inscribe exclusionary laws.

BLINDNESS AND EDUCATION

In many countries, blind (and other disabled) children have systematically been subjected to school segregation. Even though the curriculum was purposefully similar to general public education, blind children were segregated into their own schools, and many of these schools are still in existence. The first school for the blind in America was founded in Baltimore, Maryland, in 1812. In 1832, a school named the Massachusetts Asylum for the Blind opened. It later changed its name to Perkins Institute (and is currently named Perkins School for the Blind) (Shapiro 1994).

BLINDNESS AND RELIGION

While it is so that the writers of the Bible used earthly language to describe and explain the inexplicable (God), one need only scratch the surface of metaphors of impairment to unearth negative attitudes toward and societal stereotypes of the blind and the damaging consequences of being blind. “You shall not curse the deaf or put a stumbling block before the blind” (Leviticus 19:14) has been interpreted throughout the centuries to symbolize various negative actions. The Bavli (Babylonian Talmud) used the stumbling block metaphor in cases of serving wine to those who ascribe to prohibitions against drinking wine (Avodah Zarah 6a-6b); lending money without witnesses (B. Baba Metsia 75b); or deliberately irking someone to test their temper (B. Kiddushim 32a). In these examples, blindness is used to illustrate enticement and temptation, inability to control one’s desires, or deliberately acting cruelly toward another human being. All the examples equate blindness with helplessness. Blinding someone seems to be the weapon of choice in the following examples: In Genesis 19:11, young and old alike were struck with blindness so that they would wear themselves out groping for the exit; Samson was blinded by the Philistines (Judges 21).

The stigma ascribed to visual impairment is found, for example, in the story of Leah, who was devalued as a potential wife because she had “weak eyes.” Under the cover of darkness, Leben, Leah’s father, deceived Jacob into marrying Leah (Genesis 29:16–25). The inference is that blind people are easily tricked and that sight is the most valuable sense despite evidence that touch is the most reliable of all the senses. Exodus 23:8 warns, “And you shall take no bribe for a bribe blinds the officials, and subverts the cause of those who are in the right.” Again, blindness represents corruption and deceit. By sheer number of mentions, blindness appears to be the favorite disability metaphor in Scripture.

The use of blindness metaphor in religious contexts is not confined to Judeo-Christian texts. The Qur'an uses allegorical descriptions of eyes to connote faith in Allah, e.g., “Thus Allah strengtheneth with His succour whom He will. Lo! herein verily is a lesson for those who have eyes” (The Family of Imran, The Third Surah of the Qur'aan [verse 13], Pickthall Translation). Thus, impairment, illness, and disability have become bound up in institutionalized religious doctrine of sin, evil, God-decreed punishment, uncleanness, sorrow, and pity. However it is talked about, blindness is almost always perceived to be a “tragedy.”

Blindness has been used as a metaphor to describe ignorance, denial, stupidity, naïveté, prejudice, drunkenness, carelessness, unconcern, thoughtlessness, and unawareness. “Blind” has represented something tricky that is intended to conceal the true nature of a thing, as in “blind taste test” and “double blind” research study. And, in botany, a plant is “blind” when it fails to flower.

MODELS OF BLINDNESS

Until the advent of disability studies, blindness was conceptualized only as catastrophic. Artists and writers used blind figures to represent either pitiful, lost creatures groping their way through an unseen world or vessels of supernatural powers. Blind people were to be avoided because they could see inside your thoughts (Barasch 2001).

Research on blind people has been dominated by literature written from the perspectives of medicine, rehabilitation, and psychology. The focus of these studies has tended to be disease and its effects, psychological aspects of blindness (loss, grief, and eventual “acceptance”), adaptation, and coping strategies.

Blindness is positioned absolutely on the individual with little societal context taken into consideration, as if blindness occurs in a social vacuum. This approach tends to assume that blindness is solely a physiological event, and not a social process. One exception to this pattern was Scott's (1969) pioneering social constructionist approach to blindness and society. Scott's phrase "blind men [*sic*] are born, not made" emphasized the role of blindness workers in the socialization of blind people. Scott's work has been built upon in the past decade by interdisciplinary blindness literature, strongly influenced by blind disability studies scholars (e.g., Michalko 1998, 1999; Kleege 1999; Kudlick 2001; French 1993, 1999, 2001).

CURRENT TRENDS IN BLINDNESS LITERATURE

Type in "blindness" on any Internet search engine and the typical search results mainly concern disease, rehabilitation and counseling services, product catalogues, blindness "etiquette," blindness prevention, and medical research. There is a sparse sprinkling of information about organizations *of* the blind, which are initiated and controlled by blind people themselves and are consumer and rights oriented. More common, however (and more well funded), are associations *for* the blind, which have deep historical roots in the medical model and are usually administered by sighted people. These organizations are often charities that promote blindness prevention media campaigns, information about specific eye diseases and related services and product information, and reports of medical research aimed at prevention and cure. Generally, neither type of blindness organization conducts independent social or medical research.

Some charity-based organizations may raise money to help fund prevention and/or cure research (and to fund their own jobs). However, the actual protocol decision-making and research work in these cases is usually left to medical and educational establishments. Medical institutions typically devote their energies to prevention, diagnosis, treatment, and cure. On the other hand, educational institutions tend to address matters of adaptation, accommodation, and rehabilitative training.

Many medical, rehabilitation, and educational establishments have laudable achievements in helping to improve the lives of blind people. However, the gaze of medical model research is on the function of the eyes, so it largely fails to inquire about social processes or even about the personal experience of blindness. The new interdisciplinary discipline of disability studies is changing all that by re-theorizing blindness within sociocultural contexts.

Disability studies tends to promote work *by* organizations of disabled people, as opposed to organizations *for* disabled people. There is a significant distinction between the two types of organizations in that disabled people themselves organize, lead, and set their own purpose and policy agenda in organizations *of* disabled people. On the other hand, organizations *for* disabled people are most often administered by nondisabled people who speak for and assert authority over disabled people.

At present, disability studies literature tends to be dominated by projects based in the humanities, so actual participant research projects are rare. Until now, the most common genres for addressing issues of blindness have been historical literary analysis, memoir, autobiography and autoethnography.

The writings of a young blind girl in postrevolutionary France were translated by Kudlick and Weygand in 2001. The first half of the book contains Thérèse-Adèle Husson's writings about her experiences, while the translators devote the second half to commentary. What is most remarkable and valuable about this brief story of one person's blindness experience is how little things have changed with regard to dominant societal attitudes toward blindness and blind people. Husson (2001) wrote:

> When they [blind people] appear in public the stares of the multitude are fixed upon them, and agonizing words strike their ears: "what a shame!" "How unfortunate!" "Death would be preferable to such a cruel privation!" There are even some people who seek out the blind to tell them these things so that they don't miss any of the sad exclamation. (p. 25)

Kudlick (2001) framed blindness within the cultural context of Victorianism by analyzing historical documents. She explores the origins of an important ideological split within the blindness community, which continues to this day. Some blind people believe that to be perceived as equal in a sighted society, blind people should not seek environmental accommodations such as audible signage or tactile warning strips. They also believe that only blind people can help other blind people and have instituted their own vision training centers run entirely by and for blind people. Conversely, other blindness organizations actively advocate for environmental access, accept training from sighted guides, and perceive blindness as more of a medical and consumer issue than one of social acceptance. Kudlick's commitment to recording the cultural aspects of blindness history is important, because it is a marker of the growing respect for disability studies as a legitimate, serious discipline, as well as a reflection of the strength of the disability civil rights movement. Social movements are often measured by new interest in their histories.

In *Sight Unseen,* Georgina Kleege (1999) described her experience of growing up with progressive vision loss. Throughout this memoir, Kleege used examples from her own life to place blindness within a cultural context. Her book is divided into three main sections: Blindness and Culture, Blind Phenomenology, and Blind Reading: Voice, Texture, Identity. These topic headings might convey the idea that the book is oriented within the social model of disability. However, Kleege's exaggerated emphasis on impairment rather than disability often contradicts such an approach. For instance, she stated, "Writing this book made me blind" (p. 1), "This book made me understand for the first time how little I actually see" (p. 2), and she characterizes the book as "my attempt to specify my own visual experience" (p. 103) and "a coming out narrative." Clearly, the main theme of her memoir is identity formation.

Rather than embracing blindness as an alternate way of being in and knowing the world, Kleege writes that blindness "really isn't as terrible as you were always led to believe" (p. 34) and that it is "not so bad" (p. 32). Throughout *Sight Unseen,* Kleege often uncritically reproduced the concept of normativity—a problematic concept for the discipline of disability studies. She often used the word "normal" in a phrase without italics or quotation marks to contest the concept. For instance, she refers to "normal daily activities" (p. 167). This uncritical citation of the term "normal" seems to indicate that she accepts the notion of normality, which is highly problematic from a social model perspective. By using such controversial terms in her descriptions of the blindness experience, Kleege may be unconsciously endorsing a nondisabled, medicalized discourse that positions blindness as a loss and an exclusively negative experience. Other personal narratives from blind people suggest that the experience is far more complex and nuanced than such simplistic descriptions would suggest.

The humanities play an important part in the interdisciplinary nature of disability studies, and *Sight Unseen* is a significant contribution in that regard. In her review of this memoir, Sally French (2002) said she found *Sight Unseen* "unsurprising," but she states that it "provides good material for anyone interested in the meaning of visual impairment and the growing field of disability studies" (p. 859).

Given that she uses the genre of memoir, it should not be surprising that Kleege's work focuses largely on the individual's adaptation to blindness rather than turning the gaze back onto society's treatment of blind people. Nevertheless, from the perspective of disability studies, memoirs can be problematic because readers may understand them to be "inspirational" stories about personal triumph over tragedy, or as reinforcing other medical model stereotypes about disability as an individual problem.

A memoir such as *Sight Unseen* can also be criticized for relying solely on one individual's perspective, which could be seen as enabling the author to develop theoretical generalizations without being required to apply the rigors of social scientific citation, which builds on prior academic knowledge and requires the author to substantiate such positions. Consequently, even when an author committed to the social model of disability writes a memoir, the danger is that the theoretical reframing of disability and impairment from the perspective of the social model of disability may fail to be noticed or understood.

In contrast to literary analyses and memoir writing, White (2003) relied on an interdisciplinary approach that combines queer theory, disability studies, and blindness literature. White examined the social construction of blindness as a heterosexual experience by critiquing the social construction of heterosexuality in blindness sex education for young blind people. White delved into dominant beliefs about sexuality being a visual process, and how this construct frames young blind people as sexually underdeveloped. He wrote, “Blind people are in a sense queer, in that heterosexuality, at least in its institutionalized forms, presumes a sighted subject” (p. 134).

Sally French (1993, 1999, 2001) used prior social model of disability literature to buttress her analysis of how society disables blind people. She stated that “conflicting discourses arise when sighted people define what is ‘acceptable’ and ‘normal’ behavior for a visually disabled person and use these definitions to contest that person’s identity” (1999:21). French (2001) used a grounded theory approach in her study of visually impaired physiotherapists so that she could address issues of both impairment and disablement. French relied on the use of questionnaires and semi-structured interviews to examine such issues as how society has perceived physiotherapy as a legitimate profession for visually impaired persons, and she uses participant interview transcripts to elucidate how visually impaired physiotherapists perceive their engagement in the profession as points of advocacy. Her informants describe how they meet and manage barriers that arise in their everyday work lives. French’s growing body of work combines both her personal experience of blindness and a social model analysis; thus, her work helps shape the future of disability studies literature, in general, and blindness research in particular.

Rod Michalko, a postmodern sociologist, deconstructs medical, psychological, and societal ideas and practices around blindness. In particular, Chapter 4 of *Mystery of the Eye and the Shadow of Blindness* (1998) is devoted to a critical examination of blindness rehabilitation. Noting that once ophthalmologists have diagnosed their patient as destined for permanent blindness, they refer the patient out for rehabilitation. Michalko wrote, “Ophthalmology is recommending *agency* as an *actor* presented as qualified to speak about, and act upon, permanent blindness. This suggests that blindness requires agency and needs to be acted upon in order for it to be lived with. . . . Rehabilitation, too, conceives of the seeing life as the only good life” (pp. 66–67).

In another book, *The Two in One: Walking with Smokie, Walking with Blindness* Michalko (1999) used autoethnography as a methodology so that he could describe and analyze his experience of vision loss and his acquisition of a guide dog. He relied on postcolonial concepts of “home” and “exile” to describe his personal experience of living in a world built by and for sighted people and explained how his dog, Smokie, lives in exile in a world built by and for humans, but how their relationship brings “home” into both of their lives. Michalko also examined how the dog guide school creates expectations of blind students’ behavior and the school’s physical environment based on sighted notions about the blindness experience. Sherry (2003) argued that Michalko’s most important contribution to blindness and disability studies literature is his postmodernist deconstruction of the blindness/sightedness binary, which extracts blindness from its perceived “lack” and places it, instead, on its own merit as an alternate way of knowing the world. Michalko (1998) wrote: “Blindness, when compared with sight, becomes a thing of shadows . . . anything seen as a mere shadow of its former self is understood as less than or not as good as the original. . . . Sight *is* status and is a status *former* to blindness. Sight is not a mere shadow of its former self since it has no former self. Thus sight is not regarded as needful of restoration” (pp. 67–68).

Michalko’s work is important and will have far-reaching impact on both blindness research and on how societal institutions perceive, teach about, and treat blind people. However, one largely ignored theoretical approach to blindness is materialism, which is important in several other areas of disability studies. Although a materialist approach has been adopted by disability scholars such as Oliver (1990), Gleeson (1999) and Thomas (1999), it is a relatively underexplored perspective within studies of blindness. Oliver (1990) argued that material factors are fundamental to understanding the social model of disability. In this regard, it is important to note that blind people experience economic oppression and social isolation in even larger percentages than other disabled people, through higher unemployment and underemployment rates and lack of access to basic print information and accessible transportation. Potential employers, community development and urban planners, mainstream technocrats, rehabilitation agencies, and retailers alike often balk at the financial cost of environmental barrier removal and universal design, leaving blind people stranded in or altogether shut out of the workplace and, therefore, exiled from a consumer economy. In addition, government agencies, nonprofit charities, and for-profit businesses employ tens of thousands of sighted workers engaged in maintaining institutionalized oppression of blind people. Failure to examine these factors as influences in blind people's lives is failure to mine a deep and rich source of research data.

Another flaw with some of the blindness literature is that it generally focuses *either* on impairment or disability, but not both. In addition, distinctions between impairment and disability are muddied because authors often use these terms interchangeably. Such conceptual blurring can cause confusion and linguistic chaos because it becomes difficult for readers to grasp theoretical concepts when key terms such as *disability* or *impairment* are being used in inconsistent or ambiguous ways.

FUTURE DIRECTIONS

Advances in technology and medicine, demographic trends, a global economy, and political developments can be expected to shape the futures of blind and visually impaired people around the world. Technological advances will assist in agricultural practices reform and improvements in sanitation, which will further the current trend toward reduction in cases of bacterial-related blindness. On the other hand, medical advances continue to prolong life; therefore, a steady rise in cases of age-related blindness such as glaucoma, macular degeneration, and cataracts is expected. Coupled with general population gains, the overall number of blind people will most likely increase, especially in the developing world. The WHO (1997) estimated that by the year 2020, 50 million blind people will be living in developing countries, which will put a tremendous strain on eye health care and social service monetary and human resources. More cost-effective technologies such as outpatient cataract surgery may help alleviate the strain on service provision.

Gene therapies and genetic counseling may play a role in the future size of the blind population, especially in the majority world. Genetic manipulation of the human race is a controversial topic. Societal attitudes about disability and disabled people strongly influence decisions about which children are worthy of existence. Disability studies as a discipline is addressing the ethical issues and implications for disabled people and the science of genetic manipulation. Because many eye diseases are genetic, it is likely that those interested in the social model of blindness will participate in the discourse.

CONCLUSION

There are approximately 148 million blind people in the world, with most of them living in underdeveloped countries, and many international health promotion organizations are implementing blindness prevention and treatment programs. Blindness is a continuum, which can be measured according to different scales. For instance, most government departments distinguish between people who are totally blind, legally blind, and partially sighted, and they use these categories to determine eligibility for services. However, these definitions of blindness rely on a medical model of disability, which places most emphasis on measuring impairment levels, but which does not focus on the experience of disabling barriers.

It should not be assumed that there is a direct relationship between a person's degree of blindness and the difficulties he or she faces in everyday life. Some of the factors affecting the social inclusion and exclusion of blind people include the accessibility of their environment, the degree of support they have, and their financial resources. For many blind people, the experience of disabling barriers greatly limits their rights and freedoms. Some of those barriers include discrimination in employment, exclusion from regular education, and stigma. Prejudice and stereotypes affect many perceptions of blindness and are present in religion, education, charities, the media, and many other areas of life. In response to these barriers, organizations of blind people have been struggling for increased rights, and blind authors within disability studies have made an important contribution to the cultural reevaluation of blindness.

—*Beth Omansky*

See also Autobiography; Blind, History of the; Disability Studies; Religion.

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▣ BOBATH, BERTA AND KAREL
(BERTA, 1907–1991; KAREL, 1906–1991)
English (German-born) physiotherapist (Berta) and neurologist (Karel)

Mrs. Berta Bobath, physiotherapist, and her husband, Dr. Karel Bobath, originated a therapeutic approach to the treatment of persons with neuropathology and resultant sensorimotor impairments currently called the neuro-developmental treatment approach (NDT). Berta and Karel Bobath were born in Berlin, Germany, but developed these therapeutic concepts after they immigrated to London, England, prior to World War II. The treatment approach grew out of Mrs. Bobath’s astute observations of normal posture and movement and Dr. Bobath’s belief that scientific evidence must support clinical practice. They published many books and journal articles, teaching doctors and therapists their methods of examination and treatment from 1948 through 1990.

Although the Bobaths did not conduct any original research or collect clinical data in ways that offered the medical and scientific community evidence for the effectiveness of their treatment approach, NDT continues to be a commonly used method for the management of motor dysfunction following adults who have had a stroke or children who have cerebral palsy. The Bobaths committed their time and energy to developing their treatment approach, which, while it has evolved over the years, includes the following characteristics. Examination and treatment strategies target the neuromuscular and musculoskeletal impairments that interfere with functional skills in clients with neuropathology. Treatment includes hands-on facilitation of selective posture and movement and inhibition of unnecessary, inefficient motor responses so that ultimately the client can develop effective movement synergies that are in tune with task demands and contextual requirements. Treatment outcomes are defined as measurable, observable functional changes made in meaningful contexts.

—Janet M. Howle

See also Cerebral Palsy; Neurological Impairments and Nervous Disorders; Neuropathy; Stroke.

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BODY, THEORIES OF

"Body theory" is shorthand for a nexus of contemporary scholarship concerned with the definition, tracking, and management of kinds of bodies and the social ideas about bodies that configure self-perception. Work in body theory resists the Enlightenment idea that human definition should be based on a quality of consciousness. Instead of the often cited conceptualization of humans in the terms espoused by the Enlightenment-era philosopher René Descartes, "I think therefore I am," body theorists take human commonality to reside in the inhabitation of bodies. Rather than participating in a lengthy philosophical tradition (largely Western) that eschews bodies as secondary to the intellectual life of the mind, body studies reintroduces the materiality of lived experience as a significant site of analysis.

Premises in body theory have provided a basis for scholars to study the effects of management practices. Most important, in studying discourses and ideas about bodies, a scholar does not need to simply oppose or endorse institutional practices as necessary for the conduct of institutional life. Michel Foucault, a post-Holocaust historian of confinement practices, evaluation methods, and professional discourse, often receives mention as formative to body theory. Partially as a result of Foucault's methods, many contemporary policy studies, for example, now also investigate social ideas about the means for regulating the conduct of bodies without having to endorse them. Foucault himself studied the origins of disciplinary and regulative techniques for the operation of institutional life in schools, hospitals, prisons, asylums, and clinics. When social workers and prison guards complained that his book *Discipline and Punish* did not have much use for them, Foucault replied that he had not written it for them.

In work that theorizes the dynamics of power, Foucault contended that public executions, inasmuch as they directly display brutality and torture, deliberately expose the violent operations of a state in seeking compliance from its citizens. Rather than implicate the state in practices presumably enacted to deter transgressions, the Victorian era sought to conceal the workings of state power upon bodies: Executions became sequestered, judicial affairs as the product of massive deliberations that conceal directly punitive acts. Within this approach, oppression occurs as a matter of excessive evaluation, regulated body life, and administrative protocols so that the operations of power become diffuse. Increasingly, punitive bureaucracies came to implement such operations. During this period, definitions of a variety of "mental defects," in a casebook that is put to use by medical and judiciary organizations alike, subjugate citizens by casting an ever-expanding number of human characteristics as abnormal. Discussion of human abnormalities is entered into wholesale by the judiciary and a field of psychiatry that grows up as an adjunct to the courts, in France, and as the operators of institutions in the United States. Psychiatry was a field that had taken discourses about human pathology as a primary domain of expertise and qualification. In part, because of the collusion of German psychiatrists in eugenics and murder practices of disabled persons during the period of National Socialist Governance, psychiatry was also in general disrepute after World War II.

Contending that professional discourse about anomalous bodies such as the kind undertaken by rehabilitation and medical professions had become a "monologue," and one that had literally silenced subjects to death in state-mandated evaluation procedures in Germany, many of Foucault's writings contemplate the silencing of the voices of objects of study by discourses ostensibly "about" them. Body theory thus resists the idea that one can ascertain the views of the confined, the subjugated, the studied, and the disciplined from the case notes and judiciary records of those who write about them. Nonetheless, scholarship can effectively study the confinement of bodies and the techniques to control and illicit kinds of "abnormality" that make manifest the operations of power in a social order.

A principal innovation of institutional life was to develop a written case study, and maintain observational notes, on each client. This is likewise the case for the advent of contemporary practices in judiciaries that are also concerned with identifying and punishing abnormality. With these notes from psychiatric institutions now making up a substantive archive of collected materials, other scholars have also sought to find ways to listen to the voices of confined objects of medical observation and scientific study. Some study the discursive patterns of expression that have been recorded by professional observers in order to contemplate the messages avowed by, for instance, someone termed "schizophrenic." Others study locations in clinics and hospitals as spaces for the performance of anomaly and abnormality, noting, for example, that the performance of hysteria in the famous medical school of Jean Martin Charcot often entailed inciting an epileptic seizure in one of the subjects.

Hence body theory has provided for a means to study the classification of bodies and their performance of symptoms without having to validate (nor necessarily refute) medical findings. Many subjects viewed as abnormal also expressed symptoms bound up with violation of feminine norms and standards. Understandably, then, body theory is also largely associated with feminist and gender studies. This line of thinking contends that, under patriarchal societies, women experience disqualification from tasks on the basis of perceptions concerning attributes associated with an inferior biology. Feminist scholars thus research historical and professional locations that gauge equal participation in terms of body qualification. Cast as the "weaker sex," women have historically struggled with being limited and defined on the basis of bodies that were rigidly classified in terms of reproduction, as well as feminine norms and expectations. Body theory might say that humans with feminine reproductive organs, under a gender classification system that divides the world into those with wombs and those without them, will view women's bodies as making them innately unsuited for leadership, moral vision, certitude, or professional life. Intimately bound up with body theory, gender studies researches the ways in which different reproductive anatomies in bodies have been opposed in a dualistic fashion. Herein, masculinity comes to define a specific set of qualifications associated with body features whereas femininity offers a contrasting, and frequently less stable, range of possibilities.

Existentialism, a significant branch of philosophy during the first half of the twentieth century, grounds a substantial part of theorization about gender and the body. The primogenitor of existentialism, Jean-Paul Sartre, formulates feelings of emancipation in terms of the success of exceeding limits so that one experiences momentary escape from one's body demands. In contrast, Simone de Beauvoir, Sartre's partner, and the author of *The Second Sex* (1949), demonstrates how a masculine subject's sense of liberation from material constraint casts women in perpetual association with the fleshy, immured life of bodies. Within this patriarchal schema, women are made secondary by their continual association with the fluids and constraints of bodies while male agency occurs through its dominion and escape from the body into the life of the mind.

As a rejoinder to this detrimental tradition, a school of thought termed *l'ecriture feminine,* or "writing the body," is associated with feminist philosophy in France from the late 1960s to the present. Preeminently, Helene Cixous, in pieces such as "The Laugh of the Medusa" (1975), sought to expand imaginary associations between feminine body elements such as breast milk and the act of written expression. Whereas the classical story of the Medusa involved a male hero who turned the tables on a gorgon who had an appearance that, when gazed upon, turned men to stone, Cixous rewrites mythology from the perspective of a femininity that was only perceived, by masculine storytellers, as monstrous. Her philosophical tracts are thus also explicitly efforts to refigure denigrated and mythological female bodies by pressing the limits of poetics.

The feminist philosopher and gender ethicist Luce Irigaray, in many of her philosophical works, but most explicitly in *The Sex Which Is Not One* (1985), casts femininity as a purely negative, nonexistent state supplied only as a contrasting "other" to masculine subjectivity. She points out, for example, that a masculine philosophical tradition sees women's sexual organs in terms of mere absence of a phallus. Since femininity exists only as negation, one can attempt to realize a feminine subjectivity through interrogative questions and bodily experiences that escape masculine definition. The semiotics theorist and philosopher Julia Kristeva famously recorded her experience of embodiment during parturition in "Stabat Mater" (1983). In doing so, Kristeva reclaims feminine fluidity as a value rather than an abject vehicle. While influential in vastly divergent fields, all these writings nonetheless seek to expand imaginative thinking about the bounded nature and singularity of bodies. They also seek to resist equations of femininity with less and masculinity as the ideal of normative embodiment.

In a significant divergence from *l'ecriture feminine,* transgender theorist Judith Butler challenges the political utility of inverting values associated with a masculine/feminine dualism. Instead she argues against the existence of any embodied experience not already filtered by language. For Butler, gender is not the cultural layering of meaning upon the raw material of sex, but rather sex itself proves fully conditioned by cultural investments in naturalized bodily capacities. Studies of transgender experience interpret the effects of dualistic gender thinking upon bodies that do not suit an either/or classification of masculine/feminine. Instead a transgender studies approach analyzes the production of ambiguously gendered bodies that exceed inflexible sex/gender divisions. Transgender theorists analyze the resistant potential of gender ambiguity as undermining of normative heterosexual conventions.

Since body theory undertakes a historical tracing out of the ways in which bodies are viewed in different societies, analyses of racial discourse are also key to the field. Such an undertaking immediately necessitates parsing out the operations of racial and ethnic thinking in body image production. As late-eighteenth- and nineteenth-century ideologies produced gender-related pathologies, race itself moved from a marker of cultural difference fueling ethnic tensions to a physical sign of biological inferiority itself. Increasingly, one finds justifications for enslavement, for instance, based on paternalistic models of racialized populations' presumed inability to care for themselves. African and South Asian societies in particular came to be referenced by European anthropologists as evolutionary throwbacks. Freud, for instance in *Totem and Taboo* (1913), identified Maori communities in New Zealand and Zulu peoples in Africa as evidence of premodern totemic societies that had not effectively repressed their baser, primeval impulses. In addition, some ethnic populations such as Jews were cast under suspicion because they were thought to be hyperequipped to handle the demands of rapid industrialization and modern economic orders. Consequently, scholars examine the ways in which Nordic Western races have historically bolstered their biological superiority through the denigration of other bodies as inherently deviant based on subjective racial characteristics.

Outside of more psychoanalytic models, other traditions in body theory interpret the role of body classification in terms of economic and class-based effects. Second-wave feminism, for example, explored how Karl Marx, in *Das Kapital* (1867), conceived of the worker's body under industrial capitalism as inherently male. As a result, feminist socialist theory has worked to expand definitions of labor by querying formerly unrecognized modes of labor such as the role of reproduction as erased under capitalist economies. Theorists in this tradition have pointed out that work in the domestic space, though not usually and directly remunerated under professional business practices, qualifies nonetheless as expended labor and thus should be recognized as work that results in use value.

Likewise, disability body theory examines how Marx's conception of workers' bodies necessarily excludes from labor participation those bodies deemed less evidently productive by ableist labor orders. Indeed, the enemy element under industrial capitalism is the capitalist himself who parasitically invests capital but does not expend his own labor in the production of commodities. The capitalist's body is thus traditionally depicted as corpulent and excessive while the debilitated laborer's body provides evidence of capitalist indifference. While unbridled industrialism would therefore be culpable for disabling otherwise healthy worker bodies, there is also little room to discover alternative routes of employment for disabled bodies if they do not pass muster as "able" laborers from the start.

In a parallel effort to body studies, disability studies takes up the necessity of evaluating the often restrictive location of bodies identified as nonstandard. In doing so, disability scholarship often investigates sites of transportation, sequestration, confinement, seclusion, disenfranchisement, regulation, display, promotion, and clustering of disabled bodies. Like studies of obesity or age, disability studies analyzes the social world, from airplanes to classrooms, to discuss the ways in which an environment is built to anticipate some bodies while excluding others. Just as the politics and oppression of prostitution became a central concern for feminism, so does the history of employment in freak shows galvanize scholarship for disability scholars. Some kinds of disabled bodies, like racialized and exotic "others," seem particularly qualified for employment as an exhibition or freak act. These include bearded women, atrophied men, obese persons, those possessed of extraordinary height, persons of short stature, conjoined twins, and persons who appear to lack arms, legs, or body sections. Toward the end of the nineteenth century, medical researchers sought to examine persons employed in freak show exhibits. Discussion abounds concerning the efforts of sideshow barkers and managers, such as Phineas Taylor (P. T.) Barnum, to protect his band of freaks from them.

Cultural theorists such as Leslie Fiedler propose that the attainment of freak spectacle was reserved for only a special class of human anomalies and that the rest were simply consigned to the experience of regular disability and social suffering. Objecting, most of all, to being called a "freak," transgender and disabled commentator Eli Clare examined the economic realities that would bring about employment as an exhibited "extraordinary" human. She likens work in freak show industries to labor as a prostitute—drudge labor that nonetheless pulls one out of life as a beggar or a charity case. Then, in a key turn for disability studies, she returns to the insights of body theory and queries the medical team approach to examination that continues as a common practice in hospitals. Disability studies braves the radical insights of body theory by asking about the value of gait training examination and medical theaters from the perspective of those who have experienced being exhibited in these forums. For example, the gaze of medical and therapy practitioners upon different bodies may result in more harm than good and be utterly ancillary to the supply of a useful brace or mobility aid. Thus, disability studies also begs a question of political economy at its foundation in its querying of the necessity of medical evaluation regimes and the experimentation entailed by treatment plans, such as limb casting. How much does medical discourse have to produce "proof" of unacceptable traits and features in bodies? How much of the habit of gazing on body features involves merely assuring the professional gazer about their own normalcy? How much do professional practices rely on demonstrating the unacceptability of different body traits and features in terms, not only of standards of health, but merely for aesthetic purposes? And what are the implications of the rampant medical photographing of so many abnormal bodies during the twentieth century?

In addition to these methodological alliances, disability studies also reviews the significant absence of disability awareness in contemporary body theory. After all, body theorists may reference "cyborgs" as exemplary of a highly technological postmodern subject and toss in examples of someone "with detachable parts," without contemplating the sudden appearance in public of post-deinstitutional-era disabled persons. In other words, body theory often dematerializes into elegant discussions of the ascription of homophobic, racist, and sexist associations onto bodies in order to show that queer, racialized, and gendered bodies are socially produced. In many ways, this means that such bodies are not really "defective" or insufficient but only perceived as such by unjust social views of them.

Embodiment analyses in disability studies propose that physical disabilities are perceived as a private room in a public space—and that ideologies of disability assume a transparency to the motives and psychic life of physically disabled subjects. Thus, while disabled bodies have been rendered largely invisible historically, popular literary and media texts often present such bodies as readily interpretable. A prime example occurs when malevolency and vengeance are easily assigned to persons with physical anomalies or illiteracy to someone who may be hard of hearing. A simple discounting of disabled persons occurs as the result of onlookers making assumptions about someone's "inner" disposition and thus rendering them transparent. Because such simplistic ascriptions between psychological deviance and physically disabled bodies are common, these representational tactics constitute a significant layer of oppression for physically, cognitively, and sensory disabled persons alike. This historical intertwining of forms of deviance that seem to mutually reference each other has resulted in the deepening debasement of all bodies, particularly given that oppressive and discriminatory treatment often proceeds by making one form of devalued difference underwrite another.

Disability body theory has recently begun to analyze the degree to which eugenicist writings depend on the diagnosis of cognitive defects through scrutiny of physical anomalies and vice versa. Practices under eugenics where syphilis in one generation was argued to result in cerebral palsy and a propensity for promiscuity in the next provide a potent instance of cross-referencing practices that devalue bodies. Another area of interest is the degree to which racialized populations have been socially disqualified due to presumed inferior intelligence. Thus, one of the key insights of disability body theorists is that social disqualification occurs in a stigmatizing process whereby multiple identities are cross-referenced, and insomuch as these traits are configured in the same body, family, or communal unit.

—Sharon L. Snyder

See also Feminism; Michel Foucault; Freak Show; Gender; Gender, International; Identity; Racism.

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BORDERLINE PERSONALITY DISORDER

The term *borderline* was first brought into psychiatric terminology by A. Stern in 1938 to describe patients "on the border" of psychosis, and it has since been used to define alternately a clinical entity, a syndrome, or a personality organization. For roughly 70 years, the diagnosis of borderline personality disorder has been and still is a subject of intense debate.

Personality disorder is characterized by chronic instability in the individual's sense of identity, mood, and relationships. Afflicted individuals exhibit a deep lack of confidence and instability in relation to their sexual, professional, and social identities. They frequently experience disappointments and are prone to express anxiety and depression symptoms. Antisocial acts, affinity for psychoactive substance abuse, erratic lifestyles, a tendency for self-mutilation, and suicide attempts are common, and a sense of emptiness and meaninglessness prevails all along. The clinical presentation may show wide variability depending on the cultural background.

In individuals younger than age 18, these symptoms warrant a diagnosis of identity confusion. The prevalence of borderline personality disorder is in the order of 0.2–4 percent in the general public overall and 15–25 percent among hospitalized psychiatric patients. It is two to three times as common in women as in men. Alcohol and substance abuse and eating disorders are commonly co-diagnosed.

Etiologic explanations vary. Some hypotheses focus on constitutional defects in the brain's various neurotransmitter systems such as the adrenergic, cholinergic, dopaminergic, and serotonergic systems. Other hypotheses examine the association of this disorder with past or present history of head trauma, epilepsy, encephalitis, severe hyperactivity, distractibility, and learning disabilities. From a developmental perspective, arrest in normal development, excessive frustrations in early childhood and constitutional predisposition (weak ego structure prone to regression), disturbed separation-individuation process, early parental loss, traumatic separation from parental figures, and childhood physical-sexual abuse leading to ongoing posttraumatic stress disorder are all considered to be possible contributing factors.

Long-term analytic or reality-oriented supportive psychotherapy is a therapeutic mainstay along with the use of a wide range of pharmacologic agents including antidepressants, antipsychotics, and mood stabilizers for specific symptoms, often used in low dosages.

—Selahattin Şenol

See also Psychiatric Disorders.

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▣ BOURNE, RANDOLPH (1886–1918)

American literary critic and essayist

Randolph Bourne was born in New Jersey in 1886. Facially disfigured as a result of a "messy birth," he was further impaired by spinal tuberculosis, which developed when he was four years old.

In 1911, while still a student at Columbia, his essay "The Handicapped—By One of Them" was published anonymously in *The Atlantic Monthly.* After graduating from Columbia University in 1913, he began to write for *The New Republic.* His first book, *Youth and Life*—which included a revised version of his essay "The Handicapped"—saw young people as a force for social change and prefigured many ideas about youth culture that would gain currency in the 1960s. His strong opposition to growing militarism and to World War I resulted in the end of his association with *The New Republic.* The crucial essay that marked this break was "The War and the Intellectuals," which appeared in *Seven Arts.* Bourne saw war not as an aberration but as an inherent feature of the modern state.

Following Bourne's death from influenza during the 1918 pandemic, two more volumes of his writing appeared: *Untimely Papers* (1919) and *The History of a Literary Radical and Other Essays* (1920).

—Anne Finger

See also Journalism.

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▣ BOURNEVILLE, DÉSIRÉ MAGLOIRE (1840–1909)

French scientist and activist

Désiré Magloire Bourneville was an influential neurologist and pediatrician who made numerous contributions to the disability field in medical science, intellectual disability, clinical care, rehabilitation, and social policy. He was born in the village of Garancières in Normandy, studied in Paris with Charcot, and became an *interne des hôpitaux* at the Bicêtre, the Salpêtrière, the Hôpital St. Louis, and the Pitié. He served as a surgeon in the Garde Nationale during the Franco-Prussian War. After receiving his doctorate in 1870, he was physician at the pediatric service of the Bicêtre from 1879 to 1905 where he advanced the current understanding of pediatric neurological conditions. In 1873, Bourneville founded the journal *Progres medical* and in 1880 the *Archives de neurology*. Besides his own work, he facilitated publication of the works of the famous French neurologist Jean Martin Charcot (1825–1893). He also met with and was influenced by the work of Maria Montessori.

Bourneville founded the first French school for mentally retarded children and directed Fondation Vallée where he focused his energies on the treatment of mentally retarded children. On Saturdays, he held open house at the Bicêtre, where his disabled charges performed exercises and dances for the staff and public. In 1873, he became a member of parliament and in 1876, a member of the Paris City Council. In these capacities, he advocated for disabled people, created a school for the education of nurses, and championed special wards for sick children.

—Henri-Jacques Stiker

See also Maria Montessori.

BOWEL CONTROL

Controlling the elimination of rectal contents at socially acceptable times and places is called fecal continence. The loss of this control is a major personal and social disability. In some cultures, loss of fecal continence is cause for being ostracized from the community; in U.S. culture, many consider fecal incontinence indicative of a quality of life not worth living. Factors affecting continence include normal function of the entire muscle mechanism, adequate rectal capacity, normal stool consistency, and normal anal sensation.

Synchronized function of all components results in normal control of defecation and includes several elements: The rectum must fill, then sense the contents of the rectum; there must be relaxation or actually un-contraction of the entire sphincter mechanism, and at the same time there is a voluntary increase of intra-abdominal pressure.

Several problems can occur with the synchronized musculature: It may be cut, stretched, dented, diseased, or tired as a result of the aging process.

Cut muscle results from childbirth, surgery for abscess or fistula disease, or controlled muscle incision used to treat anal ulcer or fissure. The muscle may also be stretched or dented from obstetrical injury, extreme sex, surgery, or obstructed defecation (a malfunction of the entire pelvic floor). The mechanism is especially fragile in women, where there is only one small anterior muscular loop, which if injured, results in incontinence. The use of a midline episiotomy during childbirth, a common procedure in the United States, is a major source of injury.

The muscle may be diseased by such processes as inflammatory bowel disease, especially Crohn's disease, collagen or vascular disease, radiation injury, cancer, AIDS, or congenital abnormality. Muscle malfunction is also related to the aging process and is becoming more important with an aging population. Aging can cause overflow incontinence, which is frequently seen in combination with the pelvic floor malfunction of obstructed defecation. Special considerations exist for the surgeon who is treating a patient with Crohn's disease. Usual surgical procedures may not be safe because the future risk of incontinence necessitates preservation of all muscle function. Radiation injury to the muscle also disturbs normal function, now more common as adjuvant radiation therapy is used for various forms of pelvic cancer.

Other sources of incontinence result from disease processes in the neighboring organs, for example, in the large intestine; the small intestine, which may be shortened or diseased; Crohn's disease or ulcerative colitis; radiation injury; or irritable bowel syndrome. Another major source of lost control stems from injured nerves supplying the muscles of continence. Neural injury occurs with trauma as above, or with diabetes, spinal cord injury, multiple sclerosis, or congenital defects.

A process to differentiate causes of incontinence leads to proper treatment. Mechanical defects are sought first, but if absent, a diffuse impairment is sought. Specific diagnostic studies help in the process. The necessary studies include systemic evaluation, digital rectal exam, sigmoidoscopy or colonoscopy, and sometimes a small retention enema, which tests the function of the entire mechanism. Specialized diagnostic procedures include transrectal ultrasound, manometry, nerve function studies, defecography, and psychological studies.

Incontinence has various therapies. The simplest is an attempt to control bowel function, dealing with such problems as constipation and fecal impaction. Next is treating such diseases as Crohn's disease, colitis, radiation injury, or irritable bowel syndrome. If simple measures fail, biofeedback can be used to retrain the muscle and allow relearning of the process of defecation.

Should these simple measures fail, surgical correction becomes a consideration. If it is a straightforward problem, reconstruction of the sphincter mechanism is possible, as in the case of obstetrical injury in healthy women or acute trauma to the muscle itself. The issue becomes more complicated with sphincter reconstruction complicated by previously unsuccessful repairs, an elderly patient, or systemic diseases, as above. In these cases, specific diagnostic procedures are selected, especially to evaluate nerve function, quantity of muscle, and function of the organs of the pelvic floor.

In some cases, surgical repair is not a possibility, as when the nerve is severely damaged, when there is severe scar tissue, or when there is inadequate muscle to allow repair. In these cases, special complex surgery is a final recourse. These include encircling the incontinent muscle, a special repair of the muscle itself, bringing in muscle from elsewhere in the pelvic region, insertion of an artificial mechanical anal sphincter, or construction of a good colostomy. It is important to realize that in desperate cases with complete fecal incontinence, the patients have a de facto colostomy because they have no anal muscle control; these patients are better served with a well-constructed colostomy on the abdominal wall where they can affix an appliance, and live an otherwise normal life.

In summary, to understand bowel control, disability, and their relationship, it is important to know the cause of the disability, to diagnose and treat any systemic disease, to verify the presence of muscle and adequacy of nerve function before contemplating any surgical correction, and to remember that the quality of life of the individual is paramount.

—Ira Kodner

See also Aging; Bladder Control.

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BOWEN, ROBERT WALTER "MIKE"

(1887–1948)

South African lawyer and politician

Robert Walter Bowen, "whom everyone called Mike" (Lord Fraser of Lonsdale 1961: 208), began work as a railway clerk in Natal, South Africa, and served in the militia. He was blinded during war service at Ypres, Belgium, in 1917, after which his life changed gear. He passed through St. Dunstan's in London, studied at Cambridge University, became a barrister in 1920, and practiced in Cape Town. There he did some important legal work for black South Africans. By 1925, he was in the Cape Provincial Assembly, and from 1929 until his death he was a member of the South African Parliament. A skilled Braille user, Bowen worked tirelessly for educational and vocational training for blind people of whatever race. Together with Reverend Arthur Blaxall, Bowen set up the National Council for the Blind, which he chaired from 1929 to 1948. Blaxall (1965) noted Bowen's typical response on hearing of obstacles in starting a first school for blind African children: "Mike Bowen said forthrightly, 'It is a damn shame,' picked up the telephone receiver and dialled a number. That same day we were sitting with the Minister for Education" (p. 34).

—Kumur B. Selim

See also Blind, History of the; Experience of Disability: Sub-Saharan Africa.

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BRAILLE

See Blind, History of the; Blindness and Visual Impairment; Braille, Louis

BRAILLE, LOUIS (1809–1852)

French teacher and organist

Louis Braille was born in Coupvray (Seine et Marne) in 1809. Blinded in childhood, he created a writing system for the blind consisting of raised (embossed) dots. His system was an immediate success and today bears the name of the Braille alphabet.

At the age of three, Louis Braille was injured, and he progressively lost his sight. He was totally blind by the age of five. In 1819, he enrolled as a pupil at the Royal Institute for Young Blind in Paris, where he became a teacher in 1828. He modified a raised-dot system of code invented by Charles Barbier, and it became a new means of writing that permitted his pupils to take notes during his lessons. His system makes silent reading possible for people without sight and facilitates written communication with the sighted. It is based on an alphabet consisting simply of two vertical rows of three raised dots. Reading is effected by passing the fingertips over the raised dots. To write manually, heavy paper and a punch are used.

In 1854, two years after Braille's death in Paris, his system was officially recognized in France. In 1878, the Universal Congress for the Improvement of the Lot of the Blind came out in favor of using the Braille system in all countries. There were problems with the lack of uniformization and, in part to resolve this, the World Braille Council was officially created by UNESCO in 1952. The remains of Louis Braille, a historical figure in the world of the blind, were moved to the Panthéon in Paris at that time.

—Jean-François Ravaud

See also Blind, History of the; History of Disability: Early Modern West.

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BRAZIL

See Experience of Disability: Brazil

BREAST CANCER

One in eight American women will be diagnosed with breast cancer during her lifetime, and in 2001, more than 40,000 women died of the disease (men are also occasionally diagnosed with breast cancer, and make up about 1 percent of all cases). Most physicians and cancer advice books urge breast cancer patients to think of the disease as a chronic, rather than a terminal, condition. For this reason, one can understand breast cancer in many of the same ways one understands disability—as a state of physical difference that may require some accommodations in order to function in particular physical environments. The connections between breast cancer and disability go deeper, however, especially when one considers some important moments in the history of cancer activism and disability rights in the United States: the public acknowledgment of breast cancer as something that is not shameful, the emergence of organizations of patients dedicated to activism on behalf of other patients, the appearance of art and literature specifically dealing with the disease, and the specific link made between breast cancer and the Americans with Disability Act in *Alabama v. Garrett* in 2001.

Breast cancer diagnoses have been rising since 1900. There is much debate over whether the increased incidence of the disease is due to better detection methods (mammography), longer lifespans, or increased toxicity in the environment and food supply. Breast cancer is the most common cancer among American women (excluding skin cancers). It is second only to lung cancer as the leading cause of cancer deaths among women, but even though diagnosis rates have been steadily rising, mortality has declined throughout the twentieth century and into the twenty-first century, underscoring the status of the disease as a chronic condition.

Even though many famous women writers in the twentieth century were diagnosed with (and often died of) breast cancer—most notably reform writer Charlotte Perkins Gilman and environmentalist Rachel Carson—it was not until 1974 that breast cancer became a public topic of conversation. During that year, the year after Section 504 of the Rehabilitation Act was passed (though not signed), both First Lady Betty Ford and Rose Kushner, an investigative reporter, were diagnosed. Ford broke the public silence about breast cancer by acknowledging her disease on national television. Thereafter, she worked to increase public awareness of the disease. Kushner began a campaign to work on behalf of patients' rights that did not end until her own death from breast cancer. Starting with her book in 1975, *Breast Cancer: A Personal History and Investigative Report,* and ending with her advocacy of a congressional bill to provide Medicare coverage for screening mammograms, Kushner argued for the rights of patients to have a say in their treatment, to be allowed options and choices when it came to surgery, and to fund breast cancer research.

Another important figure in the history of breast cancer advocacy is Audre Lorde, whose *Cancer Journals* serves as a touchstone for disability studies. In addition to recording some of the journals she wrote during her treatment and recovery, the book includes essays about the silence that surrounded breast cancer and mastectomy in the 1970s, and about the falseness of prosthesis and reconstructive surgery. Though Lorde does not mention disability explicitly, much of the book resonates with the disability theory and activism of that era. She argues that prosthesis is a means of silencing bodily experience, a way of hiding women with breast cancer from each other, and of keeping them from being able to share their sense of rage and the knowledge they have gained from the experience. She argues further that prosthesis hides breast cancer from public awareness, allowing people to ignore its politics. Lorde claims that prosthesis works as a lie, a way to avoid the reality of amputation, and that the emphasis on "looking normal" after mastectomy works to keep women within a stereotypical femininity, treating their bodies as aesthetic objects. It is perhaps this last argument, against the falsity of "the normal," that connects Lorde most clearly to contemporary disability studies. Lorde lays the groundwork for a theory of bodies that emphasizes diversity and difference in both appearance and experience. Furthermore, she argues for a politicized understanding of illness that likewise connects to disability studies, urging an awareness of environmental factors that cause cancer, and political coalitions to work against pollution and carcinogenic working conditions.

Following Ford's, Kushner's, and Lorde's leads, many women who had lived through breast cancer or who had lost close friends and relatives to the disease undertook conscious campaigns of activism in the late 1970s and early 1980s. In 1978, Mimi Kaplan and Ann Marcou founded the Y-Me organization to provide support to breast cancer patients; in 1982, Nancy Goodman Brinker founded the Susan G. Komen Breast Cancer Foundation to raise funds to study and eradicate the disease. Since then, more than 60 other nonprofit organizations have been formed around the disease, to promote research, environmental health, patient support and information, and financial assistance for poor patients. By the early twenty-first century, breast cancer may well be the most publicized disease in the United States, with innumerable products marked with pink ribbons, and with fund-raising events modeled after the Komen Foundation's "Race for the Cure"—"Shop for the Cure," "Plant for the Cure," "Art for the Cure"—becoming ubiquitous.

Breast cancer has also become a frequent subject in the arts and literature. Since the appearance of Deena Metzger's 1988 poster, "I Am No Longer Afraid" (also called "The Tree" after her book of that name), and Matuschka's self-portrait of her postmastectomy body on the cover of 1993 issue of the *New York Times*

Magazine, artists have not shied away from representing bodies affected by breast cancer. Often this art joins with activism, as in the collection *Art.Rage.Us.* Writers have also followed Audre Lorde's lead in resisting silence about breast cancer, often writing about it directly, as in autobiographies such as Christina Middlebrook's 1996 *Seeing the Crab: A Memoir of Dying before I Do,* collections of stories, poetry, and essays, and Hilda Raz's *Living on the Margins* from 1999, or documentaries such as Gerry Rogers's *My Left Breast,* released in 2000. Breast cancer may also play an indirect part in fiction, as it does in Margaret Atwood's *Bodily Harm* or Jane Smiley's *Thousand Acres.*

During the 2000 term of the U.S. Supreme Court, breast cancer and disability activism became firmly linked, when the Court ruled that the Americans with Disabilities Act (ADA) does not give anyone the right to sue a state. Patricia Garrett was a nurse at the University of Alabama hospital and was asked to take a lesser position because she was in treatment for breast cancer, despite having been acknowledged to be able to perform her job adequately. On the face of it, *Alabama v. Garrett* was decided as a states' rights case, the Court arguing that Congress did not have the right to pass a law that would award money damages to a citizen from a state unless it had clear evidence that the states had historically violated their citizens' constitutional rights. The language of the decision and concurrence, however, suggest to some that the decision has broader ramifications for people who would bring suit under the ADA, since Justice William H. Rehnquist argues that the ADA does not provide for "special accommodation" and since Justices Anthony Kennedy and Sandra Day O'Connor argue against using the law to redress discrimination by the states and suggest that it may be instinct to recoil from people who are different from ourselves. Despite the work of breast cancer and disability activists, there is still much to be done to challenge public attitudes about chronic disease and difference.

—*Diane Price Herndl*

See also Autobiography; Cancer.

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Y-Me National Breast Cancer Organization, http://www.y-me.org

BRIDGMAN, LAURA DEWEY (1829–1889)

American deaf-blind pioneer

Laura Dewey Bridgman was the first deaf-blind person to receive a formal education. Bridgman achieved worldwide notice for her accomplishments. Charles Dickens visited her one time and then wrote a chapter about her in *American Notes* (1842).

Bridgman was born in Hanover, New Hampshire. She contracted scarlet fever at two years of age, which left her without vision, hearing, and sense of smell or taste. Her only mode of communication with the world around her was through her sense of touch. By touching her mother as she went about the daily household chores, Bridgman learned how to clean, sew, and knit. When she was seven years old, Dr. Samuel Gridley Howe took Bridgman to live at the Massachusetts Asylum for the Blind (later renamed Perkins Institute, and currently known as the Perkins School for the Blind) in Boston. Like other blind children, Bridgman was made to wear a green scarf around her head to cover her eyes. Through a progressive series of exercises and grooved paper, she learned the manual alphabet used by deaf-blind people. When she learned something new or repeated a lesson correctly, her teacher patted her on top of her head. If she answered incorrectly, the teacher struck her on her left hand.

Bridgman lived out the rest of her life at the institution, and died on May 24, 1889. Six of her letters, photos of Bridgman, and a piece of lace she made are preserved at the Leonard H. Axe Library, located at Pittsburgh State University, in Pennsylvania.

Many educational publications have been written about Bridgman's life. Current deaf-blind education methods can be traced back to those used to teach Bridgman communication and daily living skills.

—Beth Omansky

See also Blind, History of the; Blindness and Visual Impairment.

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BRIGHAM, AMARIAH (1798–1849)

American institution administrator

Amariah Brigham was one of the leaders of the asylum movement in mid-nineteenth-century America who sponsored the creation and public support of specialized, congregate insane asylums led by experts in the emerging profession of psychiatry. His approach characterized the powerful optimism of these early asylum superintendents. As superintendent of the Utica State Asylum in New York from 1842 until his death in 1849, Brigham was also one of the 13 founders (along with Thomas Kirkbride, Isaac Ray, Pliny Earle, and others) of what is now known as the American Psychiatric Association. Brigham himself began publication of the *American Journal of Insanity* (printed with the help of inmates at Brigham's asylum in Utica), one of the first English-language journals devoted exclusively to mental illness. The scientific optimism of the era is illustrated in this passage from Brigham's introductory essay to the initial issue of the journal: "Insanity is but a disease of that organism [i.e., the human brain], and when so regarded, it will often be prevented, and generally cured by the early adoption of proper methods of treatment."

—Philip M. Ferguson

See also Mental Health.

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BROCA, PAUL (1824–1880)

French surgeon and anthropologist

Paul Broca was a French surgeon, pathologist, anatomist, and anthropologist. Today, he is best remembered for localizing speech in the frontal lobes, recognizing cerebral dominance, performing the first surgery based on localization, studying race and intelligence, and investigating ancient trepanned (opened) skulls.

In 1859, Broca founded the world's first anthropological society, the Société d'Anthropologie. It was here that scientists discussed human origins, intelligence, and the functional organization of the brain. In 1861, he used the case of Leborgne to argue for localization of fluent speech in the anterior lobes of the brain (Broca's area). A few years later, he recognized that the left hemisphere is more important than the right for speech (cerebral dominance).

Broca hypothesized that the right hemisphere may be able to take over for a damaged left hemisphere, particularly if brain damage occurs early in life. He also recommended speech therapy for aphasic patients. In 1868, Broca conducted the first successful brain surgery based solely on functional localization.

In the late 1860s and 1870s, Broca concerned himself with ancient trepanned skulls. One of his theories was that cranial openings were made during the New Stone Age to treat childhood seizure disorders. At the time of his death in 1880, he had more than 500 publications.

—Stanley Finger

See also Aphasia; Speech and Language Pathology; Traumatic Brain Injury.

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BROWNING, CHARLES ALBERT "TOD" (1880–1962)

American filmmaker

The 1930s Hollywood horror film director Charles Albert "Tod" Browning was born in Louisville, Kentucky. Best known for *Dracula* (1931) and *Freaks* (1932), Browning's career was clearly influenced by a childhood interest in carnival life. His experience acting in nickelodeon pieces and D. W. Griffith films is often overshadowed by his later directorial success. His early work in silent cinema, especially directing the esteemed character actor Lon Chaney, prepared him for his most famous portrayal of people with disabilities in the most controversial Hollywood feature film to depict people with disabilities playing themselves. In addition to his time spent traveling with circus performers, the year Browning spent hospitalized after a serious car accident (1915) may have affected his characterization of people with disabilities in *Freaks.* During his recovery, he penned film scripts leading to his feature film debut, *Jim Bludso* (1917).

Throughout his career, Browning challenged acting norms by having actors play Harlequin puppets (1916), by using double-exposure techniques so that Mabel Taliaferro could play opposite herself (1917), by casting Lon Chaney as more than one principal character in the same film (1925), and by casting circus sideshow artists in a cinematic treatment of their world (1932). Browning was nicknamed "Hollywood's Master of the Macabre" and "The Wizard of Odd."

—*Sally Chivers*

See also Film; Freak Show.

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BUCK (EAGLE DETAMORE), CARRIE (1906–1983)

American sterilization plaintiff

Born to Emma Buck, an unmarried and institutionalized woman, Carrie Buck was raised by J. T. and Alice Dobbs in Charlottesville, Virginia. At age 17, she was assaulted by a nephew of the Dobbses and became pregnant. Mr. Dobbs then had her committed to the Virginia Colony for Epileptics and Feebleminded in Lynchburg. There, in 1927, she was sterilized against her will, in compliance with the Virginia Statute for Eugenical Sterilization, upheld by the U.S. Supreme Court earlier that year in the *Buck v. Bell* decision. Carrie Buck married her first husband William Eagle in 1930 (he died in 1966), and during her middle years worked as a housekeeper and agricultural laborer. Buck's only daughter, Vivian, was raised by the Dobbs family until she died of an acute illness in 1932. Buck's younger sister, Doris Buck Figgins, was also sterilized as a teenager. Carrie Buck Detamore died as a result of poverty-related exposure and malnutrition. Her second husband, Charles Detamore, survived her. In 2002, a roadside historical marker was erected in Charlottesville, marking the 75th anniversary of the *Buck v. Bell* decision and telling Carrie Buck's story.

—Penny L. Richards

See also Sterilization.

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BUCK, PEARL S. (1892–1973)

American author

Pearl S. Buck was an American writer and Nobel Prize winner for literature in 1938. Buck described her own experience as the mother of a child with mental retardation in the widely read "The Child Who Never Grew," an essay for *Ladies' Home Journal* in 1950, which was later expanded to book length and translated into many languages. Along with other mid- twentieth-century parent narratives, it increased visibility for middle-class families of children with developmental disabilities while assuring parents that institutionalization was the best possible solution. (It is still in print today.)

Buck also wrote themes of family and disability into her fiction. Her best-known novel, *The Good Earth,* published in 1931, concerns a Chinese family in which the eldest daughter has developmental disabilities and cannot speak. Other works share this concern for the care of children, especially girls, with disabilities, among them, *The Mother* (1934). Buck's literary success allowed her to fund research that eventually discovered the metabolic cause of her daughter's developmental disability—phenylketonuria—which, in turn, led to universal newborn PKU testing and food labeling in the United States. Buck's daughter, Carol (1921–1992), lived at Vineland Training School in New Jersey for most of her life.

—Penny L. Richards

See also Developmental Disabilities.

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BULWER, JOHN (1606–1656)

English physician and author

Influenced by Francis Bacon, who criticized Aristotle for his inattention to gestures and the role of the body in rhetorical delivery, and also apparently influenced by contact with his deaf daughter (named Chirolea) and his work as an early deaf educator, John Bulwer wrote three late-Renaissance texts that called on his knowledge of deafness and sign languages: *Chirologia, or, The naturall language of the hand* (1644); *Philocopus, or the Deaf and Dumbe Mans Friend* (1648); and the unfinished *Pathomyotamia, or, A dissection of the significative muscles of the affections of the minde* (1649).

Chirologia is an important text in the history of elocution, a movement in rhetorical theory and practice that focuses on the effects of gestures, expressions, and body language on persuasion. *Philocopus* explores the "philosophical verity" of lipreading, which, according to the book's frontispiece, is "that subtle art, which may enable one with an observant eye, to hear what any man speaks by the moving of his lips." *Phathomyotamia* was intended to further the work of *Chirologia* and to do for the head—and its affective powers of movement—what Bulwer had already outlined for "the naturall language of the hand."

—Brenda Jo Brueggemann

See also Deaf, History of the; Sign Language.

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BUNKER, CHANG AND ENG

(1811–1874)

American (Thai-born) performers

Conjoined twins Chang and Eng Bunker were nineteenth-century freak show performers who were known as the "Original Siamese Twins." They were born in Thailand, which was then known as Siam. For much of their childhood, they worked as duck egg merchants until they met Robert Hunter, a British merchant based in Bangkok. In 1829, Hunter and his associate, Abel Coffin, secured permission from their mother and Siamese King Rama III to take Chang and Eng to the United States to undertake a touring career. They became naturalized U.S. citizens, adopting the surname Bunker.

The twins took a break from performing in 1843. Chang married Adelaide Yates, and Eng married Sarah Yates in a double wedding. They settled in Wilkes County, North Carolina, bought a plantation with slaves, and had 22 children between the two of them. The end of the Civil War brought Chang and Eng out of their temporary retirement, and they reentered the touring circuit. Over the course of their career, they traveled throughout much of the United States and Europe, along with engagements in Canada and Cuba. They died in 1874 with Chang expiring first and Eng following a few hours later.

—Cynthia Wu

See also Freak Show.

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BURNOUT

See Stress

BURNS

Burns injuries are traumatic, functionally impairing, excruciatingly painful, and cosmetically disfiguring. The key to minimizing disability after injury is rapid wound closure and early aggressive rehabilitation. Burn severity and outcome are directly related to the depth and percent total body surface area burned.

Burn depth is measured by degree. First degree is a superficial burn involving the epidermis. Second degree is partial thickness involving part of the dermis. Third degree is a full-thickness burn involving the epidermis and all of the dermis. A fourth-degree burn extends to muscle, tendon, or bone. Full-thickness burns need to be grafted with skin taken from another part of the body. With this depth of burn, hair follicles, sweat and sebaceous glands, and nerve endings are destroyed and do not regenerate. Therefore, areas of full-thickness burn do not have hair or normal sensation and do not perspire or self-lubricate.

A major disability after burns is scarring. Areas of burn can be lighter or darker than normal skin. Scars can also become thick and dense (hypertrophic). Although pigmentation may improve and thick scars may soften, it is important to recognize that most burn scars are permanent. Pain in the scars and itching may persist for years. Custom pressure garments or silicone patches may help flatten scars and decrease pain and itching.

The key to maximizing outcome and minimizing disability after burn injury starts with aggressive prevention measures. Contractures, which limit joint range of motion, are a common complication following major burn injury, affecting 30–50 percent of patients. Treatment focuses on stretching and proper positioning. If full range of motion cannot be obtained, the patient can be treated with splinting or serial casting. If a scar band is unresponsive to conservative treatment, surgical release will be necessary.

Neuropathy, a nerve injury, with associated weakness occurs in 10–15 percent of patients after major burn injury and is more common with an electrical etiology. Amputations are necessary following burns that involve muscle and bone. Careful prosthetic fitting is essential to avoid skin breakdown over the stump. A silicone sleeve can be used to maintain moisture and decrease shear forces across the residual limb.

Psychological distress following burn injury is common. Severe pain can escalate anxiety. Sleep disturbance, itching, and nightmares may add to distress. Posttraumatic stress disorder is rare but can be seen particularly in those patients injured by electricity.

Most burn patients perceive themselves as having a good quality of life. Return to work usually occurs in 14 to 17 weeks. Ninety percent are back to work at 24 months, but only 37 percent return to the same job with the same employer.

Burn care has changed dramatically in the past century with a significant improvement in overall survival. Patients with much larger burns now are surviving the acute care treatment but are often left with significant long-term functional impairment including decreased hand function, amputations, heat intolerance, cosmetic changes, pain, itching, and psychological difficulties. These can be limited by aggressive early comprehensive care.

—Karen J. Kowalske and
Phala Helm

See also Amputation; Neuropathy; Pain.

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American Burn Association, www.ameriburn.org

BYRON, LORD (GEORGE GORDON) (1788–1824)

English poet

The celebrated English Romantic poet Lord Byron enjoyed substantial renown during this lifetime. He became a cult personality of sorts and often found himself condemned for questionable morality by his peers. Diagnosed with “clubfoot” at birth, the label seems to cloud rather than reveal much useful information about the nature of his impairment. For instance, whereas his mother referred to the affected foot as his right one, his prosthetics manufacturer of the time claimed to have constructed a raised shoe for his left foot. Furthermore, his close military colleague Edward Trelawny, who fought with Byron in the war for Greek independence, claimed that both feet exhibited the effects of spasticity. Most contemporary researchers now suggest that Byron had Little’s disease (an early diagnostic category for cerebral palsy). Many friends and relatives have claimed that Byron proved particularly sensitive about his disability. He would act defiant and melancholy when others discussed his lameness.

These descriptions of his attitude toward his disability bear much in common with the extreme sensitivities of the “Byronic hero,” a characterization method he created in his poetry and fiction. Yet one might argue that such parallels are merely the product of a conflation of author with character; or, it might be equally insightful to identify something of the Byronic sentiment as akin to a defiant disability demeanor toward the world. In either case, Byron only wrote about his disability explicitly in his final, unfinished work published posthumously as *The Deformed Transformed.* In this play, the hunchbacked protagonist, Arnold, despairs about his disability status as a socially maligned condition and considers suicide. A “stranger” appears just as he is about to commit this desperate act and offers him a deal of Faustian proportions: Trade his disabled body for a more able-bodied prototype from history. Arnold accepts the offer immediately. After rejecting a number of possibilities on the basis of superficial defects, he chooses the physically idealized body of Achilles from Greek mythology. Ironically, the stranger dons Arnold’s former disabled body to demonstrate that one can navigate the world successfully despite a visible disability. In fact, Byron’s ironic commentary in the drama turns on the idea that once Arnold adopts an “unblemished” masculine exterior, he runs off to fight a war and puts his new, able body immediately at risk. This text further contextualizes Byron as one who did not despair over the presence of impairment as much as he condemned the false superiority that sometimes attends able-bodiedness itself.

—Sharon L. Snyder

See also Poetry.

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C

CAMPANELLA, ROY

(1921–1993)

American baseball player

Roy Campanella was one of the best offensive and defensive catchers in professional baseball in North America. After seven years in the Negro Leagues with the Baltimore Elite Giants (1937–1941, 1944–1945) and two in a Mexican league (1942–1943), Campanella joined the Brooklyn Dodgers not long after Jackie Robinson. One of the first African Americans in the major leagues, he was a leader by successful example who helped to integrate baseball. In his 10 seasons with the Dodgers (1948–1957), Campanella made the All-Star team eight times and won three National League Most Valuable Player (MVP) awards. Campanella helped the Dodgers win five pennants and the 1955 World Series. Although his Major League career was plagued by injuries, he batted .276 with 242 home runs and 856 runs batted in. In his 1953 MVP season, he led the league with 142 RBIs, batted .312, and set a record for catchers with 41 home runs.

On January 28, 1958, Campanella's car skidded on a patch of ice and crashed into a telephone pole. He broke his back between the fifth and sixth vertebrae and was paralyzed from the chest down. Through physical therapy Roy learned to move his arms and hands, feed himself, and use a wheelchair. On May 7, 1959, ''Roy Campanella Night'' was held at the Los Angles Coliseum with record attendance of 93,103 fans. In 1964, he began working as a catching instructor for the Dodgers and was inducted into the Baseball Hall of Fame in 1969. In 1978, he joined the Dodgers Community Service team and was active in providing support for youths with disabilities. He worked and spoke for the Dodgers and on disability issues until he died of a heart attack on June 26, 1993. The Roy and Roxie Campanella Physical Therapy Scholarship Foundation provides support to physical therapy students whose cultural competence and ethics aid patient well-being.

—Daniel J. Keys, Christopher B. Keys, and Robert I. Westerholm

See also Paralysis; Sports and Disability.

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Roy and Roxie Campanella Physical Therapy Scholarship Foundation, http://www.hihard1.com/dtw/dtwcampy.html-ssi

CANADA

See Disability Law: Canada

CANADIAN CENTRE ON DISABILITY STUDIES

The Canadian Centre on Disability Studies (CCDS) is a nonprofit, consumer-directed, university-affiliated center dedicated to research, education, and information dissemination on disability issues. Using a participatory approach to research, CCDS promotes full and equal participation of people with disabilities in all aspects of society. Members of the disability community are key participants in directing CCDS activities: 51 percent of the CCDS Board of Directors are designated persons with disabilities.

Housed in Winnipeg, CCDS works in concert with academics, government, and the disability community. CCDS has participated in the development of an interdisciplinary graduate program in disability studies at the University of Manitoba and is currently working in partnership with the University of Winnipeg to develop an undergraduate interdisciplinary degree in disability studies.

Research by CCDS is known nationally and internationally, with projects in Russia, Mexico, Ukraine, and Thailand. In 2002, the Canadian International Development Bank announced the approval of the Canada-Russia Disability Program, a four-year, $4 million project, focusing on education, disability studies, social work practice, social policy, and information dissemination. CCDS is involved in a variety of innovative projects such as the Arts Ability Project and the Pan-Canadian Leadership Project—Creating Opportunity and Sharing Knowledge: Leadership Development in the Canadian Disability Movement, which takes a social rather than medical approach to integrative programming.

See also Disability Studies; Research.

—Canadian Centre on Disability Studies

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Websites

Canadian Centre on Disability Studies, http://www.disabilitystudies.ca

CANCER

Some nine million people living in the United States today have a history of cancer. These people, of course, do not have a universal disability, though cancer is clearly associated with a range of physical, psychological, and other disabilities. When all cancers are combined, 62 percent of the people diagnosed with cancer in the United States will still be alive five years after the initial diagnosis. In 1996, the National Cancer Institute established the Office of Cancer Survivorship "in recognition of the large number of individuals now surviving cancer for long periods of time and their unique and poorly understood needs."

The concepts of cancer-related disability and rehabilitation developed in the 1970s, as cancer survival rates rose and research studies started to examine the psychosocial and economic ramifications of cancer diagnosis and treatment. Issues of disability linked to cancer, however, are not always openly discussed, and this silence may have contributed to the relative dearth of knowledge about the health and disability of cancer survivors. Large cancer organizations, both now and historically, have tended to downplay discussion of disability to focus on hopeful, positive messages for those diagnosed with the disease. Many of the now ubiquitous cancer fund-raising feats of physical endurance, from walks to runs to mountain climbs, are done "for the cure" and display celebratory, athletic images of winning cancer survivors. An emphasis on survivorship and returning to normality can overshadow those with long-term disabilities.

Physical disability and rehabilitation needs vary greatly with the type of cancer, the choice of treatment, and the extent to which normal functioning is affected. Cancer resulting in loss of a limb has long been recognized as an obvious disability. But a person with colon cancer may need a colostomy, a person with prostate cancer may experience sexual dysfunction, or a person with head or neck cancer may lose the ability to speak. Cancer treatments, including surgery, chemotherapy, and radiation, are often debilitating and difficult, with some treatments themselves resulting in long-term disabilities. Physical, emotional, psychological, sexual, and financial problems can persist for years. On a more practical note, cancer survivors may have difficulties obtaining health and life insurance coverage or experience employment discrimination.

CANCER SURVIVORS AND DISABILITY

National Cancer Survivors Day was founded officially in 1988 with a goal of demonstrating "that a diagnosis of cancer is not an automatic death sentence." Since then, the term *cancer survivor* has permeated the national vocabulary. Typically, people who have had cancer and are now free of disease are described in popular literature not as passive cancer sufferers or victims, or even as neutral "former cancer patients," but as active cancer survivors. *Coping,* a consumer magazine widely available in waiting rooms of oncology treatment centers, for example, instructs its writers to be "informal, upbeat and positive (assume that everyone diagnosed with cancer has a chance to beat the odds)," avoiding "grim statistics" and "lengthy treatment descriptions." Writers are also advised to avoid the words *death*, *dying*, *suffering*, *victim*, and *patient*, substituting more positive words such as *coping* and *survivor*. As the website notes, "*Coping* challenges readers to develop a positive, proactive attitude for a better quality of life by becoming cancer survivors, rather than remaining patients and victims." This is not the language of disability awareness.

It does not matter when the cancer diagnosis was made, or how long the cancer has been in remission, or whether any physical disability resulted; the patient is considered a cancer survivor until the end of his or her life. This lifelong association with disease and the fear of recurrence and metastasis may give cancer survivors a different psychological outlook than survivors of many other disability-causing conditions. Patients can be cured—go into remission and live cancer-free lives—but are always called survivors. Unlike many other conditions that cause disability, cancer survivors may not have obvious physical signs of their history of cancer. They do, however, continue to have higher rates of recurrence and delayed sequelae of treatment.

McNeil estimated in a 1999 study (McNeil and Binette 2001) that 792,000 adults living in the United States have been disabled by cancer, making it the 13th leading cause of disability in this country. To better understand the nature of cancer survivors' disabilities, a 2003 study used data from more than 95,000 Americans enrolled in the National Health Interview Study. The study found that cancer survivors (as compared to people without a history of cancer) were significantly more likely to be in poor or fair health, to have a psychological disability, to have physical limitations, and to be unable to work. The researchers concluded that chance of poor health and disability are doubled by a history of cancer. In addition, cancer survivors had significantly lower self-reported measures of physical functioning, with nearly one in six (16.8 percent) of the survivors of working age saying they were unable to work due to a physical, mental, or emotional problem.

BREAST CANCER

Breast cancer is the most common cancer diagnosis in women in the United States (excluding skin cancer) and is the second leading cause of cancer death among U.S. women. For many patients, sobering mortality and morbidity statistics combine with concerns about sexuality, mothering, or body image. Physical limitations after treatment of breast cancer can be significant, as arm mobility and lifting ability may be affected. If a woman has the lymph nodes under the arm surgically removed or radiated, lymphedema, a sometimes severe swelling of the arm caused by a buildup of lymph fluid in tissues, can result. The affected arm may swell significantly, and it will need protection from infection, cuts, sunburn, and trauma. In addition, a 2003 study by Hewitt, Rowland, and Yancik comparing long-term breast cancer survivors to women with no history of cancer found that the cancer survivors reported significantly worse sexual functioning, using indices ranging from a lack of sexual interest to an inability to relax and enjoy sex, to difficulty becoming aroused or achieving orgasm.

Historical shifts in the surgical treatment of breast cancer and the attention to emotional and psychological effects of the disease illuminate the increasing awareness of disability concerns in breast cancer. Operations that would now be considered unnecessarily disfiguring and needlessly aggressive in removing muscles and lymphoid tissue were the standard of care for decades. In 1882, William Halsted, a professor of surgery at Johns Hopkins University, developed an operation for breast cancer that removed not only breast tissue and lymph nodes under the arm but also chest wall muscles. Eighty years later, through the 1960s, most American breast cancer patients were still treated with Halsted's radical mastectomy. This operation, however, caused considerable disfigurement and disability. Removing the muscles resulted in a deformed chest wall and limitations in arm motion, and the aggressive operation sometimes resulted in long-standing pain at the site of operation and an increased likelihood of lymphedema. But these disabling effects were considered less important in the calculus of survival, and concern over what came after surgery was downplayed.

Some surgeons turned to even more aggressive "superradical" surgeries in the years after World War II, trying to halt future spread of the disease by removing more and more tissue. In the 1960s, for example, George Pack, a surgeon at Memorial Sloan-Kettering Hospital in New York, sometimes performed interscapulothoracic amputations, in which he, in effect, removed a quarter of the body, taking the collarbone, scapula, and arm along with the affected breast. Other surgical procedures targeted additional lymph nodes that required rib removal and splitting of the sternum. In this manner, some surgeons caused permanent disability in their breast cancer patients. Ironically, this disfigurement was for naught. Studies eventually showed that superradical operations did not effect significant improvements in lifespan.

During these years, cancer was a diagnosis to be concealed. Stigma surrounding the disease was very high, and women typically accepted physicians' treatment plans without question. But after the mid-1970s, breast cancer entered the national dialogue, fueled in part by national figures, such as Shirley Temple Black and Betty Ford, who disclosed their own diagnoses. Some feminists saw the treatment of breast cancer as a prime example of problems within the male-dominated, authoritarian medical system. They called attention to the disability that resulted from radical mastectomies and the lack of research testing the efficacy of such aggressive operations. A modified radical mastectomy, which removed the breast but left one or both chest muscles intact, had been developed in the 1950s, and some women started demanding this operation with a goal of reducing postoperation disability. Today, patients very rarely undergo radical mastectomies, and they often have partial mastectomies (lumpectomies), which remove only a small area of tissue around the tumor, accompanied by radiation therapy and sometimes chemotherapy or hormonal therapy. While a significant advance over radical surgery, these adjuvant treatments can also contribute to disabilities and have their own short- and long-term side effects, such as an increased risk of other cancers.

PATIENT-CENTERED REHABILITATION: REACH TO RECOVERY

Individual patients played a large role in changing the system and bringing emotional and psychological issues into the medical realm. After undergoing a radical mastectomy in New York in 1952, Terese Lasser became frustrated when she received no answers to her questions: How should she obtain a prosthesis, explain her breast cancer diagnosis to her children, or return to sexual activity with her husband? As Lasser later wrote, "When told that my right breast had been removed, I wanted to shrivel up and die. How could I face life, a scarred woman? . . . How could such a life be worth living?" She worried that her husband would be repelled by her or would only feel pity for her, asking, "Was it possible for a man to desire a woman who wasn't whole?"

In time, Lasser's concerns motivated her to begin Reach to Recovery. In this program, volunteers without medical expertise who had previously undergone radical mastectomies visited and provided emotional support to hospitalized women who had just had the operation. These volunteers were encouraged to stay upbeat and positive and to dress in attractive clothing that emphasized the bustline to demonstrate that women could return to their "normal lives." The Reach volunteers gave the newer breast cancer patients temporary prosthetics, answered their personal questions, offered a "Letter to Husbands," and served as a source of information outside the medical establishment. The name of the organization came from the reaching arm exercises used to improve recovery.

Lasser had established 300 chapters of Reach to Recovery by the time the American Cancer Society took control of the program in 1969. Within five years, half of all women having mastectomies in the United States received a visit from a Reach volunteer. Today, Reach for Recovery continues its work under the auspices of the American Cancer Society with the slogan "No one should have to face breast cancer alone." The program emphasizes that its volunteers "offer understanding, support, and hope because they themselves have survived breast cancer and gone on to live normal, productive lives." Today, some 87,000 women in 44 countries are visited by 16,000 Reach to Recovery volunteers each year. In recruiting volunteers, the program asks, "Are you a breast cancer survivor who has overcome cancer to regain a well adjusted and emotionally stable everyday life?"

Reach to Recovery was one of the first programs to focus on what came after a cancer operation, using a particular psychological slant to enhance the physical recovery. Its emphasis on returning women to "normal" life, with an emphasis on continued attractiveness, was a theme that would continue in later programs. Currently, the American Cancer Society sponsors Look Good . . . Feel Better for women with all kinds of cancer. As noted on its website, the program is a "community-based, free, national service that teaches female cancer patients beauty techniques to help restore their appearance and self-image during chemotherapy and radiation treatments." This emphasis on normality and attractiveness, of course, also downplays disability awareness.

Until the 1970s, such a high percentage of breast cancers quickly killed women that reconstruction was not a priority. During that decade, however, surgery became more commonplace, and today, most women who undergo mastectomies choose reconstructive surgery.

EMPLOYMENT AND DISCRIMINATION ISSUES

Our understanding of how a history of cancer affects workers remains incomplete. While the great majority of cancer survivors who were employed before their diagnoses return to work, they may find it difficult to obtain or change health insurance and therefore may find themselves unable to switch jobs.

While the Americans with Disabilities Act of 1990 (ADA) does not mention cancer explicitly, the act has been used to protect cancer survivors from discrimination in the workplace. Each year, individuals with cancer or a history of cancer bring approximately 2 to 3 percent of the complaints brought under the ADA.

The Rehabilitation Act of 1973, which covers federal employees, specifically mentions cancer. It also discusses the "perception of disability," an important topic for many cancer survivors. Even if employees with a history of cancer have no physical or emotional disability from the disease, the act recognized that employers could still discriminate against them based on the perception of disability.

In 2002, cancer accounted for 4.2 percent of the total lost workdays in the United States, with an incidence of 35 days per 100 workers.

FUTURE

Today, surgery, chemotherapy, and radiation therapy remain the main treatment options for cancer. Some breast cancer researchers have turned to genetic studies to help discover which women are more likely to respond to specific types of chemotherapy, and to modify treatments accordingly. The aggressive nature of treating breast cancer has been tempered by some measured concern over the long-term physical and psychological effects of treatment. Also, the treatments are now all less toxic.

Much is still unknown about the biology of cancer. Early detection has long been touted as the key to improving cancer outcomes, and Americans in recent years have become more willing to discuss prostate cancer and colon cancer and to undergo various cancer screening tests. When breast cancer is detected while still localized to the breast itself, 97 percent of patients will be alive five years later. If the cancer is found at the regional stage, before further metastasis, the five-year survival rate is 79 percent. Today, in part due to screening mammography, 9 out of 10 breast cancers are detected at one of these stages.

Yet early detection, while potentially limiting the amount of aggressive treatment, does not eliminate it altogether. Indeed, we should not lose sight of the fact that lumpectomies or less toxic radiotherapy and chemotherapy still cause disability. And so, from the psychological standpoint, does any diagnosis of cancer.

—Allison Arwady and Barron H. Lerner

See also Breast Cancer.

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CANGUILHEM, GEORGES

(1904–1995)

French philosopher and physician

Trained as a philosopher (at the École Normale Supérieure, 1927) and medical doctor (1943), Georges Canguilhem devoted himself to medical practice and to the life sciences. His philosophical work was as an epistemologist. He reexamined notions of the norm, normality, and normativity.

According to Canguilhem, the normal is always secondary in relation to the exception. Normality is relative, since the norm is a statistical average. As for the normativity of a human being, it rests in the capacity to create norms that are otherwise without a common measure among living creatures and are organized in a relationship of force that fully informs the individual human being. Health is the risk recognized and accepted by the individual to go beyond personal limits to open a perspective on new horizons, since the threat of death, which is the true antithesis of health, constitutes "the limitation from without, the negation of the living by the non-living" (Canguilhem 1962:31). Disability is a limitation from within the living, or rather "an order other than the most probable order" (p. 29).

By renewing the notions than inform the life sciences, Canguilhem made it possible to abandon the traditional categorizations of disabled people. His principal works are *La connaissance de la vie* (1965), *Le normal et le pathologique* (1966), and *Études d'histoire et de philosophie des sciences* (1970).

—Henri-Jacques Stiker

See also Normality; Normalization.

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CAPACITY BUILDING

Capacity building is a term used to describe the process by which individuals with disabilities and/or their organizations develop their ability to solve problems, address unmet needs, and maintain their well-being with less dependency on outsiders or professional help. The construct has special relevance to individuals with disabilities because of a long history of social biases and misperceptions about the "lack of capacity" of most people with disabilities to take charge of their own destinities, solve their own problems, and meet their own needs. The process of capacity building is central to the development of community supports and services for individuals with disabilities moving away from institutional settings and into community and independent living. It is also important for the empowerment of individuals with disabilities.

There are several important premises to capacity building: (1) the mobilization of existing resources (either at the individual or organizational level) to pursue a desired objective, (2) the development or improvement of social networks or coalitions (addressing affective or instrumental needs), (3) the emergence of leaders and/or the development or improvement of leadership skills, and (4) the active participation of individuals with disabilities or groups in solving problems through collective action. In addition, the construct of capacity building generates expectations for greater participant involvement, fairness, efficiency, democracy, and cost savings. Capacity building can take place at the individual, group, or organizational level.

Capacity building at the individual level implies the development of skills and competencies that allow individuals to increase the degree of control and influence they have over relevant aspects of their lives. This includes greater involvement in selecting services and treatments, as well as pursuing satisfying life outcomes. Individuals are encouraged to lessen their one-way dependence on outsiders in order to meet their own needs. Greater self-reliance and interdependence become desirable outcomes of the capacity-building process at the individual level. In this framework, the service provision is seen as an opportunity for the individual with a disability to learn and become competent in managing the particular situation. It is an opportunity to work with others as a contributing partner rather than only as a passive recipient of services. For example, instead of relying on an agency to manage their attendant care needs, individuals with disabilities learn to recruit, hire, manage, pay, and fire their own personal care attendants. People with disabilities learn to function more independently of service providers and instead, take control of the situation for their own benefit. Individuals learn to live and work interdependently with others.

Capacity building at the group level reflects the needs of most consumer-directed organizations to improve effectiveness for advocacy and social action. The process may imply training at the organizational level but also coalition building as a strategy to enhance the influence of consumer groups at the local, state, and national levels. Grassroots organizations often develop and grow over time, but they can also stagnate and die if they fail to develop their capacity to have an impact or to achieve intended goals. Learning to lead action-oriented meetings, to plan actions, and to promote change are all relevant aspects of capacity building at this level. Coalition building has demonstrated that it is a very useful strategy to multiply the political influence of advocacy organizations of people with disabilities. Such coalitions are more likely to influence policy and to demand compliance with established policies or procedures.

At the organizational level, capacity building requires significant changes in the way many helping professionals deliver their services. Such changes may include (1) the preparation of practitioners who facilitate and encourage local experts (e.g., paraprofessionals, peers, and family members) to be the primary care providers; (2) a professional mission that promotes innovation and community collaboration; and (3) new theories that recognize capacity building and economic and occupational development as key aspects of the functioning and well-being of people with disabilities. Building the capacity of local communities to better serve individuals with disabilities is a central goal of independent living centers (ILCs). These agencies encourage consumers to participate actively in advocating for their own needs and services. ILC consumers are also expected to learn skills that would allow them to become more independent and interdependent in the future. In the United States, the ILCs are often at the forefront of capacity-building efforts at the local level, working in collaboration with other social service agencies. Capacity building at the organization level also affects the way in which an agency operates. For instance, a rehabilitation hospital implemented a peer-mentoring intervention in which trained peer mentors with spinal cord injury (SCI) interacted with new SCI patients to help them better understand the rehabilitation process and set goals for the future. The mentors became an integral and valuable part of the services provided by the hospital.

It should be noted that capacity building represents a paradigm shift taking place both in developed and developing nations. It is reflected in practices such as person-centered planning, individualized supports and individualized funding projects, community-based options, and multiple consumer-driven initiatives in the areas of housing, transportation, attendant care services, accessibility, employment, and education. Community-based rehabilitation has been proposed by the World Health Organization as a low-cost way to reach out to people with disabilities by integrating rehabilitation services in already existing infrastructures of health service delivery. This approach has been supported in many developing nations by nongovernmental organizations (NGOs) that are helping governments develop community-based services for people with disabilities. Two of the main challenges of these efforts have been the lack of sufficiently trained professionals in promoting community participation and organizing and the limited involvement of community volunteers and leaders who may see disability and rehabilitation as low priority among other community needs.

There are multiple approaches for promoting capacity building. People with disabilities can develop new competencies either through formal training or by learning new skills as they perform a particular function or pursue new services. They can also engage in advocacy activities to develop greater capacity in local organizations to address unmet needs and honor unrecognized rights. Depending on the anticipated receptivity of those in power, disability advocates can use either conflict strategies such as protests, boycotts, or sit-ins or consensus strategies such as identifying opportunities for mutual benefit and promoting mutual respect to advance their capacity-building agenda. On the other hand, people with disabilities can strengthen existing organizations or help start alternative organizations when the existing ones are not willing to change. Local governments can also foster collaboration among community organizations by promoting the creation of broker agencies such as clearinghouses that are effective for sharing information. They could also support the creation of coalitions and partnerships among multiple organizations to improve coordination of services, reduce costs, and improve quality.

A capacity-building intervention designed to empower ethnic minorities with disabilities to address issues of independent living and disability rights was developed and tested by researchers at the University of Illinois at Chicago. This model has been used effectively to influence decisions about programs, policies, budget allocations, accessibility modifications, and issues of independent living for various organizations of people with disabilities. Capacity building, in this case, involved multiple agents working together in an organized coalition to meet identified needs. The process follows a participatory action research methodology that requires the active involvement of people with disabilities in identifying needs, and prioritizing and analyzing the dimensions of such needs. People with disabilities organize action groups to seek solutions to their most critical needs. In Chicago, these efforts resulted in an increased level of involvement of Latinos with disabilities and family members in determining the services and decisions made to address employment and educational needs and advancing their agenda at the local level.

Capacity building offers the promise of increasing the degree of awareness and self-sufficiency of people with disabilities both nationally and internationally. It can contribute to improvements in their quality of life and the availability of services. Only through active consumer involvement and organized advocacy can individuals with disabilities influence local politicians and community leaders to move disability-related issues and service needs to the forefront of public agendas. Researchers in this area recognize that strengthening associational networks among individuals with disabilities and their supporters is critical to foster communication and mobilize the participation necessary to achieve desired community change.

—Fabricio Balcazar

See also Activism; Advocacy; Consumer Control; Empowerment and Emancipation; Independent Living; Peer Support.

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CARDIAC CONDITIONS

Heart disease remains the leading cause of death and disability in affluent societies for both men and women. According to the World Health Organization, one-third of global deaths are attributable to cardiovascular disease, and it is projected to be the leading cause of death in developing nations by 2010. According to the American Heart Association, 64.4 million Americans have some form of cardiovascular disease, which may include congenital cardiovascular defects, coronary artery disease, cardiac arrhythmia, heart valve disease, and stenosis, among others. Individuals with severe heart problems may require intensive long-term care, restrictions of activity, or restructuring of lifestyle. Others may be able to return to a near-normal lifestyle as a result of adequate treatment and monitoring of their cardiac conditions.

Decades of heart research involving animals and patients have been devoted to learning heart anatomy, physiology, and dysfunction to diagnose and treat heart disease more effectively. Clinicians gained knowledge about heart function through the use of the stethoscope, pulse-recording devices, and the electrocardiograph (a recording of the heart's electrical activity). Physicians explored various drug regimens to relieve symptoms, to remedy malfunction, and even to fight causes of the disease. Surgeons adopted the procedures of cardiac catheterization and angiocardiography to detect heart defects and obstruction, and they devised procedures to repair and replace damaged hearts. Mortality from cardiovascular disease is declining, not as a result of these medical innovations, according to some health experts, but due to the success of preventive measures. This entry focuses on both congenital and acquired heart diseases, their resulting levels of disability for people with these diseases, and methods of treatment and prevention.

Congenital heart diseases are those present at birth. Minor defects may not warrant intervention, and in fact may correct themselves over time. In cases of severely malformed hearts, such as holes in the interior heart walls (atrial and ventricular septal defects), open fetal ducts, or transposed heart vessels, the child's skin, lips, and fingernails turn blue because of the insufficiency of oxygen in the blood. Blue babies may suffer unusual murmurs or thrills of the heart, a slow or stunted rate of growth and development, and/or an alternation in the size, shape, and/or position of the heart. With age, they suffer increasing shortness of breath, dizziness, spells of unconsciousness, chest pain, and respiratory distress from oxygen deprivation. Most cyanotic children are not capable of participating in such normal activities as playing outside or walking to school. Historically, few of these blue babies lived to adulthood. Open-heart surgery, developed in the 1950s, made it possible for surgeons to correct many congenital heart malformations, rerouting the blood to the lungs, closing openings, or replacing damaged valves. These operations usually take place at an early age and may require multiple operations, but aim to enable these children to lead unrestricted lives. Some complex heart defects still cannot be cured, limiting these children in their activities and opportunities.

Acquired heart disease refers to disorders of the heart contracted after birth. The most common acquired heart disease conditions are coronary artery disease and cardiac arrhythmias. As the coronary arteries become clogged and then narrow, blood flow to nourish the heart muscle is impeded, particularly during stress or physical activity. An accumulation of plaque may result in clogging the coronary arteries completely, thus stopping the flow of blood to the heart muscle that the artery services. The result is a myocardial infarction (heart attack).

Individuals with cardiac arrhythmias have a heart that beats either abnormally fast (tachycardia) or abnormally slow (bradycardia). An irregular heartbeat interferes with the contractions of the heart muscle to pump deoxygenated blood to the lungs and to pump oxygenated blood to the body. With unsynchronized contractions, the heart does not pump blood effectively.

In some cases, the coordinating electrical pulses within the heart are blocked altogether (referred to as "heart block"), also impeding pumping blood.

Congestive heart failure (impaired contraction of the heart resulting in congestion of blood in the heart and lungs) is the end result of many diseases affecting the heart. Like individuals with congenital heart defects, those with acquired heart disease experience symptoms of breathlessness, tiredness, and sometimes chest pain. Some experience painful swelling of the feet and ankles. These symptoms can escalate with increased levels of disability such as inability to climb stairs easily, limited exercise tolerance, or difficulty in performing daily dressing, washing, or preparing meals.

Drugs are the dominant treatment for acquired heart disease. Various medications are prescribed to improve heart contraction, to reduce heart work, and to protect against blood clots. For the treatment of chronic heart failure, digitalis, a derivative of the foxglove plant, is the most frequently used drug to assist the heart muscle's contraction. Other similar drugs include dopamine, terbutaline, and levodopa. Many patients, however, experience difficult side effects, possibly increased heart rate, palpitations, and nervousness. Vasodilator drugs, such as hydralazine, pinacidil, dipyridamole, and the nitrates, act to decrease the work of the heart by widening blood vessels, making it easier for blood to flow. Antithrombotic drugs or blood clot inhibitors, such as aspirin or heparin, help prevent obstruction of the circulation from blood clots. Drug therapies seldom reverse heart damage but can successfully stabilize the disease for patients to carry on a near-normal lifestyle.

In addition to prescribing drugs, cardiologists and cardiac surgeons offer a range of interventional procedures to repair, pace, assist, or replace the damaged heart. For individuals with irregular heartbeat or heart block, internal pacemakers (in use since the 1960s) can be implanted to deliver a controlled electric shock to pace the heart. More sophisticated pacemakers introduce a sensing function activating the device only when needed. To treat arrhythmias, implantable defibrillators and cardioverters also administer electric shocks to restore heart rhythm. For individuals with coronary artery diseases, intra-aortic balloon pumps and cardiac stents dilate and keep open blood vessels to prevent blockage as well as to facilitate blood circulation and demands on the heart. Coronary bypass operations since the late 1960s have helped mitigate the damage from obstructed arteries feeding the heart. After many of the above interventions, cardiac rehabilitation programs contribute to improved recovery, strength, and functional stamina.

For individuals in end-stage heart failure, heart transplantation, first introduced in 1967 with limited success, has become the treatment of choice today. With the development of more effective antirejection drugs in the 1980s, the majority of transplant patients survive at least five years and sometimes longer. However, there is a chronic shortage of donor hearts to meet demand. For those patients on heart transplant waiting lists, mechanical artificial hearts may replace or assist the natural heart. The total artificial heart replaces the failing ventricles (pumping chambers) of a damaged human heart, which is removed from the body. In 1982–1983, the first patient to receive a total artificial heart as a permanent implant was Barney Clark, who lived 112 days with the Jarvik-7 artificial heart. A partial artificial heart or ventricular assist device attaches to a failing heart (which remains in the body) and serves to assist in the pumping function of the heart. Over time, both total and partial artificial hearts have changed from large devices situated outside the body (paracorporeal and extracorporeal) to smaller devices intended to be placed inside the body (intracorporeal and fully implantable). Although the total artificial heart still remains experimental, several ventricular assist devices have been approved as temporary, bridge-to-transplantation devices with ongoing studies for their use as permanent devices.

Despite the introduction of new drugs, improved surgical procedures, and more reliable devices to treat cardiovascular disease, the medical community urges people to take preventive measures. As a result of the Framingham Heart Study, one of the most important twentieth-century epidemiological health studies, a new emphasis on preventing heart disease emerged. Beginning in 1948, the Framingham Heart Study examined 5,200 men and women in Framingham, Massachusetts, at regular intervals for decades. From this data, scientists were able to identify major risk factors including diet, nutrition, stress, obesity, smoking, and others that contribute to cardiovascular death and disability. National awareness campaigns distributed information to the public on how to control heart disease risk factors, recommending that individuals monitor high blood pressure, lower high cholesterol levels, stop smoking, watch their diet, and exercise more. As these campaigns warned, heart disease does not discriminate by race, gender, or socioeconomic status. As a result of preventive measures and early detection of heart disease, the prognosis for the next generation's battle with cardiovascular disease and disability continues to improve.

—Shelley McKellar

See also Exercise and Physical Activity; Health Promotion.

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American Heart Association, http://www.americanheart.org

CAREGIVING

Caregiving is the act of providing hands-on or supervisory assistance to an individual with a disability who has difficulty performing the basic tasks needed to sustain life in the community. Millions of individuals worldwide, both young and old, have physical, mental, and/or emotional problems that make it difficult or impossible for them to perform the day-to-day tasks of life. While a minority turn to formal caregiving services to assist them with these tasks, the typical type of care that persons with disabilities need on a regular basis does not require specialized training and more often family members and friends take on the role of caregiver. A large percentage of caregivers are women in midlife who have competing demands of family and work. The care that is provided can be as limited as running errands for an elderly person who has difficulty getting around outside, or as intense as around-the-clock care for a child with a developmental disability. At particularly high levels of need, caregiving responsibilities create a great level of burden for the caregiver.

The majority of individuals with disabilities are cared for within the community, rather than in institutions. This has been true throughout history. While institutions exist for children with developmental disabilities, individuals with persistent mental illness, and frail elderly persons, the disability rights movement of the twentieth century paved the way for deinstitutionalization. Today, it is a worldwide priority to provide community, rather than institutional, support to individuals in need. A minority of this support is provided formally through federally subsidized home- and community-based services. In addition, some individuals with disabilities hire personal assistants to attend to their needs. For the most part, these formal services are used when there is no informal support available or when the care needs of an individual are too great for family or friends to handle on their own. The vast majority of community-based support is provided informally by family members and friends, and this is what is referred to as informal caregiving. In the United States, it is estimated that as many as one in five adults provide care to someone age 18 and older with a disability. This estimate does not include the many who care for the approximately 400,000 children with chronic care needs in the United States. Rates are comparable in other countries.

Informal caregiving is a gendered role, falling primarily on women. While women are entering the workforce at increasingly steady rates and dual-earner families are common, they are still considered the primary caregivers to those in need. They are often mothers of children with special health care needs, spouses of adults with disabilities, or adult daughters of frail elderly persons. Men do assume the role of caregiver, but they do so much less frequently than women. Sons, for instance, are more likely to provide care to elderly parents when there are no daughters available. Men also provide fewer hours of care overall, and less intense care than women. There are two groups of care tasks that are commonly referred to in the literature on disability. These are activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs consist of personal tasks such as dressing, bathing, transferring out of bed, eating, toileting, walking, and going outside. IADLs, though less essential on a daily basis, are important for adults to maintain independence in the community and include grocery shopping, housework, using the telephone, and managing money or medications. Male caregivers are more likely to provide assistance with these less personal IADL tasks than with ADLs. In addition, male caregivers tend to receive more help from others in their caregiving responsibilities than do females. Finally, mothers are more likely than fathers to adjust their work schedules or leave the workforce altogether to care for a child with special health care needs.

Caregiving is an extremely personal and varied experience. The impact of the experience on the caregiver depends on the characteristics of both the caregiver and the care recipient, as well as their relationship with one another. Responsibilities and experiences differ for those caring for children with mental retardation, adults with persistent mental illness, and frail elderly adults. The average caregiver is a woman in her 40s caring for an elderly parent. However, even children take on the role of caregiver to parents with a disability, chronic condition, or mental illness. Australia, for example, has estimated that 10 percent of all 15- to 25-year-olds have been identified as caregivers. Among caregivers to adults with disabilities in the United States, while nearly half provide fewer than 8 hours of care per week, almost one in five provides greater than 40 hours per week. At these more intense levels of caregiving, caregivers are often given the added responsibility of acting as case managers for the care recipient, having to navigate through an often complicated and disjointed health care delivery system. They may also receive minimal specialized training in order to perform specific tasks in the home such as replacing a catheter or fitting a prosthesis.

The care needs of a person with disability can be temporary and sporadic, as with the intense bouts of assistance a person going through cancer treatment might require. Caregiving, however, can also last for years. An increasing concern for parents of individuals with Down syndrome, for example, is who will care for their children once they pass away. Where those with Down syndrome once died at a young age, many are now living well into adulthood largely as a result of improvements in the management of heart disease. So, too, elderly persons with Alzheimer's disease often live for many years with progressively debilitating effects of the disease.

Individual experiences of caregiving can be rewarding, strengthening the bond between caregiver and recipient, but the reality is that caregiving responsibilities create a great level of burden for many. The transition to a caregiving role may be unexpected and involuntary, as when a parent suffers from a sudden and debilitating stroke. At other times, though an increasingly greater caregiving role is expected and perhaps prepared for by a caregiver to someone with Alzheimer's disease, the difficulty of watching someone lose all memory of you can be intense. Isolation, depression, financial hardship, emotional and physical strain, and disruption in workforce participation are some of the hardships associated with the caregiving experience.

The provision of appropriate social support to caregivers is critically needed. The Third International Conference on Family Care that took place in October 2002 and included participants from 22 nations worldwide recognized the important role that family caregivers occupy within society. Many nations are taking steps to develop federally subsidized means of supplying at least a minimum of support to those who take on the role of caregiver. For instance, Sweden, which has one of the oldest populations in the world with an expectation that 21 percent of their population will be 65 and older by the year 2020, offers two types of caregiver income support, as well as a family leave program for workers caring for terminally ill relatives. Grants have been established in the United Kingdom to offer respite services to caregivers. Other countries such as Israel, Canada, the United States, Australia, and Japan are also developing programs to offer various degrees of support to caregivers. No country believes, however, that the needs of caregivers are being adequately met.

The importance of caregiving will only continue to grow. So, too, will its potential burden. The majority of care recipients are elderly adults. The population is aging worldwide, with the proportion of the population age 85 and older growing at the most rapid rate. While there are numerous debates as to whether the elderly population is getting healthier, sheer increases in the number of individuals living well into old age will dictate that the need for caregivers will increase. Reduced fertility rates across much of the developed world and a continued increase in female workforce participation will decrease the availability of adult children, particularly women, who are available to care for aging parents. As advancement in science and medicine continue to be made, children with special health care needs will undoubtedly age into adulthood, bringing with them the concern for availability of caregivers over their lengthened lifespan. Caregivers will increasingly balance caregiving responsibilities with other family and work obligations. The profile of caregivers will undoubtedly change, with more men assuming the role. Efforts to support the needs of caregivers must improve as informal caregiving will continue to play a dominant role in the long-term care experiences of individuals with disabilities worldwide.

—Julie C. Lima

See also Child Care; Family; Family, International.

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CARROLL, THOMAS J.

(1909–1971)

American priest and advocate

Long an advocate for newly blinded individuals, the Catholic priest Father Thomas J. Carroll was born in Gloucester, Massachusetts, and attended Holy Cross College before his ordination in 1938. His first assignment was to the Boston Archdiocese's Catholic Guild for the Blind, where he became assistant director, and in 1947, director. He worked extensively with the blinded American veterans of World War II, serving from 1944 to 1947 as a chaplain at the Army's blind rehabilitation facility at Avon, Connecticut, and from 1944 to 1949 as a chaplain at the Army's preliminary blindness treatment center at Valley Forge General Hospital. He was for years chaplain for the Blinded Veterans Association. In 1954, he established the diocesan St. Paul's Rehabilitation Center, one of the first civilian facilities offering comprehensive rehabilitation, including white cane training, for newly blinded civilians. In 1963, he founded the American Center for Research in Blindness and Rehabilitation, which was merged into St. Paul's in 1973. In 1977, St. Paul's became the independent, nonsectarian Carroll Center for the Blind. Carroll served on the President's Committee on Employment of the Handicapped and on the Special Legislative Committee on blindness of the Massachusetts legislature.

The philosophy guiding Carroll's work was rooted in his Catholic faith and was presented in his *Blindness: What Is It, What It Does, and How to Live with It* (1961). Carroll believed blindness incurred in adulthood led to the death of a former self and the necessity of a type of rebirth. Rehabilitation had to be more than the learning of skills and involved the nurturing of emotional as well as physical resources.

—David A. Gerber

See also Blind, History of the.

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CARTAGENA, TERESA DE
(1415–1420 TO ?)
Spanish nun and author

Very little is known about Teresa de Cartagena outside of her authorship of two treatises, *Arboleda de los enfermos* (*Grove of the Infirm*) and *Admiração operum Dey* (*Wonder at the Works of God*), written most likely in 1452 and 1454, respectively. In both treatises, her deafness figures prominently. She was a Catholic *converso* (convert) nun, whose grandfather had converted from Judaism to Christianity in 1390/1391, and whose father was active in both literature and the Church. She was born in Burgos, Spain, and lost her hearing, probably through illness, when she was very young.

In her first treatise, often labeled "consolatory," de Cartagena claims she belongs to a "convent of the suffering," and she works to address her place in the world and with God through her deafness: "What I used to call my crucifixion, now I call my resurrection." This treatise prompted a reaction from those who read it, as de Cartagena was discredited for authoring it, considered incapable (both as a woman and as deaf) of such learned expression. In response, she wrote the second treatise, *Wonder at the Works of God,* to defend herself from the "malicious wonder" surrounding her authorship.

—Brenda Jo Brueggemann

See also Deaf, History of the.

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CARTOONING

In a sense, cartoons have been around as long as the ability to draw. Thus, painting England's Richard III as a hunchback, or drawing New York City politician William "Boss" Tweed as fatter than he was, was part of a long and universal tradition of emphasizing or altering one body part or another for purposes of commentary. Any comprehensive list of such art would be a separate volume; this entry will look only at some examples from the latter part of the twentieth century, from the contrasting cultures of America and Japan.

THE UNITED STATES

Comics in America are a relatively marginalized medium of popular culture. Since the 1950s, comic books have been increasingly relegated to children's literature, and even the four-panel gag strip of the daily newspaper is being squeezed out by space and money constraints. The following comics can generally be divided into two categories: disability as a minor nuisance at best and disability as meaningless or irrelevant.

Disability as Nuisance

The Marvel comics website describes the setup of Daredevil thus: "A Good Samaritan act stole young Matt Murdock's sight, but also enhanced his remaining senses to superhuman level! After becoming a lawyer—and suffering the murder of his father—Matt now uses his powers to protect the innocent in New York City's Hell's Kitchen as Daredevil, the man without fear!" Conventional wisdom has it that losing one sense heightens the others, but this is a bit extreme. Written and drawn by a variety of writers and artists of the Marvel stable over the decades since its premiere, Daredevil started out as relatively benign, in the words of writer Jeph Loeb:

> There was a time when [Daredevil] was about the *joy* of being a hero. . . . He was not only able to do things that no blind person could do; he was doing things that *no* person could do. . . . Stan Lee's Daredevil took to his role like a duck to water. And I think it very much had to do with being blind. He saw being Daredevil as liberating. But, unlike Spider-Man where [Spider-Man alter ego Peter Parker]'s home life and school life was [*sic*] incredibly oppressive and depressing (for Peter, not the reader) and in turn, being Spider-Man was a party, [Daredevil alter ego Murdock] had it pretty good. He was with his best friend, starting a business where he was a terrific lawyer. They hired this wonderful, bright ray of sunshine named Karen Page. And together, they won in the court room and Daredevil won as a hero. New York loved him. He had none of the problems that Spider-Man had. (http://www.manwithoutfear.com/interviews/ddINTERVIEW.shtml?id=Loeb)

Apparently, blindness didn't qualify as a problem.

"The Aesop Brothers: Siamese Twins" by Charles Rodrigues ran for years in the *National Lampoon*. Rodrigues created the Aesop Brothers to explore exactly those questions of sex, hygiene, intimacy, and privacy that lurk in the back of many minds when faced with conjoined twins. Of course, the answers here are not meant to inform but to amuse, and in the *National Lampoon* tradition, amusement and outrage are often conjoined.

Cartoonist John Callahan has continued the *National Lampoon* tradition of outrageous humor, some of it inspired by his own quadriplegia. Disabled in 1972 when a drunken friend drove into a telephone pole, Callahan continued drinking heavily himself. His account of his transition to a disabled life and transcendence of alcoholism, told in cartoons, was published as *Don't Worry, He Won't Get Far on Foot*. His style is limited by his disability, but his humor has stayed in the "sick" category.

In 1998, the "Luann" comic strip by Greg Evans included a story-arc in which one character, an African American high school student named Delta James, is diagnosed with Hodgkin's lymphoma. Yet the worst that we see her suffer is fatigue and hair loss as a result of chemotherapy. She maintains a positive attitude throughout the treatment because she does not want to depress anyone else. In a way, it is not surprising that her diagnosis of remission was announced around the Christmas holidays; Delta endured a very reader-friendly cancer. The series also gives Luann's friend Bernice a wheelchair-bound boyfriend named Zane, who is described on the comic's website (ostensibly in Luann's words) as "cute and funny and interesting and cute and kind and sensitive and cute"—without mentioning his chair, although it does mention his service dog, Monroe.

Berkeley Breathed's "Bloom County" (1980–1989, 2003–) is actually based on another strip by Breathed, "Academia Waltz," which appeared in the *Daily Texan*, the newspaper of the University of Texas at Austin, beginning in 1978. The wheelchair-bound "Cutter John" first appeared in "Academia Waltz" (as "Saigon John") and made the leap to national syndication. In "Bloom County," Cutter John has a girlfriend, schoolteacher Bobbi Harlow, but he seems to prefer spending time with the critters of the strip, fantasizing that he is Captain James Kirk in command of the Starship *Enterprise*.

Disability as Irrelevant

Cartoonist Bill Griffith created Zippy the Pinhead in 1970, shortly after joining a San Francisco community of "underground" cartoonists. A microcephalic who always wears a clown suit (and named after a microcephalic man exhibited at the Barnum & Bailey Circus between 1864 and 1926 as "Zip the What-Is-It"), Zippy became a comic icon with the slogan, "Are we having fun yet?" The comic, which went from a one-shot to a weekly to a daily, still runs, showing the title character in surreal environments, uttering non-sequiturs (not unlike actual microcephalics, who often parrot back whatever they hear). Whatever the rest of us may think, Zippy seems to be having fun.

In 1964, African American cartoonist Morrie Turner began his "Wee Pals" daily strip. Predating debates on "diversity," "political correctness," and other buzzwords, "Wee Pals" resembles Charles Schulz's "Peanuts" given a collection of multiethnic children (black, white, Asian, Jewish) just living life and getting along, occasionally stopping for a didactic tribute to someone (usually) of color. One of the children, Charlotte, is in a wheelchair, but she has had relatively little strip time, and even that has been cut into by her parrot, Polly Esther.

The Exceptions

Shelley in "Omaha the Cat Dancer"

One singular depiction of a disability in comics was the odyssey of Shelley Hine in "Omaha the Cat Dancer." Writer and artist Reed Waller began this sexually explicit example of the "furry" genre (animals given human characteristics) in 1981; after a few years, Waller's lover Kate Worley took over the writing of the comic. Omaha continued sporadically until 1995, when both the comic and the relationship between Waller and Worley ended.

The title character in this elaborate and erotic picaresque is Omaha, a voluptuous feline exotic dancer whose circle of friends includes Shelley. Intelligent but easily misled by her emotions, an avid bisexual, Shelley was mistress to the father of Omaha's lover, Charles Tabey. The elder Tabey had created a club/brothel for the corrupt politicians of Mipple City (a disguised version of Minneapolis-St. Paul, Minnesota). An assassination attempt by one of Tabey's partners left Shelley with a bullet in the back.

Shelley's story is unsparingly accurate in its description of her mood swings; her quest for adapted housing, physical therapy, and social services; the mutual attraction between Shelley and Kurt, her personal care attendant (a Vietnam veteran); and her desires for women outside of her relationship with Kurt. She has her small triumphs, such as rolling her wheelchair over the feet of paparazzi who invade Tabey's funeral, or her rejection of older rehabilitation models (Interviewer: "What is your religious affiliation?" Shelley: "Pagan.") in favor of a doctor who himself wears a leg brace. She even gets to point out to the clerk at a feminist bookstore that its books on disability are on a shelf out of reach to anyone in a wheelchair. The story was left unresolved, and the final image is of Shelley, after an argument with Kurt, alone in bed, her crutches on the floor, crying into her pillow. "Omaha the Cat Dancer" is a one-of-a-kind portrayal of physical disability.

BD in "Doonesbury"

Cartoonist Garry Trudeau has never been a stranger to controversy, and his reaction to the 2003 invasion of Iraq was as visceral as could be: He had the comic strip's character BD (who fought in Vietnam) go to Iraq. His Humvee was hit by a rocket-propelled grenade, and he lost his left leg below the knee. A few months later, while in rehab at a German hospital, postoperative infection caused him to lose more of his leg above the knee. It's an ongoing plot-thread of loss, adjustment, and attitude.

JAPAN

During the 1950s, when comic books in America began to be marginalized, Japanese comic books (*manga*) exploded with a postwar vitality and immediacy. The medium in Japan is now comparable to television in America, with various target audiences of all ages and both genders. This section is a necessarily abridged look at disabled people as portrayed in Japanese manga, or comics.

The revitalization of Japanese comics is due in large part to the innovations of a medical student named Tezuka Osamu. Dr. Tezuka's medical background appeared in some of his comics, especially "Black Jack," the story of a gifted but renegade surgeon who was himself in a disabling accident as a child; he was confined to a wheelchair for a time. He also had to receive a skin graft on his face from a Negro friend, which gave rise to his nickname and established him as a member of the out-group. The medical establishment refuses to sanction some of his more unusual surgical methods; consequently, although he may be the most skilled surgeon on Earth, he still lives the life of a lone wolf, a prominent archetype in Japanese culture. Even though Black Jack may be a heroic character with a disability, the comic also includes messages, implicit and explicit, warning readers away from trying to imitate his life.

Some of the medical problems portrayed in the hundreds of episodes of “Black Jack” are, to put it mildly, fantastic—exotic diseases either seldom encountered or dreamed up by Dr. Tezuka, or bizarre societal situations in which the doctor becomes involved. One episode in which the disability is real, the solution is far-fetched, but the social orientation underlying it is essentially Japanese, hence at least true in the idealized world of popular culture, is titled “Kaizoku no Ude” (The Pirate’s Hook). Its protagonist, Ichinoseki Kazuo, is an impressive high school gymnast. Because of his prowess, acquired by constant practice, he is popular with his classmates—including an overweight girl, whom he ignores. The girl, Furukawa (who Kazuo describes as “that pig”), warns Kazuo’s mother that his constant practice is bad for his arm. This is confirmed by a doctor (who is a character of cartoonist Tezuka). The doctor warns Kazuo that the arm is becoming gangrenous; if he doesn’t give it a rest, the arm will have to be amputated. Kazuo keeps practicing, the arm reaches the point of amputation, and the doctor calls in Black Jack. After stating that his fee would be 7 to 8 million yen, Black Jack says he will operate anyway “to reintegrate Kazuo into society.”

When Kazuo returns to school, with a mechanical claw instead of a hand, he is greeted by fear from the girls and ridicule from the boys; they give him the name “Kaizoku,” meaning “pirate.” Kazuo bitterly blames his hook, beating it against a fence—until the hook cries out in pain and tells him to stop. The hook suggests that Kazuo can assert himself in another way: the traditional board game shogi. The hook tells him that, with practice, he can become the best student player in Japan. This he does, ultimately confiding to the hook that he owes everything to its friendship; he says that the hook is the only real friend he has.

It doesn’t occur to him until this moment, however, to explore the nature of a talking prosthesis. Actually, Kazuo’s conversations with a prosthetic device are perfectly natural, when seen in the context of Shinto, Japan’s native animistic religion. In Shinto, *kami*, which can be translated as “gods” or “spirits,” inhabit literally everything, from plants and animals to inanimate objects. Kazuo discovers that the hook contains a two-way radio, and on the other end of the circuit is Furukawa. The close-up on his teary-eyed smiling face as he realizes this is a manga convention: Kazuo is in love.

In this case, Black Jack’s vow to “reintegrate Kazuo into society” was deliberately ambiguous, but was accomplished in this unorthodox manner. The manga took one Japanese cultural assumption (that one must always strive for excellence in whatever one does) and modified it by tying it to another cultural assumption (that the clan must rely on marriage and childbirth to continue). Excellence at shogi would not be enough in itself to reintegrate Kazuo into society, if society were still to shun him because of the hook. Those who flocked around Kazuo the stellar gymnast avoided the handicapped Kazuo. Furukawa was similarly shunned, by Kazuo and the entire class, because of her obesity. She is shown throughout the story as being alone, eavesdropping on conversations rather than participating in them. When she speaks, it’s never to her peers, but to an adult or (through a microphone) to Kazuo. This also provides yet another example of the belief that it is easier for disabled people to relate to each other than for disabled and nondisabled people to relate to each other: The group of disabled people are presumed to have a shared experience that the nondisabled majority cannot understand. Yet, in Japan, where the groups you belong to make up who you are, even belonging to a group of other disabled people is normal behavior. As long as Kazuo belonged to a group—even a group of two—with a shared experience, he was accepted into Japanese society.

This in-group dynamic is also illustrated in a sequence from “Hadashi no Gen” (Barefoot Gen), a semiautobiographical story by Nakazawa Keiji about surviving the atomic bombing of Hiroshima, Japan, in 1945. Gen, the title character, was in grade school when the United States bombed Hiroshima; he and his pregnant mother are the only members of his family to survive the blast, although both were mildly affected by radiation poisoning. They leave Hiroshima for the fishing village of Eba to begin life again. To earn money, Gen does what nobody else is willing to do: He becomes an attendant to Yoshida Seiji, who was also caught in the blast. His family will have nothing to do with him, for fear of "catching" radiation sickness; added to the isolation is the fact that Seiji, a promising artist before the war, lost the use of his hands in the blast. He thus despairs of ever being able to paint again, and he takes it out on Gen.

This is another part of the pattern in Japanese pop culture depictions of people with disabilities: that a physical disability manifests itself in a corrupted spirit as well (rage, callousness, depression). If the disabled person cannot rise above this himself, he must do so with the help of other members of the group. In the story, Gen's friendship and cheerful demeanor in the face of Seiji's abuse help to change his outlook; Seiji resolves to continue painting, even if he must hold the brush between his teeth.

What happens when one chooses to accept one's disability? This happens to two different young women in a series of stories by Wada Shinji: "My Friend Frankenstein," in which Dr. Frankenstein's creation wanders nineteenth-century Germany befriending and helping women and children. The monster first meets Mia, a young noblewoman who was ostracized as a child because of a large birthmark on the back of her neck; accordingly, she developed a cold and cruel personality reflecting the coldness and cruelty directed toward her. Through her friendship with the monster (whom she perceives as being tormented because of his appearance just as she was), she stops trying to cover up the birthmark, saying that she must accept herself before anyone else can accept her—including the man she will eventually marry. (As was the case with Kazuo and the hook, Mia—although a German character—acts on assumptions shared by the comic's Japanese audience.)

On the other hand is Hilda, a pretty young deaf-mute who also forms a bond of friendship with the monster. Both are captured and put to work as servants for the greedy and corrupt nobleman Herr Kurzhardt. Hilda is actually worked to death by Kurzhardt, which sends the monster, whom Mia renamed Silas, into a homicidal rage, as he massacres the nobleman and his equally corrupt guests at a dinner party.

Hilda violates the expectation that a disabled person is dissatisfied with life with a disability; she has adjusted to life with a kind and caring disposition. However, there is no way in which her disability can be either hidden or compensated for. For failing to fit in with the "group" of characters with disabilities, Hilda must die by the end of the episode—poignantly, of course, and in a manner that brings to the eye of the reader the tears that Hilda never sheds. This is another mark of her difference: the fact that she doesn't cry at all during the story, not for sorrow or for joy, sets her apart in a lachrymose medium where tears are often used as proof of a character's compassionate spirit. In this case, the spirit was there but the tears were not, and this was, in a sense, an additional disability.

These examples, and a few others, were drawn from the author's private collection of Japanese comics, of various genres, assembled over some 30 years. However, the simple fact that a disabled character is featured in perhaps 10 out of more than 2,000 short stories or series episodes—less than one-half of 1 percent—reflects the segmentation of the pop culture version of Japanese society in which those with disabilities can, at best, participate in society by joining a distinct and separate group.

—Patrick Drazen

See also Experience of Disability: Japan.

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CASE MANAGEMENT

Case management is a process of care planning and coordination of the services and resources used by people with disability and their families. Primary functions of case management include assessment, development of a care plan, securing access to services, and monitoring to ensure service timeliness, comprehensiveness, and quality over time. Many types of care professionals provide case management, including social workers, nurses, rehabilitation counselors, mental health providers, and physical and occupational therapists. Case managers are employed in many settings, including vocational rehabilitation providers, health insurance plans, government agencies, mental health centers, social service providers, workers' compensation carriers, health care organizations, and private practice. Family members and consumers themselves also act as formally designated case managers within particular programs.

While case management has been a cornerstone of community-based care since the late 1960s, its structure and functions have evolved in response to broader changes in health care and disability policy. Emphasis on cost containment has promoted professionalized models aimed at service rationing, while the independent living movement has advanced consumer direction of case management programs. Many, and often competing, objectives are embedded in case management programs, and research repeatedly demonstrates that expectations for them exceed their accomplishments. Case management nonetheless remains an important mechanism for coordinating fragmented service systems and ensuring access to needed services over time.

For people with developmental disabilities and persistent mental illness, case management originated in the United States in the community-based care movement of the late 1960s. As mandated in federal and state legislation, case managers were responsible for developing and implementing individualized care plans in coordination with interdisciplinary teams of service providers. Their primary objectives were to ensure that disabled people received care that was accessible, comprehensive, and continuous to enable them to live in the least restrictive environment as independently as possible. In some states, parents received training to become case managers for their own children, and overall the emphasis of case management programs was on developing independent living skills and self-direction.

Inflation in the costs of both health care and workers compensation in the 1970s led to case management's adoption within vocational rehabilitation services. Rehabilitation nurses and counselors became case managers coordinating medical and vocational services. Here, as in mental health and long-term care more generally, policy goals of increasing service access came into conflict with those of rationing care and decreasing expenses. These translated into role conflict for case managers, especially those more therapeutically oriented. The next decade saw cuts in federal and state support for mental health and rehabilitation accompanied by Medicaid Home and Community-Based Services (HCBS) waiver programs and other demonstrations of integrated delivery systems with case management at their core. Case management remains central to HCBS waiver programs throughout the United States.

Throughout this time, a variety of models of case management developed, with differential degrees of specialization, control over service resources, emphasis on medical versus social services, and extent of consumer direction. Starting in the mid-1970s, the independent living movement pushed for case management conducted by disabled individuals themselves to the greatest extent possible. Developed in concert with personal assistance services (PAS), in this approach professional case managers train consumers to acquire, monitor, and evaluate services, based on a consumer-directed care plan. Ideally, professional case managers serve only until the consumer is able to assume the role, at which point the former assumes more of a "consultant" position. In practice, however, professional case managers often still retain dominance in determining care plans and authorizing payments. Criticism of this has promoted "cash and counseling" demonstrations (similar to programs found in West European countries), where disabled consumers receive a cash benefit to negotiate for services with as much or little case manager involvement as they desire.

The ascendance of managed care and integrated health care systems since the mid-1990s has led to the employment of case managers who follow patients with chronic illness and newly acquired disabilities from their initial medical treatment onward. At the same time, insurance carriers, home health agencies, and other private providers have developed an industry of "disability case management" focused on returning disabled employees to work. Responding to the increased role and skills required of case managers in these areas, organizations providing case management have pushed for it to be recognized as a professional credential. The Commission for Case Management Certification (CCMC), incorporated in 1995, administers requirements for certifying case managers, while a related organization, the Case Management Society of America (CMSA), promotes professional development of case managers in diverse service areas.

In part a legacy of the divergent policy currents shaping case management's agenda, there are inherent conflicts built into the role. In particular, it is antithetical to expect case managers to advocate for consumers' access to services while also being gatekeepers to service resources. Related to this are the dilemmas of attempting to increase client autonomy through a professionally dominated position, as connoted even by the terms *case* and *management*.

Similar trends and issues are apparent in applications of case management in Canada, Europe, Scandinavia, and elsewhere throughout the world. In the United Kingdom, *care management* was the cornerstone of the community care policy 1989 White Paper, which relied on workers in local authority social services to coordinate care for disabled and older people. Program critics focused on the conflicts involved in asking care managers (as they are termed there) to curtail expenditures while also serving those at risk, or in attempting to ally simultaneously with families, consumers, and service providers. A 1996 act allowed the disabled to employ their own care managers using money that otherwise would have gone to social service authorities.

Attempts to evaluate the effectiveness of service programs have also been beset by the inherent ambiguity and complexity of case management. In long-term care as well as mental health care, random assignment demonstration programs have demonstrated limited results of professional case management in facilitating cost-effective community-based care. Meta-analysis of two decades of mental health case management programs found them yielding small to moderate improvements in service outcomes. Equally modest findings emerged from Project NetWork, a demonstration conducted by the Social Security Administration to evaluate case management as a means to promote employment among people receiving Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) assistance. Small increases in net earnings for participants did not reduce their reliance on SSI or SSDI long term, and the program increased net costs in public funds.

Case management remains ubiquitous in services for people with physical, developmental, and mental disability. While there are many variants of the role of case manager, it is possible to identify a continuum of approaches. At one end, case management involves professional control over care planning, referrals, and coordination of specialized services. The case manager depends on extant services and is charged with fiscal oversight and cost containment. At the other end, case management is consumer driven. The case manager consults with and trains individuals and families to obtain, coordinate, and evaluate services of all types, including those for all family members. These different roles reflect various modes of allocating service dollars as well as divergent service philosophies. The philosophy of consumer-direction drawn from the independent living movement is increasingly being applied to case management for disabled people of all ages. This refocuses such programs on the process of disablement and shifts their objectives from lowering health care costs and reducing institutional care to the maintenance of social participation and personal autonomy.

As a "Band-Aid" approach patching services together one consumer at a time, case management by itself cannot achieve broader coordination of the service systems used by disabled people. Service gaps and fragmentation, divisions between social and medical care, and inadequate financing are redoubtable problems barely touched by case management approaches. At the same time, any broader attempt at service integration will be inadequate unless it also works at the level of the individual. Because of this, and because of its ability to transform itself to the variable climate of service system design, case management will remain a central fixture of disability policy.

—Ann E. P. Dill

See also Independent Living; Social Work.

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CEREBELLAR ATAXIA

In one of the earliest descriptions of the cerebellum, Galen (AD second century) speculated that it was the source of the spinal cord and motor nerves, and with a portion called the cerebellar vermis acting as a valve to control the flow of animal spirits from the ventricles. Views of cerebellar function changed through later centuries and have included control of memory and intellect, involuntary actions such as heartbeat or breathing (Willis, seventeenth century), and even sexuality (Gall, nineteenth century). In the nineteenth and twentieth centuries, animal lesion experiments and careful observations of humans with cerebellar damage indicated that the cerebellum did indeed have a significant role in movement control, though the nature of that role was (and still is) debated. Opinions about cerebellar function ranged from a tonic influence on movement (Rolando, nineteenth century; Luciani, late nineteenth century; Holmes, twentieth century), to a coordinator of movements produced by other motor structures (Flourens, nineteenth century; Babinski, early twentieth century), to the principle regulator of postural muscle tone (Sherrington, early twentieth century). In this period, scientists also thought that the cerebellum had a unitary function, with no localization of control for different body parts or types of movement.

The modern view is that different cerebellar regions play an integral role in the control of different behaviors including voluntary limb movements, eye movements, balance, and locomotion. This view is based on the anatomy of cerebellar connections as well as studies of neural recording and the effects of cerebellar damage. It is also clear that the cerebellum exerts control over the flexibility of these behaviors; the cerebellum is very important for learning to adjust motor behaviors to new situations.

The most striking and debilitating effect of damage to the cerebellum is ataxia, which comes from the Greek words *a*, meaning "without," and *taxis*, meaning "order." Originally, it was a general term for incoordination and was applied to a number of different medical disorders including heartbeat and bodily movements. It is now typically used to mean the incoordination of movement following damage to the cerebellum.

Cerebellar ataxia can result from damage to the cerebellum itself, or pathways to and from the cerebellum. This is typically caused by stroke, degenerative disease, or tumor. If there is damage to only one side of the cerebellum, the resultant symptoms manifest on the *same* side of the body as the damage (e.g., right cerebellar damage causes right-sided ataxia). There are many signs of ataxia, and different individuals can have some or all of them, depending on the location of damage. Since ataxia is a very general term that globally incorporates any incoordination, it is often used in reference to a movement of a specific body part (e.g., arm ataxia) or type of movement (e.g., gait [walking] ataxia). There are many common manifestations of ataxia. *Dysmetria,* for example, is the inability to make a movement of the appropriate distance, with under- or overshooting the desired target. People with cerebellar damage tend to overshoot when they move rapidly and undershoot movements when they move more slowly, wishing to be accurate. Overshooting can be a significant problem that leads to breakage of objects or even personal injury. *Dysdiadochokinesia* is an inability to make rapid, alternation movements of a limb, and it appears to reflect abnormal control of opposing muscles. *Asynergia* refers to an inability to combine the movements of individual joints of the body into a coordinated multi-jointed movement. This leads to movements looking clumsy and abnormal. People with cerebellar damage may also show *hypotonia* or abnormally decreased muscle tone (e.g., floppier motions). Often hypotonia is either present only during the early phase of cerebellar disease or may not be present at all.

Damage to the cerebellum can cause a variety of other problems, including abnormal eye movements such as overshooting of eye movements, or *nystagmus,* which is an involuntary and rhythmic beating movement of the eye. Another common finding is *action* or *intention tremor* during limb movements, which is an involuntary oscillation occurring during movement and disappearing when the limb is at rest. Cerebellar damage can also cause a speech disturbance called *dysarthria,* where words become slurred and more difficult to understand. This tends to be a major problem and frustration for individuals with cerebellar damage, as it makes communication (particularly on the phone) more difficult. In addition, other people often assume that people with speech abnormalities have impaired intelligence, which is not the case in people with cerebellar damage.

Possibly the most common and disabling impairments of cerebellar damage are *balance deficits* and *gait ataxia.* Balance abnormalities are characterized by increased postural sway, either excessive or diminished responses to perturbations, poor control of equilibrium during motions of other body parts, and abnormal oscillations of the trunk (*titubation*). Gait ataxia, or walking incoordination, is often described as a "drunken gait," with distinctive features including variable foot placement, irregular foot trajectories, a widened stance, a veering path of movement, and poor coordination of the joints of the legs. Thus, walking tends to look clumsy and unstable. Some people with gait ataxia report that they have been accused of being intoxicated, based on their slurred speech and walking abnormalities. This can lead to social embarrassment and inconvenience because they must explain (sometimes in great detail) what their condition is and that they are, indeed, not intoxicated. Some people report carrying a cane or keeping it in the car with them, even if they do not need it for walking, just to make it clearer to other people that they have a neurological disorder and are not intoxicated.

People with ataxia can have mild to severe motor disorders in these areas but can live long and full lives. However, more often than not, the ataxia impinges on their job, home life, and recreation. Many people find that their job is harder to do with ataxia. Ataxic hand movements make handwriting illegible, causing difficulties with typing on the computer. For people with more physically demanding jobs, the balance disorder and walking ataxia can affect their work. Often people find that they have to modify their job or require new training in another area in order to continue working. Speech dysarthria can make talking on the phone at work or home more difficult. Sometimes people are frustrated enough to stop answering the phone and instead to let their spouse or partner do it for them. At home, modifications such as installation of handrails and grab bars usually make walking ataxia quite manageable. Recreational activities also can be modified to allow people with ataxia more participation.

There are few treatments for cerebellar ataxia at this time. There are no known medications that consistently improve the symptoms of ataxia across diagnoses or slow the progression of degenerative diseases. The main treatments are therefore rehabilitation training, including physical, occupational, and speech therapy. It is not known if there are ways to optimize rehabilitation training, particularly given that the cerebellum is involved in not only movement coordination but also the learning of new movements. Regardless of how robust practice effects are, even nonspecific effects of exercise including increasing aerobic capacity and strength are important and can improve movements of people with cerebellar ataxia.

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See also Neurological Impairments and Nervous Disorders.

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CEREBRAL PALSY

Resulting from a lesion in the brain that is static, cerebral palsy is characterized by consequent motor impairments, which do not progress over time. So briefly summarized, cerebral palsy (CP) is nevertheless a condition with a long history and an extraordinary culture.

Earliest records suggest people with CP from ancient Egypt, whence a stele depicts a young man with the inturned and atrophic feet strongly suggestive of spastic diplegia. The Bible also makes frequent references to "lame" figures, some of whom may have had CP, given their temporal associations. For example, Acts 3:2 and 3:7–8, written by the physician Luke, describe a beggar "who had been a cripple from birth" and who, when the Apostle Peter "grasped him by the right hand and pulled him up," "at once his feet and ankles grew strong; he sprang up, stood on his feet, and started to walk."

Throughout the Middle Ages, many examples of children crippled since birth are found in the listings of saints' miracles; these describe the divine cures of those who frequently defied medical intervention. One case from early-fourteenth-century Umbria, Italy, tells of a boy, Ceptus, who had learned to walk by ambulating on the sides of his feet because his ankles and feet had been twisted from birth. When he was about 10 years old, doctors having failed to heal him, Ceptus went on pilgrimage to the tomb of Saint Clare of Montefalco. There he laid upon the tomb and suddenly rose up throwing off his crutches; he walked normally into the waiting arms of the excited parishioners with the church bells pealing in the background. In the early fifteenth century, the painter Raphael (1483–1520) depicted a beggar with sufficient verisimilitude to suggest that he had observed such figures with equinus deformities in Renaissance Italy. Medicine struggled against these miracles.

The early textbooks dealing with the diseases of children, Metlinger's 1497 *Regimen for young children* and Felix Wurz's text, translated into English in 1656 as *The Children's Book,* describe cases of lame children, but without sufficient details to make reasonable retrospective diagnoses. In 1827, the Frenchman J.-B. Cazauvielh described the case of a palsied individual with a partially atrophic brain on autopsy in the *Archives générales de médecine.* Coincidentally, the noted French pathologist Jean Cruveilhier published an anatomic plate of a brain, strongly suggestive of an in utero ischemic event. In 1828, Maurice Delpech, studying poliomyelitis, developed the tendo-achilles lengthening surgery for the equinus deformity, also associated with CP.

It was nearly 16 years later, however, that William John Little, a British orthopedist who had polio and an equinus deformity himself, delivered a series of lectures at the Royal Orthopedic Hospital (1843), which appeared in the *Lancet.* He described the aggregate clinical features of CP. By 1889, in Philadelphia, Sir William Osler published a small tome depicting a series of CP cases. Osler focused on the pathology and neurological findings of the patients he saw. In effect, this approach characterized the medical view of CP for the next century. Osler coined the term *cerebral palsy* to collectivize the cases. Much of his evidence seemed to corroborate Little's conclusion that CP is a direct result of birth trauma. Scientists from Little's time through the 1940s continued to characterize different cerebral lesions to associate with CP. Only the celebrated psychiatrist Sigmund Freud challenged this theory in 1897, suggesting that perinatal difficulties were not the cause but the marker of intrauterine insults. It was not until 1986 that Nelson and Ellenberg successfully challenged this concept, well over a century after Little advanced it.

In the history of medicine and CP, development of therapies and etiologic hypotheses has been slow but steady. Unlike epidemic conditions such as poliomyelitis, CP's "background" nature has not galvanized the public imagination to reallocate research and care dollars in the same way. However, with the creation of the field of pediatrics in the late nineteenth century, CP was included in the canon of children's ailments that pediatricians had to know. While CP affects both children and the adults they become, its scientific and clinical advocates have since often been pediatricians.

CP is caused by events that occur before, during, or after birth. There are many possible causes, including inherited genes, fetal exposure to chemicals like mercury or to infections like rubella, strokes in newborns, and interruption of oxygen to the fetal brain (asphyxia). The incidence of CP in developed countries is approximately 2 percent and does not appear to be changing with "improved" technological care for newborns. In the United States today, there are more than 500,000 people with CP.

Rather than a single condition, CP is actually a constellation of conditions. They are unified in having disabilities of chronic movement and/or posture. A person with CP has muscles that can either be too loose (hypotonic CP) or rigid (spastic), or they can have reduced control of these muscles, including impaired coordination (athetoid) or balance (ataxic). Their condition may include a combination of these effects (dystonic). Only one's legs (diplegic or paraplegic), one side (arm and leg; hemiplegic), or all four limbs (tetra- or quadriplegic) may be affected. As the conditions are variable, an individual with CP can have manifestations anywhere along a spectrum from mild awkwardness to profound impairments of walking, fine motor control, and other voluntary movements. As CP is not a progressive condition, it entails long-term impairments including contractures and other musculoskeletal deformations.

CP may be associated with seizures and altered hearing, vision, or other senses. There is a roughly 66 percent association with mental retardation, although CP itself does not affect cognitive function itself. It is important to recognize that, as a technical condition, CP need have none of those associations. Many people with CP have normal or supernormal IQs.

Despite this modern understanding, for many years, people with CP were lumped together with others into a general clinical and social category of "idiots," often resulting in institutionalization. Work by reformers and physicians such as Séguin, Bourneville, Crothers, and Phelps shifted both the diagnostic and therapeutic perception of those with CP. Medical care of children with CP had a significant impact on the development of the field of medical rehabilitation and child neurology, particularly in the United States. Today, such care is often multidisciplinary and resource intensive, including medications, surgeries, assistive devices, and physical, occupational, and speech-language therapies. The application of this sociomedical therapeutic model in other cultures often suggests its limitations. Increasingly, people with CP have been changing the perception of the condition as well.

In literature and art, CP has been an uncommon motif until the latter half of the twentieth century, when authors such as Christopher Nolan and Christy Brown helped propel CP into lay consciousness outside of the spheres of charity and institutionalization. The development of electronic and other media has helped bring together personal experiences of those with CP, as have growing sports leagues and cultural organizations. From Egyptian images and the rhetorical power of medieval miracles, people with CP have had a significant if slowly cumulative influence on the culture around them. They continue to have a great deal to teach socially, medically, and culturally.

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See also Desire Magloire Bourneville; Bronson Crothers; Edouard Onesimus Séguin.

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CHANGELING

Changeling are most commonly said to be beings exchanged for a human child by fairies, trolls, demons, devils, or witches and are common in world folklore and mythology. They also appear in the lives of saints, treatises on witchcraft, Shakespeare and other literature, and theological and philosophical works. The word *changeling* derives from *cambiones,* from the late medieval Latin *cambio,* an unusual transformation of matter; also *killcrop,* from the German *kielkropf*; and the German terms *wechselkind* (exchange child) and *wechselbag* (exchange brat). While most examples of changelings conform to the idea of a child exchanged by other-worldly beings, many early modern and modern usages came to denote “those with changeable wills” and in some cases, intellectual disability, notably in John Locke’s *Essay Concerning Human Understanding.*

Germanic legends and those of countries surrounding the Alps typically describe the changeling as having a “thick head and staring eyes who would do nothing but eat and drink,” most later accounts deriving from the brothers Grimm tale “The Elves.” Recent scholarship has questioned the folkloric roots of this story and indeed the whole changeling myth, identifying the roots of the myth with elite medieval theologians such as William of Auvergne, who questioned that such beings existed, though contemporaries saw them as evidence of the devil’s work.

British literature tends toward much broader descriptions of changelings, with little reference to the features generally found in the Germanic legends.

There is some evidence that the nature of the changeling was in part determined by common regional disease patterns. Scottish changeling stories frequently refer to infants simply wasting away in a form of "consumptive disease." A Welsh source notes a reputed changeling "who was deformed, his legs being so short that his body seemed only inches from the ground when he walked" but goes on to note "that he was very sharp." Many modern interpretations of these legends endorse the view that these were children with various disabilities or congenital diseases. The standard psychological interpretation is that this was a means of coping with the birth of a disabled child, though this has been questioned by recent scholarship.

Cretinism, whose physical characteristics roughly match those of the typical Germanic changeling, was endemic in certain regions of the Alps due to mineral deficiencies in the water. Goiters are commonly associated with cretinism, which would account for the common German term for changeling, *killcrop*, from *kielkropf*, meaning "crop in the throat." This has contributed to the common association of changelings with intellectual disability.

The modern association with intellectual disability has dominated much of the contemporary literature on the subject. The most often cited example of the association of intellectual disability and the changeling is in relation to Martin Luther's alleged comments on changelings as "having no souls" and recommending they be disposed of. Others have made the direct association between the changeling legend and infanticide and abuse of people with intellectual disabilities. In both cases, these interpretations have been questioned both for their historical accuracy and their imposition of modern psychological notions onto historical reality.

—Tim Stainton

See also Cretinism; Folk Belief.

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CHARITY

The word *charity* is a Christian term derived from the Latin *caritas,* which signifies the disinterested love of one's fellow human beings, *agapè* in Greek, as opposed to the love that is desire, *eros*. The meaning of the word was often realized over the course of centuries by alms to the poor and destitute, with the condescension that this entails and the absence of social analysis that it hides. The use of the term should be rigorously exclusive, if we do not wish to make a caricature of what charity has produced in history. To situate the genesis of charity and then its avatars, we should first speak of the word *love*, which is, in a sense, its basis.

The Hebrew Bible (the Christian Old Testament) speaks a great deal of love. The word means a host of different things: We say that we love certain foods, that we love our friends and family, and that we love to travel. The Hebrews knew all these meanings, but they elaborated a notion of the love of God, that is, the love that is God and the love that we owe God, which goes well beyond current secular significations of the word. This conception is exemplified in Israel's affirmation that God displays a concern for, an unfailing fidelity to, his people and that he maintains with Israel a dialogue of tenderness but also of reprimand, which makes him the ideal of the Father. It is rather the people who, from time to time, distance themselves from Yahweh, preferring the cult of idols.

Deuteronomy tirelessly recalls that the love of God for Israel is unearned, for example, 7:7, to cite one text among innumerable others. This perfect love of God for his people, that is, disinterested, gratuitous in the sense of unearned, faithful, tender and firm, is realized, tentatively but equally and progressively, in a relation and personal dialogue with him. This evolution in the realization of God's love is chiefly observable in the texts of the Psalms, which are principally ascribed to the decade of 580 BCE, the period after the Exile. This tradition of love is also found in the New

Testament. The affirmation of the fullness of God's fatherhood dominates, since Jesus presents himself as issuing directly from the intimacy of God and as the gift of God, given to all men. Jesus, in the course of his short career, through gestures and statements reveals himself as this love incarnate, and his crucifixion its culmination and supreme proof.

This biblical background must be borne in mind to understand the exact sense of charity. In the current Christian vocabulary, the words *love* and *charity* are often used interchangeably. God is love in the sense of charity, *caritas*, which designates as much the love from God as the love that humans should bear toward one another. It is in fact essentially the fraternal consequences of the love of God to which the word charity refers. If God loves us and we should love him, we must give witness to this, first, by loving one another. We remember that Christ said that two commandments are equivalent: to love God with all our hearts and to love our neighbors as ourselves and as they are loved by God.

Here Christ is clearly following in the great spiritual tradition of the prophets who preceded him. Reference could be made to a great number of texts, in particular Mark 12:30-31 and the parallel passages in the other Gospels. Thus, waiting for the end of time and bearing faithful witness to the Gospels, the essential activity of the disciples of Jesus is charity. It is preferentially addressed to the poorest, to the most destitute, those who suffer most, for they are in the greatest need and are, indeed, the image of Christ on the cross. This is the context in which we will be tried on Judgment Day.

Matthew's Gospel established the six "acts of mercy": provide food, provide drink, receive the stranger, cloth the naked, visit the sick, and visit the imprisoned. In the course of the 10 centuries of the Middle Ages, iconographical representations of these acts of charity would flourish, and at the same time they were constantly driven home in homilies. It is here that alms become the principal form of charity toward fellow humankind and its movement from the rich to the poor.

The risk of narrowing the evangelical commandment and the symbolic thrust of the Gospel of Matthew to these acts of mercy is evident, and the very word *mercy* is indicative of this contraction. We should not believe, as it too often the case, that the medieval period reduced the commandment to be charitable to the gift of food and lodging to the poor and to strangers. Spiritual leaders such as Francis of Assisi, Saint Dominic, and Saint Bernard show otherwise. The scorn currently directed toward the Middle Ages is unmotivated. On the other hand, we must understand the deep signification, despite the ambiguous evidence, of alms during this period. As Saint John himself said, we do not see God and so must give him proof of our faith through the concrete works named by Matthew. The touchstone of salvation will be acts of mercy.

It must be emphasized that the rich, or those who possessed property (the bishops, monasteries, and parishes as well as the lords and later the bourgeoisie), were obliged to devote a substantial portion of their goods to the relief of the poor and the sick. Foundations dedicated to the indigent and vagrant flourished for centuries; this is the origin of the leper houses all across Europe, organized like real towns or monasteries. This was also the origin of the hospices, what we might call care centers and hospitals (an early name was Hôtel-Dieu); the latter were institutions specifically established to provide care. These were the first institutions to be "medicalized," if this anachronism is allowed in reference to facilities of this period. We see, then, that acts of mercy entailed considerably more than the donation of a few coins or clothes. Alms represented a great system of social organization, just as it was a system for the circulation of wealth.

As an example with regard to the infirm (for in the Middle Ages there was no conception of handicap or disability), it should be noted that charity generated multiple establishments that provided lodging as well as some specialized institutions. The hospices were not specialized and admitted all the poor. Generally speaking, for the entire period from the fourth to the fifteenth centuries, the infirm were also poor. To be infirm meant not to be able to meet one's needs and the needs of one's family through work. Being infirm meant being reduced to beggary. There were few infirm in seigneurial families, given the demography of the times, and they remained more or less hidden in castles and manor houses, when they did not die young. Thus, infirmity was synonymous with poverty, and charity, in the form of the provision of lodgings, was the principal social response to their situation.

We should, however, note the Quinze-Vingts for the blind, founded in France by Louis IX, Saint Louis. The name means "fifteen score," or 300, and indicates that the royal foundation was dedicated to the reception of this number of individuals who had lost or never had sight. It was a building in Paris where 300 blind people found room and board but were not confined. By day, they would go begging like the others in the streets, because they still had to pay a basic fee to the institution. The Quinze-Vingts had a long history, which will not be summarized here, until its present incarnation as a hospital specializing in ophthalmology.

Starting with this institution-building potential of the principle of charity, its history can be traced up to its end, when charity was replaced by public aid in the eighteenth century, during the Enlightenment. In fact, when charity did eventually generate social institutions, these were above all in what can be called "short relationships." By this is meant that it is one individual who addresses another individual or a group of individuals, without any intermediary of a public authority. Even Saint Louis, founder of the Quinze-Vingts, acted as an individual in providing comfort for 300 blind people and thus participating in his own salvation. Even when supported by royal funds, the foundation was not an obligation of the state. In the eighteenth century and in particular during the French Revolution, the state's duty to see to the needs of the indigent and the infirm would be affirmed. But this initiates another regime other than that of charity: public assistance. Thus, the state, especially in Europe, began to provide a social insurance so that those in need did not have to rely totally on charity or their families.

Charity, as we here understand it, comes to a close at this forking of the way. It should be added, however, that a third system for the relief of poverty and infirmity would emerge at the end of the nineteenth century: solidarity, itself made possible by the insurance system, based on the principle of contributions by each worker or each member of the association and then a redistribution to each according to certain rules.

Charity has been the object of much negative comment, and many of the slogans of disabled people have been of the type, "We don't want charity–we want our rights." History does not move backward and does not repeat itself. As a consequence, the system of charity, in its capacity as a system that addressees social problems, is behind us. Yet charity as a personal act remains active and often comes to fill the gaps left by insurance and assistance programs. With the substantial unemployment that all developed societies now know, a considerable portion of citizens are marginalized, even finding themselves victims of a process of social exclusion. The safety nets formed by insurance or social protection systems no longer work for them. They are again left to the good will of private persons who finance charitable works, foundations, or hostels.

Thus, we see forms of aid reappearing that seem to belong to the past. It should be noted, however, that there is no dedicated system that addresses itself exclusively to human risks or human misfortune. In European systems of social security, in many of the elements of aid, just as in similar types of aid from the eighteenth and nineteenth centuries, the traces of charity are numerous. Should we rise up against this state of affairs? Certainly, disabled people no longer tolerate the condescending charity that relieves those who practice it from the greater duties of solidarity. Demands for civic rights, nondiscrimination, and equality of opportunity are now primary. Historically, the situation is more complex than a simple opposition between charity and rights, since it is also from charity that the demand for rights was born. But, as noted, history does not repeat itself.

—Henri-Jacques Stiker

See also History of Disability: Medical Care in Renaissance Europe; Religion.

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CHILD ABUSE

Child abuse, be it physical, sexual, or emotional, at its essence involves the exploitation of a vulnerable person by another person who by virtue of age, development, or social rank has power over the victim. Child abuse can happen to any child, but disabled children are particularly at risk because of their physical or mental limitations and because of their increased dependence on caretakers.

While child abuse is an age-old problem, it was "discovered" and packaged as a medical problem in the last half of the twentieth century. Beginning in the 1960s and 1970s, physicians began to recognize child abuse as a distinct social problem with important medical and psychological features. The description of the battered child syndrome in 1962, for instance, identified a constellation of symptoms caused by abusive injury that doctors had not previously recognized. It was no accident that doctors in particular, and society in general, were awakened to child abuse during a period of heightened social awareness. The social activism of the 1960s and 1970s primed Americans to the needs of many oppressed and victimized groups. Doctors and other members of the helping professions felt called to advocate for children. With the decline of many once-deadly infectious diseases, pediatricians shifted their attention to issues of development and prevention; child abuse seemed a natural topic for their interest.

The medical recognition of child sexual abuse followed the discovery of child physical abuse. By the 1970s, physicians involved in child physical abuse broadened their focus to include victims of sexual as well as physical violence. They asked fellow doctors to be alert to the signs and symptoms of sexual abuse in their young patients and used their influence to protect these children. Child physical and sexual abuse increasingly entered the public discourse. Researchers explored who was at risk and how best to identify child abuse and treat it. National surveys of abuse, conducted in the 1980s and 1990s, demonstrated that disabled children were at increased risk of abuse.

The relationship between child abuse and disability can be viewed from multiple perspectives. Why are disabled children at increased risk of both physical and sexual abuse, and do certain types of disability make a child particularly vulnerable? What unique identification and treatment challenges exist in abused children with disabilities? How do physical and sexual abuse of children contribute to long-term disabling conditions? Can the answers to these questions help shape effective prevention, identification, and treatment programs?

RISK OF CHILD ABUSE IN CHILDREN WITH DISABILITIES

The true prevalence of child abuse in children with disabilities is unknown and will always be difficult to determine with accuracy, in part because definitions of abuse vary, as do definitions of disability. Nevertheless, researchers have estimated that the incidence of maltreatment in children with disabilities is between 1.7 and 3.4 times greater than in children without disabilities. Child protective services workers believe that in almost half of child abuse cases involving children with disabilities, the disability either led to or contributed to the abuse. In addition, children with disabilities tend to experience longer durations of maltreatment. Possessing multiple disabilities also increases a child's chances of physical and sexual abuse and is associated with longer durations of abuse.

These statistics have prompted researchers to ask why disabled children are more likely to be abused. Do particular disabilities place children at higher risk? Are there unique features of the perpetrators or the environment of abuse that makes these children more vulnerable? Neglect appears to be the most common form of child maltreatment in disabled children, followed by physical and then sexual abuse. Emotional and behavioral disorders place children at the highest risk of abuse and neglect. A number of factors (personal, medical, familial, and societal) influence a disabled child's risk of abuse. Communication disorders, for instance, may hamper a child's ability to disclose abuse effectively. Power inequities between a child and caregiver are more exaggerated in disabled children and may make a child more vulnerable to abuse. Some researchers have proposed that the added stress of caring for a child with disability, increased social isolation for the caregiver, and lack of respite care for the caregiver may place some children at higher risk for abuse. The increased dependence that disabled children may feel on their caretakers may prevent or inhibit them from reporting the abuse. Issues of power and control may be more exaggerated for children living in institutional settings. And social factors, such as the stigmatized nature of abuse in our culture and the dehumanization of some disabling conditions, make abuse less likely to be addressed and add to its impenetrable nature.

VULNERABILITY TO ABUSE

Various authors have offered explanations for the increased risk of abuse in children with disabilities. Some adopt a "frustration model" of abuse, suggesting that social and familial stressors, parental inadequacies, and characteristics of both the child and his or her disability result in the abuse. Others focus on the extra vulnerability of disabled children: their increased dependency on others, their relative lack of control over their lives, a lack of knowledge about how to respond to sexual advances, their social isolation, an increased desire to please, communication difficulties, and the relative immaturity of many disabled children. Clearly, the nature of each child's disability affects his or her risk for abuse. The learning disabled child will have different types of vulnerabilities than a child who is deaf or blind. How and to what extent these different factors affect a child's risk of being abused and the child's response to the abuse remain to be rigorously explored. Some researchers have pointed out that the stigma around disability can foster abuse: If a disabled child is somehow perceived as less human than an able-bodied child, then the abuse will be viewed as less problematic.

DISABILITY AS A CONSEQUENCE OF CHILD ABUSE

In addition to disabled children being at increased risk of abuse, physical and sexual abuse can contribute to or cause a variety of disabling medical and psychiatric problems. These problems may be the immediate results of the abuse or they may have a more complex etiology that takes years to be fully elaborated. Identifying past or ongoing child abuse and recognizing that it may contribute to or compound the disability can be an important part of protecting the abused child from further abuse, and ultimately treating the child.

The results of physical abuse of children occur on a spectrum. Abusive head injury in children, especially shaken baby syndrome, can cause neurological devastation and even death. The survivors of shaken baby syndrome are being studied currently to better understand the spectrum of behavioral and developmental consequences of nonlethal shaking. To some extent, the type and forcefulness of the physical abuse determine the severity of the developmental outcome. Some children with intentional burns, for instance, may have problems with fine and gross motor skills, other burn victims may have posttraumatic stress disorder as their major outcome of their abuse, and still others may have minimal adverse results.

The neuropsychological consequences of abuse, whether physical, sexual, or neglect, are currently being investigated. In addition to the physical harm inflicted, the stress of abuse appears to alter the brain's ability to react to later stressors, thus "rewiring" the brain. These changes in brain chemistry may be particularly important in early childhood when brain development is rapidly occurring.

Many researchers have looked at the mental health consequences of child abuse. Psychiatrists have recognized that survivors of child physical and sexual abuse are disproportionately represented in the mental health population. In addition, survivors of abuse are more likely to have chronic somatic complaints such as various chronic pain syndromes. Although these problems have been more studied in adult survivors of abuse, abused children may develop somatic complaints or mentally disabling conditions.

POLICIES AND PRACTICES

The abuse of any child does not occur in a vacuum; the familial, social, and medical milieu must be considered to protect children from further abuse and optimize their recovery from the abuse. The unique problems of each disabled child pose methodological challenges to those who study the abuse/disability relationship. Nevertheless, research in this area is important, not only because these children are at increased risk of abuse but also because conclusions made about nondisabled abused children cannot necessarily be extrapolated to disabled children. Finally, increasing society's awareness of this problem will help stop ongoing abuse and can lead to effective prevention.

—H. Hughes Evans

See also Childhood, Youth, and Adolescence; Children with Disabilities, Rights of; Crime and Delinquency.

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CHILD CARE

In modern societies where most parents work outside the home, families often have trouble finding affordable, quality child care. The parents of children with disabilities have historically faced even greater hurdles, since almost no formal child care services accepted disabled children during the nineteenth and much of the twentieth centuries. Accordingly, many families have found no other alternative but to place their disabled children in full-time institutions. With the rise of the deinstitutionalization and disability rights movements in the 1960s and 1970s, disabled children in Western Europe, the United States, Canada, and Japan have increasingly gained access to child care, albeit often through segregated programs. In industrializing and developing nations, however, child care for those with disabilities remains deeply problematic.

In the United States, the limited supply of child care overall is the result of its public-private organization (a pattern typical of much social provision in the United States). Formal child care originated in charitable day nurseries in the mid-nineteenth century and did not become a matter of public concern until World War II, when the federal government funded centers for the children of defense workers. This arrangement, however, lasted "for the duration only," and direct federal funding for child care did not again become available until the 1960s, when it was linked to efforts to move public aid recipients into the labor force. In the meantime, the government encouraged the growth of private child care (either voluntary or commercial) through tax breaks to providers and parents paying full fees. Federal subsidies for child care for poor and low-income families declined in the 1980s under the administration of President Ronald Reagan but rose again with passage of President Bill Clinton's "welfare reform" plan in 1996; current funding is, however, still inadequate. Because of resistance to setting federal standards and weak regulation in many states, the quality of both public and private services is uneven. By contrast, in many other advanced industrial societies, the state has played a more active role in organizing, funding, and regulating child care. Particularly since World War II, France, Sweden, Denmark, and parts of Italy and Canada have developed model services that are affordable, high in quality, and universally available.

INSTITUTIONAL CARE

Prior to the development of institutions for disabled people in the early to mid-nineteenth century, most disabled children were cared for at home by extended families and communities. Some children with disabilities found basic care amid the larger population of dependents in poorhouses, asylums, and orphanages. But the mid-nineteenth-century rise of state and private institutions (along with state schools for disabled children) in many West European nations, the United States, and Canada marked the real beginning of segregated care. These institutions, inspired by growing populations of urban poor, the pathologization of disability, and eugenicists' fears of "racial degeneracy" and "feeblemindedness," were designed to separate disabled people from the broader population, often permanently. While state schools for the deaf and blind and programs for crippled children, unlike those for the feebleminded, did not aim at lifelong segregation, they did require the removal of disabled children from their families and communities. These schools thereby reinforced the assumption that children with disabilities could not be properly cared for and educated at home.

The institutional model—and the primitive care it offered—increasingly gained sway, to the point that parents found keeping their disabled children at home logistically challenging and socially unacceptable. In 1851, the United States had 77 residential institutions for children; by 1910 there were 1,151, and by 1933 there were 1,613. Parents who needed care for children with disabilities, especially if they were working class or lived in urban areas without extended families, increasingly found institutionalization their only option. Day nurseries refused to accept sick or disabled children, and orphanages routinely sent feebleminded children to state institutions. Many doctors pressured parents to relinquish disabled children to the state just after birth. In the 1950s, one doctor told a father: "It will sap [your wife's] life, and seriously injure yours. It will create a home atmosphere that will be impossible for future children."

In the 1950s and 1960s, family members and politicians throughout Western Europe, Canada, and the United States began to advocate for the deinstitutionalization of people with disabilities. In particular, activists were emboldened by reports exposing the mistreatment and long-term emotional and intellectual harm suffered by institutionalized disabled children. In Illinois, young inmates were sometimes punished for infractions by being locked alone in "quiet rooms" for weeks or bound spread-eagled for days. The idea of "normalization"—that disabled people should be able to live at home with their families and be integrated into the broader community—and the burgeoning disability rights and independent living movements also played critical roles in spurring deinstitutionalization. The push toward community-based living was aided by a growing realization that it was cheaper than institutionalization. By the late 1970s, so many disabled children were living at home that many state institutions closed for lack of clientele.

Despite the success of the deinstitutionalization and disability rights movements in Western Europe and North America, the institutional model of care for disabled children remains prevalent globally. In the early to mid-twentieth century, industrializing nations such as China and the Soviet Union established state institutions to care for abandoned children, disabled and able-bodied alike. Today, little has changed in these countries. Deinstitutionalization and disability rights movements capable of challenging the deadly conditions in these institutions and the social prejudices underlying them have not emerged. Facing extreme prejudice and almost no social and financial support, parents of such infants routinely abandon their progeny at institutional doorsteps. In Russia, despite a 1990 law mandating social integration of institutionalized, disabled children and promising disabled people full civil, political, and economic rights, Human Rights Watch (2003) reported, "Infants classified as disabled are segregated in 'lying-down' rooms, where they are changed and fed, but bereft of stimulation and essential medical care. Those who are officially diagnosed as 'imbeciles' or 'idiots' at age four are condemned to life in little more than a warehouse, where they may be restrained in cloth sacks, tethered by a limb to furniture, denied stimulation, training, and education. Some lie half-naked in their own filth, and are neglected, sometimes to the point of death." By removing disabled children from the community, this segregation reinforces the social attitudes making such ill-treatment possible.

CHILD CARE IN THE DEINSTITUTIONALIZED ERA

In Western Europe, Canada, and the United States, deinstitutionalization has had mixed, even paradoxical, effects on the care of disabled children. In the United

States and Great Britain, deinstitutionalization and family support programs have enabled families to care for children with disabilities at home. These initiatives, however, have not fully addressed parents' problems in finding acceptable child care, nor do they address the segregated care that is available. Although programs dedicated to children with disabilities—respite care, early intervention, residential schools, and specialized day care services—cost more than integrated programs (even those that bring in experts and additional staff), segregated services remain the norm. Such programs provide invaluable aid and training for disabled children and their families, but they lack sufficient spaces. In addition, few run for a full day or workweek and respite care hours are limited by month and year, leaving parents scrambling for additional coverage. Children with disabilities are also overrepresented in group homes and foster care, where they make up 20-25 percent of populations (as compared to only 5–10 percent of children overall). These expensive programs help reinforce the notion that disabled people do not belong in the broader community and add to the profit margins of the private companies that have largely replaced public institutions.

Programs integrating disabled and able-bodied children, such as Head Start in the United States (which requires that 10 percent of enrolled children have disabilities) and some church, public school, and family day care facilities, have made significant strides. Most parents desire integrated programs for children with disabilities, and many studies have demonstrated that they teach tolerance to all children and serve disabled children better. Yet, for much of the 1970s and 1980s, these programs were rare and underfunded in comparison to their segregated counterparts. Operators feared that they could not adequately serve disabled children and that children with disabilities would dramatically increase costs; some were uncomfortable with the principle of integration itself.

In the United States, the Americans with Disabilities Act of 1990 (ADA) has significantly improved parents' chances of finding quality child care for children with disabilities—especially in integrated programs. The ADA specifically covers child care services (both family and center based) and bars them from rejecting children with disabilities unless they present "a direct threat to the health and safety of others" or require "a fundamental alteration in the center's program." The Department of Justice has mandated that centers cannot charge parents for disability-related services (e.g., administering medicine, monitoring diabetes, or helping with toileting), operators must admit older children who use diapers and children with HIV/AIDS, and programs must integrate children (including those with cognitive disabilities) into age-appropriate classrooms.

The ADA has opened up many more child care options to families with disabled children, but problems remain. More than 45 percent of mothers of disabled infants do not return to the paid labor force because they cannot find appropriate child care. Children with disabilities often require care into their teens, when finding care is particularly challenging. Centers do not have to accept a disabled child if it would force them to hire another worker, and operators may dismiss children for being disruptive or needing individualized attention, definitions that many parents feel can be manipulated. Parents can challenge operators' rejections through mediation, but not all families are aware of this right.

Parents' continuing inability to find appropriate child care reduces their incomes, a critical issue given the extra medical expenses often associated with disabled children. These mothers are particularly likely to have lowered incomes due to intermittent participation in the labor force. In desperate situations, lack of child care may lead parents to reinstitutionalize their children. One mother told a congressional committee:

> There is no such thing as day care available to my daughter [who has tuberous sclerosis]. It does not matter who pays for it or what the cost is, it simply does not exist. . . . Lack of day care was the deciding factor in my decision to place my daughter [in an institution]. I could not continue to disrupt my daughter with constant changes and I refused to lose a third job over day care. (quoted in Fink 1988:1)

Other industrialized nations such as Sweden, Italy, and Canada have pioneered inclusive child care programs. Building on such countries' long history of providing social services, these programs emphasize restructuring environments to reflect the needs of all children rather than just integrating disabled children. Sweden, which established universal child care in the 1970s, emphasizes that the needs of children with disabilities "are primarily to be met in regular child care and not by singling them out for special treatment. High overall quality in the preschool or leisure-time centre is viewed as the best kind of support for many of these children." Inclusion is seen as key to both teaching able-bodied children tolerance and ensuring that disabled people experience "normalization" from a young age. Italy, in 1977, mandated that children with disabilities be integrated into child care. Teachers hired to support children with disabilities work with all children to ensure integration and avoid singling out disabled children. Most Canadian provinces support some inclusive programs; Alberta's Integrated Day Care Program pays all extra costs associated with disabled children (including full-time special needs coordinators who focus solely on integration) and provides mobile teams for special training. Not all parents of disabled children in industrialized countries are able to find spots in inclusive programs, however; in Germany and the Netherlands, for example, segregated care persists.

UNEVEN DEVELOPMENTS

The 85 percent of the world's disabled children living in developing countries encounter a complicated mix of integrated and increasingly segregated child care. The institutional model of care once common in industrialized countries is rare in the Third World, with only 5 percent of children with disabilities (mostly children of the urban elite) in institutions. In villages and small towns, the extended family system often plays a critical role in helping care for disabled children and easing their incorporation into the broader community. In the past 20 years, the rise of community-based rehabilitation programs has enabled disabled children to receive specialized education and training at home and taught their communities to be more tolerant.

Yet many children with disabilities in developing countries have historically encountered extreme prejudice and segregation in care—an isolation that is now increasing. Certain cultures have long interpreted disability as a curse, contagion, or evidence of past sins, resulting in the loss of all support from the extended family and social isolation. In countries from Thailand to Uganda, investigators have found disabled children who had never been allowed outside their home for fear of family shame. These children generally receive only the most basic level of care and no training or education.

Poverty, urbanization and industrialization, HIV/AIDS, and the structural adjustment politics of the International Monetary Fund and World Bank also lead to limited, isolating care for children with disabilities. Labor migrants with disabled children face a double disadvantage, especially in urban areas: Not only have they lost the support of extended family and community, but their countries lack the extensive social services provided to disabled people in industrialized nations. Consequently, mothers going to work often have to leave disabled children with older siblings or even lock them inside their homes. With structural adjustment programs increasing basic living costs, more parents must migrate to find work and mothers are compelled to work even longer hours outside the home. The HIV/AIDS epidemic in sub-Saharan Africa has also created millions of orphans, often infected themselves and facing severe discrimination. Few receive any formal care; only 35,000 of the 800,000 AIDS orphans in Kenya, for instance, can be accommodated in orphanages, leaving most of the rest to wander the streets and work in odd jobs or prostitution.

—Sarah Rose with Sonya Michel

See also Caregiving; Childhood, Youth, and Adolescence; Family; Family, International.

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CHILDHOOD, YOUTH, AND ADOLESCENCE

It is a truism for parents: The birth of a child is a transformative experience. Priorities, perspectives, and plans change. The power of the child to transform adults is almost boundless. Like a bioemotional philosopher’s stone, the child transmutes an adult into a parent. This change often compromises primal urges, such as self-preservation, changing them into a stronger urge of self-sacrifice for the child. Certainly, there is a measure of biological imperative here, the propagation of one’s genes, making the self-sacrifice in fact a kind of self-preservation and a hoped-for immortality, but the motivations are also cultural and psychological.

This truism is even more applicable for the child with a disability. Such children have an incredible power to transform the world and the people around them. For example, children with seizures, limps, and sensory impairments were carried hundreds of miles by their parents to be cured at medieval saints’ shrines. Children with disabilities at medical institutions in nineteenth-century Europe altered the development of a wide spectrum of medical professions as well as the distribution of government budgets and private organizations. In mid- to late-twentieth-century America, the children of the March of Dimes drives and muscular dystrophy telethons inspired extraordinary numbers of people to charitable action. Similarly, the experience of disability in childhood has radically altered the personal development of world leaders, artists, and writers, as well as ordinary people. While international and national debates have raged across time about how to “respond” at a systemic level to children with disabilities, their individual and collective impact on humankind has been profound and irrefutable.

The interface of the child and of disability exists at multiple levels. These include (1) children with disabilities themselves, (2) the families of children with disabilities, (3) children in families with other children with disabilities or with parents with disabilities, (4) societywide care systems for such children, and (5) social perceptions of children with disabilities and the impact of that perception on adults with and without disabilities. These patterns have played out across time and culture with remarkable variation and similarity. What follows is a brief suggestion of the many examples of the role of children and disabilities in our societies.

DEFINITIONS

In the West, the definition of a child has traditionally been a human who is younger than 14 years old, although adulthood is now moving internationally to 18 years old. Around the globe and across time, this definition has varied. In premodern, rural Japan, boys who were 15 and girls 13 were considered adults; it is now 20 for both. In Samoa, cultural changes have altered both the age of adulthood and its cultural identifiers over the course of the twentieth century. In sub-Saharan Africa, shifting definitions of child and adult have challenged researchers for years.

From antiquity into the early modern period in the West, the life cycle of humankind was characterized by the Ages of Life, which varied in number from 3 to 12; with 7 being the most common. These ages were variable by time period and geography, but generally broke down as Infancy and Childhood, which covered the period up to about 14 years old; followed by Adolescence, up to 21, 28, 30, or 35; then Youth, to 45 or 50; Senectitude; Old Age; and Death. Importantly, disability was inherent in at least the first stage, infancy, usually judged to be less than two or three years old. It was characterized by inadequacy of the limbs for walking and inability to produce articulate speech. In the Middle Ages, the mimicry by old age of childhood's disabilities was a frequent topos in literature.

Today, in industrialized countries, a variety of ages may represent the boundary between adult and child—21, 20, 18, or 16—based on the bestowal of certain societal privileges such as voting, military service, driver's licenses, or drinking ages. Biological shifts have often represented that transition, such as the age when a female bears her own child. The age of consent to marry, in such cultures as it is necessary, has varied dramatically; gender too, significantly alters the status of child versus adult. While legal definitions vary by country and governmental body, familial or wider cultural expectations vary more widely and personally. Is the 30-year-old who lives with her parents still a child? Is the 12-year-old runaway fending for himself on the streets an adult? The meaning of "child" is highly dependent on context.

The terms of childhood are important to the understanding of disability too. The Latin word *infans* meant "unable to speak." Over time, it also took on the meaning "unspeakable." Similarly, the word *monster*, so often associated with children with congenital malformations, derives from the Latin *monstrere,* which means to show or demonstrate. In English, *youth* and *adolescence* are near synonyms with *child*. Yet youth has the added resonance of lost youth as opposed to senescence. Thus, *youth* carries an intrinsic hint of disability to come. The Renaissance and early modern fascination with the fountain of youth, for example, speaks of the inherent disability in youth's absence. Similarly, adolescence, a comparatively modern term that existed in Latin from the verb meaning to grow up, carries in its current incarnation a kind of disability itself; in this sense it is often perceived as the social maladjustment in the transition from child to adult; the disabilities of reduced danger aversion and experimentalism provoke many functional consequences. Adolescence in fact is often considered a state of frank social disability. This entry, however, will consider the child and childhood as the central focus.

THE CHILD ACROSS TIME

Philippe Ariès, a twentieth-century French demographer and social historian, proposed that the concept of childhood started in the late sixteenth and seventeenth centuries. He argued that the utility of a separate stage of human experience—the child's—emerged in the upper classes, gradually growing into a focus of study by the twentieth century. But the chronological thrust of this thesis has been vigorously denied by subsequent historians. It is impossible to ignore the potential danger seen in children during the Middle Ages, for example, when Pseudo-Albertus Magnus, writing *De secretis mulierum* in the thirteenth century, implored his readers in the preface of his "serious" work to prevent any child or anyone of childlike disposition from reading it. Knowledge in the misguided hands of the cognitively limited was hazardous. On the other hand, the extraordinarily positive influence of the child was undeniable, as when the birth of an heir to a throne sparked celebration among a populace, or in the profound growth in influence of the *baby* Jesus in medieval Catholicism. Children provoked adult reactions in a variety of ways.

For a family with a disabled newborn, those reactions started at home. During antiquity and the Middle Ages, the abandonment of unwanted infants did occur. Medieval theologians suggested it was possible that the number of affected infants was such that a man might unknowingly sleep with his previously abandoned daughter in a brothel. However, abandonment was not common in either ancient or medieval cultures, at least to the level of exposure and death, even for the child with a disability. Because of their intrinsic emotional and rhetorical power, children, either with or without disabilities, have often been social, metaphoric lightening rods.

The child with a disability could also be a source of inspiration, or of warning. In 1449, the burgers of a German village mutilated and blinded the children of criminals to act as a warning for other adults not to steal. This was an extrapolation of punishments of maiming and blinding the thief, stemming from Hannibal and before through medieval kings such as Charlemagne and Saint Louis to the Arabic cultures of today. A similar episode is recounted in the twelfth-century *Roman de Rou* during a Norman peasant revolt. The emotive power of a disabled child was such that in some medieval cities, poor parents were accused of blinding and mutilating their children to provoke more alms. This may not have worked well. A blind man from the Hôpital des Quinze-Vingts, founded in thirteenth-century Paris, told the story of a "little boy" who helped him beg. Passers-by maltreated the boy, filling the begging bowl with mud, knocking it from his hands, or giving him stones instead of coins. They even took the rock on which he sat while begging.

The able-bodied child also saw in disability a sense of "otherness." Their reactions could also be a danger to the disabled because of their mischievousness. William Coe, a yeoman who was a boy in Suffolk ca. 1680, remembered leading a blind beggar into a body of water as a joke. At the same time, early modern, like modern, children played games that broke the bonds of expected (or normal) posture, imitating disabilities—like hopping on one leg or spinning to get dizzy. Today's "Marco Polo," "Blind Man's Bluff," and three-legged races continue that theme of the child and the disabled.

Despite Ariès's thesis, a fairly consistent concern for children and for their distinctive nature from adults has existed in Western history. What is evident, however, is that during the seventeenth and eighteenth centuries, a shift in how we consider children in the West took place. Previously, children were seen philosophically as inherently sinful. Pierre Bayle, a Dutch Calvinist at the end of the seventeenth century, felt children's native sins were added to by their "blindly" believing whatever they were told.

Especially under the aegis of Jean-Jacques Rousseau and John Locke, children were reconfigured as innocent, only corrupting under the influence of adults. The ramifications of this shift have been profound. In Locke's *Second Treatise on Government,* he argued that during the imperfect state of childhood, one holds one's children in custody from God. For Locke, disability was also at the interface of connecting the child and the adult. A man blinded by smallpox could forget his childhood's memories of what colors look like. Consequently, the continuity between child and adult could be severed by any kind of memory loss. Education was a critical component in preserving children and the continuity of being into adulthood. This argument was enhanced dramatically by the French philosopher Jean-Jacques Rousseau. He minimized the importance of book learning and recommended that a child's emotions should be educated before his reason. He placed a special emphasis on learning by experience.

A close linkage between children and the disabled was also made in the eighteenth century. Locke suggested that children and "idiots" do not have the least apprehension of innate truths, thus equating the two groups. The subsequent fascination with the child was a staple for Enlightenment philosophers and scientists as they tried to understand humankind's role in the natural world. Describing the role of language in the development of the child led to a string of sensational "discoveries" of feral children, the so-called wolf-children, into the twentieth century. Jean Itard and Arnold Gesell observed and experimented with children raised without social interaction with other humans. These children's social isolation crippled their physiological ability to think and communicate, and vice versa. This research altered the understanding of child and language development. The "nature versus nurture" question continually turned on understanding children. Similarly, Charles Darwin's impact on eugenics was usually mediated through offspring and child-bearing, thus provoking discussions, laws, and actions of euthanasia, sterilization, and institutionalization.

Nevertheless, medical concern for children as a specialty probably reached a critical mass during the Enlightenment. In France, at least, in 1772, Gilibert was calling for specialists in pediatric care, especially for children with chronic ailments. Such arguments undoubtedly led to the founding of the world's first pediatric hospital in Paris, L'Hôpital des Enfants Malades, in 1802. That focus was soon echoed in the Germanic countries and throughout Europe. Such institutional support eventually provoked the specialization of physicians in children's diseases and sparked a similar rise in the United States by the later part of the nineteenth century. One of the ideological drivers for separate institutions was to protect innocent children from the corrosive effects of adults also hospitalized.

Arguably, a significant change in the nature of disability and childhood came, in the United States at least, during the Progressive Era and the growth of industrial-capitalism. With rising working-class employment in urban settings attracting youths and a rise in modest disposable income for these employees, a significant youth culture of independence provoked concern among the middle class at the dawn of the past century. Coupled with a declining age of menarche and a rising age of marriage, these changes sparked progressive reforms for child labor and welfare, including robust requirements for school attendance (rising from 6.7 percent of adolescents in 1890 to more than 50 percent by 1930). These changes increased the functional requirements for children with disabilities, but they did not offer solutions for the ensuing social challenges. At this same time (ca. 1900), children were also converted from objects of "utility," that is, laborers on farms or factories, to objects of "sentiment," that is, into so-called consumer goods. In effect, the middle-class child's relative value had become worthless by the middle of the nineteenth century. Similarly, child labor laws made the lower-class child less "valuable" by the early twentieth century. Child insurance policies became more complex social devices as a consequence. Finally, a sequence of international wars provoked an escalating concern for the physical "fitness" of U.S. and European male youths. The public welfare seemed inextricably linked with the health and able-bodiedness of its adolescents, and by extension, its younger children. Children with disabilities thus became a perceived national threat.

One result of such mingled social concerns was the rise of eugenics and its situation within official and unofficial policy. In the United States, celebrated cases such as that of Harry Haiselden, MD, a Chicago surgeon in the 1910s who practiced and promoted the "euthanasia" of newborns with disabilities, sparked both sympathy and debate. Laws allowing the sterilization of both girls and boys with disabilities synergized with concerns to safeguard future generations from the "burden" of their own disabled offspring. While such efforts continued well into the second half of the twentieth century in the United States, they found their apotheosis under the Nazi regime in 1930s Germany and the institution of the Aktion T4. Under this official program, children and then adults with disabilities were selectively killed both in hospitals and in special centers. Even after Hitler officially ended the program a period of so-called Wild Euthanasia continued into the 1940s. In addition, experiments on children with disabilities using tuberculosis vaccines touted the idea that these children were not the objects of minimizing suffering, but rather of obviating the "ballast-existence" for the public. In the United States, echoic experiments occurred with institutionalized children, such as those at Willowbrook.

While elimination of children with disabilities became one mechanism to reduce disabilities in future generations, specialists discovered new disabilities to describe and prevent. Childhood development was critical in the early mental health movement and dynamic psychiatry of the 1900s–1920s in the United States. The experiences of childhood became the cause of many mental disabilities, as perceived by psychologists and psychotherapists. One's life as a child could impair one's life as an adult, putting the two in tension and, at times, at war. The application of preventive measures in childhood—a kind of mental health "prophylaxis"—could be seen as early forms of disability prevention, beyond the venues of the eugenicist. Lawrence K. Frank argued that society had become "mentally disordered," thus disabling the entire U.S. social body because of the "sickness" of adolescent/youth culture. Certainly, some of the social anxiety came from fears of technology and the inadequacy of the family to absorb them without conflict.

DEVELOPMENT AND DEPENDENCE

The duality of dependence of the child with a disability—dependent as a child and dependent as a person with a disability—at once intensified and negated a child's disability. For the caregiver, the dual dependence can add more "work" for the adult; for society, the dependence can be nullified. The child is already dependent and so is less apparent than a newly disabled and dependent adult. At times, the child's disability and its developmental potential can even invert the disability. Society frequently turns disabled children into heroes, as in Great Britain during World War I or in the United States during World War II. The hybrid relationship of disabled veterans, infantilized by society, and the heroicized congenitally disabled child was evident in England during World War I. The close identity of disabled children and soldiers has played itself over and again, as, for example, in the United States of the 1960s when veterans with amputated limbs were taught to ski; children with amputations learned at the same time, the two groups idolizing each other.

The issue of normality was especially central in childhood and adolescent culture as it came to be typified in the early twentieth century in the United States. There, Viennese psychoanalyst Alfred Adler's notion of the inferiority complex was quickly absorbed and disseminated. Similarly, the "defects" of adolescents could become a target of national concern during wartime recruiting efforts. Approximately 25 percent of U.S. military recruits ages 18–19 years were evaluated as being physically or mentally defective after the Great Depression. Like concerns were expressed in Great Britain, France, and Germany.

Fears over normal development extended beyond the militaristic. The effect of parenting on the chronically ill child with a disability in the 1940s was considered a possible venue for degendering. If not raised "properly," a parent's anxiety could rob a boy of his manhood or a girl of her femininity. The nexus of the parent, the child, and disability could thus cross the bounds not only of (in)dependence but also of gender identification and sexual behavior because of, for example, coddling. Thus, a curious multilevel interdependence between able-bodied children, disabled children, able-bodied adults, disabled adults, and society at large has existed for many years. This was also seen in the early modern relationship between some noble children and the court dwarf, who could be delegated as nurse, companion, or tutor to the child. Paintings of the dwarf and child together evoke multiple levels of sociocultural comparison. From the late nineteenth century, there was a progressive, at-once practical and symbolic comodification of the child's body, particularly with respect to life insurance, which by the mid-twentieth century had begun to wane in favor of a pricelessness of the child, irrespective of its able-bodied state.

In 1930, a citywide survey of New York City concluded that the issue of disabilities was significantly one of childhood as so many children had disabilities and so many adults had disabilities that started in childhood. Responding to such concerns and others, by 1950 most advanced industrial societies had introduced comprehensive family allowance systems (the United States was a notable exception). France was the pioneer and also the most generous with almost 5 percent of its national income in 1961 allocated for children.

With the growing valuation of the child with(out) disabilities has come a shift in causation. Where until the mid-twentieth century in the United States a child's disability was often blamed on his or her parents, over the past 50 years the blame has shifted to the child itself. Unlike the medieval image, neither parental poverty nor moral inequity is the cause of familial harm, but rather the presence of the disabled child. Scholars and researchers have assigned to the child blame for difficulties faced by the family and by society at large: divorce, social isolation, geographic immobility, national or state debt. The mechanisms invoked have ranged from anger to grief, denial to guilt, marital incohesion to social withdrawal and a host of other social and emotional processes. A 1981 article created a new "medical" condition, parentaplegia, to characterize the impact of the disabled child on its parents.

Simultaneously, by the 1980s, historians of Western childhood raised an alarm about the loss of notions of childhood. They observed that 12- and 13-year-olds were among the highest-paid fashion models, that from 1950 to 1979 crime by children had increased more than 100 times, that children's clothing was now adultlike, and that children's sports such as Little League now had world championships, with adultlike umpiring. The distinctions between the child and the adult were blurring. Children were at once harming and being harmed by the nature of modernity. The veracity of these concerns has yet to be proven, but it is clear that as in other centuries, our perception of the reciprocal impact of children and society is heightened.

The impact of a child with a disability is also evident prior to conception. It was a common medieval belief that the Devil could substitute a dysmorphic child for a "normal" child if the parents were sinful. By the late Middle Ages, the mother's body was often the source of disabling forces upon the fetus. Like an umbrella, the liver protected weeping humors falling in the abdomen from reaching a child implanted on the right side. Thus, a child on the right side of the womb was likely to be a boy and well formed; on the left side, the child was more likely to be a girl and deformed. Claude Quillet, much admired by Nicolas Andry, the founder of orthopedics, wrote *Callipaedia* (1656), a treatise on how to produce beautiful children during pregnancy. This work extols many positive actions, but it also invokes the fear of causing physical deformities in inchoate children if husband and wife are intimate during the mother's menses. Such cautions were quite old, dating back to antiquity at least, and readily generated fears of harming infants/creating disabilities even before a child was conceived.

On the other hand, the fetus can disable the mother. Today, in sub-Saharan Africa, a disproportion between the birthing fetus' head and the mother's pelvic outlet can cause fetal death and fistulae (pathologic connections) between the anus, rectum, uterus, and vagina. The result is an unchecked flow of urine or feces through the vagina and severe social and medical disability.

Finally, the absence of a child can be a disability. The inability to conceive (whether because of the mother, the father, or both) has often been blamed on the potential mother, perceived as a disability for those seeking heirs throughout time. The social consequence has been ostracism, divorce, or death, as suggested by Henry VIII and Anne Boleyn. In the twenty-first-century United States, it is quite common for women to refer to their "biological clock," which includes not only the approach of menopause and the inability to procreate but also the increasing likelihood of birth defects and Down syndrome after age 35. Such concerns were common in history as well.

CHILDREN'S CONDITIONS

Starting from the newborn period, children are subjected to environmental events that can result in impairments with disabling consequences. From malnutrition to infections to trauma and child abuse, infants acquire traumatic brain injuries, spinal cord injuries, and skeletal defects. From metabolic disorders to genetic defects, children are also born with conditions that can restrict their development.

In the United States, the incidence of children with physical disabilities is about 6.5 percent; in central Asia, the rate is reported as approximately 10 percent, though all such statistics are highly dependent on definitions, cultural context, and sample sizes. The most common conditions associated with American childhood disability are respiratory diseases and mental impairments; in Vietnam movement disorders are the most prevalent, accounting for about a quarter of childhood disability. Considering conditions demographically, the older a child is the likelier it is to have a disability; nevertheless, in some developing countries, more than one-half of disabilities are acquired congenitally. There is also a higher incidence among boys and children from low-income and single-parent families. The functional impact on society is considerable. Thus, disability among U.S. children provokes some 66 million days of restricted activity each year, of which more than a third are lost school days. Medically, this combination, in our medicalized society, creates each year nearly 26 million physician contacts and 5 million hospital days.

These numbers suggest some of the ways that childhood disability has been pathologized at a social level. Yet the pathology has been even more metaphoric. The notion that children become a type of disability for their parents (e.g., a social handicap, limiting adult-adult interactions; a financial impediment) was generalized to the image of adolescent culture being an infectious disease or pathology to disseminate to the "body politic" in the 1940s of the United States. Similarly, the growing perception of the "harm" of the child with a disability on its family has grown in Western culture over the past 50 years. In other parts of the world, stigmatization can be profound. More than 80 percent of parents with disabled infants in

Zimbabwe receive no assistance from their nuclear or extended families; they most frequently cite stigma as the cause—that the disability becomes a bad omen for the family in general and so must be ritually expunged or else eliminated from the family unit.

Among the unique features of children are some of the disabilities associated with them. Children may have conditions peculiar to their age provoking their disability, such as Osgood-Shlatter disease, an inflammation of the adolescent knee of typically short duration. But in other conditions, such as juvenile rheumatoid arthritis, or congenital conditions, such as cerebral palsy, the symptoms may begin in childhood but last a lifetime. In still different settings, a condition may start symptomatically postnatally, such as cystic fibrosis (CF), and last throughout childhood with an early death. CF has thus traditionally been considered a child's disease. But now increasingly people with the condition are living into adulthood with a lengthening life expectancy. Such shifts provoke sociological changes in health care distribution and professional identity, as insurance companies alter their life-expectancy tables for a given diagnosis and internists are forced to learn more about CF as those with the condition transfer their care from their pediatricians. Still other conditions have become associated with childhood, as scoliosis and adolescence, because of medical screening and professional identification. Certainly, this kind of perception can change over time with cultural shifts.

Development, the change of the child as it ages, is a key Western concept underlying the experience of children and disabilities. The Latin term, *infans,* above spoke to the infant's inherent dependence on adults, but that dependence ultimately gives way through growth to independence—the disability evolves into ability. But for disabled children, evolving ability and disability over the life course changes the meaning of their disability. Thus, the differing life stages of children can alter the experience of disability, both because of changes within their own body and psyche and because of the shifting perception of the infant, child, youth, or adolescent by society around them. The infant with cerebral palsy has different expectations of self and culture than does the nearly adult adolescent with cerebral palsy. Particularly in adolescence, transitioning from childhood to adulthood with disabilities can present unusual challenges.

Such chronological variation can also be useful or instructive. A recurrent motif in the story of children with disabilities is that many, born with disabling conditions, often do not realize that they have an "abnormal" condition until they leave the home and interact with other families. Congenitally deaf children commonly experience the sense that other families are behaving oddly, compared to their own, when they first visit a friend's home and see them talking orally. These experiences highlight the social component of disabilities, which can be mitigated or obliterated by cultural adaptation. At a community level, Martha's Vineyard, an island in Massachusetts, culturally developed widespread sign language use because of a high prevalence of hereditary deafness in the nineteenth century.

Today in the West, most children with chronic health conditions survive to adulthood. Simultaneously, rates of disability among younger Americans have increased dramatically during the past 40 years, mainly through the rapid growth of a few common conditions (obesity, asthma, and mental health conditions). The growth of these disabilities among young people has tremendous implications for quality of life of these individuals as they mature, as well as for national health and related expenditures. Consequently, where positive and negative eugenic policies were the norm previously, contemporary societies struggle with different means of prevention as well as decreasing the social component of disabilities through education, access, and support.

In Western medical models, caregiving often extends outside the family. For children with disabilities, while the family still remains the core caregiver, assistance is also given by many health professions, from nursing to social work to the therapies to pediatrics to pediatric rehabilitation, as well as educators. Two common factors that distinguish child care from adult care are child development and education. Children since before antiquity have been recognized as having anticipatable stages in their growth and capabilities, both physical and cognitive. But since the nineteenth century, educators, clinicians, and investigators have established "normal" patterns and relative stages of growth and development, from height/weight charts to tables of expected abilities at each age. The implications of development for the child with a disability include naturally changing/improving facility with both physical and cognitive tasks. Thus, infants with exacerbations of asthma are more dependent on others for monitoring and keeping their airway clear and stable; adolescents with attention deficit disorder have greater self-awareness and cognitive/physical coping skills to care for themselves. And through all these changes, teachers and school systems must respond to the growing needs of the child.

On the other hand, the developing child experiences shifts in both physical and emotional balance. Thus, the infant's head-to-body-size ratio is almost one-third, but the adult's is almost one-tenth; the infant with a static myopathy, a condition affecting muscle strength, has to use different strategies to keep his or her head up than the adolescent with the same condition. Similarly, the adolescent has very different emotional motivations than the infant for keeping his or her head up. Consequently, children with disabilities are biologically a "moving target" for their family, for their medical team, and for those giving longitudinal assistance. The developing nature of their biological substrate provides both basic hopes for improving function over time and specific challenges for adaptive strategies, which distinguishes them from adults.

The inherent "plasticity" of the child's body also affects reaction to potentially disabling conditions. Children's ability to recover most or all of their function from a broken bone is radically better than that of nonagenarians. Immunologic and hematologic systems also frequently give hope for notable recovery or improvement beyond that of an adult with a similar impairment. On the other hand, a child's ability to establish a "higher" quality of life long term with a spinal cord injury than an adult who acquired that injury during adulthood may have more to do with psychological and cultural plasticity.

CHILDREN WITH DISABILITIES IN SOCIETY AND CULTURE

Unlike adults, children already exist in a state of long-term dependence on (or cooperation with) others for subsistence. Where nondisabled adults are usually expected to be able to see to their own daily, bodily functions and needs, children, in a developmental fashion, only slowly are able to control their excretory, nutritional, and daily living needs. In most cultures, care for the child, with or without a disability, is expected to be the responsibility of the biological parents or their designees. In this sense, the child with an acquired disability has expected, designated caregivers, another standard difference from the adult situation. A young, single adult might fall back on this model of care, or an adult with a partner might depend on his or her partner for care. In the child's case, examples of abandonment, orphaning, and poverty have necessitated broader social support and care for children when parents are unable to fulfill their commonly expected roles. Thus, in the West, religious institutions for many centuries have offered that support, and in more recent centuries, governmental systems, such as homes, institutes, and hospitals, have filled those roles.

As a consequence of the different expectations of dependence of the nondisabled child and adult, the presence of a significant disability for an adult often includes a form of social stigma akin to infantilization. That an adult would need the long-term care of another adult for excretory or nutritional needs is so like the typical pattern for an infant or young child as to symbolically provoke a comparison to the child.

A child's cultural, developmental dependence is also evident in education. Integrating the child with a disability into an educational system, usually designed for a spectrum of the "normal child," represents one of three recurring settings of broader social integrations and disabilities, the other two being (re)integrating the worker with a disability and reintegrating the soldier with a disability across many societies and time periods. The history and description of "special education" are crucial topics, which are dealt with elsewhere in this encyclopedia, and remain fundamental to the notion of the child with disabilities in our society.

Differences of the child at various developmental stages have also provoked philosophers who consider disabilities. At one extreme of these discussions is Peter Singer. Among others, he has suggested that an infant's lack of long-term and continuous memory affects definition of self. This identity changes as the child acquires a continuous sense of self over time. To inflict suffering on the younger child in hopes of improved quality of life in the older child creates a moral dilemma, which should not always be decided in favor of the older child. Using this logic, Singer has notoriously argued, and some physicians have enacted, a form of euthanasia for infants with severe disabilities in hospitals, based less on the societal politics of the early twentieth century and more on elements of individual's rights. Cognate arguments regarding abortion and children's end-of-life care are also rife. Throughout the West, disability rights activists have vigorously and intellectually reasoned against such arguments. The critical and compelling nature of these debates clearly indicates the power of children and disabilities in contemporary cultures.

But the role of the child and disability is not restricted to philosophy, medicine, and politics. The power of the child to evoke notions of innocence, purity, and vulnerability, especially since the "discovery" of childhood in the seventeenth and eighteenth centuries, has been an active principle in many cultural developments. In art, the child with a disability has most frequently been depicted with a range of provocative, equivocal, or more positive emotions. The bust of an ancient Egyptian princess preserved in Berlin depicts with neutrality a congenital cranial abnormality. The mingled spirituality and quietude of a Roßlan child of the seventeenth century with a possible neural tube defect evokes the sanctity of disability. And the inviting joviality of the club-footed boy in the seventeenth-century painting by Jusepe de Ribera or the fetching shyness of Annibale Carracci's sixteenth-century *Hunchback* cry out the simple humanity of people with disabilities. The power of children and disabilities extends into the creation of artistic movements as well. Primitivism and other movements in art were motivated in part by fascination and envy at the untutored nature of children's attempts at art. Paul Klee, the expressionist painter, noted that art's primal source is discoverable in the work of uncorrupted children and psychotics, making both conditions highly functional for the primitive arts.

In addition, the motif of a child with a disability is extensive in literature. From Charles Dickens's pivotal Tiny Tim in *A Christmas Carol* to the Spanish-Arabic story *The Girl Without Arms,* from Clara Sesseman in Johanna Spyri's *Heidi* to E. B. White's title character in *The Trumpet of the Swan,* children are continually exposed to disability in fear and triumph, isolation and companionship. Scholars have divined a shift over the past 200 years in the thematic tone of disability in children's literature, in English at least. Victorian culture typically took advantage of the immoral stigma of disability to evoke charitable pity and to stimulate moral uniformity. Gradually, more recent authors use disability as a device to highlight similarities across physical difference, critiquing intolerance and social myopia. Even in movies and advertisement, childhood disability is becoming more integrated and mainstream, from the covers of runners' catalogs to Luke Skywalker's amputation in *The Empire Strikes Back* (*Star Wars*), the quintessential adolescent crossing into adulthood.

One can speak of children with disabilities as fragile. But inherently, and paradoxically, they are extremely durable and potent, able to change families, institutions, experiences, and social values in ways adults with disabilities never could. Yet despite their power, children and especially those with disabilities often remain hidden at the level of international policy, analysis, and culture. Confronting this paradox remains a profoundly important task for us all.

—Walton O. Schalick III

See also Early Childhood Intervention; Family; Family, International; Feral Children; *Healthy People 2010;* Infanticide; Jean-Jacques Rousseau.

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CHILDREN OF DISABLED PARENTS

Broadly defined, children of disabled parents include any child from birth to age 18 who is being raised by at least one parent with a disability. In the United States, it is estimated that there are at least 15 to 20 million children of disabled parents and an additional 25 to 30 million adults who were raised by a disabled parent. The implications of being raised by a disabled parent have been the source of numerous studies, public conjectures, and professional scrutiny—all of which touch on the fundamental rights of disabled people to be parents as well as the fundamental rights of children to be raised in an environment conducive to maximal development. Despite the lack of appropriate resources for most disabled parents and their children as well as persistent negative assumptions about these families, the vast majority of children of disabled parents have been shown to have typical development and functioning and often enhanced life perspectives and skills.

The exact numbers of children of disabled parents vary considerably depending on several subjective criteria used to estimate them. Each of these factors not only determines which children are included as "children of disabled parents," but these factors also contribute to the diversity of perceptions and experiences among these children. How significant is the parent's disability? Does the parent's disability routinely affect parenting tasks and responsibilities? Has the parent been disabled during most of the child's upbringing? Does the parent describe himself or herself as having a disability? For example, most Deaf parents, parents with multiple sclerosis, and parents with short stature or parents from several ethnic communities would not self-identify as "having a disability"—yet children from all these parent groups are typically included among "children of disabled parents." Children of disabled parents may also include children raised primarily by a grandparent or other relative with a disability.

As with children from any group of families (e.g., African American families, Catholic families, rural families), there is no single picture to describe children of disabled parents. As in all families, each child's temperament, personality, gender, and birth order as well as the family's ethnicity, and social and economic status are important factors that contribute to childhood experiences and outcomes. However, a number of additional factors are part of each child's experience of being raised by a disabled parent, notably: What is the nature of the parent's disability? Has the child experienced changes or loss of the parent's capacities (e.g., a newly acquired disability or change in functioning)? Does the child also have a disability? If there is a second parent or other primary caregiver, is he or she also disabled? What meaning does the child learn about the parent's disability from the parent, other family members, peers, or the larger society? How isolated from or integrated into the local community is the child's family? What disability-appropriate information, technologies, or resources are available to the disabled parent and the child? How does the parent's disability affect specific age-dependent parenting tasks (e.g., diapering, reading stories to the child, assisting with homework)? Ultimately, however, research has shown the best predictor of outcomes for children of disabled parents to be the same as for children of nondisabled parents: the quality of the relationship between the parent and child.

National data indicate that the majority of children of disabled parents (86 percent) are not disabled. Overall, the number of disabled children of disabled parents is somewhat higher than the number of disabled children of nondisabled parents. The higher figure may be partially due to higher rates of adoption of disabled children by disabled parents, although available data cannot confirm this explanation. However, disabled children of disabled parents are often seen as having the advantage of having a parent who has the experience and can serve as a role model for their disabled child.

Many people assume that being raised by a disabled parent is potentially risky and even damaging to the child—ranging from concerns over the child's physical safety to whether a disabled parent can adequately meet the child's social, emotional, or developmental needs. In his studies of caretaking responsibilities among children of disabled parents, Richard Olsen discusses how these children are often presumed to be victims, with criticism explicitly extended to their disabled parents for even having children in the first place. This negative expectation confirms the widespread social prejudice many parents with disabilities report about their rights or abilities to parent. Such speculations are further fueled by a number of studies that concluded that being raised by a disabled parent invariably leads to significant negative outcomes. Children of disabled parents are thought to be at risk for numerous problems including behavioral problems, psychological impairment, delayed language development, poor self-concept, psychodynamic conflict, developmental delay, and child neglect or child abuse.

Yet many of these studies of children of disabled parents that predict negative outcomes fail to make important clarifications and generally mirror broader societal prejudices about the capabilities of people with disabilities. For example, several studies generalize from a single case study of a child of disabled parents to all children of disabled parents. Often these case studies are drawn from clinical populations and represent the most troubled extremes. Other studies fail to distinguish between different types of parental disabilities or blur the age distinctions of the children. Many studies of children of disabled parents also fail to identify or investigate important contextual factors—particularly, known risk factors such as poverty, a parent's history of abuse in childhood, parental substance abuse, parental depression, or lack of adequate family resources and supports. Without considering these distinctions and contextual factors, problems within the family are invariably attributed to parental disability.

In contrast to studies that presume pathology and ignore important distinctions among these children and their parents, several more recent investigations are characterized by nonpathologizing hypotheses as well as their focus on specific parental disabilities and a specific age range of children. In one of the first major studies to contradict the prevailing negative research hypotheses and suggested outcomes for children of disabled parents, Frances Buck and George Hohmann found that children whose fathers had spinal cord injury displayed normal development in all areas investigated (personal adjustment, sex role identification, body image, health patterns, athletic interests, interpersonal relationships, parent-child relationships, values and attitudes). They concluded that children raised by parents with spinal cord injuries grew to be healthy, well-adjusted adults.

Although investigating different populations of disabled parents and their children, a number of other researchers have similarly adopted a nonpathological framework as well as clarifying important family characteristics. From these studies as a whole, several consistent themes emerge among these families: a notable lack of norms and role models for disabled parents and their children, more fluid and more flexible family roles available to parents and children, barriers to positive family functioning located in external social and environmental obstacles rather than the result of a parent's disability, greater resiliency and problem-solving skills among family members, and a desire for greater public awareness and more informed professional practice. Most of these investigations conclude there is average to better-than-average development and functioning among children of disabled parents and found positive outcomes as well: enhanced coping and problem-solving skills, greater acceptance of difference, and more positive attitudes toward disability.

Despite these positive findings, the pathological supposition that children of disabled parents will be parentified is pervasive and persists among professionals as well as among the general public. *Parentification* is defined as a functional or emotional role reversal in which the child takes on responsibilities normally reserved for the parent or other adult figure. Such children sacrifice their own needs to accommodate the needs of the parent, and long-term and persistent parentification is presumed to lead to developmental delays as well as adult dysfunction. Children of disabled parents are frequently presumed to be parentified, assuming the physical and emotional responsibilities that their disabled parents cannot.

Yet several recent studies question this assumption. Studies by Megan Kirshbaum and her colleagues at Through the Looking Glass found, for example, that disabled parents frequently took on increased responsibilities and risks rather than stress their infants or ask their young children for assistance. Lisa Cohen found that physically disabled parents were often reluctant to ask their older children to do tasks common to children of nondisabled children (e.g., taking out the garbage) if the parent felt it was necessitated by the parent's disability. A national study by Rhoda Olkin and Kelley Abrams documented that adolescents of disabled parents perform the same number of household tasks as teens of nondisabled parents. In his national studies of deaf parents and their hearing children, Paul Preston questioned the inflexible and ethnocentric notions of family functioning used to assess families with deaf or disabled parents, finding such values are frequently normed on Western, Caucasian, middle-class, and able-bodied families. Instead, he and others suggest that some children's responsibilities are normal and appropriate within the disability and Deaf communities, and it is more often negative social expectations and misinterpretations that pathologize these families. Finally, a number of these and other researchers stress that the availability of resources is an important mitigating factor in the degree and type of assistance required within the family.

Additional nonpathologizing and focused studies of adult children of disabled parents complement findings from studies of younger children of disabled parents. First, adult children consistently distinguished between their internal family norms and functioning (which considered the parent's disability as normal) and the persistent stigma and social exclusion directed at the family from outsiders. Second, adult children remained protective of their parents and identified numerous social and environmental barriers as far more problematic than their parent's disability. Third, most adult children described positive outcomes of being raised by disabled parents: greater social awareness, better problem-solving skills, increased comfort with and acceptance of difference, increased adaptability, and generally having better life skills and being more worldly. Fourth, adult children identified similar factors that contributed to more positive life outcomes: the parent's positive self-esteem, the availability of extended family support and community resources, and the presence and support of other adults in addition to their parents. Finally, and most significantly, adult children underscored the most pivotal issue regarding the impact of their parents' disabilities: the quality of the relationship they had with their parent.

One group of children and adult children of disabled parents is notable not only for the number of studies conducted about the group but also for the group's social and organizational visibility. Children raised by culturally Deaf parents are typically raised within a distinct linguistic and cultural community, and these childhood experiences have a lifelong impact whether the child is hearing or deaf. Ninety percent of the children of deaf parents are hearing, and these hearing children frequently develop strong bilingual skills and bicultural identities as both Deaf and hearing. As adults, a majority of these hearing children continue to participate in the Deaf community socially and often professionally (e.g., as interpreters, teachers, counselors). Children of Deaf Adults (CODA) is an international organization of adult hearing children of deaf parents. Founded in 1983, this organization's mission is to promote family awareness and individual growth in hearing children of deaf parents. A complementary organization KODA (Kids of Deaf Adults) is dedicated to deaf parents and their hearing children under age 18. Deaf children of deaf parents are also noteworthy as transmitters of Deaf language and culture among their deaf peers who come from hearing families. Considered core members of the Deaf community and frequently assuming leadership roles within the Deaf community, deaf children of deaf parents outperform deaf children of hearing parents on almost all intellectual, social, and psychological tests. Although this cultural heritage from their childhood experiences is particularly evident among hearing and deaf children of deaf parents, research and anecdotal evidence suggests comparable perspectives also exist among many other children of disabled parents as well.

—Paul Preston

See also Childhood, Youth, and Adolescence; Deaf Culture; Parenting.

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CHILDREN WITH DISABILITIES, RIGHTS OF

In every society, children's inferior roles and limited ability to advocate for themselves render them uniquely vulnerable to deprivation of their rights. That vulnerability is significantly increased for children with disabilities whose heightened dependence on others and need for support exacerbates their inferior role. For children with disabilities, deprivation of rights may take the form of denial of treatment, lack of accessibility to settings and experiences, isolation, neglect, exploitation, and abuse from caregivers. The recent history of Western countries reveals that it was only a few decades ago that a child with disabilities was deprived of the most fundamental rights of citizenship in the form of denied access to public education and to participation in community life. Instead they were assigned to institutional or custodial care and experienced a lifetime of isolation, neglect, and deprivation of opportunities for academic, social, and personal growth. Unfortunately, that situation still exists today in countries around the world reflected in rejection of children with disabilities by family and community and their subjection to discriminatory and abusive practices in orphanages and institutions.

Advocacy efforts by, and on behalf of, adults with disabilities have contributed to a growing awareness of human rights internationally. Awareness of the rights of children and youths with disabilities has also been addressed although not as extensively. The priority for making children's rights the basis for policy development, legislation, and service provision is reinforced by emerging issues in developing and developed countries. Within a global perspective, disability is disproportionately distributed in the developing world. Children in turn account for the largest number of those with disabilities, reflecting the combined consequences of poverty, endemic disease, inadequate health care, poor nutrition, and lack of education. In developed countries, the rights of children with disabilities and chronic conditions are central to debates about societal responsibilities and resource allocation. If the premise of human rights is to serve as the basis for equitable services for all children and to address their unique vulnerabilities, it is essential to define what constitutes the rights of children in general and of children with disabilities in particular.

In 1959, the United Nations published the first Convention on the Rights of the Child. Thirty years later, in 1989, the second UN Convention on the Rights of the Child was published and went into force in 1990. The convention consists of 54 articles with 41 articles specifying the nature and conditions of the rights of children and the remaining 13 articles pertaining to implementation of the convention. Major principles underlying the convention are based on the premise of the child's integrity as a person and inherent right to life and survival, to an identity, to be the first to receive services, to a family environment, to protection and assistance in institutional care, and to protection from exploitation. In a related area, the convention speaks to protection of the family unit as the context of the child as a right of children with particular reference to its caregiving responsibilities.

Of particular relevance to the rights of children with disabilities are the paragraphs of Article 23 that define the responsibilities of member states. Paragraph 1 declares that States Parties recognize "that a mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promotes self reliance and facilitates the child's active participation in the community." Paragraph 2 reads,

> States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the circumstances of the parents or others caring for the child.

Paragraph 3 further specifies that the assistance

> be provided free of charge, whenever possible and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest social integration and individual development, including his or her cultural and spiritual development.

An essential right defined in the convention is the right of children to be heard and to have the legitimacy of their perspectives, interests, and preferences recognized. In most societies, the right of an individual to be heard in a formal sense is not afforded until late adolescence or early adulthood with societal affirmation of maturity, often in conjunction with the right to vote. The right to be heard is likely to be limited for children in general as it is for persons with disabilities. For children with disabilities, that right may essentially abridged. This is particularly problematic in that their ability to express their feelings or wishes is restricted making them vulnerable to neglect and abuse. How to ensure this right for children with disabilities and chronic illnesses is an ethical challenge, in that their physical or mental needs may require medical treatment or therapeutic interventions for which they are unable to provide or withhold consent. Ensuring the means and conditions under which the child can exercise choice to withhold or provide consent for treatment or intervention is an ongoing issue that needs to be addressed.

A central principle in the Convention on the Rights of the Child is access to education for all children including those with disabilities. This principle is recognized and extended to children in the preschool years in a related UN document, the Standard Rules on the Equalization of

Opportunities for Persons with Disabilities published in 1993. It was further elaborated in the Salamanca Statement and Framework for Action in 1994 specifying the provision of special education for children with disabilities or learning difficulties. The Salamanca Statement specifies that the educational approach for children with disabilities should build on an inclusive approach and be child centered in its application. Education for children with disabilities in the preschool years should be defined by goals of fostering development and school readiness. A review of legislation for education of children with disabilities in different countries indicates that there is not a clear position concerning these rights. While the goal of such legislation may be to ensure the rights of children to education, the legislative acts are mainly defined in terms of the provisions, resources, and manner of services to be provided.

The UN Convention on the Rights of the Child, Rule 6 of the UN Standard Rules on the Equalization of Opportunities, and the Salamanca Statement represent universal standards for equalization of opportunity for children and youths. As such, they formalize the child's protection from discrimination, abuse, neglect, and denial of access and the right to care, support, and education. Most of the member states of the United Nations have ratified the convention. It should be recognized that ratification does not mean that the rights of children are in fact fully or even partially upheld in countries that have ratified the convention. However, the convention makes the rights of children explicit, constituting a universal bill of rights that can serve as a framework in the development of national policies, legislation, and practices pertaining to the rights of children. Adherence to the principles of the convention also implies obligation by society to honor the rights of children with the provision of identified needs.

—Rune J. Simeonsson, Eva Bjorck-Akesson, and Joaquim Bairrao

See also Childhood, Youth, and Adolescence; United Nations Disability Convention.

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CHINA

See Disability in Contemporary China; Experience of Disability: China

CHIROPRACTIC CARE

The chiropractic profession was founded in 1895 after magnetic healer Daniel David Palmer adjusted the thoracic vertebra of janitor Harvey Lillard and restored a hearing loss that the unfortunate janitor had suffered. From such modest beginnings, the profession has grown into one of the three major branches of Western medicine; the other two are allopathic medicine and osteopathic medicine. What sets chiropractic apart from its two brethren is that it does not use either surgical or pharmacologic interventions as one of its therapeutics. It focuses, rather, on the spine as intimately involved in helping to maintain health for the human, and it pays special attention to the nervous system as the most significant contributor and coordinator for function and health in the human body. Given this focus, chiropractic uses as its approach the desire to maintain optimal neurophysiological balance in the body, which is accomplished by correcting and reducing structural or biomechanical abnormalities and disrelationships, which have been referred to as "subluxation" and/or "fixation." The main procedure a chiropractic physician uses to provide balance is the spinal joint adjustment, which is usually delivered by hand.

Once a marginalized profession, chiropractic has been increasingly accepted by the public, whose satisfaction with treatment has been found to be rather high. There are now more than 60,000 chiropractors in the United States alone, and there is a growing presence across the globe. Of the complementary and alternative medical (CAM) professions, chiropractors are used more often than any other provider group. Studies have shown that in just a 20-year period the use of chiropractic has tripled, from 3.6 percent of the population in 1980 to 11 percent in 1997. This growth has been accompanied by improvements in education, research, public perception, and public acceptance.

The average chiropractic educational program consists of 4,820 classroom and clinical hours of training. Of these, approximately one-third are spent in basic science education, with the remaining two-thirds spent in clinical science training and internship. The educational program is similar in many regards to medical education, with the chiropractic student spending more time in anatomy and physiology and less in public health. The emphasis in chiropractic education is toward musculoskeletal function and biomechanics as well as manipulative and other manual therapies. Postgraduate training in a number of disciplines is required for relicensure, and the profession offers a number of specialty training programs and residencies (e.g., radiology, orthopedics, neurology, and sports medicine).

Spinal manipulation, or adjustment, is the core clinical procedure used by chiropractors. Many technique systems exist, and discussions about the merits of each comprise an active part of professional discourse. With regard to manipulation, at root it refers to the application of a force (load) to specific body tissues with an intent to create a therapeutic effect. The many systems provide guidance as to the specific methods used to deliver that force (i.e., amplitude, velocity, location, contact on the body, and force direction).

Most people seek chiropractic care for painful complaints of the musculoskeletal system, which is one of the most common causes of disability. Of those who do seek such care, about 60 percent are suffering from low back pain, with the rest suffering from neck pain, headache, and extremity symptoms. Many of these people have chronic problems. More than 80 randomized clinical trials have been conducted using spinal manipulation, with the majority supporting benefit for the treatment of back pain and neck pain as well as headache, all significant causes of disability. Economic analyses have shown cost benefits with chiropractic intervention as well. It is likely that decreased disability can result if chiropractic management is introduced early in the therapeutic process.

—Dana J. Lawrence and William C. Meeker

See also Complementary and Alternative Medicine; Pain.

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CHRISTOFFEL-BLINDENMISSION

Christoffel-Blindenmission (CBM) is an independent aid organization of Christians of various denominations united by the commission to help blind and other disabled people in third world countries, irrespective of nationality, race, sex, or religion. One major field of work is the prevention and curing of blindness, another one the rehabilitation of disabled people. This was already the urgent request of Pastor Ernst Jakob Christoffel. In 1908, he founded the first project—a home in Malatia (Turkey) for blind and otherwise disabled and orphaned children.

In all, this interdenominational agency supports more than 1,000 development projects in 108 countries, most of them in the third world. The projects comprise hospitals with eye departments, mobile eye care services, primary health and rehabilitation facilities, schools, and training centers, besides others. In 2002, approximately 264,000 people with disabilities were part of disability programs that concentrated on schooling and training to promote their inclusion into society and independent living.

In the 1960s, CBM departed from the traditional mission approach of establishing or maintaining its own stations. Instead, CBM saw itself as a provider of services and set itself to the task of enabling the national churches by giving them professional advice and financial assistance and by seconding personnel. Today, CBM cooperates with almost 700 partners (national churches, international missions, local self-help groups, and Christian aid agencies).

The seconded staff, numbering approximately 110 and made up of eye doctors, nurses, special educators, physiotherapists, rehabilitation experts, project managers, and consultants, consider their main task to be that of training national coworkers. This is in line with the theory that by training hundreds, one can help hundreds of thousands of people. Via the partner organizations, almost 9,200 national experts are funded by CBM.

Between 1976 and 1984, independent groups of mission supporters formed in the United States, Canada, and Australia began to handle the administration of incoming donations themselves and supported their own projects. Over the past few years, CBM member associations have also been founded in Austria, Italy, Switzerland, Belgium, the United Kingdom, and New Zealand. All member associations are united under Christian Blind Mission International (CBMI).

In 1999, CBM, other agencies, and the World Health Organization (WHO) initiated VISION 2020: The Right to Sight—a global initiative for the elimination of avoidable blindness by the year 2020. The program will enable all parties and individuals involved in combating blindness to work in a focused and coordinated way.

The worldwide services are largely enabled through donations, bequests, and legacies. In Germany alone, some 100,000 mission friends provided approximately £34.2 million in 2002. CBM has been awarded the seal of approval of the German Central Institute for Social Affairs (DZI). CBM works interdenominationally and has been officially recognized by the WHO. It is among others a member of the Social Service Agency of the German Evangelical Church, the Association of German Development NGOs (VENRO), and the Association of Evangelical Missions (AEM), and it is a partner by agreement with the Association of Protestant Churches and Missions.

—Patrick Devlieger

See also Developing World.

Websites

Christoffel-Blindenmission, http://www.christoffel-blindenmission.de

▣ CHRISTOPH, FRANZ (1953–1996)

German activist

Franz Christoph, industrial clerk, journalist, and cofounder of the German disability rights movement, was born in Furth im Wald, located in the upper Bavarian Forest. At age 1, Christoph contracted polio, after which he used assistance devices to walk, propelling himself forward with his left leg. At age 8, he came to the Landesanstalt für körperbehinderte Jugendliche (Bavarian Institution for Physically Handicapped Youth) in Munich, from which he escaped at age 14. His mother found him an apprenticeship as an industrial clerk.

Through engagement in the Arbeitskreis für aktive Behindertenhilfe (Working Group for Active Disabled People's Assistance) in Berlin, Christoph discovered his life purpose in 1976: confronting the "disability experts." From then on, he attended scientific conferences and argued with professors over the concept of a "disability standpoint." His premise was that disabled people were oppressed by nondisabled people on the basis of societal norms and values. For him, the issue at stake was the recognition that disabled people had competences of their own. In 1979 in Bremen, Christoph became one of the cofounders of the first German Krüppelgruppe (Cripples' Group), a cross-disability group with emancipatory aims. The members of the so-called cripples' movement, out of which the German disability rights movement evolved, categorically rejected the term *behindert* (handicapped or disabled) opting instead for the old, discriminating description, *Krüppel*, of which the self-chosen use was to make clear the claim to self-representation and self-consciousness. Looking back, however, Christoph regarded this first attempt of reinterpreting disability in positive terms as failed.

As a disability rights activist, Christoph gained wide publicity and suddenly became famous when at an event to celebrate the International Year of the Disabled on June 18, 1981, in Düsseldorf he hit the federal president, Karl Carstens, with his crutches. This public action led to his first book, titled *Krüppelschläge. Gegen die Gewalt der Menschlichkeit* (*Cripple Punches: Against the Power of Humanity*). Christoph also played an important role in the German anti-euthanasia movement. In 1990, he chained himself to his wheelchair at the entrance of a large publishing house to protest against the "deadly zeitgeist" of the contemporary utilitarian euthanasia debate.

After a long stay in Hamburg, Christoph returned to Berlin in the early 1990s and became politically active with the Party of Democratic Socialism (PDS). At the same, time he wrote an extensive manuscript that was published after his death in 1998 under the title *Ich bin (k)ein Felix* (*I am (not) Felix)*. His own life formed the background for this character-driven developmental novel. He died on December 28, 1996, in Berlin. Christoph remains in memory not only as an influential activist of the German disability rights movement but also as a storyteller with great quick-wittedness.

—*Christian Mürner*

See also Advocacy Movements: Germany.

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CHRONICALLY SICK AND DISABLED PERSONS ACT OF 1970 (UNITED KINGDOM)

The Chronically Sick and Disabled Persons Act (CSDPA) was introduced to Parliament as a private members bill aimed at strengthening the provisions in the 1948 National Assistance Act (NAA). The NAA had been introduced after World War II, along with a raft of provisions (e.g., the legislation that established the National Health Service) aimed at eradicating what are known as the five "giant evils": want, disease, ignorance, squalor, and idleness (Timmis 1996). It was the first legislation of its kind. Section 29 of the NAA gave local authorities the power to make arrangements for welfare provisions for certain disabled adults. The duty is vaguely worded, and largely discretionary, whereas the CSDPA attempted to create legally enforceable duties to individual disabled people in relation to a variety of welfare provisions.

The parts of the CSDPA that have had most significance have been Sections 2 and 21. Section 2 is an extensive provision, stating that where a local authority has functions under Section 29 of the NAA, are satisfied that it is necessary to meet a person's needs that it make arrangements for the following matters:

- The provision of practical assistance in the home
- The provision or assistance in obtaining wireless television library or similar recreational facilities
- The provision of lectures, games, outings, or other recreational facilities outside the home
- Assistance in traveling to participate in services provided under Section 29
- Assistance in adaptations in the home
- Facilitating the taking of holidays

- The provision of meals
- The provision of or assistance in obtaining a telephone and any special equipment for using the telephone

It shall be the duty of the authority to make those arrangements in exercise of their functions under Section 29.

While the scope of Section 2 is very broad, and while the decision in *R. v. Gloucestershire CC ex p Barry* (1 CCLR 7, 1997) confirmed that, where a local authority has carried out an assessment of the needs of a disabled person and decided that the provision of services under Section 2 is necessary to meet that person's need, then the authority is under an absolute duty to provide that service, the issue of resources has nevertheless been a major barrier to the full efficacy of this provision. This is because the House of Lords' decision in that case also meant that while recourses are irrelevant to the provision of the service, they can be taken into account when reaching a decision as to whether or not a person's need for services is such that it is necessary to provide the service.

With regard to the other provisions of the CSDPA, Section 21 (as amended) provides that local authorities shall issue badges for display in the cars of disabled people (essentially for the purposes of exemption from parking restrictions, to ensure greater mobility for disabled people). The badge scheme has proved extremely popular, although it has recently been the subject of a review by the Disabled Persons Transport Advisory Committee, which made recommendations aimed at, among other things, clarifying the purpose and use of the badge and tackling abuse of it. Section 21 was more recently amended by the Disability Discrimination Act (2005) to, among other more minor amendments, provide that the holders of foreign disabled persons' badges be afforded the same concessions as holders of domestic "blue badges" in respect of parking concessions. The clause makes provision to formalize existing (nonstatutory) recognition of parking badges issued in the European Union or in certain other European countries (for which there is reciprocal recognition), and to extend this recognition to badges issued in other countries.

The CSDPA also contains provisions relating to access to and facilities at premises for disabled people where those premises are open to the public (Section 4), as well as provision relating to toilets and universities and school buildings. These provisions are somewhat weak, however, and have been largely overtaken by the provisions of the Disability Discrimination Act of 1995.

—Catherine Casserley

See also Disability Discrimination Act of 1995 (United Kingdom).

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CHUAS OF SHAH DAULAH, THE

The shrine of the Muslim saint Shah Daulah (ca. 1581–1676), at Gujrat in the Punjab, used to receive children with microcephaly left by their parents or collected by agents, starting perhaps in the eighteenth century. These children, who were cared for in the informal shrine community, were called *Chuas* ("rats" or "mice") from their appearance. Most had some degree of mental disability. The first published description appeared in 1866 from Wilson Johnston, a British physician. He saw nine Chuas, ages 3 to 40 years.

Later reports generated speculation that the children's heads had been artificially deformed to produce microcephaly, to extract charity from the public. No evidence has been produced to support this hypothesis. In 1902, a senior British psychiatrist examined 12 shrine Chuas and found they were cared for there as well as they would have been at his own government hospital (Ewens 1903). Meanwhile, ethnographers discovered the widespread regional practice of applying clay bowls to infants' heads to shape the broad, open forehead considered desirable. This maternal cosmetic manipulation, which continued through the twentieth century, probably served to sustain suspicions, which still surface intermittently in the mass media. The government of Pakistan took control of the shrine in 1969 and prohibited reception of any additional Chuas.

—Kumur B. Selim

See also Middle East and the Rise of Islam.

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CICERO, MARCUS TULLIUS

(106–43 BCE)

Roman statesman and author

Cicero is a byword for rhetoric. He lived in the troubled times of the failing Roman Republic and in fact was killed as political revenge late in the year 43 BCE, the year following Julius Caesar's assassination. Cicero is important to disability studies because he summarizes the Roman attitude toward rhetoric and disability; that is, it seems always to have been perfectly acceptable to call attention to someone else's physical characteristics. Bodily disfigurement, he states, is always good material for jokes. Robert Garland summarizes Cicero's views in *The Eye of the Beholder* (1995: 74, 76). Indeed, the biographer Plutarch (*Life of Cicero* 1.3–4) tells us that the family name Cicero is based on *cicer,* Latin for "chickpea," because one of Cicero's ancestors had a nose that resembled a chickpea. Far from being embarrassed by the name, Cicero once engraved a chickpea following "Marcus Tullius" instead of spelling out his surname (Plutarch, *Life of Cicero* 1.6). Cicero wrote voluminously; his surviving works can be found in a 28-volume Loeb Classical Library collection.

—M. Lynn Rose

See also History of Disability: Ancient West.

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CITIZENSHIP AND CIVIL RIGHTS

Citizenship may be defined in narrow legal terms as a status recognizing formal, associational membership of a nation-state. This juridical status confers rights to persons who are members of a nation-state and who participate fully in society. It is assumed that there is a high degree of correspondence between the rights and duties of citizenship expressed as a relationship between taxation contributions and entitlements to welfare, health, and educational benefits. What we might call *juridical citizenship* is the possession of civil and political liberties, while *social citizenship* is the enjoyment of the social and economic benefits of membership of a nation-state through residence or birth.

Social citizenship is the central issue in modern interpretations of disability and impairment. The effective enjoyment of the benefits of citizenship is based either on a principle of contribution or benefice. Where the contributory principle is dominant, individuals who do not pay taxes do not in general receive the full range of entitlements. People who do not have employment and hence do not pay taxes tend in practice to be second-class citizens. Whereas the medical model of disability concentrates on the individual limitations of physical impairment, the social model of disability defines disability as the absence of the full array of rights that conventionally flow from social and political participation. Disability in this sense is a lack of citizenship.

Disability typically involves some explicit, or more frequently implicit, form of social exclusion and hence some curtailment of social, political, and economic rights. For example, political rights were limited in Britain because the 1949 Representation of the People Act prevented people resident in institutions with "mental illness" or "learning difficulties" from being included on the electoral list. A subsequent act in 1983 allowed patients to vote but only under narrowly defined conditions. These prejudicial limitations were alleviated somewhat by the 1995 Disability Discrimination Act, but parliamentary legislation still follows the individualistic medical model, which fails to recognize the various ways in which society disables people with impairment by denying their rights and dignity as citizens. It is assumed that impairment prevents people from fulfilling their duties because they cannot fully contribute to society, for example, through work, military service, or parenting.

In the United Kingdom with the creation of the welfare state and the full development of citizenship, it was assumed that the state would recognize not only the right to economic welfare and security but also the right to share fully in the social heritage and to live the life of a civilized being. As an absence of rights, disability implies that individuals are partly excluded from this social heritage and cannot live their lives fully in terms of prevailing social standards. Disability involves the curtailment of social rights because, especially in the contributory model of citizenship, it is assumed that people with impairment cannot participate fully in society. Disability means there is an imbalance between contributions and entitlements, and hence disability raises problems relating to respect, identity, and status. Work earns not just income but respect and status, and therefore impairment typically involves both a loss of social rights and lack of recognition.

In disability studies, there is much controversy about the status and meaning of *impairment* and *disability*. The social model concentrates on the socially constructed nature of disability, treating it as a loss of social rights. The social model has criticized the medical or individual model, which treats disability as a personal tragedy for which professional care and personal adjustment can provide solutions. The social model perceives disability as oppression for which collective action and full entitlement can provide social equality and social participation. Disability politics have in response asserted the need for the redistribution of resources to achieve equal citizenship and recognition of disability as a special social and political category. Whether recognition can result in enforcement will depend on a set of justiciable rights, state support, and political action.

This distinction partly rests on epistemological arguments about the social construction of disability and the distinction between impairment and disablement. Radical constructionism regards the difference between impairment and disability as artificial. What is labeled in society as "disability" is the historical and social product of cultural values and not an incontrovertible fact of nature. Anthropological research shows that disability is culturally variable. Although constructionism has been a powerful perspective in disability studies, there are arguments in favor of retaining a notion of human embodiment to understand the physical limitations of impairment. However, we should not accept a simple dichotomy between the impaired and the able. Impairment is, like health, complex and heterogeneous. It is also a process stretching over the life cycle of the individual, and the majority of the population will, especially in old age, experience some degree of infirmity and impairment. Disability as a loss of rights is in some sense socially constructed, but impairment has real consequences, for example, on mobility. We can capture this common experience of impairment through the notion of human vulnerability.

The vulnerability perspective suggests that, first, we have to attend to impairment as a set of real restrictions on movement and mobility for which modern technology and medical science provide some solutions. Second, we should recognize disability as the curtailment of social rights for which we need political remedies. Finally, impairment is a set of circumstances that affects everybody at some stage in the life cycle, because with increasing age impairment is a consequence of chronicity. In old age, impairment typically combines with unemployment and poverty to produce an erosion of entitlements. The concept of vulnerability indicates the universal character of impairment over the life course. In societies with graying populations, there is a complex interaction between disadvantages associated with aging, chronicity, and impairment that constitute "disability"—a condition of social marginalization resulting from an erosion of rights in societies whose values are grounded in ableism, work, and youthfulness.

In British sociology, the debate about citizenship and social welfare was dominated by the social theories of T. H. Marshall (1893–1982) and Richard Titmuss (1907–1973). According to Marshall, citizenship expanded through three stages: The development of legal rights in the seventeenth century was indicated by habeas corpus, jury system, and rule of law; political rights in the nineteenth century were institutionalized in the parliamentary system, free elections, and the secret ballot box; and social rights in the twentieth century were enshrined in social security and the welfare state. Social citizenship was a status position that ameliorated class inequalities arising from a capitalist market, because the social rights of citizenship involve some level of redistribution of wealth through subsidies and welfare benefits. According to Titmuss, the mass mobilization of the population for warfare during World War II was an important condition for the growth of postwar social rights, but he traced the origins of the National Health Service to the medical inspections of the South African Boer War, which showed that the British working class was generally unfit for combat. The expansion of social rights, especially rights to health care in the twentieth century, was connected with military discipline and combat requirements, because warfare promotes an internal process of social and political criticism. In the United States, the Vietnam War played a part in extending the recognition of social rights, especially for disabled war veterans.

We can detect in these historical examples the important nexus between the able male body, imperialism, nation building, and social rights. Citizenship is primarily an institution in which able-bodied men create a nation-state in which military service is rewarded by social benefits such as housing, education, and a health service. In this sense, the polity is an imaginary fraternity of masculine bodies that are bound together by notions of discipline and duty. It is perhaps ironic that Lord Nelson, who was the archetypal citizen of a nation of free and heroic Englishmen struggling against what they saw as the tyranny of French revolutionary terror, was himself a disabled war veteran.

These sociological perspectives on social citizenship can be regarded as parallel to the economic arguments of John Maynard Keynes (1883–1946), who argued that the economic depressions of the business cycle could be alleviated through demand management, for example, by building the economic infrastructure and developing welfare systems. State intervention in the market place was an instrument of postwar reconstruction. Keynes's analysis of the Depression, the problem of funding the war and rebuilding postwar society, was influential on both sides of the Atlantic. Social Keynesianism contributed to "the postwar consensus," namely, the agreement that the state had to assume some responsibility for developing social welfare programs to alleviate poverty, disability, social deprivation, and economic recession.

Access to health care was an important aspect of the development of citizenship. The Beveridge Report of 1942 envisaged a "welfare state" that was implemented in 1946 by the National Insurance Act and the National Health Act. The latter was designed to secure improvement in the physical and mental health of the people of England and Wales and the prevention, diagnosis, and treatment of illness and disease and to provide or secure the effective provision of services in accordance with the act. The services were to be free of charge. The act to some extent assumed a finite level of sickness and disability, which would be removed by the introduction of a national health service. It did not take into account rising expectations of health and health care and the elasticity of health needs. It did not fully consider the graying of the population and the growth of chronic illness and disability in the elderly. It could not envisage the current inadequacy of pension provisions or the rising costs of medical technology and medical provision. It did not adequately understand the contradictory interests of professional medical care and bureaucratic management of hospitals and clinics.

There are important differences between the liberal legacy of the United States and the European tradition of social citizenship. Alexis de Tocqueville (1805–1859) recognized that the strength of American democracy was a function of the vitality of its local associations, community groups, and churches. Tocqueville noted that a powerful administrative apparatus did not develop in America, and political participation was effective at the local rather than the national level. American federalism has reinforced this tradition of local and regional participation. Self-help and community involvement have been important ingredients of the American response to disability. There are consequently two important issues that shape citizenship in the United States. First, American democracy emphasizes civil and political rather than social and economic rights. Second, whereas in Britain citizenship arose to ameliorate inequalities associated with social class, in American citizenship ameliorates inequalities associated with ethnicity and migration. The result is that historically charity and philanthropy have played a more significant role in the delivery of services in the United States than in Europe and the United Kingdom. Civil activism has been particularly important in the United States in attempts to sustain social security safety nets for vulnerable social groups. Current proposals to privatize Social Security by investing part of the payroll tax receipts in stock and bonds through either the trust fund or individual accounts may increase the precariousness of elderly, disabled, and sick individuals. These privatization strategies would not be economically sufficient to maintain current benefit levels for the disabled.

NEOCONSERVATISM AND WELFARE POLICIES

Despite significant national differences, Western societies experienced a remarkable period of economic growth from 1945 to 1977. The postwar consensus saw the emergence of the right to health care as a universal principle that was assumed to be necessary for economic prosperity and social harmony. Societies such as Germany, Britain, Canada, and the United States moved toward universal coverage of their populations by publicly funded schemes. Even the United States, where collectivist welfare has been resisted, almost half of all spending on health care for the population (or 46.7 percent) is raised from the public purse to fund programs such as Medicare and Medicaid. This period of social consensus with full employment, high levels of economic growth, and relative stability in welfare services came to an end in the 1970s. President Richard Nixon's announcement in 1970 of the existence of a health care crisis was indicative of a new era of fiscal constraint. The postwar welfare system came to an end with the development of neoconservative economic strategies, the social policies of prime ministers Margaret Thatcher's and John Major's conservative governments (1979–1997), and the political dominance of the Republican Party in the United States. The transformation of health care delivery and the collapse of the postwar consensus was brought about by many causes: the OPEC oil crisis (1973–1974) and the increase in energy costs, the decline of corporate profitability, the combination of high inflation and high unemployment, the graying of the population, the simultaneous growth in chronic illness and new communicable diseases such as HIV/AIDS, the rising expectations of health care, the rigidity of health care bureaucracies, and the costs of technological and medical research.

The neoconservative revolution of the 1970s created a political environment in which governments were no longer committed to the universalistic principles of full employment, health care, and welfare benefits. Welfare profligacy, according to neoconservative reformers, was no longer to be funded through deficit budgets. Welfare had to be paid for by responsible, that is, working, citizens. New principles of active citizenship were embraced, namely, welfare for work, private insurance for health care, private education, flexible retirement, and healthy lifestyles. Neoconservatism promoted individualism and responsibility rather than collective involvement. Although social Keynesianism was in decline before the advent of policies of privatization and deregulation, Thatcherism in Britain rolled back the "nanny state" and promoted private initiatives in an enterprise culture, and Reaganomics in the United States established similar principles of fiscal constraint, private provision, and individual responsibility. In the United Kingdom, New Labour or the Third Way strategy encouraged joint ventures between public and private sectors in health care and education. Community enterprise and partnerships between state, business, and the voluntary sector were intended to replace voluntary associations in the delivery of welfare and health services. Similar policies were adopted in Canada where health care expenditure declined by 5 percent between 1991 and 1996.

These policies of cost containment in the 1970s were driven by conservative strategies derived from the philosophical individualism of writers such as F. A. Hayek (1899–1992). Neoconservatism has three important political components: Individuals should take responsibility for their own health (e.g., by not smoking), rights talk has obscured the importance of duty, and welfare benefits should be dependent on work. These policies have negative consequences for disabled people, because impairment often precludes people from full-time employment. Neoconservative philosophy implies that disease, for example, sexually transmitted disease, is often the result of irresponsible individual lifestyle and irrational behavior. However, the increasing prevalence of disability in Western societies is a result of the epidemiological revolution associated with the graying of populations. Disabilities associated with chronic illness and aging, or those that result from industrial accidents, are not amenable to policies derived from neoconservative individualism, because they are not attributable to irrational behavior and inappropriate lifestyles.

The underlying problem of welfare state systems is that the emphasis on individual contributions and the work ethic rather than needs and social solidarity inevitably curtails the social rights of people with impairments. The curtailment of social rights leads to marginalization and low respect. The social democratic model provides a high level of service and support, but it also produces a passive and dependent community. The liberal model provides a residual welfare state, but it paradoxically enhances the social conditions that result in social activism. The provision of welfare services depends significantly on the contribution of the family to the welfare state, and the burden on women is particularly important. The economic constraints of the contributory model of citizenship have been reinforced by the prevalence of the medical model of disease and the concomitant reluctance to recognize the social and political roots of disability.

IDENTITY POLITICS, NATURAL TALENTS, AND FAIRNESS

T. H. Marshall understandably assumed that British society was socially and culturally homogeneous. His influential theory of citizenship did not as a result address a range of problems that have subsequently become salient in contemporary politics, namely, the issues of identity, difference, and diversity. Citizenship confers status and identity to members of a political community, and as modern societies have become more diverse with the growth of labor migration, the flow of refugees, and the increase in asylum seekers questions of identity or "identity politics" have become central to contemporary citizenship. The traditional issues of economic citizenship—safety at work, full employment, access to union membership, the right to strike, retirement and security of pension rights—continue to be important aspects of social policy, but new issues concerning cultural identity now shape what has been called "cultural citizenship." Disability politics belongs to a wider category of representation that political scientists have called "ascriptive identity groups" that organize around characteristics such as race or age that individuals cannot freely choose. Political identification by ascription creates important problems of representation. For example, people with learning difficulties may not want to accept the label that creates the basis of ascription.

Disability has also become an issue in identity politics and cultural citizenship, because the disability movement has questioned the taken-for-granted assumptions about equality and participation that historically underpinned Marshallian citizenship. Critics of the social rights model argue that universal assumptions and expectations about equality cannot be delivered by modern states, and furthermore these assumptions cannot address the special needs of particular social groups. We need a differentiated not a uniform definition of citizenship. Achieving standardized equality of outcomes or opportunities may be neither feasible nor desirable, and hence fairness of treatment rather than equality of outcome may be more relevant to differentiated citizenship.

Although this argument has been directed primarily toward the inclusion of ethnic minorities, it applies with equal force to the politics of disability. Political philosophers such as John Rawls and Ronald Dworkin have argued that equality of opportunity makes sense only if people start life with the same or similar resources and chances. Societies are fair if people's fate is determined by their choices rather than their circumstances. Theories of equal opportunity have primarily concentrated on the arbitrary nature of gender and race in determining people's life chances. More recently, attention has turned to the role of "natural talents" in the distribution of social rewards. Very talented athletes should be rewarded for their skills and training by winning competitions; the same arguments might apply to the social competition for wages and other economic rewards. But what is a natural talent? Demographic research shows that the members of higher socioeconomic groups have longer life expectancy, lower morbidity, and lower infant mortality than lower socioeconomic groups. Generally speaking, richer people are taller people, because diet and genetic legacy play an important part in height. Therefore, what appear to be natural talents are often socially produced.

The "natural lottery" is unfair if we assume that all human beings have equal moral worth. Citizenship mitigates the social consequences of the arbitrary lottery of nature; it exists to ensure that some level of equality can be achieved, for example, through some redistribution of resources through collective sharing of wealth. However, what are the grounds on which we can justify the claim that all human beings are morally equal? Philosophers have traditionally claimed that equal moral worth has to be justified either by religious arguments (we are all equal in the eyes of God) or by reference to natural law (we are equal in terms of an ideal notion of Nature) or by a theory of social contract (we were all equal in a state of nature before the existence of social inequalities). These three principles of justification have an arbitrary element—what happens if you do not believe in God, in Nature, or in the original state of nature? The argument about human vulnerability suggests a possible solution. We are all equal in the sense that we are all vulnerable over the life course in terms of the arbitrary contingencies of human existence. Society should be organized to protect those individuals whose lives are the most precarious in order to achieve some fair distribution of resources.

Although political philosophy has recognized the importance of fairness as a principle of democracy, conventional theories of citizenship have failed to address adequately the issues of impairment, disability, and social rights. We have seen that the effective entitlement of citizenship has been historically based on three contributions: work, war, and parenting. In return for economic employment, military service, and family formation, individuals are regarded as active citizens and rewarded accordingly. We can immediately understand the disjunction between disability and social rights, because citizenship implies a set of cultural assumptions about ability and competence. The very word *disability* indicates that able-bodied citizens are not handicapped and can participate readily in work and military service. If employment and career are constitutive of respect, then the exclusion of people with impairment from continuous employment, regular income, and retirement benefits is not only a material hardship, but it also undermines the conditions for self-respect and social recognition. For example, social rights to sexual activity and reproduction are often denied, because disabled people are imagined to be without sexual desires or sexual needs. This negation of sexuality does not protect people from victimization, and disabled women are often the targets of sexual abuse. The conventional view of citizenship assumes an ideology of ablement that excludes people with impairments from social participation.

If we regard employment as de facto a fundamental condition of social participation, then physical impairment often prevents people from participating as effective citizens. The underlying assumptions are that there is a necessary conceptual connection between a right and a duty, and empirically an almost perfect balance between entitlements and contributions. These assumptions are controversial. For example, in ethical discourse we often ascribe a moral status to the human embryo and hence attribute rights to unborn children. Pro-life activists believe that abortion is murder and hence a denial of the rights of the fetus. While children may have rights, it is not clear that they have duties. There are many circumstances in which there does not appear to be a clear connection conceptually or empirically between rights and duties. Because the citizenship rights of nation-states have often failed to support people with impairment, the disability movement has found more effective support under the banner of human rights.

HUMAN RIGHTS AND DISABILITY

Human rights, which are enjoyed by individuals simply as human beings, have expanded with contemporary globalization. The social rights of conventional citizenship have not always served disabled people adequately, and citizenship often appears to favor duties over rights. As a result, human rights have an obvious appeal, because they are not necessarily connected with the contributory model of social citizenship. While the social rights of national citizenship often collide with the individual rights of universal human rights legislation, the individualistic tradition of civil and political rights is increasingly influenced by the social dimension of the International Covenant on Economic, Social and Cultural Rights (CESCR) (a covenant proposed by the Office of the UN High Commissioner for Human Rights, which was ratified by the UN General Assembly). The national framework of disability organizations is also being replaced by international organizations, as the disability movement becomes a global social movement, for example, through the creation of Disabled Peoples' International (DPI) in 1981 with its first world congress in Singapore. The DPI exists as a political grassroots organization to advance debates on the impact of war, inequality, poverty, and industrial exploitation on creating impairments and sustaining disability. In the future, we can expect that the issues of disability and impairment will be addressed, not by social citizenship in the framework of nation-state but by human rights in the framework of global governance.

The social rights model of Marshallian citizenship has also been criticized because it promoted bureaucratic welfare strategies that were not sensitive to cultural differences and as a result employed undemocratic and patronizing methods that normalized conditions that were deemed to be socially deviant. The management of mental abnormality and physical disability through total institutions was famously criticized by sociologists such as Erving Goffman and Howard S. Becker. Social inclusion often meant in practice the normalization and suppression of difference in the interests of social uniformity and social control. The medicalization of disability has often meant that issues of social rights and individual needs could be ignored by treating the impairment rather than attending to the person. In response, alternative strategies of deinstitutionalization were adopted in the 1970s, but decarceration was also criticized when it became merely a cost-cutting exercise. Successful deinstitutionalization requires significant professional and community support, if it is to provide alternative forms of care. These issues surrounding the framework of institutional care expose a more fundamental problem of social inclusion versus personal autonomy.

DEAFNESS, COMMUNITY, AND EXCLUSION

The tensions between social rights, inclusion, and normalization can be illustrated by the history of the treatment of deafness, because it provides us with an important example of the social and political issues that surround impairment. The social struggles over the rights of deaf people illustrate the contradictory processes of inclusion and exclusion that frequently attend impairment. The traditional response to deafness, especially to the prelingual deaf, was to regard it as a personal calamity. Those who were unable to acquire speech were automatically labeled "dumb" or "mute." Before the late eighteenth century, there was little prospect that people with hearing impairment could acquire any education, and their opportunities for employment were severely limited. Hence they were effectively segregated from society. Medical interest in the diseases of the ear began in France in the seventeenth century, and mastoidectomy was developed in the early nineteenth century by James Hinton in London and Rudolf Schwartze in Halle, but the important advances were educational and cultural rather than medical. In 1755, Abbé Charles-Michel de l'Épée founded a school in France to teach sign language whereby students could write down what was communicated to them through a signing interpreter. De l'Épée's interest in sign language was a product of

Enlightenment debates about the historical origin of language, and whether a universal language had existed prior to the differentiation of modern languages. According to de l'Épée, the "mimicry" of the deaf was the root of such a foundational language.

De l'Épée's pedagogy had a dramatic impact on social attitudes toward the deaf. The philosopher Étienne Condillac (1714–1780), exploring the origin of language and the creation of symbols, was interested in the deaf, whom he had regarded as merely "sentient statues," being incapable of thought. However, on seeing de l'Épée's pupils, he became a convert to the beneficial effects of education and the use of sign language. In the United States, Thomas Gallaudet and Laurent Clerc established the Asylum for the Deaf in Hartford, Connecticut, in 1817. The French sign system, which was imported into America by Clerc, was rapidly amalgamated with the indigenous signing conventions, and American Sign Language (ASL) evolved under the influence of deaf people, who came to Hartford during its early years. In 1864, Congress passed a law recognizing the Columbia Institution for the Deaf and the Blind in Washington as a national deaf-mute college, and by 1869 around 41 percent of deaf teachers in the United States were themselves deaf.

The success of ASL meant that deaf people were able to acquire education, but it also reinforced the social solidarity of the deaf as a distinctive community with its own language, educational system, and culture. Sign recognized the difference of the deaf and celebrated their social distinctiveness. However, toward the end of the nineteenth century, there was a new emphasis on assimilation and conformity, and cultural differences were regarded as divisive, unnecessary, and undesirable. The assimilationist strategy was expressed through an emphasis on speech rather than sign, and oralist educators set up "progressive" educational institutions that ignored signing and imposed a curriculum that required speech. The Clarke School for the Deaf in Northampton, Massachusetts, was opened in 1867 to teach speech, and at the Congress of Educators of the Deaf in Milan in 1880, where deaf teachers were excluded from a vote, the use of sign was officially proscribed.

The social effects of this new pedagogy were dramatic. Whereas almost half of all deaf teachers in the United States were deaf in 1850, this proportion declined to one quarter in 1900 and to 12 percent in 1960. The costs of speech education are prohibitive. Deaf people show no "native disposition" to speak and speaking is an ability that must be laboriously and oppressively taught to them. By contrast, they have an immediate propensity for sign, and can achieve considerable fluency by the age of 15 months. The underlying problem is that many people outside the deaf community do not regard sign language as a "proper language," and hence it requires the supplement of speech, or indeed the replacement of sign by speech.

As a consequence of the civil rights movement and the political organization of the deaf themselves, social attitudes began to change in the 1970s. The social and political problem is that while deafness is an impairment of hearing, deafness is transformed into a social disability—a denial of social rights and status. There is a Deaf culture and a Deaf community, whose members include people with a congenital hearing impairment and hearing people who have grown up in the ASL community because they are children of deaf people. This community is held together culturally and socially by a separate and distinctive language and by the experiences of exclusion and stigmatization. In this case study of deafness, we can detect an important illustration of the intersection between bodily impairment, the historical stigma of being a "deaf-mute," and the mobilization of a community to achieve social citizenship. It also illustrates the argument that social inclusion is often achieved at the cost of difference and distinctiveness. One challenge to the National Association of the Deaf (NAD) as an ascriptive identity group was the growing medical use of cochlear implants to provide deaf children with hearing. Because 90 percent of deaf children are born to hearing parents, cochlear implants would undermine the existence of a distinctive deaf community. NAD has accepted the use of such implants while supporting the dignity of deafness and the pride of the deaf community.

LEARNING DISABILITY: COMMUNICATIVE RATIONALITY

This discussion so far has been primarily based on concerns about physical impairment, and hence "learning disability" raises important but different problems and issues. The concept of learning disability includes people with significantly reduced ability to understand new or complex information or to learn new skills and a reduced ability to cope independently (impaired social functioning). These disabilities normally start before adulthood with lasting effects on development. This definition is obviously broad and refers to a heterogeneous population. It has in fact two components—an IQ element and a social-behavioral dimension. An IQ of below 70 does not immediately classify somebody as having a learning disability. People with autism often have high intelligence. The category is further complicated by the fact that people with learning disability often also have physical or sensory impairment. It is estimated that in England there are 210,000 people with severe learning disability and 1.2 million with moderate learning disability or 25 per 1,000 people.

Models of citizenship, like models of economic action, presuppose intelligent and rational agents who are capable of understanding and articulating their own interests and needs. Adult citizens can read about and generally understand their legal entitlements. It is assumed that they are capable of undertaking collective and individual action to express their needs and achieve desired outcomes. The notion of an "active citizen" assumes effective and rational agency, and hence the idea of communicative competence is a presumption about the capacities of a rights-bearing agent. Despite the importance of the concept of communication to any understanding of rationality in critical social theory, the problems, for example, of Alzheimer's disease in the aging process and learning disabilities in the practical competence of citizens discursively engaging in the public domain have not been adequately considered as problems of citizenship.

People with severe or moderate learning disability have difficulties expressing or articulating interests and needs. While the deaf and dumb have sign language, it is difficult to assess how much people with learning difficulties actually understand. Deaf people have been able to establish a range of deaf rights that express their interests, but the mobilization of people with learning disabilities presents severe limitations on their political involvement. More problematically, it is difficult for people without this disability to actually know what are the needs of people with learning disabilities. In the case of learning disability, the role of helpers and carers becomes crucial. People with severe learning disabilities might engage with society by proxy, that is, through the interpretative activities of caregivers who become expert in the interpretation of the communications of people with such disabilities. However, because learning disability is profoundly stigmatized, social psychologists have found that people are reluctant to identify with the label. As a result, the political organization of people with learning disabilities by groups such as People First is itself limited by the stigmatic label.

RIGHTS TO HEALTH OR HEALTH CARE?

Despite improvements in the recognition of the rights of disability and impairment in the twentieth century, we might reasonably argue that social citizenship has failed as a mechanism of recognition and redistribution. This failure of national forms of welfare has created opportunities for the development of global responses, especially through the legal instrument of human rights. The emergence of a global discourse of rights for disability has been indicated by the Declaration on the Rights of Mentally Retarded Persons (United Nations 1971), the Declaration on the Rights of Disabled Persons (United Nations 1975), and the World Programme of Action Concerning Disabled Persons (United Nations 1982). Human rights discourse is a promising arena for the development of rights for disabled persons, because they are not based on a notion that entitlement must be based on duty and contribution, but rather on a concept of human dignity. Disability rights within a human rights context have the disadvantage that they are difficult to enforce. More positively, the individualistic strand of the International Covenant of Civil and Political Rights has been progressively supplemented and expanded by the CESCR. Whereas the social rights of national citizenship were often dependent on an assumption about ablement, human rights are primarily based on a notion of human vulnerability, which we all share, not as workers, but as human beings.

We often refer to the rights of disabled people under the general rubric of "health rights," but these are difficult to define; Article 12 of the CESCR recognizes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Article 12 notes that nation-states must take steps to reduce infant mortality, improve the environment, control epidemics, and make adequate provision of health services. However, there is widespread skepticism that a health right can be defined because the right to health is not a right to be healthy. Because there is an important aspect of genetic inheritance in human illness (e.g., in diabetes, Huntington's disease, or Down syndrome), it is difficult to enforce a health right retrospectively. Illness and disability are in part a function of aging, and hence there are life cycle problems. It is also necessary to distinguish between health and subjective health, and it would be difficult to legislate for subjective health satisfaction. Some authors have attempted to define a right to health by reference to some international consensus on health issues or by reference to the empowerment of individuals. Rights to health care rather than to health offer a more practical strategy that can monitor states that fail to maintain conditions promoting health. Many people may not be able to enjoy healthy lives as a result of the "natural lottery," but human rights provisions can constrain governments to meet certain minimum conditions of health care.

CONCLUSION: CITIZENSHIP, CHRONICITY, AND CARE

Modern theories of rights have placed growing emphasis on the issue of human difference and fairness rather than universalism and equality. Theories of difference are sensitive to the anthropological notion of cultural relativism in which disability is seen to be socially constructed and hence variable between cultures. In this social model, the very notion of disability is culturally specific. The social model of disability and the social constructionist account of illness have provided powerful sociological arguments for the disability movement. However, the problem with cultural relativism in political theory is that it cannot effectively develop an ethic of care and satisfy questions about justice. If we argue that disability is in fact a social or cultural difference rather than a natural condition, how can we provide for justice across these social categories? The recognition of cultural differences does not easily provide a theory that can give a convincing account of the general conditions of justice. There is therefore an ongoing and unresolved question: How can we defend universality of the treatment of human beings as human beings? Against cultural relativism, it can be argued that human beings share a common vulnerability, because they are embodied. The conviction that human embodiment is a fruitful platform for an argument in favor of the universality of human rights via the notions of frailty and vulnerability is grounded in the notion of the ubiquity of human suffering. We are, to quote the brutal maxim of Keynes, all dead in the long run. More elegantly, disability is a generic aspect of human vulnerability, and it is therefore part of the human condition. There is a direct relationship between disability, the recognition of human vulnerability, and the defense of human rights as entitlements of human beings, regardless of their social and cultural differences.

The fundamental question of moral philosophy is, Why should I care for strangers, that is, people who are different from me? One answer is that while we are all different in physical, social, and cultural terms, we are all vulnerable, and therefore exposed to circumstance. Citizenship and human rights, however defective, provide strategies for exercising choice over circumstance.

—Bryan S. Turner

See also Activism; Anthropology; Disabled Peoples' International; Deaf Culture; Globalization; United Nations Declaration on the Rights of Disabled Persons.

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CIVIL RIGHTS BACKLASH

When a population that is presumed powerless—people with disabilities—demonstrates the clout to effect social change, it is not surprising that negative reactions from others, or backlash, is vehement. An example is found in the U.S. context of people with disabilities invoking such legislation as Section 504 of the Rehabilitation Act of 1973, the 1975 Individuals with Disabilities Education Act, and the 1990 Americans with Disabilities Act (ADA). Federal civil rights for people with disabilities are embodied in two laws: Section 504, a statement of only 40 words that provided civil rights protection for people with disabilities in programs and activities receiving federal financial assistance, and the ADA, which extended such protection to the private sector.

Section 504, however, required implementing regulations that would give it "teeth" by providing the specific means to bar disability discrimination in hospitals, in schools, and for other recipients of federal funding. Despite the jubilation after the nationwide demonstrations that played a significant role in the 1977 signing of the regulations, the backlash evident in the first two Section 504 cases (*Southeastern Community College v. Davis* [1979] and *APTA v. Lewis* [1981; D.C. Circ.]) disappointed disability advocates. The U.S. Supreme Court ruled for the college against Frances Davis, a hard-of-hearing practical nurse, deciding that accommodations allowing her to be a student were too expensive and difficult. Citing *Davis,* American Public Transit Association (APTA) attorneys successfully contended that "reasonable accommodations" in public transit to provide accessibility would be too costly and burdensome, while serving few people with disabilities.

Noting that they were losing the Section 504 cases, disability attorneys devised a tactic in *Dopico v. Goldschmidt* (1982; 2nd Circuit). Rather than making the case for retrofitting *old* buses, they successfully argued for the requirement that only *new* buses be accessible, thus countering the backlash regarding undue expense and hardship. *ADAPT v. Skinner* (1989; 3rd Circuit) affirmed the rationale used in *Dopico.* Accessibility would be mandated not for the old, but rather only for newly purchased vehicles and newly constructed or newly altered facilities. Backlash against Section 504 therefore served as a catalyst for disability rights attorneys to argue for an interpretation of "reasonable accommodation" that courts would deem neither too difficult nor too expensive. Such an approach was to be embodied in the language of the ADA.

In the case of education of children with disabilities, backlash has taken two forms: first, fear that nondisabled children are being shortchanged to pay for the education of children with disabilities; second, reluctance to include children with special needs in regular classrooms, especially when schools are being held to strict testing standards. So fervent is the backlash that proposals to dilute standards, or even exclude accountability, for educating children with disabilities is given serious congressional consideration. In response, disability advocates support monitoring individualized education program (IEP) accountability and having money follow the child to appropriate educational venues, rather than providing financial incentives inflating special education programs. Disability rights advocates also propose that schools accommodate diverse learning styles.

Judicial backlash against the ADA is evident in the Supreme Court's narrowing the definition of disability and elevating the new federalism, contrary to congressional intent that reflects the nation's need to expand employment of people with disabilities. Recent rulings have practically eviscerated Title I, the employment title of the ADA. In 1999, the Court ruled in three joined employment cases (*Sutton et al. v. United Air Lines, Inc.; Murphy v. United Parcel Service, Inc.;* and *Albertson, Inc. v. Kirkingburg*) that individuals whose conditions do not substantially limit any life activity and/or are easily correctable are not disabled according to the ADA. Dissenting, Justice John Paul Stevens stated, "The Court's approach would seem to allow an employer to refuse to hire every person who has epilepsy or diabetes that is controlled by medication . . . or every person who functions efficiently with a prosthetic limb" ("Supreme Court Rules" 1999). As Georgetown University Law Center's Chai Feldblum, who helped draft the ADA, observed, "These decisions create the absurd result of a person being disabled enough to be fired from a job, but not disabled enough to challenge the firing" (Justice For All 1999).

Denying that Williams's impairment entitled her to a "reasonable accommodation" in *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams* (2001), the Court continued limiting the definition of disability. As a consequence of this ruling in Toyota's favor, employees in Williams's position face a catch-22 situation. They have to demonstrate how significantly their disabilities affect their daily lives to warrant coverage under the ADA. Yet they also have to show they are qualified for their jobs. By revealing their impairments, people with disabilities risk jeopardizing their employment. Also in *Williams,* the Court seems to have reacted against what Berkeley law professor Linda Hamilton Krieger (2003:3) refers to as the "dramatic shift in the ordinary power relationship between employers and employees" inherent in the ADA: the *requirement* that an employer engage, "with a disabled employee or applicant in a good faith interactive process to find ways to accommodate the employee's disability" as long as no "undue hardship" is imposed on the employer.

In ruling on disability legislation, say disability rights advocates, the Supreme Court is usurping the role of Congress, treating Congress as a lower court rather than as a coequal branch operating by different standards. In *University of Alabama v. Garrett* (2001), the Court found insufficient past history of disability discrimination to abrogate sovereign immunity embodied in the Eleventh Amendment and to justify invoking the equal protection clause of the Fourteenth Amendment. Justice Stephen Breyer pointed out in his dissent that this decision, a major departure from past rulings, revealed a misunderstanding of the role of Congress as opposed to the courts. But despite Justice Breyer's citation of more than 300 examples of disability discrimination, the Court, which treated these examples as anecdotal, ruled that the discrimination was not egregious enough to give Congress the power to override state sovereign immunity.

Without invoking the definition of disability or sovereign immunity, the Supreme Court continued to chip away at the ADA. In *U.S. Airways, Inc. v. Barnett* (2002), the Court ruled that workers with disabilities should not have priority over more senior workers who do not have disabilities. Characterizing "reasonable accommodations" as "special" and "preferential," the Court added credence to the misconception that the ADA gives people with disabilities undeserved advantages over those who are nondisabled. In *Chevron U.S.A., Inc. v. Echazabal* (2002), the Court decided that, under the ADA, an employer can invoke the Equal Employment Opportunity Commission regulations to reject a qualified applicant by claiming that, due to the applicant's disability, the job could be detrimental to his or her health. Disability rights attorneys assert that the ADA allows employers to refuse an applicant *only* when he or she poses a direct threat to the health or welfare of *other individuals* in the workplace; the law's intent is not to support paternalistic attitudes that have been keeping people with disabilities unemployed.

Holding that only compensatory damages, not punitive damages, are available under Section 504 or the ADA's Title II, the Court in *Barnes v. Gorman* (2002) has made it increasingly difficult for people with disabilities to seek appropriate recourse under these laws. Continued threats to the ADA were reflected in the unsuccessful challenges by Texas and Tennessee to the constitutionality of Title II's ban on discrimination against people with disabilities by state or local governments. Although in *Tennessee v. Lane* (2004) the Court upheld the constitutionality of Title II, the narrow character of the 5–4 decision, applicable only to access to courts, caused disability advocates to fear that the protection of Title II is still imperiled.

Among the multiple reasons for the pernicious backlash against civil rights for people with disabilities is the presumption that this population seeks unwarranted considerations in the form of generous benefits, windfall legal settlements, and excessive accommodations, all of which allegedly burden the rest of society. The tendency of the mainstream media to treat disability issues as a consequence *only* of impairment, not discrimination, reinforces these stereotypes. Fear of perceiving disability as part of the human condition to which all are susceptible preserves the myth of disablement as an all-or-nothing experience, properly residing only in a medical—never in a civil rights—context.

—Doris Zames Fleischer and Frieda Zames

See also Americans with Disabilities Act of 1990 (United States); Individualized Education Program; Rehabilitation Act of 1973 (United States).

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CLAPARÈDE, ÉDOUARD
(1873–1940)

Swiss physician and psychologist

Édouard Claparède is a notable personality in the history of psychology and the pedagogical sciences. Born in Geneva, he belonged to a French family that had emigrated after the Revocation of the Edict of Nantes and was admitted to the Geneva bourgeoisie in 1724. A physician and psychologist, he is known as the founder, in 1912, of the Jean-Jacques Rousseau Institute and of a school of pedagogical sciences, as the editor of the journal *Archives de psychologie*, and as president of numerous international psychological congresses. But it is above all his published work that has established his worldwide reputation, translated and reissued numerous times in many different languages (see Further Readings below).

An advocate of experimentation in psychology, functional education, and the application of psychology to pedagogy, he was also a scholar, with liberal, middle-class, and leftist views, who took up many causes, in particular the rights of children, world peace, psychology, and cultural and intellectual exchanges among nations. His ideals and experience are summed up in his last work, a kind of will and testament, *Morale et politique, ou, les vacances de la probité* (*Morality and Politics, or Honesty on Vacation*, 1940).

—Henri-Jacques Stiker

See also Psychology.

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CLASSIFICATION IN PARALYMPIC SPORT

Classification is simply a structure for competition. Not unlike wrestling, boxing, and weightlifting, where athletes are categorized by weight classes, athletes with a disability are grouped in sport classes defined by the degree of function presented by the disability.

Traditionally, athletes belong to six different disability groups in the Paralympic movement: amputee, cerebral palsy, visual impairment, spinal injury, intellectual disability, and a group that includes all those that do not fit into the aforementioned groups (les autres). Some sports are specific only to one disability group.

Classification systems can be categorized into two models, sport specific and general. Sport-specific classification systems evaluate and assess athletes taking into account the specific tasks required to compete in each sport (e.g., passing a ball). Therefore, in sports where sport-specific classification systems are used, an athlete who uses a wheelchair for mobility may compete not only against other wheelchair athletes but also against amputees or those with cerebral palsy, if they have the same or similar functional ability.

General classification systems evaluate and assess athletes taking into account only the type and degree of impairment (e.g., degree of sight or visual impairment). In sports where general classification systems are used, classification is disability specific, meaning competition is only between athletes in the same category, for example, amputees against amputees.

Classification enables athlete performance to be measured by the skill and physical ability of athletes, regardless of training effect and genetic superiority or inferiority.

Athlete sport classes are determined by a variety of processes that may include a physical and technical assessment and observation both in and out of competition. This process is performed by an expert team of officials known as classifiers. Classification systems are continually being modified due to the requirements of the sports and the advances in the methods of measurement.

Sport classes are defined by each sport and form part of the sport rules. Each sport class is denoted by a combination of letter and number (e.g., T42—T meaning track, 40 for amputees and 42 for a single-leg amputee). For team sports, such as wheelchair basketball, players are assigned a point value according to their sport class, and the cumulated points for team members participating at any one time (i.e., the five players on court) must not exceed a set number. This ensures that any player, regardless of the degree of disability, has an integral role to play within the team structure.

Classification is an ongoing process, and athletes may be classified not only once but several times throughout an athlete's career. Athletes with changeable conditions may be reclassified over time into different sport classes depending on whether their condition improves or deteriorates.

The classification processes used by the International Paralympic Committee (IPC) was designed to encourage participation rather than exclusion, to provide equitable competition, to distinguish and encourage high levels of performance, to create a simple yet objective process in which sport classes are unaffected by training, and to encourage integrated rather than disability-specific competition.

—Andy Parkinson

See also Paralympics; Sports and Disability; Sydney Paralympics.

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CLAUDIUS, EMPEROR

(10 BC–AD 54)

Roman emperor

Tiberius Claudius Drusus Nero Germanicus became emperor of Rome in his 50th year. Bringing some stability to the Roman Empire between the disastrous reigns of his notorious predecessor, the emperor Caligula, and his even more notorious successor, Nero, Claudius reigned AD 41–54. Claudius was never considered fit for imperial administrative duties, perhaps because throughout his childhood he "was so troubled by various diseases that he grew dull-witted and had little physical strength" (Suetonius 2), but in the volatile political vacuum following Caligula's assassination he was declared emperor to everyone's surprise, including his own. Suetonius tells us that Claudius "stumbled as he walked owing to the weakness of his knees," and, when stressed or angered, had the mannerisms of "slobbering at the mouth and running at the nose, a stammer, and a persistent nervous tic of the head" (30). Claudius' autobiography is lost, but Robert Graves's twentieth-century fiction immortalizes Claudius' wisdom and kindness; indeed, it is difficult to reconcile Graves's portrait with the less sympathetic record of the historian Tacitus, or with Suetonius' charges of "cruelty and bloodthirstiness" (34). Derek Jacoby further immortalized Claudius' erudite joviality and portrayed his physical characteristics charmingly in the BBC television production *I, Claudius,* based on Graves's novels.

—M. Lynn Rose

See also History of Disability: Ancient West.

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CLEVER HANS

Clever Hans was a performing horse who became quite celebrated in the first decade of twentieth-century Berlin (roughly from 1900 to 1909) for demonstrating remarkable intelligence. The feats performed by the horse were eventually exposed as simple behavioral responses to subtle cues provided (perhaps unintentionally) by his handler. Since this episode, behavioral researchers have referred to the "Clever Hans effect" to denote the danger of unintentional cueing of the desired behavior by the questioner if experiments are not carefully designed.

Led by his trainer Wilhelm von Osten (1838–1909), Hans would demonstrate almost "human" intelligence by responding to questions with a variety of hoof taps or other actions. Using this method, Hans amazed both the general public and leading psychologists of the day with his apparent ability to perform arithmetic functions, identify colors, read and spell, and even identify musical tones. In 1909, after a series of carefully designed experiments and close behavioral observations, the psychologist Oskar Pfungst concluded that Clever Hans was, in fact, simply responding to very subtle (and probably unintentional) behavioral cues from his handler. The rigor of Pfungst's trials and the detail of his observation are considered classic early examples of experimental design in behavioral psychology.

—Philip M. Ferguson

See also Psychology.

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COLLEGE AND UNIVERSITY EDUCATION

See Education, College and University

COLOMBIA

See Experience of Disability: Colombia

COMMUNICATION

Communication is defined as any act by which one person gives to or receives from another person information about that person's needs, desires, perceptions, knowledge, or affective states. Communication not only allows the exchange of information (transaction) within a specific social and physical context but also permits the fulfillment of social needs (interaction). Through communication, an individual develops and maintains an identity and sense of self, provides connections with other people, and promotes membership or affiliation in social groups.

Human communication is a complex phenomenon that is accomplished through the interactions of various components. It may be intentional or unintentional, may involve conventional or unconventional signals, may take linguistic or nonlinguistic forms, and may occur through spoken or other modes.

The primary components of communication are cognition and language. Cognition refers to the mental activities or operations involved in processing information and acquiring knowledge about the world. It refers to all the processes by which sensory input is transformed, reduced, elaborated, stored, recovered, and used. Processes such as attention, perception, memory/learning, organization, reasoning, and problem solving are dynamically interrelated in most acts of cognitive processing. There are many competing theoretical descriptions of cognition and its development; however, most agree that cognition and language are intricately related both in their development and use.

Language is a system of symbols that when expressed and understood, transmit thoughts, ideas, desires, emotions, and information. Language includes content, form, and use. Language content or semantics refers to the meaning, topic, or subject matter involved in an utterance. Language form includes the three rules systems of phonology, morphology, and syntax. Phonologic rules govern the sound system of the language, morphologic rules are concerned with the structure of words in a language such as the patterns of word endings that indicate tense or number, and syntactic rules refer to the grammatical arrangement of words and morphemes in a sentence.

Language use or pragmatics refers to a system of rules and knowledge that guide how we use language in social settings. It includes knowledge of how to converse with and what to say to different communication partners and in different contexts, and how to initiate, maintain, or terminate discourse and conversation. For example, the Cooperative Principle assumes that conversational participants cooperate by contributing to the ongoing speech event, while the Politeness Principle maintains that participants behave politely to one another, since people respect each other's face. Pragmatics also refers to the use, purpose, or function that a particular utterance serves.

MODES OF COMMUNICATION

Communication may occur through a variety of different output channels. Therefore, in addition to cognition and language, other areas are crucial depending on the mode of communication selected. For example, if speech is the mode of communication, then both speech and hearing become critical for the giving and receiving of the information. If signing or writing is the preferred mode of communication, then vision and some form of upper extremity mobility are required for the successful exchange of the message.

Speech is perhaps the most common mode through which communication is achieved. Speech is a complex motor process involving the coordination of several physiologic systems—respiration for the air stream, phonation for voice production, resonance for voice quality, and articulation for specific sound formation and intelligibility. During the process of phonation, the airstream generated by the lungs vibrates the vocal cords of the larynx, creating sound. Then the movement of the articulators (tongue, teeth, mouth, and lips) shapes the sound into speech sounds. The sounds are made richer and more complex as they pass around and through the vocal tract (larynx, throat, sinus cavities, and mouth). The size, shape, and flexibility of these structures vary from individual to individual and give us our unique "voice personality." While the spoken word itself carries the linguistic message, the voice also communicates much to the listener and is an important part of the total pattern of self-concept. In voice alone, people differentiate maleness or femaleness, estimate age, and identify happiness or sadness, patience or irritability.

Nonverbal communication influences both how people encode messages and decode them. Nonverbal communication refers to those behaviors that are mutually recognized and socially shared and that have a focus on message meaning. Although nonverbal behaviors are dynamic and situation specific, seven categories of nonverbal codes have been delineated. These codes are distinct, organized means of expression that consist of both symbols and rules for their use. Although each code is presented as a separate class, nonverbal behaviors occur together with each other in patterns. They are naturally integrated with verbal expression, with several of them contributing to a single message or thread of messages. The nonverbal codes include the following:

1. Kinesics—messages sent by the body, including gestures, facial expression, body movement, posture, gaze, and gait
2. Vocalics (i.e., paralinguistic)—vocal cues other than words, including volume, rate, pitch, pausing, and silence
3. Physical appearance—manipulable cues related to the body, including hairstyle, clothing, cosmetics, and fragrance
4. Haptics—contact cues, such as frequency, intensity, and type of touch
5. Proxemics—spatial cues, including interpersonal distance, territoriality, and other spacing relationships
6. Chronemics—the use of time as a message system, including punctuality, amount of time spent with another, and waiting time
7. Artifacts—manipulable objects in the environment that may reflect messages from the designer or user, such as furniture, art, pets, or other possessions

In general, nonverbal communication helps people accomplish various goals. First, nonverbal communication creates impressions. Physical appearance cues contribute greatly to this function, but kinesics, chronemics, and other cues also contribute to how others form perceptions of competence and character. Second, nonverbal communication is used to manage interaction. Facial expression, vocalics, and even proxemics are used to signal turn taking in conversations as well as leave taking. Third, nonverbal communication is a primary means of expressing emotion. Some experts have identified nonverbal expression to be an integral part of the emotional experience. In addition, each cultural community has its own display rules for emotional expression appropriateness. Fourth, nonverbal communication allows people to send relational messages. Affection, power, respect, and dominance are all conveyed through nonverbal cues. Fifth, deception is conveyed and detected via nonverbal cues. Finally, nonverbal communication also is used to send messages of power and persuasion; leadership is conferred on the basis of nonverbal cues.

Several factors influence how nonverbal messages are sent and received. Nonverbal messages are shaped by three primary factors: the culture (with the understanding that cultural differences exist), the relationship, and the situation. Although research has identified some universal facial expressions, culture remains a strong influence on nonverbal communication. Cultural values of specific groups affect space and touch norms. Furthermore, gender roles within a culture will determine, to some degree, dress and even baseline kinesics activity (e.g., eye gaze). As culture provides an overall template for nonverbal communication, the specific relationship also determines important norms for interactants. The type of relationship (e.g., helping, adversarial, work, friendship) and the stage of relationship (e.g., a new friendship vs. a sibling bond) influence what is expected nonverbally between interactants. In addition, each communication situation presents its own parameters for nonverbal behaviors. These could include the physical environment, timing, temporary physical or mental states, or the number of people present.

PROPERTIES OF HUMAN COMMUNICATION

Although human communication is an intricate human trait that is difficult to describe, a number of properties of human communication have been identified and detailed. These properties include the complexity of communication, the systematicity of human communication, the relativity of communication to context, the purpose of communication as social action, and the collaborative nature of communication.

The complexity of communication is apparent when one considers that communication is not predicted by the behaviors of its parts taken separately. Communication is more than just the combining of grammatical and lexical units. It is a multilayered system in which the traditionally defined components of cognition, language, and speech function as an integrated whole to accomplish appropriate and effective communication. In addition, several variables extraneous to language are integral components of the communication process (e.g., cultural beliefs, situational features, audience variables, social constraints, and motivations) and influence its use. In addition, the multifunctional nature of communication (interactional and transactional) is further demonstration of the complexity of human communication.

The systematicity of human communication behaviors has been demonstrated across languages and across cultures. For example, the sequence of actions and the structure of conversations have an order and sytematicity that translate into a set of turn-taking "rules" or principles. There are also broad rules, not restricted to any one language or culture, that govern repair of communication breakdowns, question-answer sequences, and conversational openings and closings.

The concept of contextual relativity suggests that communication can only be interpreted in the social and cultural context in which it occurs. Context refers to more than just the physical environment but includes factors such as past experiences and expectations of the individuals engaged in the interaction. Since context is dynamic and may change from moment to moment, the actual words a person states may be interpreted differently at different times.

Communication is a tool for achieving social action. Even within the most routine everyday interactions, communication is used as a means of getting something done. In negotiating social action, subtle strategies or devices such as laughter, facial expressions, or gestures may be used together with or in place of words themselves.

Effective communication is collaborative in nature. Conversations are not a series of discrete statements that pass from active speaker to a passive listener. Rather, as conversations proceed, participants actively construct and negotiate meaning in a coordinated and joint manner.

A COMMUNICATION BILL OF RIGHTS

The National Joint Committee for the Communication Needs of Persons with Severe Disabilities promotes research, demonstration, and educational efforts directed to helping persons with severe disabilities communicate effectively. The committee consists of members from the American Speech-Language and Hearing Association, American Association on Mental Retardation, American Occupational Therapy Association, American Physical Therapy Association, Council for Exceptional Children with Communication Disorders, Association for Persons with Severe Handicaps, and the United States Society for Augmentative and Alternative Communication. The interdisciplinary composition of this committee reflects the importance of communication in all spheres of human functioning and across traditional boundaries. The shared commitment to promoting effective communication by persons with severe disabilities thus provides a common ground on which the disciplines represented by the member organizations can unite in their efforts to improve the quality of life of such persons.

The National Joint Committee for the Communication Needs of Persons with Severe Disabilities developed, in 1992, the Communication Bill of Rights, which states that all people with a disability of any extent or severity have a basic right to communication during their daily activities and across the lifespan. Each person has the right to (1) request desired objects, actions, events, and people; (2) refuse undesired objects, actions, or events; (3) express personal preferences and feelings; (4) be offered choices and alternatives; (5) reject offered choices and request and receive another person's attention and interaction; (6) ask for and receive information about changes in routine and environment; (7) receive intervention to improve communication skills; (8) receive a response to any communication, whether or not the responder can fulfill the request; (9) have access to augmentative and alternative communication (AAC) and other assistive technology (AT) services and devices at all times; (10) have AAC and other AT devices that function properly at all times; (11) be in environments that promote one's communication as a full partner with other people, including peers; (12) be spoken to with respect and courtesy; (13) be spoken to directly and not be spoken for or talked about in the third person while present; and (14) have clear, meaningful, and culturally and linguistically appropriate communications.

—Leora R. Cherney

See also Accessibility; Assistive Technology; Communication: Law and Policy.

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COMMUNICATION: LAW AND POLICY

Communication is an important component of human experience. Throughout history and across geopolitical boundaries, communication laws and policies have shaped the ability of people with disabilities to participate in society. Legislation and policy have been used both to discriminate against and to increase opportunities for people with disabilities. Technology continues to provide new tools and methods for communication, allowing individuals to interact more effectively while prompting additions and changes to existing communication laws.

HISTORY

Before the Enlightenment, philosophy and unwritten social policy often excluded individuals with communication disabilities. Plato and Aristotle believed that speech was audible thought. People with communication disabilities were often considered incapable of thought or learning and were not viewed as intelligent human beings. During the Middle Ages, participation in religious and civic life was often denied to people with communication disabilities. The notion that communication, intelligence, and humanity were interdependent remained prevalent well into the sixteenth century, when academics began to challenge earlier philosophical ideas. In the twentieth century, many countries passed legislation that specifically addresses the need for governments, businesses, and institutions to communicate effectively with citizens regardless of disability.

COMMUNICATION LAW

The Americans with Disabilities Act (ADA) of 1990 and the Disability Discrimination Act (DDA) of 1995 require public entities and businesses to provide effective communication to individuals with disabilities. The ADA covers the United States and the DDA covers the United Kingdom; many similar laws exist in other countries. Methods to ensure effective communication are wide in scope and may require the use of auxiliary aids and services. Braille and large-print publications may be forms of effective communication for a visually impaired person trying to access written information. A transaction involving a deaf person may require the provision of an American Sign Language interpreter. A person with a mobility impairment might have difficulty operating an ATM machine and may require the services of a bank employee to complete a transaction. The entity providing the service is responsible for costs incurred in providing auxiliary aids or services, and the form of communication used needs to be appropriate to the context and needs of the person with a disability.

In the United States, additional provisions regulating communication are found in Title IV of the ADA. Title IV mandated that nationwide telecommunication systems be accessible to persons with speech or hearing disabilities. Telecom carriers in each state were required by the Federal Communications Commission (FCC) to provide telecommunication relay services by July 26, 1993. The Telecommunications Relay Service (TRS) allows a person using a text telephone or nonvoice device to converse with someone using a voice telephone; an operator acts as a neutral relay between the two parties. On March 1, 2001, the FCC expanded the TRS to include service in Spanish, and speech-to-speech (STS) relay. Using STS relay, a person with a speech disability can have his or her voice relayed to the other person on the phone by a trained communications assistant. Services such as STS are also available in Australia and Sweden, and many TRS services are available through the Internet for individuals who do not own specialized telephony equipment.

The Telecommunications Act of 1996, also enforced by the FCC, added provisions to the Communications Act of 1934 to increase communications access for people with disabilities. These provisions, contained in Section 255 of the amended Communications Act, require manufactures and providers of telecommunications equipment and services to ensure accessibility to persons with disabilities. Telecommunications devices need to have accessible input and output systems, and documentation about telecommunications equipment and services must be available in accessible formats. Operator, directory assistance, and emergency services must be accessible to persons with disabilities. The Telecommunications Act of 1996 additionally mandated the phase-in of captioning requirements; the timeline requires the captioning of all English-language broadcasts by 2006 and of Spanish-language broadcasts by 2010, with some exceptions for small broadcasters, public access television, and certain live broadcasts and commercials. In July 2000, the FCC adopted rules requiring video description in a portion of television broadcasts, but the rule was overturned by a federal court in November 2002.

SIGN LANGUAGE AND DEAF EDUCATION

People who are deaf often communicate using different forms of sign language. Sign language is still not universally accepted as a language, even though American Sign Language (ASL) and many other sign languages are linguistically complete forms of communication. It is a common misconception that ASL shares the grammatical structure and vocabulary of spoken English. While some sign languages are closely related to spoken languages, many have a unique grammar that cannot be translated in a sign-to-word manner. Though there are many signed languages in practice throughout the world, ASL has its origins in the deaf communities of France and Italy.

Abbé Charles-Michel de l'Épée, a French priest, is credited with the establishment of the first sign language school for the deaf in 1775. The sign language he taught was a formalized sign system he had developed based on his observations of the communication of the local Deaf community in Paris. His sign systems form the basis for ASL and other similar sign languages practiced today. Thomas Hopkins Gallaudet, an American Congregational minister, studied sign language in Paris beginning in 1816. He returned to the United States with Laurent Clerc, a deaf sign language instructor, and established the first educational programs for the deaf in the nation. By 1900, more than 50 schools for the deaf operated in the United States.

Educational policy makers have advocated for two methods of deaf education, *manualism* and *oralism*. Manualism was used in the original residential deaf education schools, and it emphasized the use of sign language in the classroom. Advocates of oralism encouraged the exclusive use of oral communication skills. Oralists opposed the use of sign languages and encouraged students to use lipreading and speech as primary communication methods. Oralists believed that teaching sign language would limit student ability for speechreading and oral communication. Alexander Graham Bell, inventor of the telephone and instructor of deaf students, was a prominent advocate of oralism, and among others had a large influence in the increasing use of oralist methods in deaf education throughout the late nineteenth and early twentieth centuries. These trends continued until the 1970s and have deprived many individuals of an adequate education in sign language. Scholars today are generally critical of oralism, and encourage sign language education in the manualist tradition. While lipreading and oral communication are still taught to deaf students as useful skills, sign language as a primary form of communication is again a standard aspect of deaf education.

TECHNOLOGY AND COMMUNICATION

Technology is changing some of the primary ways in which people communicate, and recent legislation and policy have attempted to address some of the changes resulting from new technologies. E-mail has become an instant and low-cost means of communicating across the globe. Instant messaging systems are increasingly used by the Deaf community and have become a popular form of interaction for young people. Many public and private organizations publish reports and other information using electronic versions instead of print. As the Internet has become a dominant source of information at home and in the workplace, a variety of entities have proposed and enacted laws and policies governing the accessibility of electronic resources. Both the United States and the United Kingdom have laws that require the accessibility of most public websites, though the scope of these laws is still being determined by the court system. Section 508, a recent example from the United States, was signed by President Bill Clinton on August 7, 2000, and establishes regulations governing the accessibility of the electronic and information technology used within the federal government.

The United States included specific requirements for information technology accessibility through an amendment to Section 508 of the Rehabilitation Act of 1973. Section 508 requires that any electronic and information technology developed, procured, maintained, or used by the federal government be accessible to people with disabilities. As the government continues to increase its use of technology for internal systems and public services, compliance with the law helps ensure effective communication with federal workers and to the public they serve. While Section 508 covers only federal agencies, the requirements for effective communication within the ADA and DDA are increasingly being interpreted to cover electronic communication. Many businesses and institutions are establishing policies to ensure that web pages and other electronic and information technology used internally or by the public are accessible to individuals with disabilities. Communication laws and policies today provide more opportunities for individuals with disabilities than in previous times, and technology continues to introduce new forms of communication. It is likely that current laws and policies will require frequent revision as the modes and methods in which individuals communicate continue to change.

—Nathan White

See also Accessible Internet; Americans with Disabilities Act of 1990 (United States); Assistive Technology; Communication; Disability Discrimination Act of 1995 (United Kingdom); Information Technology.

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COMMUNITY LIVING AND GROUP HOMES

Community living and group homes refer to the Western-based philosophy and movement that holds that people with disabilities should have opportunities to reside in community-based homes. This movement seeks to promote community-integrated living, primarily for people with intellectual disabilities and mental illness, by moving them from large institutions into smaller (fewer than 15 residents), community-based home settings. These settings respond to the desire of people with disabilities to participate in community life. There is increasing research evidence that community living can enable them to exert control over their lives and improve their quality of life. Providing opportunities for community living may also be less expensive than institutional care.

Group homes typically bring together individuals who do not previously know one another into a collective, homelike residence. The residence may be an apartment or a freestanding home and is located within a residential neighborhood. Many models of group homes exist. Sometimes there are live-in care providers; others times there are shift workers, who may or may not be continuously present in the home. Likewise, sometimes the residents have primary responsibility for household matters such as cleaning, cooking, and grocery shopping; other times staff carry such responsibility. As a result of these and other factors, some group homes retain an institutional atmosphere, while others create a more resident-driven, homelike atmosphere. In general, group homes provide less restrictive environments for residents thereby increasing their satisfaction with their living arrangement. They accord residents with disabilities greater opportunities to exercise choice over day-to-day matters and increase their skills and adaptive behaviors. Group homes enable their residents to enjoy greater engagement in and/or responsibility for domestic and personal activities. They have a more active, normalized, and less regulated lifestyle in the community.

HISTORY

Historically, people with disabilities have been cared for by their families and have not had a long life expectancy. Starting in the seventeenth century in England and its colonies, people with disabilities began to be placed in separate facilities with other "social undesirables." By the mid-nineteenth century, state-run large residential care facilities were built or former tuberculosis hospitals and other facilities were adapted to house people with disabilities. Although intended to provide services, opportunities, and resources for living and protection from an unsupportive society, these facilities often were characterized by limited life choices for residents. They frequently experienced a low level of quality of life, abuse, and neglect. Staff showed a general lack of interest in returning residents to their communities.

By the mid-1950s, critiques of institutional care, the availability of new psychotropic medications, advocacy groups, and the international disability right movement were taking root. As a result, there was growing support for changes in the residential care of people with disabilities. Interest increased in reducing reliance on residential institutions and promoting community-based supports. In the early 1960s in the United States, President John F. Kennedy gave the first major presidential address devoted to society's treatment of people with emotional and cognitive disabilities. In ensuing legislation, his administration called for and obtained stronger community supports including community mental health centers, university centers for excellence in research and treatment for people with cognitive disabilities, state planning councils for innovative disability policies and programs, and state protection and advocacy agencies for people with disabilities. These new organizations began in the 1960s and have helped provide support for the development of group homes and community living.

Today, there is great variation among community-based living arrangements. Over time, the trend has been to reduce the numbers of people living together.

Today, there are often fewer than 6 people with disabilities who live together in group homes, although some settings continue to contain 7 to 15 individuals in one home. Some of these community living arrangements involve simple, intermittent staff oversight, whereas others involve almost complete control by and continual presence of nonresidential staff.

CHALLENGES

A serious shortage of community-based options persists, with great disparities in resources within and across countries. Although worldwide the majority of children and many adults with intellectual disabilities live in family homes, many people in Western countries with disabilities now reside in community living arrangements. As the struggle to attain inclusive communities continues, opposition has sprung largely from many communities' attitudes commonly referred to as "not in my backyard" (NIMBY) or a lack of acceptance for integrated housing options. These attitudes often lead to the development of local zoning and land use restrictions that create significant barriers to the creation of new community living residences. Overcoming these restrictions and promoting more positive attitudes toward people with disabilities are currently major activities in the quest to promote inclusive communities. In addition, research continues to question whether the current structure of group homes is able to significantly improve the quality of life of people with disabilities. Low staff pay and high staff turnover rates are among those factors that may thwart people with disabilities' ability to exert greater control over their everyday lives and improve their life satisfaction. Last, the current service system often wrongly associates a need for high levels of support with restrictive environments, thereby leaving many people with significant support needs seldom considered for community living opportunities.

—*Katherine E. McDonald*

See also Advocacy; Housing: Law and Policy; Independent Living; Normalization.

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COMMUNITY-BASED REHABILITATION

Generally speaking, rehabilitation involves the restoration of independence and agency in persons with sensory, psychiatric, physical, and/or cognitive disabilities. *Community-based rehabilitation* is broadly defined as rehabilitation efforts occurring outside medical or institutional contexts. Community contexts of practice can include, but are not limited to, advocacy-based organizations, not-for-profit residential programs, drop-in centers, community health and mental health centers, religious settings, public parks and other outdoor venues, employment settings, and homes of people with disabilities. Community-based rehabilitation programs can focus on just about any disability including autism, intellectual disabilities, learning disabilities, deafness, drug addiction, schizophrenia, depression, traumatic brain injuries, and spinal cord injuries. Community-based rehabilitation allows counselors to vary the contexts of practice based on the specific needs and backgrounds of persons with disabilities. Doing so increases the likelihood that rehabilitation services will be culturally and contextually anchored and therefore relevant to the persons receiving services. Grassroots community leaders, advocates, and professionally trained individuals from a wide range of disciplines can practice community-based rehabilitation. These include occupational therapists, physical therapists, rehabilitation counselors, developmental therapists, community psychologists, social workers, nurses, public health professionals, and physicians specializing in physical medicine or rehabilitation.

In the United States, the community-based rehabilitation movement derived from the deinstitutionalization and community mental health initiatives of the late 1960s and early 1970s. For many years, rehabilitation had almost exclusively occurred in hospital and clinical settings. Early community-based initiatives followed the medical model of treatment. Although in theory they embraced concepts of community participation, in practice many used professionally developed strategies that failed to include the voices of community members in program planning and implementation. In response to a growing dissatisfaction with community-based services among persons with disabilities and rehabilitation counselors, a community development model was proposed in the late 1980s and early 1990s. The community-based rehabilitation movement then began to shift from a treatment/deficit model that served to isolate and stigmatize persons with disabilities to one that promoted societal integration and the improvement of the everyday lives of individuals with disabilities. With this shift, community-based rehabilitation emphasized a strength-based model of social inclusion, political equality, and the translation of clinical and technological knowledge into relevant health care information and self-help skills.

Today, the practice of community-based rehabilitation varies along a continuum ranging from institutional, medical treatment approaches to community-integrated, participatory approaches. Medical treatment may involve biomechanical approaches to rehabilitation, including manipulating the body or teaching and assisting patients with movement and daily living skills. Medical approaches are criticized by disability rights activists and other scholars, researchers, and practitioners who support a more consumer-centered or participatory approach to rehabilitation. They argue that treatment-based rehabilitation approaches are similar to clinic-based approaches that promote the isolation and stigmatization of persons with disabilities; the only difference being that rehabilitation occurs with fewer resources and within community contexts. They argue that medical approaches assume that persons who provide treatment are experts. Recipients of services, or patients, are dependent on experts to direct the course of therapy, which promotes feelings of helplessness. Conversely, proponents of the medical approach to rehabilitation argue that some persons with disabilities are too severely disabled to direct the course of their treatment. Also, a lack of adequate resources prevents implementation of more consumer-driven rehabilitation services.

Alternatively, participatory community-based rehabilitation service approaches emphasize empowering consumers to function more independently. They encourage people with disabilities to advocate for their rights as citizens who are consumers of health care. Participatory approaches work to reduce professional-client power hierarchies by engaging consumers as leaders and treatment providers. Participants are encouraged to organize to develop, implement, and evaluate empowerment-oriented community-based services, not only for each other but also for the larger health care and social communities in which they interact. According to William Boyce and Catherine Lysack, true participation involves a process of personal as well as social transformation in which decision making takes place in the hands of the consumer group and social conditions are thereby affected or changed. This approach is typically associated with social action projects that emphasize the achievement of local, consumer-driven goals. The central tenet of this approach to rehabilitation is that it begins with the problems and needs of community members, rather than with the professional's conceptualization of those problems.

Professionals using participatory approaches to community-based rehabilitation become active knowers and members of the communities they work within. They fulfill these roles by becoming community organizers, meeting facilitators, educators, peer trainers, community advocates, activists, or resource persons for technical or material aid. This involves allowing the consumers to dictate the essential elements of the therapy process. The necessary requirements for legitimate empowerment within the therapeutic relationship are flexibility in establishing the variety of possible roles assumed by both service providers and consumers and the relinquishing of power by service providers to consumers when establishing those roles.

A growing number of integrative, community-based approaches to rehabilitation have developed based on the reconceptualization of persons with disabilities as citizens instead of patients. These approaches seek to combine education, training, practice, and advocacy efforts. One well-known example of an integrative approach to community-based rehabilitation is supported employment. Since the early 1980s, supported employment programs have enabled thousands of people with disabilities to become employed in their communities. Prior to supported employment, persons with significant disabilities who wanted to work were often placed in sheltered workshops. There they earned only pennies an hour in piecework wages. Supported employment programs promote a more integrated and higher quality of life by helping persons with disabilities pursue job opportunities in traditional work environments at pay equal to that of nondisabled persons.

Job specialists work with consumers, exploring their vocational aspirations and supporting them in their efforts to find jobs. Once consumers have a job, they receive on-the-job training and support. Eventually, support is faded out and consumers work independently. Job specialists in supported employment programs work to remove the barriers persons with disabilities face in obtaining employment. Job specialists work to remove the consumers' internal barriers by increasing their feelings of self-efficacy and self-esteem. Persons with disabilities experience a lifetime of oppression and marginalization that often leads them to believe that they are incapable of gaining meaningful employment. Job specialists also work to reduce external barriers to employment by advocating for their consumers as capable contributors to society. In addition to the benefits to consumers and to businesses, who receive dedicated and capable employees at reasonable pay rates, supported employment programs benefit society by reducing the stigma associated with having a disability. Promoting real-life interactions between disabled and nondisabled individuals can lower stigma and build positive relationships. Today, supported employment programs have been established in many other countries including Peru, England, Scotland, France, Ireland, Norway, South Africa, Japan, and Australia.

Internationally, the community-based rehabilitation movement began with two World Health Organization initiatives of the 1970s and 1980s: (1) the primary health care (PHC) campaign Health for All by the Year 2000, introduced in 1978, and (2) the community-based rehabilitation movement that emerged, in part, from the PHC campaign. Generally, the PHC campaign focused on efforts to raise the level of health in the world by increasing access to health care in developing nations. The community-based rehabilitation movement reflected an international recognition that rehabilitation is a key aspect of the campaign for global health. Rehabilitation has to take into account the cultural contexts of participating nations. Today, the World Health Organization helps improve access to rehabilitation services in underdeveloped countries by delivering simple, low-tech, community-based rehabilitation services.

An example of an international community-based rehabilitation program is Jamaica's 3-D Project. 3-D stands for Dedicated to the Development of Persons with Disabilities. 3-D provides home training programs, counseling, educational placements, and job placement or employment development to persons with disabilities in Jamaica. Another example is Guyana's Hopeful Steps. This program works to combat the marginalization of persons with disabilities by educating communities about their needs and abilities. Hopeful Steps also provides individuals with disabilities and their families training and support in becoming integrated and contributing members of society.

Supported employment, Jamaica's 3-D Project, and Guyana's Hopeful Steps programs share common philosophies. Their participatory approaches to community-based rehabilitation are based on the idea that all persons with disabilities deserve opportunities to participate and benefit from society equal to those enjoyed by persons without disabilities. In addition, they work to correct society's misperceptions about persons with disabilities by demonstrating that persons with disabilities are capable of not just participating in society but contributing to it. A philosophy of social justice and respect for basic human rights drives the international movement of community-based rehabilitation to advocate for the rights of persons with disabilities. The community-based rehabilitation movement is helping to change our basic conceptualization of disability from an individual deficit model to a diversity model, where persons with disabilities are no longer considered as categorically different than nondisabled persons. Instead, persons with disabilities are beginning to be viewed as disabled, not by internal deficits as much as by environmental and culturally determined limitations. Working to remove these limitations holds the promise for "curing" disabilities.

—Renee R. Taylor and Curtis J. Jones

See also Developing World; Job Training; Rehabilitation Counseling; Supported Employment; Vocational Rehabilitation.

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COMORBIDITY

Comorbidity is a disease or condition that is present in a patient in addition to the principal disease or condition. For example, suppose the principal reason a person visits a doctor, goes to a hospital, or has rehabilitation is because of an acute condition such as stroke; if the person also has diabetes, hypertension, congestive heart failure, or other conditions, these are called comorbidities.

A synonym for comorbidity is secondary diagnosis; the condition responsible for a visit, hospital admission, or rehabilitation is called the principal diagnosis. Comorbidities are important to consider for people with disabilities because they can influence greatly a person's need for health care, the treatments or interventions that are best, the cost of care, and the person's ability to function in the world.

Comorbidities, as well as principal diagnoses, usually are labeled with numerical codes. There are about 19,000 different codes in the International Classification of Diseases (ICD), which is coordinated by the World Health Organization. Each ICD code indicates the *existence* of a disease; it does not indicate the *extent* (severity) of the disease. Comorbidities can be more or less severe. Occasionally, the code itself indicates that the disease is very severe, for example, having the plague, since many people die from plague. In most cases, however, the same diagnosis code is used for patients no matter what their severity level. For example, suppose a rehabilitation patient has congestive heart failure as a comorbidity. The heart failure can be mild and not interfere with the patient's care or activity level, or it can be severe, leaving the patient weak and unable to do almost any activity, making the rehabilitation care process more complicated and the cost of care much higher.

Rehabilitation and other care processes of persons with disabilities are affected by functional status, as measured, for example, by the Functional Independence Measure (FIM) as well as type of impairment, such as stroke, traumatic brain injury, or spinal cord injury. Because medical acuity and comorbidities can also affect care processes, resource use, and ability to function in community settings, the Centers for Medicare and Medicaid Services has grouped comorbidities together into four tiers—three tiers for different levels of comorbidity severity and a fourth tier for no comorbidities—that are designed to represent more or less medical acuity. In analyses to date, however, these diagnosis-driven tiered approaches do not explain differences in rehabilitation care processes and resource use. Recent research suggests that comorbidity descriptors should incorporate levels of abnormality of various relevant signs and symptoms, such as those in the Comprehensive Severity Index (CSI®), to explain variation in needed rehabilitation care processes, resource use, and community function.

—Susan D. Horn

See also Disease; International Classification of Functioning, Disability, and Health (ICF/ICIDH).

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▣ COMPETENCE

A person's *competence*, or *decision-making capacity*, is his or her ability to make and communicate a decision to consent to medical treatment. As such, competence is a threshold issue that is central to the determination of consent and reflective of the law's concern with individual autonomy. A person's decision regarding medical treatment must be respected when the person is competent to make that decision. Conversely, if a person is not competent to give informed consent, it will be necessary to employ an alternative decision-making process before the issue of whether treatment should be provided can be determined.

The test for competence is legal and not medical. While many health and medical tests are used in the determination of capacity (e.g., the Mini-Mental Status Examination or the MacArthur Competence Assessment Test), it should always be recalled that the ultimate issue is whether the person has competence according to the law. Therefore, a person should not automatically be presumed incompetent because he or she has a disability or mental illness. Rather, incompetence must be determined by examining whether a person's illness or disability affects the ability to make a decision to the point where the person should be treated as incompetent. Similarly, a person should not be treated as incompetent because the person makes a decision that is unusual or out-of-step with community expectations. Unusual or irrational behavior may mandate an investigation into a person's competence, but it is not synonymous with incapacity.

PRESUMPTIONS OF COMPETENCE

The common law begins by presuming that adults (those people who have reached the age of majority) are competent. The law also presumes that minors are incompetent (although in some jurisdictions the age of competence to consent to medical treatment has been lowered). Both presumptions can be rebutted by applying the test of competence to the person.

The Test for Competence

The legal test for competency is surprisingly similar across jurisdictions in the United States, United Kingdom, Australia, New Zealand, and Canada. Support can be found in all these jurisdictions for a functional capacity test that examines the patient's ability to receive, understand, and process treatment information. For example, in the English case of *Re C (Adult: Refusal of Medical Treatment)* (1 WLR 290 [1994]), a patient who had schizophrenia refused to consent to an amputation of a gangrenous leg. The judge found that patient was competent to refuse because he was able to

1. comprehend and retain treatment information,
2. believe that information, and
3. weigh the information and reach a decision.

A similar formulation was adopted in the American case of *Matter of Schiller* (372 A 2d 360, 367 [NJ, 1977]) where the court stated the test for capacity as follows:

> Does the patient have sufficient mind to reasonably understand the condition, the nature and effect of the proposed treatment, attendant risks in pursuing the treatment, and not pursuing the treatment?

Some jurisdictions have enshrined the test in legislation. For example, in the Australian state of Queensland, the Powers of Attorney Act of 1998 defines *capacity* as

a. understanding the nature and effect of decision about the matter; and
b. freely and voluntarily making decisions about the matter; and
c. communicating the decisions in some way.

In England, Australia, and New Zealand, the application of the functional competency test to children is referred to as the "*Gillick* competence" test, in honor of the case that stated that a child was competent to consent when that child was able to understand benefits and risks of proposed treatments (*Gillick v. West Norfolk AHA,* AC 112 [1986]). Courts in the United States and Canada apply an almost identical standard but refer to the test as the "mature minor" doctrine.

The Functional Competence Test

Step 1: Comprehending and Retaining Treatment Information

A person must be able to comprehend and retain treatment information to be competent. This reflects a concern with the patient's level of understanding. There are two main issues in this context.

The first relates to the issue of what sort of information must be comprehended by the patient. There are differing opinions as to whether the information needs to consist of basic treatment information or whether it should include more detailed information in line with the doctrine of informed consent. Generally speaking, British commentators and courts have only required the patient to understand very basic information about the broad nature and purpose of treatment for the patient to be treated as competent. Constrastingly, American courts and commentators have required that the patient not only understand the broad nature and effects of treatment but also benefits and risk of the treatment, of alternative treatments, and of no treatment.

The second issue concerns the type of understanding that is required of the person. Some commentators require the person to demonstrate an actual understanding of the treatment information, while others require the person to have a general ability to understand the treatment being offered. The reasons for adopting an "actual understanding" standard is that it focuses in a practical way on the treatment problem faced by the person. On the other hand, the actual-understanding approach is open to abuse in that it may allow a medical professional to withhold information and then claim that the person does not understand what is being proposed. An "ability to understand" approach prevents this abuse from happening because it is not dependent on the person possessing specific understanding of the treatment being offered. In practice, it appears that the courts look at both factors, and the Canadian Law Reform Commission has suggested that either standard can be employed.

Step 2: Believing Treatment Information

This step requires a person to be able to believe the treatment information, or, if the person does not believe the information, that nonbelief must not be caused by delusion brought on by mental illness or disability. For example, in *Tennessee v. Northern* (563 SW 2d 197 [1978]), the patient was found incompetent because she could not believe that she had gangrene. Contrast that with the case of *Re C* (mentioned above) where the patient did believe that he had gangrene, but he just preferred to die with two feet instead of live with one, and was consequently found to be competent.

Step 3: Weighing Factors and Evidencing a Choice

Patients must be able to effectively reason and communicate a choice. There are three main issues in this context. The first relates to an inability to communicate. In the New Jersey case of *Matter of Conroy* (486 A 2d 1209, 1241 [1985]), it was said that a patient may be incompetent because he or she lacks the ability to communicate a decision. For example, in the New Zealand case of *Auckland Area Health Board v. Attorney-General* (1 NZLR 235 [1993]), a patient with a "locked-in" syndrome was found incompetent because of his complete lack of ability to interact with the outside world. Of course, every effort should be made to find a way of communicating with the disabled person, and it may be possible for communication systems, such as letter boards or electronic devices, to bridge the communication gap.

The second major issue here concerns the person's ability to reason. This refers to the subjective reasoning process of the person and not whether the patient's decision would be considered objectively reasonable by other people. Once again, the concern is with whether the person's reasoning is being affected by a misperception of reality or delusion. Determining this is not an easy task as some personal and religious beliefs are not easily distinguishable from delusions. Staunch has argued that religious beliefs are distinguishable from delusions because they are nonrational rather than irrational. Grisso and Appelbaum have stated that it is also useful to see whether the religious belief predates the treatment decision, whether it is held by others, and whether the person has behaved consistently with those decisions in the past.

INQUIRIES INTO COMPETENCE AND RISK-RELATED TESTING

It has been argued by some judges, such as Lord Donaldson MR of Britain, and commentators, such as Buchanan and Brock, that there should be a greater level of competence required of people when they make high-risk decisions. Others, such as Grisso and Appelbaum, have stated that it is not greater competence that is required but rather greater evidence of competence. Arguably, this is because a person either has competence to make a decision or the person does not. Nevertheless, there is the danger that the requirement for greater evidence in higher-risk cases may discriminate against people who make unusual decisions. Only they will be subjected to greater levels of scrutiny. Someone who complies with treatment options in line with medical opinion will be less likely to trigger an assessment of competence. On the other hand, the requirement that competence be disproved in adults mitigates against discrimination because the onus is placed on doctors to rebut the presumption in favor of the person being competent to decide.

—Cameron Stewart

See also Consent to Treatment; Decision Making; Patients' Rights; Refusal of Life-Sustaining Treatment.

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COMPLEMENTARY AND ALTERNATIVE MEDICINE

Disability in modern Western societies is often seen as the terrain of orthodox biomedicine. Biomedicine is primarily centered on individual interventions using drugs and surgery to correct malfunctions following breakdown of specific parts of the body. On this conception, the body is typically conceived as a machine differentiated from the mind and spirit. Many mainstream official notions of disability in the past, including that of the World Health Organization, have been based on medical definitions focused on the functional limitations of individuals with impairments, such as those who are unable to walk or are partially sighted. The corollary of this approach is that, with the growing development of modern medicine, there is felt to be a rising need for medically led rehabilitation. The medical model, though, has been challenged as the social dimensions of disability have been more fully exposed, not least by drawing attention to socially defined concepts of normality and discriminatory social constraints on participation. As will be seen in this entry, however, biomedical conceptions of disability have also now been increasingly challenged both generically and in specific instances following the recent expansion of interest in complementary and alternative medicine in the West.

Complementary and alternative medicine is the term used in this context to describe approaches ranging from acupuncture and aromatherapy to herbalism and homoeopathy that are not part of mainstream Western medicine. These are typically used in a manner that is complementary, or opposed, to orthodox medical practices. Such approaches are sometimes referred to as holistic or traditional medicine, although these do not cover all forms of complementary and alternative medicine. While some classical systems such as ayurvedic medicine and traditional Chinese medicine are centered on bringing together the mind, body, and spirit, it is difficult to see how the work of, say, osteopaths who focus on treating bad backs is holistic, particularly when compared to their more eclectic counterparts. Equally, not all complementary and alternative medicine can be seen as traditional, as the cases of chiropractic, which was founded in the late nineteenth century, and biofeedback, which was established even more recently, amply testify. Complementary and alternative medicine is therefore defined as those practices that are politically marginal in comparison to the medical mainstream—as they are not usually a central part of the medical curriculum or extensively funded from official research funding agencies. As such, the approaches that constitute the orthodoxy of one age can readily become the unorthodoxy of another and vice versa.

In this sense, the concept of complementary and alternative medicine arose only once the medical profession had emerged in the West in the late nineteenth and early twentieth centuries. Before this time, there was a relatively undifferentiated field, in which those with disabilities in the seventeenth and eighteenth centuries were free to choose whomever they wished to consult in the health care marketplace. Importantly, the range of practitioners on offer included not only the precursors of contemporary doctors but also groups such as bonesetters and healers—with the public also having the opportunity to take the various pills and preparations for sale on a self-help basis. In addition, sufferers were able to make use of what was typically a stronger cradle of neighborliness and community support in a culture in which the human condition was viewed more holistically, with greater stress on personal constitution in maintaining health. With the rise of modern medicine and the development of the medical profession underwritten by the state, though, all this was to change; as greater unity emerged around biomedicine and the orthodox health care division of labor proliferated, those involved in practicing complementary and alternative medicine were increasingly marginalized as the mid-twentieth century arrived.

However, although the practice of complementary and alternative medicine had diminished in scale in the West by this time, it was buoyed in the 1960s and 1970s by the medical counterculture that came to the fore. This was part of the more general countercultural trend against materialistic values, involving among other things, revolutionary changes in fashion and rising interest in meditation and mysticism. In the medical area, there was growing awareness of the limits to medicine—underpinned by the widespread belief that modern biomedicine had reached a watershed in which it was becoming increasingly counterproductive—in a climate given to debunking the notion of scientific progress. A related challenge to professional authority was also launched that was aimed at overcoming the depersonalization and disempowerment of the patient endemic in biomedicine and allowing consumers to take more control over their own health. This was associated with the development of self-help, where a number of campaigning groups were emerging that lobbied on behalf of the disabled and other health consumers in such areas as cancer and HIV. In the wake of the counterculture, in which there was a particular fascination with Eastern philosophies, public interest in complementary and alternative medicine gained a new impetus.

In this respect, the numbers of users of complementary and alternative medicine in Europe and North America expanded to between one-fifth and two-fifths of the population, although the main therapies employed and the extent of their use vary considerably by country. The majority of this growth involves self-help usage. However, there has also been an associated expansion of practitioners of complementary and alternative medicine. In Britain, for example, these have increased from 30,000 to 60,000 in the past 20 years—a figure that is currently paralleled by the number of chiropractors alone in the United States. Growing numbers of orthodox practitioners including doctors, nurses, physiotherapists, and other health professionals have also employed complementary and alternative medicine as popular and political demand for such therapies has expanded. However, in the hands of doctors—with some notable exceptions—complementary and alternative medicine has tended to be applied in quite a restricted manner. Thus, in the case of acupuncture it has mainly been used by the medical profession for pain and addictions rather than as a panacea as in classical Chinese medicine. It has also largely been medically justified with reference to neurophysiological theories about endorphins as opposed to the traditional principles of balancing the polar forces of yin and yang along meridians.

One reason for this typical pattern in the West of using therapies such as acupuncture in more of a complementary rather than alternative mode is that it is not in the interests of the medical profession to do otherwise in situations where they risk legitimating unorthodox competitors, given the threat this poses to their income, status, and power. Another explanation for the broader reticence of doctors about using complementary and alternative medicine, though, may be their desire to protect the well-being of patients in light of the present limits on the evidence base in this area. Despite the ideology of a safe, "natural" approach to health care frequently espoused by complementary and alternative therapists, there are hazards posed to disabled and other users ranging from punctured lungs in the case of acupuncture to potentially fatal overdosing from herbal remedies. There are also major gaps in the evidence that has been provided for such therapies in terms of randomized control studies. This in part is because complementary and alternative therapies have not attracted the same level of investment from governments and the pharmaceutical companies as have more orthodox remedies.

This, however, is a controversial area. Orthodox medicine plainly has its own problems in terms of safety—as starkly illustrated by the devastating and disabling effects of thalidomide in the 1960s and more recently the growing number of potentially fatal infections contracted by patients in hospitals. In addition, there is much debate about how to assess the efficacy of complementary and alternative medicine. While large-scale randomized controlled trials are rare in this field, many areas of conventional medicine have not yet been subjected to such scrutiny in a thoroughgoing manner for ethical and other reasons.

There are also significant methodological questions about whether the randomized controlled trial is the best way to evaluate complementary and alternative therapies, especially when they are employed holistically. Where treatments associated with complementary and alternative medicine are targeted toward individuals rather than standard conditions as in orthodox biomedicine, their practitioners often argue that other methods of assessment are more appropriate. In this respect, rather than trying to eliminate the placebo effect through the randomized controlled trial methodology, it is frequently claimed that it should be more fully employed in complementary and alternative therapies. This makes other methods such as case studies and consumer satisfaction surveys all the more attractive as evaluative tools.

When looked at in these terms, there is a growing and ever more substantial evidence base for certain types of complementary and alternative medicine in relation to various specific forms of disability—as well as in health care more generally. Part of this evidence base is actually derived from the many small-scale controlled trials of complementary and alternative medicine that have been conducted as compared to placebos and more conventional approaches. Some of these have produced encouraging results, as, for example, in relation to the use of spinal manipulation and acupuncture in the relief of chronic pain. However, from the viewpoint of orthodox research methodologies the numbers of participants have usually been too restricted to make firm judgments about the likely efficacy of particular therapies. In such cases, systematic reviews of trial data can be very helpful, provided that clear criteria for inclusion and exclusion linked to the quality of the studies are employed and there are enough credible trials on which to build the meta-analysis. In the field of herbal medicine, for instance, such systematic reviews have recently suggested that St. John's wort can provide symptomatic relief in cases of moderate depression and peppermint can do likewise in the treatment of irritable bowel disease.

Once we look beyond this form of randomized controlled trial evidence on a more eclectic basis, though, the data set on complementary and alternative medicine becomes even richer. A plethora of individual case studies indicate the positive qualitative outcomes that can be obtained from such therapies, including in relation to different types of disability. The use of complementary and alternative medicine also tends to produce high levels of consumer satisfaction. Of course, the subjective views elicited in such research should not simply be treated at face value, as there are a variety of methodological pitfalls in interpreting such results. Nonetheless, they do at least suggest that unorthodox therapies could help to fill the vacuum created in areas where orthodoxy has little to offer, such as in a number of chronic conditions. In this regard, it is important to acknowledge that complementary and alternative medicine contains many diverse approaches, not all of which are equally well founded. A recent government report in the United Kingdom, for example, suggested that research evidence was currently much stronger for such therapies as herbalism, homoeopathy, and osteopathy than those such as crystal therapy, iridology, and radionics. This underlines how vital it is that the evidence for specific forms of complementary and alternative medicine is carefully and critically scrutinized before claims about its curative or palliative powers are accepted.

However, even where it is felt that complementary and alternative medicine can bring benefit to the disabled and others in the West, there are major organizational challenges to address. One issue is how accessible such therapies are to consumers within state-financed health provision and insurance programs, given that they are still primarily concentrated in the private sector. In this respect, it should not be assumed that complementary and alternative therapies can simply be slotted in as cheaper versions of orthodox medical provision; even when they appear to be more effective they are not necessarily less costly as they can be more labor-intensive than biomedical practices despite the technology that is often involved. This clearly raises equal-opportunities questions in relation to the disabled and other users of such therapies.

Another organizational issue concerns the extent to which complementary and alternative medicine is appropriately regulated in terms of protecting the interests of health consumers, including those with disabilities. In this respect, the remedies themselves and practitioners of these therapies are now increasingly subject to regulation, but the parameters of this are not always well balanced. For instance, despite growing trends toward professionalization, the practice of complementary and alternative medicine in the West is too exclusively concentrated in some countries in the hands of doctors and allied health professionals. In other countries, it is too loosely assigned to anyone who wishes to be engaged in the field—in systems largely based on voluntary regulatory arrangements to which not all practitioners are legally bound.

Finally, it should be noted that complementary and alternative medicine in the West does not simply challenge biomedicine in terms of best practice. In its most radical forms, it also challenges some of the wider assumptions underpinning medical orthodoxy, paralleling the increasing questioning of the medical concept of disability noted at the outset of this entry. Many of those currently involved in practicing complementary and alternative medicine, for example, no longer see consumers in medicalized terms as patients, but rather as more active participants in their own well-being. Given its links to the counterculture, the self-help aspect of this area is therefore not now seen just as an appendage to medicine but also as challenging the power of the medical profession. While biomedicine is currently dominant, the approaches that are now categorized as complementary and alternative medicine could at some stage in the future become more fully incorporated as the basis of a new orthodoxy. Whatever happens, though, it is vital at present that we strive for a greater accommodation between orthodox and complementary and alternative medicine so that those in need of assistance—including the disabled—can draw on the most useful and well-evaluated support from the viewpoint of potential cures, palliative care, and health maintenance.

—Mike Saks

See also Acupuncture; Chiropractic Care; Medicine.

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COMPUTER SOFTWARE ACCESSIBILITY

The short definition of *computer software accessibility* is as follows: Properties of a computer program or system that allow for the widest possible range of users to access the software system's functionality. To define the term more fully, we should look into the definition of each term in the phrase.

Computer software refers to the programs and instructions that specify calculations and direct computer hardware operations. Software comes in two main forms: system software, which controls the basic functions of the computer system (such as the basic input/output system and resource management), and application software, which perform higher-level tasks, such as word processing and productivity software. Software can range from a single program running on a single machine to a distributed system that runs on multiple machines and communicates over a network.

Accessibility in general refers to an item's properties that allow for the greatest range of use by users with the widest range of abilities and disabilities. Therefore, accessibility can refer to the level of access to a resource by a user, regardless of ability level. Accessibility can range from relatively *high accessibility,* which allows for little to no modification or concession to gain access or use, to relatively low accessibility, which allows only for specific users to gain access and use the product's features.

Therefore, *computer software accessibility* refers to the degree to which a computer program or computer system's properties allow it to be used by the widest variety of users with abilities and disabilities. This also entails accessibility of software that can reside on a single computer, or software systems that run on multiple machines to perform a task.

Accessibility of computer software running on multiple computers can involve accessibility from a number of fronts. An example of this can be an enterprise software package that has database components running on various machines, logic on other machines, and user input handled on yet other machines. The accessibility of the database components can be measured by the ease of use for a database professional with a disability, while the accessibility of the user interface can affect novices using the system for the first time, or experts who are trained in the software package.

Accessibility of software can be affected by a number of factors. First, the architecture of the software may or may not take into account programming standards that allow for third-party systems or devices to extract information from the target software. Much like a computer monitor is able to extract graphic information about software, other output devices have the ability to extract information only if the software programmer specifies it to do so. This includes access by assistive technology, such as text-to-speech systems, tactile feedback systems, and other systems that allow for non-video representation of the software.

Second, the user's control over the software settings is directly affected by the amount of control the software programmer allows the user to have over the specified software. Examples of this include access to change the software system's font sizes, ability to change color and contrast settings in the software, or ability to specify output mode. Changes can be made directly by the user via features in the software itself, or indirectly via the operating system in which the software is running.

An *accessible* software system entails a relatively *high* level of accessibility. Accessible software adapts to a user's needs or preferences without reducing functionality or access to the system. An example of an accessible software system would allow a hearing-impaired individual to transform audio output in software to a textual/visual representation, or allow a visually impaired individual to choose to use audio capabilities to access data from the same system, or allow a person with a physical disability to use other input devices to function with the software system, other than limiting functionality to keyboard or mouse-only use. Accessibility of software is important to ensure that a wide spectrum of people can use the same technology with little to no modification.

In the larger scope, accessible information technology (AIT) encompasses not only computer software but also computer hardware, including desktop computers, laptops and notebooks, and computer peripherals. Accessible environments are the result of having accessible information technology implemented in a setting.

—Bob Alvarez

See also Accessible Internet; Computer Technology.

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COMPUTER TECHNOLOGY

Computer technology is an ever-changing and evolving technology. While the personal computer may be the most common association with computers and computer technology, computer technology has integrated across devices as diverse as copy machines, cell phones, and other communication devices. The integration of computers with power wheelchairs, electronic aids to daily living, telephones, and communication devices has given people with disabilities the potential to control more of their environment than ever before. For a person with a disability, a computer can provide opportunities for communication, education, banking, shopping, or employment that may not otherwise be possible. However, to make use of the advantages offered by computers and their integration with other systems and devices, a person must be able to access the computer.

ACCESS

When considering access to a computer, one must investigate both input and output methods. Input methods to the computer commonly include a standard keyboard and mouse, while output is generally associated with a liquid crystal display (LCD) monitor, speakers, and a printer. Without any adaptations to the system, a person with a disability may have trouble entering data, controlling the mouse, or reading text from the monitor. Those who may have difficulty using standard input and output methods include people with visual impairments, hearing impairments, cognitive impairments, and motor difficulties.

For those who are unable to use a standard keyboard or mouse to input data, alternative keyboards and mouse emulators are available. These alternatives are generally plugged into the standard keyboard or mouse ports on the computer and may be used exclusively or in addition to the standard keyboard and mouse.

ADAPTATIONS TO COMPUTER INPUT

For an individual with a motor impairment who has difficulty accessing the standard size or location of keyboard keys, a smaller- or larger-size keyboard may be useful. Smaller keyboards may be beneficial for those with limited range, such as individuals using a mouthstick or people with weakness in their upper extremities. Larger keys may benefit those who must use a larger surface area such as their thumb, a pointing device, or their entire fist to access each key, rather than one finger. People with visual impairments may benefit from simply larger key labels affixed to a standard keyboard, without changing the size of the keys themselves. A concept keyboard that allows for programming individual keys with pictures versus standard characters, or limiting the number of keys to work in conjunction with a specific software program, may be beneficial for a person with a cognitive impairment.

Although many keyboards have been developed as an alternative for using a standard QWERTY keyboard, manual text entry is not always an option. An alternative to manual text entry that has become widespread commercially is voice recognition. Voice recognition software allows a person with clear diction and strong breath support to dictate commands to a computer, via the use of a calibrated microphone. Voice recognition programs require extensive training by the user, for the creation of voice files that will be assigned to each individual user. Although voice recognition programs have become much more accurate and reliable over time, the level of cognition and dedication required can be a disadvantage for some individuals.

Another alternative is the use of indirect means of manual text entry. These include single or multiple switches and scanning or coded input such as Morse code. Each provides a means of accessing multiple keys. To access keys through switches and scanning, an individual needs to time the activation of a switch to a highlighted or speech feedback scan. The scan singles out each key or set-of-keys option as it moves along at a calibrated, timed pace. With Morse code, the activation of the correct sequence of switch hits allows one to enter text as if using a standard keyboard. The benefit of scanning and coded input is the flexibility offered in terms of access site. A person who is unable to use his or her hands may be able to activate a switch placed near the person's head. Drawbacks to using scanning input are its slow means of text entry and timing of switch activations to the scan. A drawback to coded input is often the cognitive load required in learning the designated key combinations to use the system efficiently.

One method of switch access that is currently in the research-and-development stage is the use of direct brain interface and switch closure. This method is designed to allow a person to select a desired target strictly by concentrating and imagining selecting the target. The signals generated by the person's brain are captured and translated to a switch closure, which in effect acts as if the user activated the switch manually.

Most computer interfaces are based on a graphical user interface (GUI), in which a mouse is used to access icons, windows, and menus. Using the mouse can often present difficulties for a person with a disability. Alternatives to the standard mouse can range from a simple device such as a trackball to a more advanced solution such as a touch screen or an eye gaze system.

An ergonomically shaped mouse, a joystick, or a trackball or track pad are simple alternatives to the standard mouse for an individual with a motor impairment. For example, a person who experiences hand tremors might find rolling the ball of a trackball easier than controlling a hand-held mouse to move the cursor to the desired location. For a person who is unable to use his or her hands, a mouse operated by moving the person's head may be an option. Head-mouse systems range from infrared technology by way of a reflected dot worn on the glasses or forehead to ultrasound technology with location sensors to a camera that translates movement of the head into cursor movement.

For a person with limited vision, software that enlarges the pointer/cursor in conjunction with enlarging the icons, characters, and windows on the display makes using a pointing device possible. For an individual with no vision, keyboard equivalents in conjunction with a screen reader are often used to access the computer.

One of the latest advances in computer-aided assistive technologies is the use of eye gaze technology. An eye gaze system allows an individual to make selections on a computer screen or communication device through the use of eye movement. A camera mounted near the user's eye tracks eye movement through the use of infrared technology. The system allows the user to direct the mouse cursor across the screen through eye movement. Through the use of a separate switch or a dwell-click of the cursor, the user is able to activate desired targets. It should be noted that eye gaze technology is in its early stages, and most systems require repeated calibrating to ensure accuracy for each individual.

ADAPTATIONS TO COMPUTER OUTPUT

Just as there is more than one way of entering data into a computer, there are several means of presenting data to the user. The most common source is generally through a standard LCD monitor. For people with visual impairments, additional auditory output such as indicator alarms, tones, or synthetic speech can be beneficial. The use of high-contrast colors or screen magnification is also commonly used by people for whom standard 12-pt. font or standard screen colors are not appropriate.

For blind users or people for whom screen magnification is insufficient, screen readers are another option. Software programs are available that will read text aloud to the user, navigating through text boxes as well as graphics. Often the user is able to control the speed, pitch, and volume of the output, as well as fast forward or move back to a specific location in the text.

A standard computer printer is the most common source of hard-copy output from a computer. However, for those who are unable to read copy from a standard printer, Braille printers provide blind users with an opportunity to read text that has been converted to Braille and printed out on hard copy.

Refreshable Braille displays provide blind users with the option of reading on-screen text that has been converted to Braille characters through the use of vibrating pins in the shape of individual Braille cells. Refreshable Braille displays allow users to read longer passages of text without using any paper.

For a person with a hearing impairment, visual output in the form of blinking indicator alarms or text messages provide alternative feedback to sound or speech feedback. Newer technologies involve text captioning of spoken and or auditory information presented on a website or DVD.

Adaptations to computer input and/or output can make accessing and using a computer possible when standard available options are insufficient. Computer technology in relation to disability encompasses these alternatives by which an individual is able to access a computer. While many technologies are readily or commercially available, others are still in the research-and-development phase.

—Kathy Hooyenga and Dana Mavros

See also Accessible Internet; Assistive Technology; Augmentative Communication; Computer Software Accessibility; Information Technology.

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CONFINEMENT

Western communities explain and legitimize the confinement of persons with supposed "impairments" through medicalized notions of treatment and care. Bodies deemed impaired are confined for their "own good" and for their "best health." Guided by biomedical logics of beneficence, Western common sense claims that bodily impairment necessitates confinement.

What this popular position overlooks—or, perhaps, actively obscures—is that when social communities confine those they mark as impaired, they create a major source of disability oppression. Confinement either directly causes, or indirectly reinforces, all five major forms of disability oppression: marginalization, powerlessness, exploitation, cultural imperialism, and violence. First, confinement, or the ever-present threat of confinement, removes and marginalizes those categorized as impaired from active integration with the community. Second, confinement leaves the impaired powerless to follow their own will or meaningfully contribute to community life. Third, confinement exploits the impaired by making them the raw material for a vast therapeutic industry. Fourth, confinement creates, symbolizes, and shores up a culturally rigid binary between the able-bodied and the disabled. This binary generates an able-bodied cultural norm that imperially looms over the disabled in an ever-present position of privilege and desire. And, finally, confinement provides the ideal space for violence. Through the exclusion and seclusion of confinement, the impaired may be, and often are, the victims of physical, sexual, and psychological abuse, not to mention sterilization and extermination through eugenic policies and ideologies.

Popular common sense not only overlooks these oppressive realities of confinement, but also covers over the historical dimensions of confinement practices. The popular perspective—which, working through a biomedical lens, sees confinement as necessary and beneficent for those marked as impaired—too readily neglects the historical roots and social imperatives of confinement. Also, it does not acknowledge the historically and socially constructed dimensions of the terms *impaired* and *disabled*. Furthermore, it does not acknowledge how confinement helped bring about and shore up these notions of impairment and disablement. It fails, in short, to acknowledge how confinement practices, which emerged in the industrial era, have been a major source of disablement.

In Western feudal society, the impaired were not confined, primarily because the distinction between the impaired and the nonimpaired was much less marked. Most of the population lived on rural manors. Chronic difficulties due to injuries and communicable diseases (such as tuberculosis) meant that many people were impaired (as we understand the term today) in some way. Whether they were impaired or not, most people spent their lives very close to home because feudalism meant little or no travel. In addition, the impaired and able-bodied worked alongside each other, and feudal work was not commodified into classes of paid and nonpaid activities. It is true that work was gendered (home-work for women; field-work for men), but it was not hierarchically arranged by an outside value system that paid for some work but not others. Work was work and it had to be done. Family and community members, regardless of bodily difference, pitched in as best they could. Since no one traveled much and everyone worked side by side, there was much less difference in experience between the impaired and nonimpaired. Thus, the distinction between the two was not marked in the way that it is today.

Industrial capitalism dramatically changed this feudal scene and set the stage for what Michel Foucault calls "the great confinement." The spread of free market economy, wage labor, and mechanized systems of production created conditions highly unfavorable for flexibly integrating the impaired through family-based work and support systems of feudal societies. Industrial capitalist systems relied on rapid-paced factory work, enforced discipline, and regulated norms of production, which effectively excluded the integration of a diversity of bodies.

This social exclusion of bodies by the capitalist community of normative work roles created a *social problem.* What to do with the newly dis-integrated bodies? As Foucault documents, Western societies responded with a *social solution.* Foucault uses the example of seventeenth-century France, which created a network of enormous houses of confinement—known as *hôpitaux généraux*—across the country. Within a period of several months time, one out every hundred inhabitants in Paris found themselves confined. Foucault emphasizes that these hôpitaux généraux were not medical establishments. They were a cross between a workhouse and a prison, part of a system of administrative supervision established to create social containment for those "outside" the new capitalist system. The confined in these institutions were not "patients" but a mixed population of the unemployed, the poor, the idle, the criminal, the impaired, and the mad.

The developing bourgeois order of industrial capitalism did not admit these people to the hôpitaux généraux for medical causes or medical treatment. They admitted them because the confined were unable, or unwilling, to cope with the newly established order of rigid work roles. Though internment was billed as a form of public assistance, once placed in confinement, forced labor was the rule. Foucault (1987:68) argues that the compulsion to work, in addition to providing a source of cheap labor, had the role of moral sanction: "In the bourgeois world then being constituted, the major vice, the cardinal sin in that world of trade, had been defined: it was no longer, as in the Middle Ages, pride or greed, but sloth." As a result, the common category that grouped the confined together was their inability to participate in the production and circulation of wealth in the new economy. Exclusion and internment due to inability to work created a new division in social space and a powerful new social solution for the social problems of the industrial order.

Though we no longer have *hôpitaux généraux*, their legacy remains very much with us today. Generalized internment lasted for just over a century when political denunciation began to break up this form of confinement. Liberal reformers argued that generalized confinement created a dumping ground that failed to separate those unwilling to work from those who were unable to work (in other words, it failed to separate the deserving poor from the undeserving). In response to this political critique, the eighteenth- and nineteenth-century reforms created ever more specialized institutions for ever more specialized populations. For example, the English Poor Law Amendment of 1834 stipulated five categories of those unable to work: children, the sick, the insane, defectives, and the aged and infirm. These specialty categories set the stage for the development of specialty institutions familiar to us in current times: orphanages, medical hospitals, asylums, residential care facilities, and nursing homes. All but the first of these institutions are administered through medical superintendents and medical logics of expertise. But, as the history of confinement reveals, medical issues are not the primary social function of these institutions. These institutions retain their function as a social solution that fails to integrate the "disabled" into the community (see Snyder and Mitchell [2003] for a particularly evocative presentation of institutional life and institutional social function).

Recently, the process of reform has started once again. Since the 1960s and 1970s, the broad social movement of "deinstitutionalization" has reduced the population of specialty institutions. But, once again, this reform only reshuffles the deck. The logics of confinement remain firmly in place. In other words, deinstitutionalization has not been effective at community integration. The previous medicalized relations of power continue to exist in the new "community settings." Deinstitutionalized community placement has done little to adjust community rules, norms, and expectations for successful social function and social contribution. Well-established standards of universal design for an accessible environment have not been widely adopted. Even though, for many disabled persons, adjustments to the environment represent the only feasible means of improving lives and joining with the community. Without these adjustments, too many disabled people today are condemned to live indefinitely in the remaining specialty institutions or in newly formed community residences and "back bedrooms"—where they once again become virtually incarcerated without any real chance of interacting with others (Hahn 2002).

There is very little that is voluntary or emancipatory about these deinstitutionalized community settings. People's choices in these community settings too often represent serious compromises based on severely limited options. In the most blatant examples, community confinement is enforced with all the state pressure of previous institutional internment. For example, recently passed outpatient commitment laws across the United States require mentally disabled people to stay on medications, and compliance with these laws is enforced through state sanctions. The common slang for these medications, "chemical confinements," clearly indicates the continuing logics of confinement in the transition from institutional to desinstitutionalized care.

It is important to note that, whether one is currently confined or not, the continued specter of confinement haunts everyone. The failure of community integration should not be understood as a "minority" issue. This failure hurts not only the disabled, it hurts the abled (or temporarily abled) as well. It leaves in place an archipelago of confinement that forms an ideologically oppressive threat for all. There can be no escaping that the failure to set up the structures of accessibility and interdependence leaves everyone either trapped and confined, or caught in the relentless fear of becoming trapped.

In sum, confinement must be understood as a social intervention much more than a medical one. But confinement is a bad social solution to physical and psychological difference. The social solution to the social problem of disintegrated community members is not social exclusion and social confinement. The social solution is social integration.

—Bradley Lewis

See also Deinstitutionalization; Institutionalization and Segregation.

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CONFUCIUS (551–479 BCE)

Chinese philosopher

The teachings of Confucius were adopted as the official moral and political ideology of China in the former Han Dynasty (206 BCE–AD 25). Since then, they have exerted a profound influence on Chinese state and society. Among the Confucian virtues are benevolence (*ren*) and filial piety (honoring one's parents; *xiao*).

Ideals of benevolent but authoritarian rule have shaped a paternalistic approach to society's most vulnerable: those without families and with serious impairments. There are references dating back several thousand years to imperial Chinese emergency relief and tax exemptions for people with specific and serious impairments.

Confucian ideals of state and society are firmly centered on the family and on the concept of order: everyone and everything in their proper place and rigid family hierarchies based on age, gender, and filial obligations. Disorder is inherently undesirable—and this is applied equally to the body as to the family or state. Bodily difference through impairment or illness is constructed as not-complete, not-correct, not-normal, and not-filial. One of the Confucian classic texts (*Book of Filial Piety*) states that to injure even one's hair or skin is to dishonor one's parents. Confucianist teachings also restrict the potential for people with certain impairments from attaining personhood through exclusion from marriage and ancestral rites.

Thus, Confucianist approaches to bodily and mental difference simultaneously afford protection (placing obligations on the family to provide support) while labeling difference as disorder. The result is a strong sociocultural legacy in China and other parts of East Asia of marginalizing disabled people and treating them as the "Other."

—Emma Stone

See also Disability in Contemporary China; Experience of Disability: China; Experience of Disability: Taiwan; History of Disability: Korea.

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CONSENT TO TREATMENT

WHY CONSENT?

Historically, many physicians believed that it was their right and responsibility to make treatment decisions for their patients, particularly if the patient in questions was considered to be incapable of making his or her own decisions. Over time, however, courts have made it increasingly clear that treatment without consent violates fundamental legal principles.

Arguably, modern consent law grew out of the need to protect physicians from allegations of assault for touching the bodies of others without consent. In more recent times, courts have tended to view lack of proper informed consent as an issue of negligence. Practitioners have been held liable if treatment that later results in harm to the patient is administered without proper informed consent and it can be shown that the patient would likely not have consented had he or she been provided with the appropriate information on which to base the decision.

Whatever its genesis, modern consent law represents a fundamental cultural shift and has immense symbolic significance. It marks a fundamental shift away from medical paternalism. It makes the patient a partner in his or her own care and symbolizes the fact that patients, not health professionals, are at the center of health care and the very reason for its existence. It stands for the uniqueness of each individual and the right of each person to make health care decisions if capable of doing so. More than all of this, consent principles stand tall as a monument to personal autonomy and self-determination, the fundamental rights of every individual in a free and democratic society.

THE REQUIREMENT FOR CONSENT

Treatment Requires Informed, Capable, Voluntary Consent

With the exception of certain emergency situations, all treatment requires informed, capable, voluntary consent. If capable, the patient makes the decision. If the patient is not capable, a surrogate makes the decision on his or her behalf.

The Meaning of Consent

Valid consent does not mean a signature on a piece of paper. For consent to be valid, it must be informed and be given voluntarily by a capable person. Consent may be oral or written, expressed or implied.

Informed consent means that the health practitioner has given information that a reasonable person would need to make the decision and has answered any relevant questions that the person asks. The consent must not be obtained through misrepresentation or fraud.

Consent may be withdrawn at any time by a person who is capable of doing so. A person who is capable of consenting to a treatment is considered to be capable to withdraw the consent. A person who becomes capable after a treatment starts is entitled to take over the decision making from the substitute decision maker.

EMERGENCY TREATMENT

A health practitioner may treat without consent in situations where the patient is incapable of making his or her own treatment decisions, a surrogate is not available, and there is a risk of imminent loss of life unless the practitioner has reasonable cause to believe that the person expressed a wish to refuse consent to the treatment while capable.

CAPABLE OF CONSENTING TO TREATMENT

Capable individuals make their own treatment decisions. A person is capable of making decisions about a treatment if able to understand the information relevant to making a decision about the treatment and able to appreciate the consequences of a decision or lack of decision.

Some people are incapable of consenting to one treatment, yet capable of consenting to others. The concept of global capacity or global incapacity does not exist in law. A person may be incapable of consenting to a treatment at one time but capable at another time.

A person is presumed to be capable of making a treatment decision unless there are reasonable grounds to believe that the person is incapable. Persons should not automatically be presumed incapable purely on the basis of age, physical frailty, or diagnosis, although all these factors may be important in the assessment of capacity. In many jurisdictions, there is no fixed age of consent.

INCAPABLE OF CONSENTING TO TREATMENT

An incapable person cannot provide valid consent. Even if a person is willing to have a treatment, a health practitioner may not presume that he or she is capable of consenting to the treatment when it is unreasonable to do so.

A health practitioner who is proposing a treatment may determine that the person is incapable of making decisions about the treatment. The proper surrogate must then make the treatment decision. A person does not become incapable only because a health practitioner does not speak his or her language or has other difficulties in communicating with the patient. The health practitioner is obliged to take the steps necessary to establish communications.

A finding of incapacity must be made on the basis of an appropriate inquiry and objective criteria. The best interests of the patients should not play a role in the evaluation of capacity and the person conducting the evaluation must always keep in mind the fact that capable people have the right to make bad decisions. Capacity determinations should be carefully documented. An otherwise incapable person does not become capable because he or she goes along with the proposed treatment.

SURROGATES

Capable people are entitled to make their own treatment decisions. When a person has been found incapable of consenting to a treatment, a surrogate must make these decisions.

Applicable legislation or common law will generally set out potential surrogates in rank order. Court-appointed surrogates generally top the list followed by surrogates appointed by the patient and then family members in a specified order. It is the obligation of the health practitioner proposing the treatment to identify the legally appropriate surrogate. In some jurisdictions, a committee makes substitute decisions. Depending on the jurisdiction, the committees are commonly made up of health professionals, administrators, and family members.

RULES FOR MAKING SUBSTITUTE DECISIONS FOR TREATMENT

Capable Patients

Capable patients making decisions for themselves are not bound by any rules. They may make treatment decisions as they see fit, even if others see their decisions as ill advised, foolhardy, or even dangerous.

Decision Making by Surrogates: Prior Wishes

Surrogates are generally bound by a set of rules established by statute or common law.

Every person has the right to expect that his or her capable wishes will be respected.

A surrogate must follow a person's most recent capable wishes. Capable wishes may be expressed in writing or in some other way. It is always difficult, however, to decipher the precise nature of nonwritten wishes. Depending on the jurisdiction, written wishes may be set out in powers of attorney, advance directives (sometimes referred to as living wills), or similar documents. Depending on the jurisdiction, alternative formats, such as video statements, may be acceptable as well.

Values and Beliefs

Surrogates are expected to respect the values and beliefs of the patient when making a treatment decision. In some jurisdictions, values and beliefs are to guide the surrogate if there are no binding prior capable wishes. In other jurisdictions, values and beliefs are to be considered together with the other best-interest criteria, set out below.

Best Interests

If there are no binding prior capable wishes (or a decision dictated by the patient's values and beliefs in those jurisdictions where values and beliefs take priority), a surrogate must act in the incapable person's best interests. In deciding whether a treatment is in the best interests of the incapable person, the surrogate must generally consider all of the following:

- The values and beliefs that the substitute knows the incapable person held when capable and believes that he or she would still act on if capable
- If the proposed treatment is likely to
    - Improve the incapable person's condition or well-being
    - Prevent the incapable person's condition or well-being from deteriorating
    - Reduce the extent to which, or the rate at which, the incapable person's condition or well-being is likely to deteriorate
- Whether the incapable person's condition or well-being is likely to improve, remain the same, or deteriorate without the treatment
- Whether the benefits the incapable person is expected to obtain from the treatment outweigh the risk of harm to her or him
- Whether a less restrictive or less intrusive treatment would be as beneficial as the proposed treatment

THE USE OF FORCE

Properly obtained substitute consent allows a health practitioner to treat a patient without facing the legal censure that can flow from treatment without legally valid consent. What is not clear, however, is how much force a practitioner is entitled to use when a treatment-incapable patient for whom substitute consent has been provided chooses to physically resist the treatment, leave the area, or simply not appear as scheduled.

It can be argued that substitute consent rules are meaningless unless minimal force can be used to carry out the directions of the substitute decision maker. What is the point, for example, of declaring a person suffering from mental illness incapable of consenting to treatment if he or she is free to simply absent himself or herself or refuse the treatment?

It is equally clear, however, that substitute decision makers are neither the guardians nor custodians of the patient. Health practitioners and their assistants do not possess powers of arrest or detention. In democratic societies, the right to forcibly apprehend, detain, or forcibly interfere with the body of another can be granted only by the appropriately constituted legislative authority and must be subject to clear limitations, regulation, and oversight. No such authority or regulation is generally provided in the case of substitute decision making for health care. There is no clear solution to this conundrum. What is clear is that legislatures and courts will eventually have to sort out the issue if the modern principles of consent to treatment are to be respected and truly integrated in health practice.

THE PROBLEM OF COMPLIANCE

Many physicians and health care professionals understand and respect the principles of consent to treatment and do their best to apply them in their day-to-day practice. Other practitioners are misinformed, disinclined to follow the law, or both. Many practitioners believe that consent is not an issue as long as the patient acquiesces, or at least does not vigorously resist any treatment that is proffered. Others hold the false belief that all patients, regardless of mental capacity, are entitled to reject treatment.

The problem of disregard for consent-to-treatment principles is particularly acute when vulnerable people are involved. Many practitioners are inclined to ignore the voice and rights of vulnerable people who may be legally entitled to make their own treatment decisions. Some practitioners believe that they are entitled to make decisions on behalf of patients who have cognitive problems or severe physical limitations. Others routinely turn to substitute decision makers without any consideration of the patients' capacity to make their own decisions. The problem is particularly acute in long-term care facilities where the elderly are routinely stripped of their fundamental civil right to make decisions about their own care without the benefit of any formal consideration of their capacity.

Progress has been slow and there has been no shortage of bumps in the road along the way, but there is every reason to believe that the picture is not as grim as it might appear. Canadian medical schools, for example, now require that law and ethics be taught as part of the undergraduate curriculum. This process is having a profound effect on the students. Medical students, residents, and young physicians in Canada by and large understand the consent rules and struggle to integrate them into their day-to-day practices. As time moves on and similarly trained and inclined professionals move through the professional ranks, respect for the consent rules should become the norm. In the meantime, there is a clear need for a vigorous training program for health care practitioners and administrators, the development of standard and legally valid consent protocols for health facilities, and the use of enforcement mechanisms including professional discipline to deal with recalcitrant practitioners.

—Michael Bay

See also Competence; Consumer Control; Decision Making; Patients' Rights; Refusal of Life-Sustaining Treatment.

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▣ CONSUMER CONTROL

Consumer control is a principle that refers to the process of individuals with disabilities increasing their decision-making power over services affecting their lives. The principle implies that individuals with disabilities—as consumers of professional services provided by social service and/or health care agencies—have a say in the decisions that affect the quality or quantity of the services they receive. The underlying philosophy of consumer control is that people with disabilities are in the best position to identify their own needs, goals, and solutions to problems with service-providing agencies. This orientation transforms people with disabilities from passive clients to respected citizens. The principle of consumer control recognizes the strengths of people with disabilities and allows them to influence the services that let them participate fully in society.

The principle of consumer control is also predicated on the assumption that people, regardless of their status or condition, have the capacity to make informed decisions in order to gain greater control over relevant aspects of their lives. This position reflects a fundamental belief in people's ability to transform their own social reality. Unfortunately, disability has historically been used to prevent many individuals from engaging in this practice. Even today, many people with disabilities face great obstacles to exert meaningful control over relevant aspects of the services they receive. Negative attitudes toward people with disabilities have led to their status as an oppressed sociopolitical minority group. Treatment of people with disabilities, built on assumptions of incompetence, has led to a false sense of inferiority among many people with disabilities and to limited access to resources and opportunities. As a result, many people with disabilities are ill equipped to make decisions regarding the services or choices that affect them.

Consumer control is a principle integrally connected with the independent living and disability rights movements and it is also a reaction to the historical treatment of individuals with disabilities. In many cultures, people with disabilities have often been abandoned, hidden, and shunned by their families and communities. The negative attitudes informing many societies' treatment of individuals with disabilities have resulted in their physical and social segregation. These attitudes have also led to a lack of opportunity to exercise choice and control over issues affecting their lives.

People with disabilities have often had little consumer control over their medical and rehabilitative services. The medicalization and professionalization that characterize these two service systems have been based on the assumption that the service provider is the expert. Therefore, the service provider is in the best position to make decisions about the need for treatment and the form that the treatment should take. These assumptions have fostered passivity, dependence, and compliance with treatment plans and services among people with disabilities. However, as recognition of the competence and rights of people with disabilities took root, people began to challenge these features of the medical and rehabilitative systems. The process grew stronger with the establishment of centers for independent living (CILs) in the United States in the early 1980s but was ideologically rooted on the grassroots movement to enact the Rehabilitation Act of 1973.

In addition to asserting that people with disabilities have the right to exercise choice, a primary critique of the service system traditions was that for treatment and services to be most effective, they needed to be personally relevant. Personally relevant treatment and services focus on creating solutions that fit within the context of individuals' lives. Such approaches emphasize the feasibility of solutions given clients' life circumstances. In other words, these approaches are most concerned that solutions are practical and beneficial for consumers. Consumer control intends to promote personally relevant services that meet the needs of people with disabilities.

Advocacy efforts related to consumer control have centered on improving three elements of service provision: gains over the types of services offered, the quality of services provided, and where and how services are made available. A critical thrust of the principle of consumer control has centered on improving the variety of service options available to consumers. Except for large urban areas, most communities have very limited choices of programs, supports, and services to individuals with disabilities and their family members. But even where such services are potentially available, long waiting lists for government-sponsored programs or high costs of privately offered services limit their access to those in need.

The movement to increase consumer control has also focused on improving the quality of the services available to people with disabilities. This component of consumer control refers to ensuring that the services people with disabilities receive are appropriate and delivered by qualified individuals and that they are done respectfully, affirming the dignity of the person receiving services. The principle of consumer control also strives to increase the quality of services by creating mechanisms for consumers and families to complain about poor quality, improper treatment, or abuse. An important achievement was the establishment of the Client Assistance Program to address complaints about the services offered by vocational rehabilitation counselors working with state vocational rehabilitation agencies. Finally, consumers have advocated expanding services to underserved areas or populations. A good example has been the gradual growth of CILs by the Rehabilitation Services Administration in the United States. The most limited area of influence of consumer control is probably the way in which services are provided. The independent living movement has been marginally effective in influencing the preparation of future professional service providers in colleges and universities. It is expected that the recent appearance of disability studies programs will generate a more substantial change in the way professionals learn to respect and listen to individuals with disabilities and their family members.

In practice, the principle of consumer control exists along a continuum of control ranging from complete control of service provision to minimal consumer input regarding types of services and service delivery. Several contextual elements affect the level of control experienced by any one client or group of people with disabilities. Among these contextual elements affecting the degree of consumer control are an individual's age, type of disability, and type of service. As expected, given societal norms in general, individuals with disabilities have less control over important decisions as children; their degree of control generally increases with their age but then decreases again with senility. Family members and legal guardians can make all types of decisions regarding care and services for their children with disabilities until they reach adulthood.

There are also differences in the degree of control accorded to groups with different types of disabilities. Determined and reinforced by negative societal attitudes regarding the limited ability of people with some types of disabilities, the principle of consumer control is not always conceptualized and practiced equitably across disability types. In practice, individuals with intellectual disabilities and mental illnesses have been historically denied control over most relevant decisions regarding their housing, employment, treatment, and other services. People with either of these forms of disability often are allowed to exercise fewer of their legal rights and are less respected than people with other disabilities. However, the last generational efforts to deinstitutionalize and promote self-determination among these individuals has resulted in greater consideration of personal choices and options, based on the individual's ability to make informed decisions. Self-advocacy organizations of individuals with mental illnesses and/or intellectual disabilities have been instrumental in advocating for the individual's right to choose where and how to live and to refuse unwanted treatments. These issues have often become contentious, as parents or legal guardians sometimes seek legal recourse to force particular treatment or service options.

Finally, the degree of consumer control afforded to people with disabilities varies with the types of services provided. Highly professionalized services often accord less voice to clients (e.g., individuals who are being treated for severe traumatic brain injuries in rehabilitation hospitals), whereas less highly professionalized services often accord more voice to clients (e.g., support for activities of daily living provided by personal care attendants from community agencies such as in CILs).

To promote the principle of consumer control and thereby perhaps self-actualization, it is critical that governments create and maintain institutional settings and policies that promote such goals. Educational, vocational, and rehabilitative systems, among others, need to work to ensure that people with disabilities have the knowledge and experience required to be informed consumers and be allowed to exercise choice. This transformation implies political will and leadership to transform state agencies and change current policies and practices. In addition to creating and maintaining societal structures that foster consumer control among people with disabilities, people with disabilities themselves must also contribute to this process. Unfortunately, oppression has led to a false sense of inability among many people with disabilities. To challenge those notions, people with disabilities need to be exposed to new paradigms of disability that assert that disability is not inherently negative. New paradigms of disability emphasize how oppressive social conditions handicap the individual's capacity to participate actively and independently in society.

Realizing that the functional limitations experienced by most people with disabilities are often largely a function of environmental constraints is a step toward developing critical awareness. This awareness allows individuals to begin to recognize themselves as having the capacity to affect and perhaps transform their own social realities. It allows people with disabilities to realize their need to take control of relevant services and opportunities in their lives. The promotion of this critical awareness has become a priority among organizations of people with disabilities and is directly related to gains in consumer control around the world.

Several programs have been developed and implemented to assist individuals with disabilities in becoming better consumers and making choices that are better informed. These programs are typically designed to assist individuals with disabilities to identify needs, learn to examine available options to address identified needs, learn to select the most adequate choices for particular situations, and then practice the newly acquired skills. Examples include the following:

- Programs to assist individuals in locating appropriate housing in the process of moving from institutions into the community
- Programs to help individuals who use personal attendant care services in learning to recruit, select, and supervise their attendants
- Programs to aid individuals in managing long-term care services
- Programs to support consumers in selecting services
- Programs to help consumers of rehabilitation services in making informed choices
- Programs to assist youths in becoming actively involved in making choices and planning for their transition from school to work
- Programs to help consumers in making independent living choices
- Programs to support individuals in finding jobs or pursuing education goals

Increases in the degree of voice that people with disabilities have over services that they receive have resulted from advocacy efforts by and for people with disabilities. Through the disability rights movement, people with disabilities have become increasingly organized and able to effect real change over relevant issues in their lives. International organizations such as Disabled Peoples' International (DPI), a global organization to promote consumer control and advance the human rights agenda of people with disabilities around the world, have played important roles in promoting and expanding the principle of consumer control. DPI's central message is that of consumer control and self-representation. This international organization is one example of how the philosophy and values of consumer control and self-determination are shared among people with disabilities on every continent.

The concept and practice of the principle of consumer control have helped inspire the development of many recent policies affecting services to individuals with disabilities in the United States (e.g., the Americans with Disabilities Act of 1990) and other countries. These laws and policies all emphasize allowing individuals with disabilities to take greater control of services and choices relevant to their lives. Here are some examples:

> Disability Discrimination Act enacted in Australia in 1992
>
> Disability Discrimination Act enacted in Britain in 1995
>
> Standard Rules on the Equalization of Opportunities for Persons with Disabilities enacted by the United Nations in 1993
>
> Constitutional changes adopted in countries such as Germany, Austria, Finland, Brazil, Colombia, South Africa, Uganda, and the Philippines, among many others

As the disability rights movement gains strength worldwide, the amount of consumer control available to people with disabilities is gradually increasing. Years ago, people with disabilities were hardly ever given the opportunity to participate in decisions about their services and rehabilitation. For example, people with disabilities were often given goals or objectives by professionals that were impractical or irrelevant to their daily lives. Now people with disabilities are sometimes more equal partners with professionals in shaping service goals and objectives. Unfortunately, there are uneven practices and multiple variations of the principle of consumer control across professionals, communities, and national service systems. Despite the progress, there is a real need for consumers to remain vigilant to avoid losing the ground that has been gained over the past 25 years. Regressive political movements always remain a possible antidote to social innovation and have to be carefully monitored.

—Fabricio Balcazar and
Katherine E. McDonald

See also Advocacy; Americans with Disabilities Act of 1990 (United States); Disability Discrimination Act of 1995 (United Kingdom); Disabled Peoples' International; Empowerment and Emancipation; Independent Living; Participation; Self-Sufficiency.

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CONSUMER SATISFACTION

A central goal of all human services is that they, as far as possible, meet the needs and aspirations of their clients. It may seem obvious that producers competing in the marketplace to provide other goods and services should above all be attentive to their consumers' views and preferences. However, only recently has the concept of consumer satisfaction been explicitly applied to the field of health care and social services. In health care particularly, one consequence of the rise to prominence of the medical profession was that the success and value of services were professionally determined. Now it is increasingly recognized that the value of human services must be judged in terms of the extent to which clients or customers are satisfied as well as by more established criteria such as effectiveness, efficiency, and equity in provision.

Clinicians and service providers have come to accept the importance of satisfaction in health care for other, more practical reasons. Patients dissatisfied with their health care are less likely to follow advice or treatments, less likely to return to the provider with whom they are dissatisfied, and less likely actually to experience as many benefits of treatment as do satisfied patients.

We now have much more evidence available as to how consumers and patients view the services that they receive. Consumer satisfaction is widely monitored by services in most health care systems, most frequently by self-completed questionnaires but often also by means of in-depth interviews, focus groups, consumer panels, and other more interactive methods. There are at least 11 aspects of satisfaction with health services that have been shown to be of concern to patients: overall or global satisfaction, satisfaction with access, cost, overall quality, humaneness, competence, information, bureaucracy and waiting times, physical facilities, and attention to psychosocial problems.

The evidence also suggests seven fundamentally important issues of concern to patients and reflected in their responses to satisfaction surveys: dignity (being treated as a person, rather than a case), autonomy, confidentiality, prompt attention, quality of basic physical amenities, choice of care provider, and access to social support networks during care.

Overall, the main aspect of services that has consistently been found to influence levels of satisfaction has been the relationship between the health professional and the patient. The more successful the health professional is in establishing rapport and a personal relationship with the patient, the more likely is the patient to be satisfied. More specifically, the quality of communication between professionals and customers is the biggest single determinant of satisfaction. Numerous studies have obtained independent assessments of communication in consultations and patients' subsequent ratings of satisfaction with their care. Such studies consistently show that satisfaction is more often reported when the health professional adopts a more client-oriented style, asking open-ended questions, eliciting the patient's concerns, being responsive to verbal and nonverbal cues about such concerns, and providing information and advice in ways appropriate to the patient.

One complicating factor in the interpretation of evidence of consumer satisfaction is that properties of the respondent in a survey also appear influential. The most consistent trend is for older patients to report higher levels of satisfaction. It is not likely that this is due to older patients receiving higher quality of care, and it is more likely to be due to modified expectations. Another common observation is that respondents with poorer health status and greater psychological distress are more likely to be less satisfied with their care. From the evidence available it is not possible to say to what extent such trends arise from real differences in the quality of care rather than differences in expectations arising from poorer health status. The one clear implication of such trends is that apparent differences in levels of consumer satisfaction between services cannot immediately be interpreted as evidence of differences in the quality of care without at least adjusting for possible influences of patients' characteristics.

The greater the level of disability, the more likely are patients to be dissatisfied with their care, not only with regard to issues such as access and ease of getting to care but also in relation to overall quality of care, including the quality of communication. Such evidence helps make the case for the need for the physical redesign of health care facilities to adequately provide for individuals with disabilities. However, communication by health professionals also needs redesign to be appropriate to individuals with disabilities.

Reference has already been made to patients' expectations as an explanation for variations in levels of satisfaction. In practice, it is not easy to identify patients' expectations. Individuals may be unsure when asked to articulate their expectations whether they should consider the ideal or optimal or rather what they predict to be likely or realistic. Individuals may also be unsure whether they are "entitled" to hold expectations regarding their care. In any case, we are more likely to infer expectations from expressions of satisfaction than to be able reliably and independently to measure them.

Measurement of satisfaction is not without controversy. Levels of positive satisfaction are almost invariably very high in surveys of patient or consumer views, even with groups such as the young and those with disabilities and poorer health status who, relatively, express more dissatisfaction. Typically, over three-quarters of any sample express positive satisfaction. This regular skewness of consumer satisfaction data raises in some minds the possibility that there is a flaw in our methods of obtaining views and that with better methods respondents would be more diverse in their views. In particular, it is thought that there are strong prevailing norms that make it difficult for individuals to express critical comments about their health care. However, while it is clear that patients often have real difficulties in expressing dissatisfaction, there is no actual evidence to support the notion that different methods than the standard fixed-choice questionnaire would produce more diverse views.

Nevertheless, reservations about whether focusing on satisfaction inhibits respondents has led to increased emphasis on finding out patients' experiences rather than their subjective reactions to such experiences. When asked about experiences of specific problems, a more balanced picture of negative as well as positive aspects of services may emerge. For example, surveys in several Western health care systems reveal that the most common problem across types of hospital, experienced by over 40 percent of patients, is that no one explains the daily routines of the hospital to the admitted patient. Other problems experienced by patients across health care systems include not having side effects of medications explained and not receiving appropriate advice about what to do once discharged from hospital, for example, in relation to the decision of when to resume normal activities.

It can be argued that a focus on consumer satisfaction results in a very inert and reactive view of patients or clients, emphasizing solely how they respond to services received. Increasingly, it is argued that we must seek ways of actively involving the consumer. Collectively, this active involvement may take the form of collective community participation in prioritizing and governance of services. For individual patients, there are growing arguments for shared decision making between patient and doctor with greater emphasis on the treatment preferences of the patient. The evidence base to support both collective and individual-level involvement is not strong and identifies some problems of consumer involvement. For example, collective preferences regarding services may hold back development of public health and preventive health strategies and weaken services for socially undervalued groups. At the individual patient level, there may be minorities of patients who would prefer not to share decision making, and there may also be unwanted distress from the additional burden of greater involvement in difficult decisions. However, there is now in place an irreversible process of enhancing the consumer's role relative to that of experts.

The trend to enhance the consumer's voice regarding services is well under way and will pose fresh challenges for health care systems. Is there a point at which the erosion of professional autonomy excessively undermines professionals' confidence to undertake difficult responsibilities of care? Does consumer sovereignty risk increasing the access of the privileged at the expense of the weak? No model of health care, even one that has completely enshrined respect for the consumer, can be completely free of such tensions.

—Ray Fitzpatrick

See also Accountability; Health Management Systems; Home Support.

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CONSUMER-RUN BUSINESSES

Consumer-run businesses emerged in the 1980s as one way of addressing the systemic exclusion of people with disabilities from mainstream labor markets. Prominent forms include cooperatives, incorporated businesses, societies, partnerships, and sole proprietorships. This entry uses Canadian examples to illustrate these more generic forms and to highlight the strengths and limitations of their practice.

Regardless of how they are organized, consumer-run businesses have a dual purpose. First, they seek to generate income for the people involved through the production, marketing, and sale of goods and/or services. Markets include disability communities, health and social services sectors of the economy, and the general public. Second, equally important is that these initiatives are owned, managed, and operated by people with disabilities. They are concerned with questions not just of employment but of personal and collective empowerment. Consumer-run businesses fall into two general categories: self-employment and community businesses.

SELF-EMPLOYMENT

Self-employment is the predominant form of consumer-run business, referencing what most people in Western societies imagine by the term *business*. It describes the situation in which a disabled individual is the sole proprietor of some kind of entrepreneurial enterprise from which he or she derives a livelihood. In recent years, various levels of government have been encouraging self-employment among marginalized populations by participating in special lending and mentoring programs. So, for example, in Victoria, British Columbia, a woman disabled by a severe illness decided to start a secretarial services company. On the strength of skills acquired in the workforce, she received a loan that enabled her to purchase equipment and to advertise. Along with professional advice, the loan was delivered through a project called Advice and Business Loans for Entrepreneurs with Disabilities (ABLED). The financial base for ABLED was generated by a three-way partnership involving two credit unions and a federal investment organization. That partnership was encouraged by local agencies representing the disability community and by local business groups.

This story, brief as it is, illustrates some of the core dilemmas of self-employment. On the positive side, the woman was able to get to work fairly rapidly under conditions that used her strengths and responded to her needs. She earned enough to offset the fact that she was ineligible for a disability pension. In fact, she reports surpassing every financial goal that she forecast, hiring a part-time worker and beginning to envision hiring other people with disabilities. Her account is energized by a feeling of success and hope. It demonstrates the broadest advantage of self-employment, namely, that it enables disabled people to claim the powerful discourse of business in an increasingly entrepreneurial culture.

There is an opportunity for redefinition here, as those involved move from identifying as unemployed service recipients to productive business people. ABLED argues that "removing barriers for people with disabilities means moving from a service mentality to one that affirms good ideas on their own merits." This is an important shift in that it opens up depathologized subject positions from which people can become active in re/constructing their lives.

In a more critical vein, our protagonist has become the equivalent of a "pieceworker" in the new economy. Catching a wave of contracting out, she is paid separately for tasks that—taken together—used to constitute whole jobs. Her workplace has been blended into and will impinge on her domestic life, space, and time. She is relatively isolated and dependent on her own energy and initiative to keep earning. She has no union to represent her concerns, no way to collectivize the problems that arise with this form of labor.

This disabled entrepreneur must repay her loan with earnings that are probably modest and will fluctuate depending on demand. She is responsible for her own bookkeeping and taxes. If she falls ill in the future, she has no unemployment insurance benefits to draw on. Unless she establishes one herself, she has no pension or disability plan. As an entrepreneur, even though she is significantly disadvantaged, she will still be held accountable for her business according to private sector values and performance measures: individual initiative, competition, and fiscal profit as the bottom line.

COMMUNITY BUSINESS

The second type of consumer-run business is *community business,* sometimes referred to as *social enterprise.* By contrast with self-employment, initiatives in this category are collective. They involve a group of people creating and taking charge of the development and operation of a business. Examples from two different disability communities in Toronto illustrate the general form: Lemon and Allspice Cookery, and A-Way Express Courier Company.

Lemon and Allspice Cookery (the Cookery) is a wholesale bakery and catering business. It began in 1998 with a grant from the Ontario Ministry of Community and Social Services. The parents of a young woman with an intellectual disability were the driving force behind the project. They parlayed their daughter's skills at baking and selling cookies at a service agency snack bar into a legal business partnership that took in seven more disabled people. These eight have a leadership role in the business that includes decision making at monthly partnership meetings.

The partners are also the Cookery's core laborers, working in shifts to produce baked goods, sandwiches, and bag lunches as well as fruit, vegetable, and cheese trays. They deliver the goods personally using public transit. Customers include a core sympathetic market: community living associations, church and community groups, friends, and neighbors. The kitchen operates 35 hours per week plus some weekends. The partners each work 15 to 20 hours per week. A support worker and job coach work alongside them. Their salaries are paid by government grants.

The Cookery is supported in its ongoing evolution by a nonprofit cooperative corporation called Common Ground. Comprised of interested community members, its goal is to use members' collective wisdom to advance this approach to employment for more people with intellectual disabilities. On the co-op's list of concerns is the fact that, under Ontario's current income benefits program, the Cookery's partners are not allowed to earn more than $160 per month without a 75 percent "clawback" to their income.

A-Way Express is a courier service run by psychiatric survivors. It opened its doors in June 1987 following a feasibility study that generated start-up and initial operating funds. By 2001, the business had grown to 45 couriers, 17 part-time office staff, and more than 1,200 customer accounts. While it began as a worker cooperative, the company currently operates on a combination of revenues generated from its service and grants from the Ontario Ministry of Health. Couriers get around the city on public transit: by subway, streetcar, and bus. Many of their customers are located in government offices and nonprofit organizations, but over half are in the private sector. Couriers work part-time on commission. The rate of pay is set at about 70 percent of service charges. A minimum shift is four hours, but couriers may work as many hours as each decides will fit his or her needs. Their decision is strongly influenced by the fact that, because they remain on disability benefits, government policy caps their earnings at the same level it does the partners of the Cookery.

This unique company has been through many stages of development. Its primary growth crisis was the shift from being run by service professionals to being run by service users. For the past 10 years, its executive directors have been self-identified psychiatric survivors. On the 10-member board of directors, at least half are employees. The rest are "outsider" members who may or may not also be psychiatric survivors. The management team includes the executive director, office and marketing managers, head dispatcher, bookkeeper, head phone order-taker, and two courier representatives. This team meets biweekly to discuss current business, and it is responsible for all operations, office administration, implementation of board policies and procedures, and purchases. From the beginning, full staff meetings have been held once a month so that members can raise concerns and make recommendations. Staff members have ultimate decision-making power because of their representation at every level of the business, and through formal reviews of goals and objectives at annual general meetings.

Especially during the late 1990s, A-Way Express both contributed to and was supported by the work of the Ontario Council of Alternative Businesses (OCAB). OCAB is an umbrella organization for psychiatric-survivor-run businesses in the province. The organization's understanding of business development goes well beyond job creation and training to include a complex layering of community development, knowledge creation, and on-the-job, noncredentialed learning. It views the process as a way of bringing survivors together to challenge the delegitimized place that they hold in society. Part of business development then becomes helping employees question authority in their lives, particularly the authority of health and social service systems.

OCAB links the analysis of the psychiatric survivor movement to the emergent practice of alternative businesses. The work is political, not simply technical. Similarly, in a rare support manual, the National Mental Health Consumers Self-Help Clearinghouse in Philadelphia (online) gives as much attention to consensual decision making in consumer-run businesses as it does to financial operations. This reflects the self-help philosophy that underpins community businesses in the American experience and the desire that they act as sites of democratic participation for people whose voices are not easily heard.

Once again, the core dilemmas of these ventures are woven through their stories, crossing the differences they exhibit with respect to the role of families, professional service providers, and the disability rights movement. In a capitalist economy that reinforces the emphasis of disability discourse on independence and autonomy, collective enterprises such as community businesses are highly suspect. Are they not just a fancy new form of ghettoization that reinforces the segregation of workers in the face of attempts at integration?

The answer from the Cookery is that the business form delivers to its partners a mix of contact between people of similar background, language, and culture, and people from a variety of other backgrounds. The psychiatric survivor perspective is more challenging. They view consumer-run businesses as places where people who share similar experiences of oppression can congregate, speak in their own language, for their own purposes, without professional intervention. The connection being facilitated is not with the mainstream but with the mental health self-help movement—to draw from and build its capacities.

So is there a role for professionals in consumer-run businesses? "It depends" is probably the best answer. Clearly, the Cookery has made space for service workers who know how to advance the goals of the business. Organizers appear to be comfortable with this assistance. Psychiatric survivors exclude professional and especially clinical/therapeutic expertise in favor of hands-on peer training and support. At the same time, the most successful businesses connect with a range of people in the broader community who can offer the kind of technical and organizational expertise that will strengthen their operation—usually through board involvement.

But can initiatives such as these truly be called businesses when they rely on government grants, and show no signs over time of becoming self-sufficient? OCAB's response is to make a strong argument for the kind of "hybrid" (public/private) funding that has worked so well for A-Way Express over the past 15 years. This approach recognizes the heavy social agenda carried by community businesses as they work with and for some of the most socially and economically marginalized people of the Western world. It costs money to support these people properly in employment and especially to ensure that the jobs are flexible. All parties involved need to recognize a "multiple bottom line" when it comes to evaluating successful outcomes.

The Cookery and A-Way Express both depend for their local success on strong public institutions and public policies in the broader socio/political environment. Members of Common Ground identify four necessary supports: supportive legislation for incorporating cooperatives and business partnerships; public, cooperative, and private subsidized housing; affordable, physically accessible transportation; and guaranteed employment or day programs. The psychiatric survivor wish list would include short- and long-term strategies for creating and sustaining survivor leadership in survivor-run organizations of all kinds, as well as remedial "training" for service providers so that they can learn what it takes to become effective, less controlling partners to these emerging forms.

Consumer-run businesses in general would be well served if policy makers sorted through the conundrum of a pension/benefits system in which different levels of government (and sometimes private corporations) work at cross-purposes. For community businesses, an immediate and welcome solution would be to raise or remove completely the cap on earnings that currently acts as a disincentive in this sector.

CONCLUSION

In an early literature review, Fontan (1993) divided community economic development activities into liberal and progressive types. Liberal development aims to repair the economic fabric of the private sector to create jobs, while progressive development invests the economy with social concerns. This is a helpful formulation to keep in mind as consumer-run businesses spread. Given disabled people's desperate need for income, and the systemic barriers that exclude them from regular employment, it is difficult to dispute the "goodness" of any type of regular employment. Yet buying into approaches that emphasize work/jobs alone results in repair strategies that ignore deep structural inequities.

As brilliant and hopeful as consumer-run businesses can be, they are not an adequate substitute for using enlightened macrolevel economic and fiscal policies to address the crises of jobs and poverty. The risk of trying them out is to support neoconservative policies that dismantle state-supported social service provision in favor of individual self-reliance through entrepreneurship. Even as attention turns to economic development, disability advocates must continue to fight for access and high-quality support in the beleaguered areas of health and community/social services, subsidized housing, and criminal justice.

—Kathryn Church

See also Affirmative Businesses; Employment; Sheltered Employment.

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CONTRACTING OUT SERVICES

Governments throughout the world are increasingly contracting out the health care and social services provided to persons with disabilities. Although historically, most modern national governments have contracted out their purchases of architectural, defense, and engineering services for many years, contracting out the provision of health care and social services to the private sector is a relatively new phenomenon. *Contracting out* can be defined as a voluntary, binding agreement or contract between a government agency and a private firm to do something that is legally enforceable. The number, type, and scope of these service contracts are increasing because of government economic reform efforts and world trade agreements.

Contracting out the provision of services to the private sector is one of the most common forms of government privatization. Governments are increasingly contracting out services to reduce costs and to improve quality. They also are contracting out to obtain special skills and expertise, to meet temporary demands quickly that are beyond current capacity, and to increase services without having to hire permanent staff. Occasionally, governments are contracting out to experiment with vouchers to provide citizens with more choices as to service providers. Last, because of increasing public pressure, legislators are forcing many government agencies to contract out services to hold down taxes, limit the growth of the public sector, and reduce the overall role of government in society.

Proponents of contracting out services argue that the single most compelling reason for doing so is to reduce government costs. They argue that by contracting out services to the private sector, the competitive forces of the market will lead to lower costs. They also argue that unlike large government bureaucracies that tend to maximize their budgets and “build empires,” the profit motive of the private sector firms will lead to greater efficiency in providing the services.

Those advocating contracting out services cite a number of additional reasons why private firms will provide the services to the public at lower costs. They argue that large regional and national firms may provide the services at lower costs because of economies of scale. These large firms will be able to spread the costs of the services over a large number of units or agencies. In addition, the private firms may have lower overhead and startup costs. They may also have lower personnel costs because they do not have public employee unions. Private firms frequently have greater flexibility in the use of their employees, because they do not have to deal with rigid public personnel systems such as civil service. This flexibility may be very beneficial when undertaking short-term projects, using part-time workers, supplying specialized needs, or providing new services to clients.

Proponents of contracting out services expect that competition for contracts among private firms will produce better-quality services for the price paid, since a direct monetary incentive for good performance by the supplier exists. If the services delivered are judged to be inadequate by the overseeing government agency, other suppliers could be granted contracts.

Last, proponents argue that a major benefit of contracting out services is that it will slow, if not halt, the rapid growth of government. They believe that contracting out services will keep government budget growth to a minimum, limit the total number of public employees, and ultimately result in government having greater control over the services it provides.

Critics identify a number of inherent problems with contracting out government services. One major problem is that it may reduce accountability. The ever-present problem of making public officials accountable to citizens is greatly magnified with the addition of private sector firms carrying out the work of government. In a contracting system where structure is not hierarchical and where clear, straight lines of authority are often absent, political and legal accountability of a chief executive or legislative body are difficult to establish and enforce. Critics charge that it is much more difficult for citizens to hold contractors responsible than elected officials and bureaucrats when the services provided are unsatisfactory.

Contracting out services can lead to widespread corruption. Contracts are one of the most common and lucrative sources of corruption in government. Critics argue that purchasing services from one or a few private firms on a continuing basis can produce corrupt relationships between government officials and the companies. These relationships may erode both competition and quality control, which, in turn can lead to higher costs and poorer-quality services. Such relationships have resulted in numerous scandals at all levels of government involving conflicts of interest, bribes, kickbacks, collusive bidding, billing for work never performed, and other illegal activities.

The profit motive of private sector firms may result in incentives to cut corners on service quality. Critics point out that high financial stakes often bring with them temptations to maximize profitability by skimping on quality and discouraging access to services by high-cost clients. To increase profits, private firms may skimp on contract requirements or provide inadequate supervision. The for-profit firms may also avoid clients who are expensive to help, such as individuals with major physical and mental disabilities.

Contracting out services may increase the risk of interrupting services. Private firms are much more likely to curtail, interrupt, or cease operations due to such circumstances as financial problems, strikes, and the rebidding of contracts. Specifically, the services may be disrupted because the contractors have labor problems or are plagued with poor management. Contractors may also close down because of bankruptcy. Such actions can seriously affect client safety and health.

Critics argue that contracting out services is just a method of bypassing public employee unions and civil service regulations. They charge that private firms are able to provide services for less because they tend to hire inexperienced, transient personnel at low wages.

Another problem with contracting out services and a growing reliance on the use of private firms is that it may impede the creation and implementation of coherent public policy by government agencies. This difficulty is particularly great in areas that use a variety of different private firms that are concerned about maintaining their own individual autonomy and accountability. Planning for and coordinating the multitude of fragmented activities of private service suppliers only add to the already confused, overlapping, and complex divisions within government.

Last, some argue that governments are contracting out services as a method of complying with imposed hiring freezes, while at the same time they are expanding programs and services that are increasingly expensive and intrusive. Critics state that the mixing of public and private activities only masks the true growth of government. This illusion maintains the myth of less government, while government actually whittles away at the essential substance of private autonomy.

Some of the problems that plague contracting out services may be prevented by comprehensive contract preparation, careful contractor selection, proper contract implementation, and continuous and comprehensive monitoring of performance.

To ensure a successful outcome, government agencies considering contracting out services should start by conducting a feasibility study. The feasibility study should determine which services, if any, should be contracted out. The study should determine the agencies' direct and indirect costs of providing each service and appropriate direct and indirect measures of performance.

After a positive feasibility study, a well-written, detailed, and explicit contract must be developed. The contract should specify the desired levels of the service and identify specific performance (e.g., number of client visits, number of counseling sessions, and level of patient satisfaction), effectiveness (are the correct outputs, such as reduced number of disability days, being achieved?), and efficiency measures (are the outputs being produced cost-effectively?). The contract should precisely define the scope and quality level of the service, specify service and staffing levels, and identify service event (training sessions) and performance reporting schedules. Exact penalties and incentives should also be clearly stated. To prevent poor performance, the contract should require a performance bond and a termination penalty. The agency should have the right to reduce or suspend payments for a contractor's failure to meet appropriate standards. Incentives such as bonuses for exceptional service should also be specified.

After developing the contract, the government agency will issue either invitations to bid (ITBs) or requests for proposals (RFPs). ITBs involve sealed bids and public hearings and are normally used when contracting for a standardized service that is clearly defined. In contrast, RFPs involve negotiations among the parties prior to signing a contract and are mainly used for personal services, sole-source suppliers, and emergency procedures. Although the processes for ITBs and RFPs differ, success with either method requires competition among contractors.

From those firms that submit bids or proposals, the government agency must select the most appropriate contractor to provide the service. It is crucial that firms that are likely to perform poorly or that are unsuited for the contract be eliminated. When selecting the contractor, the agency must consider the final bid or proposal as well as the firms' professional qualifications, special experiences, capacity to perform the service, familiarity with the work, and past performances on similar contracts.

Once the contractor has been chosen and the work begins, the government agency must carefully monitor the contract for adherence to all of its provisions. Monitoring ensures tighter quality control, more cost awareness, and a reduced likelihood of contract abuse by the contractor. The monitoring process should be both continuous and comprehensive. It should include carefully reviewing the contractor's periodic progress reports, conducting citizen surveys and interviews, listening to citizen complaints, and making frequent onsite observations and inspections of the contractor's work.

In terms of the public policy implications for persons with disabilities, the available evidence of the success of contracting out government services is mixed. Switching to private sector firms to provide services does not guarantee cost savings. Many government agencies could provide the services at the same or lower costs. It also appears that in most instances, the quality of services provided by private firms and government agencies is very similar.

The success of contracting out services appears to be highly situational. It depends on such factors as the particular situations of the government agencies involved, their geographic locations, and the particular time periods. Success is greatly affected by the performances of the current service delivery system, special circumstances such as the number and quality of potential private suppliers, absorption of displaced employees, and the relationship between employee associations and government.

The appeal of contracting out government services becomes less apparent when one takes a closer look. In theory, contracting out these services brings to the public sector all the virtues of the private market—competition, efficiency, and lower costs. In practice, however, contracting out government services begs the ancient political question posed by the Roman satirist Juvenal: *Sed quis custodiet ipsos custodes?* (“Who shall keep watch over the guardians?”). There is a danger that beyond a certain point, government-by-contract may couple the inefficiencies of the public sector with the abuses of the private sector.

—Ross M. Mullner and Kyusuk Chung

See also Health Management Systems; Privatization.

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COSMOLOGIES OF MORALITY AND ORIGIN

A well-constructed cosmology of morality and origin traditionally tells how the world began; what it was made of; who was there; how things went wrong; some laws of correct and incorrect behavior between humans, deities, spirits, and animals; and perhaps a hierarchy of intelligence and moral superiority. A short version should be recitable in under 20 minutes and should require no higher mathematics. Hundreds of cosmologies have been collected and studied during recent centuries. Some involve disability in various significant ways. A few sketches follow.

In the Japanese classic *Nihongi,* versions appear of how Izanagi and Izanami first formed the Japanese islands, then “produced the leech-child, which even at the age of three years could not stand upright” (Aston 1986). The parents put this child Hiruko in a boat, and set it adrift. Their next child was Sosa no wo no Mikoto. His behavior, that is, continual wailing and cruel actions, led to banishment. Interpretations are many, yet the significance of these “strange” offspring remains unclear. Links appear with the deities Ebisu and Sukuna-bikona, the latter supposedly a dwarf.

Partners for the earliest progenitors were restricted to parents and brothers or sisters, for nobody else existed. Some accounts display unease about the inevitably incestuous relations. Another example is the Creator Prajapati who fertilized his daughter (Sky, or Dawn) in Hindu mythology. The cosmology might reflect later taboos, or the realization that endogamous relations increase the chances of congenital deformity; or there may be quite different explanations. These cosmologies suggest a very early human desire to explain congenital impairment.

A Samoan cosmology has the creator Nareau setting up the physical world and a great many creatures, then leaving it to the first two people to build the human world. They tell their son (“Mischief Maker”) to take up this job. He finds the created beings inert, deaf, dumb, and responseless, so he massages them into physical activity, gets their ears working, teaches them their names, and evokes speech from them. After a lot of trouble the human world gets organized.

A modern retelling of southern African cosmologies shows the Great Mother, Goddess of Creation, as both immortal and imperfect. She transmits physical imperfections to her creation, and there follows the birth of the first deformed child, the call to destroy this child, and its mother’s flight. Saved from death, the baby grows into a monstrous and destructive tyrant. An interpretative postscript suggests this as a reason why Africans used to “destroy crippled and otherwise deformed children” (Mutwa 1998).

A contrasting eastern African cosmology suggests a deity concerned with inclusive attitudes and practices toward disabled humans. The Wagogo tell of several men who tried to obtain fire from heaven. All were sent home empty-handed because they had laughed at disabled people whom they met on the journey. Finally, a woman went to get fire. She behaved sensitively with the disabled people she met, and also got along well with God, so was rewarded with a pot of fire.

—*Kumar B. Selim*

See also Folk Belief.

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COSTA RICA

See Experience of Disability: Costa Rica

COUNCIL OF EUROPE DISABILITY POLICY

The Council of Europe is an intergovernmental organization that was founded in 1949. At present, it has 46 European member states with a total population of about 800 million. The headquarters are at the Palais de l'Europe in Strasbourg, France. The Council of Europe aims at protecting and promoting human rights and fundamental freedoms; strengthening pluralist democracy and the rule of law; promoting awareness of a European cultural identity, while enhancing cultural pluralism; seeking solutions to problems facing European society and contributing to the reinforcement of social cohesion; and supporting central and eastern European countries in carrying out and consolidating their political, constitutional, legislative, and judicial reforms, thus contributing to developing and consolidating democratic stability all over the continent.

The Council of Europe's activities cover all major issues facing European society other than defense. The main instruments of the Council of Europe are standard setting, policy recommendations, and project management. Legal instruments can take the forms of conventions or agreements, recommendations or resolutions. Conventions and agreements are legally binding on the states that ratify them. At present, some 200 conventions provide the basis for member states to harmonize their domestic laws, for example: the European Convention on Human Rights (1950). Recommendations and resolutions addressed to governments politically commit governments to follow a common course of action, for example. Reports and comparative studies analyze current issues and provide information and advice to decision makers, often by identifying examples of good practice.

Since the scope of Council of Europe activities is so extensive, states wishing to engage in some action in which not all their European partners desire to join can conclude a "Partial Agreement," which is binding on themselves alone. It was on this basis that in 1959 the Partial Agreement in the Social and Public Health Field was concluded to work, among others, for the integration of people with disabilities. Today, that Partial Agreement has 18 member states. Several countries participate as observers, including Canada (the only non-European state).

Human dignity, equal opportunities, independent living, active participation in the life of the community—in short, full citizenship—form the heart of the Council of Europe's activities in relation to people with disabilities. To reach that goal, the Council of

Europe disposes of the following set of instruments, consisting mainly of the Revised European Social Charter, several policy recommendations addressed to member states' governments, and relevant reports to serve as source of inspiration and guidance.

The European Social Charter (1961) is the counterpart of the European Convention on Human Rights in the field of economic and social rights. It protects some 23 fundamental rights in the field of employment and social protection. Article 15 is of particular importance to people with disabilities: "The right of physically and mentally disabled persons to vocational training, rehabilitation and social resettlement." Although today the concepts and language used seem outdated, in 1961 they provided a landmark.

To take account of social changes, the Revised European Social Charter was adopted in 1996, coming into force on July 1, 1999. It updates and strengthens the rights guaranteed by the charter and also includes new rights. The scope of Article 15 has been extended considerably and now goes much beyond employment issues. It reads: "The right of persons with disabilities to independence, social integration and participation in the life of the community."

The Social Charter is monitored with the help of a reporting system and an independent committee of experts (European Committee for Social Rights). Since July 1998, however, a revolutionary collective complaints procedure allows also nongovernmental organizations to bring allegations of violations of the charter before that committee.

The Committee on the Rehabilitation and Integration of People with Disabilities (CD-P-RR) has drawn up general policy principles for the rehabilitation and integration of people with disabilities, which are enshrined in Recommendation No. R (92) 6 on a Coherent Policy for People with Disabilities, adopted by the Committee of Ministers of all member states of the Council of Europe in April 1992. This recommendation contains a model program for a coherent disability policy, recommending to member states' governments to develop comprehensive and coordinated national disability policies, taking account of all successive stages in the integration process and all areas of community life, such as prevention, diagnosis, treatment, education, vocational training, employment, social integration, social protection, information, and research. The recommendation has set benchmarks both nationally and internationally, thus prompting numerous amendments to legislation in member states.

The report *Integration of People with Disabilities: Policy and Legislation,* a compendium of current, national legislative texts and policy programs, helps to identify achievements and shortcomings of national disability policies. It is thus an indispensable complement to the Recommendation No R (92) 6 on a coherent policy. The seventh edition of the report (2003) covers 16 European states.

The 1995 Charter on the Vocational Assessment of People with Disabilities calls for a shift in focus: from disability to ability. The person's vocational abilities and not disabilities should be assessed and related to specific job requirements.

The 2001 Resolution on Universal Design aims to improve the accessibility of the built environment by recommending the inclusion of the principles of universal design into the curricula and training of all vocations working on the built environment, in particular architects, engineers, and town planners.

The 2001 Resolution on New Technologies recommends drawing up national strategies to ensure that people with disabilities benefit from the manifold opportunities offered by new technologies, rather than being excluded due to newly created barriers caused by inappropriate technology design or provision. All products and services for people with disabilities should take account of the following quality criteria: availability, accessibility, affordability, awareness, appropriateness, attractiveness, adaptability, usability, and compatibility.

The report *Legislation to Counter Discrimination against Persons with Disabilities* (2000, second edition 2003) takes stock of existing legislation and identifies three main approaches to achieving equality of opportunity for people with disabilities: antidiscrimination legislation, preferential treatment, and compensatory measures.

The report *Safeguarding Adults and Children with Disabilities against Abuse* (2002) aims to make visible the extent and nature of such abuse and to ensure that people with disabilities are safeguarded against deliberate and/or avoidable harm at least to the same extent as other citizens and that where they are especially vulnerable additional measures are put in place to ensure their safety.

The report *Access to Social Rights for People with Disabilities in Europe* (2003) describes general principles and measures designed to give people with disabilities access to social rights in Europe. However, it also identifies those obstacles that still impede access for people with disabilities to social rights and consequently to full participation in society, particularly in the areas of education, vocational training and employment, the built environment and transport, information and communication, health care, and social protection. It gives numerous concrete examples of good practice, that is, action taken by member states to overcome those obstacles. Finally, the report issues cross-sectoral recommendations for integrated policies aimed at facilitating access to social rights for people with disabilities in Europe.

Council of Europe Conferences of Specialised Ministers provides an opportunity for ministers to exchange information, views, and experience on topical matters of political significance. The First European Conference of Ministers responsible for integration policies for people with disabilities, Independent Living for People with Disabilities (Paris, France, November 7–8, 1991), led to the adoption of Recommendation No. R (92) 6 on a coherent policy for people with disabilities in April 1992 by the Committee of Ministers.

The Second European Conference of Ministers responsible for integration policies for people with disabilities, Improving the Quality of Life of People with Disabilities: Enhancing a Coherent Policy for and through Full Participation (Malaga, Spain, May 7–8, 2003), discussed (1) promoting citizenship and full participation by developing effective legal and policy provisions to ensure equality of opportunities for people with disabilities; (2) developing innovative approaches in services, intended to meet the needs of people with disabilities as consumers; and (3) proposals to enhance the integration of women with disabilities and that of people with disabilities in need of a high level of support, as cross-cut issues.

In the Malaga Ministerial Declaration on People with disabilities: "Progressing towards full participation as citizens," adopted at that conference, ministers recommended the elaboration of a Council of Europe Action Plan for people with disabilities: a new European policy framework for the next decade, based on human rights and partnership between different actors, setting up strategic objectives and priority issues to achieve full citizenship and active participation of people with disabilities in the life of the community, through workable, affordable, and sustainable policies. At the same conference, the secretary general of the Council of Europe launched the initiative to extend the disability activities from the Partial Agreement with its 18 members to all Council of Europe member states. Activities are currently under way to implement the ideas emanating from the Malaga ministerial conference.

—Thorsten Afflerbach

See also European Commission Policy; European Disability Forum.

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COUNSELL, JOHN (1911–1977)

Canadian spinal cord injury pioneer

Lieutenant John Counsell became paraplegic in 1942 during World War II, in an era when individuals with spinal cord injury (SCI) lived sheltered lives as invalids. Returning to Toronto, Counsell developed his own rehabilitation program, purchased one of the first Everest & Jennings collapsible, self-propelled wheelchairs in Canada, and had hand controls made for his car. Because of his efforts, he was able to travel independently in the community. Recognizing the value of rehabilitation, he joined with others to lobby the Canadian government to develop new programs and services for all veterans with SCI. He played a key role in the establishment of Lyndhurst Lodge in 1945, the first specialized rehabilitation center for SCI in the world.

In 1945, Counsell, along with other Canadian veterans, established the Canadian Paraplegic Association (CPA), the first association administered by individuals with SCI in the world. CPA pioneered a system of self-help, called "mutual aid" where individuals successfully living in the community helped others with SCI to return to community living. The central philosophy of CPA was full participation of individuals with SCI in all aspects of community life. During the 1950s and 1960s, members of CPA were at the forefront of efforts to develop rehabilitation programs and disability policies across Canada.

When Counsell stepped down as president of CPA in 1967, the organization had spread across Canada with members becoming leaders in the newly emerging disability consumer movement in Canada. The disability consumer movement called for new policies and legislation that would remove barriers to participation in community life for all Canadians with disabilities. Counsell and other members of CPA were pioneers in the history of disability activism.

—Mary Tremblay

See also Spinal Cord Injury; Veterans.

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CRETINISM

Cretinism is a state caused by the absence or lack of thyroxine (a hormone produced by the thyroid gland) during the developmental period (congenital hypothyroidism). Intellectual disability and stunted growth are two characteristics of a person with cretinism.

Doubt remains concerning the origin of the term *cretin* despite the numerous etymological explanations that have been advanced. According to Littré's *Dictionnaire de la langue française* of 1873, the word derives, via *Kreidling,* from the German *Kreide* (chalk), because of the whitish tone of the skin of those affected. A more probable derivation would be from the Latin *christianus*, for which a first attestation dates from about the year 1000. In a deed from the Abbey of Lucq in Béarn, a *crestina* is mentioned (Marcel Fay [1907], *Contribution à l'étude de la lèpre en France: La lèpre dans le sud-ouest de la France: Les cagots,* Coulommiers).

In nonmedical literature, the first reference to cretinism in the Alps was made by Jacques de Vitry in his *Historia orientalis et occidentalis* (1220). Illuminated manuscripts of Thomas of Cantimpré's *De monstruosis hominibus* have representations of cretins. The term first appears in medical literature in 1754 in *L'Encyclopédie ou dictionnaire raisonné des sciences, des arts et des métiers.*

Cretinism seems to have been present on all continents and in all ages without it being possible to estimate the number of persons affected. The first epidemiological studies date from the beginning of the nineteenth century. A first official inquiry into goiter, an enlargement of the thyroid gland, was made in the Valais by Rambuteau, prefect under the First Empire.

As in the case of other pathological states, the most diverse hypotheses were formulated as to the causes of cretinism such as the calcareous water of the mountains, the humidity of the air in the valleys, poor hygiene, early marriages, alcohol abuse, drunkenness during intercourse, and masturbation.

The treatment of endemic goiter and of cretinism may have begun in the early nineteenth century. As early as 1820, Dr. Jean-François Coindet showed that iodine was a very active principle against goiter. But it would require 30 years for this discovery to be taken effectively into account.

Boussingault was the first, in 1831, to suggest the use of table salt for prophylactic purposes. Around 1852, as a consequence of work done by Chatin, a variety of prophylactic tests took place in France, Austria, and Italy. But these trials were interrupted. Fears of the effect of iodine on the human organism divided the medical world, since the first tests had not proven conclusive and the secondary effects had proven serious. In 1923, iodized salt was introduced in Switzerland on the recommendation of the Commission on Goiter, and by this means cretinism was eradicated in those regions where it had been rife since the dawn of time.

If cretins were the object of curiosity from a very early date, it was not until the beginning of the nineteenth century that interest turned to the possibility of their education. About the same time as Eduoard Séguin in France, a Swiss physician, Johan Jacob Guggenbühl, attempted to educate cretins. In 1840, he opened the first institution for cretins, the Abendberg. These experiments resonated widely in all of Europe. Experiments were, however, short-lived because of the challenge to the results obtained by this physician. The closure of the institution was ordered in 1858, and Guggenbühl died in 1863. The Abendberg remained the only establishment that had the education of cretins as its exclusive objective.

—Jean-Louis Korpes

See also Changeling; Johan Jacob Guggenbühl; Mental Retardation, History of; Eduoard Onesimus Séguin.

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CRIME AND DELINQUENCY

This entry addresses the problematic interface between disabled persons and the criminal and juvenile justice systems. The issues include, how do disabled people enter a justice system, how are they treated once they get there, and what happens to them following any court intervention? Disabled people may come into contact with the justice system as victims of a crime or witnesses to a crime and, in turn, may be handled responsibly and appropriately or may face possible victimization by officials. Persons charged with a crime may have a disability that may or may not receive proper understanding or treatment. Juveniles, by definition, maintain at the least a disability of age and immaturity. How disabled people, adults and children, are treated in justice, or unjustly, is reviewed here.

ADULT CRIME AND DISABILITY

There are reports that adults with disabilities are more likely to be victims of crimes than adults without disabilities and that the rate of victimization may be shocking while going largely unnoticed. Developmental disabilities and cognitive impairment especially increase one's vulnerability to sexual abuse. The sexual abuse may occur at home, within a protective setting, or in the community. These offenses may go unreported, or if reported may be perceived as less authentic and less actionable than similar offenses reported by persons without disabilities.

Law enforcement officers, particularly those who lack specialized training, may choose to terminate an ostensibly valid injury complaint without forwarding this on to a prosecution official. If forwarded, a prosecution official may choose to avoid bringing this matter before a judge or magistrate, believing the victim will not be a good witness in a court proceeding and the case will not be provable. Developmentally disabled persons, as crime victims or witnesses, may experience a credibility problem when there is a trial, either by judge or jury, although few criminal matters indeed proceed to a full-fledged trial. Yet there is the possibility a judge or jury will be more empathetic on hearing this person's testimony. Disabled persons, called to serve as potential jury members, may well experience difficulty being accepted for this important citizen duty.

A person who may be mentally ill also may experience credibility problems as the justice system confronts his or her complaint of offense victimization. Persons with severe hearing impairments will need particular assistance in providing testimony both at informal and formal levels of the justice system process. Persons with a combination of disabilities are likely to experience more significant problems with these encounters. The use of victim-witness service assistants who enable handicapped persons to better thread their way through the justice system is an important adjunct to the accomplishment of justice.

One needs to carefully examine and evaluate data claims as to the extent of mental disabilities among criminal offenders, as data sets may combine and aggregate both mental illness and retardation under the category of a mental disability. Nonetheless, persons who fit along the continuum of a mental illness tend to be proportionally overrepresented in committing crimes. Persons with disabilities who commit crimes are likely to be handled differently from other offenders, though this will depend on one's nation of residence. Nations that are concerned with one's ability to formulate the criminal intent to commit a crime will have difficulty filing or fulfilling a criminal charge against one who is severely mentally disabled or mentally ill. Not all crimes require proof of a criminal intent, however.

An approach may be to hold such a mentally ill offender in a mental hospital until improvements are noted and the alleged offender is ruled able to proceed to trial and to assist an attorney, provided or retained, with the conduct of the person's defense. Another approach may be to enter a judicial finding, following the production of evidence, that the person is guilty but mentally ill, thus disallowing a matter from continuing indefinitely for adjudication, possibly for years, until a time when witnesses can no longer be found who would have testified at an earlier trial. This form of plea would enable a judge or jury to consider the circumstances of mental illness in fashioning any appropriate sanction.

There are new legal questions, due to today's psychotropic drug availability, as to whether administration of a drug should be done to enable an alleged serious offender to have the capability to stand trial and assist in his or her defense, or be able to perceive for what reason the offender may be executed in jurisdictions that permit the death penalty.

Criminal offenders, with or without mental health issues, are seen as experiencing a disproportionate amount of significant emotional problems during incarceration. Jails and prisons in many nations are seen as inducing or exacerbating these problems. Treatment resources are often extremely limited, even miniscule, in these facilities, and the illnesses of many will worsen.

Cohen (1998), assessing mentally disordered inmates and the law from a U.S. perspective, comments that "the toughest prisons and the most secure cell blocks within them are too often candidates for the toughest, and often sickest, inmates, and creation of this sort of psychiatric ghetto is in no one's best interests" (p. 13.1). The repeated behavioral infractions of these inmates, such as harming other inmates or destroying property, may result in disciplinary proceedings. He suggests that mental health staff employees see this misbehavior as symptomatic of illness and a need for greater treatment provisions, while prison guard staff perceive this as wrongful and requiring punishment. He contends disciplinary proceedings should not take place unless the prisoner is sufficiently competent to understand the charges and aid in his or her defense by way of explanation or mitigation.

More countries prohibit or fundamentally avoid the death penalty (112 nations) than permit its practice (83 nations). China, Japan, Indonesia, Iran, numerous African nations, and the United States are among the countries that retain the death penalty and may carry out executions despite a UN Commission's resolution that urges a death penalty moratorium (or notwithstanding this directive, to refrain from imposing this on one suffering from mental retardation or mental illness). The U.S. Supreme Court finally, in 2002, ruled that executing persons with mental retardation was unconstitutional, as it comprised cruel and unusual punishment. The Court has not categorically banned executions of mentally ill defendants.

JUVENILE DELINQUENCY AND DISABILITY

While definitions of mental retardation and mental illness may have arguable criteria, there is a general international consensus that juveniles under 18 years of age at the time of commitment of a murder or other heinous crime should not be executed. Still, a handful of nations such as Iran, Nigeria, and Somalia allow this to occur. International human rights laws and the United Nations Convention on the Rights of the Child seek to prohibit this. States within the United States have executed a number of persons who committed their crimes as juveniles. The executions, following court appeals, did not occur until the offenders were adults. The U.S. Supreme Court, in 1989, had held executions were prohibited for juveniles younger than 16 years of age at the time the offense was committed but allowed executions for those whose severe crimes were committed at 16 or 17 years of age. The High Court, however, reversed this prior judgment and on March 1, 2005, held that the 8th Amendment to the U.S. Constitution, which prohibits the infliction of cruel and unusual punishments, does not allow the execution of offenders whose offense took place prior to their 18th birthday.

Psychological reasons to explain the commission of delinquent offenses have long accompanied the development of juvenile courts in many nations. In the main, these rationales have not been equated with mental illness, but rather with problems in adjustment, impulse control, overdependence on peer group acceptance, rebellion against one's parents, or other psychologically related issues. Psychological evaluations and recommendations for various forms of treatment of juveniles persist in these courts even though the courts are most often the courts of the poor and poor youngsters may have more overriding social, economic, broken family, and delinquent neighborhood problems to deal with than emotional concerns.

Although juvenile institutions, characteristically, are not very nice places, the euphemistic mantra that these facilities are for rehabilitation and treatment rather than punishment has led numerous jurists to believe that adult-like approaches that seek to equate mental illness or retardation as legal defenses have no place in juvenile court. The rhetoric goes that these courts are to help youngsters and their families, and while juveniles, increasingly, are to be held accountable for their offenses, the court is not to be one of punishment.

Since the purpose is not punishment, then, the court or institution will seek to insert mental health treatment or services rather than entertain strictly legal defenses related to one's disability and criminal intent. Indeed, the ability to formulate a criminal intent is hardly a consideration here as the concern is what to do to help or control a youth while applying a relatively modest sanction, one that is less severe than regularly occurs in adult courts.

Placement onto probation status is the most common juvenile court disposition. Probation status is accompanied with conditions such as attending school, reporting to one's probation officer as required, adhering to any child curfew requirements, performing a community work service or monetary restitution requirement, shunning criminalistic companions, avoiding drug and alcohol usage, and not violating any law. But these conditions are violated frequently, and reoffenses occur often. Juvenile courts, then, depending on the nature and frequency of violations of these conditions or the severity of a reoffense, may scan the horizon to place a youth into either a psychologically oriented residential treatment facility or a secure and controlled institutional setting.

Certainly, numerous youths can benefit from psychological intervention in its various forms, as well as from drug treatment, at the various stages of juvenile justice intervention. But across the world, these services tend to be scant. When available, their effectiveness may be modest. Likely due to limited mental health clinical services in many venues, juvenile courts become the receptacle for youngsters whose problems are better suited for diversion to clinical services.

Juvenile courts tend to grant far more discretion to its officials than is true of adult courts. Skilled probation officers, even prosecutors, may divert juveniles with obvious intelligence or emotional problems to community-based noncoercive program interventions and even dismiss the police complaint. Family group counseling, birthed in New Zealand and Australia and exported from those settings, offers an attractive front-end substitute for court handling of numerous nonserious offenders by mobilizing family, friendship, and community resources to address approaches that might avert further offending. Peacemaking and healing circles, as used over generations by Native American and Canadian First Nations entities, present another inclusive method.

Note should be made of the severe juvenile violence wave in the United States, during the period 1987–1993, that led to legislative changes in virtually all states to expand the transfer of more serious juvenile offenders into the sphere of a criminal court. These jurisdictional changes have been sharply criticized as painting with too wide a brush, allowing far too many youths to be subjected to adult court handling and lengthy prison sentences than is necessary or wise.

Elsewhere, in Japan, a series of horrific murders committed by 14- and 15 year-old youths prompted 2001 legislation that lowered family courts' exclusive jurisdiction from 16 years to 14 years. Highly publicized violent crimes in the United Kingdom led to enactments, beginning in 1991, that dropped the age of criminal responsibility, that is, when one might be treated as an adult, to 10 years, to expanded criminal sanctions for minors, and to custodial sentences that were authorized for longer periods and for younger children.

Juvenile courts, typically, are responsible for another matter that is often known as child dependency, child neglect, or child abuse. Here the court's role is a protective one, to consider a complaint from police or a child protection agency, and direct actions aimed at enabling a safe-and-sound environment for a child. But a child's parents disabled by mental illness or retardation, a physical or language handicap, or a drug addiction have difficult, or at times insurmountable, obstacles to overcome in seeking to regain the custody of their child when officials have removed the child from their custody. Interventions based on drug treatment or psychological theory is commonly used in these matters when services are available.

HIV/AIDS-orphaned street children overwhelm the social services available in countries such as Kenya; an estimated 250,000 nationwide and 75,000 alone in Nairobi. These street children all too frequently move on to commit thefts, property damage, trespass, and child prostitution and become wards of a juvenile court there. The Kenya justice system's handling of these children has been sharply criticized by Amnesty International and Human Rights Watch for allowing jailing in deplorable police cells for prolonged periods, a commingling with adult prisoners, for police brutalities, and for permitting "in need of protection or discipline" children to end up in delinquency facilities, which are, in turn, grossly overcrowded and inadequate.

The several million street children of Brazil do commit crimes. There has been documentation, conversely, that crimes, including homicides, have been committed against more than a few of these children by police officers or adults acting with the acquiescence of police officers. Juvenile facilities used by Brazil's justice system are reported as inhumanely overcrowded, filthy, allowing torture or physical aggression against inmates, and failing to provide adequate education or medical care.

Despite the earnest and committed efforts by countless citizens and officials around the world, too many young people do harm others, or are harmed by juvenile care or justice systems whose mission is to enable bright futures. Both the juvenile and adult justice systems have far to go.

—H. Ted Rubin

See also Death Penalty; Developing World; Substance Abuse; Violence.

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CRIPPLE

A term used to describe people with mobility impairments, especially impairments affecting one or more limbs, *cripple* is an ancient term, first recorded in the Lindisfarne Gospels of the tenth century. *Cripple* is both a noun and a verb. The noun form refers to a disabled person (e.g., "FDR became a cripple after he contracted polio."), while the verb means to disable or impair—to make a cripple of (e.g., "A fall from a horse crippled actor Christopher Reeve."). The adjective form, *crippled,* has also been commonly used (e.g., "hospitals for crippled children").

The term was used as a disparaging epithet as well a descriptor, and in the latter half of the twentieth century, *cripple* fell into disfavor for two key reasons. First, it came to be viewed as a negative and derogatory label, one that focused shaming and stigmatizing attention on one aspect of a person's body and away from the person as a whole. Second, disabled people began to realize that the term focuses on one disability category and does not adequately describe the wide range of impairments that affect people with disabilities. With a growing emphasis on common experiences of disability, the term was seen as limiting and not particularly useful. By the end of the century, *cripple* had become rare in public discourse, though it remained a favorite metaphor of journalists, especially headline writers.

But even as the term receded from common parlance, disability rights advocates, artists, and scholars began to reclaim *cripple* and similar terms (e.g., *gimp*), recognizing the power available in taking over and redefining terms that had previously been used to oppress them. The reclaimed term was often shortened to *crip*–clearly derived from the older term, but transformed. Activist and writer Laura Hershey (1999) explains: "It was short and harsh and uncompromising. It was and wasn't *cripple.* It reminded us of our history, but it took us forward. *Crip* transcended our past subjugation by making fun of an old-fashioned word."

Spurred by the advances of the disability rights and independent living movements, people with disabilities began actively promoting crip culture and crip pride, and the transmuted term *crip* became an important symbol of that cultural transformation. *Crip* came to be seen as less exclusionary as well, since the term was really about claiming a disability identity, claiming a space in crip culture, not about a particular class of impairments.

Some writers have continued to prefer to use *cripple* to describe themselves, preferring among other things the word's greater specificity than more generic terms such as *disabled* or *handicapped.* "As a lover of words," Nancy Mairs (1986) writes, "I like the accuracy with which it describes my condition: I have lost the full use of my limbs." Another benefit for Mairs is the reaction the word receives: "People—crippled or not—wince at the word cripple, as they do not at handicapped or disabled. Perhaps I want them to wince. I want them to see me as a tough customer, one to whom the fates/gods/viruses have not been kind, but who can face the brutal truth of her existence squarely. As a cripple, I swagger" (p. 9).

At the beginning of the twenty-first century, scholars used a verb form, *cripping,* to describe the way some disabled people critique the dominant culture's norms. Theater scholar Carrie Sandahl (2003) explains: "Cripping spins mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects." Cripping, she notes, exposes "the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity" (p. 37), disarming what is painful with sharp-edged humor.

—Jim Ferris

See also Disability; Handicap; Humanities; Impairment.

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CROTHERS, BRONSON

(1884–1959)

American physician and researcher

Born in Cambridge, Massachusetts, Bronson Crothers was the son of a popular Unitarian minister in Harvard Square. He took his M.D. at Harvard and his clinical training at the Massachusetts General Hospital and the Children’s Hospital, Boston. After several more years in private practice in Minnesota and the Army Medical Corps during World War I, he developed an interest in neurological diseases, studying in Walter Cannon’s physiology laboratory at Harvard and at the New York Neurological Institute. Crothers returned to the Children’s Hospital in 1920, in what he described as “the experiment of assigning a pediatrician to the neurology service,” when he was made the first chief of neurology.

Crothers had two large fields of clinical research: birth trauma, particularly brachial plexus injuries, and cerebral palsy. His first responsibility became the creation of a highly interdisciplinary outpatient clinic for children with cerebral palsy. Therein he brought together psychologists, nurses, therapists, teachers, surgeons, and social workers to collaboratively help their charges and to explore the nature of the condition. Crothers’s work with some 1,800 people with cerebral palsy culminated in a monograph with Richmond S. Paine (1920–1969), *The Natural History of Cerebral Palsy* (1959), which is still consulted today.

Beyond his intellectual contributions, Crothers was a prominent national consultant in issues relating to children with disabilities, chairing President Herbert Hoover’s 1932 White House Conference on Child Health and Protection. In addition, he helped found the multidisciplinary American Academy of Cerebral Palsy with George Deaver, Winthrop Phelps, Temple Fay, Earl Carlson, and Meyer Perlstein. Finally, his trainees absorbed Crothers’s fascination with interdisciplinary clinical research and, in turn, trained many more leaders. These disciples included Winthrop Phelps, who went on to establish the institute that would later become the Kennedy-Krieger Institute in Baltimore, Maryland.

—Walton O. Schalick III

See also Cerebral Palsy.

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CRUICKSHANKS, WILLIAM

(ca. 1802–1876)

Educationist

William Cruickshanks was abandoned as a young boy at Madras Military Orphan Asylum and became blind at age 12 or 13. His education was irregular but he persevered in memorizing whatever he could, and eventually worked as a private tutor. Cruickshanks was married twice and had children. By 1838, he had so impressed educationists at Madras that they made him headmaster of the Native Education Society’s School with 100 pupils. In 1841, he became head of the asylum where he had grown up, and then headed the missionaries’ Anglo-Vernacular School in Palamcotta (Palankottai) for 26 years, becoming a famous educationist. Cruickshanks was also a devoted Christian evangelist and brooked no objection from his Hindu pupils to this endeavor. Trading on his blindness, he ignored boys’ efforts to leave when he was preaching at them individually—the hapless lads could not use visual signals of their wish to go, and were too polite just to walk away. Some of them, while ignoring Cruickshanks's proselytising, recognized him as a man whose character and spirit influenced them deeply. He continued in educational work until his death.

—Kumur B. Selim

See also Blind, History of the.

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CULTURE

See Deaf Culture; Disability Culture

CULTURAL CONTEXT OF DISABILITY

This entry discusses three significant aspects of disability contexts cross-culturally: (1) the cultural construction of impairment; (2) disability as negative social response to impairment; and (3) the influence of intersecting social categories such as gender, sexuality, class, ethnicity, and age on disability. Throughout this entry, we draw cases from the anthropological literature to illustrate particular points.

In our view, an impairment is a negatively construed, cultural perception of a bodily, cognitive, or behavioral anomaly in terms of individual functioning or some other ethnopsychological or ethnophysiological status. Disability is the negative social response or social exclusion that may come into play because of perceived impairments (Kasnitz and Shuttleworth 1999, 2001a, 2001b; Shuttleworth 2004; Shuttleworth and Kasnitz 2004). We use the hyphenated term *impairment-disability* to highlight the processual and interconnected relationship that can exist between the negatively constructed cultural perception of an impairment and any negative social responses to that perception (Shuttleworth 2004; Kasnitz and Shuttleworth forthcoming; Shuttleworth and Kasnitz 2004). This sociocultural understanding of impairment-disability develops from the growing acknowledgment in disability studies that not only is disability culturally constructed but impairment is likewise not a *natural* category (see, e.g., Hughes and Paterson 1997; Paterson and Hughes 1999; Corker 1999).

TOWARD A THEORY OF SOCIOCULTURAL IMPAIRMENT

In the International Classification of Impairments, Disabilities, and Handicaps published in 1980, the World Health Organization (WHO) defined *impairment* as any loss or abnormality of mental, physiological, or anatomical structure or function (WHO 1980). In this biomedical understanding, impairment is viewed as separable from social circumstances and implies diminishment or limitation of an individual's neuromusculoskeletal capacity or functional ability measured against a normative standard. The WHO's 2001 revision of the International Classification of Impairments, Disabilities, and Handicaps, now termed the International Classification of Functioning, Disability, and Health, de-emphasizes impairment in its model and presents a more holistic biopsychosocial approach to health, functioning, and disability (WHO 2001). Yet its definition of impairment remains similar to the spirit of the biomedical understanding and its own earlier definition. Impairment remains both underlying pathology and its manifestation as problems or deviations in cognitive, physiological, or anatomical function (Hwang and Nochajski 2003; Stewart and Rosenbaum 2003). Deviation from norms, however, inherently refers to an evaluative system. As Canguilhem (1989) observes, "Norms, whether in some implicit or explicit form, refer the real to values, express discriminations of qualities in conformity with the polar opposition of a positive and a negative" (p. 240). However, understanding function in this evaluative way is not only a product of biomedicine. The disciplinary mechanisms of modern institutions, especially hierarchical observation and normalizing judgment (Foucault 1979), also permeate the lay evaluative gaze. Normalizing judgment has become a typical modern cognitive style classifying "people in terms of their relationship to a social norm" (Douard 1995:154). Classifying people in terms of social norms includes not only the categorization of an individual's behavior but also the classification of an individual's bodily and cognitive functions. Thus, in modern societies such as the United States, normalization takes up, as one of its evaluative dimensions, the judgment of individual function (Shuttleworth 2000, forthcoming).

The critique of instrumental rationality has been a pervasive theme in social thought from Weber through the Frankfurt theorist to poststructuralist such as Foucault. Social philosopher Cornelius Castoriadias (1987) contributes to this tradition by showing how modern rationality increasingly focuses on functional efficiency. He argues that modern rationality is obsessed with the perfect lining up of aspects of any particular system in terms of its functional efficiency, but a functional efficiency stripped of an awareness of a raison d'être. It is because functionality has no intrinsic relation to ultimate ends, that Castoriadis sees it as the materialization of "the extreme autonomization of pure symbolism" (1987:159). In other words, function itself has become fetishized. From this perspective, the fetishization of function illuminates the groundwork for the cultural construction of our understanding of impairment as not only referring to the underlying structural pathology at the cellular or molecular level but also as manifesting in cognitive, physiological, or anatomical functional deficitor inefficiency (Shuttleworth 2000, forthcoming). Within the realm of everyday life, evaluations stemming from socially embodied codes of normative function within particular carnal contexts of meaning (Paterson and Hughes 1999) such as mobility or verbal speech are the yardsticks by which an individual's impairment is implicitly measured, albeit in popular understanding the term disability or handicapped may be used.[1]

However, some other societies may not accord the same degree of importance to functional efficiency as modern Western societies do, or at least not individual functioning. Pertinent indices other than an individual's bodily, cognitive, or behavioral functioning may play a more or less significant role in identifying a human anomaly as a *sociocultural impairment.* Burck (1999), for example, while subsuming the concept of impairment within disability as most anthropologists are wont to do, notes how certain bodily conditions attended to within a Shona ward in Zimbabwe are given impairment status but contrast to the modern Western sense of impairment as simply being about individual functioning. An example of one of the conditions included is

> children who [get] their upper teeth first; throughout my fieldwork area this was considered a very serious disability that would affect a person throughout life. . . . Function loss, which is an important determinant in our Western taxonomy, only played a minimal role. In actual fact it was not function loss, but the dryness of the affected part which determined the seriousness of the disability.

The "minimal role" Shona accord to function loss likely tells us we are dealing with a different understanding of impairment not disability. One can infer from Burk's description that for the Shona an important dimension of an impairment is the imbalance between wet/dry and hot/cold within their humoral ethnomedical system. It can be surmised that this negative understanding is a core aspect of the cultural perception of a child who gets upper teeth first. Since Burk mentions that children would be affected by this impairment throughout their life, we can infer from her account that disabling social responses likely follow this cultural perception. After all, there appears to be no physiological or individual functional disadvantage to getting upper teeth before lower teeth.

The task of cross-cultural researchers is to enlarge our understanding of impairment beyond its biomedical diagnostic and also modern lay meanings and conceptualize it so that it lends itself to cross-cultural relevance. What are some relevant points to remember in assessing *sociocultural impairments* cross-culturally? First, while in U.S. society an impairment is primarily seen as an individual affair and functionally limiting at the bodily or cognitive level, in many nonmodern societies what is perceived to be the cause and/or consequence of an impairment may be dysfunctional social relations or the transgressing of social order. Whether or not the individual's functioning is perceived as diminished, it is often the social relational functioning of the family and community that are the sites of major concern. Devlieger (1995), who conducted research among the Songye of Zaire, comments, "It is important to consider . . . that the belief in sorcery and the inquiry into relations within the family assume that the problem of disability [impairment, *sic*] is not a problem of the individual but rather a problem of the family" (p. 101). Burck (1999) states, "The physical condition (e.g., disability [impairment, *sic*]) is seen as a symptom of an underlying social problem" (p. 204). Devlieger discusses how inquiry into the cause of an impairment proceeds via the interrogation of past group and family relations: past social observances of food and sex taboos, envy between family members, proper respect for the ancestors. Perceived transgressions of social taboos or problematic family and group relations may be seen as causing the impairment. Often the impairment itself is not viewed as shameful but the underlying social conditions that caused it are seen as shameful (Burck 1999; Ingstad 1997). If the transgression of social taboos or problematic social relations cannot be blamed, for the Songye, the last resort for a causal explanation is God (Devlieger 1995). This perspective on ill health and impairment is exemplified by the Maasai of Kenya who "perceive disease as a sign of social or cosmic disorder projected onto the human body. Therefore the most effective prevention against disease and other misfortunes is to care for and manage social and divine relations properly" (Talle 1995:61).

Prevention is the watchword and acts as a powerful social control mechanism. The desire to correct or rehabilitate, which is an implication of our understanding of impairment as affecting an individual's functional efficiency, appears to be absent in many of these nonmodern societies (e.g., Devlieger 1995; Talle 1995). Incorporating the above kinds of data, a sociocultural theory of impairment-disability must widen its understanding—viewing impairment as the negative construction of a human anomaly with causal or consequential implications for some combination of physical, cognitive, or psychological functioning and/or social ordering or group relations.

Second, in any particular society or among groups within a society, impairments may be seen as distinct from diseases/illnesses or may be indistinct from diseases/illnesses in people's understanding and in their accommodation and health-seeking practices, depending on many factors including the particular society's medical belief systems, time since onset and social contexts, among other factors. In fact, in many nonmodern societies there may not be a clear if any separation between impairments and diseases/illnesses, especially early on (see, e.g., Devlieger 1995; Helander 1995). For example, Helander (1995) states that "the Hubeer [a community in the Bay region of southern Somalia] do not discriminate firmly between disability [impairment, *sic*] and disease. The practices and ideas surrounding disabled people can be described within the framework of health seeking and health management through which all health problems are processed" (p. 89). This is probably the case in many nonmodern societies. Devlieger (1995), for instance, also notes that among the Songye, disability (impairment) is initially perceived and responded to as illness. Yet there cannot be a clear delineation between these cases from Africa and the health-seeking mentality that pervades the treatment of children born in the United States, for example, with a condition such as cerebral palsy. The difference is likely only a matter of degree of buy-in to health seeking. For while ostensibly, in the case of those concerned in the United States, primarily parents and physicians, they may understand that cerebral palsy is not a disease like cancer, health-seeking behavior (in other words, the search for a cure) may predominate over more pragmatic rehabilitation and accommodation issues for quite some time.

Helander, however, also shows how Hubeer health-seeking behavior for an individual's intractable illness eventually falls off when funds run out and the gamut of therapies is exhausted. Does this perceptual change on the part of Hubeer constitute a foregrounding of impairment, which now trumps the previously dominant illness/disease categorization? In fact, Helander characterizes this shift in perception by Hubeer, as seeing "disability [impairment] as incurable illness." While still subsuming impairment within an illness/disease framework, there is nevertheless here an acknowledgment of the often enduring nature of these kinds of conditions. There is likely some understanding, either implicit or explicit, in all societies of the difference between illnesses/diseases that are amenable to therapeutic treatment and conditions that endure indefinitely. As Burck (1999) also notes among the Shona, "Disability [impairment, *sic*] was considered an illness that lasted very long" (p. 204).[2]

DISABILITY AS NEGATIVE SOCIAL RESPONSE

Depending on the particular impairment and its associated cultural meanings in a society, the person may be easily integrated and assume a valued social role, accorded supernatural status with certain accompanying privileges, or stigmatized and excluded from various social relations and cultural domains (Shuttleworth 2004, Kasnitz and Shuttleworth forthcoming; Shuttleworth and Kasnitz 2004, forthcoming). Persons perceived as impaired who are excluded from various social relations and cultural domains are in the sociopolitical sense in which we are using the term—*disabled.* In this schema, a particular society with its unique cultural meanings defines and situates any functional limitations or other physical/psychological statuses as impairments (see also Marshall 1996), and constructs its social responses as inclusionary or exclusionary, just as it also constructs the meanings of and responses to health and illness. For critical cross-cultural disability researchers, it is the cases of disabling responses that constitute the primary data. Of course, the above schema is meant only for analytical purposes. In actuality, a society may perceive that a person has an impairment and depending on the contexts of everyday life, the person may be included in some cultural domains but not included in others. It is up to the disability ethnographer to document the contextual complexity of impairment-disability in a particular society.

In terms of body and behavior, any out-of-the-ordinary manifestation may be perceived as anomalous. Each society considers some anomalies impairing, which can lead to disabling responses. A 1980 survey on leprosy, an aesthetic impairment, in Nepal found that a majority of persons would separate family members who got leprosy, and a third said they would put them out of the village. Ten years later in 1990, there was little change in expectations (Hyland 2000). Turmasani (1999a, 1999b) reports widespread negative social attitudes toward physically disabled people in Jordan resulting in charity, the attribution of cognitive impairment, and asexuality. The birth of twins constitutes a social disgrace among the Punan Bah, and one of them is usually given away or withers away (Nicolaisen 1995). For the Hubeer, stupidity and madness are viewed as similar to infertility and death, and the mentally impaired are often treated with abuse outside of their family (Helander 1995:89). Talle (1995) states that among the Kenya Maasai mentally retarded or mad persons are regarded not as disabled in a physical sense but as "abnormal" ("fool"). Nicolaisen (1995) echoes an observation made by many cross-cultural researchers about some forms of severe cognitive difference such as severe forms of mental retardation: "among the Punan Bah, I suspect that children born with such impairments 'wither away'. . . or die at an early age" (p. 44).

Much depends on the interplay of beliefs, social expectations, and economic imperatives of the particular society as to whether some human anomaly will be considered impairing and whether the person will experience social exclusions (Groce 1999). For example, in China today the ability for men especially to be active and mobile outside the home in terms of public life and also in one's livelihood is highly prized. Combined with ideas about national development and mobility and the Confucian emphasis that transmutes bodily imperfection into social meaning, men who have difficulty walking experience stigma and discrimination (Kohrman 2000). Here cultural beliefs, social and gender expectations, and also economics conspire and contribute to the creation of a devalued identity based on a negatively perceived bodily difference, that is, an impairment. In the case discussed above for the Hubeer, the termination of health-seeking behavior coincides with a sense of hopelessness by family members and exclusion of the affected individual from many of the social activities that construct their sense of personhood. This exclusion should be considered a disabling social response regardless of the Hubeer's conceptual understanding of the condition, that is, whether they explicitly perceive it as an impairment or simply as enduring illness/disease.

INTERSECTIONS WITH DISABILITY: THE CASE OF GENDER

The kinds of social exclusions faced by disabled people cross-culturally are significantly influenced by intersecting social categories of experience such as gender, sexuality, class, ethnicity, and age. For the purposes of this entry, the focus will be on the intersection of gender and disability. To show concretely how disabled people in various societies can be differentially included or excluded based on perceptions of gender, it is necessary to specify a cultural domain, or a couple of related cultural domains, of action to interrogate. The sexual and marriage domains are ideally suited for this kind of comparison because of the widespread sexual oppression that disabled people experience cross-culturally. In fact, sexual and/or marriage access appears to be greatly reduced for disabled people with various impairments in a wide range of societies (Shuttleworth 2000, 2001, 2004; Devlieger 1995; Nicolaisen 1995; Sentumbwe 1995; Ablon 1984, 1996, 1999; Kohrman 2000). A number of studies specifically note gender differences in the availability of cultural resources and in the opportunities to find sexual or marriage partners (see, e.g., Sentumbwe 1995; Ablon 1996, 1999; Wolf and Dukepoo 1969; Kohrman 2000).

An anthropological study that explicitly examines the differential access to intimacy and sexual experiences for men and women is Ablon's (1996) research on gender response to neurofibromatosis 1.[3] Based on their review of the literature, the sociologists Asch and Fine (1988) reported that disabled women in U.S. society were more likely to be without a partner than disabled men. Although Asch and Fine's work was a long-overdue plea to include gender as an important variable in research on disability and drew attention to the multiple oppression that disabled women are often subjected to in U.S. society, the findings of Ablon's study challenge any blanket assessment of the greater disadvantages that disabled women have compared to men in developing intimate relationships in the United States. In short, Ablon found that of her sample, two-thirds of the women were married, while only one-third of the men were married. In addition, the single men in her sample were much less likely to have had sexual experiences than the women. Ablon notes the persistence of women in finding a partner, while some of the men socially withdrew. She argues that since women have been socialized in U.S. society to be connected in a relationship, these women with neurofibromatosis continued to fantasize about and strategize to connect with a man. Conversely, for men, attachment is overridden by the cultural expectation of male achievement. The lack of individual achievement by some of these single men with neurofibromatosis 1, due to early learning difficulties and social failures, and thus their lack of being able to meet U.S. society's male gender role expectations, negatively affects their gender identity, effectively blocking any desire they might have for an intimate relationship (Shuttleworth 2000, 2004; Kasnitz and Shuttleworth 2004).

Sentumbwe (1995) has provided a finely grained analysis of the cultural knowledge and social dynamics operating in the sexual and marriage arena for blind Ugandan women and compares their situation to that of blind Ugandan men. First, he elucidates why sighted Ugandan men will have sexual relations with blind Ugandan women and/or keep them as mistresses but rarely marry them. Cultural beliefs that blindness is physically incapacitating and blind persons are especially vulnerable compared to persons with other impairments contributes to the assumption that blind women cannot adequately fulfill their domestic role; reinforcement of this assumption by disapproving relatives and friends generally results in the restriction of relations between sighted men and blind women to less socially legitimate relationships based primarily on sex. Sentumbwe suggests that although adequate for sexual relations, blind women are unattractive as marital partners for sighted men because "most men refuse to take on any 'woman's activities'; consequently, men still need competent housewives," which they assume must be physically able and thus sighted (p. 172). On the other hand, blind men are more likely to have sighted wives because sighted women are actively involved with income-generating activities and have "progressively embraced male dominated activities" (p. 172). Therefore, they do not have to totally depend on their blind husbands or assistance from kin (Shuttleworth 2000, 2004; Kasnitz and Shuttleworth 2004).

What Ablon's and Sentumbwe's studies clearly show is that in addition to elucidating the cultural understanding of and response to a particular impairment, an analysis of the different gender role expectations for men and women in a society and the cultural knowledge, values, and practices that legitimize them is important to consider in assessing the avenues open or closed to disabled people in a particular cultural domain, in this case, the sexual and marriage possibilities for disabled people. Whether men or women perceived as having a particular impairment are seen as legitimate sexual or marriage choices by others can sometimes differ drastically depending on the interplay between cultural beliefs about the impairment and, using Bourdieu's (1977) terms, the degree to which they are perceived as embodying the society's gendered dispositions in *hexis*, bodily habits and intentions. Being unable to adequately effect a masculine or feminine performance and being evaluated by others and themselves in terms of this inadequacy may have significant consequences for people with various impairments depending on the society. Divergent patterns of response by men and women with the same impairment (e.g., social withdrawal/continued strategizing) may be due to their perceptions of how well they embody masculinity or femininity and/or differences in the sociocultural resources available to these genders (Shuttleworth 2000, 2004; Kasnitz and Shuttleworth 2004).

Interrogating social categories other than gender would similarly show how disabled people are differentially included or excluded given the divisive terms that organize the particular social category. For example, a disabled person from a privileged class in a modern capitalistic society such as the United States might experience less stigma and oppression in many cultural domains than a disabled person who lacks the cultural and symbolic capital of status, as well as the economic capital to purchase adequate human services and technological aids. An analysis of all relevant social categories that intersect with disability is the goal of a critical, disability ethnography.

CONCLUSION

This entry has suggested that impairment is a variable concept whose meaning will diverge in different societies. Several cases were presented showing how different societies construct impairment from human anomaly. Also presented were a range of examples of the kinds of negative social responses to impairment that *disable* persons in different societies. The intersection of gender and disability as it plays out in the domains of sex and marriage was further presented as an example of how exclusions can differentially affect disabled people given the divisions of a particular social category within a specific cultural domain across cultures. At the very least, critical anthropological study of impairment-disability must elucidate how these three aspects—impairment, disability, and relevant social categories of experience—articulate in any particular cultural context.

—Russell P. Shuttleworth and Devva Kasnitz

See also Anthropology; Gender; Inclusion and Exclusion.

Notes

1. Contrary to the biomedical ideal, the functional aspect of an impairment cannot strictly be separated from the body's normative social uses and cultural meanings. Rather, the context of these normative social uses and cultural meanings are what informs the clinical identification of the functional aspect of an impairment. This identification of individual function by biomedicine is simply a more explicit and conceptualized version of the implicit perception by laypersons of an individual's functional differences and limitations during everyday life with its culturally constructed activities and roles.

2. Although many impairments are enduring, that is, permanent features of a person's physical, cognitive, or psychological makeup, some clearly are not. The example given for the Shona of children who get their upper teeth first exemplifies the latter. This human anomaly is a physiological event and not part of the objective features of a child's physical makeup once her other teeth emerge. What does endure for the Shona is the group members' memory of the event—an event perceived as an impairment.

3. Neurofibromatosis 1 is a progressive, neurological genetic disorder, which manifests in tumors that develop along nerves and nerve sheaths. External tumors may be cosmetically disfiguring.

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CYBORG

The term *cyborg* was originally proposed in 1960 to describe a human altered "by suitable biochemical, physiological, and electronic modifications" (Clynes and Kline 1960) to allow the augmented human to survive in nonhuman environments such as space. The concept was to go beyond simply encapsulating the human in a spacesuit and spacecraft. The idea was to change the human.

Sometimes the *cyborg* term is used in connection with artificial limbs and rehabilitation but more often it is used in the science fiction context. People with artificial limbs have long been a part of literature and the visual arts. In nongenre fiction, the artificial limb has been used as a symbol of traumatic loss or sacrifice as with the characters of Captain Ahab in *Moby Dick* (novel, 1851) or Homer Parrish in *The Best Years of Our Lives* (film, 1946). The stories examine how persons, albeit fictional, respond to a life-changing event. The amputation and artificial limb are dramatic devices to signal to the reader or viewer the severity and personal nature of the loss.

When artificial limbs are used centrally in science fiction, it is often that the prostheses bestow superhuman abilities on the character or lead to dehumanization and alienation from society. The astronaut Steve Austin in Martin Caidin's novel *Cyborg* (1972) is exemplary of the superhuman. Following a devastating crash in an experimental space plane, Austin is rebuilt—"Better than he was before. Better, stronger, faster." Provided with nuclear-powered prostheses, Austin becomes a special agent for the government. Caidin's book led to a popular television series, *The Six Million Dollar Man,* which aired from 1973 to 1978. The concept of better, stronger, and faster through prosthetic enhancements is important in Bernard Wolfe's early antiwar novel *Limbo,* published in 1952.

Science fiction has many Steve Austin type cyborgs who are better because of their prosthetic enhancements, but science fiction also considers the darker side of the human/machine cyborg, treating it as a metaphor for the dehumanizing and threatening effects of technology. Movies such as *Robocop* (1987) and the first *Star Wars* trilogy (1977, 1980, 1983) have central characters that have become so much machine that their humanity appears to have been crowded out. In *Robocop,* a severely injured police officer is rebuilt to serve as a robot-like law enforcement tool. The cyborg struggles to regain its memories and reclaim its humanity from its corporate handlers. In the *Star Wars* trilogy, the galactic emperor's chief enforcer, Darth Vader, is a cyborg striving to enslave the galaxy's inhabitants under the emperor's rule. So removed is Vader from his human origins that he appears prepared, in the climatic confrontation of the third movie, to sacrifice his own son and daughter to the will of the emperor.

In the genres of fantasy and science fiction the artificial limb is often explicitly a part of the story because of some magical power or physical advantage that the prosthetic device provides, but this is not always the case. The members of Jules Verne's Gun Club in *From the Earth to the Moon* (novel, 1865) are Civil War artillery designers. Although "there was not quite one arm between four persons and two legs between six," their amputations were treated as an occupational hazard that did not significantly influence the story. Similarly, characters in Robert Heinlein's novels *Citizen of the Galaxy* (1957) and *The Moon Is a Harsh Mistress* (1967) have artificial limbs. In the first, the use of an artificial leg is concealed by a spy who removes it when disguised as a street beggar. In the second, a variety of artificial left arms are used by the story's narrator, a machine troubleshooter and repairman. In each case, the prosthesis provides the user with an occupational advantage that is valuable but not central to the overall story.

There are many facets in science fiction to the characterization of persons with prosthetic devices. However, one aspect that seems almost universal is that the fictional prostheses are better than anything that science and technology can provide in the real world.

—*Craig Heckathorne*

See also Body, Theories of; Film; Novel, the.

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CYSTIC FIBROSIS

Since its initial description by Dorothy Anderson in 1938, cystic fibrosis (CF) has been transformed from a lethal diagnosis in infancy to a chronic but ultimately fatal disease of children and young adults. Although the precise mechanism of action is under dispute, the genetic mutations in CF cause abnormalities in a protein expressed on epithelial cells, which occur throughout the body but are particularly important for normal functioning of the respiratory and digestive systems. The disease is autosomal recessive, with a high carrier frequency and more than 1,000 different mutations. One of every 25 Caucasian Americans is a carrier, and one of every 2,500 Caucasian newborns will develop the disease. The mean age at death for CF is now approximately 29 years; the most common cause of death is respiratory failure. Pressure to expand newborn screening is increasing in the United States, supported by those who believe that it prevents so-called late diagnoses; there is as yet no consensus that treatment in early infancy will improve overall survival.

As the patient population ages, chronic symptoms have begun to surface, any one of which can lead to significant disability. Common symptoms include diabetes and its complications, chronic sinusitis, osteoporosis with resulting rib fractures and vertebral compression fractures, hepatic disease, gallbladder disease, chronic hemoptysis, chronic pancreatitis, and chronic pulmonary infection leading to respiratory failure. In addition, previously well-known complications of CF, such as male infertility, have begun to have a more significant impact in the young adult population. Chronic pain, primarily due to headache and chest pain, has also become more frequent.

With the transformation of CF from a cause of early death to a chronic illness, issues of psychosocial adaptation and development become more prominent. The peculiar trajectory of CF compounds the developmental challenges of an adolescent with chronic illness: the respiratory symptoms, and the intensity of medical interventions, usually accelerate at just the time adolescents seek increased independence from parents and caregivers. Adherence to a medical regimen thus becomes more important when resistance to such a regimen may be maximal. Adaptation to changing levels of independence brought about by a fluctuating disease trajectory can greatly complicate other developmental challenges such as schooling, independent living, family life, sexuality, and employment. The psychosocial challenges of advancing CF can place great stress on other family members, some of whom may also have the disease.

The most common illness trajectory in CF is one of intermittent acceleration of symptoms superimposed on a gradual decline in lung function. The paradoxical combination of short-term uncertainty and long-term clarity about outcome makes medical decision making difficult for families and caregivers. The increasing availability of aggressive therapies, including lung transplantation and assisted ventilation (especially so-called noninvasive methods such as BiPAP), has disrupted the previous consensus against the use of technological interventions in the final months of life. Decisions regarding lung transplantation, especially those that involve donation of lung lobes by family members, are particularly challenging. As well, in an era of increasing technological intervention, those who wish to decline aggressive treatments in favor of quality-of-life measures may find it difficult to interact with a technologically driven medical system.

—Walter M. Robinson

See also Childhood, Youth, and Adolescence; Consent to Treatment.

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D

DANCE

Disability dance sees disabled people engaged in dance and movement activities. The personal and social aims of the dance work are multiple, and they relate to the framings of disability. Some disability dance, in particular in the contact improvisation scene since the 1970s, including training organizations such as DanceAbility, explores the multiplicity and specificity of human bodies. Here, impairment recedes, and "difference" remains as bi-pedals, wheelchair-users, floor-dancers, or people with visual impairments explore connections and tensions between their bodies. Companies such as CandoCo (United Kingdom), AXIS (United States), Taihen (Japan), dancer Homer Avila (United States), and Touchdown (United Kingdom) are examples of this kind of modern dance work that emerges from an interest in bodily and sensorial difference as aesthetic impetus. Different historical dance aesthetics are explored within this framework, as well: U.S. companies Cleveland Dancing Wheels and Light Motion use classical ballet approaches to the development of techniques for disabled dancers.

Other forms of disability dance have more therapeutic aims—this dance approach aims to make the disabled person feel well inside his or her skin, using the positive effects of exercise, shared movement, and the pleasures of music to move people. When this form of disability dance reaches a public, it shares the pleasure of being alive and can create positive images of disability in the social scene. At the same time, though, some artists query the political efficacy of these forms of positive images of happy dancing disabled people, as the historical and public oppression of disabled people in the social scene are elided. A more fractured choreography that plays with images of social stereotypes combined with the pleasures of movement as a form of social communication is at the heart of much political disability dance work.

Some of this political disability dance uses the historical framework of dance theater—the affect of the moving body as a kinesthetic spectacle becomes the vehicle for political messages about what bodies are seen on what kind of stages. Examples of this form of dance are Germany's DIN A 13, the United Kingdom's Blue Eyed Soul, Austria's Bilderwerfer, and U.S. dancer Bill Shannon's work, where the act of putting on an act is queried.

Shannon's show AOW Remix (2002) cites the street and the hip-hop club as interlocutors to the theater stage. A brief look at moments in the show can show how different aspects of disability dance merge, in particular disability dance as a take on a particular technique (hip-hop), as a political commentary, as a play on the embodied effects of language, and as a performance of the everyday.

Before the show, the performance starts. The waiting audience in the Dance Theatre Workshop in New York City can watch a video in the foyer. In the video, a man with crutches (Shannon) moves down a flight of steps, he falls, passers-by look, some move in to help. The man with the crutches recovers easily, and he makes a fast getaway. One man in the video steps back and crosses himself.

The reaction of this passer-by in the video to the falling crutch-user is a form of disability dance: not the aesthetic product of artists dealing with bodily difference, but social movement patterns. Multiple scripts exist for dealing with difference—crossing oneself half-unconsciously, warding off evil, is one reaction. In the man's action, various mechanisms are combined: He steps back, puts distance between himself and the spectacle of the fallen man, his hand in his quick cross-shaped weave creates a shield between him and the scene, and the connotations of the crossing evoke a third presence as a godly or saintly helper and guardian is called on to intervene into the little act played out here. The short choreography in the street presents the deep cultural strata of distress, negativity, and fear of disability that still pervades attitudes. No positive images, no disability rights legislation has yet been able to undo these old habits, excavated in the unconscious bodily behavior in the street.

We are finally allowed into the theater, and we find our way to our seats. They are mostly inaccessible to many disabled people. I have trouble storing my crutches. I catch the eye of another disabled person, a woman one row behind me; we talk and acknowledge that we are the only visibly disabled people we've seen tonight in the audience. This checking of numbers, and of assessing venues for access, is a ritual enacted by many politically conscious disabled people who see themselves as part of a minority movement and are aware of the only recent history of access to stages and auditoriums.

The lights go down.

A man appears, and sprays a graffiti handle on the black backdrop of the empty stage. Stage right back, a VJay station is set up, and a man begins to scratch video-loops against one another to heavy, loud hip-hop music. A stylized knife-fight ensues. The dancers throw poses at one another: a slow routine with long held freezes, aimed at the opponent with attitude. The 1986 documentary *Paris Is Burning* explained similar moves in the gay black scene: "shade" is happening, a dissing of one's dance opponent, without touching. Skills are shown off: moonwalking, breakdance, and crutchdancing. As an audience member, I am aware that I lack language to describe what I see: This is not the kind of dance move conventionally seen in stage shows. More and more, the scene takes on the quality of a different place: a club. Six dancers square off against one another, in a solo competition. All the dancers get their turn, and while the circle is watching, they present their moves in a casual yet calculated framing. One of the six dancers is Bill Shannon. He seems older than the others, and various gestures and arrangements show that he is in charge. He is wearing his baseball cap, and I can make out what it says: Crutchmaster—a title he earned in the New York club scene. His first solo sees him flying around his crutches: Gripped by his arms, they stand in the middle, moving from side to side, as his legs swing out behind him in a circle. His dance is powerful and acrobatic, but his choreography is clearly knowledgeable of how his crip performance is likely framed by a nondisabled audience: At the end of his dance, he takes off his cap and sinks down in a pathetic, "handicapped" "cap-in-hand" gesture.

The energy drops. The dance disperses. Shannon is alone on stage. He moves about, seemingly aimless. We hear him mutter to himself, occasionally loud enough to be understood by the audience: "What happened to the show?" "Are we faking the show?" This commentary on transplanting a hip-hop club scene into the theater is expanded on as a man in a trench coat enters. A fake chimpanzee is taken out and played with and finally packed into the suitcase, one hand sticking out, and carried off. Who is the monkey? The "street scene," commodified as a spectacle rather than a participatory event? Bill himself, the crutchmaster, performing tricks on sticks?

The cap-in-hand, the performing monkey, the drops in energy and the agonized whispers of "faking the show" persist throughout the performance, reminding the audience again and again of the price that is paid by the set-up of the stage. The performance emerges *as* a performance, as a set of choices within constraints. Shade and pride are relative phenomena, born out of the knowledge that difference has to fight for its spaces.

Accessible disability dance clearly means physically accessible stages, auditoriums, dressing rooms, and rehearsal spaces, as well as accessible educational opportunities. But fundamentally, it also means accessible aesthetics. Disability dance is one of the practices where the body is queried, where experiments about who can be/should be/ought to be on stages can be explored. What is beautiful? Why are we looking? What are the politics of the stare, what are the politics of shared embodiment and affect? These are the kinds of questions raised in political disability dance. They can affect and play with the ingrained choreographies of the man crossing himself on the street, of the person changing the side of the road when she sees a disabled person approaching, and all the other little choreographies that still speak about the distance between disabled and nondisabled lives.

—Petra Kuppers

See also Aesthetics; Body, Theories of; Disability Culture; Drama and Performance.

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CandoCo Dance Company, www.candoco.co.uk

DART, JUSTIN (1930–2002)

American advocate

Justin Dart has been widely recognized as the founder of the Americans with Disabilities Act (ADA) signed into law on July 26, 1990. Dart's grandfather established the Walgreen's Pharmacy chain. However, Dart was also a highly successful entrepreneur himself who made his own fortune by introducing Tupperware to Japan during the mid-1960s. At age 18, he contracted polio and was admitted to the Seventh Day Adventist Medical University in Los Angeles. Doctors told him he had three days to live. While living on the polio ward, Dart found himself surrounded by the companionship and support of other disabled people. As he would explain later: "These beautiful people not only saved my life, they made it worth saving" (quoted on website: http://www.aapd-dc.org/justindart/jdobit.html). In 1951, Dart matriculated at the University of Houston where he studied to be a teacher. The university withheld his teaching certificate because he was a wheelchair user and posed an insurance risk to would-be educational institutions that might employ him.

President Ronald Reagan appointed Dart to be vice-chair of the National Council on Disability in 1981. During this time, the council members drafted a national policy on equal rights for disabled people; the document ultimately became the foundation of the ADA and advocated for an expansive inclusion of disabled individuals including psychiatric survivors and individuals with HIV/AIDS.

—David T. Mitchell

See also Americans with Disabilities Act of 1990 (United States); Polio.

DARWIN, CHARLES (1809–1882)

English naturalist

Charles Darwin did much to stimulate scientific interest in the field of intellectual disabilities. Lacking convincing fossil evidence of intermediate species to connect humans and higher primates, Darwin described persons with intellectual disability as evolutionary stand-ins for missing ancestral forms. The careful observation and reasoning that characterized his work on pigeons, worms, and barnacles was notably missing in his discussions of these human beings.

In *The Descent of Man* (1871), Darwin argued that "idiots" were (1) an intermediate rung on the evolutionary ladder connecting humans and primates; (2) examples of the inevitable waste and loss produced by natural selection acting upon variability; (3) the floor of a scale representing the "lowest," most unfit variety of human being; and (4) atavistic reversions to extinct forms whose study could reveal earlier stages of human development. The latter argument led to an explosion of scientific interest in mental disability in the late nineteenth century, and, in the early twentieth, to the myth of the menace of the feebleminded.

The full humanity of persons with intellectual disability was denied in service of evolutionary theory. If persons with intellectual disabilities were, in fact, the "ape/men" that paleontologists had searched for, there were no benefits to this unnatural designation. Viewing persons with intellectual disabilities as nineteenth-century monstrosities, Darwin and other evolutionists found them useful for proving a scientific point, but not much else.

—Steven A. Gelb

See also Biological Determinism; Evolutionary Theory.

DE LABAT, B. J. G. (1858–1942)

South African educator

Bernabé J. G. De Labat, of Worcester, 80 miles from Cape Town, was asked in 1879 to initiate teaching at a school for deaf and blind children planned by the Dutch Reformed Church, only the second such school in the country. He was a trained ordinary teacher, whose brother Piet was deaf. De Labat took training in the Netherlands, opened the Worcester school in 1881, and ran the deaf side for 45 years. In 1927, he handed it over to his son, the Reformed minister Gabriel De la Bat (*sic*) (1896–1953), who had studied new approaches to deaf education in the United States. De Labat built up the Worcester school from one pupil to 150 enrolled at his retirement, with a few coming from hundreds of miles away in neighboring countries. His methods and curriculum might now seem limited, but an inspector in 1881 reported that De Labat's pupils "mastered the art of reading more quickly than did normal children" (Biesenbach 1972), evidence strongly contradicting the prevalent idea that deaf children could not learn.

—Kumur B. Selim

See also Deaf, History of the.

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DE L'ÉPÉE, ABBÉ CHARLES-MICHEL (1712–1789)

French priest and educator

Abbé (a member of the French secular clergy) Charles-Michel de l'Épée was a Jansenist priest and the founder of the first establishment for the training of young deaf-mutes.

De l'Épée was born in Versailles in 1712. In 1760, he met deaf twin sisters who had received some initial Christian instruction from a teacher named Simon Vanin. When Vanin died, de l'Épée offered to receive the girls at his residence to continue their education and "save their souls." The sisters did not speak, so de l'Épée communicated with them by means of gestures. He had the idea of elaborating a communication system based on gestural signs, to teach them the truths of the Christian faith and the grammar of the French language. But instead of employing only the signs of deaf-mutes, he added others of his own devising, based on Latin and his own imagination. He called these "methodological signs," and they were designed to translate, feature for feature, the elements of French syntax.

Most of de l'Épée's pupils were lodged in nearby boarding houses, and he paid for their room and board from his own finances. The deaf youngsters received catechism and French language lessons on Tuesdays and Fridays at his residence on Rue des Moulins, a building that has since disappeared.

De l'Épée's work was well received by the scholars, men of science, and philanthropists of his time, but the authorities did not act on the state decrees of 1775 and 1786 that his school be housed in an unused convent, Les Célestins. He died in Paris on Christmas Eve 1789, and the following year the Paris Commune installed the bereft pupils in Les Célestins. The director of the institution was Abbé Sicard, an ideologue whom Abbé de l'Épée had trained but would not have wished to see as his successor.

—Jean-René Presneau

See also Deaf, History of the; Pierre Desloges; Sign Language.

DEAF, HISTORY OF THE

The history of deaf people has been written as a history of hearing perceptions of deaf people, as a history of the education of deaf people and as the history of the lives and communities of deaf people themselves. This history embodies some of the major strands of disability studies scholarship: the reactions of outsiders to those with a physical difference, shifting understandings of normalcy, and the existence of a community of people who create lives based on a different sensory universe than that of those around them.

EARLY DEAF COMMUNITIES

Unique among individuals with a sensory difference in that they are also a linguistic minority, deaf people have long formed communities whenever they come together in a specific geographic location. Most scholars attribute the development of Deaf communities to the establishment of schools for the deaf and the desire of its alumni to associate with one another afterward. But there is also evidence that whenever a significant number of deaf people exist in one geographic location, they will form social relationships with one another and with hearing people who use sign language. The island of Martha's Vineyard, off the Massachusetts coast, was an example of such a community. From the seventeenth to the mid-twentieth centuries, a significant population of deaf people coexisted alongside their hearing counterparts in certain towns on the island. In these towns, nearly everyone was able to use some form of sign language and deafness was an accepted, unremarkable fact of daily life.

Communities such as that found on Martha's Vineyard are likely rare. There were few, if any, politically organized European communities of deaf people in the Early Modern era. There were, however, early small-scale attempts by European religious orders to educate the deaf children of rich noble families. Benedictine monk Pedro Ponce de Leon is the most prominent of these early teachers, and in the 1540s taught the deaf brothers Don Francisco and Don Pedro de Velasco, as well as 10 to 12 other deaf people, at his monastery. De Leon's work would be replicated in other small-scale schools throughout Europe, but state sponsorship of Deaf education would begin only in the eighteenth century.

THE EIGHTEENTH CENTURY

The Enlightenment brought about a new faith in reason and a new curiosity on the part of scholars on the ability of deaf people to achieve rational and abstract thought. In this period, the education of deaf people attracted prominent attention, and historians have generally pointed to Paris as the crucible of Deaf education in the modern era. In Paris, the Abbé Charles-Michel de l'Épée founded what would eventually become the first state-supported school for deaf children, today known as the Institut National des Jeunes Sourds (INJS). Beginning with a class for two deaf sisters, de l'Épée's school served as a model and source of inspiration for the establishment of other European schools. These schools generally followed the INJS's use of a signed language to teach deaf children in their national spoken and written language. A school established in Leipzig, Germany, in 1778 by Samuel Heinicke exemplified the "oral method," a method emphasizing training in speechreading and articulation as a means for deaf people to learn their national language.

The Methods Debate

The respective methods used by de l'Épée and Heinicke became touchstones in a centuries-long "methods debate" in the field of Deaf education. On one side are those who supported the use of sign language to teach deaf children in both subject matter and their national written language. On the other side are those who saw the use of sign language as hindering deaf people's ability to learn to speechread and orally speak the national spoken language. (This claim has been disproved. Linguists today recognize the use of sign language actually enhances second-language acquisition in both deaf and hearing children.) Generally speaking, both sides supported teaching deaf people to speak; the difference lay in how much sign language would be used and how much emphasis would be given to speech training. The users of "sign method" or "manual method" decried what they felt was an overemphasis on speech training to the exclusion of academic content. De l'Épée and Heinicke entered a debate in the 1780s over the merits of their respective methods, a debate judged by the rector and fellows of the Academy of Zurich to have been won by de l'Épée. This was hardly the end of the matter, and the "methods debate" has figured prominently in nearly every history of deaf people written to date.

As with any ideological debate, the true positions taken by historical actors have varied considerably across time. Those who supported the use of sign language also sought to minimize its use, and those who supported oral teaching also used some sign language. The popularity of one or another method at different points in history has not been solely contingent on internal factors in the field of Deaf education or the wishes of deaf people themselves (which have generally been supportive of sign language), but also on the surrounding social and cultural context in which deaf people lived.

THE NINETEENTH CENTURY

Deaf education in the first part of the 1800s was largely inspired by an impulse to save deaf people's souls, to ensure they received sufficient religious training to understand the word of God. In the United States, this period is generally known as the heyday of manualism. In 1817, a deaf teacher from the INJS, Laurent Clerc, together with an American evangelist, Thomas Hopkins Gallaudet, established what is today known as the American School for the Deaf, the first school for deaf people in the Western Hemisphere, in Hartford, Connecticut. Aside from a short stint as principal of the Pennsylvania Institution for the Deaf in Philadelphia, Clerc would go on to teach at the school for the next 41 years. Clerc's influence cannot be understated: Through his interactions with his deaf students, his French Sign Language (LSF) influenced the makeup of contemporary American Sign Language (ASL). Through the apprenticeship and training of teachers at the American School, Clerc shaped an entire generation of American teachers of deaf people. A well-educated user of early ASL and written English (as well as French and LSF), a pious Christian and an upstanding citizen, Clerc was an exemplar of what Deaf education could achieve in this period.

The late nineteenth century saw a shift in public discourse on deaf people, which emphasized the need for training deaf people to become good national citizens. While there is some discussion among historians on just how much ASL was suppressed in the United States during the Progressive Era, it is generally agreed that the oralist method had the momentum in this period. The number of deaf teachers in schools declined and the oralist method was predominantly the method of choice in classroom at schools for deaf people. The reasons for its rise are complex, but can be traced back to a shift to assimilation into national spoken-language communities as the primary motivation behind educating deaf people. The influx of immigrants led to nativist fears in American society, and oralists saw speech training as the best way to assimilate deaf people into modern American society. The social Darwinism of the late nineteenth century supported an oralist discourse that portrayed sign language and its users as relics of a primitive era, now superseded by the "modern" use of spoken language and "modern" pedagogical techniques in speech training.

The portrayal of deaf people as evolutionary throwbacks resonated in an era that saw the creation of ideas of "normalcy" and "degeneracy." Deaf people were no longer seen as children of the Enlightenment, but rather as imperfections in the public body. In 1883, Alexander Graham Bell, inventor of the telephone and a prominent supporter of the oral method, posed the threat of a "deaf-mute variety of the human race" and urged measures preventing the "intermarriage" of deaf people. Bell's ideas about educating deaf children with their hearing peers were gradually enacted, but the marriages of deaf people in the United States was never forbidden by legislative statute. In fact, deaf people have consistently married one other in high rates, feeling most at home with one another.

Organized Deaf Communities

From early beginnings in urban centers or schools for deaf people, Deaf communities in the United States and Europe established formal associations at the local, state or provincial, and national levels in the nineteenth century. A number of Deaf community periodicals were established in this period and widely reprinted from their counterparts in other states and nations, thus further expanding community networks beyond local connections. In the United States, these periodicals were either independently run or part of the "Little Paper Family" of papers printed by schools for the deaf. European and Australian periodicals were commonly published by missionaries and religious workers. Through periodicals, associations, and organizations, deaf people sought both to maintain a community of their own and foster their full participation in public life. The United States National Association of the Deaf (NAD), the first organization of deaf or disabled people in the Western Hemisphere, was founded in 1880, and still exists today. Similar associations of and for deaf people were established across the world in the nineteenth and early twentieth centuries. These associations have largely been concerned with ensuring the place of sign language in the education of deaf people and securing the rights of deaf people to participate in all aspects of daily life.

THE TWENTIETH CENTURY

The twentieth century saw the twin factors of the ongoing suppression of sign language in the schools and the increasing importance of clubs and associations of deaf people as sites of cultural and linguistic interaction. International organizations were also established, the Comité International des Sports des Sourds and the World Games of the Deaf (today known as Deaflympics) being founded in 1924 and the World Federation of the Deaf in 1951. Deaf people in the early twentieth century were largely concerned with maintaining a foothold in the new industrial age; access to blue-collar employment opportunities was a dominant concern, and the NAD led several campaigns to ensure employers and the general public saw deaf people as good workers and contributing citizens and taxpayers. Deaf Europeans did the same in their own countries. Books such as Albert Ballin's 1930 *The Deaf-Mute Howls* and the 1932 German film *Misjudged People* tried to counter popular impressions of deaf people as inferior. In their own media, deaf people represented themselves to hearing society as healthy, vigorous, and thoroughly modern individuals.

World War II

World War II proved to be a boon to deaf Americans; as hearing men went to the front, employers hired deaf people to take their place. The rubber factories of Akron, Ohio, employed large numbers of deaf workers and became a Deaf Mecca of sorts during the war years. In Nazi-occupied Europe, however, deaf people became targets of Nazi persecution. During the 1930s, 17,000 deaf people were sterilized. Under Nazi rule, a number of deaf Germans were sterilized, underwent forced abortions, or were killed. Deaf Jews were also sent to concentration camps; only 34 of Berlin's prewar population of 600 deaf Jews survived the war. Altogether, an estimated 1,600 deaf people died at the hand of the Nazis.

The Twentieth-Century Deaf Renaissance

The rediscovery of sign language by Dr. William Stokoe in the 1960s, together with his deaf research assistants Dorothy Casterline and Carl Croneberg, led to a renaissance within the Deaf community. This research in sign language, together with a social climate generally more amenable to difference—be it in hair length, skin color, or language use—brought about a corresponding change in how hearing people saw deaf people and deaf people saw themselves. After years of oralist strength, deaf people were able to advocate for the increased use of sign language in Deaf education. Deaf American Roy Holcomb was a leader in the 1970s total communication movement, which advocated the use of all possible means to educate deaf children, which often panned out in practice to mean speaking and signing simultaneously. ASL was increasingly accepted for foreign language credit in colleges and universities across the country in the 1980s and 1990s. A growing body of research on sign language led deaf leaders, also inspired by research into bilingual education models with other linguistic minorities, to establish a bilingual-bicultural approach to Deaf education, which stressed the use of ASL as the native language of deaf children and the parallel acquisition of English, which would follow from this native language base.

A prominent example of the global Deaf awareness movement of the late twentieth century is the 1988 "Deaf President Now!" protest over the appointment of a hearing person, Elizabeth Zisner, to head Gallaudet University, the world's only liberal arts university for deaf people. After a week of protest by American deaf people and generally positive coverage of their demands for a "Deaf president now" in the national media, I. King Jordan was appointed the first deaf president of the college on March 13, 1988. The "Gallaudet Revolution" was only the most prominent of a number of largely localized political activities by deaf people around the world aimed at putting deaf people in positions of control over their own lives and restoring the use of signed languages in Deaf education.

Deaf communities have prospered across the world for several centuries and are now politically organized in a myriad of organizations on all levels: local, national, and international. Deaf people have long participated both in their own cultural community and that of the larger cultural community they live in. In the twenty-first century, the increasingly widespread use of cochlear implants, an auditory enhancement device, has brought about a resurgence of the oralist philosophy and the medical/education nexus. As well, research into the genetic causes of deafness presents deaf people with, quite literally, an existential dilemma. Hearing perceptions of deafness could very well lead to the elimination of certain genetic forms of deafness and a sharp reduction in the size of Deaf communities worldwide. The history of deaf people to date, however, has been one of survival and indeed, prosperity, in the face of a larger society that knows little of their lives and their languages.

—Joseph J. Murray

See also Abbé Charles-Michel de l'Épée; Alexander Graham Bell; Deafness, on Martha's Vineyard; Edward Miner Gallaudet; Thomas Hopkins Gallaudet; Oralism.

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DEAF CULTURE

CULTURE DEFINED

Culture is quite possibly one of the most difficult notions to grasp at any time in recorded history. As Raymond Williams has said, *culture* is

> one of the two or three most complicated words in the English language. This is so partly because of its intricate historical development in several European languages, but mainly because it has come to be used for important concepts in several distinct intellectual disciplines, and in several distinct and incompatible systems of thought. (as quoted in Ladd 2003:197)

There have been a plethora of attempts to define this concept, with virtually no two reading the same. It is not the goal in this entry to attempt a redefinition of the complex notion of culture. Instead, this entry builds on the prevalent perspectives that define *culture* as a group of people's "way of life," which involves "cultural practices" that function to signify, or rather to "[produce] meaning," including practices in the United States such as pop music, soap opera, and comics (Storey 1998:2). Or in other words. "a set of control mechanisms—plans, recipes, rules, instructions . . . for the governing of behavior" (Geertz 1973:44). Therefore, "by definition, cultures are highly specific systems that both explain things and constrain how things can be known" (Padden and Humphries 1988:24).

DEAF CULTURE

However Deaf culture is approached, it is presented as having to do with this particular group of people and their way of life, their behaviors, their means of interacting, their belief systems, and their systems of knowing and knowledge.

Visual Way of Being: Linguistic

In the United States, and the world in general, the majority culture (hearing) focuses on deaf as an issue of hearing loss, emphasizing the idea that deaf people are people who are lacking something. However, for those members of Deaf culture, hearing is not put to forefront, nor is its supposed loss a concern or factor of identity. Deaf people have a value system that reveals a different foundation—not a value of that which is heard, but instead a value of that which is seen. Edward Hall (1982) points out that "people of different cultures not only speak different languages but, what is possibly more important, inhabit different sensory worlds" (p. 2). As George Veditz (1912), a deaf leader in the early twentieth century, exhorted, deaf people are "first, last, and all the time, the people of the eye" (p. 30). The visual way of being for deaf people is inherent and present in all aspects of their lives. And the foundation of this existence is in their visual communication system. As Bahan (2004) asserts, "Deaf people, being of a human variety, have refused to be reduced to the status of things and found ways to communicate visually and developed visual languages. That is the essence of their being. All other things are constructed around this, channeled through and by vision" (p. 3).

The existence of the use of a visual gestural communication system by deaf people has been documented as far back as ancient Greece. In *Cratylus,* Socrates poses a question to Hermogenes, "Suppose that we had no voice or tongue, and wanted to communicate with one another. Should we not, like the deaf and dumb, make signs with the hands and head and the rest of the body?" (Plato 1961:457).

It has been observed that a deaf child born anywhere in the world will, as she grows up, whether surrounded by visual linguistic input or isolated from regular communication among those who hear and speak, develop home signs as means of expressing herself. This development has been shown to emulate the natural language acquisition process. It is within the being of deaf people to do so given that society does not intervene (see Lane, Hoffmeister, and Bahan 1996; Goldin-Meadow 1985, 2003). As Deaf schools were established, different deaf people were brought together and with them different home signs, allowing for the emergence and eventual development into a complete linguistic system. Various signed languages of the world, such as French Sign Language and Nicaraguan Sign Language, were born from such situations (see various essays in Lane 1984; Social, Behavioral and Economic Sciences 2004). In using sign languages, it is not just that the language is produced using the hands and understood through the eyes that suggests a strong visual center of deaf people. As Bahan (2004) explains, “Signers manifest many different kinesthetic features which are depicted visually: the body, head, hands, arms, facial expressions, and the physical space surrounding the signer and his/her eyes” (p. 4). They also develop over time various adaptations for vision and visuality, among them we see increase in saccadic (rapid eye movement) and head movement, enhanced peripheral vision, multilayered use of eye gazes to transmit and receive communicative and linguistic function (for more information, see Bahan 2004).

In the United States and Canada, American Sign Language (ASL) is another example of a signed language rooted in visual gestural communication that, as mentioned briefly above, was allowed to develop when deaf people were brought together in the first deaf schools in the United States shortly after the beginning of the nineteenth century. ASL today is a language that “has a grammar, with rules of word and sentence formation” (Lane et al. 1996:43) and is “a symbol of social identity, a medium of social interaction, and a store of cultural knowledge” for the Deaf-World (Lane et al. 1996:67).

Visual Way of Being: A Way of Life

Not only is the visual essence of a deaf person seen in the existence of signed languages, but research has shown that, “among signing deaf people, the role vision and the use of eyes expands exponentially” (Bahan 2004). Therefore, the recently discussed visual way of being “is carried over into the cultural lives, values, consciousness, social spaces, and literatures of signers” (Bahan 2004). This is due to the fact that, as language flourishes in complexity, rules of engagements are naturally formed. In other words, standards for how the language is used and the sociocultural constraints for language use are developed as the language becomes more and more intricate.

From these engagement culture rules, values and behavior systems come into being over time. Thus, within American Deaf culture as an example, many of the values expressed are directly related to the idea of Deaf as having a visual orientation. In the well-known text on deaf studies, *A Journey into the DEAF-WORLD,* the authors state that the values of Deaf culture “are stored in sign language, so to speak, for transmission across the generations” (Lane et al. 1996:70). Thus, each value relates directly to the visual language used to convey this value. The values of the American Deaf culture include the identity of being, thinking, and behaving like a deaf person when among other deaf people. Also, deaf people value their signed language and have a tendency to prefer group-decision making, reciprocity, and mutual aid as important parts of how they believe they should interact with one another. As part of the value of cultural reciprocity, one can find deaf people exchanging various adaptive strategies for being a visual person in an auditory dominant world through narratives of personal experience. Examples of such adaptive strategies include how to be aware of the ways sound bounce off visual cues, and so on (Bahan forthcoming, 2004). Deaf culture also values informality and physical/tactile contact, along with the promotion of unity among members of this community.

Visual Way of Being: Expressions and Locations of Deaf Culture

The previous section reflects on the notion that culture itself can often be thought of as adaptation systems where people “relate their community to their ecological setting” (Keesing 1974:74 as quoted in Ladd 2003:201), doing so in order to survive (Meggers 1971:4 as quoted in Ladd 2003:202). This leads us to examining various environments, places, and sites where these visual cultural ways are expressed.

There are numerous organizations run by and for deaf people, at local, state, regional, national, and international levels. These organizations, including athletic, social, religious, educational, and political associations and institutions, serve a variety of purposes and roles in the lives of deaf people. Some examples in the United States include local Deaf clubs, Deaf residential schools, state associations of the Deaf, the USA Deaf Sports Federation (USADSF), National Congress of Jewish Deaf, the National Association of the Deaf (NAD), and the World Federation of the Deaf (WFD) (for more information, see Lane et al. 1996:131–138).

Deaf people who grow up in residential schools often see the place as their home and consider their classmates, peers, and the deaf mentors as an extended "family." So Deaf schools are more than just an educational site. It is often the first place deaf persons come to be a part of this visual world and a place where they began to learn sign language. A sense of sacredness is often adhered to these places. Many deaf people return annually for homecoming, football games, and special events. Many deaf people, upon graduation, will stay in the area near their school, get jobs at their school, or, if they do move away for college or a job, may later return to the area where they grew up, maintaining close ties to the school (Lane et al. 1996:70–71).

As in all cultures, the Deaf-World also includes and values artistic means of expression. At these community sites, one will find a rich history of ASL literature. ASL literature includes a variety of genres, including stories, poetry, folk tales, legends, anecdotes, and allegories, to name a few. Within the Deaf-World, there are story-tellers, poets, and comedians who are known for their abilities and called on to give performances in a variety of venues. Many of the deaf artists travel around the country and around the world entertaining and inspiring deaf and hearing audiences, while passing on Deaf culture, language, and history through their stories and poems (Bahan forthcoming).

Yet another site where the visual culture of deaf people, along with their history and language, are conveyed is through deaf theater. "The earliest plays by deaf actors on Deaf-World themes in the U.S. probably originated in the mid-nineteenth century in the residential schools, where plays develop around Deaf school life, Deaf history, and Deaf family situations" (Lane et al. 1996:145). In the 1940s, Gallaudet University started providing formal drama classes, and deaf actors founded the National Theatre of the Deaf (NTD) in 1967. After almost 40 years in existence, NTD can boast more than "fifty touring seasons and twenty-eight foreign tours, and more than 6,000 performances of some fifty productions and numerous awards for its work" (Lane et al. 1996:145–147; Peters 2000). One of its most well-known pieces has had a huge impact on the perception of ASL and Deaf culture. This play was titled *My Third Eye*, and it included five parts about ASL and deaf people. Both NTD and other regional deaf theaters have had a large impact on deaf people not only in the United States but also around the world (Lane et al. 1996:147–148; Peters 2000).

Finally, an important means of expressing Deaf visual culture is found in deaf art, which conveys various deaf themes, such as pride and beauty of deaf identity, expression of frustration or anger related to a lifetime of oppression, and visual images that represent the deaf experience in the hearing world. In 1989, during Deaf Way International Conference in Washington, D.C., nine deaf American artists came together to establish a manifesto about deaf art, naming this form of art De'VIA (Deaf View/Image Art), "meaning one which 'uses formal art elements with the intention of expressing innate cultural or physical Deaf experience.' The manifesto explains that De'VIA often includes focus on the hands and face" (Lane et al. 1996:140). Deaf art can be seen in many places, with a large collection housed at Gallaudet University and displayed in various locations across campus (for more information, see Sonnenstrahl 2002; www.deafart.org). Deaf art allows deaf artists to express who they are, while visually representing their language, culture, and experiences. In so doing, other deaf people find something to which they can relate, be inspired by, and an art form that reflects their lives.

These examples give a general view of the ways that Deaf culture as a visual culture are expressed. They very much exemplify what Padden and Humphries (1988) described as a Deaf center, referring to a Deaf-centric, rather than a hearing-centric, perspective of the world, "where DEAF, not HEARING, is taken as the central point of reference" (p. 41). As one deaf community leader has pondered,

> In retrospect I can't help but wonder about the "what ifs," because it has taken society so long to acknowledge the role of vision and signed languages in the lives of Deaf people. So many generations of signers

> have been handcuffed in a society intoxicated by the ideology that speech is language and vice versa. It is amazing that with these impositions, deaf people have developed into one of the most visual groups of people on the face of the Earth. One wonders what the possibilities would be if they were allowed to proceed in life unbounded . . . how far would this human variety push the boundaries of vision? (Bahan 2004: 21)

DEAF CULTURE AND MICROCULTURE

Based on this presentation of deaf people as visual people, it might seem that Deaf culture results in a community that is a completely separate, self-contained entity. This is not really the case. In his recent work *Understanding Deaf Culture: In Search of Deafhood,* Paddy Ladd (2003:224–225) presents the idea of Deaf culture as a minority culture that is embedded in majority culture. Similarly, Graham Turner explains that deaf people and their culture are indeed a minority culture in majority speech cultural community, resulting in most members of Deaf culture being bicultural in the sense that they share the values and language of a larger culture but also have language and values of another culture within. As Turner (1994b:98) explains, deaf people, regardless of where they live, "share more or less fully in the wider culture of the nation, region, or tribe they belong to." Thus, Deaf culture cannot clearly be separated from the hearing culture of which it is a part (p. 98). These structural descriptions correspond with the definition of microculture put forward by Spradley and McCurdy (1987), who describe it as "subsystems of cultural knowledge characteristic of subgroups within larger societies. Members of a microculture will usually share much of what they know with everyone in the greater society, but will possess a special cultural knowledge that is unique to the subgroup. . . . It is this shared knowledge that makes up their microculture" (p. 13 in Turner 1994a:113).

However, this approach is also complicated by the fact that Deaf culture cannot be compared to other microcultures, such as a biker microculture or a punk microculture. The complicating factor involved in tackling the analysis of Deaf culture and microculture is the fact that another language is used that has lead to the creation of a Deaf culture. But it is also true that deaf people are not leading separate lives. They are usually bilingual and bicultural to a various degree and are very much part of the majority culture. This issue of language is the reason that Deaf cultural studies does not fall in to any one of the cultural studies categories that exist presently. Thus, a creative approach is needed in studying Deaf culture (Ladd 2003:208). Possibly the idea that "people of different cultures . . . inhabit different sensory worlds" (Hall 1982:2) coupled with this idea of Deaf culture as a microculture is just such an approach.

—Benjamin Bahan
and Elizabeth Parish

See also Disability Culture.

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DEAF PEOPLE AT THE OTTOMAN COURT

Deaf people worked as Ottoman Court servants at Istanbul from the fifteenth to the twentieth centuries. Their sign language became a recognized means of communication among hearing courtiers from the late sixteenth century. Courtly use of sign language may date from Mehmed II's reign (1451–1481). He cultivated an image of imperial sacredness, withdrawing from public appearances and speaking with very few people. During Suleiman I's reign (1520–1566), some deaf people certainly served him and he communicated with them by sign. From the 1570s onward, more visitors witnessed signing at court, and the deaf servants numbered between 50 and 100. In the mid-seventeenth century, the linguist Bobovius, a senior court interpreter, specified the place in Topkapi Palace where the older deaf men taught sign language to younger deaf people. The number of deaf servants had probably fallen by 1700, but in the 1880s Sultan Abdul Hamid was recruiting deaf people from Africa. A photo published in 1917 shows two deaf servants signing. The Ottoman deaf servants were in a rare historical situation where their sign language was needed by hearing people, and they taught it to Sultans, courtiers, and the younger generation. Recent linguistic research on modern Turkish Sign Language (Türk Isaret Dili) suggests that it has existed for centuries independent of other sign languages.

—Kumur B. Selim

See also Deaf People in African Histories; Sign Language.

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DEAF PEOPLE IN AFRICAN HISTORIES

Deaf people have left traces in African history and legend over several thousand years (Miles 2004). Records suggest that they often had little status in society and were sometimes targets for abuse or ridicule. Yet some also won respect and honor from hearing people. Deaf people's sign languages were noticed in antiquity, and they were studied in greater detail in the past century. The great majority of deaf people seem to have led ordinary lives like anyone else, living with their families in villages and towns, while using some different methods of communication. They worked with agricultural, domestic, or artisan skills, and more recently in the full range of modern jobs.

ARCHAEOLOGY, FOLKLORE, HISTORICAL TEXTS

Evidence of deafness exists from the twenty-fifth century BCE in North Africa, when hearing loss in old age was lamented (Erman 1927). The Ebers Papyrus shows that deafness was well understood 3,500 years ago, and clinical knowledge had developed in ancient

Egypt (Nunn 1996; Pahor 1992). Mention of "one who is deaf and does not hear, to whom men make (signs) with the hand" appears in the Koller Papyrus dated ca. 1200 BCE (Gardiner 1911). Among the earliest named and located deaf people was Munah the Deaf (in Arabic: "Munah al-Asamm"), house-owner and head of family at Tutun in the Fayyum province of Egypt. Two sale contracts dated 962 and 963 CE mention the house belonging to "the heirs of Munah the Deaf," which delineated one border of properties that were being sold (Frantz-Murphy 1981).

The African theologian Augustine, writing at Tagaste (now in Algeria) in the late fourth century CE, gave perhaps the earliest clear and positive description of deaf people using sign language in Africa, "to ask and answer questions, to teach and make known either all their wishes or, at least, a good many of them" (Augustine [ca. 389]). Sixteen hundred years would pass before governments in Africa began to take sign language as a serious medium for education and communication.

HOW MUCH FOR THAT DEAF GIRL?

Folk legends from the southern Bantu people mention the woman Luojoyo communicating by sign with her one hand. The "deaf-mute" Muwende-Lutanana and others also used signs (Mutwa 1998). Signed communication was a recognized activity in these stories handed down over centuries. Folklore and also current African literature sometimes portray deaf people as "dumb," meaning stupid and useless (Odebiyi and Togonu-Bickersteth 1987; Sarr 1981; Naniwe 1994; Oteng 1988). Yet some Malian folk tales involving a deaf wife suggest the need for patience and understanding rather than denouncing stupidity (Calame-Griaule 1987). Deaf Africans were also found useful as servants. At Kuka, capital of Bornu, west of Lake Chad, deaf slave girls fetched high prices to serve the wives of businessmen in some Arab countries (Nachtigal 1971–1987). Some deaf people were presented as valuable gifts to the Ottoman Sultan, who was traditionally served by deaf people (Gaden 1907).

The balance of abuse and exploitation, as against everyday acceptance and integration, is hard to estimate. Abusive treatment of deaf people certainly happened and was sometimes recorded, while any amount of "ordinary life" passed unnoticed, as it does today. For example, in 1848, Charles Orpen, minister at Colesberg, South Africa, saw that the chief constable had an excellent African servant, "sober, honest, and faithful." The servant also happened to be deaf, and this was noticed by Orpen, who had earlier founded a deaf school in Ireland (Le Fanu 1860). Many other deaf servants probably remained "invisible."

READING THE SIGNS

In rural South Africa 200 years ago, the traveler Henry Lichtenstein was delighted to understand "home sign" by Mr. Gildenhuis, a good-humored deaf craftsman who flourished in the 1790s and 1800s. Gildenhuis was "uncommonly clever in handicraft employments, and was exceedingly useful to the inhabitants of the country, in making gun-locks, tools for all kinds of work, and in general in all the finer kinds of smith's work," as well as artistic carvings and engravings (Lichtenstein 1812). Lichtenstein described some of Gildenhuis's wittily executed gestures, which are easily recognizable. More formal documentation efforts were begun by James Sibree in the 1880s, with brief descriptive notes on sign, gesture, and symbolic acts used in Madagascar (Sibree 1884).

The missionary educator David Forbes, reporting work at Rumasha, Nigeria, in 1917, noted that "the deaf and dumb are not forgotten, and two boys are receiving instruction in the signs of the deaf and dumb language. Every morning a short lesson is given to all the boys to enable them to communicate with the two mute lads." This suggests that a recognized sign language existed and was taught to deaf and hearing alike, 40 years before education for deaf children would officially begin in Nigeria. It is one of the earliest descriptions of deaf children being integrated in a thoughtful way in an ordinary school in Africa.

The first substantial historical group of African deaf people with a documented sign language lived at Adamorobe in Ghana, probably from around 1800. Formal research on signing at Adamorobe began in the early 1970s, and the inheritance of deafness over several generations was also traced (David 1972). Systematic linguistic study is in progress, comparing

Adamorobe Sign with other African Sign Languages. Hausa Sign Language and South African Sign Languages already have scholarly documentation (Schmaling 2000; Penn and Reagan 1999). More than twenty African Sign Languages have had some formal study, and the field is growing steadily in complexity.

Some observations in Ghana, Mali, Niger, and Nigeria suggest a high level of social integration of deaf people. In Kano State, "Many hearing people, old and young alike, are able to converse with the deaf freely and effectively through signs or sign language, at least on a basic level" (Schmaling 2000). However, earlier experiences of the deaf writer Florence Serwaa Oteng give a less positive picture, from southern Ghana (Oteng 1988, 1997). The lengthy battles of this intelligent Ghanaian woman, deafened in early adulthood, appear in her largely autobiographical novelette set amid the petty politics of a boarding school for deaf children.

DEAF PEOPLE OF DISTINCTION IN AFRICA

Gallaudet University's "Deaf Biographies Index" lists Nelson Mandela and Desmond Tutu, whose hearing impairments arose after they became public figures, and also Francisco Macias Nguema (1924–1979), who became deaf during his unhappy dictatorship of Equatorial Guinea 1968–1979. By contrast, Godfrey Huggins (Lord Malvern), who became ruler of Rhodesia and Nyasaland (now Zambia, Zimbabwe, and Malawi), had seriously impaired hearing from childhood (Gann and Gelfand 1964).

Many years of scientific work in North Africa earned Charles Nicolle the 1928 Nobel Prize for medicine, the first awarded to a deaf person. Nicolle lost his hearing as a medical student. He became director of the Institut Pasteur at Tunis in 1903, and died there in 1936 (Lang and Meath-Lang 1995). Another Nobel Prize winner, the Algerian writer Albert Camus (1994), was raised by a deaf uncle and a partly deaf mother. His unfinished autobiographical novel includes a chapter on the uncle, Etienne Sintès, who worked locally as a cooper. It is a vivid portrait from the 1920s of a lively, sporting, deaf man in Algiers, popular among his hearing friends, an expert hunter with gun and dog, and a surrogate father to the young Camus.

The Senegalese writer Moussa Ly Sangaré (also known as Dono Ly Sangaré) reports a more personal experience with deafness, starting ca. 1953 when he was a schoolboy. He began asking people to repeat what they said, a habit noticed both at home and at school. His kindly teacher, M. Diabâté, asked young Moussa if he had difficulty hearing, which the boy denied, unaware that the problem might lie in his own capacity. One day, however, during a dictation exercise, silence fell upon him. Moussa saw that his teacher was still speaking and the other boys still writing, but for him there was only a distant jumble of sound. Between one phrase and the next, his hearing had gone (Sangaré 1978).

Deaf people with nationally recognized artistic skills in Africa include an Ethiopian, Afework Mengesha; an Egyptian woman, Hanan Marzouk; a South African, Tommy Motswai; and doubtless many more. An earlier generation produced the prize-winning Algerian/French monumental sculptor Joseph Ebstein, born at Batna in 1881. Ben Hurwitz, a champion chess player in South Africa, was deaf and then became blind (Blaxall 1965).

For many deaf people in Africa, the outstanding role model of the twentieth century was a charismatic deaf African American, the Reverend Dr. Andrew Foster. He studied at Gallaudet University and went to West Africa in 1957 on a mission to reach deaf people. Before his untimely death in 1987, Foster had trained and inspired a generation of deaf African leaders who carried forward the work of educating and equipping deaf people across the continent for independent living on equal terms with the hearing world (Okyere and Addo 1999).

DEAF PEOPLE IN ORDINARY LIFE

Fr. Lechaptois, missionary in Nyasaland in 1890, pictured a deaf man's hands at work: "There was another craftsman close by, a deaf mute, who was making a magnificent fishing net. . . . The mesh was beautifully even and neatly tied . . . it looked deceptively simple" (Mponda Mission diary 1889–1891). Simple goodness characterized the young deaf workman in a novel by Kenyan author James Ngugi (1971). He was strong, good looking, popular with other young men, caring for his old mother, using his hands to communicate.

Apparently, this figure was based on Ngugi's own deaf stepbrother Gitogo, who was shot by troops during a disturbance in the 1950s.

Between spells of work, many deaf people could find themselves in difficulties such as befell Moses, Simon, Piet, and others, lost between cities, illiterate, without papers, arrested by the police, unable to give an account of themselves. For some of these in South Africa in the 1930s, the Reverend Arthur Blaxall would be called in to mediate:

> In due course I find myself confronted by a grimy man in dishevelled clothes. I lift an eye-brow and smile, at the same time touching my ears with an enquiring look—a faint glimmer springs into his eyes as I go on with natural signs of sleeping, growing up, and a wide gesture of both hands with an open expression of surprise. Where do you come from? Where did you grow up?—he surely recognises the signs. (Blaxall 1965)

The impulse to protect and teach was not exclusive to missionaries. Mrs. Oyesola, a Nigerian leader of Girls Brigade activities in the early 1960s, was faced with her own Brigade girls' scorn and rejection of a poor, homeless, deaf girl, Seliatu. Mrs. Oyesola adopted Seliatu and set about finding some ways to teach her. Eventually, she got training at Gallaudet to become a teacher of the deaf, and she opened the Ibadan Deaf School in 1963, starting with Seliatu and three deaf boys (Ojile 1999).

Many deaf children learned to fend for themselves. Karen Blixen observed a deaf nine-year-old living on her farm in Kenya in the 1920s. Karomenya was tough, a skilled stone-thrower and an eager fighter with other children. Blixen gave him a chance to learn domestic work and make himself useful, but the boy did not care for such tasks. The Danish lady left him free, though she saw that he would have a hard time later in life (Blixen 1954).

VOICE AND VALUE

Acquiring a voice and presence in public affairs has been a long, slow process for deaf people in Africa. Probably the earliest public meeting about deaf people was at Bloemfontein in 1928, organized by Blaxall, concerning education. Hearing professionals "represented" deaf people. The next known conference, organized in 1965 by Andrew Foster at the University of Ibadan, Nigeria, had deaf people speaking for themselves. Yet it would be another 25 years before most countries would have deaf organizations that could make an impact at a national policy-making level. The World Federation of the Deaf (WFD) included "legislation" in a survey of national situations of its members, and it received replies from Benin, Burkina Faso, Egypt, Gambia, Ivory Coast, Kenya, South Africa, Swaziland, Togo, Zaire, and Zimbabwe. Responses suggest a very slow movement toward recognition of the value of deaf persons, whether in legal systems or the societies that run them (Michailakis 1997).

—Kumur B. Selim

See also B. J. G. De Labat; Deaf People at the Ottoman Court; Experience of Disability: Sub-Saharan Africa; Hearing Impairment.

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DEAFBLINDNESS

The term *deafblindness* describes a disability in which an individual has both a hearing impairment and a visual impairment. Deaf-blind individuals form a highly heterogeneous group that tends to have varying degrees of hearing and visual impairments. Deaf-blind individuals tend to prefer being referred to as "Deafblind," "Deaf-Blind," "Deaf-blind," "deaf-blind," or "deafblind." As with other disability classifications, deafblindness can be viewed from two opposing perspectives: the medical model and the cultural or social model. The terms *deafblindness* or *deaf-blindness* tend to emphasize the medical condition of the disability, whereas the terms *Deafblindness*, *Deaf-Blindness*, or *Deaf-blindness* tend to focus on the cultural membership of the individuals with the disability. The labels *deaf/blind* and *individuals with a dual sensory impairment* should be avoided because they are ambiguous. The term *deaf/blind* is ambiguous because it seems to refer to deafness or blindness instead of the combination of both impairments. The term *dual sensory impairment* leaves open to interpretation which two senses are actually impaired.

An individual is diagnosed with a hearing impairment if the individual has a hearing loss greater than 30 db in the better ear. There are different types of hearing loss. A conductive hearing loss consists of damage to or obstruction of the outer or middle ear. A sensorineural hearing loss is caused by damage to the inner ear or the auditory nerve. A mixed hearing loss is diagnosed when an individual has both a conductive and a sensorineural hearing loss. Cortical deafness is caused by damage to the auditory cortex of the brain. A hearing loss of any kind can range from mild to profound. A conductive hearing loss can often be aided with hearing aids and/or surgery. A conductive and a cortical hearing loss often cannot be improved by hearing aids or surgery because of the nerve damage, which causes distortions of sound.

A visual impairment is commonly defined as poorer than 20/70 visual acuity after correction or a restricted visual range of 45 degrees or less in the better eye. A visual impairment can be caused by damage to the eye itself, damage to the visual nerve, or damage to the visual cortex.

The causes of deafblindness vary greatly among the population of deaf-blind individuals. The potential causes of deafblindness include genetic syndromes (e.g., Usher's syndrome, CHARGE Association, Goldenhar syndrome), illnesses or diseases of the mother or child (e.g., rubella, meningitis, cytomegalovirus, and tumors), or accidents (e.g., head injury). A combination of any of the above causes is also possible (e.g., an individual is born deaf due to a genetic syndrome and later loses her vision due to an accident or illness). The most common genetic syndrome causing deafblindness is Usher's syndrome and the most common disease to cause deafblindness is rubella. Depending on the underlying cause of deafblindness, the type of hearing and vision loss is also likely to vary. For example, individuals who experience a vision and a hearing loss secondary to Goldenhar syndrome are most likely to have a conductive hearing loss and damage to the eyes due to differences of the structure of the skull, whereas individuals who had meningitis tend to have a sensorineural hearing loss and a vision loss due to damage to the visual nerve.

Deafblindness must definitely also be viewed from a cultural perspective. Similarly to the medical background of deaf-blind individuals, deaf-blind individuals' cultural identity varies greatly. Depending on the age at which individuals became deaf and blind, they are more likely to associate and feel close to others most similar to themselves. This similarity is often based on the preferred method of communication used within the different groups. Individuals involved in the blind community and the mainstream community are likely to use spoken language as their main means of communication, whereas individuals involved with the Deaf community are likely to communicate by using a signed language. The Deaf-blind community is the community with the most diverse communication methods. Some may use a signed language, while others may use a spoken language; others may use writing, Braille, Tadoma (i.e., tactile speechreading), while still others may use a combination of all of these.

For a number of decades, research on the Deaf community has yielded a wealth of knowledge about Deaf culture as a minority culture. Deaf individuals tend to view themselves as members of a linguistic minority within American society and often do not view themselves as disabled. Members of the Deaf community tend to have a number of characteristics in common: They share a physical attribute (i.e., their deafness) and tend to identify as members of the Deaf community. Most Deaf individuals are very proud of their language (e.g., American Sign Language), which is commonly used in poetry and art. Deaf individuals also display a number of culturally characteristic behaviors. The most pronounced are possibly the attention-getting behaviors, which include stomping feet, waving arms across a large room, tapping on the shoulder, or even flashing lights. Deaf individuals tend to marry other Deaf individuals. Similarly to members of other minority groups, Deaf individuals often experience oppression by mainstream society.

Individuals who were born blind or became blind early and later became deaf are more likely to use spoken language as their main means of communication. Due to their hearing loss, they might later add some signs, fingerspelling, Tadoma, or other forms of manual communication (e.g., printing on the palm) to aid in communication. These individuals tend to identify with and therefore associate primarily with the blind community, individuals from the mainstream culture, or the disabled community. Due to their deafness they are later also likely to associate with the Deaf-blind community where they are more likely to have more equal access to communication.

Individuals who are born or become deaf early and later become blind are likely to use a signed language as their main communication method and therefore associate with other members of the Deaf community and be mostly involved in Deaf culture. Because of their ties to the Deaf community, they are likely to remain involved with Deaf culture, but later also be involved with the Deaf-blind community. At least one scholar has argued that a substantial number of deaf individuals who become blind feel ostracized by the Deaf community and thus withdraw and associate more with the Deaf-blind community.

The individuals who are born deaf-blind are likely to associate either with the Deaf community, the blind community, the Deaf-blind community, the disability community, and/or mainstream society. It will most likely depend on the severity of their hearing and vision loss, on the community in which they grew up, on the type of schools they attended, and on which language they prefer to use. For example, individuals who consider their deafness to be the most important aspect of their identity and who use a signed language are likely to associate with the Deaf community, whereas individuals who have significant amounts of residual hearing and vision and primarily rely on spoken language will associate mostly with mainstream society.

The individuals who spent most of their lives as sighted and hearing individuals and then all of a sudden became Deaf-blind are most likely to feel the most disoriented regarding culture and community membership. They are most likely to have spent most of their lives in mainstream society and to have used spoken language to communicate. As Deaf-blind individuals, they are likely to need to learn alternate methods of communication and depending on which of the plethora of options they choose and prefer they may join any of the communities. This group is especially likely to be drawn to either the Deaf-blind community or the disability community because in both of these communities a diversity of communication options seems to be accepted allowing these individuals full participation and access.

When considering deafblindness from a developmental perspective, it is possible to consider deafblindness from both the medical and the cultural or social perspectives. Researchers following the medical perspective, the most common point of view within the field of developmental science, tend to focus on the deficits of deaf-blind children and on the delays they experience in comparison to their typically developing peers. Within the developmental science framework, the cultural model, however, allows researchers to study the plasticity of development in general and to learn about the development of identity and cultural affiliation of minority groups.

From a developmental medical point of view, the most important aspects of deafblindness are the age of onset and the severity of the hearing and visual impairments. According to the developmental model, the two sensory impairments multiply the effects of one another and intensify the impact each one has on an individual. Having two impairments likely inhibits the compensation of one impairment through the use of the other (e.g., compensating for deafness by lipreading). Consequently, the earlier the auditory and the visual impairments occur and the more severe the level of each impairment is, the greater are the consequences on development.

Deafblindness is likely to affect cognitive, language, social, and emotional development. Individuals who are born both deaf and blind commonly experience significant delays because they are not able to observe and thus learn about the world as readily as sighted and/or hearing infants. According to Piaget, whose research focused on cognitive development, individuals need to gain experience within their environment to acquire the skills and the knowledge necessary to successfully complete the tasks for each of the four developmental stages. The sensorimotor period, the stage between birth and two years of age in which infants learn about the basic properties of objects, progresses through a series of substages, and culminates in the infant's ability to mentally represent objects. Infants acquire object permanence, the knowledge that objects continue to exist even when they are hidden. This is considered a difficult task for blind and deaf-blind infants because they only learn about the world within their reach. There are limited or no visual and/or auditory clues to provide them with information. Interesting objects within the environment encourage infants to investigate their surroundings. For blind and deaf-blind infants, this is not the case. Therefore, they spend a lot of time in the position they were put down in often resorting to self-stimulating behaviors. Similar observations can be made throughout deaf-blind children's development. With increasing age, the delays become greater and it becomes difficult for them to catch up to their peers. It is therefore beneficial for the development of deaf-blind infants that they are diagnosed and that age-appropriate stimulation is started young.

Deaf-blind children's language development is also at risk for significant delays. First, deaf-blind children, as blind children in general, are likely to be delayed in their mental representation abilities and subsequently in their language development because language requires mental representation and actually is considered a complex form of mental representation. Second, deaf-blind children with a significant hearing impairment tend to be delayed in their language development because they are likely to not have access to language. They cannot hear spoken language and they cannot see and thus imitate gestures or signs. Some deaf-blind infants, similarly to deaf infants, may develop their own rudimentary gestures for certain objects or events. However, due to the likely lack of mental representation skills, infants born deaf-blind are even less likely than deaf infants to be able to string together individual gestures to form complete thoughts or express desires. On the other hand, those young children who either became deaf-blind after already acquiring mental representation and those who have significant residual vision and/or hearing are likely to learn mental respresentational skills more easily than their peers who were born completely deaf-blind.

When discussing the medical model within the field of developmental psychology, it is important to ask whether this model provides a complete picture with all the answers. Most likely this is not the case. As research studies have shown, the environment is essential to the prediction of later outcomes in children. This is particularly the case for deaf-blind children. If deaf-blind children are provided with an accessible language and an accessible environment in which they are stimulated and encouraged to investigate their surroundings, they learn at a similar rate as their hearing and sighted peers.

In summary, deaf-blind individuals represent a highly diverse group of individuals. Deaf-blind people can acquire their impairments at different ages. They have varying degrees of hearing and vision impairments, which can affect their developmental pathways. They may communicate in a plethora of ways. They can identify as members of a variety of cultural groups. Each one of these factors can have an impact on the individual who is deaf-blind. As will all people, it is important to view and respect each deaf-blind person as an individual.

—Ingrid C. Hofmann

See also Blind, History of the; Laura Dewey Bridgman; Helen Keller.

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DEAFNESS, MILAN CONGRESS OF 1880 ON

In 1880, a congress for the Deaf was held in Milan. The delegates saw an attack on sign language and thereby on the possibilities for their emancipation. Even for some years previously, the "oral method" for the instruction of the deaf had predominated in state institutions and private schools in Europe. Yet there was still not unanimity in the matter. Some schools remained faithful to the French method inherited from Abbé de l'Épée, which consisted of gestural signs and writing. And within certain national institutions, some teachers, deaf and hearing, defended the use of signs despite the increasing hegemony of partisans of the oral method. Among the latter are some of the hearing teachers at schools in Paris, Bordeaux, and Chambery; the instructors in the schools created by the Pereire family; the Brothers of St. Gabriel, a religious order devoted to the education of the deaf; and the Protestant teachers of St. Hippolyte du Fort in the Cévennes in the south of France.

All these educators wished to ratify the dominance of the oral method and make it exclusive. Debates took place at the Milan congress, and they were at times quite fierce, especially on the part of Italian delegates, who advanced religious arguments: the need for communication in order to confess and be absolved, or the fact that, since God had given man the faculty of speech, all good Christians ought to speak whereas signing was proof of mental retardation or degeneration.

A vote was taken, and an overwhelming majority of delegates (almost all hearing; France had only one deaf teacher as representative) passed resolutions that all had the same orientation: The oral method was to be preferred over mimicry. Since deaf signing had the disadvantage of being detrimental to speech and even to the precise expression of ideas, it was preferable to suppress sign language. Yet all deaf-mutes needed to be educated and governments were encouraged to take the necessary steps. Not all participants supported these resolutions and the American representative, Edward Miner Gallaudet, criticized them sharply, arguing that the country with the greatest number of deaf pupils, the United States, had only 5 delegates at the congress, while Italy had 87 and France 56, of a total of 164.

Since their passage by state and private teachers, and by administrators from France and Italy, the resolutions in favor of the strict oral method have been experienced by the deaf as an injustice and a denial of their language—sign language—all the more so since they were thenceforth also excluded from the education of their peers. The oral method, far from facilitating social integration of deaf children, had the opposite effect: withdrawal, underpaid employment, and medicalization while at the same time the deaf were proving their social competence through the creation of newspapers, the foundation of mutual aid societies, and the administration of athletic associations, in particular, for cycling. The newspapers, aid societies, and associations were confiscated from the deaf on the pretext that they should stop signing and that they must speak. Otherwise, they would be abnormal, disabled.

—Jean-René Presneau

See also Abbé Charles-Michel de l'Épée; Deaf Culture; Edward Miner Gallaudet; Sign Language.

DEAFNESS, ON MARTHA'S VINEYARD

For 300 years, the island of Martha's Vineyard, Massachusetts, was home to a population with recessively inherited deafness. Such deafness is usually caused by a genetic mutation in an individual whose descendents mate in subsequent generations.

The mutation for Vineyard deafness—which appeared as complete deafness at birth with no associated anomalies—occurred in the British county of Kent. The inherited trait was brought to America by settlers who came as members of a Puritan congregation in 1634. A group of these immigrants arrived on Martha's Vineyard in the 1670s, where their descendents still live.

The overall rate of Vineyard deafness was high: In the nineteenth century; while 1 in every 5,728 Americans was born deaf, on the island the overall rate was 1 in every 155, and in one small island community, 1 in every 4.

The first individual with Vineyard deafness was born in 1657. This man used a highly developed sign language, probably based on a language brought from Kent. (This sign language may have also made a contribution to American Sign Language [ASL], as Vineyard children were in the first classes at the American School). What is noteworthy about this individual and all who would follow is that hearing islanders were able to communicate with them freely, adapting to the deafness by becoming bilingual in English and sign language. Hearing islanders learned sign language in childhood and used it regularly throughout their lives. With so many family, friends, and neighbors deaf, sign language was a necessary part of daily life.

This use of sign language raises an important question: What happens to individuals with a disability such as deafness when nondisabled members of society are willing to adapt to the disability? On Martha's Vineyard, individuals with disability fared well. With no communication barrier, deaf individuals were fully integrated into island life, making comparable livings as fishermen and farmers and participating in all social, civic and religious activities. Interestingly, there was no "Deaf" society—no activities exclusive to the deaf. Indeed to have had a separate social network, deaf islanders would have had to exclude spouses, family, and neighbors. Signing was so much a part of life that nineteenth-century visitors reported regular use of sign among hearing individuals when no deaf islanders were present—on boats and farms and during social gatherings.

The only identifiable difference began with the founding of the American School. Because the state paid for this education, nineteenth-century deaf islanders were somewhat better educated than many hearing islanders and would occasionally be asked to interpret newspaper articles or legal documents by hearing neighbors.

The number of deaf Vineyarders began to decline in the 1880s with improved transportation, as islanders began marrying off-islanders who did not carry the inherited trait. The last deaf Vineyarder died in 1952 (although a child with Vineyard deafness could be born tomorrow).

Martha's Vineyard provides an example of how well individuals with disability in general—and deafness in particular—can fare if society is willing to adapt to ensure inclusion for all. It is not unique. Worldwide, communities with inherited deafness—many yet unstudied—have been identified. These will provide models of adaptations that warrant careful consideration.

—Nora Ellen Groce

See also Deaf, History of the; Sign Language.

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DEATH

"When all is said and done," observed a 1968 editorial in the *Journal of the American Medical Association* (*JAMA*),

> it seems ironic that the end point of existence, which ought to be as clear and sharp as in a chemical titration, should so defy the power of words to describe it and the power of men to say with certainty, "It is here."

More than irony attended a perceived uncertainty about how to define death. Physicians at this time identified an increasingly pressing issue. The expanded use of respirator and intensive care technology after the mid-twentieth century started to concern physicians and the public alike that some seriously ill patients were kept "alive" in appearance only. The ability to keep familiar signs of breathing and heartbeat going seemed no longer satisfactory as meaning someone was alive, especially when brain function in particular was perhaps hopelessly lost.

Correct determination of when death occurs would seem to be one of the most fundamental tasks of a society. Historically, there has always been discussion and even dispute over the correct signs of death, stimulated at times by waves of fear that people were mistakenly determined dead and consigned prematurely to the grave. But the ambiguity that surfaced in the 1960s, and pointed to the eventual widespread adoption of the idea of brain death, reflected a set of new challenges especially relevant to thinking about the notion of disability. What "death" meant changed, and it became a more explicit topic of discussion. This happened as a part of increased scrutiny that fell as well on the appropriateness of "heroic" medical care, and the related growing emphasis on a patient's cognitive impairment as a barometer of the value of continued medical treatment.

THE HARVARD BRAIN DEATH COMMITTEE

On August 5, 1968, a report of the Ad Hoc Committee of the Harvard Medical School appeared in the pages of *JAMA*. Known since as the Harvard Brain Death Committee, the report set out specific neurological criteria that should be used to diagnose *irreversible coma*. Those criteria were, essentially, the following: unresponsivity, complete areflexia, apnea, and confirmatory loss of brain waves as determined by electroencephalography (EEG). The report was arguably ambiguous about whether irreversible coma was a condition that was in fact equivalent with death or was predictive of it. That ambiguity continued to animate debate over the criteria and coherence of brain death in decades since.

The Ad Hoc Committee was, literally, an ad hoc committee of the Harvard Standing Committee on Human Studies, a forerunner to institutional review boards and research review groups later uniformly established through federal law to oversee and approve human subjects research throughout the United States. The chairman of this ad hoc group was Henry K. Beecher, chairman of anesthesiology at Massachusetts General Hospital (MGH). Beecher established this ad hoc group from his role as chairman as well of the larger human subjects committee. This reflected how Beecher tended to view the issue of brain death through the topic of experimentation. By this time, he was a nationally recognized authority on human experimentation ethics. In several of his own speeches and writings, he framed the increasingly apparent problem of the potential overuse of medical technology to sustain futile care and hopelessly ill individuals within his understanding of experimentation ethics. Brain death provided a clear line beyond which treatment became unethical experimentation.

Thus, brain death, at least within the small group that first established widely supported criteria and clinical description for it, was seen as a solution to a long-standing and growing concern about the need to define parameters for increasingly extraordinary and intrusive medical interventions. Other advocates for brain death were instead much more focused on the necessity of such a legally recognized definition in order to develop the field of transplantation, especially the transplantation of vital organs such as the heart. In either case, framing a definition of death based to a large degree on the particular needs or challenges posed at a given time by medical technology raised certain problems. In the decades following the report's appearance, a torrent of literature was produced, especially by writers and thinkers who identified themselves with the bioethics movement (the early work of which appeared soon after the Harvard report), seeking a theory, concept, or argument that justified brain death as a reliable description of death, independent of the exigencies of medical care. At the same time, a clinical literature flourished that sought to better clarify what medical features, tests, and neurological phenomena best comprised the brain death diagnosis.

AFTER THE HARVARD COMMITTEE

In terms of philosophical and conceptual challenges, the ambiguities of brain death as death indeed, or instead as death as needed in the context of certain medical necessities, motivated efforts to come up with logical proofs and conceptual descriptions of what death fundamentally meant, and the degree brain death, or some other sort of criteria, concretely captured those fundamental meanings. So, for example, arguments that death was essentially the loss of biological integration of the body was argued by some to provide both a rigorous, experiential, logical, and philosophical justification; it could as well be manifested in brain death criteria since the brain arguably performed these fundamental integrative functions. Others argued for a conception of death as the loss of personhood, focusing on certain categories of cognitive and experiential capacity as the sine qua non of life. Their loss thus indicated death. This conception was often used as a criticism of brain death as generally practiced, pointing instead toward a "higher" notion of brain death, which would involve the loss not of the functions of the "whole" brain, as with the Harvard criteria, but of the more intellectual and cognitive functions generally associated with the cortical regions of the brain, as opposed to the "lower" midbrain and brainstem regions.

As many of these conceptions had trouble neatly describing a more messy reality, increasing calls were heard toward the end of the twentieth century to give up on the notion of brain death since criteria would never be able to live up reliably to the conceptions advocated to justify them. Higher notions were compelling but the ability to identify reliably and clinically the injuries and symptoms that indicated something as elusive as the capacity for adequate "awareness" was particularly problematic with presentations of actual patients with severe comas and persistent vegetative states. Similarly, the notion of death as loss of integration through loss of the whole brain was challenged as closer study and improved intensive care revealed the capacity of the body to sustain many complex metabolic tasks while meeting Harvard criteria, and the capacity for physicians to sustain such impaired functions. Both rendered brain death more a gray area than the solid line it needed to be.

Parallel with efforts to sort out the conceptual consistency or inconsistency of one notion of death over another was work in clinical medicine to tinker with the Harvard criteria themselves and the neurophysiological understanding of increasingly detailed types and degrees of severity of coma. Soon after the Harvard criteria appeared, several large-scale studies were performed to see how well these criteria, or whether a more streamlined set, predicted death. The irony in this is apparent. The gold standard for brain death criteria was its prognostic power for predicting ultimate cardiopulmonary death. Which, then, was really death? The original Harvard criteria were themselves justified through a similar sort of prognostic validity by MGH neurologist Robert Schwab, through the 1960s. With the ink barely dry on the report in *JAMA*, the Ad Hoc Committee of the American Electroencephalographic Society on EEG Criteria for the Determination of Cerebral Death collected through questionnaires more than 2,000 instances of flat EEG to corroborate the reliability of that specific finding as a predictor. A more sophisticated prospective study took place over several years in the 1970s;

it focused more in the predictive value of other clinical characteristics as well. The National Institute of Neurological Diseases and Stroke coordinated the work of nine medical centers to study brain death criteria. The Collaborative Study of Cerebral Death followed more than 500 patients who eventually died and who at the outset demonstrated a minimum of unresponsivity and apnea. A range of factors was followed to establish a minimum set that could reliably predict cardiopulmonary failure. The authors of the study concluded that an absence of brainstem reflexes, apnea, unresponsivity, and a flat EEG for at least 30 minutes' duration at least 6 hours after onset of coma and absent intoxication, hypothermia, or other clearly treatable illness (e.g., cardiovascular shock) were adequate criteria. Curiously, they did so despite the lack of relative independent predictive importance of loss of brainstem reflexes. However, the study authors concluded that "semantically, the absence of brainstem function, as demonstrated by inactivity of these reflexes, should be included in the criteria of brain death." The degree that EEG, brainstem findings alone, or brainstem findings in addition to other signs was important was the subject of much debate and ongoing consensus group revisions of the criteria.

A distinction was often made between brainstem advocates, particularly in Great Britain, who emphasized the loss of brainstem and cranial nerve functions as the crucial and adequate signs of brain death, and whole-brain clinicians, more typical of practice in the United States, who were more concerned about the complete loss of reflexes and responsiveness and loss of all EEG. For American practice, the President's Commission on Ethical Problems in Medicine and Biomedical and Behavioral Research published its conclusions with regards to these controversies in its 1981 report, *Defining Death*. That publication rejected higher and lower views, opting for the whole-brain criteria and a "biological integration" rationale, which also, somewhat controversially, was used to support the argument that brain death was thus a more precise updating of the familiar heart-based custom of declaring death. Still discussion along these lines continued. An array of "confirmatory" tests of brain death have been advocated and studied such as the use of angiography, cerebral ultrasonography, and radioactive brain scans, or cerebral scintigraphy. Detailed methods for apparently more reliable measures of apnea have also been developed and debated.

In many ways, however, the general framework of Harvard remains—unresponsiveness, apnea, and absence of reflexes with EEG confirmation. What has also importantly continued, however, is the ambiguity as to whether brain death describes versus predicts a state that is death itself. Increasingly refined imaging of brain activity, studies of the severely brain injured, and more aggressive efforts to rehabilitate severely comatose individuals have left open the question of how far the boundaries can be pushed in terms of establishing the brain's death, and the death of either an experiencing person or simply a responsive physiological organism. In addition, the "better dead than disabled" philosophy highlights the close apposition that severe disability and medical definitions of brain death have experienced. Severe brain injury in particular continues to challenge the boundary between rehabilitation, euthanasia, and definition of death.

While, as mentioned, these ongoing uncertainties and conceptual inadequacies have led some to question the value and use of brain death, they perhaps instead reflect an important aspect of the nature, and value, of this sort of definition. As it grew out of a search for a sensible marker of the end of salvageable humans as persons and as organisms within the context of medical possibilities, marking the point at which medicine turned into intrusive experiment, the fact that brain death may be a moving target should not be a surprise, or necessarily a problem. New knowledge about neural regeneration and neurobehavioral rehabilitation should also not surprise us with even further possible future complexities as to how much of death can be defined though the brain. Such developments would further illustrate how the brain, a logical choice under the circumstances, became the focus with which to flexibly ponder and set the dividing line, in an age of increasingly intrusive medical technology, between the disabled and the futile.

—*Gary Belkin*

See also Bioethics; Euthanasia.

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DEATH PENALTY

OVERVIEW

After reaching a postwar maximum of 157 in 1947 U.S. executions fell to zero from 1968 to 1977. In 1972 in *Furman* the Supreme Court ruled that the death penalty was unconstitutional. Some states then passed death penalty statutes that provided for guided discretion in the application of capital punishment. In 1976, the Supreme Court in *Gregg* and other cases reversed and ruled that these statutes were constitutional. Guided discretionary statutes attempt to achieve uniformity across state courts by requiring that standardized instructions be given listing aggravating or mitigating factors that must be considered by juries in the now mandatory separate sentencing stage of capital trials (Zimring and Hawkins 1986; Paternoster 1991), but this goal has not been reached. After *Gregg*, executions grew sharply, reaching a maximum of 98 in 1999. The great majority of executions are conducted by the states although offenders can appeal to the federal courts after exhausting their state appeals. Appeals are critical as less than 10 percent of death row inmates are executed. Almost all offenders who win appeals are resentenced to long prison terms (Liebman et. al. 2000). In many states, largely due to state appeals and perhaps some reluctance on the part of state officials, mean time on death row before an execution has grown to beyond 20 years (Aarons 1998; Zimring 2003).

INSANITY

A core tenet of U.S. law is that the blameless must not be punished. The law therefore forbids the execution of the insane. Legal tests include whether the defendant knew the difference between right and wrong, whether the defendant was compelled by an irresistible impulse, or, most commonly, whether the defendant had the capacity to appreciate the criminality of his or her conduct or to conform to the law (Neubaurer 1988). As the burden is on the defense to prove insanity and because defendants who successfully use this tactic typically are incarcerated in mental institutions for long periods, this plea is unusual, and it rarely is successful. Yet many of the condemned have committed heinous acts. Some common legally aggravating factors that increase the probability of a death sentence include the deliberate killing of a child, multiple killings, or victim torture. Defendants, however, typically reject claims that they are insane. Yet given the nature of such crimes, such denials often are questionable. And decades spent on death row are unlikely to improve the already tenuous mental health of such offenders. One ironic consequence is that states have successfully engaged in litigation to force clearly insane offenders to take medication so they can be executed.

MENTAL RETARDATION

The same blameworthy principle implies that the retarded should not be executed, but the courts were slower to act on this logic. In *Thompson* the Supreme Court held that defendants under the age of 16 cannot receive the death penalty. Most definitions classify individuals with a child's mental age as retarded. Capital punishment opponents therefore claimed that mental development should determine death penalty eligibility and that retarded persons with a child's mental capacity should not be executed (Streib 2003). During the 1990s, public action forced many legislatures to address this issue. Nearly half of the states with a legal death penalty excluded offenders with IQs below 70 from capital punishment. In 2002, in *Atkins* the Supreme Court followed this evolving standard of public decency and held that retarded persons have less culpability for their crimes and thus do not merit the retribution imposed by the ultimate punishment.

—David Jacobs and Stephanie L. Kent

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DECISION MAKING

There are a variety of competing models of how individuals and organizations make decisions. While the dominant model continues to be the rational perspective, there is a broad array of alternative approaches including bounded rationality, behavioral decision making, and political, escalation, and garbage models. These reflect the broader intellectual turmoil over the nature of reality and both mirror and can inform current disputes over competing models of disability.

While specific formulations of rational decision making vary, a representative example might consist of the follow steps. A problem or opportunity is identified. All the possible alternatives to address the problem are generated. Agreed-on criteria exist to evaluate the alternatives. Complete information is gathered. Each potential course of action is evaluated. The course of action that maximizes utility is selected.

To illustrate this model, let us take the example of an individual who is involved in a serious car accident. Several months after being discharged from the hospital, the woman is experiencing numbness in the legs, a symptom not clearly associated with the accident. Soon she is experiencing complete paralysis from the waist down.

Under the rational decision making formulation, all potential tests are undertaken to evaluate the disabled person's status. All potential treatment interventions are considered. The best intervention is then undertaken to "cure" the patient of her disability.

The rational model continues to be the dominant model in the social sciences and the applied fields based on them. Acceptance of this maximization framework enables a variety of elegant and rigorous analytic techniques to be brought to bear on complex decisions. Yet each step of the rational decision making model has been subject to aggressive criticism for a lack of descriptive accuracy.

The bounded rationality perspective provides a long-standing alternative to the rational model. Proponents of this perspective argue that because of limitations in individuals' and organizations' information processing capabilities, pure rationality is impossible to achieve. The bounded rationality model suggests that decision makers have limited perspectives in their initial grappling with problems or opportunities. When decision processes are undertaken, there is a sequential evaluation of alternatives. The alternatives themselves are generated using heuristics or simplifying "rules of thumbs." A common heuristic would be to search for solutions similar to those already being used. Finally, decision makers do not maximize utility but instead "satisfice"; that is, they select a solution that meets the criterion of being "good enough" and thus stops the evaluation of further alternatives. This descriptive model provides a powerful alternative to rational decision making while remaining palatable to those embracing rationality as a desideratum.

In the past 30 years, psychologists from the behavioral decision making camp have devoted enormous energy to an in-depth, if extraordinarily narrow, examination of how individual decision makers employ or diverge from basic rules of logic and probability theory as they assess information to arrive at decisions. In general, these investigations declare off-limits assessments about the values and preferences of decision makers. Even within these narrow confines, a formidable body of evidence has been assembled documenting systematic and widespread departures from basic rules of logic and probability theory. Specific examples include prospect theory, sunk costs bias, representativeness heuristic, and deviations from logical reasoning.

Prospect theory documents that individuals often do not attach equal utility to gains and losses. People appear to be risk averse in gains but risk seeking in losses.

Researchers examining sunk costs bias point to the fact that costs previously expended in a course of action are supposed to be irrelevant, since they are in the past. Yet there is substantial evidence that sunk costs are not sunk psychologically but instead continue to influence decisions about future courses of action.

The representativeness heuristic refers to people's tendency to assess whether an individual belongs to a certain category based on the degree to which the individual resembles the prototypical class member rather than through the use of probability information.

There is also substantial evidence that people systematically depart from simple principles of logical reasoning. When reasoners are asked to evaluate whether sets of assertions are consistent, they succumb to predictable illusions. Thus, when information is presented in some fashions (e.g., "A or B or both"), respondents may have difficulty in corresponding to rules of logical reasoning.

Returning to our case of the woman disabled subsequent to the car accident, bounded rationality perspectives would suggest a different decision-making process. For instance, not all potential tests would be conducted to assess the patient's condition. Nor would all potential interventions be considered. Rather, alternative assessments and interventions are likely to be sequentially considered, often based on the training and experience of the attending physicians and staff, until one approach appears to be "sufficiently" appropriate.

Behavioral decision makers would point to systematic biases and shortcomings in how information is gathered and interpreted. Thus, even among highly trained sophisticated professionals, whether a treatment's likely impact is framed as a gain (50 percent chance of improvement) or a loss (50 percent chance of further suffering with no improvement) often produces a different decision.

These findings of systematic departures from rationality are perhaps especially impressive given how conservative the investigations are. The research situations examined are typically both simple and sterile. Emotions, unwieldy as they are, have been banned from most of the examined contexts. This is despite that current evolutionary biologists would argue that emotionally hardwired features are essential to understanding how human being respond to stimuli. This wealth of experimental data strongly undermines the pure rationality formulation. Yet these studies also support the notion that human choices are orderly, even if not strictly rational.

A number of alternative models of decision making criticize the rational framework not for its assertions about how data are gathered and assessed but instead for the assumption that there exist agreed-on criteria for the evaluation of alternatives. These perspectives focus on how decision making in groups or organizations is invariably a political process in which the elements most worthy of attention are the varying points of view or values of the actors.

In these perspectives, decisions are made not by reified entities such as organizations but rather by fluid coalitions of actors. These actors begin the decision process with different viewpoints and interests—factors that influence both problem identification and problem solutions. Decisions that are arrived at simply reflect the interests of the dominant coalition at a particular point in time.

In our example of the individual disabled following the car accident, the perspectives of the medical team and the disabled person are viewed as identical. In reality, we know the interests of these parties (as well as other parties such as family members, insurers, and employers) often diverge. Economic and psychological incentives may push the medical team to favor certain interventions, while the disabled person and other groups may view the situation very differently.

While political perspectives on decision making generally have high descriptive face validity, they are not without their critics. There are a variety of organization models that suggest the political models are themselves too rational—that they too directly assert that decisions are a manifestation of some group's intentions. Some critics of the political perspective would argue that "conspiracy theorists are optimists"—for they assume that someone is in control.

Organizational theorists have developed a number of models that incorporate both individual psychological factors and also broader organizational and contextual factors to explicate decision making. One such approach, escalation theory, focuses on understanding commitment to failing courses of action. Rational decision making and theories of efficient markets would suggest that individuals and organizations quickly correct decisions that lead to poor outcomes. Yet everyday observation reveals that long-run persistence with failing courses of action is commonplace for both individuals and organizations

Escalation theory suggests that four classes of determinants combine to contribute to commitment to failing courses of action. Project determinants pertain to the objective features of the decision or course of action. Examples would be whether a setback was viewed as temporary or permanent and the number of attempts that had previously been made to obtain the objective. Psychological determinants would include the cognitive limitations and heuristics currently the focus of behavioral decision makers but would also include factors such as reinforcement traps, which create difficulties in discontinuing previously rewarded activities and individual motivations such as the need for self-justification.

There are also a variety of social determinants that contribute to escalation. Decision makers may continue along a previously selected course of action not just because they do not want to admit to themselves that they may have made an error, but because they do not wish to acknowledge that error to others. Social norms such as the "hero effect" and modeling may also play a role. Organizational and contextual factors may also lead individuals and organizations to persist with failing courses of action. Prominent among these determinants are simple administrative inertia, political constituencies favoring the course of action, and a linkage of the course of action to organizational values and identity.

Thus, our individual disabled following the car accident may follow the strong advice of a physician to undergo surgery to increase her ability to use her legs. The surgery is intrusive, expensive, and yields no improvement in the patient's condition. Objective observers and statistical evidence might well suggest that further surgery is unlikely to be effective. Yet escalation research suggests that individuals who feel personally responsible for failed decisions often do not respond objectively to negative feedback. Thus, both the patient and the physician may be biased toward investing in still further surgical interventions.

Other organizational perspectives on decision making emphasize the randomness and anarchy components of decisions, particularly those emerging from large organizations. For instance, the "garbage can model" suggests thinking of organizations as having streams of participants, streams of problems, streams of solutions, and streams of choice opportunities. These different streams collide with often difficult to predict outcomes. Some problems do get solved. However, there are a variety of other outcome possibilities not recognized by either rational or political perspectives. Solutions may be proposed or implemented when there is, in fact, no problem. In other instances, problems may continue to go unaddressed. The entire thrust of these perspectives is to emphasize the unpredictability and at times unresponsiveness of our institutions to anyone's agenda.

Our individual disabled subsequent to the car accident may find herself having to interface with a wide variety of groups and organizations. These might include doctors, hospitals, rehab centers, insurers, and government agencies. Each of these groups faces constant changes in personnel, alterations in missions and funding, upheavals in domain, evolving information systems, and changing core technology. As a result, the interactions with the disabled person may take on a Kafkaesque character. Effective and responsive treatments may coexist with completely irrelevant or even damaging interventions as potential decision-making outcomes.

There is an interesting overlay between these contemporary models of decision making and the evolution and current areas of dispute in the disability literature. Certainly, a dominant dispute in the disability literature is between the medical model and social model of disability.

The medical model sees disabled people as a series of individuals with specific medical problems. Thus, the response is typically a deficit interpretation followed by a cure or care intervention. This model fits very closely with the rational model of decision making and, like the rational model, has predominated the area in the past decades.

There are studies that suggest that the modest revisions to the rational decision making framework are equally appropriate in the context of applications of the medical model to the disabled. The rational calculus of medical intervention implicitly suggests a joint decision by the physician and patient, in which the patient's value system is assessed to ensure a maximum utility intervention subject to the existing limitations in medical technology.

Both the bounded rationality of decision making and critics of the medical model of disability would agree that many medical interventions fail to maximize the utility of the disabled patient. Bounded rationality would emphasize that the treatment of a patient as a person requires resources of time, energy, and involvement, resources that are quite scarce in most health care delivery contexts.

The behavioral decision making framework also supports those who suggest suboptimal treatment outcomes. Information is not rationally combined and assessed, either by medical professionals or by the disabled themselves. Laypeople rely on physicians to frame the results of tests and provide guidance about how to proceed. Yet, consistent with prospect theory, how the information is presented both to and by physicians results in different preferences for action and treatment on the part of both physicians and patients. Research also indicates that medical patients have difficulty in accurately processing information about treatment outcomes. Even within the scope of the medical model of disability, the potential for wider investigation and appreciation of behavioral decision making models' implications would seem to be great.

The major alternative movement in disability studies has been the development of the social model. For many espousing the social model, the central reality is that disabled people and their organizations are almost completely absent from the decision-making process, both in regards to individual treatment decisions and also more broadly in the planning and delivery of services that affect disabled people's lives. This perspective depicts disabled people as a collective that is often oppressed by a dominant outside group. From this perspective, the key to understanding decision making vis-à-vis the disabled is power. This mindset, proponents suggest, leads to new perspectives on the real cause of disabled people's problems and thereby on methods for eliminating them.

There is an obvious natural affinity between the social model of disability and political models of decision making. Both would question the rational model of decision making's assumption that there are agreed-on criteria that can be used to evaluate alternative courses of action.

Advocates of the social model of disability would urge that decisions in regards to the disabled should result in enabling and empowering the disabled in the same manner that these decisions currently serve the able-bodied. In some instances, this will involve challenging the taken-for-granted assumptions of the dominant able-bodied class. Extreme advocates of the social model might also "push the envelope" of the behavioral decision making model that values or preferences are not themselves irrational. Thus, deaf individuals might assert their desire to produce deaf children because they see such children, as themselves, as simply differentially endowed as opposed to creations of some lesser god.

The conflict between medical and social models of disability occurs not only at micro-level interpersonal interactions but also at the macro level of structural policies and institutions. Thus, there is emerging interest and research on the history and current status of organizations representing and acting on the benefit of the disabled. Here, as in the general literature on decision making, those adopting a social model of disability or a political perspective may come to be viewed by some observers as optimists—for they would assert that a lack of organizational and institutional responsiveness is the result of the intended actions of oppressive "Others," and thus subject to ready remedy.

Escalation perspectives in disability research would dispute this. Escalation theorists would argue that whether it is in individual treatments of the disabled in the "medical model" formulations or in the actions of organizations designed by and for the disabled in the more radical version of the "social model" of disability, resources may long continue to be expended in courses of action despite a lack of successful returns.

Similarly, garbage can perspectives of decision making may enlighten and enrich both proponents of medical and social models of disability. Problems of extreme specialization and division of labor adversely affect the performance of both for-profit and not-for-profit organizations. With the ever-growing complexity of modern organizations and institutions, randomness and unpredictability will remain components of both individual treatment protocols and broader institutional responses. Garbage can models of decision making fit with the broader poststructuralist's abandonment of a search for underlying causes of how particular decisions are "made."

The rational decision making and political decision making perspectives fit well with the medical model versus social model debate in the disability literature. Future studies in the disability area that more deeply incorporate a wider range of decision making perspectives, such as behavioral decision making, escalation, and garbage can models, may result in a broader and more nuanced appreciation of factors affecting the disabled and their organizations in contemporary society.

—*Jerry Ross*

See also Ableism; Consent to Treatment; Consumer Control; Empowerment and Emancipation; Models; Normality; Patients' Rights.

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DECLARATION ON THE RIGHTS OF DISABLED PERSONS (UNITED NATIONS)

See United Nations Declaration on the Rights of Disabled Persons

DEFORMITY

A *deformity* is a significant difference in the shape, color, or other aspect of appearance of some part of the body in relationship to the perceived statistical average shape of the part in question. Deformities can result from complications during birth, genetic mutation, accident, growth or hormone anomalies, reconstructive surgery following severe injuries, and rheumatoid disorders such as arthritis.

Deformity is a very problematic term, because the concept itself is based on two assumptions: first, that there is such a thing as a “normal” body from which the deformity can be said to deviate; second, that there is widespread agreement on what attributes in fact constitute such a deviation. Much of the subjective definition of deformity is a function of context and power. Sarah Baartman, for example, possessed physical attributes very common to her tribal ancestry in South Africa but was described as “deformed” by the white Europeans who forced her to appear semi-nude before European audiences as “the Hottentot Venus.”

Historically, cultures have responded to deformity in many ways. In the ancient world, deformity was often seen as a bad omen, a sign of wrathful gods, or the influence of demons or wizards. Some babies with deformities were killed at birth, often by ritual exposure. There is evidence, however, that other children with deformities were considered holy or magically powerful, and these children could become shamans and priests. Leviticus, from the ancient Hebrew Bible, specifically forbids the participation of deformed persons in religious rituals. Most cultures imagine a link between deformity of body and the moral corruption of character; the Greek poet Homer does so in the *Iliad*’s Theristes, but elsewhere Greek culture seems more tolerant: Clever god Hephaestos is deformed, and King Theseus seems to accept deformity when he slays the wicked giant Procrustes, who killed anyone who did not conform to his ideal of bodily perfection. The Romans also sometimes linked deformity to magical power, and certain deformed persons became highly regarded figures in Imperial courts. In medieval times, deformity was often scourged as a sign of God’s wrath, but it was sometimes welcomed as an opportunity to practice Christian charity and mercy, and in some persons, such as Gregory of Tours and Teresa of Avila, deformity was even regarded as a mark of saintliness. During the explosive emergence of science in the eighteenth and nineteenth centuries, deformity became a titillating challenge to scientific classification, and such titillation gave rise to the golden age of the freak show. In modern times, deformity is seen as a marker for disease, and doctors regularly give patients the option of aborting fetuses who may exhibit deformities.

In some persons, fear of deformity in oneself can become so grave that mania and suicidal obsession can result. This condition is known as *dysmorphophobia,* and it can be generated from conditions as minor as skin lesions or male pattern baldness. People with dysmorphophobia are so appalled by the prospect of their own bodies deviating from a perceived norm of beauty or regularity that they chronically go to great lengths to conceal their “defects,” visit doctors multiple times, and develop compulsive, often dangerous habits, such as plucking incessantly at nonexistent hairs.

—Michael M. Chemers

See also Aesthetic Surgery; Folk Belief; Freak Show; History of Disability: Ancient West.

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DEGENERATION

The word *degeneration* was used in the eighteenth century in the natural sciences to describe variation in certain living species. At the start of the nineteenth century, it also referred to modification in body structures as shown by pathological anatomy. Representatives of the natural sciences, finding that the word had a somewhat negative connotation, attempted a new definition for its use in their domain. Those who considered variation a perfectly normal phenomenon in the evolution of living species wanted to restrict its use to define unwelcome alterations such as stoppage of development for physical aberrations, many instances of which can be seen in humankind.

It is against this background that a French doctor, Bénédict-Augustin Morel (1809–1873), introduced a new term—degeneracy—and a new definition in a book he published in 1857. The shift from *degeneration* to *degeneracy* was necessary because of the radical change he brought into the definition by synthesizing the concept used in natural sciences and the one used in the pathological anatomy.

Morel's intention was twofold. On the one hand, he linked degeneracy to a modification process that is in essence pathological, variation as formerly referred to in natural sciences becoming deviation. On the other hand, he claimed that degeneration, considered henceforth as a disease, is contracted by humankind when in contact with harmful natural surroundings and is passed on to its descendants. Morel did not use the word *heredity* because he introduced two new ideas with this concept, understood then as the mechanism of morbid transmission: the law of double fertilization and the law of progressivity, as he called them. The first law established that degeneracy emerges only by the coming together of several factors. The second law introduced the accumulative character of the transmission process: the further away in time from the starting point of the disease you go, the further away from the normal features of humankind you drift, descending deeper into a deviation process.

The term *degeneracy* did not replace the term *degeneration* except in France and some French-speaking countries. The concept was well received in psychiatric circles in the second half of the nineteenth century both in Europe and the United States, but it was subject to a plurality of interpretations. The most prominent one was the hereditary process, and this helped the determinist and fatalist approach of mental disease and allowed notions such as incurability and chronicity to develop and remain popular well into the twentieth century.

The term *degeneracy* became obsolete with the advancement of genetics, but insanity has nonetheless remained associated with the notion of heredity in psychiatric circles despite the dissemination of new concepts brought about by dynamic psychiatry and psychoanalysis.

—Jean-Christophe Coffin

See also Friedrich Nietzsche.

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DEINHARDT, HEINRICH MARIANUS (1821–1880)

German educator

The German reform pedagogue Heinrich Marianus Deinhardt was born on January 29, 1821, near Weimar, Germany. Deinhardt studied theology, history, and philosophy in Jena and Halle, but he never graduated. He is said to have been an intimate expert of the dialectic philosophy of George W. F. Hegel (1770–1831). He acquired his knowledge in pedagogy through private instruction. Even as a student, Deinhardt had already written radical position papers arguing for the restructuring of elementary pedagogy in the interests of the lower classes, and he also developed thoughts in the direction of a polytechnic education system. He played an active role in the German Revolution of 1848 and avoided arrest by fleeing to Switzerland. After returning to Germany, Deinhardt found himself banned from professional practice and instead had to give private lessons.

In 1857, he followed Jan Daniel Georgens (1823–1886) and Jeanne Marie von Gayette (1817–1895) to Austria. There they founded Levana, a model institution for nondisabled and disabled children. By 1861, however, Deinhardt had already abandoned the joint project. In 1861 and 1863, the special education lectures, which he had given with Georgens in 1860, were published. The two-volume work was titled *Die Heilpaedagogik. Mit besonderer Berücksichtigung der Idiotie und der Idiotenanstalten* (*Pedagogy of Special Education: With Special Consideration to Idiocy and Institutions for the Feeble-Minded*) and provided a theoretical foundation of the special education discipline. After the personal disagreement with Georgens, Deinhardt was not able to secure a stable livelihood for himself. He was repeatedly fired from schools in Vienna and had to eke out a living through hourly wage positions. Deinhardt died in Vienna, Austria, on March 11, 1880.

—Anne Waldschmidt

See also Heinrich Hanselmann; Special Education.

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DEINSTITUTIONALIZATION

Deinstitutionalization is a profound historical movement that advocates the transfer of physically and intellectually disabled people, the mentally ill, and other incarcerated individuals from public and private institutions such as hospitals, nursing homes, and prisons back to their families and to community-based homes. The philosophy behind this movement is the use of least restrictive alternatives to permit individuals to live as active a life in the community as possible. In a historical context, *deinstitutionalization* refers to the transfer of activities from one institution to another.

Before speaking of deinstitutionalization, institutions and institutionalization must be defined. Although there is debate among sociologists, *institutions* may be defined as a specific social group's ways of acting, thinking, and behaving that have become crystallized; almost constant, they are distinctive, recognized, and sanctioned. Thanksgiving Day in the United States and Bastille Day in France, for example, have been *institutionalized* as holidays and comprise certain fixed expressions. They are not institutions like the Senate or a court of law, but they nevertheless meet the criteria of the general definition of institution, since they constitute days, crystallized and official, devoted to memorialization and ceremony.

Deinstitutionalization, then, occurs when a complex of customs, structures, and activities is modified or even loses its reason for being. Let us consider three examples of deinstitutionalization.

Deinstitutionalization of the family. In essence, this means that the family, which was a public matter, responsible for the formation of socially conforming adults, became privatized in the sense that it became the site of well-being and affectivity, based on mutual attraction and love, something that can be constructed and deconstructed. Even procreation is understood in affective terms. It then follows, for example, that in the juridical sphere, the normal motive for divorce becomes mutual agreement. The justice system no longer has to express an opinion with respect to the rules of an institution; rather, it registers the consequences of a meeting of private wills. As Philippe Ariès has shown, beginning in the seventeenth century the family has been invested with something other than a purely social alliance, up to the point where the dependency of women came to an end in the sweeping revolution in relations between the sexes in the 1950s and 1960s.

Quite clearly, the limitations and difficulties of this form of deinstitutionalization become most acute in the matter of children. People do not divorce their children, and the indissolubility that was earlier ascribed to the couple now references the bond with children. The essence of this deinstitutionalization lies in the fact that the family no longer is the site where one becomes a citizen but rather where one develops affective dimensions; the family no longer is asked to produce social beings but rather happy individuals. Thus, the institution of the family lost several of the institutional characteristics of its first function.

Deinstitutionalization of the school. A second example can be found in the schools. In France, for example, schools during the Third Republic (1870–1940) had as their function to instruct and through this instruction, regulated by the public authority, to produce the kind of man who was in conformity with revolutionary morality, who had interiorized his allegiance to a fatherland and to a precise history, and who was equipped with a basic knowledge that allowed him to situate himself and find his place in society.

But, with mass education, changes in the family, cultural diversity, and the opening to a wider world, the relationship that school must maintain with the world beyond the school changed—the school no longer knows how to exercise its very diverse functions, functions that may even be contradictory, to instruct, socialize, educate in the widest sense, contribute to the happiness of children and yet subject them to a discipline, and inculcate them while preparing them for the world of work. The school is pulled between opposing demands; its exact function is no longer clear-cut, and we see, throughout the immense body of writing on schools, the most irreconcilable theories being formulated. The school, like the family, has lost its fixed points of reference and seeks to determine a new identity.

Deinstitutionalization of the church. All religious institutions are confronted with the weakening of their regulatory capacity. It is not primarily the loss of influence of these institutions, but rather that the relationship between individual believers and the institution has been modified—the exclusive authority to state what shall be believed and what shall be done. Personal initiative will supersede believer conformity.

The institution of the church is not disappearing, but it is no longer as capable as before of establishing its points of reference and finds itself confronted with a culture of the individual, which relativizes the norms of belief and practice. The institution is no longer asked to define a common identity, but rather to accommodate and support a personal agenda.

In these three forms of deinstitutionalization cited here, two far-reaching features of modernity are present and also go some way toward explaining them:

Modern individuals more and more lay claim to irrevocable rights and to the freedom to construct their own worlds. The essential task has become the work of the individual alone to take a place and a role in a society that, admittedly, defines its members less than before but no longer supports them in the same fashion as did the school or the family of an earlier time. As a consequence, modern individuals want to be, and are obliged to be, mobile, changeable, in circulation. Deinstitutionalization is less the disappearance of institutions than modern individuals' claims and demands that such institutions be engaged in their projects. This, then, is the challenge to the regulatory and normative role of institutions.

Concurrently with this social uncertainty, strong claims for the recognition of identity are being made: "we women," "we the disabled." These claims to self-defined identity are to be understood in a society where traditional institutions no longer function in the same way and where individuals are obliged to find their own bases from which to present themselves, bases other than those offered by the family and the school: cultural bases, religious bases, gender bases. In this dual and at times contradictory individualist movement, traditional institutions appear to offer little help.

This long historical development is paralleled by psychiatric deinstitutionalization.

PSYCHIATRIC DEINSTITUTIONALIZATION

In Milos Forman's 1975 film *One Flew over the Cuckoo's Nest*, we saw the incredible treatment of the mentally ill of only 30 years ago. Not all the traces have since disappeared. Treatment in a closed environment, a closed universe sure of its uncontested right and its science (which later would reveal its unsound foundation), had an urgent need to evolve, in the name of human dignity.

Thus, a massive social movement was born, in a North American context even though the theorists who transformed the American vision were often European. What were the principal factors?

The great influx of psychotropic medications, which better permitted the mentally ill to regain a life among others and to overcome what had been called "crises." Once we had gained mastery over this new pharmacology, excursions, walking cures, and reimmersion in the community could be envisaged. Insanity gave way to mental illness, even to the fuzzy but revealing vocabulary of "psychological problems" or simply "psychological suffering."

The influence of psychoanalysis, which introduced a noninstitutional type of cure. "Madness" had been addressed in an institutional framework, with treatments still drawing their fundamental inspiration from Philippe Pinel and Esquirol, that is, a context in which institutionalization was supposed to cure, or at least relieve, by means of its own internal dynamic: application, internal socialization, work. All this complemented by various techniques such as electroshock therapy and baths. Obviously, in the 1960s and 1970s institutional psychiatry had a vision where psychoanalysis had a recognized place. But in larger terms, the arrival of psychoanalysis contributed to the emergence of the concept of deinstitutionalization, since work on the psyche could be undertaken in dual relationships, quite outside any institution.

The antipsychiatry movement. From these same decades, 1950–1970, the ill-named movement of antipsychiatry emphasized that social factors played a significant role in psychological disorders. It focused on social pathologies and on the deindividualization of mental illness. At the same time, this movement held that in the link to the community lay the best path toward amelioration and affirmed that institutional confinement was fundamentally harmful.

To these factors must also be added economic analyses. In the United States, for example, but also in France, the thesis was advanced that the welfare state, by developing segregative models of social control, incurred excessively high and hard-to-justify costs.

It is fair to say that by the end of 1975, the advocates of deinstitutionalization dominated the public scene. Opposition to deinstitutionalization was strong but divided. In certain environments, there was panic at the possibility of former internees from psychiatric hospitals being present in public places. In the United States, there was strong opposition from trade unions because of the risk of unemployment and intensive lobbying by professional associations professing concern for standards.

When the effects of deinstitutionalization were reviewed in the early 1980s, there were serious concerns. The report by K. Jones in 1984 found alarming similarities everywhere and stated that reform in Italy was only a late and poor reaction to reforms carried out in the United Kingdom and the United States. The overwhelming argument against suppression of the psychiatric institution was that deinstitutionalized persons were even more unhappy, ill-treated, and stigmatized than they had been in the institutional setting. Predictably, the defenders of deinstitutionalization readily responded that the deficiency lay in the fact that the community had not been given the means to receive and accommodate the mentally ill in its midst.

In Europe, it is the Italians who went farthest, since, as a consequence of Franco Basaglia's struggle against abuses in institutions for the mentally ill, they passed a law closing the psychiatric hospitals. It is not possible in this entry to give a full account of the differing and opposing views that were advanced by the advocates and adversaries of antipsychiatry and of deinstitutionalization in the United Kingdom, France, and Italy. It may be stated that the great merit of the Italian advocates was their concern for the initial stages of institutionalization in a psychiatric hospital and the direction of their analysis toward the sphere of the social reproduction of poverty and its associated conditions, thus to be concerned with the determining factors which led people to a psychiatric institution, and to link firmly the social and the health related. To project our vision beyond the institution we must also analyze what happens before admission to the institutions.

The forms taken by deinstitutionalization, both in the United Kingdom and Italy, have been numerous and diverse, such as alternating periods in the institution and in the community, host programs in the institutions, and the creation of work cooperatives. This means, it must be emphasized, that the struggle against institutionalization should not be made an object of caricature by setting up a radical opposition: everything institutional or everything community based. And it is perhaps these efforts, in their various forms, to leave the psychiatric institution that have permitted the extension of the deinstitutionalization movement into areas well beyond psychiatry.

As concerns disabled persons, three principal claims have been voiced. The first of these claims is the affirmation that society is unadaptive and that disability is not initially a deficiency but a series of social obstacles. Opposed to the medical model, which emphasizes the deficiency of the individual and finds its fullest form in rehabilitation, is the social model, which asserts that if society were fully accessible, on all levels and in all domains, disability would be only one small difference among thousands. This is a systemic model, which attempts to understand the exact relationship between the "deficient" individual and disabling society. By means of a certain number of accommodations, life among others is possible and desirable.

The claim that society is unadaptive. In the early 1960s, we were in the grip of a notion of unadaptation, defined as the defects or insufficiencies of the individual, quasi-natural in being. We have already overturned the idea of disability that emphasizes the exogenous burden that weighs on persons with perceived deficiencies. It is the complex of social institutions that creates obstacles to the life and development of "deficient" persons.

The claim of the disabled themselves that individual rights must be affirmed. We return here to ideas earlier expressed on the way in which contemporary individuals situate themselves on their social path. The affirmation of individual rights, based on the declaration of human rights, and the desire to construct oneself, have led to currents, fed by disabled persons themselves, to criticize those institutions that Erving Goffman has called "total."

We should not confuse rejection of the institution with rejection of specialization. Those who wholly reject the institutions would certainly not deny that the specialized actions that the institutions offer are necessary to them.

Deinstitutionalization is not simply exiting or avoiding specialized establishments; it is the fact that these institutions are now being called on to play another role than that which earlier devolved onto them or which they assumed. But it is not because deinstitutionalization is not coincident with avoidance of specialized agencies that the latter do not consistently conceal their temptation to remain "total" institutions, that is, with pretensions to dominate the whole person and this for a long period of time.

The claim that deinstitutionalization can be carried out in the facilities. Deinstitutionalization can be carried out in the facilities, just as institutionalization can occur in hidden form in ordinary community surroundings, but the temptation is certainly greater to try to establish full control over disabled persons within facilities than if one strives simply to be of service to them in the midst of our common social realities.

As for the influence of European and UN policies, these revolve around the principle of nondiscrimination. These international instances, strongly marked by developments in English-speaking countries, have insisted on this fundamental principle, issuing from the declaration of human rights, that discrimination should not occur by reason of a disability any more than on grounds of gender, skin color, or ethnicity. This has occasioned an interrogation of the systems, such as those in France, that still widely practice sequestration within structures and facilities whose rules, aims, and forms are predetermined.

Discrimination can be conceived of in positive terms as the totality of aids that permit each individual to live in the communal space. It is within the context of the common space that the human singular must find the means to live, to develop. The common space must be equipped with the means to accommodate each one of us. It should not be hard to understand that it is the *metamorphosis* that is at issue.

Deinstitutionalization, then, with regard to disabled people, is less the disappearance of institutions or specific assistive resources than their mutation to meet new social demands and a new historical context.

—Henri-Jacques Stiker

See also Antipsychiatry Movement; Modernity.

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DELIRIUM

Delirium, a complex neuropsychiatric syndrome comprising a diminished level of consciousness, cognitive impairment, and perceptual abnormalities including both hallucinations and illusions with reduced ability to focus, sustain, or shift attention, is a common disease state that has been described for centuries. Delirium occurs in about 15 to 25 percent of all general admissions to hospital. Most at risk are elderly, postoperative, and terminally ill patients. Although it is a common cause of morbidity and mortality, it is often unrecognized. The consequences are prolonged hospital stays, nursing home placements, prolonged cognitive disturbance, or protracted disability.

Delirium is a highly distressing experience for both caregivers and patients. Appropriate evaluation and treatment of delirium should be an imperative, not just for psychiatrists but for all physicians.

The term *delirium* has a very long history since the early Graeco-Roman period and has been used with many different meanings. In modern psychiatry, it was used to cover all types of acute disturbance of consciousness with general impairment of cognition, whether or not the patient was overactive and disturbed. Unfortunately, etymological confusion remains common, especially in medical fields; some of them are encephalopathy, acute confusional state, and acute organic brain syndrome.

The symptoms of delirium are wide ranging with poor specificity, but their fluctuating nature is highly characteristic and serves as a valuable diagnostic criterion. The core disturbance involves an acute generalized impairment of cognitive function that affects orientation, attention, memory, and planning and organization skills. Other disturbances, such as those of the sleep-wake cycle, thought processes, affect, perception, and activity levels, are underemphasized in diagnostic systems but are important in identifying and managing delirium. Much attention has been given to differentiating delirium from dementia, by noting temporal factors and by recognizing the level of consciousness and attention. The electroencephalograph shows diffuse slowing of background activity. Diagnosis can be improved by clinicians becoming more aware of hypoactive as well as hyperactive presentations, incorporating cognitive assessment with the Mini-Mental State Exam (MMSE) into routine practice, and using screening instruments such as the Delirium Rating Scale (DRS).

Underlying general medical conditions, substance intoxication or withdrawal, or multiple etiologies can cause delirium. Prescribed drugs (particularly those with anticholinergic properties, sedating drugs such as benzodiazepines, and narcotic analgesics) as well as cardiovascular disease and acute infections are perhaps the commonest causes, particularly in elderly people. Delirium tremens is caused by alcohol withdrawal.

The four main aspects to management of delirium are identifying and treating the underlying causes, providing environmental support (e.g., attention to noise, lighting, and mobility levels), pharmacotherapy (e.g., haloperidol, risperidone, olanzapine, trazodone), and regular clinical assessment and monitoring severity with use of an instrument such as the Memorial Delirium Assessment Scale (MDAS).

—Yutaka Matsuoka

See also Neuropsychiatry; Substance Abuse.

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DEMENTIA

As the baby boom generation reaches retirement age, and increasing numbers of individuals are surviving into older age ranges, the prevalence of dementing illness is also rising. Alzheimer's disease, the focus of this entry, is the most common cause of dementia, accounting for more than half of all dementia cases.

Currently, 4 million people in the United States have Alzheimer's disease, and estimates project that its prevalence will rise to 14 million by 2050. Its devastating consequences will continue to escalate and affect us either directly or indirectly in many ways. In short, Alzheimer's disease will increasingly become the dominant disorder in late life.

Alzheimer's disease is a progressive degenerative brain disease that is characterized by neocortical atrophy, neuron and synapse loss, and the presence of senile plaques and neurofibrillary tangles. The plaques and tangles were first identified and reported in 1907 by Alois Alzheimer, a German physician and neuropathologist, who autopsied a patient who had recently died from what appeared to be a mental illness. A definitive diagnosis confirming the presence of significant neurofibrillary tangles and neuritic plaques can be made only at autopsy or with a brain biopsy. As no effective cure for Alzheimer's disease is currently available, strategies for the management of disease symptoms focus on behavioral modification and the use of medications for behavioral management or slowing of the progression of disease.

The dementia of Alzheimer's disease is characterized by severe memory defects with additional deficits in language, "executive" functions, attention, and visuospatial and constructional abilities. Patients may also experience depression, psychosis, agitation, or changes in personality as well as a loss of awareness of their deficits (termed *anosognosia*) and impaired judgment. The cognitive, behavioral, and emotional changes result in an increasing dependency of dementia patients on others in their day-to-day functioning.

CLINICAL FEATURES

Definition of Dementia

Dementia refers to a syndrome of acquired cognitive impairment sufficiently severe so as to interfere with social or occupational functioning. According to the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*–Fourth Edition (*DSM-IV*; 1994), "Dementia of the Alzheimer's Type" involves memory impairment and cognitive deficits in at least one other domain, demonstrated by defects in language, praxis (or skilled movements), knowledge (agnosia), or impaired executive functioning, which are not due to other neurological disorders, medical conditions resulting in dementia, or substance abuse. The cognitive decline must be gradual, progressive, and severe enough to interfere with social or occupational functioning. The cognitive impairment must also represent a significant decline from a previously higher level of functioning, and it must not occur in the context of delirium. Other forms of dementia (e.g., dementia due to Parkinson's disease, dementia due to head trauma, and dementia due to endocrine dysfunction) will share at least some symptom overlap with Alzheimer's, although the pattern of cognitive deficits and underlying neuropathologies will differ.

Diagnosis and Course of Alzheimer's Disease

Because the dementia syndrome is associated with more than 50 different causes of brain dysfunction, and there are no known peripheral markers for Alzheimer's disease, a definitive diagnosis still requires autopsy verification of the presence of histopathological neurodegenerative abnormalities (i.e., neuritic plaques and neurofibrillary tangles. However, documentation of the presence of dementia and the exclusion of all other known potential causes allows Alzheimer's disease to be clinically diagnosed during life with relative certainty (i.e., 90 percent). Once diagnosed, patients with Alzheimer's disease often live for many years, eventually succumbing from conditions like pneumonia or organ failure. The duration of the disease varies widely and can be as long as 20 years or more, although the average length is 4 to 8 years.

Prevalence

Studies suggest that approximately 6 percent of persons over age 65 have severe dementia, and 10 percent to 15 percent have a mild to moderate dementia. The prevalence of dementia is age related, doubling approximately every 5 years after age 65. Not surprisingly, the prevalence of dementia is higher among hospital and nursing home residents than among those living within the community.

Risk Factors

A number of reliable risk factors for Alzheimer's disease have been identified. First, age is the single most important risk factor for dementia. Prevalence rates rise exponentially between the ages of 65 and 85. Second, women may have a slightly greater risk for Alzheimer's disease than men, although this finding may be due to their longer life expectancy. Third, the risk of developing dementia is increased fourfold by a family history of Alzheimer's disease. Given the discovery of certain specific gene mutations, there is now little question that this familial association is genetically based.

Finally, the risk of developing Alzheimer's disease is doubled for individuals with a history of a single head injury that led to a loss of consciousness or hospitalization. If one assumes that these risk factors are simply additive at the population level, then the attributable risk of developing Alzheimer's disease from these and other lesser known factors appears to be between 40 and 50 percent, or perhaps more.

Neuroimaging

A variety of neuroimaging techniques have been used to characterize brain changes in dementia. Some of the most recent techniques include structural analysis of the brain with magnetic resonance imaging (MRI), computation of regional cerebral metabolism with positron-emission tomography (PET), regional cerebral blood flow with single-photon-emission-computed tomography (SPECT) and determination of regional biochemical concentrations with magnetic resonance spectroscopy (MRS). More recent work with functional MRI techniques offers considerable promise as a noninvasive method of studying brain dysfunction associated with Alzheimer's disease. All of the above techniques may provide complementary information to the usual diagnostic procedures and may contribute to the early and more specific detection of the disease, although their routine use—apart from identification of alternative causes of the dementia syndrome (e.g., presence of tumors)—has not been recommended for diagnostic purposes.

NEUROPSYCHOLOGICAL DEFICITS

Failure of recent memory is usually the most prominent feature during the early stages of Alzheimer's disease. Numerous studies have shown that tests measuring the ability to learn new information and retain it over time are quite sensitive in differentiating between mildly demented patients and normal older adults.

In addition to memory deficits, patients with Alzheimer's disease, for example, also experience deficits in attention and concentration abilities. In fact, subtle impairments in the earliest stages of Alzheimer's disease may be seen on complex attention tasks depending on divided and shifting attention. Some patients in the early disease stages do not have attention problems, but such deficits typically emerge and increase in severity as the disease progresses.

Deficits or disability in some aspects of language increase in severity throughout the course of Alzheimer's disease. Certain language abilities tend to remain intact, however. Patients exhibit little impairment in articulation abilities, and they also have little of the severe grammatical deficits seen in other neurological disorders. With relatively few phonetic and syntactic deficits, the fluency of patients' spontaneous speech and oral reading typically remain intact. Difficulty with word finding is seen early in Alzheimer's disease patients, although usually not as early as memory deficits.

Disability in spatial cognition is evident in some patients with mild Alzheimer's disease, and in nearly all patients in the later stages of the disease. A progressive decline in drawing ability is also characteristic of patients with Alzheimer's disease. An early onset of impairment is often seen on complex tasks. For example, patients are significantly impaired compared to healthy older adults when asked to draw a clock or when copying complex geometric designs.

Although patients are typically aware of their earliest symptoms, such as memory problems, there is an increasing loss of insight as Alzheimer's disease progresses. Gradually, patients are unable to recognize their cognitive impairments and to judge the quality of their own behavior. Progressive decline in patients' executive function is also seen in their ability to think abstractly and to solve problems, with deficits occurring early in the course of the disease.

AFFECTIVE AND PERSONALITY CHANGES

Personality changes represent one of the most common alterations in Alzheimer's disease, affecting upwards of 75 percent of patients at some time during the course of the disease. Changes can vary widely in a number of ways such as disengagement or disinterest in one's surroundings, disinhibition or inappropriate social behavior, psychosis, delusions, or other disruptive behaviors. Affective changes can occur as well, and depressive mood and symptoms are common in Alzheimer's disease (e.g., 50 percent report symptoms of sadness or demoralization), and anxiety is reported in approximately 50 percent of patients as well. Hallucinations, which occur in approximately 25 percent of Alzheimer's cases, are typically visual or auditory in nature, although gustatory, olfactory, and haptic hallucinations have also been reported. Delusional preoccupation is not uncommon either. For example, Capgras syndrome, in which the individual believes that his or her family member has been replaced by an imposter, represents one of the most common types of delusional disturbances. Finally, agitation is also one of the most frequently cited symptoms in patients (up to 75 percent), which creates a tremendous burden for caregivers. In sum, abnormal behaviors as a consequence of affective or personality changes in Alzheimer's patients are quite common and typically give rise to more caregiver-related burden than do the cognitive sequelae.

—*Mark W. Bondi*

See also Alzheimer's Disease; Neurological Impairments and Nervous Disorders; Neuropsychiatry.

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DEMOCRACY

It is impossible to give a fixed definition of *democracy*. It has taken diverse forms both historically and theoretically. North American democracy is significantly different from European democracies. Democracy is not only what is carried out in its name, it is also what people think it is and should be. It is more a "horizon" than a definitive reality, a set of principles and desires that constantly guide and inspire us but that are never fully realized.

Democracy is always ahead of us. In one sense it is as imaginary as it is real. Democracy is a task, something that must be constructed. One can, however, draw the principal lines of this horizon. Democracy is above all the affirmation that sovereignty should belong to everyone, and its first principle is the liberty of individuals and their civic rights (this is political democracy). But for sovereignty and liberty to be exercised, access to goods and services must be as equal as possible, and there must be a form for the distribution of common wealth (social democracy).

In turn, the achievement of political and social democracy requires solidarity among the people, the sharing of fundamental values, and a desire to live together according to these values. This level might be called ethical democracy. Since democracies are always being made and remade—which constitutes their dynamism but also their fragility—they evolve and continuously face new questions. Today, democracies are confronted by certain issues that have become more crucial than they were in the past, questions that concern disabled people in particular. These questions are centered on *participation*, a word that tries to cover both the sphere of political freedoms and a part of the sphere of distributive justice. Second, democracies have to resolve the multicultural fact of how to bring individuals and groups with very diverse religions, languages, ethnic origins, traditions, and customs to live in a space that must remain a common space.

Throughout history, disabled people have often been excluded from democracy in its concrete form and thus from active participation in social life, from respect for their specificities, and from the solidarity that would have allowed them a life with dignity. When they were not put in a kind of ultra-human category (signs from the gods), they were, at least in extreme cases, relegated to an infra-human one (between animal and human), or, in less radical fashion, put under total guardianship and confined to institutions or, more recently, sequestered in specialized structures and aid programs. Certainly, since institutional democracy in the United Kingdom and France, fundamental rights were recognized for disabled people as for everyone else, but their citizenship continued to be conceived as conditional, since the essential concern was their well-being, their protection, and their adaptation to existing society.

The intent of legislation, the practices of social work, and the demands of the families themselves were all directed at the assumption of responsibility rather than the affirmation of the disabled as citizens. This constituted a movement toward the disabled that did not solicit their own contribution. Even when they were the object of close attention, even a disinterested love, they were in principle subaltern, not autonomous. Even when they had guarantees of public or private forms of solidarity (foundations, gifts, or allocations), the disabled were most often within the framework of "total" institutions, to employ Erving Goffman's phrase. Even when the principle of nondiscrimination was exercised with respect to them, they were not asked to engage themselves and to contribute, on one level or another.

Seen at close hand, our democracies, which we believe so advanced, here affirm liberty, there equality, elsewhere nondiscrimination, and beyond that even positive discrimination. But only rarely, and perhaps never, do we gather together the full set of notions that contribute to democracy, in their reciprocal limitations and their organic articulation: dignity, liberty, equality, nondiscrimination, equality of opportunity, equalization of opportunity, positive and specific acts. We must affirm, one at a time, each of these requirements to better establish those preceding, and not allow them to come into competition, even when they appear opposed or difficult to reconcile.

We know that if we develop only liberty, injustice will take the place of the idea of equality. If we enhance only equality, we create a form of totalitarianism that denies liberty. If we agree to set aside the idea of equality in favor of simple equity, we reinforce privileges to the detriment of citizens without them, but if we want equality without equity, we neglect the insurmountable social division. If we allow only the rule of nondiscrimination (which, moreover, is only a development of the recognition of the equal dignity of all human beings), we risk falling back into the formalism of abstract human rights, but if we go too far in the direction of specific measures to come to the aid of vulnerable or excluded groups, we stigmatize them and set them apart.

It is possible to continue at some length, showing that breaking the components of democracy down into constituent parts poses a threat to democracy itself. It is starkly obvious that no present democracy or other form of government groups the full series of elements that make up the democratic horizon in coherent and balanced fashion. Any given state may be more or less deficient in one respect or another.

Now, we must note two important challenges involving disabled people that make democracies vulnerable: participation and multiculturalism.

PARTICIPATION

The first challenge is that of participation. Participation is doubly threatened at the very moment when it is increasingly claimed, and in particular by the disabled. The first threat is overdriven individualism: When an interest in and preoccupation with "me," disregarding others and indifferent to the common good, is unilaterally in force, participation has scarcely any meaning. What counts is not the social link but rather the expansion of personal subjectivity. The social factor, other social beings and common agencies (e.g., the justice system, taxes, unions, and athletic associations), is there to serve the individual, and the individual's concern for them is only proportional to his or her self-interest. It is doubtless because of this individualism that demands for participation are becoming more insistent. Disabled people, sensitive to the weight of past exclusion and the risk of present individualism, demand to be the actors in their own existence and thus not only to be consulted but also to be implicated in the processes and policies that affect them. Beyond even their personal destiny, they increasingly want to become citizens concerned for the general life of their cities and their countries. Gaining such recognition is a difficult struggle, even if it is supported by the international community, for example, through the International Classification of Functioning, Disability, and Health.

Disabled people contribute to the advancement of democracy in proportion to their numbers and their dynamism. If they need democracy, democracy needs them. Along with other groups and social categories that are calling for greater participation (immigrants and women, to name two examples), disabled people are a factor in the progress of democracy.

Another threat lying in wait for participation is the huge number of people involved. This is an old problem, since the exercise of sovereignty within a nation takes place through representation. The power that theoretically belongs to all the members of the community in question must be delegated through the electoral process. The complexity of election modes makes such delegating opaque. Moreover, once elected, representatives can betray the people from whom they have received their mandate. In any case, how are we to be assured of their legitimacy over time and even more of the legitimacy of the weighty and complex administrations that have been put in place to govern? Another problem of our modern democracies is public opinion. How are we to organize it without manipulating it? How can we manage to establish public debates that are not cut short? How to reach minimal consensus?

There are no good and easy answers to these questions. Clearly, disabled people can play only a modest role. However, by calling to public attention their circumstances and their questions more and more, by denouncing the physical factors of their surroundings that impede their existence, by being members of international organizations (e.g., Disabled Peoples' International and the United Nations), they can contribute to greater transparency in the public debate and to a redisposition of society that is profitable to everyone.

MULTICULTURALISM

The second challenge to be reviewed here is that of multiculturalism. All democratic countries are experiencing an influx of populations with ethnic, religious, and cultural origins different from those of the population already present. The overriding question is one of the inclusion of persons and groups that are so diverse—inclusion in the same legal system, in the same school and same business, in the same values of respect, tolerance, freedom of opinion. The entry "Inclusion and Exclusion" in this encyclopedia develops some models for this relationship with the "other." On the one hand, assimilation may end in blindness toward differences through an overdriven normalization—this model is the current tendency, and thus the current temptation, in Europe. On the other hand, differentiation, through excessive fissuring, may end up destroying every real community in favor of a simple juxtaposition. This is the tendency, even the risk, in North American democracies.

The principle of nondiscrimination provides a response to this challenge. But it cannot alone be sufficient. We need the daily exercise of proximity, integrated neighborhoods, reciprocal recognition, and understanding. Here, disabled people can play an emblematic role. They exemplify a difference in comparison with average citizens, each in his or her own way. They highlight the question of living in proximity. By increasingly refusing separate treatment, special institutions, denials of or limitations on activities and participation, they force all those sites where social life takes place to be receptive and equipped so that every person, just as he or she is, finds fulfillment there.

Disabled people can show the way toward democratic inclusion. They are pushing to find means of every kind to accomplish this: physical accessibility to spaces of every kind, educational accessibility to schools, the establishment of support measures, and the techniques to practice the arts, to play sports, to travel, and to live without obstacles in their own homes. In this way, they impose their presence and point up the fact that every difference must find its own place among all the others. To take the example of schools, disabled children would have their specific needs met but within the framework of regular classes, with all the necessary support. As Stainback and Stainback wrote (1990):

> Total inclusion does not mean that special educators are no longer indispensable; they are even more necessary in order to work with regular teachers and with appropriate school programs that are stimulating for all pupils. On the other hand, special educators need to be integrated and to become regular or general teachers, and thus competent in areas relative to teaching, school programs, and the control of knowledge. (p. 4)

This idea has been articulated in different ways. David Cooper wrote of being oneself with others, a simple formula that illustrates that the community and the individual should advance together.

It would be better to conclude an entry on democracy with concrete examples rather than with abstract concepts, for democracy is, at base, what people actually make of it. But these visions can be understood only in the wider perspective that is opened by the word *democracy*, in which lies the very power of our life together.

—Henri-Jacques Stiker

See also Cultural Context of Disability; Inclusion and Exclusion.

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▣ DEMOSTHENES (384–322 BCE)

Athenian orator and statesman

Demosthenes is today both an emblem of rhetorical skill and a model of overcoming speech impairment. It is commonly reported that Demosthenes overcame his speech impairment by various exercises such as holding pebbles in his mouth while speaking. We do not actually know what sort of speech disorder Demosthenes had, if any. In fact, we have little information about any individual in the ancient world with a speech disorder. Oddities of speaking were seen as personal characteristics, not as pathology; still, these oddities, if not the people affected by them, were seen unfavorably. More than a mere interpersonal skill, articulate speech was necessary for civic participation. Public speaking was an important mark of civic responsibility, duty, and membership in ancient Athenian society. The course of the Athenian community was steered by the one who had the most convincing argument. A good argument, though, had everything to do with presentation: The quality of the voice itself had the potential to sway one's audience. In addition to Demosthenes' surviving works (available in a seven-volume Loeb Classical Library translation), Plutarch's biography of Demosthenes is an important source of information, though it was written approximately five centuries later.

—M. Lynn Rose

See also Speech and Language Pathology.

▣ DEPRESSION

Depression has been recorded since antiquity. It is estimated that the prevalence of depression in U.S. populations ranges from 3 to 13 percent, with an average of 20 percent of the adult population experiencing some depressive symptoms at any time. The lifetime incidence of depression is thought to be between 20 and 55 percent. The incidence of depression in women is twice as high as it is in men; this has been shown in many different countries and cultures. In elderly populations, depressive symptoms range between 11 to 59 percent among the medically ill elderly. These prevalence rates and gender differences are comparable in most countries where there are sufficient data to compare.

TYPES OF DEPRESSION

There are many forms of depressive disorder, such as major depression, dysthymia, and bipolar disorder. Major depression has a combination of symptoms that affect individuals' working ability, study, sleep, eating habits, and participation in pleasurable activities. Frequently, depression reduces capacity for work or results in unemployment; according to the World Health Organization, it is one of the leading causes of work-related disability of all medical disorders. Depression may occur only once but more commonly occurs several times during lifetime. Dysthymia is a less severe type of depression. Chronic symptoms may not lead to disability, but they do prevent individuals from ideal or even good functioning and chronically detract from enjoyment of life. Another type of depression is bipolar depression, which is characterized by cycling mood changes, from severely high mood, or mania, to low mood, which is depression. Sometimes mood fluctuates dramatically and rapidly, but most often changes are gradual. Once the person is in a depressive mood, he or she can have any or all of the symptoms of major depressive disorder. However, when he or she is in manic cycle, the individual may be very hyperactive and expansive, engage in high-risk-taking behavior, and make decisions that can be hazardous to his or her health and personal and social life.

Some types of depression may run in families, and genes may pass biological vulnerability. People with low self-esteem always consider themselves as overwhelmed by stress and are therefore prone to develop depression. Research shows that physical changes in the body are highly associated with depressive symptoms. Chronic medical illnesses such as stroke, heart attack, and Parkinson's disease can cause depressive disorder, which makes people apathetic and unwilling to take care of themselves. Likewise, medication for medical conditions including steroids, antihypertensives, and cardiac medicines are also associated with depression. Also, a serious loss or any stressful change in life pattern may trigger a depressive episode. Significant risk factors for depression among elderly people include bereavement, sleep disturbance, disability, prior depression, and female gender.

People with chronic illness are at high risk of developing depression. They are less able to control many aspects of their lives. Their functional impairments will be further exaggerated by the perceived limitations. Reduction of their psychosocial resources in terms of mastery, self-efficacy, and social support may also lead to depression. This hypothesis is supported by data showing that nearly one-third of widows experience symptoms consistent with a major depression during their first year of widowhood.

People with depression suffer from depressed mood or loss of interest or pleasure in activities on most days. They may also have appetite loss, significant weight loss, sleep disturbance, fatigue or loss of energy, and difficulty thinking, concentrating, or making decisions. Some of them may think of death or possess suicidal ideation.

People with depression decline in health-related quality of life. The degree of depression is associated with levels of energy, emotional well-being and social function, bodily pain, and general health perceptions. People with depression experience disabilities in family, job, and social aspects of their life. Depressed individuals often have negative self-perceptions of their social competence and have a negative impact on people around them. They may have behavioral skill deficits. They tend to be less assertive and less positive, have negative facial expressions and poor eye contact, and participate less actively in group interactions.

In addition to checking for the symptoms listed, each patient should be carefully evaluated for a contributing medical illness or medication or the presence of disorders related to and/or occurring with depression including dementia and substance abuse.

Depression, especially among elderly, seriously affects one's health status. Major depressive disorder has been associated with the decline of immune function in adult population. The depressive symptoms found in older people increase the risk of subsequent decline in physical functions. In the extreme case, death is the result. The most compelling consequence of depression among elderly is increased mortality from suicide as there is a causal relationship between depression and the hopelessness associated with suicide.

Depression is often associated with physical disabilities. The psychological problems in people with disability and depression are commonly associated with pain. About 20 to 35 percent of patients with rheumatoid arthritis show depressive disorders. Reduced physical competency also induces depression. In one study, some 37.8 percent of stroke victims during the first year showed depression; 25 percent of people with myocardial infarction suffered from major and minor depressive disorders; and 10 to 15 percent of people with diabetes were observed with major depression. Selective serotonin reuptake inhibitors (SSRIs) are considered the first line therapy for depression in recent years and are better tolerated by patients than the heterocyclic antidepressants, although occasional agitation, insomnia, gastrointestinal distress, and delayed ejaculation are known side effects. The dosage of antidepressant medication used during acute phrase often is also appropriate dosage for use during long term or maintenance.

As other drugs, traditional antidepressants bring about other side effects. People receiving heterocyclic antidepressants may have dry mouth, blurred vision, urinary retention, constipation, delirium, sedative effects, cognitive deficits, speech blockage, excessive perspiration, and weight gain.

For those who are nonresponsive to antidepressants, electroconvulsive therapy (ECT) may be prescribed. It is believed that ECT works by using an electrical shock to cause a seizure and a short period of irregular brain activities. However, people receiving ECT may have high rates of relapse and recurrence even if switched to continuation and maintenance drug therapy following response ECT and often experience difficulty in their memory for recent events for several weeks following ECT.

TREATMENT OF DEPRESSION

Psychological and Behavioral Treatment

Cognitive-behavioral therapy (CBT) is commonly used in treating people with depression, and studies show it to be nearly as effective as medication for less severe forms of depression. Cognitive-behavioral interventions or behavioral therapies involve the teaching of skills and assignment of homework to patients. During these therapies, specific achievable goals are set to help provide a new cognitive focus for patients. By addressing cognition, a therapist can help patients focus on positive life events, instead of just focusing on what makes them depressed.

Social skills training and interpersonal psychotherapy address the social interaction deficits experienced by people with depression. Skills such as communication, behavioral productivity, social interaction, assertiveness, decision making, problem solving, and cognitive self-control are taught during training sessions. Assignments aim to help patients generalize skills learned during treatment to real-life situations.

Complementary and Alternative Treatment

Recently, a kind of Chinese physical and mind exercise, *qigong*, has been shown to be beneficial to some depressed elderly with chronic physical illness especially in the Chinese population. Qigong features postures and movement, state of mind, and breathing. Patients' psychosocial functioning improved after practicing qigong, which included feeling more relaxed, more comfortable, and more optimistic and experiencing better sleep. This may be due to the fact that qigong emphasizes breathing relaxation. When the body and mind are calm, physical and mental functions improve. Correct posture, proper movements, clearing the mind of stray thoughts, and long and deep breathing all help a person attain a state of well-being and reduce mental and physical tension.

—Hector W. H. Tsang and Ellen Y. L. Chan

See also Acute and Chronic Conditions; Anxiety Disorders; Behavior Therapy; Bipolar Disorder; Psychiatric Disorders.

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DESLOGES, PIERRE (1742–ca. 1790)

French author

Pierre Desloges was born at Grand Pressigny in Touraine, in central France. He became deaf as a consequence of an infectious childhood illness. A member of a well-to-do family, he learned to read and write, but because he had an oral deformation that made his voice inaudible, he chose to remain mute. Near the age of 20, he took up residence in Paris, where he learned the trade of bookbinder and billposter.

He was a frequent companion of Abbé de l'Épée, who introduced him to Abbé Copineau, a disciple of Condillac, who would assist him in the preparation of a response to a book published in 1779 by Abbé Deschamps on the education of the deaf. Desloges's work, titled *Observations d'un sourd et muet sur un cours élémentaire d'éducation pour les sourds et muets* (*Observations of a Deaf-Mute on a Course of Elementary Education for Deaf-Mutes*), is of interest in several respects. Drafted in a new style, inspired by Copineau, that consisted in dropping double letters and those that were not pronounced, for example, *fam* instead of *femme* "woman," it furnishes information on the Deaf community of Paris and illuminates early French Sign Language usage. In sum, Desloges judged Deschamps's method reprehensible and useless for the deaf, since it consisted of teaching them articulated speech.

—*Jean-René Presneau*

See also Abbé Charles-Michel de l'Épée; Sign Language.

DEVELOPING WORLD

Seventy to 80 percent, or approximately 400 million, of the world's disabled people live in the developing world and of the world's poorest of the poor, 20 percent are disabled. The number of people with disability in developing countries is increasing due to poverty, malnutrition, violent conflict, HIV/AIDS, traffic accidents, work-related injuries, and "lifestyle diseases" such as heart disease and diabetes. Many efforts have been made to address disability in the developing world, from grassroots community programs to United Nations declarations and strategies. Despite this, the vast majority of disabled people in developing countries remain socially, politically, and economically marginalized and among one of the most vulnerable groups in the world.

This entry discusses the context and experience of disability in the developing world; the cycle between disability and poverty; the role of rehabilitation professionals in developing countries; and approaches that have been taken including community-based rehabilitation, rights-based approaches, inclusive education, and prevention. It examines the work of the "development sector," looks at reasons why disability has been ignored by the sector, and discusses reasons for and approaches to ensuring that disabled people access the benefits of development. The entry lists the major agencies working in disability and closes with a discussion of what the future holds for disabled people in the developing world.

Various terms have been used to describe the developing world, including "developing countries," "the South," "the majority world," "low-income countries," and "the third world." Classification of countries is derived from comparison of variables such as life expectancy, literacy rate, enrollment ratio, per capita income, percentage of people without access to safe water, percentage of people without access to health services, and percentage of children under age five who are underweight. Nonindustrialized countries are generally considered "developing countries" and these include all countries other than those in the Organization for Economic Cooperation and Development (OECD). Readers are referred to the United Nations Human Development Report for greater detail on classification and ranking of countries.

DISABILITY IN THE DEVELOPING WORLD CONTEXT

The context of living with and responding to disability in developing countries is significantly different from that in industrialized countries. The majority of people live in rural areas and have farming lifestyles, where water is often accessed from a central pump or well; bathing and washing clothes is done in rivers or from a bucket; and accessing services generally requires walking to the village and catching a bus to the nearest town, which can be many hours away. Urbanization is increasing as countries modernize and people move to towns and cities seeking education and employment. Increasingly, millions of small-scale farmers are unable to compete with imported foreign agricultural products since the deregulation of world markets, and they are having to give up their land and move to cities, looking for work. In many places, this has led to an increase in urban slum populations. The experience of disability in urban slums is very different from rural village settings; slums are often crowded with narrow, uneven paths between improvised shacks or tents; people are frequently living close to sewerage with limited access to clean water; slums may exist along train tracks, on flimsy huts on stilts overhanging water, or on the edge of towns; accessibility is difficult and privacy is often unachievable.

Access to basic health care is limited for the general population in many developing countries, and options for those with rehabilitation needs are a rarity. Health budgets are often very restricted and it is common that priority is given to preventing "killer" diseases such as malaria, tuberculosis, diarrhea, and HIV/AIDS, over the less evident issue of disability. Social welfare programs and pensions are rare, and the responsibility for supporting the elderly, sick, or disabled generally lies with the family. In some cultures, begging is an accepted means of society supporting the needy, and having a visible disability can be a viable means of income.

Massive indebtedness of most developing countries to industrialized countries has a major impact on disability. As a condition for receiving loans, most developing countries must adhere to structural adjustment programs, which frequently include cuts in social, health, and education expenditures; removing subsidies on basic foods and fuel; reducing public sector employment; increasing interest rates; introducing user pay systems for social services; increasing taxes; and a shift to export orientation. Budgets are cut to public health programs that would have prevented disabilities, such as immunization or water and sanitation programs; staff in health settings are overstretched and less able to provide the time required for disabled people; school class sizes are increased, making it even more difficult for teachers to cope with disabled children in the classroom; and inflated interest rates for small loans make it more difficult for disabled people to make a successful business from income generation activities. Producing export cash crops rather than growing locally eaten food crops further exacerbates malnutrition, which increases the risk of disability.

Developing countries experience disproportionately more natural disasters and violent conflict, acutely affecting disabled people. The ability of families to support disabled members is gravely tested in crises, where survival may depend on the ability to escape by foot or to find shelter, food, and clean water. Within refugee or displaced populations, disabled people are often left behind to fend for themselves. The incidence of disabilities increases in disaster or conflict situations because of combat injuries, land mines, breakdown in medical services, and interruption of preventive health programs. Sexual abuse as a weapon of war has had an impact on the mental health of some populations, particularly the women.

Marginalization of disabled people is widespread, although it differs from place to place. In some communities and families, disability is accepted as a normal part of life and disabled people participate to their capacity and are assisted with tasks beyond that capacity. However, these situations seem to be the exception, according to the vast majority of studies and reports on disability, in which significant discrimination is recorded. Discrimination may occur because of fear, ignorance, and assumptions regarding lack of potential of disabled people. Laws that prevent disabled people from marrying, attending school, owning land, or voting are structural forms of discrimination. Disabled girls and women often miss out on health care, particularly reproductive health care; they are disproportionately affected by sexual abuse, which is exacerbated by lack of knowledge of sexual health and rights.

Accessibility restrictions prohibit many disabled people from entering public buildings and using public transport. Dilapidated roads, chaotic traffic conditions with no pedestrian crossings, and dilapidated footpaths mean that many disabled people cannot move much beyond the area around their house. People with intellectual and sensory impairments or mental illness experience significant exclusion as their conditions and needs can be less obvious than physical impairment.

As in richer countries, many disabled people in developing countries are "protected" by families who do not wish them to go out and risk being hurt or ridiculed. Community gossip may create shame for the family or may have a negative impact on the marriage prospects for other siblings. This "protection," or denial of opportunities to perform tasks and undertake risks, can render the disabled person passive, reduce self-esteem, and reduce opportunities for developing independence.

The enormous burden related to mental health problems in developing countries is being increasingly acknowledged. High levels of stigma, lack of access to services, lack of awareness of treatment options, and inability to afford medicines mean that many people with mental illness remain undiagnosed and untreated.

THE DISABILITY-POVERTY CYCLE

The cycle between poverty and disability is increasingly being studied and documented. The World Summit for Social Development, held in Copenhagen in March 1995, observed that disabled people, as one of the world's largest minorities, are often forced into poverty, unemployment, and social isolation. Disability leads to poverty by excluding people from working or accessing education or skills development. Family members, usually women and girls, are frequently required to care for the disabled family member, reducing time available for earning income, going to school, or supporting the development of other children. This further contributes to the family's poverty. In certain areas, having a disabled child is reason enough for a man to divorce his wife as it may be deemed that the child's disability was her fault. Cultural norms may prevent her from returning to her mother and father, and she may be unable to wed again, having been "soiled" by her first husband. This places the woman and child at significant risk.

Conversely, poverty can lead to disability through increased vulnerability to risks. Poor people are less likely to be able to afford firewood to boil water and may live in places where sewerage is not clearly separated from drinking water, increasing risk of disabilities related to malnutrition and water-borne diseases. They may be vulnerable to injuries from unsafe work practices—it is difficult to resist dangerous worksites when the site manager can easily employ someone else who is willing to take the risk. Inability to afford antenatal and perinatal medical services, or simply lack of ability to afford the transport to these services, increases the risk of disability to the child and mother.

APPROACHES TO DISABILITY

Approaches to addressing disability in developing countries have mirrored those in Western countries to some extent—beginning with medical and charity models, followed by adoption of social and rights-based models. Institution-based rehabilitation, typically within the medical model, is criticized as an expensive means of providing rehabilitation to relatively few, generally only in urban areas. It is seen as too isolating from normal life, Western in approach, and specialized. The social model of disability considers disabled people as members of communities with rights and responsibilities equal to all others; it states that the problem of disability is not in the impairment, but in society's response to the individual and impairment, and in the physical environment. Change must therefore happen within families, communities, and societies. This does not mean rejecting medical or rehabilitation services, but it necessitates that these be provided in the context of wider change, rather than solely focusing on improving individuals' function.

The Role of Specialist Rehabilitation Professionals

Health teams that include a range of trained therapists, such as those in many industrialized countries, are sparsely located and often found only in cities, or sporadically in rural sites. In many developing countries, therapist positions are not in the government staff structure, and the only therapists are those with nongovernment agencies. The relevance of using therapist-focused rehabilitation frameworks developed in Western settings has been frequently questioned in developing countries. The magnitude of disability and the shortfall in health infrastructure and funding often undermine the feasibility of this approach on a national scale. However, the role of qualified therapists is vital, albeit in different ways from Western health settings. Therapists are needed for training and providing technical advice and support to community-based rehabilitation workers, special needs teachers, and support workers; reviewing complex cases; training civil engineers and architects to ensure accessibility to public spaces; working alongside local artisans and disability organizations to ensure suitable and effective designs for appropriate technology; designing appropriate income generation training and adaptations to equipment; and providing evidence and technical support to advocacy campaigns.

Community-Based Rehabilitation

Community-based rehabilitation (CBR) was introduced in the 1980s in recognition of the fact that provision of rehabilitation services to the majority of disabled people was impossible through existing institution-based approaches. It was instigated by the World Health Organization (WHO) as a strategy for providing cost-effective and accessible rehabilitation services to people in their communities. The concept was that large numbers of midlevel rehabilitation workers would be trained, supervised, and supported by skilled rehabilitation professionals. The rehabilitation process was to be demystified and responsibility given back to the individual, family, and community. However, over the past two decades it has been recognized that the original model of CBR was not reaching adequate numbers of disabled people, nor was it having the desired impact, and that disabled people were still experiencing significant discrimination, marginalization, and poverty, even if they had managed to access services through CBR.

During the 1990s, the emphasis of CBR evolved. Instead of focusing on mitigating the impairment or disability, it is now seen as a strategy within community development for the rehabilitation, equalization of opportunities, and social integration of all children and adults with disabilities, taking into account social, cultural, and environmental factors and removing the emphasis on medical rehabilitation. By increasing accessibility and human rights sensitivity generally, it should benefit all people in the community, not just disabled people. Some examples of outcomes of CBR programs include providing or facilitating access to loans, community awareness-raising, providing or facilitating vocational training, facilitating formation of local self-help groups, parents' groups and disabled peoples organizations, training in mobility and daily living skills, facilitating contacts with different authorities, and facilitating school enrollment.

Rights-Based Approaches

Rights-based approaches to disability are rapidly gaining currency in many developing countries. Since the UN Decade of Disabled Persons (1983–1992), disability activists and disabled people's organizations (DPOs) have increasingly spoken out in international fora, playing a key role in promulgating this approach, which is in line with the rights-based approaches to development espoused by the United Nations. Key elements are accountability, popular participation, equality and nondiscrimination, expansion of people's choices and capabilities, and social integration. Increasing global access to information and communication has assisted networks of DPOs in gaining strength and solidarity. DPOs offer mechanisms for disabled people's voices to be heard so that fundamental human rights and self-determination can be achieved, legislative reforms enforced, and attitudinal and structural barriers removed. Self-help groups are enabling disabled people to access microcredit and income generation programs, facilitating economic empowerment for an increasing number of disabled people and their families, similar to the achievements by women's groups around the world.

UNESCAP's Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-Based Society for People with Disabilities in Asia and the Pacific sets the priorities for the extended Decade of Disabled Persons, 2003–2012. These are (a) self-help organizations of persons with disabilities; (b) women with disabilities; (c) early intervention and education; (d) training and employment, including self-employment; (e) access to built environments and public transport; (f) access to information and communication, including information and communication technology; and (g) poverty alleviation through social security and livelihoods programs. The framework's guiding principle is that disabled people are integral in all endeavors.

Inclusive Education

It is estimated that only 2 percent of disabled children in developing countries receive an education despite recognition over many decades that education is a basic human right. In 1994, the UN World Conference on Special Education produced the Salamanca Statement and Framework for Action on Special Needs Education. This was crucial in affirming the world's commitment to, and outlining the roadmap for, inclusive education (IE). The essence of IE is the improvement of education services so that all children can be enrolled in ordinary schools, regardless of differences or difficulties, unless there are compelling reasons for doing otherwise. Inclusive settings have shown benefits for disabled as well as for nondisabled students. Disabled children have shown better academic and social achievement, more appropriate behaviors, higher self-esteem and motivation, and greater likelihood of living independently, gaining employment, and becoming married. Students without disabilities in inclusive settings have been shown to have academic performance better than or equal to their peers in noninclusive classes and to have developed positive attitudes and meaningful friendships with disabled students. The self-concept, social skills, and problem-solving skills of all students have been shown to improve in inclusive settings.

Despite its potential benefits, IE has not been widely successful in the developing world. A number of developing countries have educational policies or legislation that recognize the value of IE; however, the implementation of this is generally unsatisfactory or functioning only at a "pilot project" level and has not been scaled up across countries. Some of the factors preventing the success of IE include lack of funding for relevant educational materials, inadequate training of personnel, lack of advisory or support services, and large class sizes. Successful IE requires the support of professionals who assist in diagnosis, referral, and treatment, for example, audiologists, speech pathologists, and occupational therapists. These professionals are rarely available in developing countries. It has been argued that a more realistic approach to IE in developing countries at this stage, rather than aiming for provision of equipment and facilities for special needs, is promotion of welcoming schools that recognize differences, support learning, and break down discriminatory attitudes.

A fundamental difficulty is that in many developing countries, there is gross underfunding of basic mainstream educational services. Within this milieu, the role of global lobby groups to pressure governments and donors for guarantee of resources specifically for IE as a fundamental human right of disabled people is critical.

PREVENTION OF THE CAUSES OF DISABILITIES

Prevention is integral to addressing disability in the developing world. Programs include immunization, de-mining, water and sanitation, peace building, occupational health and safety, road traffic accident prevention, neonatal care, nutrition, health promotion, medicines that prevent specific disabilities, and management of the causes of childhood fever. Many donors have justified their role in disability by citing prevention programs; however, disability activists argue that this ignores the 10 percent of the population who are already disabled and that prevention alone is an inadequate response.

DISABILITY IN THE DEVELOPMENT SECTOR

The "development sector" comprises various agencies working toward improving the situation in developing countries and includes multilateral agencies such as UN institutions, government-to-government funding, charities, trusts and foundations, nongovernment organizations, and private benefactors. Projects focus on issues such as infrastructure development, poverty alleviation, community development, education, health, women, children, human rights, agriculture, water, environment, governance, security, and many others. Efforts by the development sector to work with disabled people have largely been small scale.

Many argue that the development sector has ignored disability, allowing disabled people to miss out on the benefits of foreign assistance, and thereby further disadvantaging one of the most marginalized groups in the world. For example, in the wake of Hurricane Mitch in Nicaragua in 1998, not one foreign donor required that accessibility codes be applied to construction projects, and as a result entire towns, including schools, hospitals, and other public buildings, were rebuilt with barriers for disabled people. Water programs do not always ensure accessibility to the pumps; inappropriate choices of training venue or means of transport present barriers to disabled people participating in capacity-building programs; obstacles to accessing small loans exist, for example, applicants may be required to own land, which precludes many disabled people. The formulation of development agendas has seldom considered the needs of disabled people; representatives of the disability community have rarely been consulted in the design and evaluation of development programs; and many donors, aid agencies, and development organizations do not have, or practice, policies of disability equality.

There have been many reasons given by development agencies for not tackling disability: It is not raised as a priority by developing country governments or communities; it is too specialist, too costly; and it would be more cost-effective to fund prevention programs. Disability activists and analysts have argued strongly against these pretexts, contending that due to discrimination and ignorance, disabled people's needs are systematically ignored, which is why communities and recipient governments are unlikely to raise disability as a priority. Fatalistic assumptions often exist that nothing can be done about disability, and consultations with communities to elicit their priorities for development frequently fail to meet with disabled people. Specialist rehabilitation requirements do exist, such as aids, equipment, and particular rehabilitation exercises, but only for *some* disabled people. Evidence shows that the rehabilitation needs of at least 80 percent of disabled persons can be met by ordinary people and local communities who are given appropriate knowledge and skills. For many disabled people, access to basic human needs is all that is required.

Donor programs based on charity and medical models, in which small-scale specialist rehabilitation projects have been funded, have reinforced the belief that addressing disability is expensive and that the benefits reach only a small number. The move to more social and rights-based approaches to disability seeks to distribute the benefits more widely. Cost-benefit analyses have shown that long-term benefits of including disabled people in the economically productive sector far outweigh the initial costs of training, awareness-raising, and making services, environments, and transport accessible. The cost of disability prevention programs is indeed less than programs working with disabled people; however, disability cannot simply be eradicated through focusing on prevention—it will always exist and unless resources are applied to removing disabling barriers and supporting disabled people, human rights abuses will be perpetuated and the potential contribution of disabled people will remain underused.

Another reason why disability has been disregarded is the absence of, or limitations in, data enumerating disabled people. Compared to areas that can show strong evidence regarding estimates of people affected and potential beneficiaries of programs, for example, malaria, inconsistent definitions of disability, poor survey methods, and unreliable statistics have meant it is problematic to justify funding. There is a great need to improve consistency and reliability of disability data.

The World Programme of Action Concerning Disabled Persons was unanimously endorsed by UN member states in 1982, and its principles further sanctioned in 1994 with the UN General Assembly unanimously adopting the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which became the international legal standards for disability programs, laws, and policies. It states that opportunities equal to those of the whole population and an equal share in the improvement in living conditions resulting from social and economic development must be ensured for disabled people. During the 1990s, commitment to the rights of disabled people was demonstrated through UN policies and programs in areas such as social development, advancement of women, children, shelter, population and development, education, and environment. The development sector has acknowledged that by ignoring disability, not only are the rights of a huge number of people being systematically violated but the world's goals for economic and social development, known as the Millennium Development Goals, adopted at the UN General Assembly on September 8, 2000, can never be met without actively addressing disability in all programs and sectors.

Twin-Track Approach

A "twin-track approach" to disability in development is being suggested by various groups. It appreciates the need for disability-specific programs as well as consideration of disability in mainstream development projects. For example, if a man in a wheelchair undertakes vocational rehabilitation and successfully learns how to handle a welding machine but physical barriers prevent him accessing the workplace, then his disability-specific rehabilitation has been of little use. Or if a mother makes her daughter a special handle to help her hold her pencil and write but she is barred from attending the local school because of discriminatory policies, then her efforts have been of little use. Conversely, if a government ensures that teachers are trained in inclusive education, ramps are put in schools, and buses enable disabled children to board safely but a young child is lying at home rigid with contractures and unable to move, all the efforts at modifying the school environment have been of no benefit to him. Or if public documents are produced in Braille to enable the visually impaired access to information but no one knows how to read Braille, then those mainstreaming efforts are of little use to them. A combination of disability-specific programs and mainstreaming efforts are required.

To enable full realization of the rights of disabled people, consideration of disability must be actively undertaken by agencies across multiple sectors, not merely by health and social welfare departments or disability-focused nongovernment organizations. Disability must be mainstreamed into sectors including housing and infrastructure development, public transport, finance, telecommunication, information, legislation, urban planning, education, employment, tourism, rural development, poverty alleviation, statistics, agriculture, refugees and displaced persons, defense, and law enforcement.

Some of the many strategies for mainstreaming disability into development include involving DPOs in the design and evaluation of mainstream projects and on steering committees; ensuring that enumeration of people targeted to benefit from projects are disaggregated to include estimates of disabled; systematically screening project designs to identify and circumvent potential barriers; appointing disabled people as staff; appointing someone within each agency or department to be responsible for considering disability across the program of work; allocating a small proportion of each budget to mainstreaming disability; incorporating monitoring and evaluation tools within all projects to assess the extent to which project-related benefits are reaching disabled people in the target community; and supporting the creation of self-help groups of disabled people in target populations—for example, in a slum development project, a self-help group would work to ensure that the voices of disabled slum-dwellers are heard.

Agencies Working in Disability in the Developing World

There are numerous agencies engaged in addressing disability in the developing world. Each brings its own priorities, skills, and approaches. UN bodies most directly involved are the UN Global Programme on Disability, the WHO, the UN Educational, Scientific and Cultural Organization (UNESCO), the International Labour Organization (ILO), the UN Economic and Social Commission for Asia and the Pacific (UNESCAP), the UN Children Fund (UNICEF), and the World Bank. The United Nations Special Rapporteur on Disability is responsible for monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, and reports to the Commission for Social Development.

The UN Global Programme on Disability, housed in the Division for Social Policy and Development at the Department of Economic and Social Affairs, is the lead program on disability within the United Nations. Its mandate stems from the World Programme of Action Concerning Disabled Persons and the Standard Rules on Equalization of Opportunities for Persons with Disabilities and it also serves as substantive secretariat for the General Assembly Ad Hoc Committee on a Comprehensive and Integral International Convention to Promote and Protect the Rights and

Dignity of Persons with Disabilities. The WHO, through its Disability and Rehabilitation unit, focuses on supporting member states in framing policies, developing appropriate services, strengthening community participation, and supporting integration of rehabilitation into primary health care through CBR. UNESCO has led the "Education for All" initiative and has worked strongly toward IE. It focuses on developing IE national policies, developing human resources in support of IE, and developing materials and disseminating information in support of IE.

The ILO promotes equal opportunities for women and men, including those with disabilities, to obtain decent work, which it defines as productive work in conditions of freedom, equity, security, and human dignity. It works to overcome the obstacles preventing people with disabilities from full participation in the labor markets; improve knowledge on disability-related matters concerning training and employment; provide advocacy, guidance, and policy advice to governments, workers, and employers' organizations; and improve occupational health and safety and workplace conditions. UNESCAP hosted the Asian and Pacific Decade of Disabled Persons (1993–2002) and is now under way with activities for the next decade (2003–2012). Activities thus far have focused on web-based networking for people with disabilities, awareness-raising of public administration personnel, and training in the promotion of nonhandicapping environments.

UNICEF has focused on early detection and intervention, mainstream education, and CBR; land mine awareness and education to prevent injuries; and child-based prevention and intervention, advocacy and public education, partnership and capacity building, and data collection. The World Bank's disability goals are access, inclusion, and poverty reduction of persons with disabilities. It uses an economic approach to examine the impact of disability on poverty and is committed to disseminating knowledge resources on good practice in development assistance for disabled persons.

There are many nongovernmental organizations (NGOs) actively working in disability. Some of these include Action on Disability and Development, ActionAid, Associazione Italiana Amici di Raoul Follereau (AIFO), Christian Blind Mission International, Disabled Peoples' International, European Disability Forum, Handicap International, Inclusion International, International Disability and Development Consortium, International Disability Foundation, International Save the Children Alliance, Landmine Survivors Network, the Leprosy Mission, Pan-African Federation of Disabled People, Rehabilitation International, South African Federation of Disabled, World Blind Union, World Federation of the Deaf, and World Network of Users and Survivors of Psychiatry. Many of these have websites with information and resources.

WHAT THE FUTURE HOLDS

It has been estimated that numbers of disabled persons in the developing world will increase by over 120 percent in the next 30 years, while numbers in OECD countries will increase by 40 percent. The critical need to address disability within the developing world has been powerfully asserted by many groups, demonstrated vividly through the lobbying that occurred to bring about discussions on the Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities.

The outlook for disabled people in the developing world is mixed. There have been many gains made in terms of legislative and policy improvement, programmatic understanding about what works and what does not, changing attitudes regarding rights and discrimination, the formation of strong networks of DPOs, multiple global statements indicating the priority that disability must hold in development agendas, and strategies for ensuring that the benefits of development are experienced by disabled people.

However, there are macro forces in the world affecting the situation for disabled people that are not easily controlled. Poverty levels in many countries are increasing, and economic gains that are made have tended to benefit the rich and not the poor. Trade rules enforced by the World Trade Organization continue to advantage richer countries and have increased pressure on developing countries, forcing prices down and reducing any profits that small growers or manufacturers may have made. This mounting financial pressure at individual, family, community, and government levels diminishes energy and funds that might have been used to improve the situation of disabled people.

HIV/AIDS continues to threaten economic security in an increasing number of developing countries and is costing the world many billions of dollars in prevention and treatment programs as well as losses to economies through sickness and death of large segments of the labor force. This diverts funding that may otherwise have been available to implement action plans for disability. The amount of money spent on armaments around the world completely eclipses that spent on health, and as armed conflicts and the focus on terrorism continue, this amount is increasing rather than decreasing.

Despite these substantial forces, the disability-in-development movement is visibly strengthening and making unequivocal progress toward equity and achievement of human rights for disabled people. Governments and development agencies are being urged and trained to mainstream disability into a wide variety of programs and to work toward universal accessibility; collection of data on disability is being steadily gathered to enable greater advocacy and evidence-based program planning; the push toward inclusive schools is moving forward; several donors are beginning to require consideration of disability and accessibility in grant applications; and increasing numbers of disabled people are accessing means of financial security through micro-credit and income generation programs. Perhaps most important, a rising awareness of rights generally among disabled people has enabled a change in the way they see themselves and their place within families, communities, workplaces, schools, religious institutions, councils, governments, and manifold other settings.

—Beth Fuller

See also Community-Based Rehabilitation; Economic and Social Development, International; Inclusive Education; Poverty; United Nations; United Nations Standard Rules; United Nations Declaration on the Rights of Disabled Persons.

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DEVELOPMENTAL DISABILITIES

Developmental disabilities (DD) is an umbrella term for multiple conditions emerging from anomalies in development. The essential feature of DD is onset prior to adulthood and the need for significant, life-long supports. Conditions commonly encompassed under the DD term are intellectual disability, autism, cerebral palsy, epilepsy, and hearing and visual impairments, among others.

BACKGROUND ON TERMINOLOGY

The DD concept and terminology were first formalized in the United States in the 1960s and were not widely used internationally until the 1970s. In its original incarnation in the United States, DD was used in place of "mental retardation" (MR) in the 1969 reauthorization of the Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L. 91–517). In response to advocates urging Congress to be more inclusive of other disability groups with similar service and support needs, the DD term was substituted for MR in the amended legislation, defined as a disability originating prior to age 18, attributable to MR, cerebral palsy, epilepsy, or "other neurological conditions." The federal definition has undergone a number of revisions since the original act. Autism was added to the roster of DD conditions in the 1975 amendment (P.L. 94–103), and a significant conceptual change was the adoption of a noncategorical approach in 1978. Rather than using diagnoses of, for example, MR or cerebral palsy, DD was defined in terms of limitations in major life activity areas. The criteria of severity, chronicity, and origination prior to adulthood remained in the definition. Thus, one could have cerebral palsy or MR but not be considered DD if substantial support was unnecessary.

SIGNIFICANCE OF THE DD DEFINITION

In practice, the U.S. federal DD definition serves more as a conceptual statement than as a diagnostic standard. In its various incarnations across the United States, the term is used interchangeably with, and across, diagnostic disability categories but most commonly as an alternative term for MR. State governments within the United States employ their own eligibility standards, using the framework of the federal guidelines but anchored primarily on the older diagnostic groupings of the original DD definition. International use of the DD concept is less formalized and equally variable in application. The term is used interchangeably to represent congenital disorders, conditions arising from trauma or other damage to the brain or nervous system, and other chronic disabling conditions emerging during infancy or childhood. Nonetheless, the development of the DD definition marked an important turning point in that it formalized growing consensus about the significance of reforming what were at the time largely custodial policies and services.

UNDERLYING CAUSES AND PREVALENCE

The underlying causes of DD represent the broad array of developmental risks that can impair neurological function—hereditary disorders, perinatal and neonatal complications, malnutrition, disease, and trauma. For the majority of persons labeled as having DD, the underlying causes are of unknown origin. Since risk is not randomly distributed, the causes of DD and the rate of occurrence are highly variable, across both populations and regions of the world. Though definitions vary widely, some approximations of population size can be made. Using the core concepts of severity, life-long support needs, and emergence during the developmental period of life (vs. acquired later in life), estimated rates converge in the range of 1 to 2 percent in the developed world.

Of the limited epidemiological data available from the less developed nations of the world, reported rates are consistently higher though they tend to vary widely, ranging from 5 to 25 per thousand in the general population. Such variations are not unexpected given the differences in sampling and screening methods used across studies as well as the dissimilar circumstances of risk in different countries. Nonetheless, important causes of DD such as trauma, infectious diseases, and malnutrition are more pronounced in the developing world and it is not unreasonable to assume that greater risk translates into higher prevalence.

DD IN CONTEXT: SERVICES, RESEARCH, AND POLICY

The study of DD during the past 50 years spans the breadth of human endeavors, from molecular genetics to civil rights. A useful organizing template is the

International Classification of Functioning, Disability, and Health (ICF), which describes the disablement process across multiple dimensions: (1) body function and structure, (2) activities and participation, and (3) environmental and social factors.

Body Function and Structure

Given the prominence of genetic and neurodevelopmental events in the etiology of DD, emphasis is traditionally given to biomedical concerns, with a primary focus on prevention. Basic biomedical research focuses on the identification of specific risk in the neurodevelopmental process and development of interventions to prevent or reduce their impact. A classic example is the genetic condition phenylketonuria (PKU), in which excess phenylalanine results in neurological damage. Knowledge of biochemical dynamics led to preventive interventions in the form of protein-restricted diets. Public health approaches target understanding of the causes and distribution of DD on a population-wide basis in an effort to develop large-scale prevention programs. Examples include lead abatement in the older urban areas of the United States and folic acid supplementation in third world countries to decrease the incidence of neural tube defects among newborns.

Activities and Participation

Activities in the ICF refer to the performance of specific tasks, while participation reflects more global involvement in life situations. These notions are consistent with the U.S. federal definition, which defines DD across domains of activities (limited ability in self-care, receptive language, expressive language, learning, mobility, and self-direction) as well as the participation-like dimensions of independent living and economic self-sufficiency. The evolution of the DD definition away from specific diagnoses served to shift attention toward methods for enhancing participation in the larger society, rather than emphasizing the "repair" of individual deficits. The years since the early 1970s witnessed a dramatic expansion of publicly and privately supported services in education, employment training, family support, health care, income supports, residential care, and other related support services. Across the developing nations of the world, lack of fiscal resources limits development of publicly supported services and a professionalized workforce. Nongovernmental organizations (NGOs) funded through a variety of international organizations and agreements form the bulk of what would be considered a formal DD service system. What limited services are available are in the form of specialized and segregated schools, institutional services, and in recent years, a movement toward locally developed and controlled community-based supports. Generally, little is know about the structure services or the degree of need among persons with DD in the developing world. In both the developed and developing nations, the vast majority of persons with DD live with their families.

Social Factors

Early in the legislative development of the DD concept, the focus of DD policy was shaped by the idea that the environment in large measure determined the extent of disability, thus the emphasis on "rights" in the authorizing legislation (P.L. 94–103). Indeed, the U.S. federal effort developed in parallel with the emerging human rights-based themes of disability advocacy through the United Nations in the 1970s, and both developments were indirectly influenced by the emerging Scandinavian concepts of integration and normalization.

Policy was and remains anchored on the ideal of inclusion: abandonment of segregated institutional care in favor of community-based housing, education in the local school, and notably, emphasis on civil and human rights through legal and other legislative means. While implementation lags far behind the ideal, the efforts dramatically transformed the options available to persons with DD. Within resource-poor nations, service models are anchored on similar themes of social integration, opportunity, and the reduction of stigma. The rise of community-based rehabilitation (CBR) models in the less developed economies of the world in the 1980s, in which local resources and family networks are employed in providing supports, represents acknowledgment of the person with DD as a member of the community fabric.

SUMMARY

Ironically, the two forces that have most changed the face of DD—the ethos of human rights and the rapid advance in our understanding of the basic sciences of human development—may create difficult and as yet not fully understood ethical challenges. The emergence of human and civil rights as a relevant agenda item for persons with severe disabilities in the post-World War II era dramatically altered the character of the DD dialogue. Humane care was replaced by human rights as a guiding force for shaping services and policy. Yet the logical extension of the great advances in the biological sciences is the elimination of impairments and prevention of perceived "defects." The fit of persons with significant DD in our societies is an issue yet to be resolved throughout the world, and it is very much anchored to the larger discussion of how humanity is defined. The juxtaposition of these two trends represents one of the great new challenges in the evolving conceptualization of DD.

—Glenn T. Fujiura

See also Autism; Cerebral Palsy; Epilepsy; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Mental Retardation, History of.

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DIABETES

Diabetes mellitus is both remarkably ancient and thoroughly modern. A disease known for several millennia, the pathophysiology of diabetes has been radically altered over the past century by medical therapeutics, transmuted from an acutely lethal disease into a more stable but still-too-often debilitating condition. Concomitantly, the experience of having the condition has transformed from laboring under a "death sentence" to intensively managing this ever-changing chronic illness.

Earliest descriptions of the ailment's symptoms date to an Egyptian text written in the sixteenth century BC. In the second century AD, the physician Aretaeus of Cappodocia offered a compelling, vivid portrait, declaring that "diabetes is a mysterious illness . . . [where] the flesh and limbs melt into urine." Derived from the Greek word for siphon, diabetes made "life disgusting and painful; [and] thirst unquenchable," according to Aretaeus, "and one cannot stop [patients] either from drinking or making water," as though like a siphon all liquid entering the mouth ran through the body, exiting the bladder. In 1674, Thomas Willis noted how "the diabetes or pissing evil" rendered the patients' urine "wonderfully sweet as if it were imbued with Honey or Sugar." By 1776, Matthew Dobson had demonstrated the presence of "saccharine matter" in diabetic urine, theorizing that excessive sugar had built up in the bloodstream. A slew of dietary treatments ensued, from "animal diets" consisting of "plain blood pudding" and "fat and rancid old meats" at the end of the eighteenth century to the early-twentieth-century "starvation diets" that drastically restricted the amount of calories ingested.

Then in 1921—after a generation of previous researchers had failed—a team of investigators in Toronto isolated the hormone insulin, which proved to be a wonderful treatment but not a cure for diabetes mellitus. Frederick Banting, Charles Best, J. B. Collip, and J. R. R. Macleod managed (despite much squabbling and subsequent bitterness) to produce and test the wondrous pancreatic extract on people with diabetes by 1922, an achievement soon thereafter awarded the Nobel Prize. Since then, new formulations of insulin have been developed, some acting slower but longer, others more immediately but for shorter periods of time. All forms of insulin thus far have needed to be injected in order to work.

We now understand diabetes mellitus to exist in two major forms. Type 1 (previously referred to as juvenile-onset or insulin-dependent) diabetes arises from an autoimmune process that destroys pancreatic beta-cells, which are the producers of insulin, thus leaving the patients deficient of this vital hormone. Without adequate insulin, not only does the level of blood glucose rise but so too the levels of fats and acids produced by the faulty metabolism of fat. Type 2 (previously referred to as adult-onset or non-insulin-dependent) diabetes is due principally not to a deficiency of insulin (although this can happen as the disease progresses) but rather the impaired ability of the body tissues to respond to insulin appropriately. Resistant to the influence of insulin, the body permits the blood glucose level to rise along with fats (but not the acids that plague type 1 diabetes). The terms *type 1* and *type 2* are preferable to the older terminology because (among other reasons) sometimes type 1 arises in adults, the incidence of type 2 diabetes is increasing among children, and type 2 often requires the use of insulin. Type 2 diabetes is many-fold more prevalent than type 1.

The impairment of the diabetic metabolism poses both short- and long-term threats to health and function. The acids pose the most immediate threat to life, since as they accumulate the patient can slip into coma and die. High blood glucose also causes the kidneys to excrete excessive amount of urine, which can lead to life-threatening dehydration. If the disease is kept sufficiently in check so as to avoid these immediate problems, and time passes, the health hazards stem mostly from the damage that elevated blood glucose levels (as well as fats) wreak on the blood vessels throughout the body, especially the retina of the eyes, the kidneys, the legs and feet, and the heart. Nerve damage also occurs. These impairments of the blood vessels and nerves, in turn, account for the high risk that diabetes imposes for blindness, renal failure, gangrene and the need for amputations, heart attacks or heart failure, and ultimately death. Indeed, despite the truly miraculous power of insulin, diabetes remains one of the leading causes of disability and death in the United States.

Diabetes in the setting of pregnancy poses a particular set of problems for both the mother and the fetus. If the maternal blood glucose levels are elevated during the first part of gestation, the embryo may develop abnormally; if high blood glucose occurs later in pregnancy, the fetus may die in utero or grow so large that birth is dangerously difficult, and the baby subsequently can have grave difficulty adjusting to life outside the womb. These problems now are mostly prevented through more rigorous management of diabetes during pregnancy, and medical attention is increasingly focused on developing means to ensure that the mother's longer-term health is not compromised by the pregnancy.

Providing a telling example of physician-induced irony, the treatment of diabetes, with either insulin or (for type 2) oral drugs that increase the body's response to insulin, also poses the health hazard of low blood glucose or hypoglycemia, which, in turn, can cause giddiness, slurred speech, seizures, brain injury, or even death. For many people with diabetes, anxious concerns about how they will behave if they were to become hypoglycemic on the job or in public greatly curtails their performance in these realms.

The work involved in the self-care of diabetes can be substantial. A diet and regular mealtimes need to be followed. Regular testing—as often as several times a day—with a home blood glucose monitor is a mainstay of current regimens. With good evidence to show that "tight control" of diabetes (i.e., keeping the blood glucose level constantly in the normal range) markedly reduces the risk of secondary impairments, the ways in which insulin are used are become more sophisticated but also more complicated, with potentially several injections of insulin throughout the day or even having a tiny pump inject insulin continuously under the skin. Other technologies, such as laser treatment of the retinal disease of diabetes or renal dialysis for kidney failure, have improved the quality of life and extended life expectancy of people with diabetes, while treatments under development, such as pancreatic beta-cell transplantation, may cause even more dramatic change in the biology of the disease and the experience of the illness.

Diabetes long has had stigma attached to the condition. Famous people who had diabetes often kept this fact a secret, until the example of open disclosure was set by individuals such as the tennis player Bill Talbert and more recently the actress Mary Tyler Moore. Although public awareness and acceptance of diabetes have increased dramatically over the past century, children and adults with diabetes can still confront barriers to participation in activities such as sports, and discrimination regarding employment or insurance.

Much work remains to be done to diminish the impairments, disability, and handicaps associated with diabetes. Given the rising epidemic of obesity in the United States and the United Kingdom, and the parallel rise in type 2 diabetes, especially notable in children, the disease that is treated with one of the most phenomenal medical discoveries of the past century still awaits a lasting solution.

—Chris Feudtner

See also Health Promotion; Obesity.

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DIABOLIC POSSESSION

Belief in diabolic possession, the occupation and control of a human being by a demon, and in exorcism, its religiously effected cure, was an important part of the Christian cultural tradition for much of Western history. The vulnerability of individuals to demonic assaults of this kind was seen as representative of the general threat Satan posed to humanity; conversely, the Church's power to cast out devils symbolized (and anticipated) the final defeat of Satan by Christ.

The characteristic features of diabolic possession developed from those described in the New Testament came to include violent convulsions and contortions, paralysis, local anesthesias, the vomiting of foreign objects, hostile reactions to religious symbols, grotesquely distorted voices, memory loss, and even articulate demonic alter egos. Hard data on incidence rates are hard to come by for most of the early Christian era. What is known is that late sixteenth- and seventeenth-century observers were struck by the great increase in demonic activity in their own times. Possession cases across the Christian world in this period—a time of religious unrest and heightened eschatological anxiety—certainly numbered in the thousands. Many involved children or adolescents (both sexes), and were blamed on witchcraft. The "symptomology" of diabolic possession was relatively uniform; it was also, significantly, relatively well-known.

Modern notions of disability capture past attitudes toward possession only very imperfectly. Diabolic possession was terrifying in large measure because of the positive abilities it might confer on the sufferer, ranging from superhuman strength to prophetic knowledge. A possessed individual's intimacy with the spirit world, while fraught with physical and moral peril, was epistemically enabling; demonic pronouncements concerning the coming of the Antichrist and the (typically imminent) end of the world were often taken extremely seriously.

Unlike the more conventionally disabled, the diabolically possessed were never a marginalized group. On the contrary, they tended rapidly to become centers of religious and lay attention. Tales of possession and exorcism figure frequently in the religious propaganda pamphlets of the early modern period. The New Testament records possessing devils testifying to the divinity of Christ, and later writers were not beyond citing demonic authority to settle matters of true religion.

Diabolic possession is now a largely extinct phenomenon (though anthropologists continue to study spirit possession, a much broader category of behavior, in many non-Western cultures), and its proper interpretation is a matter of some controversy. In fact, it was controversial even at its height: Priests, doctors, and lay propagandists devoted much effort to the difficult task of distinguishing "genuine" demoniacs from the merely mad or the frankly fraudulent. The possibility of non-demonic forms of possession (e.g., by the Holy Spirit) further complicated matters; complete uniformity of opinion, then as now, was the exception rather than the rule. Some historians have sought to explain all recorded instances of possession—bar cases of conscious fraud—as misdiagnosed cases of epilepsy, schizophrenia, or hysteria. More recent scholarship has stressed the central importance of contemporary religious beliefs in molding symptoms as well as diagnoses; on this view, attempts to identify possession with the categories of modern pathology are unlikely to be successful.

—Nick Tosh

See also Folk Belief; Religion.

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DICKENS, CHARLES (1812–1870)

English author

Charles Dickens began writing fiction at age 21, and by 24 he was internationally known and appreciated. He was one of few nineteenth-century writers to remain financially viable and publicly popular during his life. When Dickens was 10, the family moved to London, where his father worked as a clerk in the navy pay office. Dickens's father had a difficult time managing money. His extravagant spending habits brought the family to financial disaster, and in 1824, John Dickens was imprisoned for debt.

As a result of his father's imprisonment, Charles, the oldest of the Dickens children, was withdrawn from school and sent to work in a shoe dye factory. It is likely that much of Dickens's sympathy with the working class, poverty, and child labor abuses is tied into this history.

There are many themes in both Dickens's life and fiction relevant to disabilities. He suffered from recurrent depression that was particularly severe toward the end of his life. He also had periods of intense, frenetic activity during which times he varied from being irritable to productive and at these times was seen walking down London streets acting out characters and dialogue in novels on which he was working.

Between 1837 and 1839, Dickens wrote three of his most famous novels, *Pickwick Papers, Oliver Twist,* and *Nicholas Nickleby.* Dickens himself acknowledged that he was mercurial in temperament and notes the accuracy of his son's recollection that he had moods of deep depression and irritability in addition to his energetic bursts of vitality. In the 1840s, he started to experience writer's block. He would spend days locked up in a room, unable to put words on paper. He wrote: "Men have been chained to hideous walls and other strange anchors but few have known such suffering and bitterness . . . as those who have been bound to Pens."

Dickens in response to material written about him in his lifetime says, "You might, I suppose, want to read this as a description of your 'manic-depression.'" It is very likely that Dickens did have bipolar disorder. But despite and sometimes because of this condition, he remained highly productive and creative most of his life, though he experienced more and more depression toward the end of his life.

Portraits of downtrodden and seriously depressed people recur through Dickens's fiction, as do many individuals with disfigurement, impairments, and disabilities. The character Tiny Tim, who hopes that "people saw him in . . . church, because he was a cripple, and it might be pleasant to them to remember upon Christmas Day who made lame beggars walk and blind men see," is arguably the most memorable literary image of physical disability in the minds of many twentieth-century people. It should be noted, however, that Tiny Tim is also a disabled character whom many literary critics and disability activists find objectionable as he quickly became emblematic of a crippled child who is supposed to accept his suffering, and appreciate charity from healthier, wealthier, nondisabled people.

—Joseph A. Flaherty

See also Novel, The.

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DIDEROT, DENIS (1713–1784)

French author

From the volume and diversity of Denis Diderot's writings—difficult even to suggest if account is taken of his editorial work on the *Encyclopédie* (1749)—his "Letter on the Blind for the Benefit of the Sighted" ("Lettre sur les aveugles à l'usage de ceux qui voient," 1749) and "Letter on the Deaf and Mute" ("Lettre sur les sourds et les muets," 1751) may be singled out as relevant to disability studies.

Beyond its numerous philosophical implications, which drew six months of imprisonment for Diderot, the first letter contains three important and novel ideas about disability: (1) The blind enjoy the integrity of human faculties (this in opposition to the prejudice that the loss of a sense cuts off the ability to reason); (2) as a consequence, their education is possible and desirable (this is the thrust of additions made to the letter in 1771 after the extraordinary success of Mélanie de Salignac); and (3) what the blind actually can accomplish must be shown (this explains the presence in the letter of Saunderson, the English mathematician, and of "the blind man from Puiseaux").

The "Letter on the Blind" had considerable influence, without which the establishment of education for the blind by Valentin Haüy would doubtless not have occurred. The "Letter on the Deaf and Mute" is more of a philosophical discussion of language, but nonetheless helped to call attention to sensory disabilities during the century of "sensualist" philosophy and to animate the education of the disabled by the invention of adaptive techniques.

—Henri-Jacques Stiker

See also Blind, History of the; Valentin Haüy.

DIDYMUS THE BLIND

(ca. AD 313–ca. AD 398)

Alexandrian theologian and scholar

According to Palladius, Didymus the Blind (not to be confused with an earlier scholar of the same name [63 BC–AD 10]) lost his sight from "ophthalmia" when he was about four years old. However, thanks to his superhuman diligence, he obtained the highest scientific education possible at the time and became a famous scholar and a most prolific writer. The fifth-century writer Sozomen says that, while attending schools and learning through listening, he first learned letters of the alphabet through touch by means of shapes engraved in depth on wooden planks, and he went on to learn syllables and names through listening and memory. This information is repeated by the fourteenth-century Byzantine scholar Nicephorus Callistus.

Didymus had a profound command of the philosophical, theological, and scientific theories of his time and was chiefly indebted to Platonic, Aristotelian, Stoic, and Neoplatonic thought. In addition, his learning embraced poetry, rhetoric, astronomy, grammar, music, mathematics, and medicine, in the last of which he was influenced chiefly by Hippocrates and Galen.

He was a pupil of Origen, and the condemnation of the latter by the second Council of Constantinople in 553 for favoring preexistence and apokatastasis of the human soul discouraged the preservation of Didymus' prolific writings. Manuscripts containing some of his writings were discovered at Tura in Egypt in 1941, but their authenticity has been debated. Didymus wrote both dogmatic and interpretative works, the latter consisting mainly of commentaries on the Old and New Testaments. He also defended the doctrine of the Holy Trinity against Arianism.

In spite of his considerable theological learning and asceticism, Didymus remained a layman. In recognition of his achievements, Bishop Athanasius appointed him director of the theological school of Alexandria, a post he held until his death more than 50 years later. His students included such famous Christian authors as Jerome, Rufinus of Aquileia, and Palladius Bishop of Helenopolis.

—D. P. M. Weerakkody

See also Blind, History of the.

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DIGESTIVE DISEASE

See Gastrointestinal Disabilities

DISABILITY AND CAREER DEVELOPMENT

People with disabilities are underrepresented in the workplace. This entry examines the issue of people with disabilities in the workplace through the lens of career development and makes recommendations. To that end, the following topics are addressed: (1) work and disability, (2) disability and career development, and (3) recommendations to facilitate positive career development.

WORK AND DISABILITY

Work is a central aspect of life. On the one hand, it provides marketable goods and services. On the other hand, it provides meaning and structure to life, economic support, identity, and social stature.

Unfortunately, people with disabilities are seriously unemployed and underemployed. National statistics and recent research suggest that the situation is getting worse despite the Americans with Disabilities Act of 1990.

An additional complicating factor is the changing nature of the workplace. There are now fewer manufacturing and more service jobs along with more temporary and contract work. In addition, due to the rapid pace of change and increased competitiveness resulting from the global economy, employers are looking for workers who are flexible and adaptable.

The recent changes in the workplace may present challenges for some individuals with disabilities. Specifically, the increase in temporary and contract positions, often without benefits, disadvantages people whose conditions require costly medical treatment. This is not just an immediate disadvantage but also a long-term one in that temporary positions often help build résumés and qualifications for more stable positions. In addition, the increased complexity and interdependence of some jobs along with the need for many workers to be flexible and adaptable may pose challenges for some individuals with cognitive or emotional limitations. Furthermore, the increased job stress in some organizations may cause or exacerbate some disabilities.

CAREER DEVELOPMENT

The concept of career generally refers to individuals' work experiences over a lifetime. This life pattern is influenced by a full range of factors. Numerous theories have evolved to explain how people navigate the world of work.

Over the years, there has been considerable discussion about the applicability of theories of career development to people with disabilities. However, my colleagues and I believe the wide variation among people with disabilities means that theories cannot be either fully applicable or fully nonapplicable. Nonetheless, disability, like minority status, is certainly a risk factor for career development.

To address the interaction of disability and career development, my colleagues and I developed an ecological model of vocational behavior that includes the basic concepts and processes from the major theories and serves as an organizing framework for discussing the impact of disability on career development. The model is made up of factors and processes that interact dynamically with each other over time to shape careers. The factors are individual, contextual, mediating, environmental, and outcome constructs; and the processes are congruence, decision making, developmental, socialization, allocation, chance processes, and labor market forces. The elements of the model are used to frame the discussion of disability and career development.

Clearly, individual differences can have an impact on career development. However, it is important to note that people with disabilities are a very diverse group. For example, career development challenges are very different for individuals with congenital disabilities than for those who acquire disabilities after an established career. Similarly, the challenges for someone with a visual impairment differ from those for someone with an orthopedic impairment. The basic issue here is the extent to which individual abilities or limitations interact with workplace requirements and the extent to which discrepancies can be accommodated through individual adaptation or job accommodation.

The context in which people live clearly influences career development. Some minorities, people living in poverty, and some people with disabilities may have limited opportunities for work or experiences leading to positive career development. Other contextual influences include the economy, types of industry, and disability-related policies and legislation. Each of these influences can hinder or promote career opportunities for people with disabilities.

Environmental factors present significant issues for the career development of people with disabilities. For example, physically inaccessible environments not only limit job possibilities for some individuals but also limit work-related learning experiences for some young people with disabilities. Accommodations can address some environmental barriers.

Mediating factors are beliefs (individual, societal, or cultural) that affect or mediate the interaction of individuals and their environments. Individual examples include self-concept, self-efficacy (i.e., individual beliefs about specific task-related abilities), and outcome expectations. Each of these can be affected by experiences, which may be limited or adversely affected by disability. Culture, worldviews, and acculturation can have an impact on how disability is perceived and how people with disabilities are treated. Similarly societal beliefs can form the basis of discrimination or stereotypes that can limit career opportunities for people with disabilities.

The interaction of all the career development constructs and processes can produce outcomes that include job satisfaction, job stability, and job stress. Interestingly, job stress is a particular concern for some individuals with disabilities. Individuals in service sector jobs that are monotonous and give them little control over their work are particularly susceptible to job stress. Unfortunately, many people with disabilities are employed in these secondary labor market positions.

As noted earlier, the congruence of individuals with their environments is an important consideration in career development. Good matches between individual abilities and job requirements contribute to positive outcomes for people with disabilities and their employers. It is important to remember that congruence can be enhanced by job modifications and accommodations.

Decision-making processes can be adversely affected by disability. This is because some people with disabilities may have limited learning experiences that may lead to a relatively flat profile of interests. Other individuals may unnecessarily rule out occupations because of limited knowledge of their own abilities or of the potential for accommodation. In addition, some individuals with cognitive disabilities may need assistance in learning how to make career decisions.

When considering developmental processes, it is important to recall that interests are not innate traits; rather, they are learned. To that end, it is critical that children and young adults with disabilities have a wide array of opportunities to learn about different types of work. It is also important to provide experiences that enable productive socialization into the role of worker rather than a “disabled” role. To that end, chores may be very important for children with disabilities.

Allocation processes are a particular problem in the career development of people with disabilities. Low expectations by teachers and counselors may limit educational and career preparation opportunities. Similarly, labor market forces, including a sluggish economy and the increased competitiveness of the global economy may limit employment opportunities for people with disabilities.

Finally, it should be noted that chance occurrences often have an impact on career development. If a disability or limited experiences compromises individual ability to cope with or profit from chance happenings, the individual may be disadvantaged.

RECOMMENDATIONS

The first and most important recommendation for professionals working with people with disabilities is to remember that people with disabilities are, first, people. The disability is not just an individual characteristic. Rather it is a complex phenomenon that affects the interaction of individuals and their environments.

A common error is to look only at the individual in planning career development. Environmental modifications such as architectural accessibility, ergonomics, and job accommodation must also be considered.

The second critical recommendation is to remember that interests are learned. People with disabilities and service providers often unnecessarily exclude career possibilities because they are not "interesting" at the time. This exclusion may result from limited experiences or from failure to consider job accommodation possibilities. For people with congenital disabilities, it is important to promote exposure to a wide range of job possibilities and to guard against premature narrowing of goals. Individuals with acquired disabilities will need assistance in reconsidering possibilities that they may have ruled out either due to perceived barriers that can be overcome or due to limited experiences.

Third, workers must maintain and expand their skills. Career development is a lifetime proposition. People tend to change jobs many times throughout their working lives. In addition, in the current economy, long-term stable employment with one employer is no longer very common. It is important for all workers, including people with disabilities, to continue to develop skills and experiences to ensure marketability. Similarly, for people with progressive or unstable conditions, it is important to seek positions in which there is flexibility. There is some evidence that higher-level positions offer individuals more control over their work and are thus more adaptable in the face of changing health status.

Fourth, career interventions must be empowering in the long run. They need to promote individual self-determination as well as long-term positive career growth. Specifically, interventions should facilitate independence, or, if appropriate, interdependence, promote maximum consumer control, and be the most natural and least restrictive for the given environment. In other words, it is not appropriate to provide services or supports that create dependence, are under the control of someone else, or call negative attention to the individual.

Fifth, career interventions must address upward mobility. Many people with disabilities start in the secondary labor market, in jobs that are temporary or may lack good benefits or working conditions. Although these jobs may provide necessary experience, it is very important for service providers to help people to move on from these jobs to better and more stable positions.

Finally, career development is a lifelong process in which we express and support ourselves through work. People with disabilities have unacceptable levels of unemployment and underemployment. It is important for professionals to be creative in helping both individuals and employers examine the many ways in which society can be enriched by tapping the talents of people with disabilities.

—Edna Mora Szymanski

See also Employment; Job Analysis and Placement.

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DISABILITY ARTS

The term *disability arts* emerged in the United States in the 1970s and generally refers to the artwork by people with disabilities that reflects a disability experience, either in content or form. Some restrict the term to artwork that is also intended primarily for audiences with disabilities. Most often, though, disabled artists create work that is intended for audiences that include both disabled and nondisabled people. Occasionally, the term is used to refer to any artwork created by a disabled person, whether referencing disability or not, but this usage is uncommon among members of the disability community.

A primary function of disability art has been to articulate for the disability community as well as for the mainstream what disability means—politically, personally, and aesthetically. As such, disability art is considered an integral aspect of both the disability civil rights movement and what is known as *disability culture*, a term that describes a subcultural community of diverse disabled people (in terms of impairment type, race, class, gender, and sexuality) who nevertheless share certain experiences, values, and perspectives. Disability art across media shares themes that have helped to shape disability culture: an engagement with political issues relevant to people with disabilities, a challenge to stereotypes, a focus on the lived experience of disability, and the development of alternative aesthetics based on the particularities of the bodies and minds of people with disabilities.

Gallery openings, theatrical performances, and film festivals that feature disability art draw large numbers of attendees with disabilities. These venues necessarily provide access (such as wheelchair ramps and accessible bathrooms) and accommodations (such as audio description and American Sign Language interpreters) unavailable in the larger community. If access and accommodation are not part of the event, then the featured artwork cannot be properly described as "disability arts," even if the work features disability themes or disabled artists.

Frequently, disability art has an explicit or implicit political edge, as its themes and aesthetics run counter to prevailing notions of disability. Disability arts can explicitly expose the marginalization and societal mistreatment of disabled people. Because of this tendency, disability art often finds audiences at events such as activist gatherings and conferences, and it is therefore considered integral to the disability civil rights movement. Disability art also forms the base of support for the emergence of disability culture. Disability art events provide an occasion for disabled people to gather and define themselves as a subcultural community.

Often disability art explicitly rejects, critiques, or complicates traditional representations of people with disabilities. These representations include stereotyping of disabled people as objects of pity, medical intervention, inspiration, fear, curiosity, or wonder. Artists use a number of techniques to engage with these stereotypes. They inhabit them through parody, thus disarming the stereotypes' power to shame through the use of humor. They call explicit attention to stereotypes and then compare them to the lived experience of disability. Or they simply offer alternative visions of their bodies and lives that run counter to stereotypical representations without explicit commentary.

Artists with disabilities often use autobiographical material, whether in individual or collaborative work. A sense of urgency is palpable in these pieces, a sense that the actual stories of disabled people have been ignored, silenced, or diminished and therefore must be told. Autobiography offers first-person testimony of life with a disability, a corrective to traditional stereotypical representations. This work helps to clarify pressing political issues and personal concerns for its audiences.

Artists also represent the lived experience of disability by making work from the lives of historical figures with disabilities in a nonstereotypical way. Another tactic is to focus on how disability influenced or informed a historical figure, when a figure's disability identity has been downplayed or omitted from the historical record.

Disability art often fosters disability pride by embracing a politicized disability identity, celebrating bodily difference, and consciously participating in the building of a distinct disability community. Theater artist and scholar Victoria Ann Lewis suggests that such work exhibits "disability cool," a term the disability community uses to describe a revaluation and resignification of the very markers of disability and impairment that traditionally connote shame.

Traditional arts have evolved and become conventionalized over time according to bodies considered appropriate to each artistic medium. The body appropriate to perform ballet, for example, is different from the body considered appropriate to painting. The ballerina must be extremely thin, petite in stature, and symmetrical, with a long neck and strong limbs. While painters may not have such extreme physical requirement, they are generally assumed to have full use of their arms, hands, and eyes. Therefore, a ballerina in a wheelchair or a painter who uses his mouth to hold a paintbrush necessarily alters the aesthetics of her or his media. The particularities of these bodies transform the media in which they work. Disability artists that are most successful take advantage of the transformative potential of difference rather than trying to fit their nonstandard bodies into standardized conventions. The sometimes startling and innovative results of these artistic experimentations are known as disability aesthetics. Such aesthetics can also include an aestheticizing of assistive devices—such as canes, guide dogs, and interpreters—into the artwork itself. This inclusion runs counter to the tendency to consider such devices "add-ons" that are not part of the artwork itself.

Disabled artists must continually struggle to have their work taken seriously by art establishments, to be considered "professional." Few disabled artists have had access to quality training programs due to discriminatory admissions practices and rigid, unimaginative curricula that do not accommodate a variety of abilities. In addition, art therapy programs were often the only art training available to disabled people. These programs are not intended to provide professional training for its participants. The lack of access to training and the medicalization of disability arts have led to a stigmatization of disabled artists as amateurish, lacking in sophistication. Conversely, artists with disabilities can be branded "outsider" artists, especially when their work focuses on the subject matter of impairments or people with disabilities. This stigma remains despite the increasing numbers of professionally trained disabled artists and the increased visibility of disability art in mainstream venues. These pioneering artists have a long way to go until their work is considered a legitimate and regular part of the art world's multicultural mosaic. Nevertheless, disability art reflects the move toward self-determination in the cultural arena; disabled artists are consciously reshaping the media that have always shaped them in the public sphere.

—Carrie Sandahl

See also Aesthetics; Disability Culture; Drama and Performance, Representations of Disability; Stigma.

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DISABILITY ASSESSMENT/ EVALUATION, EUROPE

An important element with regard to disability is the evaluation of work disability as a percentage of loss (of working capacity or earning capacity) or as a category (e.g., severely disabled, partly disabled). These evaluations are the crossroads for people in the journey from work through sickness to disability or reintegration and open (or do not open) the way to social rights.

We believe it is important for readers of this encyclopedia to acquaint themselves with practices of disability evaluation in different countries. Knowledge of different practices may help those concerned to gain insight into the evaluation process. Moreover, it may offer suggestions to further improve the evaluation process.

Disability evaluation is thought to be as old as humankind itself, the first indications being found in Hammurabi's codex in which an indication is given of how to compensate the loss of parts of the body. In ancient Europe, the Romans and the Germanic people had sophisticated ways of weighing the social impact of damage to the body. The principles the Romans developed to pay for damaged slaves still rule the public programs of disability, whereas the Germanic principles live on in liability and professional risk. By the end of the nineteenth century, modern, state-governed disability insurance started to develop in Europe, first in Bismarck's Prussia, quickly followed by the other countries, each country developing its own specific arrangement.

In this entry, findings of an international comparison of disability evaluation are briefly presented and discussed. We made this international comparison in 2002–2003. We present information on the following issues:

The main characteristics of the arrangements for long-term disability in European countries

The main actors involved in the assessment

The characteristics of the assessment and the process steps

Quality control

In describing our findings, we use the term *assessment* to refer to the assessment by a professional, most often a medical assessor. The term *disability evaluation* refers to the whole processing of the claim up to the decision, involving other people, such as case managers and administrative staff.

MAJOR CHARACTERISTICS OF LONG-TERM DISABILITY ARRANGEMENTS

Legal Definition of Disability

The core characteristic of the long-term disability arrangement is the legal definition of disability for work. Although we found some variation in the legal definitions, we could generally discern the common elements of the handicapped role. These elements are as follows:

- Clients' (in)abilities to do work that can reasonably be asked of them
- Health conditions that explain these (in)abilities
- Chances and opportunities of improvement/ reintegration

Whereas the legal definitions in all countries investigated contain the first two elements, only in Norway and Spain is the element of reintegration explicitly stated in the definition of disability. In some other countries, this element is tied to the law on disability in connected regulations.

Operationalization of Disability

It is obvious that all three elements of the definition represent diffuse borders between being disabled or not. In individual cases, it can be a dilemma where to draw the line, a dilemma in which social norms and cultural values apply in an implicit manner. To achieve efficiency and uniformity, the legal definition of disability for work is translated into a more detailed concept for assessors. In this entry, we use the term *operationalization of disability* to refer to this process of translation, which can occur in various ways.

- A medical operationalization is characterized by an emphasis on medical findings, such as diagnosis of symptoms and impairments, and these findings in themselves justify the making of a decision regarding disability.
- A functional operationalization is characterized by an emphasis on (restriction of) activity, and these findings lead, by themselves or through job matching, to a decision on disability.
- An operationalization of rehabilitation is characterized by an emphasis on the possibilities of, and experiences with, rehabilitation, and these findings lead to a decision on disability.

We found the following operationalizations in the countries we studied:

- Purely medical (Belgium, Italy, the Russian Federation, the United States, and probably Hungary as well)
- Medical combined with functional (Ireland, Slovenia, Spain, and the United Kingdom)
- Medical combined with rehabilitation (France, Norway, and Germany)
- Medical combined with functional and rehabilitation (Denmark, the Netherlands, Slovenia, and probably Spain as well)

Other Characteristics of the Arrangement for Long-Term Disability

There is considerable variation in other characteristics of the arrangement for long-term disability. For instance, the number of levels of disability varies between countries. In some countries, there is only one level, "fully disabled"; in the Netherlands there are seven. The length of time that elapses from the onset of sickness to application for a disability benefit varies from 26 weeks (United Kingdom) to 5 years (Denmark). In many countries, this period is flexible with a maximum.

ACTORS INVOLVED

An important element with respect to the organization of disability assessments pertains to the actors that are involved. The assessments are always carried out by medical doctors, single or several, sometimes in multidisciplinary teams of varying composition. In some countries, such as the United Kingdom, a screening of applications takes place on evident cases of incapacity, carried out by non-medical assessors.

It is believed by some that assessments take place only in the "black box" of the medical doctor's consulting room. Consequently, it is thought that these doctors are the only ones who control the assessments. However, there are various actors that are involved in assessments. There is an intricate interplay between the assessors, the organization that contracts them, curative health care, the courts, the external supervisory organism (if there is one), the former employer of the claimant, and of course the claimant him/herself. The influence of the involved parties varies considerably, notably with regard to the role of curative health care. Curative health care is sometimes closely (Norway) and sometimes rather distantly (e.g., Italy, the Netherlands) involved in the individual assessment process. Moreover, the structural influence of curative health care on medical assessors, through professional education and in the setting of medical norms, is possibly much larger.

ORGANIZATION OF THE ASSESSMENT PROCESS

Primary Goal of the Assessment Process

The goal of the assessment may not only be to check the entitlement of the claimant to the benefit but also to promote rehabilitation/reintegration. The goals of the assessment process that we found in the different countries were as follows:

- Check of entitlement (Belgium, Finland, Ireland, Italy, the Netherlands, Norway, Spain, and the United States).
- Check of entitlement plus promotion of rehabilitation/ reintegration (Denmark, France, Hungary, Slovenia, Russian Federation, and the United Kingdom). In Germany, it is decided following assessment whether a benefit will be granted or if rehabilitation should take place first.

Combining the check of entitlement with the promotion of rehabilitation/reintegration has advantages, but it also presents disadvantages. An obvious advantage is that reintegration is promoted. Limiting assessors to focus on the disability claim may result in insufficient attention for helping individuals to recover. However, the separation of rehabilitation and the assessment of disability may ensure a more "pure" assessment, in which empathy resulting from a "curing or caring" relationship is likely to be limited.

Process Steps

The process steps followed in the various countries investigated show quite some variation. In general, the evaluation of disability is preceded by a period of sick leave in which certification takes place and in which effort is put to rehabilitation. In some countries (e.g., France, the Netherlands) this period is supervised by Social Insurance. After this period, an application is made for a disability benefit. That claim is to be evaluated on file (e.g., Germany) or in an encounter of claimant and assessing professional(s). The actual decision is generally taken by the administrative staff, relying heavily on the professionals' advice. The time to reach a decision, often with help from health care institutions, is 5 days in the Russian Federation but up to 3 or 4 months in most countries. The actual time for processing varies considerably: In most countries it is around 1 hour, but in the Netherlands it is almost 7 hours. These periods are difficult to compare, however, because part of the work may be done by health care institutions. After admission, in general reassessments are scheduled periodically. In case of refusal, several ways of appeal are open to the claimant.

The process steps are described in greater detail in the publication of our comparative study.

Method of Assessment

We found the following methods of assessment in the countries under study:

- Face-to-face assessments supported with file information (Belgium, Denmark, Finland, France, Ireland, Italy, the Netherlands, Norway, the Russian Federation, Slovenia, and Spain)
- Assessments based on paper file, if necessary completed by face-to-face examination (Finland, Germany, the United Kingdom, and the United States)

Judging (some) cases on paper may be attractive for reasons of efficiency. Furthermore, assessors may feel less empathy for cases on paper than for claimants who are met during face-to-face examinations. This might contribute to a more objective assessment. However, the fact that the information present in the file stems from a personal encounter between the claimant and some kind of assessor should not be discounted. The robustness of the file information depends on this encounter in a comparable way as it does in countries that rely on face-to-face assessments.

Medical Assessors

The number of medical assessors involved in the assessment varies between countries:

- One medical assessor (France, Germany, Ireland, Italy [local level], the Netherlands, and the United Kingdom)

- Several medical assessors (Finland, Italy [specialist unit], the Russian Federation, Spain, and Slovenia)
- Number dependent on specific case (Hungary, Belgium, Denmark, and Norway)

The employment of several medical assessors seems to be primarily dictated by reasons of reliability and may in this way serve the quality of the decision: Additional assessors may correct each other. To our knowledge, however, it has not yet been empirically tested to what extent the use of several assessors increases the accuracy of the assessment.

Labor Experts

In some countries (Germany, the Netherlands, Slovenia, and Spain), labor experts are involved and routinely consulted. As labor experts are specialized in labor market conditions and job demands, they are used for establishing the relationship between disease, impairment, or functional limitation and participation in labor.

Decision-Making Process

What knowledge and what information is processed and in what manner? We found it particularly difficult to grasp the exact reasoning for determining disability for work. The decision-making process seems to rely on undefined professional knowledge applied in unique and individual cases. Moreover, the values of a specific country come into play. In some countries, such as France and Norway, factors like age and labor market are to be taken into account. In other countries, only medical aspects of the individual count in the assessment. This shows that the concept of disability for work is a relative concept, relative to values of that specific country.

Technically, evaluations should be organized in a manner that complies with the requirements of validity and reliability. It is probable that many of the practices and instruments described below are intended to enhance this part of quality, but it is unclear how the relationship between instruments and validity and reliability is viewed.

Instruments

The Netherlands is unique in using interview protocols and a computer program for selecting jobs a claimant could do. The medical decision is expressed into a list of functional capacities that are matched with existing jobs. This matching points out suitable work for the claimant and his or her earning capacity therein. The earning capacity is compared with the claimant's previous earnings and in this way a loss of earning capacity is calculated.

In the United Kingdom and the United States, we found lists that state which conditions entitle a claimant to a disability. The list used in the United Kingdom is more limited than the one used in the United States and focuses on serious conditions that do not require a personal capacity assessment. In none of the investigated countries did we find a list of diseases that do *not* entitle a claimant to a benefit.

In several countries, notably Germany and Italy, professional guidelines have been developed for specific diseases. Furthermore, in some countries (e.g., the Netherlands), guidelines have been developed with respect to the assessment process itself.

Factors Influencing the Decision Making

Several factors influence the decision making, some of which seem interrelated. These factors encompass the following:

Time pressure

Compassion for the claimant

Aggression/pressure from the claimant

Political pressure/climate

Claimant's age and prospects in the labor market

Although, formally, many of these factors should not influence the decision making, it appears to be difficult to rule out their influence. These findings hint at the importance of factors beyond the legal criterion that influence, or rather distort, the decision-making process in the assessment of disability. In many cases, these factors indicate differences between theory and practice.

QUALITY CONTROL

Knowing that disability evaluation is a vulnerable and important process, one might expect a well-established management circle in every organization so as to monitor and correct the process of evaluation. The input into the process, the process itself, the professionals, the output, and the outcome all offer possibilities to control quality. However, this is only partly done. Nevertheless, as described in the publication of our international comparison, there are a great many possibilities that may serve as inspiration to enhance existing quality management.

Criteria, Indicators, and Norms

In many of the investigated countries, quality control with respect to the assessment process is not in a very advanced phase. Criteria, indicators, and norms for the quality of the assessment process are generally not defined in a very precise, detailed manner. We have the impression that this is particularly true for the quality of the decision. Furthermore, it appears that the quality of the decision is generally controlled only by file inspection. The effectiveness of file inspection as a method for evaluating the quality of the assessor's decision is questionable. This is particularly problematic if files do not have to be very elaborate, as is generally the case.

Other Procedures to Control Quality

In some countries, quality is promoted by the specific design of the assessment process. For instance, in some countries, the quality of the assessment is promoted by using additional assessors or additional boards. This may be particularly effective when additional assessors/boards not only inspect files but also perform medical examinations.

Various other procedures to control the quality of the assessment exist. These procedures vary from intercolleague consultation, professional and continuous education, and coaching to using forms, protocols, guidelines, books, and magazines. In Slovenia, appeals are used to improve the quality of the assessment.

Individual feedback appears to be common practice in the majority of the examined countries. Moreover, in some countries (Belgium and Hungary), the assessor's performance is compared with the performance of other assessors (i.e., benchmarking).

Scientific Foundation of Disability Evaluation

As the evaluation of disability seems to be a particularly difficult task, one would expect a large scientific tradition to exist with regard to checking the validity and reliability of the evaluations. Such a scientific tradition barely exists. This is not to say that the evaluations are done in an inappropriate manner, but it is astonishing to see that such an important social activity seems so poorly funded with specific knowledge. Furthermore, if a country decides to change the organization of the assessment process, the lack of insight into the validity and reliability of assessments would make it difficult to predict the effects of these changes.

EPILOGUE

In sum, there is a large variation with respect to the organization and practice of disability evaluation in the countries under study. The exact reasoning to determine disability for work proves difficult to grasp. Furthermore, it seems that quality control is on the whole more implicit than explicit and systematic. This finding is particularly surprising because many systems of social insurance seem to be faced with problems: The volume of disabled people is in many countries considered to be too high; there are a number of people with health complaints of which the severity is difficult to establish; in many countries getting back to work from a benefit situation is very hard; and the transaction costs of the systems are high. In such a situation, a robust and tightly controlled system of disability assessments is of utmost importance.

A common framework of terms would be desirable as a first means to develop more robust practices. The World Health Organization's International Classification of Functioning, Disability, and Health (ICF), as far as the condition of the claimant is concerned, might offer such a frame although many other aspects of the disability evaluation are not addressed by ICF. Likewise the development of a taxonomy of functional assessment might offer a frame for identifying instruments of assessment. Moreover, the value of the instruments in social insurance needs to be empirically tested. In addition, research should be conducted into the validity and reliability of practices in disability evaluation. This kind of research would foster the development of more robust practices of disability evaluation, in particular with respect to quality control.

—W. E. L. de Boer, V. Brenninkmeijer,
and J. J. M. Besseling

See also Disability and Career Development; Functional Measurement.

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DISABILITY CONVENTION (UNITED NATIONS)

See United Nations Disability Convention

DISABILITY CULTURE

A universal definition of *culture* is the sum total of behaviors, beliefs, ways of living, and material artifacts characteristic of a particular group or society. Particular definitions of culture—such as *disability culture*—take many different forms and are *context bound* (dependent on the cultural and geographic context in which they are formed). Three common ways of thinking about disability culture are historical, social/political, and personal/aesthetic. Historical definitions of disability culture focus on art, poetry, language, and social community developed by disabled people. Social/political definitions of disability culture focus on a minority group distinction with common values of social and economic justice, radical democracy, and self-empowerment. Personal/aesthetic notions of disability culture emphasize a way of living and positive identification with being disabled.

Although concepts of culture vary as much as concepts of disability, one concept does seem clear. The experience of disability is embedded in culture and the social relations of culture. These relations influence the ways in which the importance and meaning of disability are defined, and the relation of disability to notions of functional impairment. To begin, it is important to recognize the distinction between impairment and disability, or *disablement*. Impairment is generally recognized as a loss or limitation of physical, mental, or sensory function on a long-term or permanent basis. Disability or disablement is generally understood as the loss or limitation of opportunities to take part in the life of a community on an equal level with others due to physical and social barriers in the environment.

Two dominant models of disability have been developed in the popular and scholarly literature on disability in relation to this distinction between impairment and disability. The social model of disability focuses on environment and assumes that impairment is not as significant as the disability that is constructed by social attitudes and cultural mores that underlie the structural environment. In the social model way of thinking, the environment disables the individual and needs fixing. The second model of disability has been termed the medical model. This model assumes that the individual needs fixing in order to adapt to the environment—either by therapy, medicine, surgery, or special treatment. A third model comes mainly from developing countries and is not as well-known as the social and medical models. This model has been termed the traditional model of disability and asserts that disablement is created specifically by traditional religion and culture. In this traditional model, people with impairments may be regarded as unfortunate, different, or blemished in some way, and as a consequence, they are sometimes perceived as having inhuman or nonhuman traits because they are considered unable to perform traditional social roles due to this difference.

All of these models relate directly to culture and provide a starting point for understanding how culture, and specifically disability culture, is developed or enacted.

To begin to understand how disability and culture might interact, and the importance of the distinction between impairment and disability, consider this example. In a particular culture, a girl child with an impaired finger might be considered unmarriageable and education therefore unnecessary. On the other hand, a boy child with severe multiple impairments might be offered comprehensive support services in school and technological communication aids that greatly minimize his functional impairment and allow him full access to social and cultural interactions. Although the girl child's impairment is strictly minimal in terms of her ability to function, the impact on her life chances and opportunities for interaction are significant compared to the boy child's in this example. As a result, it should not be assumed that the severity of an impairment equates with severe functional limitation or disablement. From this example, impairment exists, but its meaning and significance derive from treatment of the individual in the broader cultural context within which the individual lives.

DISABILITY CULTURE: THE BEGINNINGS

The notion of disability culture began to develop in the latter part of the twentieth century. Those who ascribe to a disability culture challenge the meaning of functional limitation in its broader cultural contexts, just as Deaf people have recognized Deaf culture since at least the beginning of the twentieth century. Although medical and traditional models of disability consider loss or limitation in hearing as a substantial impairment, regardless of cultural context, many Deaf people across different cultural contexts consider their deafness not as an impairment but as a linguistic difference from *phonocentric* language norms (language that relies on sounds rather than gestures). Deaf people who consider their deafness as a linguistic difference, rather than an impairment or even a disability, have self-identified as a linguistic minority and have developed a Deaf culture they consider distinct from disability culture or majority culture. Their notion of culture is primarily built on their distinctive language and associated sociocultural practices and beliefs, rather than that of a dominant or majority (mainstream) culture. As a result, Deaf people who embrace a Deaf culture claim their inalienable right to exist apart from "mainstream" society.

Deaf individuals who experience a Deaf culture do so from the experience of a lived community. It seems likely that what is commonly referred to as Deaf culture emerged from attempts to institutionalize Deaf people and to segregate them from hearing people. It is in segregation that communities—institutionalized or not, imposed or not—develop a "culture."

Institutionalization and segregation from mainstream society have also been attributed as the impetus for creating disability culture. For example, in the 1970s, young disabled people in Zimbabwe were institutionalized in residential missionary schools. Isolated from their families, and geographically removed from society-at-large, young people with impairments formed strong ties with each other and a support system among themselves. At one school, Nguboyenja, the "inmates," as they called themselves, held discussions among themselves and decided to start a social organization that they called Kubatsirana/Ncedanani (which means to help each other). They organized excursions, and through a combination of discussion and action, began to *conscientize* themselves (become aware of their solidarity and the common injustices they experienced). They launched a countrywide campaign and membership drive. Eventually, they established clubs in every district of Zimbabwe and a headquarters in the city of Bulawayo that they called Freedom House, where they could congregate as a community and develop a shared group identity.

By the same token, people with impairments in other countries who were institutionalized or excluded from mainstream activities and rights afforded to nonimpaired citizens began to organize in similar ways. In the United States and other countries, communities of disabled people such as those in Zimbabwe's Freedom House began to mushroom in the 1970s. From the centers for independent living in the United States to the sanghams in India and the working cooperatives in South Africa, disability communities sprang up and have multiplied exponentially over the past 30 years. These communities have spawned what has become known today as *disability culture*.

The beginnings of disability culture have varied in different countries and regions of the world. In the United Kingdom and parts of Western Europe, for example, organizational groups of disabled people raised the consciousness of their members and brought them together to form a social movement for change. This social movement emphasized structural inequalities in society and focused on economic and institutional discrimination. In the United States, organizations of disabled people built on the momentum of the Black civil rights movement, focusing on litigation and legislation connected to civil rights. The U.S. disability rights movement, as it is called, developed an essentially political movement that emphasized identity as citizens and individual rights. In developing countries such as India, and several African countries, disabled people's organizations were influenced by fundamental human needs (shelter, food, education) that were largely taken for granted in more industrialized countries. The need to eradicate extreme poverty in these countries led disabled people to organize a movement that coupled disability with development, or the idea of their ability to make contributions to needed social and economic development in society as a whole. In Latin American countries and in Asia, organizations of disabled people tended to focus on liberation from basic forms of institutionalized political and social oppression as well as on individual human rights and basic needs. Their agendas tended to be more broad based and all-encompassing than in other regions of the world.

From these beginnings of political and social organization to confront injustices in mainstream society and to advocate for basic needs and rights, notions of a disability culture began to be talked about and embraced. People with impairments who had been "conscientized" to think of their impairments as disabilities constructed by societal practices and norms began to develop a disability pride. Through their collective political association and social interaction with other "disabled" people, they began to realize their individual strengths and abilities and to seek ways to celebrate them. Their initial focus on external oppression that manifested itself in segregation, social injustice, and discrimination led to a realization of the ways in which they had internalized this oppression. Negative societal attitudes, discrimination in institutional practices, and cultural beliefs that dehumanized them began to be challenged at a personal level.

Supported by their disability communities (political and social), and beginning to be socialized through these communities to a different way of thinking about themselves in relation to society at large, disabled people began to create an internal revolution of unique thought, action, and beliefs. This revolution manifested itself cross-culturally in unique expressions of literature, poetry, dance, film, theater, and music.

EXPRESSIONS OF DISABILITY CULTURE

At the present time, numerous individuals who identify as disabled express disability culture as artists, poets, and actors and in theater groups and can be found in all regions of the world. Their cultural expressions of pride in a disability culture include artwork such as the Disability Historical Quilt created by Amy McWilliams; Count Us In, an artistic women's cooperative in Zimbabwe; performance poetry groups in Britain such as Frank Bangay's Survivors' Poetry; dancers such as Bruce Curtis and the AXIS Dance Troupe; and musicians such as Canada's Jane Field, England's Johnny Crescendo, and Jeff Moyer in the United States. Writers and poets in fiction and oral history include Jenny Morris's popular book *Pride against Prejudice;* Allen Sutherland's *Disabled We Stand; No More Stares,* profiles of disabled people created by the Disability Rights Education and Defense Fund; and Sibongeleni's *Through Sibo's Eyes.* Many of these individuals are increasingly supported by institutions such as the more than 26 creative art centers in various countries, the Institute on Disability Culture, and the National Institute of Art and Disabilities in the United States. These few examples represent the tip of the iceberg in expressions of disability culture.

At the same time, in academia (higher education institutions at postsecondary and university levels), the field of disability studies was born. Disability studies scholars worldwide are currently supported by their own networks of academic communities such as the Society for Disability Studies, the Disability Research Unit (University of Leeds), and the Association of University Centers on Disabilities (based in Hawaii). Over the past 30 to 40 years, disability studies scholars have challenged perceived knowledge in such wide-ranging fields as anthropology, sociology, feminist epistemologies (study of the origin and limits of knowledge concerning gender), history, arts and humanities, and education, as well as medical fields of public health, bioethics, genetics and genome research, and rehabilitation.

Cultural representations of disability in disability studies have taken many forms within these fields. Examples include genealogical histories such as the French scholar Henri-Jacques Stiker's *Corps infirmes et sociétés* (1982), in which changing images of disability are recorded and analyzed across time. In the arts and humanities, disability studies scholars such as Paul Longmore, Mairian Corker, David Mitchell, and Sharon Snyder have traced negative images in mainstream (broader society) literature, art, and film, uncovering and exposing these images as inadequate, distorted, and contrived. These critiques have focused on culture as discursive practice (the codified, visible representations of culture), and in the process have developed the subversive potential of a disability culture as a reactionary transgressive response to these negative images. Performing artist and poet Cheryl Marie Wade (1997:408) vividly expresses the transgression that is characteristic of this genre in one of her poems:

> I am not one of the physically challenged—
> I'm a sock in the eye with gnarled fist
> I'm a French kiss with cleft tongue. . . .
> I'm the Gimp
> I'm the Cripple
> I'm the Crazy Lady
> I'm the Woman with Juice

Other examples of culture as discursive practice include those from anthropology. Numerous ethnographies and narrative stories from all regions of the world provide detailed descriptions of the lived experience of disability. These stories and ethnographies provide in-depth cultural images of personhood that capture the wide variety of individual experiences of disability. Examples include Crapanzano's *Tuhami* (South Africa), Mariana Ruybalid's *A Pattern of Silent Tears* (Costa Rica), and Irving Zola's *Missing Pieces* as well as Robert Murphy's *The Body Silent* (United States).

At the same time, the Third Estate (popular media such as newspapers and magazines) has begun to preserve and record the history of disability and to disseminate cultural knowledge of disability. In the year 2000, the United States' National Telability Media Center collected documentation of 3,000+ newsletters, 200 magazines, 50 newspapers, 40 radio programs, and 40 television programs dedicated to disability in the United States alone.

Finally, expressions of disability culture often take the form of special events such as commemorations of the Holocaust, recognizing the annihilation of more than 200,000 disabled people in Hitler's Germany.

Today, celebrating difference has become the mantra and visible manifestation of disability culture in all regions of the world. These visible and codified (recorded in texts or other means) manifestations of a fast-growing disability culture have created noncorporeal (nonphysical) manifestations of disability culture: shared values such as an acceptance of difference, tolerance for ambiguity, highly developed problem-solving skills, and "dark" humor among them.

DIFFERENCES IN DISABILITY CULTURE

Both the rise of disability communities through social and political movements and the development of academic communities through disability studies have contributed to notions of disability culture. The first, disability movements, conceive of disability culture as primarily social and political. The second, academic communities, view disability culture from predominantly historical, discursive, and linguistic perspectives. A third notion of disability culture underlying both of these approaches is the notion of a personal and aesthetic disability culture. In this third notion, a disability culture is constructed through concrete and specific encounters that are linked to a mind/body consciousness of disability. This notion of disability culture focuses on individual identity and identity formation—or how culture is produced. One concrete expression of this notion is the statement "I was born colored and crippled. Now I am Black and Disabled."

From this view, Kay Gainer's (1992:31) statement "Now I am Black and Disabled" says something about the culture within which she experiences life, its values, and norms. But her statement also reveals that she constructs her identity—not only in relation to her cultural environment—but in resistance to the broader cultural norms inherent in this environment. Others see her as colored and crippled, but she understands that she is Black and Disabled. In a similar way, Cheryl Marie Wade describes being a cripple as not one of those physically challenged but as a "French kiss with cleft tongue."

The process through which Gainer and Wade transform their identities gets at the heart of the multiple meanings that can be ascribed to disability culture. Some writers, particularly in countries of the North, have described the notion of pride inherent in these statements as an aesthetic expression of culture. One disability studies scholar, Harlan Hahn, for example, has asked the question, "Can disability be beautiful?" In his writing, he has developed the notion of impaired bodies as a potentially subversive source of sensualism with an intrinsic appeal because impairments provide a kaleidoscope of beauty beyond those embodied in cultural norms. This aesthetic pride in the impaired body represents one aspect of personhood related to disability culture.

Casting disability culture in relation to constructions and interpretations that individuals make of their experiences creates the possibility for multiple expressions of cultural identity. It has been argued that social and political disability movements have not allowed individuals room for these expressions. On the one hand, various disability movements have been challenged on the basis of their notions of disability as dichotomy (Us vs. the "Other" and social vs. biological). On the other hand, disability movements have brought disabled people of all stations and backgrounds together through a consciousness-raising process that has created and embodied notions of disability culture.

However, the underside of this growing disability culture is that disability pride is not typically created in isolation. It is most often created within disability communities, but also shaped by the wider majority cultural context. First, disability pride is generally developed through membership in a disability community. But the focus on unity against societal oppression within disability movements has been criticized as exclusionary and oppressive in itself. For example, for some individuals with impairments, personal experiences of racism are more immediate and significant than being disabled. For others, being blind is more important than being disabled. Still others with no visible markers of impairment or disability have expressed the feelings that they are marginalized by those with more visible traits. To complicate the issue further, People First (an international organization of those with developmental disabilities/cognitive impairments) by and large rejects the notion of disability as the primary marker of personhood.

Second, considering personhood further complicates the notion of disability culture in the ways that identities are created, transformed, or resisted in relation to majority culture. For example, although concepts of beautiful bodies have changed over time and vary greatly across cultures, the concept of the body beautiful—a svelte athletic figure—has been particularly emphasized in Western cultures. Pride in individual identity, as it refers to the body, may be a particularly Western concept. In contrast to Western notions of personhood as connected to "the body beautiful," many other regions of the world emphasize notions of "the body functional." As an example, for the Songye of Zaire being human is to live communally and carries with it social responsibilities. For the Songye, a woman with a physical impairment that inhibits fetching water or cutting wood becomes virtually unmarriageable and thus socially incompetent and a nonperson. The Punan Bah of central Borneo also equate personhood with concepts of social competence. A person in Punan Bah society is defined primarily by age, sex, and marital status. However, young children with impairments may be assigned daily tasks, such as caring for younger siblings, that allow them to demonstrate social competence. For disabled people who do not marry and lack offspring, it is considered the moral duty of their siblings to make a gift of one of their own children so that the disabled person can maintain a social status as societal members.

Constructions of disability in different cultures may cast disabled people as heroic or autonomous and capable. Those mutilated as a result of political, ethnic, or civil wars in such countries as Nicaragua, Vietnam, Sierra Leone, and East Timor have resulted in a heroic class of disabled people identified as "living martyrs." Many famous blind poets and writers in

Iranian literature attest to the image of disabled people as autonomous and capable.

In Islamic countries such as Iran and Pakistan, religion plays a central role in cultural formation. The Qur'an teaches that serving "handicapped" people is like being in the service of the prophets of God. Qur'anic teaching also stresses family ties and loyalty. In rural areas of Iran, a high number of genetically transmitted disabilities exist because all families are blood related. As a result, disability becomes an expression of honoring strong family foundations. By contrast, marriage of blood-related individuals is strongly discouraged in many parts of China, where Confucianism also stresses a perfectionist view of mental health. In these different cultures, a disabled child may be seen as a gift of God or as divine punishment (the will of Allah).

All of these different cultural practices and beliefs influence the process of developing a positive disability identity and of identifying with a disability culture. For those who do not identify as disabled, for those who have no knowledge of or who have not experienced a disability community or culture, or for those whose primary identity lies in alternative cultural connections, disability culture remains marginal to their sense of personhood.

DISABILITY CULTURE: A SUMMARY

To summarize, expressions of disability culture take three generally distinct forms. First is the notion of disability cultures as historical, discursive, and linguistic. This notion is based on the idea of culture as depicted (e.g., in art and poetry) or received (e.g., through a common language, historical lineage, or social community). This notion reflects traditional anthropological studies of culture.

The second notion of disability culture is based on social/political dynamics of group interaction. This notion is based on sociological notions of culture that look at minority groups and their solidarity and common goals of fighting oppression. The notion also includes common values of social/economic justice. From this way of thinking, disability culture stands *in resistance to* mainstream cultural expressions of disability as pathological and unproductive and stands *for* radical democracy and self-empowerment. In making disability a social/political issue, disabled people affirm the validity and importance of disability and represent a disability culture of dissent and struggle that includes material (economic) and temporal (body) dimensions.

The third general form that disability culture takes is personal and aesthetic. In this notion, culture is created from individual experience. The disabled person is an interpreter of cultural identity. The mind/body consciousness has the capacity to resist and transform values about disability in mainstream culture. Disability culture as personal/aesthetic is what disabled people acknowledge when they say, "I am proud to be Black and Disabled."

These three forms of disability culture take expression simultaneously. The boundaries between personal disability identity pride and notions of disability community are blurred. Identities forged from personal experiences may be supported and further developed by identity with a particular disability community—whether social, political, or academic. Disability culture as social/political coexists with personal values of disability pride. All of these forms of disability culture are expressed through textual, discursive, linguistic, and artistic forms.

LOOKING TOWARD THE FUTURE

Understanding disability culture offers several possibilities for future thinking, study, and practice. These possibilities might include (1) study of changes in the way disability and difference are defined and understood; (2) changes in thinking about disability identity in relation to society as a whole, as well as in relation to disability movements; and (3) changes in the ways we think about and develop supportive communities. These three possibilities open the way for furthering current notions of disability culture.

Defining Disability and Difference

Disability, disablement, and impairment are universal. They know no national, societal, or cultural boundaries. Anyone can become disabled—regardless of age, class, race, or gender—through birth, accident, illness, war, poverty, or advanced age. Most individuals, at some point in their lives, will experience disability, disablement, or impairment. The vast majority of the current 600 million disabled people worldwide live in developing countries. Most of these individuals live in rural areas and experience their cultural identity in traditional agrarian societies. It has been estimated that in some regions of the world, as much as 25 percent of the population have impairments. In fact, in some countries such as Mali, blindness is not considered a disability but just one of the many conditions of everyday life that all Malians experience in one way or another. Under these conditions, disability and impairment are not merely the experience of a minority group, but rather the normal condition of humanity. From this perspective, distinctions between disabled and nondisabled individuals that have formed the basis for developing disability culture become problematic. When all individuals are included—because they are frail, limited, mortal—there will be no distinct identity.

Study of disability culture also shows us that people who have impairments often define themselves not by their impairments, but in relation to disablement in cultural contexts, whether political, social, or aesthetic. These cultural contexts show us that different cultural beliefs and practices make biological impairment difficult to define (consider the example of deafness) or to separate from disablement. Notions of the impaired body shift and change, depending on the cultural context and historical times. Definitions of disability culture and the processes of enacting this culture (identifying as Disabled, or not) suggest a future in which *embodiment* (the experience of disability) may be a more effective way of understanding impairment than attempting to refine or develop universal descriptions and categories of impairment. Seeing disability and impairment as embodiment recognizes the historical and cultural aspects of impairment that are inseparable from the biological aspects.

Embodiment as a line of thinking in relation to impairment characterizes a small but growing number of recent scholarship in disability studies. Two examples are the books *Embodied Rhetorics: Disability in Language and Culture* (edited by James C. Wilson and Cynthia Lewiecki-Wilson) and *Semiotics and Dis/ability: Interrogating Categories of Difference* (edited by Linda J. Rogers and Beth Blue Swadener).

Recognizing Multiple Identities

Disability culture has been associated with identity politics because of its emphasis on collective identity to work for social change. This collective identity is based on an understanding of shared oppression and has the principle goals of forging positive images and changing society to meet the requirements of social justice and equity. Notions of disability culture that emphasize a collective identity have been criticized as the paradox of disability culture by disability activists and by disability scholars. The paradox lies in the argument that claiming unity against oppression is actually a source of oppression in itself. In other words, claiming unity leads to simple dichotomies of "Us" (Disabled) and "Them" (Nondisabled), ignoring and devaluing differences among disabled people.

All people have multiple identities. Gainer's statement "Now I am Black and Disabled" points to this fact. These identities take on different meanings and importance in different contexts. As an example, for many disabled people, being a woman, being gay or lesbian, or being Black is more disabling in relation to societal discrimination than having an impairment.

One of the core values of disability culture is acceptance of difference. At the same time, the social model of disability aims to fix the environment so that differences no longer make a difference. The paradoxes of unity and difference inherent in these values and goals need to be addressed in the future—both at a practical level and in theory.

Developing Communities

In industrialized countries of the North, the rule of thumb for counting the prevalence of disability is 10 percent of the population. In developing countries of the South, this number may be greater, due largely to conditions of poverty. All in all, disabled individuals the world over arguably represent one of the largest minority groups in the world. In today's globalized world, coalescing (coming together) as an oppressed minority—whether group membership is based on discrimination from full rights as citizens or on exclusion from social roles that define personhood—has become imperative.

The rise of disability culture has depended primarily on community building, either as a result of physical exclusion from society (as in Zimbabwe) or to resist social, political, or economic exclusion from basic human rights, employment opportunities, or from social roles and responsibilities connected to personhood. The social and political movements that have developed from community building have been composed largely of middle-class individuals from industrialized countries. These movements have also created social and political agendas within a disability culture that is based on Western assumptions about disability. The growing movement in developing countries exposes the limitations and narrow vision of these earlier movements.

The challenge for the future is to develop a broader cross-cultural and comparative vision of disability culture. This vision would take into account notions of personhood and "the body functional," as well as traditional models of disability and the broad vision of disability and development.

Globalization has brought with it advances in computer technologies and other scientific advances that have greatly benefited disabled people. For example, electronic devices for blind individuals, physical mobility devices, and opportunities for communication via the Internet have greatly contributed to the expansion of disability culture. At the same time, these technologies are not available to the majority of disabled people living in poverty. For this reason, globalization carries opportunities as well as dangers. The opportunities lie in including greater numbers of disabled people with access to disability culture. The danger occurs when these numbers represent mainly the privileged, creating a greater divide and exclusiveness in disability communities.

Whether disability culture is a state of mind, a place, or membership in a community, the ultimate goal of disability culture is for all disabled people everywhere to be at home in their country. Playwright and poet Neil Marcus (n.d.) puts it this way:

> If there was a country called disabled,
> I would be from there.
> I live disabled culture, eat disabled food,
> make disabled love, cry disabled tears,
> climb disabled mountains and tell disabled stories. . . .
> If there was a country called disabled,
> Then I am one of its citizens.
> I came there at age 8. I tried to leave . . .
> But found myself, in the end staying and living there . . .
> In my life's journey
> I am making myself
> At home in my country.

—Susan J. Peters

See also Aesthetics; Deaf Culture; Disability Pride; Disability Studies; Global Inequities; Globalization; Oppression.

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DISABILITY DISCRIMINATION ACT OF 1992 (AUSTRALIA)

See Disability in Contemporary Australia

DISABILITY DISCRIMINATION ACT OF 1995 (UNITED KINGDOM)

The Disability Discrimination Act 1995 (DDA) (as amended by the Special Educational Needs and Disability Act 2001), together with the Disability Rights Commission Act 1999, constitutes the primary source of antidiscrimination legislation for disabled people in the United Kingdom.

The campaign for antidiscrimination legislation in the United Kingdom began in earnest in the late 1970s, as a result of the emergence of the disability movement in the United Kingdom. This movement—a loose coalition of disabled individuals and organizations (influenced by disabled people and organizations in other countries and by other liberation movements both in the United Kingdom and abroad) with a common understanding and consciousness—developed a new way of understanding disability through what became known as the social model definition of disability. The term *social model* was coined by Mike Oliver in 1983 to reflect the growing demand by disabled people and their allies for “nothing more fundamental than the switch away from focusing on the physical limitations of particular individuals to the way the physical and social environments impose limitations on certain groups or categories of people.” In summary, the social model sought to understand the concept of disability as the result of the relationship between people with impairments and an oppressive society, as opposed to what became known as the medical model of disability, which placed disability within the framework of medicine. Accordingly, disabled people reframed the discourse so that their experiences and lives were explained as a reflection more of discrimination and oppression than of their impairments (their medical or quasi-medical condition). As a result, in 1981, the first attempt at antidiscrimination legislation for disabled people in the United Kingdom was made by Alf Morris MP. That attempt, together with the next 16, all failed. However, over the next 15 years, the campaign for antidiscrimination legislation grew, particularly with the passing of the Americans with Disabilities Act in 1990.

THE DDA

Until the DDA, disability legislation in the United Kingdom was primarily aimed at providing welfare support in the form of financial benefits or services and by establishing special homes and schools. The DDA, however, established requirements on employers, service providers including those disposing of or managing premises, transport providers, and (since September 2002) education providers to end less favorable treatment of disabled people and make “reasonable adjustments”: amend policies, practices, and procedures; provide auxiliary aids and services; and remove physical and other barriers.

Who Is Covered?

The act limits the protection afforded to those with impairments that have a substantial and long-term (which means at least 12 months) adverse effect on at least one of eight prescribed day-to-day activities. These activities are mobility; manual dexterity; physical coordination; ability to lift, carry, or otherwise move everyday objects; speech, hearing, or eyesight; continence; ability to concentrate, learn, or understand; and perception of the risk of physical danger. In addition, the act covers those who have had (but no longer have) such an impairment, those with severe disfigurements, those with symptomatic progressive impairments, and those with impairments that would have a substantial effect on one or more of the prescribed activities were it not for the fact that the effect is controlled or corrected by the use of prostheses, medication, or otherwise. On the other hand, drug addiction, hay fever, and certain mental illnesses that have antisocial consequences (such as pyromaniacs, kleptomaniacs, and voyeurs) are excluded. In total, more than 10 million people are covered—about 17.5 percent of the UK population. Those not currently covered by the legislation include those with impairments that do not have a substantial effect on a prescribed activity, those with short-term impairments, those with a genetic predisposition to impairment, those with impairments that have yet to manifest themselves symptomatically, those assumed to have an impairment, and those associated with or related to people with impairments.

The Employment Provisions

The DDA gives a general duty on employers to treat disabled applicants for jobs and employees no less favorably than they would treat nondisabled applicants and employees. In addition, the act requires that employers make what are known as "reasonable adjustments" to remove obstacles that substantially disadvantage disabled people. Such adjustments may be physical adjustments to premises to make them accessible or, for example, altering working hours or providing training. Discrimination is, however, lawful if it is for a reason that is both "material to the circumstances of the case and substantial." However, the employment provisions of the act do not currently cover certain categories of employment including the police service, fire service, prison service, armed forces, and partnerships.

The DDA abolished the quota system established by the Disabled Persons (Employment) Acts of 1944 and 1958. Until the DDA was brought into force, large employers—those with more than 20 staff members—were obliged to ensure that at least 3 percent of their workforce consisted of registered disabled people. That duty no longer remains. In any event, most large employers never met the 3 percent target. The rationale behind abolition of the quota system was, essentially, that with antidiscrimination measures, quotas were no longer necessary. In addition, even those companies that did meet the quota tended to employ disabled people at junior levels and the fines levied on those employers that failed to meet the quota were derisory. However, abolition was not universally supported as some believed that it provided a rare opportunity for a disabled applicant to be given an advantage over a nondisabled applicant in recruitment. It is hard to tell whether abolition has itself (without the DDA) affected employment opportunities for disabled people.

Discrimination in the Provision of Goods, Services, Facilities, and Premises

The DDA also affords some protection to disabled people in the provision of goods, services, and facilities. These include access to and use of any place that members of the public are permitted to enter (including shops, churches, courts, railway stations, and public parks); access to and use of means of communication; access to and use of information services (including advice agencies); accommodation in hotels and boarding houses; facilities by way of banking and insurance and for grants, loans, credit, and finance; facilities for entertainment, recreation, and refreshment (including bars, restaurants, theaters, and leisure centers); facilities provided by employment agencies; and the services of any profession and trade (including doctors, lawyers, and hairdressers) and any local and public authority. The act requires providers of such services not to treat disabled users less favorably than they would a nondisabled person and also to make such adjustments as may be reasonably required to remove or reduce obstacles for disabled people. Adjustments may be to policies, practices, and procedures to provide alternative means of communication (such as text phones, Braille, extra staff, and other equipment) and (from September 2004) to the physical environment and buildings. Discrimination is, however, permitted if it is related to health and safety, capacity, the need to be able to provide services to others, or additional expense unrelated to the duty to make reasonable adjustments. The provisions do not apply to aspects of the general environment (such as street furniture), some private clubs, the design or manufacture of goods, or anything related to national security.

There are similar obligations on those disposing or managing premises save that there is no duty to make any adjustment.

Transport

The act establishes time frames for meeting minimum requirements for access to public service vehicles (buses and coaches), trains, and licensed taxis. However, there are currently no directly enforceable antidiscrimination provisions.

Education

Until September 2002, most education was expressly excluded from the antidiscrimination provisions of the DDA. However, amendments brought by the Special Educational Needs and Disability Act 2001 extended the DDA into the provision of education in schools and colleges. Schools must not treat a disabled applicant or pupil less favorably than they would a nondisabled applicant or pupil and must make adjustments to policies, practices, and procedures (though not, necessarily, in the provision of auxiliary aids and services—which is dealt with by separate, education legislation—or in physical adjustments to premises). Colleges must also not treat a disabled applicant or student less favorably than a nondisabled applicant or student and must make adjustments to policies, practices, and procedures; in the provision of auxiliary aids and services; and (from September 2005) to physical features. Discrimination is, however, permitted in order to comply with permitted forms of selection, to protect academic or other standards, and where it is “material to the circumstances of the case and substantial.”

Two key recent cases have illustrated the extent of the effect of these new provisions. In *Ford Shubrook v. St Dominic’s 6th Form College* (2003)*,* the Court held that the refusal of a college of further education to permit a 16-year-old student with cerebral palsy to commence academic studies, because of concerns about his ability to access parts of the building, was, having regard to all of the circumstances, unlawful. The Court issued an injunction requiring the college to admit the student. In *Buniak v. The Governing Body of the Jenny Hammond Primary School* (2003)*,* a Tribunal held that a school acted unlawfully in discriminating against a six-year-old student in a variety of ways at school, including in excluding him from school activities and in refusing to secure adequate staffing support for him.

CHANGES FOR 2005

Recently, the government passed the Disability Discrimination Act 2005. The changes extend the protection against discrimination in job advertisements, group insurance, transport services, public authorities, and private clubs, among others. The changes also deem people with HIV infection, multiple sclerosis, or cancer to be disabled for the purposes of the DDA at the point of diagnosis (not simply at the point that the impairments become symptomatic).

—David Ruebain

See also Air Carrier Access; Communication: Law and Policy; Housing: Law and Policy.

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DISABILITY IN CONTEMPORARY AFRICA

Africa is the second largest continent in the world with 40 countries and a population of 800 million people. Geographically, it is often divided into northern Africa and sub-Saharan Africa. Northern Africa is mostly Muslim, while sub-Saharan Africa is mainly Christian. Africa is a continent of contrasts—geographically, economically, and culturally. Geographically, Mount Kilimanjaro in northeastern Tanzania (the highest mountain in Africa) stands at 20,000 feet, while the Sahara Desert in Egypt sinks 436 feet below sea level. African countries range in size from Togo with a land area of 21,927 square miles to Sudan with 967,495 square miles. Economically, Africa is generally a poor continent—some of the poorest countries in the world are in Africa—and yet it hosts some very rich coastal trading countries and some of the wealthiest individuals. Add to these contrasts the extensive varieties of languages and ethnic groups; the South African government alone recognizes 11 official languages in the country.

What this means is that Africa has a mosaic array of cultures within which disability exists. It is important to understand disability in Africa within this context. Rich cultural heritages—indigenous, traditional, and modern—provide an essential context for understanding disability. Within this context, poverty and its implications are the major problems in Africa—both as a cause and as a consequence of disability. Nevertheless, disabled people and their organizations in Africa are pursuing a rich path to development that provides strength and spiritual force for economic self-determination and political empowerment at the individual and collective levels. They will need these forces for the "long journey towards inclusion in development as a contribution to the transformation of the African continent" (Lorenzo 2003:776).

CULTURAL CONTEXT OF DISABILITY IN AFRICA

Traditionally, disability was viewed suspiciously and negatively in Africa, but as Chimedza, Mpofu, and Oakland (2000) observed, the situation is changing to a certain degree. Africa today is made up of a rich cultural heritage, both indigenous traditional and modern. The majority of the millions of citizens of Africa live in rural areas, and in the main they hold indigenous traditional worldviews. A minority of Africa's citizens live in towns and cities, and in the main most of these people subscribe to modern scientific worldviews as a result of the continent's colonial heritage and modernization (Mpofu forthcoming). This affects the African people's understanding, definition of, and interaction with disability. For example, indigenous traditional African societies view or define disability as "a limitation in social role functions resulting from physical, sensory or emotional abnormalities and is of a spiritual nature" (Mpofu and Harley 2002:27). This view is reflected in the proverbs that are used in relation to disability (Devlieger 1999) and in the nature of the words they use to describe and to define disability (Burch 1989; Devlieger 1998; Mpofu 1999). Thus, the Bantu languages in sub-Saharan Africa, for instance, have the suffix *-rema* or *-lema* (i.e., becoming heavy, to fail, to experience difficulty or foolishness) in words that refer to disability. The implicit meaning is that having a disability makes one incapable of many roles. Moreover, in many of these languages the word *rema* or *lema* is prefixed by the object or animal referent *ki*, *chi*, or *isi* (for "it") as in *kilema* (e.g., in Lebe, Sanga, Songye languages: Angola, Congo, Zambia); *chirema* (Shona language: Zimbabwe, Mozambique); or *isilima* (Ndebele, Nguni, Zulu: Malawi, South Africa, Tanzania, Zimbabwe). Therefore, the traditional African view of disability places a person with a disability somewhere between a human being and an animal or object. This view is demeaning and pejorative even in those cultures and yet continues as acceptable everyday practice. Unfortunately, it promotes wrong messages, attitudes, and stigmas against people with disabilities by dehumanizing them as objects, things, and animals.

Generally, proverbs in the African cultures are used mainly as words of wisdom to advise and warn each other on topical issues and situations. Proverbs on disabilities in the African languages serve a similar function. Kisanji (1995) argued that

> in traditional Africa, proverbs generalize a community's experience and that each proverb was accompanied by a parable which provided a sketch of the original situation . . . understanding proverbs to do with disability in African languages helps understand the attitudes towards disability and persons with disability in the society.

It is therefore important to understand the nature of disability as portrayed in the African proverbs. Several themes tend to run across most proverbs in eastern and southern Africa (Devlieger 1999). There is fear by people without disabilities of becoming disabled. One sees a sense of insecurity related to disability in many of these proverbs. For instance, there are several proverbs that send strong warnings against laughing at disability or at persons with disabilities. The proverb "Tosepanga lemene, Efile kiakupanga" (Don't laugh at the disabled person, God keeps on creating you) is widely used among the Songye people. The theme is also expressed in many other countries in Africa, for example, Zimbabwe (Shona): "Seka hurema wafa" (Laugh at disability after you are dead); Tanzania (Swahili): "Cheka kilema, uzae kilema" (Laugh at a deformed person, and you will bear a deformed person); and Zambia (Chitonga): "Haaseka bacembele bulema buzya buseka" (To him who laughs at old people, a crippled state comes laughing). The implications of laughing at persons with disabilities make clear the insecurity of any person's life. This insecurity is obvious for the persons with disabilities, but the possibility of becoming disabled is emphasized as a possibility to everyone. The message "it can happen to you one day in life" is very clear.

The other theme that seems to characterize proverbs on disability in Africa especially in sub-Saharan Africa is that there seems to be a general acceptance of the limitations of disability. For instance, this acceptance is clearly illustrated not only concerning the vulnerability of being blind but the acceptance of the limitations of that condition. Examples of this can be found in Zimbabwe (Shona): "Bofu harimemi hunza" (A blind man does not inspect a game pit) and Senegal (Wolof): "Gumba du jiite yoon" (A blind person should not lead the way) (see Devlieger [1999] for more examples). These proverbs offer a different way of thinking in contrast to the rehabilitation approach to disability, according to which the disadvantages of disability may be reversed or compensated.

By contrast, the third theme shows that there appears to be a general acceptance of people with disabilities as a source of integrity and family connectedness in some of the proverbs. The point these proverbs make is that although persons with disabilities can face negative attitudes and laughter elsewhere, the family is one source of consideration and respect. People cannot laugh at or look down on a member of their family who has a disability. It is unacceptable. Examples of this can be found in Tanzania (Swahili): "Mama hawezi kumkana mtoto, hata akiwa na vilema" (A mother cannot repudiate her child, even if it has defects); Zambia (Chewa): "Mako ndi mako usamuone kuchpa mwendo" (Your mother is your mother even if she has a deformed leg); and Zimbabwe (Shona): "Benzi kunge riri rako, kudzana kwaro unopururudza" (If an idiot is a member of your family, you applaud his dancing).

One of the major challenges of understanding disability is to address the meaning of disability in a cultural context. Such meanings are no doubt situated in the tensions between language and the experience of disability. Language is the vehicle of our thoughts, feelings, attitudes, and ideas toward objects, ideas, and people. The language that people use to describe other people if negative shows the enshrined negative attitudes and stigmas that have been accepted as normal in that society. Through its language, the African traditional society perpetuates a mixed culture that generally looks down on people with disabilities. People with disabilities then continue to experience significant social stigmas. For example, studies in schools have revealed that students with disabilities are discriminated against by their peers and teachers and are more likely to be ascribed more negative characteristics (e.g., dirty, lazy, useless, dishonest) than their other classmates (Chimedza et al. 2000; Mpofu 1999; Barnatt and Kabzems 1992).

At the same time, it is important to note that in some traditional African communities disability is accepted as a positive attribute. People with disabilities are revered in some communities in Africa. Some disabilities are viewed as having extraordinary powers that influence the community (Mpofu 2000; Ingstad 1995). In such cases, positive attitudes and beliefs about disability exist. However, such communities are few and limited to specific disabilities (e.g., a one-eyed person is believed to see better than a two-eyed person and to possess extraordinary vision-based powers; some psychiatric disabilities are viewed as spiritual gifts). For instance, among the Chagga people of eastern Africa, children with disabilities are regarded as hosting evil spirits, thus guaranteeing the safety of the whole community from the same spirits (Devlieger 1995). In such situations, some African people with disabilities seem to enjoy much more acceptance among their community than elsewhere.

In contrast to these indigenous, traditional views of disability, modern African views of disability are emerging, largely influenced by the West—particularly through education and modernization. For example, a modern Zimbabwean definition of *disability* is "a physical, mental or sensory condition which gives rise to physical, cultural or social barriers inhibiting an individual from participating at an equal level with other members of society in activities, undertakings or fields of employment that are open to other members of society" (Government of Zimbabwe, Disabled Persons Act 1994, p. 51). Such definitions conform to modern worldviews of disability.

THE PROBLEMS OF DISABILITY IN AFRICA

Of the 800 million people living in Africa, estimates of the prevalence of disabled people range from 3 to 18 percent, or approximately 50 million individuals. The DISTAT (United Nations Disability Statistics Database) figures (as reported by Elwan 1999:6) provide high estimates of 18 percent of people under 15 years of age in Ethiopia, to low figures of 3 percent in Malawi, with several other African countries falling within the range of 10 to 15 percent. In some areas, this number may be higher, as in some villages in Zaire, where more than 30 percent of the population may be affected by river blindness (Coleridge 1996:106).

Poverty and disability are linked. Limited access to adequate health care, education, and employment increases the risk of illness, injury, and impairment. Perhaps one of the most dramatic examples is the AIDS pandemic. Worldwide, 39.4 million people are infected with HIV/AIDS. The World Health Organization (WHO) reports the highest rates of infection in Africa and estimates that disabled people—especially those with hearing and visual impairments—are two to three times at higher risk for infection than other groups because of their lack of access to education and health care. Disability is thus a life-and-death survival issue in many parts of Africa (Disabled People South Africa 2000). By world standards, the situation is bleak.

The main cause of disability in Africa today is poverty. Unlike developed countries, diseases that are otherwise preventable such as polio, measles, tuberculosis, and meningitis continue to cause impairments and disability in Africa. This situation exists because governments are too poor to afford preventive measures for these diseases, or they have not prioritized prevention in their development agenda. Another cause of disability that is poverty related is malnutrition. Both severe malnutrition and undernutrition cause disability. Children either die or become disabled due to malnutrition and starvation simply because there is no food to eat. This situation is more common in wartorn parts of Africa. Wars in such countries as Rwanda, Burundi, Angola, Congo, and Sierra Leone have resulted in significant numbers of injuries and disabilities. Because of wars, children and women suffer and become victims of death and disabilities. The United Nations estimates that 45 million land mines are buried in 11 African countries with Egypt, Angola, and Mozambique the most affected (Onasanya 2004). This situation will cause more disability if not managed properly.

Lack of resources due to poverty and war, in combination with cultural values, means that service provisions for people with disabilities in most African countries are very limited. For example, less than 1 percent of the approximately 6 million children with disabilities in sub-Saharan Africa who are school age attend school (Chimedza, Mpofu, and Oakland 2000). Until recently, the education of people with disabilities was left to missionaries, charitable organizations, and individual philanthropists with minimal support from governments. It is only recently that governments are beginning to participate in providing services to people with disabilities but still in a very limited way. Yet the education of people with disabilities in Africa has come a long way. In precolonial Africa, children with disabilities were educated with the rest of the community in the village under the tutorship of the elders. There were no special sessions or special institutions to educate children with disabilities. Everyone was integrated within the learning community. However, with the advent of postcolonial formal education, children with disabilities began to be educated in special schools isolated from the rest of the community. These usually were boarding mission schools. For a long time, this was the only model of special education available in Africa. Whereas special schools still exist and are used in most countries in Africa, most current practices favor the integration and inclusion models of special education.

It is important to note that the concepts of integration and inclusion as used in various countries in Africa may not necessarily mean the same both within and outside of Africa. For instance, the concept of integration in general suggests bringing the student with disabilities into the mainstream of the school system so that the student learns together with the regular students. Hence in the United States, the same concept is called mainstreaming. In integration—whether it be in schools or in communities—the focus is on changing the person with disabilities to fit into the mainstream of the system. Persons with disabilities are assisted to adapt and function so that they can cope with the system by provisions of back-up support and training. However, in real terms, in countries in Africa such as Zimbabwe, integration has often meant a geographical process of moving a child with disabilities physically into the mainstream school. This process ignores issues of whether the child with disabilities is learning or not.

Most African governments have accepted integration as the best form of education for people with disabilities without considering the implications. The issue of the integration of people with disabilities is one that has to be considered with care and detachment. Many teachers have expressed reservations about integration of people with disabilities despite its advantages. Some scholars have pointed out that the integration of children into ordinary schools has many implications for teachers and planners. For example, integration requires attitude change, additional teaching materials, resource teachers, and modification of infrastructure (Peters 2004). Placement of students with disabilities into ordinary schools without the relevant provisions is frustrating to both the school authorities and the student.

The other concept that is commonly used in the education of children with disabilities that needs unpacking for Africa is inclusion. Inclusion should not only be a policy but a practice. Inclusion should include inclusive schooling, inclusive education, and inclusive societies. Most African societies' inclusion practice is limited due to negative attitudes and stigmas that are prevalent in these communities. Inclusion should not aim to change the person with disabilities to fit the environment. Instead the aim is to change the environment to accommodate the needs of the person. In practice in most African countries such as Uganda, the inclusion of children with disabilities in schooling means all children with disabilities must go to the school nearest to their home. This is the school where their siblings, friends, and neighbors go irrespective of the accessibility and pedagogic appropriateness of the school. In other words, inclusion may mean placing the person with disabilities into the community with or without support. Unfortunately, most Africa economies are not able to support and sustain inclusion in the same manner as in the West. The idea therefore is to adapt these concepts to fit the sociocultural and economic contexts of Africa.

Governments' services and support to their citizens for education and other services are generally facilitated or enabled through legislation and budget allocations. This support is critical to ensure that the citizens get the required services. Most countries in Africa do not have legislation on disability. There are no acts of Parliament that give comprehensive attention to disability. This situation affects the funding of disability supports, and in most cases does not become part of the national budget. Disability issues are then funded through an external donor project or become a sidelined peripheral issue within a Ministry allocation. Generally, almost all national constitutions guard against the discrimination of their citizens on any grounds. Some of these constitutions (e.g., Zimbabwe) go on to enumerate the basis on which people should not be discriminated against (e.g., race, color, tribe, gender, poverty, political affiliation) and in the process they usually fail to include disability. While one can argue that disability is implied, the omission causes problems.

Finally, in terms of employment, the situation of people with disabilities in Africa is fraught with significant problems. In general, there are high rates of unemployment in the formal sector in Africa and people with disabilities are worse off than their nondisabled counterparts with regard to employment opportunities. In the past, the practice was to train people with disabilities in basic trades such as shoe mending, basketry, leatherwork, pottery, weaving and crocheting. Such trades are no longer viable. Moreover, some people with disabilities now have professional and higher academic qualifications to compete in the current professional job market. There is no country in Africa that has an affirmative action system of employment whereby people with disabilities have a certain number of jobs reserved for them in employment. Although some people with disabilities have been employed in professional and other high-level jobs, generally they are unemployed or underemployed, and they get very little promotion once they are hired. Some turn to begging for survival since there are no state "social security" benefits. The only social security for most of Africa is the family support system.

THE NEW AFRICAN RENAISSANCE

> Nothing about us without us.
>
> *Friday Mavuso*

Despite the problems, the disability rights movements in Africa have organized and grown, over the past 25 years, at a rapid rate. The activities of disabled people's organizations (DPOs) and their leaders provide much hope and lessons to learn for other regions of the world. Every country in Africa has organizations of disabled people that are growing in numbers and in power. In South Africa, Friday Mavuso (who became a paraplegic as a result of a gunshot fired by a police officer) became legendary in the township of Soweto for his charisma and political savvy. The organization that he founded during South Africa's struggle for liberation from colonial rule—Self Help Association of Paraplegics (SHAP)—became a model for bringing about economic empowerment and social transformation for disabled people throughout sub-Saharan Africa (Laclave 2004). The well-known slogan "Nothing about us without us" was popularized by Friday Mavuso and has been adopted by DPOs worldwide. Disabled People South Africa (DPSA) grew out of efforts like SHAP and now enjoys membership of more than 12,000 disabled people and is influential throughout Africa and the world. DPSA currently holds special consultative status with the Economic and Social Council of the United Nations. Disabled Peoples' International (DPI), one of the leading DPOs at the international level, benefited for several years from the leadership of another well-known African disability activist, Joshua Malinga of Zimbabwe.

In its 2002 Annual Review, Action on Disability and Development reported that in Burkina Faso alone, memberships of DPOs increased by 21 percent in that year. From the National Union of Disabled Peoples of Uganda, to the South African Federation of Disabled People, to the Federation of Disability Organizations in Malawi, much is happening at the country level in Africa. As a result of these groups' advocacy and development efforts, persons with visual impairment in Ghana and Sierra Leone now vote with tactile ballot guides, and most governments have developed not only accessible voting standards but a wide range of legislation and policies that address the basic rights of disabled people to quality of life and active participation in their communities. Some African countries now include disabled representatives in government at the national level. South Africa's 1997 *White Paper on Integrated National Disability Strategy* now guides government policy in all sectors of national initiatives.

In addition, UNESCO and UNICEF report growing numbers of community-based rehabilitation programs and inclusive education programs that seek to improve the quality of life of disabled people through education, employment, and access to health care.

The African Decade of Persons with Disabilities (2000–2009) was adopted by Declaration of the Organization of African Unity in July 2000, with its secretariat based at the South African Human Rights Commission in Johannesburg. Decade activities and Plan of Action are the responsibility of the Africa Rehabilitation Institute and are coordinated and monitored by the Pan-African Federation of Disabled People (PAFOD). Regional federations have been formed in the South, East, West, North, and Central Africa to oversee work at the regional level. The overall goal of the African Decade of Persons with Disabilities is full participation, equality, and empowerment of people with disabilities in Africa. Eight objectives have been formulated for the African Decade: (1) contributing to poverty alleviation; (2) combating causes of disability; (3) strengthening the African voice; (4) awareness raising and sensitization; (5) putting disability on the social, economic, and political agenda; (6) spearheading the implementation of the UN Standard Rules; (7) addressing issues pertaining to children, youths, and women with disabilities; and (8) using the UN Standard Rules as a basis for policy and legislation. The Plan of Action for the Decade, developed in Addis Ababa in 2002, targets 12 specific objectives, including (1) support of community-based service delivery; (2) programs to alleviate poverty; (3) ensuring representation of disabled persons at national levels; and (4) addressing the needs of the most vulnerable—women and children.

While it is impossible to adequately report the range and scope of activities related to the African Decade declaration and Plan of Action, some examples are illustrative. First, the plight of disabled women has received special attention. In Beijing, for the World Congress on Women's issues, disabled African women participating in the World Congress initiated the African Network of Women with Disabilities (WWD) formulated in 2001. The initiative focuses on reproductive health and HIV/AIDS for women with disabilities. Various disabled women's support groups throughout Africa have been formulated and have generated a variety of economic, health, and social support systems that address their specific needs.

The CBR Africa Network (CAN) was established in 2001 to promote community-based rehabilitation (CBR) as a participatory strategy in Africa (reported in *Disability World*, Issue No. 21, Nov.-Dec. 2003). CBR as a philosophy and practice has been in existence since at least the early 1970s. CBR is a "strategy within community developed for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR is implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education and social services" (ILO/UNESCO/WHO 1994 as reported in Ingstad 2001:781). However, early CBR efforts focused on the individual rehabilitation component. The new wave of CBR efforts, as envisioned in Africa, focuses first and foremost on collective equalization of opportunity and social integration of disabled people. In Kenya, for example, itinerant CBR workers conduct an "open education" program in rural areas. These workers visit blind children in their homes and work with the parents to provide early stimulation activities that will assist them in entering school. The workers also provide Braille lessons in schools, and attend teacher staff meetings to assist in planning and curriculum adaptation. Tanzania uses a similar model of itinerant CBR workers in schools, funded by the Tanzanian Society of the Blind (Peters 2004:30).

However, CBR in some African countries has met with cultural problems. For instance, CBR is based on the concept of volunteerism. This concept rarely exists in African communities in the same manner as it does in the West. People do not just volunteer to work for nothing, especially when their families do not have enough to eat. Traditionally, they worked in the village or the chief's field for free because when there was hunger the chief used the produce from that field to feed them. They volunteered to assist in the fields of a neighbor because there was a beer-drink at the end. After all, in most of Africa, disability is a family and not a public issue. This view is one reason why early CBR foreign workers complained that African families were hiding their children with disabilities. The reality is that the families were protecting their children with disabilities from these outsiders. The situation changed once the families understood the mission of CBR. A case is given, for instance, in Botswana, where a daughter-in-law who was looking after her blind mother-in-law refused to have her trained in mobility and orientation so that she could move independently around, since her husband and his relatives would view her as very irresponsible to let the mother-in-law wander around guided by a stick.

In charting the way forward, the Office on the Status of Disabled Persons in Africa has targeted economic empowerment, social services, capacity building and empowerment of DPOs, and reinforcing policy and legislative frameworks for disability rights throughout Africa. Overall, the African renaissance approach to problems of disability and African solutions to the problems hold the promise of models for the rest of the world to learn from.

—Robert Chimedza and Susan J. Peters

See also Experience of Disability: Sub-Saharan Africa; Inclusive Education; "Nothing about Us without Us"; United Nations.

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DISABILITY IN CONTEMPORARY AUSTRALIA

According to a 1998 national survey of disability conducted by the Australian Bureau of Statistics, there are more than 3.6 million Australians with disabilities. This number corresponds to 19 percent of the

Australian population. The census also found that there were another 3.1 million Australians who had an impairment that did not restrict them in their daily lives. This means that over one-third of all Australians live with some form of impairment. The vast majority of disabled Australians do not rely on government assistance. There were 658,915 Australians on the Disability Support Pension in 2002, of whom 406,893 (or 61.75 percent) were men and 252,022 (or 38.25 percent) were women. The most common primary medical conditions reported by people on the Disability Support Pension were musculoskeletal, psychological/psychiatric, and intellectual/learning impairments. The most commonly reported problems facing disabled Australians were a need for assistance with mobility, property maintenance, health care, self-care, and transport.

The overall rate of labor force participation for the entire Australian population is 76 percent, but only 53 percent of people with a disability are in the labor force (Australian Institute of Health and Welfare [AIHW] 2000). Disabled Australians are entitled to many different forms of government assistance, including income support (such as the Disability Support Pension, Sickness Allowance, and Mobility Allowance). State and federal governments also provide funding for employment programs, home and community care programs, aids and appliances programs, and other services. Work-related disability programs are also provided by the Commonwealth Rehabilitation Program, which receives more than $100 million in funding.

According to a study by the AIHW (2003), 1,737 800 people, or 48 percent of disabled Australians, used some form of aid in 1998. The sorts of aids used by disabled Australians include wheelchairs (both electric and manual), scooters, canes, crutches, walking sticks, seating and bedding aids, incontinence aids, nebulizers, dialysis machines, ventilators, and hearing aids. The AIHW reported that the use of aids was particularly prevalent among people with sensory, speech, and physical disabilities.

The commonwealth government first began providing financial support for disabled people in 1908, when it introduced the Invalid Pension and Old Age Pension. In 1944, the commonwealth government felt a need to establish a social security system that would protect citizens from the extremes of a market economy and began providing Sickness Benefit Payments and Unemployment Benefits. The period from the 1950s to the 1970s was characterized by economic and political stability, as well as full employment, and the idea of a comprehensive social security system was consolidated at this time.

Australia's modern disability policy took shape after the International Year of Disabled Persons in 1981. The 1980s saw a shift away from placing disabled people in institutions; the introduction of the Commonwealth Disability Services Act, which provided a framework for the provision of disability services; and the formation of a large number of disability organizations. In 1991, the federal Disability Reform Package was introduced, which aimed to maximize the employment of disabled Australians and a 10-year Commonwealth-State Financial Agreement clarified the roles of respective governments with regard to the provision of disability supports and services.

A number of legal mechanisms have been developed to protect the human rights of disabled Australians. The Human Rights and Equal Opportunity Commission is the main body charged with protecting the rights of disabled people and advocating on their behalf. It administers the Disability Discrimination Act, which was introduced in 1992 and which aims to eliminate discrimination against people with disabilities and to promote equal opportunity for disabled Australians. The Disability Discrimination Act covers a wide range of areas, including work, accommodation, education, and access to premises, clubs, and sports, and it prohibits both direct and indirect discrimination on the grounds of disability. There are also Disability Discrimination Act Standards, which specify in more detail rights and responsibilities about equal access in particular areas, such as employment, public transport, education, accommodation, and in the administration of commonwealth laws.

The Commonwealth Disability Strategy, first introduced in 1994 and revised in 2000, is designed to provide equal access to commonwealth government services for people with disabilities. It encourages organizations to provide information in flexible formats, purchase accessible services, employ disabled staff, and consult with people with disabilities to find out their needs.

National, regional, and local disability advocacy organizations are funded under the National Disability Advocacy Program. Some of the more influential disability organizations in Australia, which are represented in the Australian Federation of Disability Organizations, are Blind Citizens Australia, Deafness Forum Limited, the National Ethnic Disability Alliance, Women with Disabilities Australia, National Council on Intellectual Disability, Physical Disability Council of Australia, Head Injury Council of Australia, and the Australian Association of the Deaf.

A major review of Australia's welfare system (including the Disability Support Pension) was announced by the minister for Family and Community Services, Senator Newman, on September 29, 1999. The review was prompted by concern over the growth in spending on welfare payments and services (to a point where it had reached a third of total budget outlays). Also, the number of Australians in receipt of welfare had grown rapidly from 1.5 million people in 1989 to 2.6 million people (one in five Australians) in 1999. In particular, the number of Australians on the Disability Support Pension had grown from 300,000 in 1989 to 600,000 in 1999, and it was predicted to rise to 750,000 in 2006. This level of "welfare dependency" had created the urgent need for reform, Senator Newman said.

Despite the presence of this significant social welfare system, significant unmet needs have been identified within the Australian disability community. In 1998, the Australian Bureau of Statistics reported that more than 24,000 people with a profound or severe disability received no assistance at all, and more than 41,000 carers received no assistance or support. Also, many of the services that were designed to provide respite care are not able to perform those functions because they are being used by people in need of long-term solutions who cannot be housed elsewhere. An acknowledgment of this problem can be found in the 1998 report by the New South Wales Community Services Commission, which estimated that 40 percent of respite beds are not being used for this purpose.

Another of the major disability issues in Australia over the past five years has been the inappropriate placement of young disabled people in nursing homes. Approximately 6,000 disabled people under the age of 65, including 1,100 under the age of 50, currently reside in Australian nursing homes. The majority of these people have acquired brain injuries, multiple sclerosis, and other neurological conditions. A national summit on young people in nursing homes attracted 180 people in May 2002, and 500 people attended a national conference in 2003 titled Unlocking Potential: From Vision to Reality.

In recent years, a number of Australian disability rights groups have taken up the issue of discrimination against disabled immigrants and refugee seekers. Sometimes, lawsuits have been instigated around these cases. For instance, in the case of *Inguanti v. Minister for Immigration and Multicultural Affairs* (2001), a man with an intellectual disability was denied a visa that would have allowed him to live with his brother in Australia. His brother was his legal guardian, and the man had significant financial resources to support himself. However, the decision of the Migration Review Tribunal was that the man's intellectual disability was likely to require the provision of health care or community services that would result in a significant cost to the Australian community, and on this basis he was denied a visa. This decision was subsequently set aside after an appeal to the Federal Court of Australia.

The circumstances of this case were similar in some respects to another federal Court case, *Minister for Immigration & Multicultural Affairs v. Seligman* (2001). In this case, an application for a visa by a successful South African businessman and his family was denied because the family included a 22-year-old son who has a borderline intellectual disability. The son's intellectual disability was also deemed as "likely to require the provision of health care or community services which would result in a significant cost to the Australian community," even though a substantial trust fund had been established to support him, and he had an offer of employment as part of the Community Services provided by the Australian Jewish Welfare Society. The initial denial of a visa was subsequently overturned. Not all of the appeals in this area have been successful, however. The case of *Blair v. Minister* *for Immigration & Multicultural Affairs*, for instance, upheld the refusal of a visa to a 9-year-old boy, Michael Courey (who has a mild intellectual disability, hypothyroidism, and a hearing impairment), on the grounds that he would be likely to require health care or community services in Australia.

In recent years, the National Ethnic Disability Alliance (the peak body in Australia for disabled people from non-English-speaking backgrounds) has been advocating on behalf of the rights of disabled children in refugee detention centers. There were 16 children identified as disabled who were in detention centers in 2002, with impairments including cerebral palsy, hearing impairment, vision impairment, acute dwarfism, Perthes disease, and Fragile X syndrome. The National Ethnic Disability Alliance also suggested that the numbers of children with invisible disabilities may be much higher than these figures indicate. It has argued that keeping disabled children in refuge detention centers amounts to a fundamental violation of their human rights and is highly inappropriate. It also places this situation in the context of broader patterns of disadvantage and discrimination, suggesting that three-quarters of disabled people from non-English-speaking backgrounds do not receive any commonwealth-funded disability services.

Australian women with disabilities are particularly disadvantaged. Women with Disabilities Australia reports that although women make up half of the overall population of people with disabilities, they experience labor market marginalization and poverty at much higher rates than other Australians, including men with disabilities. More than half of all women with a disability in Australia earn less than $200 a week. Also, the rates of employment for disabled women are almost half those of disabled men. Entry into vocational rehabilitation programs is also more difficult for women with disabilities. However, the open employment services funded by the commonwealth government largely assist men rather than women: In 1997–1998, these services provided two-thirds of their services to disabled men. Compounding these vocational barriers, women with disabilities are also less likely to receive appropriate health services than nondisabled women, are more likely to be institutionalized than disabled men, experience higher rates of violence and abuse than other Australians, and are more likely than other Australians to experience barriers in access to telecommunications (Frohmader 2002).

The continuing, unlawful sterilization of women with intellectual disabilities is another major human rights issue in Australia. Some of the reasons given for the sterilization of women with intellectual disabilities include the need to prevent pregnancy, manage menstruation, and improve personal care. The unlawful nature of these sterilization procedures has been recognized in a number of reports from state and federal governments, as well as other organizations including the Human Rights and Equal Opportunity Commission. In 2000, a resolution was passed in the Australian Senate that called for a review into the legal, ethical, and systemic issues surrounding this issue.

Indigenous Australians have many unique experiences with regard to disability. Many Aboriginal and Torres Strait islander communities have different definitions of *disability* from those used by Western professionals. The difficulties measuring the extent of disability in Aboriginal and islander communities is compounded by the fact that there is a dearth of literature on this topic. However, one study in New South Wales conducted by Thomson and Snow (1994) found that Aboriginal people were more than twice as likely to be disabled than other Australians. This study reported that sensory impairments were most common, followed by musculoskeletal impairments, circulatory system disorders, and respiratory disorders.

—Mark Sherry

See also *Scott and Disabled Peoples' International (Australia) v. Telstra.*

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DISABILITY IN CONTEMPORARY CHINA

China is a land of contrast and change. The world’s most populous nation (1.3 billion) is in the throes of rapid development, enjoying the benefits and suffering the stresses of integration in the world economy, with widening disparities between rich and poor, rural and urban, disabled and nondisabled. Communist China’s transition to a market economy has increased the marginalization of already vulnerable individuals through dismantling the “iron rice bowl” of a job and basic security for life, introducing a competitive labor market, and the gradual weakening of nonprofitable primary care services. Partly in response to this, the Chinese government has initiated a series of laws and programs to improve the life chances of disabled people. The driving force has been Deng Pufang, president of the China Disabled Persons’ Federation (established 1988), a wheelchair user and son of the late Chinese leader Deng Xiaoping. The benefits have mostly been felt in large cities, where access to education, employment, high-tech medical services, and community-based rehabilitation has increased for those with money, good social connections, and less severe impairments. In rural areas where most Chinese disabled people live, access to such services is severely restricted and in some areas, millions of disabled people live below the absolute poverty line. With per capita gross domestic product in 2001 of US$4,020 (compared to US$34,320 in the United States), China is still a developing country.

BRIEF HISTORY

The People’s Republic of China was founded in 1949. Mao Zedong, leader of the Chinese Communist Party, propelled China toward his vision of a self-reliant socialist state. The Mao decades were characterized by upheaval: organizing the masses into collectives and work units, exhorting them to rapid industrialization and repeated revolution, with some devastating effects. Even so, when Mao died in 1976, China had higher levels of adult literacy, life expectancy, and living standards and a more stable economic base. Isolationist in relations with the West, China seemed a model of socialist development.

The Cultural Revolution (1966–1976) left a deep scar and a readiness for new direction. Deng Xiaoping responded with far-reaching reforms embracing market economics and opening China’s doors to the world. Deng legitimized personal profit and ownership to achieve a prosperous China: What difference if the cat is black or white, so long as it catches mice? Collective farms were divided and allocated to individual households. Town and village commercial enterprise was encouraged. In cities, state work units gave way to a competitive labor market. Special Economic Zones to attract and control foreign investment powered economic growth in southern and eastern coastal regions.

The demise of work units marked the end of the so-called iron rice bowl of a job and basic security for life. Millions saw their standard of living rise. More experienced job insecurity and relative poverty. The potential for social instability, compounded by large-scale rural-urban migration, strengthened the government’s resolve to restrict population growth. The one-child policy was a response to fears of endless poverty due to overpopulation. The policy became less draconian over time but it remains, in modified form, part of Chinese life. China’s economic and social landscape had been transformed again, but political reform was absent, as shown by the repression of pro-democracy demonstrations in Tiananmen Square on June 4, 1989.

Since Deng’s death in 1997, China has become more liberal economically, socially, and culturally, but the Chinese Communist Party still represses those who speak openly against the government, seek independence (Tibet, Xinjiang), or may threaten social order (Falun Gong). The third generation of political leaders (Hu Jintao succeeded Jiang Zemin as president) has continued to focus on economic growth and social stability. Integration into the world economy has been accelerated by accession to the World Trade Organization. Economic growth has now averaged 10 percent for two decades. Urbanization is predicted to reach 45 percent by 2010. In some cities, population pressures and resource shortages mean that per capita availability of water is among the lowest in the world. Environmental degradation and industrial pollution are cause for global concern. The 2003 United Nations Human Development Report ranked China at 104 out of 175 countries, yet vast tracts of western inland China would rank with the world's least developed countries. In 1997, there were 58 million people estimated to be living below the international absolute poverty standard. The aging pyramid structure of China's population (one child supporting two parents and four grandparents) is a constant anxiety. China has a vibrant economy and a dynamic population, but it faces some of the world's most daunting social, economic, and environmental challenges.

DISABILITY ON THE AGENDA

There are 60 million disabled people in China (5 percent of China's population). They are disproportionately represented among the poor and unemployed. Yet since the 1980s, and compared with countries with higher gross domestic product per capita, there has been a demonstrable attempt to raise awareness and increase life chances. The most important legislation and initiatives are the 1991 Law on Protection of Disabled Persons (promoting the comprehensive rights of disabled people to participate in all aspects of life); 1994 Regulations on Education of Disabled Persons (making education for all disabled children compulsory mainly through special education schools and classes, also promoting adult, further and higher education); and a series of National Work Programs for Disabled Persons (1988, 1991, 1996, 2001), integrating disability into the government's Five Year Plans for national development.

Enforcement of antidiscrimination legislation in China is difficult (although there have been pioneers such as the Centre for Protection of the Rights of Disadvantaged Citizens at Wuhan University). Official evaluations of progress against national program targets suggest that China's disability initiative has affected hundreds of thousands of disabled people. For example, there was an 800 percent increase in the number of disabled children in segregated (special education schools or classes) or mainstream school in 1995 compared to 1980 and a 400 percent increase in the number of segregated schools over the same period; provision of speech and hearing training to 60,000 deaf children and surgery to limit impairment from polio for 360,000 children and young adults.

Deng Pufang has spearheaded China's disability initiative. Born in 1944, eldest son of the late Chinese leader Deng Xiaoping, he became paralyzed during the Cultural Revolution. Following his father's political rise, Deng Pufang went to Canada for medical rehabilitation, where he glimpsed a different future for China's disabled people. In 1984, he set up the China Welfare Fund for Disabled Persons. In 1988, he founded the China Disabled Persons' Federation (CDPF). The CDPF is a national government agency (a quasi-ministry) and has branches at provincial, municipal, country, and township levels. It is not a membership organization. The degree of activism varies; it has been described as having a strong dragon's head and a weak dragon's body. It incorporates numerous agencies including the China Deaf Association, China Blind Association, and the China Association of Friends and Relatives of People with Mental Disabilities. CDPF aims to serve and represent disabled people. It receives government budgetary allocations and raises funds from donors inside and outside China. Deng Pufang is a well-connected figurehead for the organization: In 2003, he received the United Nations Prize in the Field of Human Rights.

Aside from Deng Pufang, two other factors have helped put disability on the agenda: statistics and international collaboration. Matthew Kohrman's illuminating analysis of the 1987 First National Disability Sample Survey reveals a complex of anxieties, pressures, and motivations relating to categorization, scientific caliber, and national self-image. The final survey comprised 1,579,314 people and covered household characteristics, self/family-identified disability, and medically certified disability. The medical survey had six categories: speech/hearing, intellectual, visual, physical, mental health, and multiple impairments. It found that 4.9 percent of individuals living in 18.1 percent of households were disabled. The statistics were sufficiently striking to legitimize a unique program of social development.

Credible statistics also enabled Deng Pufang and CDPF to participate internationally. None could have predicted the extent of China's participation in the United Nations Decade of Disabled Persons (1983–1992) or the Asia Pacific Decade of Disabled Persons (1993–2002), which China initiated. There have been numerous collaborations with UN agencies (rehabilitation pilots, training programs, publications on Western medical rehabilitation, and more recently, on practical advice for legal and social workers), not to mention the 1994 Far East and South Pacific Games for the Disabled in 1994 and forthcoming 2007 International Special Olympics in Shanghai and 2008 Beijing Olympics. Such collaborations strengthen the capacity of China's disability initiative to survive the passing of Deng Pufang's powerful father in 1997.

DISABILITY POLICY AND PROVISION

China has a long history of disability policy and provision. Fiscal and administrative disability classifications date at least to the Tang Dynasty (618–907). Ordinances on emergency relief date to the Han Dynasty (206 BC to AD 220). In the nineteenth century, foreign missionaries established schools for blind and deaf children. Under Mao, disability provision included some vocational segregated schools, mental asylums, welfare institutions (institutional provision was minimal), and Soviet-inspired welfare factories providing sheltered employment. Data on numbers and scale vary and reflect the upheaval of the Mao years, but it is likely that hundreds of thousands of disabled men and women were employed in welfare factories with larger factories operating like other state work units, providing housing and basic health services.

The economic reforms of the 1980s had a severe impact on disabled people. In urban areas, the demise and profit-orientation of work units led to unemployment, cutbacks, and shutdowns of welfare factories. In rural areas, the dismantling of collective farms seriously disadvantaged households with one or more disabled person. Free access to school and health care has been replaced by school fees, fee-for-service medical care, private medical insurance coverage (unaffordable for most), and erosion of nonprofitable primary care services.

Reversing the decline of already limited provision as well as increasing and improving services has been the task of the CDPF and the Ministries of Public Health, Civil Affairs, and Education (brought together with other government agencies in the National Co-ordination Committee on Disability, headed by a vice prime minister). The relationships between these agencies have at times been fraught and competitive. Nonetheless, CDPF has produced successive National Work Programs for Disabled Persons (1988, 1991, 1996, 2001) in line with national Five Year Plans. Key elements have been prevention, rehabilitation, education, employment, poverty alleviation, facilities, leisure, and sports. (Official statistics on progress are provided by the CDPF.)

There are continuities with the past: welfare enterprises, vocational segregated schools, minimal institutional provision, reliance on families, and limited emergency relief. There are also new developments, although many of these have been unpopular, have struggled to get beyond pilot phase (especially in rural areas), or meet only a fraction of need and demand. Examples are an unpopular employment quota of at least 1.6 percent disabled employees (many employers prefer to pay the fine, which in turn funds vocational training and support for disabled people); rural poverty alleviation programs (80 percent of disabled people live in rural areas, half of whom live in poverty); community-based rehabilitation (which has remained largely limited to a few urban areas despite its potential in rural areas); and professional training in Western medical rehabilitation and social work. Among the defining characteristics of China's disability initiative are self-reliance, population, and visibility.

SELF-RELIANCE

Disabled people are exhorted to show self-respect, self-confidence, self-strengthening, and self-reliance. Self-reliance is about earning a living and becoming a national economic asset rather than a liability, in line with the emphasis on individual and household responsibility—the touchstone of the post-Mao reforms, and on work as the central signifier of adult personhood in China. For dependent adults and children, families are expected to carry full responsibility. Welfare provision is minimal and patchy, often one-time payments to coincide with festivals, if available at all.

Employment options are self-employment, welfare enterprises (tax relief with a workforce of 35 percent disabled people, mostly run by local governments including in towns and villages) and employment under the quota system for government agencies, commercial enterprises, and nonprofit organizations (comparatively few gain genuine employment under this system).

National targets for education also feed into the goal of self-reliance. Education for disabled children is highly vocational, often linked to a specific welfare enterprise or stereotyped profession. There has also been a concerted effort to set up adult vocational training centers, retraining those who lost their jobs when some of the welfare factories closed, and assisting disabled people to find a trade for self-employment. Restoring function and enhancing employability, based on exacting notions of normalcy, lie behind some of the national targets for medical rehabilitation (speech and hearing training for deaf children, remedial surgery for children with polio), while imparting a vocational skill is seen as a central component of medical rehabilitation.

POPULATION

In 1990, the Law on Protection of Disabled Persons became China's first comprehensive piece of disability legislation (implemented in 1991). Reflecting the UN World Programme of Action, it asserts disabled people's rights to participation in social, economic, cultural, and family life. The law has been promoted extensively although enforcement through legal channels is very difficult. The law provides a framework for the development of legal, social, medical, educational, and vocational services, initiatives to reduce disabling barriers in the environment, and to limit the incidence and impact of impairment (e.g., reducing easily preventable intellectual impairments caused by iodine deficiency). More controversially, the 1994 Law on Maternal and Infant Health Care promoting better prenatal and postnatal care also includes a requirement for a premarriage medical examination to identify serious genetic, infectious, or mental diseases and, through restricting childbirth, reduce congenital impairments. The measure is repressive, even eugenic. It is consistent with government efforts to "reduce population quantity, raise population quality" and the construction of disability as a social problem (*shehui wenti*). The solution is seen as two-fold: reduce the number of disabled people, and ensure that those who are disabled can contribute to the economy.

VISIBILITY

Since its inception, the CDPF has used the media to raise public awareness of disability, to combat negative treatment and verbal abuse of disabled people, and to encourage disabled and nondisabled people to volunteer their services and raise funds (in 2003, CDPF announced 50,000 liaison centers for volunteers and 1.69 million registered volunteers). This use of national and regional media has been part of a careful and strategic approach to ensuring the long-term sustainability of China's disability initiative, and particularly of the CDPF itself, beyond the passing of Deng Pufang's powerful father in 1997 and the future passing of Deng Pufang himself. Other components of the strategy have been the National Disability Sample Survey of 1987, high-level and well-publicized international participation and collaborative programs, and the regular showcasing of individual disabled men and women who exhibit qualities commensurate with China's construct of a modern and progressive state. The need to demonstrate clear success and make a mark on China's modern landscape has also influenced decisions to pursue high-tech, high-cost urban rehabilitation centers, such as the flagship China Rehabilitation Research Center (set up in 1988 under the CDPF). The center and its equivalents in other large cities are a visual reminder of the CDPF and of what China should aspire to in line with advanced economic countries. Traditional Chinese medicine (acupuncture, *qigong*, massage) is used alongside Western medical rehabilitation, social and vocational rehabilitation, but the emphasis is on importing and developing scientific and technological rehabilitation. The handover of Hong Kong in 1997 and increased international collaboration have facilitated this, although the approach has been strongly criticized by agencies interested in expanding the access to services of poor and rural disabled people.

PROSPECTS

The current rehabilitation target of full access to rehabilitation services for all disabled people, including in rural areas, by 2015 seems remote. Imported models of community-based rehabilitation have great potential in China, but the reforms of the 1980s have weakened service infrastructures and the capacity of government at all levels to implement top-down, extensive, and nonprofitable services.

Among urban educated élites, there are signs of a discourse of rights and respect, demand for services and opportunities, and an emerging civil society of charitable and self-help groups (many led by parents of disabled children and some by disabled adults). In an authoritarian state, the capacity and sociopolitical space for genuine community-led approaches are weak and contested. The challenges for the CDPF are to empower such social enterprise, without seeing it as a threat; to continue to keep disability on the agenda in the face of growing social development pressures (including an aging population and projected exponential increase in people living with HIV/AIDS); and to expand the benefits of the disability initiative to reach the poorest of China's disabled population.

—Emma Stone

See also Experience of Disability: China.

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DISABILITY IN CONTEMPORARY INDIA

The subcontinent of India lies in southern Asia, between Pakistan, China, and Nepal. To the north, it is bordered by the world's highest mountain chain, where foothills and valleys cover the northernmost of the country's 26 states. Further south, plateaus, tropical rain forests, and sandy deserts are bordered by palm-fringed beaches. The population of India as of 0:00 hours on March 1, 2001, stood at 1,027,015,247 persons. With this, India became only the second country in the world after China to cross the one billion mark. India is home to 16 percent of the world's population, who occupy 2.42 percent of its land area, which is 3.3 million square kilometers. It has a coastal length of 7,600 km.

DIVERSITY

India's significance lies not only in its physical attributes but also in the fact that it is the world's largest functioning democracy, with regular and freely contested elections. India serves as an excellent example of facing challenges of fostering the development of plural communities and multiple identities. It is a country in which there are 15 official languages, more than 300 minor languages, and some 3,000 dialects. Twenty-four languages have more than 1 million speakers each. The most widely spoken language is Hindi, but this is the mother tongue of only about 40 percent of the population. Often Indians cannot understand each other, and they frequently use English as a link or administrative language. About 80 percent of the population is Hindu. But Hinduism is an amalgam of pluralistic beliefs and forms, often containing conflicting elements. An additional 12 percent are Muslims, deeply aware of their Islamic faith. Hindu, Urdu, Bengali, Marathi, Tamil, Telegu, Punjabi, and other languages create minorities of their own. Tribal and neoaboriginal peoples number almost 40 million. No contestant for political office can be successful without an awareness of these constituencies. This mosaic is culturally extraordinary. However, it is also a source of divisiveness in a nation where particular loyalties have a deep meaning, both spiritually and physically. Given this diversity, it is remarkable that India has remained and grown, and continues to grow, as one nation. The consciousness of the great past and the newness of the present sometimes produce an abrasive reaction.

The very word *India* implies a unity, which exists more as a tentative political form than as a human and sociocultural reality. For many in the West, India is considered as a torpid and remote conglomerate of people, which represents a combination of the exotic and tragic, a land of both poverty and plenty, a nation both powerful and weak, ancient and modern. The history of India is the history of colliding cultures—agrarian and industrial, masculine and feminine, national and imperial. Gaining independence after 200 years of colonial rule, India's progress into modernity has been fraught with all manner of fascinating entanglements, beginning of course with its knotty caste system and its ambivalent relationship with Pakistan. It seems fair to say that the identity of this great and ancient nation is at least partially defined by conflicts between the identity it wants and the one history has thrust upon it.

In all its diversity, India presents a revolutionary argument about the subtle nuances of progress and its fluid relationship with tradition. Both historically and in modern times, India has been an animated and vivacious society with a vibrant internal psyche as well as an influential relationship with the world. Modern India is home both to the tribal with his anachronistic lifestyle and to the sophisticated urban jetsetter. It is a land where temple elephants exist amicably with the microchip. Its ancient monuments are the backdrops for the world's largest democracy where atomic energy is generated and industrial development is rapidly making India a world industrial and technological leader. It is not uncommon to find fishermen along the country's coastline with simple fishing boats in a centuries-old tradition while, a few miles away, motor vehicles glide off conveyor belts in state-of-the-art factories.

Internationally, modern India has represented a middle ground in the international politics. Believing as it does in nonalignment in international politics, India has attempted to create a balance that demonstrates a viable route for nations that did not want to take sides in local conflicts. India's significance has to be understood in context of the geopolitics of South Asia. Bordering the Indian Ocean into which the Persian Gulf flows, it is a key location in an era of oil logistics. Add the proximity of Russia, Afghanistan, Pakistan, and China, and India's situation becomes critical to the tensions and interactions of current global politics.

INDIA IN A GLOBALIZING WORLD

In the past decade and half, India's economic policies have also broken new ground. They were the first large-scale test of the modern mixed economy. While these policies did usher in spectacular hopes and optimism, and assisted in the market reforms, they have also created a resurgence of ethnic politics around cultural identity, which appears poised to threaten the present world order. In India, the rise of radical Hindu nationalism, represented by Hindutva resurfaced with the integration of India in the global market. Divisive forces, in the name of religious and political ideology, have wreaked violence, chaos, and destruction violating the aspiration for a more humane order. As Indian society has moved along the road to modernity, it has led to a paradoxical scenario by creating two distinct worlds within India. There are the cities of India, where 28 percent of the population lives, and rural India, where about 600,000 villages contain the rest of the population.

Urban India is the India of modern industry, national politics and foreign policy, government planning, the national media, the major universities, business, the armed forces, science and technology. Its products are rated as some of the best in the world. This India has shopping malls, amusement parks, bowling alleys, and large department stores that seem to be drawing on the boom in the new economy sector. On the other hand, there are both urban and rural belts in which clean drinking water and electricity are not available. The onslaught of private media with innumerable private satellite channels does not fail to raise the aspiration level.

However, the drive toward upward mobility is not contained within the developing fabric of both economic and social life, creating dilemmas and discontent. With the euphoria of globalization and “high-tech civilization,” concerns about poverty, hunger, and inequality are virtually dismissed as an obsession of ideologists. This attitude has generated dangerous consequences. Both first-generation and second-generation reforms overlook various crucial issues and objectives such as eradication of poverty, prevention of concentration of economic power in private hands, avoidance of regional imbalances, and promotion of small-scale industries and village crafts. Economic development actually ran counter to these objectives. While India does and must take pride in its information technology (IT) professionals and cyber cities, it has had to recognize that there are tragic deaths by the hundreds of farmers and weavers, besides starvation deaths, in the wake of neoliberalization policies. The story of modern India is thus not simply the story of well-fed, well-clothed men; it is also the story of intense agony—loss of self and communication and relatedness. The urgent task before the government and civil society is to recover these myriad relationships so that democracy can be transformed into a rights opportunity for multiple identities and communities if a more equitable world order is to emerge.

BLEND OF MATERIAL AND THE SPIRITUAL

The most significant feature of Indian culture has been its belief that life cannot be viewed solely in terms of materialistic realities. True actualization is possible only when the attempt is made to look within, and India at its core quests for spirituality as the ultimate search. The desire to know life through, for example, yoga, art, and philosophy, persists despite the country’s modernity. Thus, an ingrained and dominant spirituality, a creative zest for life, and an intelligent combination of the rational, ethical, and aesthetical mind characterize Indian culture.

GENDERED CHARACTER OF INDIAN SOCIETY

In terms of gender issues, historically, the dominant ideologies in Indian culture have continued to operate paradoxically. While in principle they might be postulated as complementary, their actual meaning/working is oppositional. Thus, there is a strong cultural belief that while the female is opposed to the male, female is at the same time encompassed in male. This is symbolized in the figure of lord Shiva called Aard Nareshewar, where the left side is depicted as female and the right side as male. Yet the lives of women do not reflect this inclusion; large sections of women are among the most underprivileged in India. While some women from the upper classes head political parties and command large followings, women’s representation in Parliament and in state legislatures has not been more than 10 percent. There are several clear indicators of the fact that Indian women continue to be discriminated against: The sex ratio is skewed against them, maternal mortality is the second highest in the world, more than 40 percent of women are illiterate, and crimes against women are on the rise. Yet the women's movement, which gathered strength after the 1970s, has led to progressive legislation and positive change, spurred on by the participation of women in local self-government.

The most serious issue of modern India is the changing sex ratio. An alarming drop in the number of girls born in India is being blamed on a strong cultural preference for sons—coupled with cheap and widely available medical tests that can tell parents the sex of their unborn child. Data from India's 2001 census show the sex ratio for 0- to 6-year-olds fell from 945 females per 1,000 males in 1991 to 927 in 2001. The new figures give India one of the world's lowest ratios of women to men; the statistical norm is 1,050 females for every 1,000 males. The drop is largely due to the widespread but illegal practice of using ultrasound scans to identify female fetuses and then aborting them. In 1994, the Pre-Natal Diagnostic Technologies (PNDT) Act banned the practice. But it has proved toothless—seven years after enactment, not a single conviction has taken place. This is yet another indicator that technological advances may not always denote progress and growth.

CASTE SYSTEM

According to the Indian Constitution, there is a separation between religion and state. Caste discrimination is thus legally forbidden. However, in modern India, caste identity has become a subject of political, social, and legal interpretation.

Affirmative action programs in education, employment, and other spheres have been undertaken. Yet it is doubtful whether these steps have resulted in the social uplifting of the marginalized categories as there is a backlash from the communities that were high in the social hierarchy. Caste thus remains a site of contest for modern India.

DISABILITY SCENARIO

India has approximately 70 million disabled people. The unwillingness of the government to include the domain of disability in the 2001 census to obtain a conclusive idea about prevalence reflects the attitudinal barriers in acknowledging the disabled identity. Disability issues have no space in the political agenda or the most forward-looking social movements of the country. Consequently, within the dominant Indian cultural ethos, labels such as "disability," "handicap," "crippled," "blind," and "deaf" are used synonymously. The assumption of the label's naturalness is unquestioned. The roots of this assumption lie in the ideology that conceives of disability as inherent in the mind or body. This corresponds with the idea of lack and inability that is associated with these conceptions. In a culture that valorizes perfection, all deviations from the perfect body signify abnormality, defect, and distortion. Conveying feelings of inability and uselessness, disability epitomizes "failure" and is conceived of as a personal tragedy. The common perception views disability as a retribution for past karmas (actions) from which there can be no reprieve. The popular images in mythology attest to extreme negativity associated with disability in India. While sex selection is a cause for concern for social activists, killing imperfect children will not even count as a crime. The general response of the nondisabled world ranges from pity and charity, to hostility, anger, banter, and ridicule. Within this pessimistic situation, a silver lining comes in the form of disabled people themselves and their struggles to resist the system. Along with their families, their strivings to chart out a different destiny saw the first legislation for equal opportunities being passed in 1996.

Notwithstanding the different realities of education and employment, the discourse of disability activism in India itself constitutes a meta-narrative that universalizes disability. The leaders of the movement are middle-class urban men who have been educated in public schools and are representative of an "elite" background. Their fight for "disability rights" is borrowed from their Western counterparts without any clear analysis of the inherent biases. Consequently, the imported packages of "nothing about us without us," while perfectly appropriate in some contexts, are universal solutions that ignore the specifics of the Indian dilemma.

Academic and social reflection on whether these programs borrowed from the West have the potentiality of understanding and responding to the diversity of

Indian culture and concomitantly is practically nonexistent within disability activism. The fight for rights thus ends up paying lip service to the needs of diverse groups, whereas in actuality the agenda remains dictated by the understanding/needs of the leaders. While poverty exacerbates the disabled existence, the leaders fight for agendas that are their own.

India, while having a specific interpretation of disability, still has lived with values of interdependence and reciprocity. While it has a lot to learn from the West, it can contribute by becoming a role model in negotiating with diversity. It has a history of a freedom movement and struggles for land, language, and gender rights. These approaches have maintained a separate identity while keeping a unity of spirit and purpose intact. India in this sense is a perfect example of highlighting the limitations and strengths of identity politics. It demonstrates that a lot can be gained from a revitalization and reformulation of culture and tradition. India can thus contribute to disability studies a viewpoint that emphasizes a closer look at how communities mobilize locally to create a grassroots movement that initiates a culture of resistance to oppressive practices. These agendas of resistance connect local, regional, and global efforts toward the ideal of not an independent, but an interdependent, existence. India can demonstrate to the global disability movement as well as to disability studies that research and practice have to work at these interconnected levels. While according the highest priority to the rights of disabled people, it continues to adopt a sensitive, reflexive, and critical approach, thus rendering a careful interrogation of traditional values.

—*Anita Ghai*

See also Developing World; Disability Policy: India; Experience of Disability: India.

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DISABILITY LAW: CANADA

In 1982, the rights of persons with disabilities were given constitutional protection in the Charter of Rights and Freedoms, part of Canada's Constitution. As constitutional legislation, the charter applies to governmental action and legislation, including provincial and federal human rights statutes. The direct impact of the charter on the day-to-day lives of individuals is relatively limited. Indirectly, however, it has a significant impact, since it provides the framework within which provincial and federal human rights statutes operate. These statutes are considered quasi-constitutional and prohibit discrimination on a number of grounds, including disability, in areas such as housing, employment, education, and the provision of goods and services to the public.

The equality rights of persons with disabilities derive from Section 15 of the charter: "15**.** (1) Every individual is equal before and under the law and has the right to the *equal protection and equal benefit* of the law without discrimination and, in particular, *without discrimination* based on race, national or ethnic origin, colour, religion, sex, age *or mental or physical disability.*"

The charter does permit governments to implement programs that specifically help people in those groups protected by the charter. The rights of persons with disabilities are given the same degree or protection as other enumerated grounds such as religion and race.

If a statute or governmental action is found to be contrary to Section 15 of the charter, it may continue to operate if the government can demonstrate that it is justifiable in a free and democratic society. Section 1 states: "The *Canadian Charter of Rights and Freedoms* guarantees the rights and freedoms set out in it subject only to such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society." The onus is on the government to demonstrate that there is a significant societal justification for a distinction. A discriminatory provision may also stand if the government invokes Section 32 of the charter. That section states that Parliament or a provincial legislature may enact a declaration declaring that a statue or part of a statute will remain in effect despite the fact that it has been found to be contrary to

Section 15 of the charter. To date, no government has invoked this power.

The charter protections are enforced through individual actions brought in court. Administrative tribunals, including labor arbitration boards, also have the authority to interpret the charter where necessary to carry out their adjudicative functions.

Remedies available to the court under the Charter of Rights and Freedoms include declaring a statute or part of a statute invalid and therefore of no force and effect. Often when this is the result, the courts will give the government time to amend the legislation so that it complies with the charter. The court can also "read in" language to the statute so that it complies with the charter. Courts may also award damages for discriminatory treatment.

As constitutional legislation, the charter must be interpreted broadly and consistent with its overall purpose. The interests of society must be taken into account and the interpretation flexible rather than rigid. The broad purposive interpretation of the charter also extends to provincial and federal human rights legislation, which is considered quasi-constitutional.

One of the most important concepts running through recent decisions relating to discrimination on the basis of disability is the use of dignity and respect as fundamental interpretive principles. This is reflected in the duty to accommodate, the definition of disability, and the determination of undue hardship in both charter and human rights litigation. Starting with the decision of the Supreme Court of Canada in *Law v. Canada,* the courts have articulated the rights of persons with disabilities in relation to dignity. This applies not only to the underlying purpose of the charter, but it is used as a measure in determining appropriate accommodation. In *Law,* the Supreme Court of Canada set out the following steps to use in analyzing claims under Section 15 of the charter: Does the law specifically make a distinction between the individual and others or does it fail to take into account the individual's differences that may lead to disadvantage if the person is treated exactly like everyone else? Is the distinction based on a characteristic that falls within the grounds under Section 15 either those that are listed or that are considered to be analogous? Does the different treatment either impose an additional burden on the individual or does it deprive them of a benefit that others obtain from the legislation in a way that suggests that the person is a less worthy or valuable as a person or member of society or that they are less deserving of respect than others?

Some factors that may determine whether a person's dignity has been demeaned are the following: Does the individual belong to a group that has been subject to prejudice or stereotyping or is historically disadvantaged? Does the law take into account the person's own situation and needs or does it provide benefits based only on categories? Is the purpose of the law to improve the situation for people who are disadvantaged? How serious is the impact of the law and how defined is the group affected by it?

A second major aspect of charter litigation involved distinguishing between direct and indirect or adverse effects discrimination. Direct discrimination was described as intentionally treating people in one of the equality-seeking groups differently. Adverse effects discrimination in the employment context was said to occur when an employer had a policy or practice that was not intentionally discriminatory and did not treat people from equality-seeking groups differently, but nevertheless resulted in differential treatment creating a disadvantage for the individual.

In *British Columbia Government and Service Employees' Union v. Employees' Union (B.C.G.S.E.U.) (Meiorin),* the Supreme Court of Canada eliminated the distinction between the two types of discrimination in determining whether or not there was a duty to accommodate. In moving away from the bifurcated approach, the court in *Meiorin* wrote: "The distinction between a standard that is discriminatory on its face and a neutral standard that is discriminatory in its effect is difficult to justify, simply because there are few cases that can be so neatly characterized."

The Supreme Court of Canada set out a three-part test to determine whether a standard or policy is discriminatory: Is it rationally connected to the performance of the job? Was it was adopted in good faith with an honest belief that it is necessary to fulfill a work-related purpose? and Is it reasonably necessary to accomplish the work-related purpose?

The effect of *Meiorin* has been to move the inquiry from the question as to the type of discrimination to the duty to accommodate. In recent years, the Supreme Court of Canada has also expanded and clarified its approach to the duty to accommodate. The duty to accommodate is considered a significant human rights obligation. The obligation is on all parties to fully participate in the process. This includes the employer, the employee, and, where applicable, the union. The courts have been clear that unions have an obligation to participate in the process and to support accommodation measures.

An increasingly important component to the duty to accommodate is the process of determining accommodation itself. The employer has the primary responsibility because the employer controls all aspects of the work environment. However, the employee must also participate.

Accommodation must be provided to the point of undue hardship. The issue of undue hardship, however, does not arise until appropriate accommodation has been determined. The employer may not raise financial or other constraints during the initial process of deciding on the most appropriate accommodation. The onus is on the employer to demonstrate that an accommodation would result in undue hardship. What constitutes undue hardship depends on a number of factors including the jurisdiction in which the case is brought. In some jurisdictions, such as Ontario, the human rights legislation sets out specific factors that can be considered. In other jurisdictions the scope is broader. Among the factors that have been considered are the impact on a collective agreement, employee morale, the size of the employer's operation, and the operational requirements of the workplace.

In recent years, the courts have become much more demanding of the employer in terms of providing evidence of undue hardship. Concrete evidence must be provided; speculation is not sufficient. The courts have been clear that in terms of increased costs, such as insurance, there must be evidence from the insurer that the rates will in fact increase. The courts have also refused to consider the potential cost that may arise if others in the workplace seek similar accommodation, whether because of a disability or other enumerated grounds.

More recently, however, the Court has recognized that disability discrimination does not occur in isolation and that the social context and other factors must be taken into account. In *Quebec (Commission des droits de la personne et des droits de la jeunesse) v. Montréal (City),* known as *Mercier,* the Supreme Court of Canada considered three related cases involving stereotypical assumptions about disability that resulted in discriminatory treatment. The discrimination in these cases arose not because of their underlying medical condition, but because of the perceived disability in the minds of their employers.

As with the interpretation of Section 15 of the charter, and related human rights provisions, the definition of disability in Canadian jurisprudence is also broad. There is no definition of disability in the charter, and provincial human rights legislation defines it broadly. The prohibition against discrimination also applies to perceived disability, temporary disability, past disability, and association with a person who has a disability. In some jurisdictions, such as Ontario, the inclusion of these related concepts is explicit, while in others, the definitions are being expanded through the broad interpretation of Section 15 of the charter, particularly after the decision in *Mercier.*

Although there is no set list of conditions, diseases, or disorders that constitute disability, the courts have determined that alcoholism, drug addiction, smoking where it is a significant addiction, and obesity fall within the definition of disability. In determining whether a disability exists, the court is is increasingly looking at whether the condition complained of arises out of a perceived limitation, whether or not that limitation exists.

—Patti Bregman

See also Ontarians with Disabilities Act of 2001 (Canada).

Further Readings

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DISABILITY LAW: EUROPE

Disability has finally become a human rights issue in Europe. There is now a developing base of legislation in many European countries that sees its goal as the elimination of discrimination against people with disabilities, taking individual human rights as its baseline philosophy. In three countries (Austria, Finland, and Germany), the right not to suffer discrimination because of a disability is enshrined in the constitution itself, although this by no means guarantees the right is upheld, in the absence of meaningful enforcement machinery. Three constitutions provide for the general right of disabled people to be integrated into their society and place a concomitant responsibility on the state to ensure that all barriers to such integration are removed (Austria, Greece, and Italy). A number of other national constitutions also refer to the rights of disabled people in more specific, more narrowly defined contexts, for example, a constitutional right to social welfare/social security (Finland, Italy, and Portugal) or a constitutional right to appropriate education and financial support (Italy, Finland, Greece, and Portugal). In a number of countries (Austria, Finland, Greece, and Italy), the special needs of disabled people are addressed primarily through social and economic policy and associated welfare legislation, rather than through antidiscrimination laws. In other countries (Belgium, Ireland, Germany, the Netherlands, and the United Kingdom), substantive national laws have been passed developing legal rights for disabled people to equal opportunities in education, employment, or other settings. This latter trend will continue to develop apace within the European Union, at least in the context of employment and training, as EC Directive 2000/78/EC requires all member states to have introduced antidiscrimination laws in the fields of employment and training by the end of 2006 at the latest (see below), thereby marking a decisive shift within the European Union toward using the language and the tools of civil rights in the disability context.

If we look beneath the superficial modeling of legal approaches to human rights for people with disabilities, to search out the underpinning philosophy, a clear picture emerges. While all the legal approaches preach equality, and all have the potential to move toward a notion of equality, clear differentiation nevertheless exists. The basic model is premised on the concept of equal rights. This “equal rights” model ignores difference. It states that everybody has equal rights and should therefore be treated the same; for example, Article 3 of the German Basic Law states that “no person shall be disfavoured because of disability.” While it has proved a useful political tool for disability activists as a means of overcoming the medical model of disability, which remains particularly predominant in Eastern Europe, the equal rights model has severe limitations as a practical tool for reform, if only because granting equal rights to all citizens requires taking a look at difference and understanding that different people have different needs. To ignore differences helps to prevent stereotypes and stigmatization but at the price of failing to do justice to the reality of difference.

A more sophisticated model starts with equal rights and adds equal opportunities. This “equal opportunities” model accepts that where people with disabilities are at a disadvantage, for example, in their quest for employment, granting them formal equal rights without providing equality of opportunity to exercise those rights is an empty gesture. A typical manifestation of an adherence to the equal opportunities model is the requirement that employers make “reasonable adjustments” or “reasonable accommodations” to their workplaces, policies, and practices to ensure that a person’s disability does not reduce his or her opportunity to participate in the workplace on the same terms as the person’s nondisabled colleagues. Article 5 of EC Directive 2000/78/EC requires employers to make reasonable accommodations in the form of “appropriate measures where needed in a particular case” to ensure that disabled employees are not prevented from performing the essential functions of their job purely because of their disability. The directive also expressly permits these accommodations to be accompanied, if necessary by special measures or affirmative action policies, thereby recognizing that merely imposing minimal standards of nondiscriminatory conduct on employers may not be sufficient to promote equality in practical terms. Several European countries (Denmark, Finland, Ireland, Spain, and the Netherlands) have legislation in place permitting special measures of this nature to be taken in the context of employing people with disabilities. Others may follow.

The fully developed model of legal approaches to human rights for people with disabilities, which comes closest to achieving genuine equality, can be described as the "tripartite" model. This model combines equal rights with equal opportunities but adds a third and final ingredient of equal outcomes. This model recognizes, for example, that an employee with a disability who receives the same pay, and equality of opportunity, as his or her nondisabled colleagues remains disadvantaged so long as the person has to bear a disproportionate further burden of costs to support his or her personal needs. Another example is a young club-goer who uses a wheelchair and who is granted access to a nightclub at the same price, and through the same entrance, as fellow clubbers without wheelchairs but remains disadvantaged unless the dance floor itself is as safe and welcoming to the person using the wheelchair as it is to the other dancers. "Equal outcomes" builds in a redistributive balancing of resources to compensate individuals for their extra expenditure, whether it be in time or money or overcoming "attitude." By this tripartite commitment to rights, opportunities, and outcomes, the model can truly be said to have embraced a full conceptualization of equality.

The fully developed tripartite model can be deemed successful, however, only if it achieves a balance of all three factors, that is to say, rights, opportunities, and outcomes. To concentrate on equal outcomes, without equality of rights and opportunities, could lead to an undesired result that shackles other freedoms. For example, while a child with disabilities may achieve higher academic results ("outcomes") in a segregated special school, he or she may as a result have been deprived the right and the freedom to choose integrated education, notwithstanding the possibility of a lesser scholastic "outcome." Regrettably, it cannot be said that, at present, any European country has embraced the tripartite model approach to disability in any meaningful way.

EUROPEAN UNION

Article 13 of the European Community (EC) Treaty establishing the European Community (as amended by the Treaty of Amsterdam) gives the countries of the European Union (EU) powers collectively to take all necessary measures to combat discrimination. Article 13 also provides the first specific reference to *disability discrimination* within the EC Treaties. On November 27, 2000, the EU passed Directive 2000/78/EC, which seeks to establish a general framework for equal treatment in employment and occupation and to render unlawful discrimination on a number of grounds including disability. Directives reconcile the dual objectives of (1) securing the necessary uniformity of community law and (2) respecting the diversity of national traditions and structures. The goal of a directive is more that of harmonization than unification. A directive is binding on the member states as to the objective to be achieved, but it leaves it to national governments to decide how the agreed community objective set out in the directive will be incorporated within their own legal system. Each directive lays down a set time frame by which the directive must be transposed into the national law of each member state. Member states are liable to pay damages where loss is sustained by reason of their failure to transpose a directive in whole, or in part, into their national system of law (see *Joined Cases C-6 Francovich and 9/90 Bonifaci 1991, ECR 1–5403*).

By December 2003, the Non-Discrimination Directive should have been transposed into the national domestic laws of all 15 members states, although individual countries can opt to wait until 2006 before achieving full implementation. In addition, the *acquis communitaire* underpinning the accession of new countries to the EU (known as the "candidate countries") requires a specific undertaking that they will transpose directives into their national laws as a condition of entry. As a parallel initiative, the EU has established a six-year Community Action Programme (CAP), ending on December 31, 2006, aimed at promoting measures to combat discrimination. In addition, the EU Social Policy Agenda, adopted in June 2000 by the Social Policy Council, is committed to monitoring implementation of the *Communication from the Commission to Council, European Parliament, Economic and Social Committee, and Committee of the Regions. 2.05.2000COM: Towards a Barrier-Free Europe for People with Disabilities.*

The CAP to combat discrimination has three main objectives:

1. To foster a better understanding of issues relating to discrimination by improving knowledge of the problem and assessing the effectiveness of policies and practices
2. To develop the capacity to prevent and to tackle discrimination effectively, particularly by strengthening organizations' means of action and supporting the exchange of information and best practice across Europe
3. To promote and disseminate the values and practices underlying the fight against discrimination, including the use of awareness-raising activities

To achieve these objectives, the program is supporting a number of activities. First, it has established Groups of Independent Experts who assist the commission and the member states in monitoring the transposition of the antidiscrimination directives into national law. The groups, consisting of experts from all member states, meet on average twice a year and provide an annual report to the commission. The Group of Independent Experts on disability has produced a major report on the states of anti-disability discrimination legislation across the 15 member states, which became available in 2005 (European Commission 2005). In addition, the group has carried out extensive research into the particular problems associated with reasonable accommodation and its practical operation in the discrimination field, pre-employment medical testing including genetic testing, and reconciliation of health and safety measures. In 2004, the specialist groups working on each of the discrete areas of discrimination covered in the directive (religion or belief, age, sexual orientation, disability) were merged into one "supergroup" monitoring antidiscrimination legislation as a whole, across the enlarged EU. It was a major task.

Second, the program is supporting a range of sophisticated data collection initiatives to measure the extent and impact of discrimination in Europe (European Commission 2003d). Third, the program is sponsoring independent studies of the effectiveness of the various national bodies already established to promote equality and fight discrimination, looking also at the measures to combat discrimination in countries that have applied to join the EU (European Commission 2003c). These studies will focus particularly on additional steps that may need to be taken in order to take on board the provisions of EC antidiscrimination legislation. A feasibility study, on the establishment of indicators to measure the cost-effectiveness of diversity in companies, has also been carried out by the Centre for Strategy and Evaluation Services (European Commission 2003a). This study seeks to identify new ways of measuring diversity and the benefits it can bring to business and thereby makes a valuable contribution to promoting diversity programs and measures in companies and help to make EU law a reality on the ground. Other studies on barriers to access to assistive technology and other forms of obstruction to employment progress have also been carried out. Finally, the program is promoting a range of initiatives designed to strengthen the capacity of nation-states to build their own programs, independent of EU support.

The candidate countries that gained accession to the EU in 2004 (Cyprus, the Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia, and Slovenia) and those expected in 2007 (Bulgaria, Romania, and Croatia) are all moving slowly toward a rights culture similar to that which is developing within the EU. Many of the initiatives that form part of the CAP include candidate countries. The majority of the candidate countries already have specific legislation dealing with disability discrimination, although in these countries the predominant concept of disability is based on a narrowly defined medical model. There are "quota" systems (arrangements whereby employers must ensure that a percentage of their workforce have specified disabilities, or suffer financial penalties) of varying kinds in the Czech Republic, Cyprus, Lithuania, Malta, Poland, and Romania and specialized or sheltered employment programs in operation in Bulgaria, Cyprus, Hungary, Romania, and Slovakia. Enforcement machinery for discrimination claims is scant across all the candidate countries, with only Romania possessing a special body for hearing discrimination cases. Sanctions for noncompliance either with quotas or with antidiscrimination measures are also weak, and largely unenforced, although the directive requires that effective enforcement machinery is in place.

The European Union Charter of Fundamental Rights sets out in a single text, for the first time in the EU's history, the whole range of civil, political, economic, and social rights of European citizens and all persons resident in the EU. The Cologne European Council (June 3–4, 1999) entrusted the task of drafting this charter to a specially convened convention. The convention held its constituent meeting in December 1999 and adopted the draft on October 2, 2000. The Biarritz European Council (October 13–14, 2000) unanimously approved the draft and forwarded it to the European Parliament and the commission. The European Parliament gave its agreement on November 14, 2000, and the commission on December 6, 2000. The presidents of the European Parliament, the council, and the commission signed and proclaimed the charter on behalf of their institutions on December 7, 2000, in Nice. The rights set out in the charter are divided into six sections:

Dignity

Freedoms

Equality

Solidarity

Citizens' rights

Justice

They are based, in particular, on the fundamental rights and freedoms recognized by the European Convention on Human Rights (see below), the constitutional traditions of the EU member states, the Council of Europe's Social Charter (see below), the Community Charter of Fundamental Social Rights of Workers, and other international conventions to which the EU or its member states are parties. The issue of the charter's legal status—that is, whether to make it legally binding by incorporating it into the treaty—was raised by the Cologne European Council, which originally launched the charter initiative. The convention drew up the draft charter with a view to its possible incorporation, and the European Parliament voted in favor of incorporation. When the charter was proclaimed in Nice in December 2000, Romano Prodi, president of the commission, stated that "in the eyes of the EC, by proclaiming the Charter of Fundamental Rights the EU institutions have committed themselves to respecting the Charter in everything they do and in every policy they promote."

Disability is included in the charter's general nondiscrimination clause (Article 21), and Article 26 specifically states that the Union recognizes and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community.

COUNCIL OF EUROPE

The Council of Europe (COE) is a political organization, founded in 1949. Its aims are to guarantee democracy, human rights, and the rule of law and to develop common responses to political, social, cultural, and legal challenges in its member states. There are currently 43 states that are members. The COE's main instrument, the European Convention on Human Rights and Freedoms, is the core treaty with enforcement powers through which the COE influences policy on human rights across Europe. Although disability discrimination is not specifically protected by the convention, Article 2 ("the right to life"), Article 3 ("no-one shall be subjected to torture or to inhuman or degrading treatment or punishment"), Article 8 ("everyone has the right to respect for their private and family life"), and Article 14 ("prohibition of discrimination") have been used in a number of creative ways to come to the assistance of people with disabilities whose rights to equal treatment are not being respected. For example, the case of *Botta v. Italy* (1998) established (see para. 32) that the right to a private life, guaranteed and protected by Article 8 of the convention, included the need for a state or public authority to protect a person's physical and psychological integrity. The Court held that Article 8 was primarily intended to ensure the development, without outside interference, of the personality of each individual in his or her relations with other people, a statement that has far-reaching implications for disabled people who are denied such development. The duty on the state or a public authority is clearly a positive duty.

Article 8 was argued in another case against the government of Italy, *Marzari v. Italy* (1999), where the applicant, who suffered from a series of complex disabilities, filed an action against the government for failing to provide him with accommodation suitable for a person with his disabilities. The applicant was unsuccessful, because the Court decided that the state had taken all reasonable steps to provide him with suitable accommodation, which he had rejected, notwithstanding the fact that an independent tribunal had determined that the accommodation was suitable, with modification. Although the applicant lost his case on the facts, the Court nevertheless left the door open for a different outcome, had the facts been more compellingly in favor of the applicant, holding that a state has obligations of this type where there is a direct and immediate link between the measures sought by applicants and their private life.

The European Social Charter (ESC) is a COE treaty, signed in 1961, which also is designed to protect the human rights of individuals including those with disabilities. In 1996, a revised and updated charter was opened for signature. It entered into force on July 1, 1999, and will progressively replace the 1961 Charter. Article 15 of the ESC 1961 deals with the right of physically or mentally disabled persons to vocational training, rehabilitation, and social resettlement, stating that with a view to ensuring the effective exercise of the right of the physically or mentally disabled to vocational training, rehabilitation, and resettlement, all state parties undertake the following:

- To take adequate measures for the provision of training facilities, including, where necessary, specialized institutions, public or private.
- To take adequate measures for the placing of disabled persons in employment, such as specialized placing services, facilities for sheltered employment and measures to encourage employers to admit disabled persons to employment.

Article 15 has been now amended as follows: With a view to ensuring to persons with disabilities, irrespective of age and the nature and origin of their disabilities, the effective exercise of the right to independence, social integration, and participation in the life of the community, the state parties undertake, in particular:

- To take the necessary measures to provide persons with disabilities with guidance, education, and vocational training in the framework of general schemes wherever possible or, where this is not possible, through specialized bodies, public or private.
- To promote their access to employment through all measures tending to encourage employers to hire and keep in employment persons with disabilities in the ordinary working environment and to adjust the working conditions to the needs of the disabled or, where this is not possible by reason of the disability, by arranging for or creating sheltered employment according to the level of disability. In certain cases, such measures may require recourse to specialized placement and support services.
- To promote their full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities, and leisure.

Article 15 therefore no longer applies only to vocational rehabilitation but also to the right of persons with disabilities to independent social integration, personal autonomy, and participation in the life of the community in general. The words "effective exercise of the right to independence" contained in the introductory sentence to the provision imply, inter alia, that disabled persons should have the right to an independent life. Under this provision, state parties must aim to develop a coherent policy for people with disabilities. The provision takes a modern approach to how the protection of disabled people shall be carried out, for example, by providing that guidance, education, and vocational training be provided whenever possible in the framework of general schemes rather than in specialized institutions, an approach that corresponds to that of Recommendation No. R (92) 6 of the Committee of Ministers of the Council of Europe. It not only provides the possibility but, to a large extent, obliges state parties to adopt positive measures for people with disabilities.

An international monitoring system is in place to monitor the extent to which COE member states respect the articles of the charter. Governments must submit reports on the application of the provisions of the charter that they have accepted. Copies of the reports can be viewed and downloaded at http://www.humanrights.coe.int/cseweb/GB/GB1/GB1.htm. The reports are all examined by the Committee of Social Rights, comprised of independent experts, which examines the reports and gives a legal assessment of their conformity with the charter. In the light of this assessment, the COE Committee of Ministers can issue recommendations to any governments appearing to be in default. An Additional Protocol providing for a system of collective complaints was opened for signature on November 9, 1995, and entered into force on July 1, 1998. Its purpose is to improve the efficiency of the supervisory machinery of the Social Charter, by enabling collective complaints alleging violations of the charter to be dealt with, in addition to the existing procedure for examining governments' reports. A number of international organizations of employers and trade unions, and other international nongovernmental organizations (NGOs) with consultative status within the COE, are entitled to raise collective complaints. For a full list of those bodies entitled to raise a collective complaint, see http://www.humanrights.coe.int/cseweb/GB/GB3/GB31.htm. Collective complaints are examined by the Committee of Social Rights, which must first decide on their admissibility in the light of criteria listed in the protocol. In practice, the committee, after having collected information from the complainants, from the state concerned, from the other contracting parties to the charter and from both sides of industry, draws up for the Committee of Ministers a report containing its conclusions as to whether the contracting party against which the complaint is directed has, in a satisfactory manner, ensured that the provision of the charter which is the subject of the complaint is applied. It is then the task of the Committee of Ministers to address a recommendation to the contracting party concerned, in the event that the Committee of Social Rights finds that the charter has not been satisfactorily applied, or, should this not be the case, to adopt a resolution to that effect.

Finally, it should be noted that independent, state-financed bodies with a clearly defined role to educate, reform, and enforce legislation in the field of disability discrimination are an increasingly important phenomenon across the whole of Europe (European Commission 2002).

EUROPEAN DISABILITY FORUM

Created in 1996, the European Disability Forum (EDF) is now the largest independent, trans-European organization that exists to represent disabled people in dialogue with the EU and other European authorities. Its mission is to promote equal opportunities for disabled people and to ensure disabled citizens' full access to fundamental and human rights through their active involvement in policy development and implementation in the EU. EDF has national councils in 17 European countries, together with approximately 45 disability NGO members, and a number of associate group and individual members. One of the most important campaigns of the EDF in recent years has been to argue for a disability-specific directive, that covers a far wider range of discriminatory activities. EDF argues that discrimination does not occur in the field of employment only, as employment is closely linked to several other areas such as education, transportation, and access to services and goods. Therefore, a directive aimed only at employment is insufficient. For a disabled person to be an active member of society in all areas and to enhance a broad nondiscrimination approach, a new disability-specific directive is needed. EDF has prepared a draft for such a directive. For the full text of this draft directive, go to http://www.edf-feph.org/en/policy/nondisc/nond_ pol.htm.

—*Jeremy Cooper*

See also Council of Europe Disability Policy; European Commission Policy.

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DISABILITY LAW: GERMANY

Written in 1994, Section 3, Paragraph 3, Sentence 2 of the German Constitution (Grundgesetz) forbids the discrimination of people based on their disability. The concept of disability in Germany, however, is not uniformly regulated in legal documents. The most comprehensive definition can be found in Section 2 of the Sozialgesetzbuch IX-Rehabilitation und Teilhabe behinderter Menschen (SGB IX; Social Security Code IX-Rehabilitation and Participation of Disabled People, in effect since July 1, 2001) and is defined in an identical manner in Section 3 of the Behindertengleichstellungsgesetz (BGG; Disability and Equality Law, in effect since May 1, 2001):

> People are disabled if their physical function, cognitive ability, or psychological health significantly deviates from that of the typical, age-appropriate condition for longer than six months, and therefore interferes with their participation in society.

The German laws provide various instruments to prevent the discrimination of people with disabilities. Section 81, Paragraph 2 of the SGB IX, for example, forbids the discrimination against severely disabled people (*Schwerbehinderte*) at the workplace. Employers may not discriminate against people with disabilities in hiring, promotion, or termination practices. If an employee makes a believable argument that discrimination has occurred, the employer must use objective reasons to prove that the unequal treatment is or is not justified. Individuals who have an officially recognized disability can be terminated only upon approval of the Integrationsamt (Integration Office). Larger businesses are required to employ a fixed quota of severely disabled people or pay the state a specific lump-sum penalty. The regional income from this so-called Ausgleichsabgabe (equalization tax) is used to help support the gainful employment of the severely disabled.

The Behindertengleichstellungsgesetz (Disability and Equality Law) of the Federal Republic of Germany and the corresponding equality laws of individual states prohibit direct and indirect discrimination within state institutions. Official information must also be available for people with sensory disabilities. Hearing-impaired and speech-impaired individuals have the right to use sign language and communication help. The regulations also include guidelines for barrier-free new construction, public streets, paths, and public transportation and for equality in primary and secondary education. In addition, disability associations have the right to negotiate and bargain with economic enterprises for their services and products. The enterprises are not, however, obliged to come to a consensual, contractual agreement (a so-called Zielvereinbarung [target agreement]).

As yet, there has been no explicit legal sanction regarding the exclusion or discrimination against disabled people with respect to the purchase and use of economic goods and services. When private insurance companies, landlords, tour operators, airlines, restaurants, or other private businesses refuse disabled people as customers, individuals may claim illegal discrimination on a case-by-case basis. So far in such situations, however, disabled people have had to prove that they have been discriminated against. As of the beginning of 2004, a comprehensive civil antidiscrimination law had not yet been adopted. Access to medical, occupational, and social rehabilitation; nursing programs; pension payments; and social security benefits are regulated in various laws (e.g., Sozialgesetzbücher [Social Security Codes] III, V to IX, XI, as well as the Bundessozialhilfegesetz [Federal Public Welfare Law] and the Grundsicherungsgesetz [Basic Income Law]). The decision as to which benefit applies in individual instances is delegated in the German social law to various öffentlich-rechtliche Körperschaften (Official Statutory Corporations), semi-national organizations like the Gesetzliche Krankenkassen (Statutory Health Insurance Companies). The service provision is provided through social welfare organizations and private companies, for example, private nursing services, and nursing homes with ecclesiastic or associational sponsorship. According to the law, national social security only covers those who are gainfully employed or who have been in the past. Based on this fact, many disabled people are dependent instead on public welfare through the Bundessozialhilfegesetz and Grundsicherungsgesetz. These forms of benefits serve, above all, to protect an individual at the minimum income level necessary for survival. They only cover essential rehabilitation and integration assistance and only accept recipients who are indigent, people who have no or only a meager source of income, or who possess only a few assets.

At the beginning of the twenty-first century, German disability policies were newly conceived. Today, the long-term goal is to encourage the social participation and self-determination of disabled people. They should no longer be passive objects of social welfare, but should make, as much as possible, self-determined decisions regarding the forms in which to receive support. In addition, consideration is to be made of the needs of disabled women. These basic goals, however, have as yet been only partially realized in the law and in practice.

—Julia Zinsmeister

See also Disability Law: Europe.

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DISABILITY LAW: INDIA

See Disability Policy: India

DISABILITY LAW: SWEDEN

The Swedish Disability Act (Lag om stöd och service till vissa funktionshindrade, SFS 1993:387) came into force in 1994. It is hereafter referred to as LSS, the standard Swedish abbreviation. LSS complements universal legislation such as the Social Services Act and the Health and Medical Services Act, giving priority to the social needs of persons with severe disability such as intellectual disability (mentally retarded from birth or young age; autism or conditions resembling autism; considerable and permanent intellectual disability after brain damage when an adult, caused by external force or illness), and other lasting physical or mental disabilities that are manifestly not due to normal aging, if these disabilities are major and cause considerable difficulties in daily life and, consequently, an extensive need for support and service. LSS succeeded an act of similar construction, the Special Services Act of 1985, offering social support only to persons with intellectual disabilities. In accordance with LSS, the target groups are entitled to 10 different support measures, one of the most important being the right to personal assistance. Local authorities are responsible for nine and county councils for one support measures. The same kind of social support can be given in accordance with the Social Services Act and LSS. However, because LSS is a human rights statute there are decisive differences: LSS has a higher level of ambition (”good living conditions” as opposed to the “acceptable standard of living” as decreed by the Social Services Act), there is an unconditional right to support when needs are not met, applications for support may not be turned down on the grounds of insufficient funding, and LSS measures are free of charge.

The political intention with LSS is to strengthen citizenship in the encounter with the public sector. Freedom from coercion and influence over assessment of needs are ways to guarantee the civil element of citizenship. Equalization of opportunities to live a life like others and be able to participate in society and the common welfare expresses the social element of citizenship. However, the reform has not been implemented to the extent that the politicians intended. Appraisals indicate that a smaller number, half of the expected 100, 000 or 1 percent of the population, have shared in the benefits of this reform. This result particularly applies to persons with mental disabilities. Thus, first, persons with severe disabilities have not, for different reasons, been able to exert their legal rights. Second, officials and experts, such as social welfare officers and physicians, seem not always to understand the intent of LSS and its precedence over the Social Services Act. Third, local politicians, who very well may understand the intent of LSS, giving persons with severe disabilities priority, still defend municipal self-government and follow their own priorities. The result has been several cases of judicial disobedience when favorable decisions in courts have not been enforced. The state tries to overcome this problem, earlier by fining disobedient municipalities, and since 2002 by using sanctions.

—Barbro Lewin

See also Social Model: Sweden.

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DISABILITY LAW: UNITED STATES

Disability law in the United States is at a pivotal point in its development. The past half-century has seen a move from the medical and vocational models, which addressed disability as either a medical issue to be cured or a justification for welfare and benefits, to a civil rights model, which seeks to remove the barriers that impede the full integration of people with disabilities into society.

The Americans with Disabilities Act (ADA) is the current prominent national policy and legal statement affecting the lives of persons with disabilities. Though the ADA is the largest and most sweeping legislation, it does not stand alone. Among others, the Rehabilitation Act, Individuals with Disabilities Education Act (IDEA), Fair Housing Act Amendments, and various state laws all combine to complete the American disability law landscape or framework. These laws, and the legal issues involved in narrowing or enlarging their focus, are explored below.

AMERICANS WITH DISABILITIES ACT

The ADA was signed into law on July 26, 1990. It is sweeping legislation, intended to create broad social change. At the signing ceremony, President George H. W. Bush described the ADA as

> the world's first comprehensive declaration of the equality of people with disabilities, and evidence of America's leadership internationally in the cause of human rights. With today's signing of the landmark Americans with Disabilities Act, every man, woman, and child with a disability can now pass through the closed doors, into a bright new era of equality, independence, and freedom.

The ADA has a preface section and three main parts. The preface section states Congress's goals and reasons for passing the ADA. This section of the law identifies people with disabilities as "a discrete and insular minority who have been faced with restriction and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society," and sets the nation's proper goals regarding individuals with disabilities as ensuring "equality of opportunity, full participation, independent living, and economic self sufficiency."

The preface section also sets out the operative definition of disability for the entire statute. An individual with a disability is defined as someone with a physical or mental impairment that substantially limits one or more major life activities of the individual, a record of such an impairment, or being regarded as having such an impairment. In a series of cases, the U.S. Supreme Court has recently interpreted this definition to mean that individuals and their impairments must be considered in their mitigated states. Thus, for example, an individual with 20/200 vision who is rejected for a position as a pilot based on an employer's uncorrected vision requirement is not considered disabled for the purposes of the ADA, where eyeglasses can correct that individual's eyesight to 20/20.

The next three main parts of the ADA (commonly referred to as Titles I to III) cover nondiscrimination in employment, public services, and places of public accommodation, respectively. These will be discussed in turn.

Title I: Employment

Perhaps the most heavily litigated provisions of the ADA have been the employment sections. They impose comprehensive—from application to termination—obligations on covered employers.

The ADA's general rule of nondiscrimination in employment is that "no covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment."

Covered Entity

An employer is a "covered entity" if that employer has 15 or more employees. Most recently, in *Clackamas Gastroenterology Associates, P.C., v. Wells,* the Supreme Court developed a six-part test to determine whether shareholder-directors are employees for the purposes of ADA Title I. The crucial element in this test is control.

In *Board of Trustees of the University of Alabama v. Garrett,* the Supreme Court held that Congress's abrogation or limitation of the states' Eleventh Amendment sovereign immunity was invalid insofar as Title I provided for suits against the states for monetary damages. Therefore, states are treated differently for ADA Title I purposes than are private employers. After *Garrett,* a state employee does not have a viable claim against his employer for monetary damages under ADA Title I.

Prohibited Inquiries

There is a substantial body of case law relating to the range of permissible inquiries (both before and during employment) under Title I. The general preemployment rule is that a potential employer may not try to learn if the applicant has a disability, unless it is legitimately necessary for the conduct of the job. Preemployment medical examinations are not permissible. This provision allows individuals with disabilities to be judged on their qualifications and not on their disabilities. After an employer has made a conditional offer, but before the start of employment, the employer may require a medical examination or ask disability-related questions if all employees—or a least all employees performing similar tasks—must take it and it can be shown to be related to the job qualifications. The examination is subject to rigid confidentiality restrictions. During the course of employment, an employer may not make inquiries or require a medical examination "unless such examination or inquiry is shown to be job-related and consistent with business necessity."

Reasonable Accommodation

The concept of reasonable accommodation is central to Title I's antidiscrimination provision. An employee is not a "qualified" person with a disability for purposes of Title I if he or she cannot perform the essential job functions with or without a reasonable accommodation. An employer's failure to make a reasonable modification, when asked, constitutes a separate claim of employment discrimination. A reasonable accommodation is a modification or adjustment to a workplace process or environment that makes it possible for a qualified person with a disability to perform essential job functions. Accommodations may include physical modifications to a workspace, flexible scheduling of duties, or provision of equipment, assistive technologies, and job training to aid in job performance.

To be eligible for an accommodation, an employee must make his or her disability known to the employer and request an accommodation. Once the accommodation request is made, the ADA requires a consultative "interactive process." In this process, the employer retains the right to choose the accommodation according to its reasonable effectiveness and the employee's good faith opportunity to participate in the process.

Undue Hardship and Direct Threat

A common critique of Title I is that accommodations for qualified individuals create economic hardships that are costly and burdensome for employers. The statutory mechanism for dealing with this criticism is the "undue hardship" defense. Employers only are required to make accommodations that do not impose undue hardships on them. An undue hardship is a significant difficulty or expense, in light of the firm's size and resources. Undue hardship is an affirmative defense that must be raised and proved by the employer.

Similarly, an employer does not need to make a requested modification if it creates a significant risk of a "direct threat" to the health or safety of the employee, applicant, or others in the workplace. In *Chevron v. Echazabal,* the Supreme Court interpreted this defense to include instances where the employee's disability creates a direct threat to his own health or safety.

Title II: Public Entities

ADA Title II requires that the services, programs, and activities of state and local government entities be accessible to people with disabilities. Before the ADA was enacted, the Rehabilitation Act of 1973 prohibited some public entities from discriminating on the basis of disability. This protection, however, was limited to public entities that received federal financial assistance. A primary purpose of Title II was to extend the existing prohibition on discrimination to state and local government entities, regardless of whether they received federal financial assistance. Title II is therefore the least revolutionary of the major titles of the ADA.

Title II's main antidiscrimination provision is that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."

To have a viable Title II claim, a plaintiff must demonstrate that he or she was either excluded from participation in or denied the benefits of a public entity's services, programs, or activities, or was otherwise discriminated against. The regulations promulgated by the U.S. Department of Justice pursuant to Title II offer extensive guidance on what this means. Conceptually, it is useful to think about the affirmative responsibilities of public entities in five areas: making reasonable modifications to policies, practices, and procedures; administering services, programs, or activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities; modifications to facilities; communications modifications; and accommodations in transportation.

Until recently, it has been an open issue as to whether individuals can sue states for damages for violations of Title II of the ADA. In *Tennessee v. Lane*, the Supreme Court held that an individual could sue a state for damages for not providing access to courthouses. It is still an open question whether individuals can sue states for damages for the panoply of other rights that fall within Title II's scope.

Reasonable Modifications to Policies, Practices, and Procedures

The Title II regulations provide that a public entity must reasonably modify policies, practices, or procedures when necessary to allow participation by a person with a disability. Analytically, this is similar to the reasonable accommodation requirement of Title I.

The regulations set the outer limits of reasonable accommodations. The regulations provide that modifications must be made *unless* the public entity can demonstrate that making them would fundamentally alter the nature of the program, service, or activity.

Although the reasonable modification requirement of Title II does not include an undue hardship defense, the courts have read undue hardship into the fundamental alteration defense. Thus, courts determining whether a modification will constitute a fundamental alteration consider whether the change will cause an undue financial or administrative burden on the entity.

Even if a given program, service, or activity has an essential eligibility requirement, the plaintiff still can be a "qualified individual with a disability" if he or she can meet that requirement with or without "reasonable modifications to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provisions of auxiliary aids and services."

Integration

The regulations provide that public entities must administer services, programs, or activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. In *Olmstead v. Zimring,* the Supreme Court considered the interplay between this integration mandate and the "fundamental alteration" limit on reasonable modification of policies.

In *Olmstead,* two women with mental retardation and psychiatric conditions brought suit under Title II, claiming that the state of Georgia had discriminated against them by keeping them in institutionalized settings instead of community placements that were appropriate for their needs. The Court held that this unjustified institutional isolation constituted discrimination within the meaning of Title II. However, the Court recognized that the duty to accommodate was not absolute. In deciding whether this accommodation would fundamentally alter the state's mental health treatment program, the proper inquiry was *not* the cost of accommodating these two plaintiffs weighted against the states' overall mental health budget.

In July of 2001, President George W. Bush entered an executive order reinforcing the *Olmstead* decision and providing guidance to the U.S. attorney general, the secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, and the commissioner of the Social Security Administration in its implementation. As part of the administration's "New Freedom" initiative, the Centers for Medicare and Medicaid Services distributed more than $120 million in grants in 2001 and 2002 to help states increase community-based integration for people with disabilities. However, years after the *Olmstead* decision, states face a lack of coordinated community-based services and a shortfall of funds in carrying out the integration mandate.

Facilities Modification

Title II applies to a public entity's physical structures. Courts have interpreted this reach to include, among other things, city buildings, botanical gardens on the premises of a state university, publicly owned sporting arenas and theaters, and recently, city sidewalks. The regulations provide that each service, program, or activity conducted by a public entity, when viewed in its entirety, must be readily accessible to and usable by individuals with disabilities. This does not mean, however, that each existing facility must be physically accessible to and usable by individuals with disabilities.

The regulations set forth the "program access" standards for facilities. What a public entity must do to ensure program access to its facilities varies according to whether the facility is an "existing" facility, a new facility, or a facility that has been altered.

In ensuring program access in existing facilities, a public entity does not have to take action that will result in fundamental alteration in the nature of a service, program, or activity or cause an undue financial or administrative burden. The public entity has the burden of showing that compliance with the program access standard would result in such alteration or burden. The decision that compliance would result in such an alteration or burden must be made by the head of the public entity, in writing.

Notably, a program must be accessible "when viewed in its entirety." Therefore, if a government program offers identical services at more than one facility, not every facility must be accessible. To allow some facilities to remain unchanged, the alternative facilities must offer equivalent services in terms of type of service, hours of operation, convenience, and quality.

The regulations create a different set of responsibilities for public entities for construction of new facilities and alterations of existing facilities. For new construction, the regulations provide that each facility or part of a facility constructed by, on behalf of, or for the use of a public entity be designed and constructed in such manner that the facility or part of the facility is readily accessible to and usable by individuals with disabilities. Alterations to existing facilities are subject to a similar standard.

In contrast to the regulations governing existing facilities (where entities are exempted from making fundamental alterations and bearing undue financial burdens), the regulations for new construction and alteration are more stringent. There is no "undue burden" provision, with the regulations stating facilities "shall" be accessible.

Effective Communication

Like the program access standard, Title II's communications provisions have a statutory and regulatory component. Title II's definition of qualified person with a disability links the "provision of auxiliary aids and services" to the concept of reasonable accommodations. The Title II regulations have a separate section devoted to "Communication," which makes clear that communication is an integral part of a public entity's responsibilities under Title II.

The regulations provide that auxiliary aids and services be furnished when necessary to afford an individual with a disability an equal opportunity to participate in and enjoy the programs, services, or activities of the public entity. The effective communication obligation is owed to people with hearing, speech, and vision disabilities, as well as those with mental and physical impairments.

In terms of types of auxiliary aids and services, a public entity is to give primary consideration to the requests of individuals with disabilities. Auxiliary aids and services for people with hearing impairments include qualified interpreters, notetakers, written materials, amplifiers, captioning, teletypewriters (TTYs), telecommunications devices for the deaf (TDDs), and others. For people with vision impairments they include qualified readers, taped text, Braille, large print, assistance locating items, and others. For people with speech disabilities they include TTYs, computer terminals, speech synthesizers, and communication boards. The regulations provide that a public entity does not need to take any action that it can demonstrate would result in a fundamental alteration or an undue financial or administrative burden.

Transportation

Title II has a separate part dedicated to nondiscrimination in transportation provided by public entities. Transportation was an area where the ADA's framers recognized an existing pattern of discrimination and inequity.

The ADA explicitly states that "discrimination against individuals with disabilities persists in such critical areas as . . . transportation" and "individuals with disabilities continually encounter various forms of discrimination, including . . . transportation . . . barriers." The debates on ADA passage suggest that the framers viewed transportation as crucial to unlocking other opportunities that the ADA would help create.

Public transportation is especially important to people with disabilities because the evidence suggests that they are more reliant on public transportation than the general population. The legal and policy tensions specific to transportation issues are a microcosm of the entire act. These issues include mainstreaming of existing transportation to accommodate people with disabilities versus paratransit (i.e., transportation services usually performed by vans that are provided separate from mass transit's normal operations), and whether there should be a "threshold" or "necessary" level of spending on mass transportation options for people with disabilities.

ADA Title II's transportation provisions require accessibility standards for fixed-route systems (e.g., buses and rails that run on fixed schedules), paratransit, demand response systems (e.g., any system, such as taxicab service, that is not a fixed route), and rail service that is dedicated to commuters and that runs between cities.

Title III: Public Accommodations

Title III extends the ADA's antidiscrimination mandate to places of public accommodation and commercial facilities. Title III therefore is broader in scope than Title II. The goal of Title III is to integrate people with disabilities into the mainstream of American life.

The overarching requirement of Title III is set out in its antidiscrimination provision:

> No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to) or operates a place of public accommodation.

The premise of Title III is straightforward: Places of public accommodation are barred from discriminating against people with disabilities in their use of facilities and the provision of goods and services. To this extent, Title III parallels Title II of the Civil Rights Act of 1964.

However, discrimination under Title III is defined broadly to include failure to make reasonable modifications of policies, practices, and procedures; failure to ensure effective communication; and failure to take steps to make facilities physically accessible. The defenses to a charge of discrimination rely on concepts of undue burden, fundamental alteration, and lack of "readily achievable" modifications.

Title III provides general and specific prohibitions on discriminatory conduct. General discrimination prohibited under Title III includes denial of participation, participation in unequal benefit, providing a separate benefit when separation is not necessary, failure to ensure that people with disabilities receive goods or services in the most integrated setting appropriate to their needs, denying an individual with a disability the opportunity to participate in an integrated benefit because of the availability of a separate benefit, using contractual or administrative methods that have the effect of discriminating or that perpetuate the discrimination of others who are subject to common control, and discrimination on the basis of association with a person with a known disability. Specific types of discrimination under Title III include discriminatory eligibility criteria; failure to make reasonable modifications of policy, practice, or procedure when necessary to permit a person with a disability to benefit from a place of public accommodation; failure to ensure effective communication through the provision of auxiliary aids; and failure to remove architectural barriers to access when it is readily achievable to do so.

A place of public accommodation may not assess a charge to a person with a disability for any action, aid, or service required by the ADA, even to cover the actual costs of the action, aid, or service. Rather, the cost of compliance must be considered an overhead expense.

The defense to the reasonable modification requirement is that the requested modification would fundamentally alter the nature of the goods or services being provided. The U.S. Supreme Court addressed the application of the fundamental alteration defense in *PGA Tour, Inc. v. Martin.* Casey Martin, a professional golfer, has a degenerative circulatory disorder that obstructs the flow of blood from his right leg to his heart. Martin requested that the Professional Golfers' Association (PGA) allow him to ride a golf cart in its tournaments, instead of complying with the normal rule that participants walk the course.

The PGA Tour conceded that a golf cart was necessary for Martin to participate in the tour, but argued that the requested modification would fundamentally alter the nature of the event in three ways: by altering "such an essential aspect of the game of golf that it would be unacceptable even if it affected all competitors equally," by giving the individual with a disability an unfair advantage over the other players, and by imposing administrative burdens on the operator of a place of public accommodation. The Court found that none of those possible alterations rose to the level of a permissible defense in this case, and held that Casey Martin was entitled to use a golf cart as a reasonable modification.

Title III provides an affirmative defense in situations where providing a modification would pose a direct threat to the health or safety of others. The statute defines "direct threat" as "a significant risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures or by the provision of auxiliary aids or services."

The ADA regulations provide that the direct threat determination should be based on individualized assessment and on reasonable judgment that relies on current medical knowledge or the best available objective evidence. It must consider the nature, duration, and severity of the risk, the probability that the potential injury actually will occur, and whether modifications will mitigate the risk.

Title II also requires physical accessibility of public accommodations. For existing facilities, Title III requires architectural barriers to access to be removed "where such removal is readily achievable, i.e., easily accomplishable and able to be carried out without much difficulty or expense." If removal of a barrier or barriers is not readily achievable, a place of public accommodation must attempt to make its goods and services accessible to people with disabilities through alternative methods that are readily achievable. Examples of alternatives to barrier removal include providing curb service or home delivery, retrieving merchandise from inaccessible shelves or racks, and relocating activities to accessible locations.

Title III entities making alterations or renovations to existing facilities for other than barrier removal purposes must "make such alterations . . . in such a manner that, to the maximum extent feasible, the altered portions of the facility are readily accessible to and usable by individuals with disabilities, including individuals who use wheelchairs." New buildings, constructed for first occupancy after January 26, 1993, must be fully accessible to and usable by people with disabilities. The only exception to compliance occurs when the entity demonstrates that full compliance is structurally impracticable. Structural impracticability will be found "only in those rare circumstances when the unique characteristics of terrain prevent the incorporation of accessibility features."

SECTION 504 OF THE REHABILITATION ACT

The Rehabilitation Act of 1973, and Section 504 in particular, is in many ways the direct predecessor to the ADA. As originally passed, the primary focus of the Rehabilitation Act of 1973 was vocational training and rehabilitation. The stated purpose of the act was to "provide a statutory basis for the Rehabilitation Services Administration," an agency charged with carrying out the provisions of the act, and to authorize various rehabilitation programs.

The final part of the original 1973 act contains the portions of the Rehabilitation Act that over time have had the greatest impact. Section 501 requires affirmative action and nondiscrimination in employment by federal agencies of the executive branch. Section 502 established the Architectural and Transportation Barriers Compliance Board (Access Board), which also is responsible for developing accessibility standards for the ADA. Section 503 requires that to receive certain government contracts, entities must demonstrate that they are taking affirmative steps to employ people with disabilities.

The enduring hallmark of the Rehabilitation Act of 1973, however, is Section 504. This section provides that no otherwise qualified individual with a disability shall, solely by reason of his or her disability, be excluded from the participation in, denied the benefits of, or subjected to discrimination under any program or activity receiving federal financial assistance. This sweeping language was the first explicit Congressional statement recognizing "discrimination" against people with disabilities.

The regulations promulgated pursuant to Section 504 of the Rehabilitation Act introduced the concept of "reasonable accommodation" to disability discrimination law. The "employment" section of the Section 504 regulations states:

> A recipient [of federal funds] shall make reasonable accommodation to the known physical or mental limitations of an otherwise qualified handicapped applicant or employee unless the recipient can demonstrate that the accommodation would impose an undue hardship on the operation of its program or activity.

The regulations provide examples of reasonable accommodations, including altering facilities and modifying work schedules.

The Section 504 regulations' approach to facility access issues is similar to ADA Title II. The regulations provide that no qualified person with a disability be denied the benefits of, excluded from participation in, or otherwise subjected to discrimination because a recipient's facilities are inaccessible to people with disabilities. This is commonly known as the "program access" requirement. A recipient of federal funds does not have to make its facilities accessible; rather, accessibility is achieved when each program or activity within the facilities, viewed as a whole, is accessible. Examples of steps to ensure program accessibility include redesigning equipment, reassigning classes to accessible buildings, and home visits.

Another issue the regulations make clear is that education is covered by Section 504. The regulations provide that recipients of federal funds that operate public or secondary schools must provide a free appropriate public education to each qualified handicapped person, regardless of the nature of severity of that person's handicap. Similarly, the regulations provide that qualified persons with disabilities may not be denied admission or subjected to discrimination by postsecondary schools on the basis of disability.

The Rehabilitation Act and its accompanying regulations frame the issues of employment, and facility and educational access for persons with disabilities as a balancing test. Accommodation is desirable, when the methods of ensuring accessibility are reasonable. Although "reasonable" is not defined, a guiding principle is that a reasonable accommodation or modification does not require a change to the fundamental nature of the job, program, or facility.

Conceptually and doctrinally, the ADA and Section 504 of the Rehabilitation Act of 1973 have a close relationship. Both are premised on the belief that people with disabilities have a right to be included in society and that a denial of that right, including failure to make reasonable accommodations, constitutes discrimination. The ADA concepts that the courts have struggled with—reasonable accommodation, the definition of disability, and fundamental alteration—have their bases in the Rehabilitation Act. The ADA is explicit that Rehabilitation Act regulations and cases are instructive in interpreting the ADA.

SECTION 508 OF THE REHABILITATION ACT

The implementation of Section 508 of the Rehabilitation Act was designed to spur innovation throughout the e-commerce industry. Enacted as part of the Workforce Investment Act of 1998, Section 508 requires that electronic and information technology (EIT), such as federal websites, telecommunications, software, and information kiosks, must be usable by persons with disabilities.

Federal agencies may not purchase, maintain, or use EIT that is not accessible to persons with disabilities, unless accessibility poses an undue burden. The EIT Accessibility Standards, finalized on December 21, 2000, detail the requirements for federal entities. Section 508 does not require private companies that market technologies to the federal government to modify the EIT products used by company employees, or to make their Internet sites accessible to people with disabilities.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The IDEA originally was passed in 1975 (under the name Education for All Handicapped Children Act). As originally passed, this act was an express recognition of the number and needs of children with disabilities in the school system. Congress found that "there are more than eight million handicapped children in the United States today," whose educational needs were not being met. To meet these educational needs, IDEA focuses on higher expectations, mainstreaming students where possible, and an increased federal rule in ensuring equal educational opportunity for all students.

Under the IDEA, schools have to provide a free and appropriate public education (FAPE) to eligible children with disabilities. The FAPE should take place in the least restrictive environment appropriate to the child's needs. IDEA requires schools to develop an individualized education program (IEP) for each child. Each child's IEP must be developed by a team of knowledgeable persons and reviewed annually. This team includes the child's teacher, parents, and if appropriate the child, and an agency representative who is qualified to provide or supervise the provision of special education. If the parents disagree with the proposed IEP, they may request a due process appeal hearing and a review from the state educational agency, and may appeal this decision to state or federal court. In 2005, the IDEA was reauthorized with the Individuals with Disabilities Education Improvement Act of 2004.

FAIR HOUSING ACT AMENDMENTS

In 1988, Congress introduced a series of amendments to the Civil Rights Act of 1968, including a prohibition on housing discrimination against people with disabilities. These amendments are known as the "Fair Housing Act Amendments of 1988."

The Fair Housing Act Amendments make it unlawful to discriminate in the sale or rental of housing, and the terms and conditions of such sale or rental, on the basis of disability. The Fair Housing Act Amendments have a broad scope, protecting not only a buyer or renter with a disability but also a person with a disability who lives with a buyer or renter, or any other person associated with the buyer or renter.

Discrimination under the Fair Housing Act Amendments includes a refusal to permit an occupant with a disability, at his or her own expense, to make reasonable physical changes to the existing premises; a refusal to make reasonable accommodations in rules, policies, practices, or services; and a failure to construct multifamily dwellings (which contain four or more units) so that specified portions of those facilities are accessible to individuals with disabilities.

STATE DISABILITY LAWS

Before the passage of the ADA, the primary responsibility for regulating discrimination on the basis of disability belonged to the individual states. Different states had laws covering nondiscrimination in employment, public accommodations, and state services. Many states covered one, but not all, of these areas. These pre-ADA state statutes generally regulated far less conduct than the ADA.

Congress's passage of the ADA was grounded on a recognition that stronger protection was needed than that offered by the states alone. The ADA was a shift toward a comprehensive federal model of protection for a wide range of people with disabilities. The ebb and flow between and among the U.S. federal and state laws is, of course, reflective of changing views about the role of the federal and state government in the lives of citizens. With the recent narrowing by the Supreme Court of federal civil rights laws, and the ADA in particular, states' civil rights laws take on a renewed importance for the protection of people with disabilities from discrimination.

Today, every individual state has some law relating to discrimination on the basis of disability. The scope and coverage of these laws run the gamut. Some state statues offer protection that is greater than, or equal to, the ADA, while others offer less protection.

One example of a state that offers more protection for people with disabilities is California. California had a history, even pre-ADA, of offering strong legal protections for people with disabilities. The California disability antidiscrimination statute, the

Fair Employment and Housing Act (FEHA), is comprehensive in scope. FEHA prohibits discrimination in public and private employment, and it contains a reasonable accommodation requirement. Another California statute, the Unruh Civil Rights Act, guarantees people with disabilities full and equal accommodations in business establishments.

In 2000, California amended the FEHA. The amendments expand on the ADA's protections in several significant ways. For example, as discussed, to be considered "disabled" for the purposes of the ADA, an individual needs to be considered in his or her mitigated state. The FEHA amendments reject that view, providing that "under the law of this state, whether a condition limits a major life activity shall be determined without respect to any mitigating measures." Similarly, while the ADA limits coverage to individuals whose impairments result in a *substantial limitation* of a major life activity, an individual is covered by California's FEHA if his or her impairment *limits* a major life activity.

CONCLUSION

The laws discussed above make up the American legislative landscape as it relates to the rights of people with disabilities. The political and judicial climate of the United States is split between those who believe the ADA represents the federal government reaching too far into the lives of states and private businesses and those who feel this is the most important civil rights law of the past several decades. Time will tell the direction and scope that judges and politicians allow the ADA to take.

—Michael Waterstone, Charles D. Siegal,
Eve Hill, and Peter Blanck

See also Americans with Disabilities Act of 1990 (United States); Fair Housing Act Amendments of 1988 (United States); Rehabilitation Act of 1973 (United States).

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DISABILITY LEAVE

In the United Kingdom in the early 1990s, a pioneering job retention program for disabled people was introduced under the title "disability leave." Designed to assist newly disabled people or people whose impairment deteriorates to retain their employment, the program provides for a period of leave with expert assessment, advice, rehabilitation, retraining, workplace adaptation, and, perhaps most important of all, job protection.

Disability leave was developed by the Royal National Institute of the Blind (RNIB) and has subsequently been adopted by a number of major employers across the United Kingdom. RNIB has pressed successive governments to put the scheme on a statutory basis, but to date this has not been accepted. Yet with recent changes to disability employment and benefit policies, some elements are now in place. What is missing is a clear policy for job protection.

BACKGROUND

RNIB developed disability leave as a response to the large number of people in their 40s and 50s losing their sight at work who through redundancy, resignation, or early retirement also lost their jobs. It was recognized that sight loss (or any other impairment) need not be an obstacle to staying in work but that all too often both employer and employee believed it was.

Disability leave offers major benefits to both employer and employee. To the newly impaired employee, the program provides support, retraining, rehabilitation, and crucially, the chance to avoid what is likely to be a long period of unemployment with the inevitable associated drop in income. To the employer, disability leave has many benefits including the retention of experienced staff, avoidance of unnecessary recruitment costs, lower staff turnover, and a reduced early call on occupational pension funds.

WHAT IS DISABILITY LEAVE?

Disability leave does not simply refer to a "leave" entitlement, but rather to a whole process of assessment, advice, retraining, and workplace adaptation including the provision of assistive technology and job protection. Typically, a company's disability leave plan will involve early intervention to identify and engage with employees who are experiencing sickness or disability. A home visit may be arranged as early as four weeks although eight weeks is a more typical period. If appropriate, a case manager is appointed who provides support and advice to the employee and the manager. Following an expert assessment, a range of options are considered to enable the employee to continue in his or her current job including retraining, workplace adaptation, and the provision of assistive technology. However, in certain circumstances the job itself may need to be modified with possible reallocation of duties among colleagues. As a last resort, it may be necessary for the employee to be redeployed elsewhere in the organization.

RNIB developed the policy of disability leave in the early 1990s in consultation with statutory, voluntary, and trade union organizations concerned with employment and disability. Subsequently, it has been adopted by a range of mainly larger companies including Barclays Bank, HSBC, Royal Mail, and the TUC. However the great majority of employers continue to respond to the onset of an impairment in an ad hoc and typically negative manner. This reflects widely held prejudicial views about the difficulties of employing disabled people and also worries about the additional costs that may be incurred.

In the absence of widespread adoption of disability leave on a voluntary basis, RNIB has pressed successive governments to put the scheme on a compulsory basis. RNIB wants disability leave to be as well-known as the statutory maternity leave program that provides job protection and income for women during pregnancy and the first year following birth. However, to date, this has not been accepted with the government arguing that disability leave should be provided by employers as a "reasonable adjustment" under the Disability Discrimination Act (DDA).

FOUR ELEMENTS OF A SUCCESSFUL POLICY

Disability leave is one way to assist newly disabled people to retain paid employment. But, as with any voluntary program, it can have only a limited impact. Disability leave needs to be put on a statutory basis and supported by a broader set of policies that promote job retention. Overall, four elements are critical to success: job protection, cost sharing, early and timely intervention, and a flexible and supportive benefits system.

Job retention through disability leave, or indeed any other program, is not possible if there is no job to return to. In the United Kingdom, this protection should be provided by the DDA with employers being required to retain newly disabled employees and to make "reasonable adjustments" to the work environment. However, typically the DDA comes into effect only when an individual makes a complaint of unfair dismissal on grounds of disability; that is, *after* the individual has lost his or her job. Even if an Employment Tribunal finds in favor of the disabled employee, it cannot under current legislation require the employer to reinstate. At best, the disabled person will receive substantial compensation from his or her ex-employer but will, nevertheless, still be out of work.

The second key element of any job retention strategy is cost sharing. Most employers are not convinced by the business case for retaining newly impaired employees. They believe that there will be substantial costs associated with retraining and workplace adaptation and that these will outweigh the benefits of keeping an experienced employee. Without a compulsory job retention program that allows for some element of cost sharing, employers will not keep on newly disabled employees.

In the United Kingdom, this issue has been partially addressed through the Access to Work program. This provides government funding for adaptation of premises and equipment, special aids, support workers, and travel to and from work. In many cases, Access to Work can cover all of the additional costs associated with retaining a newly disabled person, which should be enough to alleviate employer concerns. However, as many as three-quarters of employers have not heard of the program and the financial support it can provide.

While Access to Work is concerned primarily with funding changes to the work environment and equipment, the Employee Retention Grant Scheme introduced in the Republic of Ireland in the late 1990s provides financial support for the development and implementation of a job retention strategy for newly disabled workers. Under a two-stage process, employers receive funding to buy in expert skills to develop a written individual retention strategy and then further aid toward implementing the strategy including retraining and job coaching. In general, cost sharing is needed to ensure the provision of return to work services through individual casework and to fund workplace adaptations and equipment.

The third necessary element of a successful job retention strategy is early and timely intervention. Within disability leave programs, there is typically a home visit at eight weeks. This is in sharp contrast to the usual practice in the United Kingdom, which has been to allow newly sick or disabled employees to drift out of work and onto long-term benefit dependency. This is changing with a stronger focus on job retention in the Department for Work and Pensions (DWP) latest Five Year Plan (DWP 2005). But the United Kingdom is still some way from the early interventions required in countries such as Denmark, Sweden, and the Netherlands.

The fourth key element of a successful job retention strategy is a benefits system that is flexible and supports a gradual return to work after a period of disability leave. In the United Kingdom, benefit rules have tended to discourage the combination of sickness/incapacity benefit with a wage, allowing for part-time working. However, this also is starting to change as the findings of DWP Pathways to Work and job retention pilots show the advantages of flexible benefit/pay packages.

DE FACTO DISABILITY LEAVE

Despite the UK government's stated opposition to disability leave, key elements are now in place. There is cost sharing through Access to Work. Timely intervention and benefit flexibility is starting to be delivered through Pathways to Work and the proposed Rehabilitation Support Allowance. What is missing is effective job protection. This is not and will not be delivered by the type of disability discrimination legislation that exists in the United Kingdom and the United States. Yet, as both Bloch and Prins and Thornton have argued, this is *the* most important element in a job retention strategy.

—Steve Winyard

See also Disability Discrimination Act of 1995 (United Kingdom); Job Retention.

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DISABILITY MANAGEMENT

Disability management is used to refer to a wide range of concepts and approaches. Most commonly, the term is used in three areas: work and work discrimination, symptom/condition management, and resource management.

Within the area of work, disability management commonly refers to a field of practice that has focused on how employers manage disability overall within the workplace, including issues such as preventing disability, returning to work after a disability event, providing reasonable accommodations within the worksite, and cost-benefit and -effectiveness analyses of the management services. Within the United States, there is a national certification system for disability management specialists, referring primarily to human resource specialists with experience in managing work-related disability issues. Given the passage of the 1990 Americans with Disabilities Act in the United States, the Disability Discrimination Act in England, and other related civil rights legislation in many countries, the focus has shifted toward evaluating discrimination in the workplace experienced by disabled people, and the effect of this discrimination on the disabled person, the disability community as a minority group, employers, and society in general. The field of disability management has also focused on organizational health, that is, how disability influences cost, cost-benefit, and productivity within worksites as organizational units. The field of disability studies has instead focused on analyzing the oppression of disabled people as a minority group, particularly evident in the area of access to work opportunities, tracing the oppression to a capitalist political economy and ideology.

Disability management has also been used to refer to the management of symptoms, conditions, and impairments affiliated with disability. In this case, *disability* is used to refer to disease, medical or chronic conditions (e.g., diabetes, heart disease, arthritis, multiple sclerosis), or broader impairment categories (e.g., physical, cognitive, mental, sensory). *Management* refers to how people who are living with these conditions manage or control the symptomology, and the use of treatments affiliated with each. Research has focused on how people respond to symptoms and control them in emergency and acute situations as well as over their lifetime, treatment strategies for managing symptoms, and the relative outcomes, effectiveness, and long-term impact of treatments, primarily related to quality of life and cost/cost-benefit issues as framed within a medical approach.

The focus on condition or impairment management has expanded beyond symptom management to self or self-care management, that is, managing everyday self-care in the home given specific conditions or a long-term disability. Self-care is often linked with overall health promotion strategies, including nutrition and exercise to maintain or prevent declines in function. Intervention programming in this area has included a range of strategies, including self-care rehabilitation within traditional rehabilitation settings, community-based health promotion groups or intervention programs, telerehabilitation in which rehabilitation or medical professionals consult remotely with clients on specific self-care issues in the home, and use of Internet and/or self-paced learning modules for specific client populations. Most programming has focused on specific groups, such as people living with diabetes, asthma, chronic heart conditions, and back pain. The focus in this application is on finding effective strategies to help people manage themselves within the home setting and preventing or decreasing use of costly emergency medical care, long-term care, or institutionalization services. The approach centers on self-efficacy and the development of active problem-solving skills. Increasingly, the use of a peer mentor approach, that is, the use of people who have been through a disability experience to mentor other people new to it, is being emphasized. Peer mentoring is being shown to be as effective as or more effective than traditional patient education delivered by medical professionals in realizing outcomes related to symptom management, overall activity, and role participation, and reduced cost related to use of medical and health-related services. The effects of remote peer mentoring, using strategies such as peer Listservs and electronic mail support groups, are also being examined, showing similar positive outcomes.

A social learning and peer mentoring approach is also a guiding tenet for another application of disability management that focuses on the right to live in the community, and the right to have access to equitable supportive resources to live and participate long term. Coming from the independent living and disability rights movements taking place in many countries, the term *disability* is reconceptualized away from the individual, and the focus on the deficit or dysfunction in the individual assumed in prior approaches, to disability as the oppression of a minority group as a result of societal and environmental barriers, including access to community living resources. Resource management involves finding, accessing, controlling or coordinating, and troubleshooting supportive resources such as affordable and accessible housing, personal attendant services, transportation, assistive technology, and any other supports for community living. This involves accessing and coordinating these resources across many systems with different policies and eligibility criteria. The emphasis is both on learning self-advocacy skills, on an individual basis, and on collective activism to change systems, assert civil rights, and improve societal conditions and opportunities for the disability community as a minority group. Resource management has been emphasized within centers for independent living and other disability activism organizations, and it is being increasingly used as a model approach within the delivery of home and community-based waiver programs to support transition out of institutions and long-term community living choices. The movement has also expanded beyond resource management to focusing on disability experiences as lived by disabled people themselves, and the sharing and critical analysis of those experiences from multiple perspectives.

—Joy Hammel

See also Community Living and Group Homes; Health Promotion; Occupational Therapy; Peer Support.

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DISABILITY POLICY: INDIA

The history of a comprehensive disability legislation in India is fairly recent. It can be said to have begun with the ratification of the 1995 Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (henceforth called PWD Act) by the Indian Parliament. Prior to that, disabled people in India were receiving services—both by the government and nongovernment agencies—but they did not have any legal protection. They could not claim these services as a matter of right. According to Ali Baquer, for the first time, through the PWD Act, it was impressed on society that it has a responsibility to accommodate its disabled citizens and treat them at par, as full and equal citizens—with respect and dignity.

The passage of the PWD Act marked a new dawn in the life of disabled in India. However, one cannot talk about this landmark act without briefly tracing the background in which this legislation became the law of the land and also at the responses of society and state toward the challenges faced by disabled in India—especially during the colonial and postcolonial period. In her pioneering work, which documents the history of disability policy and programs in India, D. Rama Mani has briefly touched on the perception of disability as an issue of charity in ancient and medieval India. She further suggests that with the inroads of Western civilization and the missionaries in the eighteenth century, the old order—of families supporting and providing for their disabled kith and kin—crumbled. If charity and welfare models were in place before the onset of India's colonization by the British, the medical/pathological/rehabilitation model was initiated during the colonial period, which again remained predominantly charity based. The efforts to rehabilitate the disabled were sporadic in the sense that certain categories were totally left out of the purview of services. The responses came from the voluntary sector and the missionaries, which started with the setting up of the hospitals and charitable homes for destitute and handicapped children in the 1880s. Special schools for hearing impaired at Mumbai in 1884 and for the blind in 1887 at Amritsar, Punjab, were opened by the Roman Catholic missionaries. By the time of independence, nearly 100 special residential schools and training centers for disabled people were running.

While echoing similar views, Maya Kalyanpur and Anuradha Mohit have stated that the institutions set up during the colonial period were patterned to perpetuate custody rather than care for disabled people. Their "asylum-like character . . . unleashed in its wake the process of dehumanization of the PWDs [people with disabilities]." In light of this statement if one looks at the responses of the state, they are manifested in the inclusion of disability in the census, which started in 1872 and continued until 1931, and the passage of the Indian Lunacy Act of 1912, which was established for the mentally retarded and mentally ill people. This act did not allow any medical or therapeutic intervention but entitled the judiciary to relegate mentally ill, then called people deemed of unsound mind, into prisonlike psychiatric institutions.

After independence, however, with India adopting a system of welfare state, policy makers started looking at disability as a rehabilitation issue. The focus was on prevention of disability and its causes, on one hand, and provision of services in the field of education and employment of disabled people, on the other. The disability groups, which were more organized and raising their voices, were able to get concessions and subsidies from the government. Special mention can be made of organizations of the blind, such as the National Federation of the Blind, which were able to obtain concessions in air travel. Like in other countries, disabled veterans were also given differential treatment compared to civilian disabled people. From the 1950s to 1981, the International Year of Disabled Persons, the government responded to the needs of the disabled by making meager budgetary allocations, to be given in the form of grants-in-aid, to nonprofit organizations, for delivering services to the disabled in the area of education, rehabilitation, training, and employment. These nongovernmental organizations (NGOs), however, remained dominated by able-bodied, philanthropic individuals and professionals. There was hardly any place for disabled people to plan the services and programs meant for them. At the same time, need was also felt to prepare a large pool of professionals who could train the disabled in different vocations and work in the national training institutes set up by the government of India. The four national institutes were the National Institute of Visually Handicapped at Dehradun, National Institute of Orthopedically Handicapped at Calcutta, National Institute of Mentally Handicapped at Secundrabad, and Ali Yavar Jung National Institute of Hearing Handicapped at Mumbai.

The year 1981 marked the beginning of change in the condition of disabled people in India. It was the International Year of Disabled Persons, and being a signatory to the UN resolution of 1976, the government of India had committed itself to mandates that provided for equal participation of disabled people in all walks of life and emphasized recognition of the rights of disabled and evolving strategies for their development. Statutory provisions were made and strengthened. For the first time in independent India, the disabled were counted in the decennial population census. The way the data were collected and questions framed, however, left out several categories of disabilities. Because of this, authentic figures could not be gathered, and, instead of improving on it, the practice was done away with in the next census, in 1991. It was in the decade of the 1980s that positive action started in favor of delivering services to the disabled—reservations in educational institutions and employment were given on extended, the Lunacy Act of 1912 was repealed, and the National Mental Health Act was passed in 1987. In the same year, the Justice Baharul Islam Committee was appointed to draft the legislation emphasizing the rights, equal opportunities, and full participation of disabled people. The new national education policy was implemented with focus on inclusive education for disabled children in integrated settings. The state governments also responded by running central government-sponsored programs for the disabled and starting their own programs as well. The public sector responded overwhelmingly by opening doors to disabled people.

Despite these developments, disability remained a marginalized issue until the early 1990s, when some young like-minded disabled advocates, prominent among them being Javed Abidi, Anuradha Mohit, Sarabjeet Singh, Ali Baquer (nondisabled advocate), A. K. Chowdhury (nondisabled advocate), and Lal Advani, formed the Disability Rights Group (DRG) in 1994 to lobby with India's policy makers to accept the recommendations of the Justice Baharul Islam Committee and accordingly pass the legislation. The NGO sector was still dominated by able-bodied people who were largely dependent on government funding for their existence; education of disabled children was still under the purview of Ministry of Social Justice and Empowerment rather than education; disabled people were still relegated to C- and D-category jobs in the government sector; and, with globalization, opportunities for disabled people in the job market were shrinking day by day.

The formation of this DRG was inspired by none other than the stalwarts of the American disability movement Judy Heumann and Justin Dart, who informed these young disability activists via a satellite conference that the Americans with Disabilities Act was a result of a sustained campaign and self-help advocacy movement of disabled people. After a prolonged campaign, several rounds of talks, lobbying, sit-ins, protest marches, press conferences, media mobilization, and agitations, the Persons with Disabilities Act was finally passed by the Indian Parliament on December 31, 1995, and became a law on February, 7, 1996, with the president giving his assent.

According to a conservative estimate, there are 70 million disabled people in India. The act places them on par with other citizens of the country in respect to education, vocational training, and employment. For the first time, the private sector was called on to respond to the disabled. It also streamlines the services existing for the disabled and extends them further; for example, the reservation of posts has been extended to groups A and B and it forces the state to ensure that every child with disability has access to free education up to the age of 18 years. The state has been entrusted with the responsibility to prevent disabilities and provide medical care, education, training, employment, and rehabilitation for persons with disabilities. Furthermore, the state must create barrier-free environments for them, protect their rights, and counteract any abuse or exploitation. It must also provide sufficient mechanisms to implement the intentions and provisions of the act through the constitution of coordination and executive committees at central and state levels with adequate representation of disabled people in them and the office of commissioner at the federal as well as state level. The act gives definition of disability and recognizes seven disabilities that are entitled to the benefits of the act. The categories that have been left out of this act have been included in the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999. The PWD Act is designed to encourage fuller participation of disabled people in the community and eliminate discrimination. The act may not yet have significantly affected the large number of Indian disabled people but definitely has highlighted disability as a development and human rights issue.

—Meenu Bhambhani

See also Disability in Contemporary India; Experience of Disability: India.

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DISABILITY POLICY: UNITED STATES

In the United States, as in other countries, individuals with disabilities have historically lagged behind the remainder of the population in terms of key socioeconomic indicators and have been excluded from full—and often even partial—participation in society. And, like other countries, the United States has struggled to find the correct mix of policies to bring people with disabilities into the larger society and to equip them to participate meaningfully.

The United States first addressed disability as a health issue and attempted to ameliorate the circumstances of people with disabilities through treatment and care. In the past 30 years, however, policy has shifted. Instead of viewing disability as a medical condition that inherently prevents full engagement in society, today’s policies view society as an institution that has discriminated against those with particular medical conditions. Thus, disability law in the United States today focuses on preventing discrimination based on disability and breaking down the structural barriers to full participation.

A cautionary note: Disability policy in the United States is a dynamic mixture of federal and state laws, regulations, and cases. Often states are on the cutting edge, forcing the national government to catch up. Sometimes the opposite is true. This entry, however, focuses on federal laws, which must be dealt with in all jurisdictions. Moreover, the scope of this entry is limited in that it ignores much substantive disability law and the compelling policy issues that arise in connection with those laws. This article, for example, focuses on the Americans with Disabilities Act’s efforts to erase those impediments to full participation in society that exist today. Much thought, however, has gone into the ADA’s role in ensuring that new obstacles to full participation do not develop as society changes. One of the most fascinating current issues involves how the ADA’s mandates should function with respect to the accessibility of new technologies such as the Internet. Thus, though this entry explores the basics of disability policy, it leaves much uncovered.

The farthest-reaching statement on disability law and policy is found in the Americans with Disabilities Act of 1990 (ADA). In broad terms, the ADA extended to the private sector employment requirements placed on the federal government and federal contractors by the Rehabilitation Act of 1973. It also mandated access to public services—with special emphasis on transportation—and to “public accommodations and services provided by private entities.” This includes everything from hotels and amusement parks to laundromats.

Although the ADA has a broad focus, the component that is perhaps central and that has stirred debate is the accommodation mandate with respect to private employment embodied in Title I of the act. This title places much (but not all) of the initial cost of integrating people with disabilities into the workplace on the private employer. Academics have criticized the approach as inefficient and ineffectual, though whether either is true remains to be seen. Given the centrality of employment as a tool of economic independence and as a route to social integration, the success or failure of Title I may announce the success or failure of the ADA.

EXTENT OF DISABILITY IN THE UNITED STATES

Tens of millions of individuals in America have disabilities. And those going through life with a disability face myriad obstacles. Much of society has traditionally been, and remains, physically inaccessible to people with disabilities. While the lack of physical access to society is troublesome, it is only the most visible of an array of concerns. As shown by the statistics below, people with disabilities lag behind the nondisabled population in a variety of social and economic indicators.

- 27 percent of individuals with disabilities are employed, compared to 78 percent of their nondisabled peers.
- Employees with disabilities with full-time jobs had average annual earnings of $29,513 in 1998, which was more than $8,000 less than the $37,961 average earnings of their nondisabled counterparts.
- Fewer than 11 percent of individuals with disabilities have more than 16 years of education, while almost 24 percent of individuals without disabilities attain that level of education.
- Fewer than 10 percent of individuals with disabilities own a home, while homeownership for the population as a whole exceeds 70 percent.
- 34 percent of persons with disabilities live in households with a total income of $15,000 or less, compared to only 12 percent of those without disabilities.
- People with disabilities are roughly 20 percent less likely to vote than those without disabilities, even after controlling for demographic and other factors relating to voting.

All agree that society has a role in ameliorating the condition of the population of people with disabilities. But how best to respond has not been obvious. Over about the past quarter century, the thinking in the United States has undergone a transformation. Whereas traditionally the government saw itself as a caretaker for people with disabilities, it has recently embraced a disability policy that seeks to integrate those with disabilities into society. The former approach is often referred to as the medical model or charity model and the latter as the civil rights model.

MEDICAL MODEL

From the viewpoint of the medical model, disability is conceived of as an infirmity that inherently precludes full participation in the economy and society. It is the job of doctors, rehabilitation professionals, government bureaucrats, and social workers to take care of individuals with disabilities and to help them adjust to a society structured around the abilities and interests of the nondisabled.

Thus, society's role with respect to people with disabilities is paternalistic; its treatment of them is viewed as a form of welfare or charity. People with disabilities are seen as one component of a larger population that, for whatever reason, cannot fend for itself in society as currently structured. Importantly, this perspective never questions whether society is structured correctly; it merely seeks to help those who cannot function normally within it.

This perception of disability evolved following the Civil War, when the United States created a pension system, in part to manage a population of disabled former soldiers adjusting to postwar society. The legislation linked the definition of disability to an inability to work and established physicians as the gatekeepers of disability benefits.

To this day, many contemporary employment, health care, and rehabilitation programs for persons with disabilities are modeled on this theory. These are policy relics, however, for with the passage of the Rehabilitation Act in 1973 and the ADA in 1990, the United States signaled a significant shift toward the civil rights model.

CIVIL RIGHTS MODEL

The civil rights model conceptualizes persons with disabilities as a minority group entitled to the legal protections of equality that emerged from the struggles of racial minorities and women. Proposing "disability" as a social and cultural construct, the civil rights model focuses on the laws and practices that subordinate persons with disabilities. It insists that society secure the equality of persons with disabilities by eliminating the legal, physical, economic, and social barriers that preclude their equal involvement. The emphasis is not on giving any group special benefits; rather, the issue involves balancing the scales. As one commentator suggests:

> The configurations of the existing environment confer enormous advantages on nondisabled persons. Machines have been designed to fit hands that can easily grip these objects, steps have been built for legs that bend at the knee. . . . Everything has been standardized for a model human being whose life is untouched by disability. All aspects of the built environment, including work sites, have been adapted for *someone*; the problem is that they have been adapted exclusively for the nondisabled majority. (Hahn 1993:103)

Thus, while the medical model focuses on caring for a population of individuals whom society has left behind, the civil rights model focuses on changing society so it leaves behind fewer people.

The shift toward the latter conceptualization of society's role in the lives of people with disabilities started in the 1970s, when individuals with disabilities began to assert their right to be independent in pursuing education and housing. As a result of these efforts, national disability policy began to recognize the right and ability of individuals with disabilities to live independently. For example, Title VII of the Rehabilitation Act of 1973 initiated funding for centers for independent living (CILs). Those centers, which provide services *for* individuals with disabilities and are operated *by* individuals with disabilities, have been enormously successful over the past two decades: Only 10 centers existed in 1979, while in 2002 there were more than 350.

The focus on independent living led to a patchwork of federal and state laws addressing the accessibility of voting and air travel, as well as the right of people with disabilities to enjoy education and independent housing. Then, in 1990 the ADA was enacted. It embraced a range of disability rights issues and made specific findings that relied on the civil rights model.

In language reminiscent of law that addresses the civil rights of other minority groups, the ADA reported that

> historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem; . . . [and] individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society.

To begin to rectify the history of discrimination, the ADA set out to ensure that, at least going forward, the disability population will enjoy "equality of opportunity, full participation, independent living, and economic self sufficiency."

THE ADA AND THE CIVIL RIGHTS MODEL

The ADA signals a shift in the underlying philosophy of disability rights law in the United States. Moreover, the legal mechanisms created by Congress and realized in the ADA to achieve these policy goals appear to be well designed to reflect the civil rights model on which the statute is based.

The ADA sets out nondiscrimination mandates and requires that society adjust to accommodate individuals with disabilities in virtually every corner of society. Those principles touch on many aspects of public life, but where they function most prominently and controversially is in the area of employment.

The ADA's treatment of employment is indicative of the structure of the ADA as a whole and can be seen as an example of how the ADA implements the civil rights model. This title sets out a general prohibition of discrimination in employment: "No covered entity shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions, and privileges of employment." And the statute goes on to realize that goal by requiring "reasonable accommodation" by employers. The concept of reasonable accommodation mandates that an employer make changes to its work environment to accommodate a qualified candidate with a disability so long as the alterations would not be unduly burdensome to the business as a whole.

This legal structure flows logically from the civil rights model. According to the model, individuals with disabilities, like certain other groups, have been suppressed by long-standing, built-in societal discrimination. For them to become equal members of society, this discrimination must be extirpated. The ADA tackles this policy imperative by prohibiting discrimination based on disability. In seeking to cure the condition that the civil rights model posits as the root cause of the marginalization of people with disabilities, the act demonstrates its commitment to this perspective.

Arguably, the civil rights model only forbids discrimination between equally qualified people on the basis of irrelevant factors. To that extent, a "passive" ADA might be acceptable and avoid problems of distributive justice among people applying for the same job. It would also be wholly ineffectual. People with disabilities may have the same capabilities as nondisabled individuals, but they face a two-pronged challenge. Not only are there biased attitudes toward individuals with disabilities, but society has been constructed in a way that physical impediments also stand in the way of full participation. Thus, to achieve a level playing field, as called for by the civil rights model, disability policy must not only outlaw discrimination, but it must also address the physical obstacles. The reasonable accommodation principle is a response to these physical impediments.

The act thus goes further than typical civil rights legislation in that it requires employers to accommodate applicants with disabilities. While most legislation designed to protect a group from discrimination mandates that the regulated individuals or entities simply *not* discriminate, the ADA requires an affirmative duty on the part of society, and in the context of employment, private employers. This accommodation mandate, however, is not a departure from the civil rights model, but rather a logical extension of it.

By requiring that the workplace be physically reconfigured or a job assignment be altered (so as to make a barrier irrelevant) to create a work environment hospitable to a qualified individual with a disability, the accommodation mandate removes barriers to equality. Thus, the reasonable accommodation mandate, when coupled with the nondiscrimination principle, seeks to create the equality envisioned by the civil rights model.

In sum, the themes of nondiscrimination and accommodation that run through the employment provisions of the ADA, as well as the text of the document as a whole, implement the civil rights model of disability policy. Having solved the theoretical problem, however, people have begun to face the practical one: Does the structure of the ADA, particularly in the employment context, represent a fair and cost-effective outcome?

LAW AND ECONOMICS PERSPECTIVE

The ADA's treatment of employment has been the subject of examination. The prohibition against disability discrimination, as well as the requirement of reasonable accommodation, put much of the responsibility of integrating people with disabilities into the workplace on private employers. Commentators have questioned whether this is an equitable and efficient means of allocating the cost of a societal good.

Concerns about distributive justice arise with respect to the ADA because it burdens certain segments of society while benefiting others. Compelled to bear some of the burden of the employment sections of the ADA are nondisabled job applicants and employers. Nondisabled job seekers are now forced to share the employment market with qualified individuals with disabilities. Although it is true that this does impose a cost on this portion of society, it seems minimal (and inherently fair).

Whether employers are suffering net costs at the hands of the ADA, however, is a closer question. Businesses seek to make a profit. To do so, they presumably strive to operate in the most efficient manner possible. Legislation affecting private companies can either help or hinder this effort. Much analysis has gone into what effect the ADA's antidiscrimination and reasonable accommodation mandates have had in this regard.

One can make a compelling argument that the antidiscrimination principle of the ADA improves the efficiency of private employers. Historically, antidiscrimination law in the United States has aimed at ensuring that a person who fits a particular job is able to obtain that job, despite irrelevant personal features: A person's skin color, gender, sexual orientation, or religion generally have little bearing on the match between the person's skills and a particular job. By forcing employers to ignore these irrelevant criteria, civil rights policies should enable the employer to build a workforce better able to perform the required tasks, thereby increasing the employer's efficiency.

The antidiscrimination principle of the ADA is in line with these laws; it performs the same filtering function that traditional antidiscrimination law performs by removing misleading signals from the employers' information mix. An employer will no longer be able to ignore a qualified individual simply because of his or her disability. Thus, there is a plausible argument that the ADA's embodiment of the antidiscrimination principle should increase efficiency.

It is much harder—though not impossible—to show that the reasonable accommodation mandate inures to the economic benefit of the private employers required to implement it. The explicit command that employers accept the burden of paying for accommodations—up to the undue hardship ceiling—sets the ADA apart from other civil rights legislation and, in turn, has created significant theoretical disputes.

The Rehabilitation Act of 1973 imposed reasonable accommodation duties on the government and government contractors; the ADA extends those duties to private employers. The theory supporting the former does not necessarily justify the latter. Although the government may have aims beyond strictly maximizing its output, such as providing employment to those who might not otherwise find it, a private entity's overriding goal is to maximize its profits. And to reach that goal, it seeks to operate in the most efficient manner possible.

It is not yet definitively established what positive impact reasonable accommodation has had on this effort. One must first look at the practical costs to an employer of accommodation. Research has suggested that many people with disabilities require no accommodation, and of those who require accommodation, the cost is usually *de minimis*. For example, a study of workers with disabilities for the U.S. Department of Labor found that only 22 percent of employees with disabilities received some form of accommodation. Of those accommodations, roughly one-half cost nothing, and of the other one-half, more than two-thirds cost less than $100. Thus, at least according to this study, the reasonable accommodation requirement often imposes little or no actual costs on an employer.

Moreover, accommodation is required only when it is not unduly burdensome. Practically, therefore, it is only in the circumstance where a substantial, but not overly burdensome, accommodation is mandated that concerns about efficiency arise. And even in this circumstance, the costs to the employer are mitigated by a variety of tax incentives. There are several tax provisions set out in the Internal Revenue Code available to businesses to foster ADA implementation and compliance: a "disabled access credit" available for small business, a tax deduction available to any business when improving accessibility for customers and employees with disabilities, and a tax credit available to any employer for a percentage of the first- and second-year wages of a newly hired employee with a disability. Beyond this, there are state tax code provisions applicable to small businesses to foster the hiring and retention of employees with disabilities.

Even with these tax incentives, some (usually large) employers may at times be forced to endure significant direct costs under the reasonable accommodation requirement. Those costs must be compared against the benefits that inure to an employer from accommodation and hiring of an employee with a disability to determine whether accommodation increases a business's efficiency.

At first blush, reasonable accommodation may appear inefficient for an individual employer. Theorists posit two applicants with identical skills, one with a disability and one without. It would be inefficient for the employer to hire the applicant with a disability and pay for accommodation, when the employer could hire the applicant without the disability and not be forced to bear those costs.

Though this is a persuasive theory, it has been countered by scholars who contend that reasonable accommodations are efficient in many contexts because they carry hidden benefits. For example, studies support the proposition that employees with disabilities as a group tend to be more efficient workers in that they tend to have lower turnover, less absenteeism, and lower accident risks. Thus, the cost of accommodation may be offset by workplace attributes that individuals with disabilities tend to possess.

Moreover, certain accommodations may be efficient in that they improve the productivity of other employees without disabilities. For example, ramps and elevators assist workers with rolling carts, and accommodations involving technology improve productivity and workplace safety for all workers.

Finally, making reasonable accommodations may be efficient in that it reinforces what would otherwise be an economically rational decision. A certain individual may possess such unique abilities that the cost of altering the workplace may be more than offset by the increased profits realized by having the person contribute to the business venture. In this scenario, the cost of accommodation would be less than the increased efficiency realized by hiring this specific employee.

Whatever the reason, research indicates that accommodations often are a profitable undertaking. One study found that for every dollar invested in an effective accommodation, companies realized an average of $50 in benefits.

Even ignoring these micro findings, reasonable accommodation may work at the macro level by increasing the efficiency of society as a whole. This is because the costs of providing accommodations may be offset by the gains realized by greater employment of individuals with disabilities. According to this theory, government benefits paid to people with disabilities will decrease because fewer individuals with disabilities will be in need of government support. In addition, the more individuals employed, the more the government collects in the form of income taxes. In other words, it may be efficient to have individual employers "run" this social welfare program, so that even if there are net costs, they are smaller than if the government ran the program.

All of this is not to say that the federal government plays no role in the employment context. In fact, aside from the tax incentives mentioned above, legislation has been recently enacted that is designed to help individuals with disabilities transition into the newly opened work environment. In the Ticket to Work and Work Incentives Improvement Act (TWWIIA), Congress sought to remove two of the barriers that stand in the path of individuals with disabilities seeking employment: potential lack of health care coverage once employed, and lack of training for and access to certain jobs.

Individuals with disabilities have traditionally faced a severe disincentive to entering the workforce in that employment income would disqualify them from Medicaid and other benefits under the Social Security Disability Insurance program (SSDI) and the Supplemental Security Income program (SSI), which have been available to individuals who could not engage in "substantial gainful activity." Thus, once individuals with disabilities gained employment, they could lose government-provided health benefits. Yet their new jobs often did not provide insurance and did not pay enough for individual coverage. And, even when insurance was available or affordable, many individuals were denied coverage because of their disabilities. This led to a situation where, among working Americans with disabilities, almost one in five had no health insurance.

TWWIIA addresses these issues by allowing states to permit qualified individuals with disabilities to purchase Medicaid health insurance after entry into the workplace even though their income may be above the poverty level. In addition, TWWIIA has provisions that address the potential loss of health benefits by those returning to work after a disabling injury.

Moreover, the lack of skills training and access to job sites often makes finding employment especially difficult for individuals with disabilities. To address this issue, TWWIIA's Ticket to Work and Work Self-Sufficiency Program provides recipients of disability insurance with a "ticket" to purchase employment training services from qualified Employment Networks (ENs). ENs are public or private entities that provide services such as workplace accommodations, peer mentoring, job training, and transportation assistance to ticket participants seeking employment.

TWWIIA and the ENs work in conjunction with broader welfare-to-work transition programs such as the Workforce Investment Act (WIA) and the

Temporary Assistance for Needy Families Programs (TANF), which provide incentives and training to help low-income individuals (including those with disabilities) find employment. The ADA requires that services provided by ENs or through the WIA or TANF be accessible to those with disabilities. Thus, TWWIIA, working alongside the ADA, has created a situation whereby individuals with disabilities are now able to access a range of job-related services to help them find and retain employment.

Such policies demonstrate America's commitment to integrating people with disabilities into the workforce. However, the costs of these programs need to be considered when determining whether the ADA's employment construct is efficient for society as a whole. This is especially relevant since some economists have questioned whether the ADA creates a net increase in employment. It has been argued that the accommodation requirement, because it hypothetically increases an employer's hiring costs, may lead to less overall employment, and thus *less* employment of people with disabilities. If indeed fewer individuals with disabilities are employed, this would defeat the argument that accommodation helps to relieve the social welfare system.

Whichever way one evaluates the efficiency argument, it is important to note that the efficiency of the program was not an overriding consideration at the time of the ADA's adoption. The ADA as a whole, and the accommodation requirement in particular, represented a national policy that costs and economic efficiency are dispensable (within limits) if more people with disabilities are employed. As explored below, it is a subject of debate whether the ADA has accomplished this goal, and conclusions are influenced by how one defines disability for purposes of the law.

IMPACT OF U.S. DISABILITY LAW

People with disabilities have been employed at substantially lower rates than people without disabilities, although the rates tended to fluctuate with overall economic conditions. The ADA was aimed at this employment gap. It came into effect for most private businesses in 1992, but as early as 1996 some commentators suggested a deterioration in the employment situation of individuals with disabilities in relation to other groups.

The period following the enactment of the ADA has been one of rapid changes in the economic structure of the United States. Manufacturing sector jobs have declined in favor of service industry jobs; job mobility has increased; and the economy has seen an upsurge and, at the end of the decade, a substantial retrenchment. In the face of those large-scale changes in the economy, researchers have attempted to determine the impact of the ADA on the employment of people with disabilities. The studies, several of which are discussed below, have yielded contrary interpretations of employment trends among people with disabilities.

One recent study attempted to trace the employment of individuals with disabilities over time using national survey data. People were identified as having a disability if they answered the following question in the affirmative: "Do you have a health problem or disability which prevents you from working or which limits the kind and amount of work you can do?" The study attempted to evaluate the ADA's impact by looking at the change in the number of weeks worked and the average weekly earnings of this group over the course of the 1990s. Based on this analysis, the authors argue that the ADA had a negative causal impact on the number of weeks worked by individuals with disabilities and had no impact on the wages of those individuals.

Other studies with similar survey data have suggested similar results, even while employing a different methodology. In one study, the authors examined the impact of the ADA on three groups of U.S. states: (1) states that, prior to the ADA, had no disability discrimination law; (2) states that, prior to the ADA, had only a "traditional" disability discrimination law—one that prevented discrimination on the basis of disability (nonaccommodation states); and (3) states that had an ADA-like statute—one that prohibited discrimination and also required reasonable accommodations (accommodation states). The authors theorized that by comparing results among the states grouped in this manner, one could better isolate the effects of the ADA, and the accommodation requirement in particular.

The authors found that for this sample the employment of people with disabilities declined. Moreover, when comparing the decrease in employment between the non-accommodation states and the accommodation states, the study found that the decrease in employment was more severe in the former group. The finding that states that had no accommodation requirement saw a decline that surpassed the states that already had an accommodation statute suggests that this mandate was the component of the ADA that was largely responsible for the employment decline.

Thus, some studies suggest that the ADA, and the accommodation provisions in particular, have a *negative* impact on the employment of people with disabilities. But other authors question the methodologies used by previous scholars, and in particular their failure to focus on people the act was designed to help—*qualified* people with disabilities—rather than all people who answered yes to the broad question: "Do you have a health problem or disability which prevents you from working or which limits the kind and amount of work you can do?"

Studies that have sampled individuals the ADA more likely covers have reached more encouraging results. When focusing on the ADA target group (i.e., those individuals who are not work limited but are functionally limited), one study found an increase in employment rates. Another study, examining a population of "disabled" individuals drawn from a Social Security Administration survey, found that the ADA had a positive impact on certain people with disabilities, although it may have had a negative impact on those people with disabilities who were not already, at the time the ADA became effective, participating in the labor market.

Authors of those later studies identify aspects of prior studies that may have skewed their results. For example, reports finding that the ADA had a negative impact may have underreported the positive influence of the ADA because, if more people with disabilities have jobs, fewer may view themselves—and report themselves—as having disabilities that limit their ability to work. Thus, the number of employed people with disabilities would not accurately be reflected.

While the studies may have underreported the number of employees with disabilities, at the same time, they may have inflated the number of individuals with disabilities who are unemployed. Increasingly stringent welfare requirements coupled with more generous federal disability laws create incentives for unemployed individuals to classify themselves as having disabilities. This effect may have caused certain individuals to exaggerate their disabilities, which would in turn inflate the number of unemployed labeled as having disabilities, possibly rendering research findings inaccurate.

It is evident that, even a decade after the ADA's enactment, the results of its employment provisions remain unclear. Some studies find that the statute has led to diminished employment. But those findings may result from limited methodologies and data sets that fail fully to account for the inherent problems with the definition of disability and the measurement of that population.

Nevertheless, even if one discounts research that suggests a negative impact on employment, the studies, when looked at as a whole, indicate that the ADA is serving its antidiscrimination and integration mandates, albeit perhaps as not in regard to large numbers of people with disabilities. Given that the ADA came into being during a time of economic prosperity, it will be important to track its results in the slow growth period that has defined the recent economy.

Broadly, the ADA raises the policy issue of the proper scope of such antidiscrimination laws as applied to private entities—necessarily enforced by private litigation—to bring people with disabilities into the mainstream. Would employment rates improve significantly if the initial costs of accommodation were shared among employers, persons with disabilities, and the government? And, at what point would a system including greater government support create an unwieldy bureaucracy?

These broad questions, concerning the proper mix of public and private endeavors, color the debate with respect to the public accommodation provisions of the act as well. And though the answers are not clear yet, it is the passage of the ADA that has allowed us to begin to ask those important questions.

—Jeffrey A. Schwartz,
Charles D. Siegal, Michael Waterstone,
Eve Hill, and Peter Blanck

See also Americans with Disabilities Act of 1990 (United States); Citizenship and Civil Rights; Disability Law: United States; Rehabilitation Act of 1973 (United States).

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DISABILITY PRIDE

Disability pride represents a rejection of the notion that our physical, sensory, mental, and cognitive differences from the nondisabled standard are wrong or bad in any way and is a statement of our self-acceptance, dignity, and pride. It is a public expression of our belief that our disabilities are a natural part of human diversity, a celebration of our heritage and culture, and a validation of our experience. Disability pride is an integral part of movement building and a direct challenge to systemic ableism and stigmatizing definitions of disability. It is a militant act of self-definition, a purposive valuing of that which is socially devalued, and an attempt to untangle ourselves from the complex matrix of negative beliefs, attitudes, and feelings that grow from the dominant group's assumption that there is something inherently wrong with our disabilities and identity.

Dr. Martin Luther King Jr. (1967) once wrote,

> One must not overlook the positive value in calling the Negro to a new sense of manhood, to a deep feeling of racial pride and to an audacious appreciation of his heritage. The Negro must be grasped by a new realization of his dignity and worth. He must stand up amid a system that still oppresses him and develop an unassailable and majestic sense of his own value. He must no longer be ashamed of being black.

Although there are many barriers facing people with disabilities today, one of the single greatest obstacles we face as a community is our own sense of inferiority, internalized oppression, and shame. The sense of shame associated with having a disability has, indeed, reached epidemic proportions. Disability rights movements in different countries have made many gains in the area of civil rights over the past decade, but what good is an Americans with Disabilities Act or a Disability Discrimination Act if people will not exercise their rights under these laws because they are too ashamed to identify as being disabled? "As long as the mind is enslaved," King wrote, "the body can never be free." As long as people with disabilities remain ashamed of who we are, we will never realize the true equality and freedom we so desire. We must first take pride in ourselves as a community. We must no longer be ashamed of being disabled.

Dismantling centuries of internalized oppression, however, and promoting a widespread sense of disability pride are easier said than done. Unlike other civil rights movements, people with disabilities do not always have the benefit of a generational transfer of disability history and pride through the family structure. There are no "disability churches" per se, neighborhood enclaves, or other communal institutions where people with disabilities can come together by choice and consistently receive positive messages that counteract the depredation wrought by the onslaught of cultural terrorism. There is a tremendous need to create a counterculture that teaches new values and beliefs and acknowledges the dignity and worth of *all* human beings. Disability pride is a direct response to this need.

—Sarah Triano

See also Disability Culture; Disability Studies.

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DISABILITY RIGHTS EDUCATION AND DEFENSE FUND

The Disability Rights Education and Defense Fund (DREDF), with offices in Berkeley, California, and Washington, D.C., has been a leading cross-disability civil rights law and policy center since it was established in 1979. DREDF carries out its mission through training, legal assistance, advocacy, policy and legislative development, litigation, and research. DREDF is unique in the disability rights movement in the United States because it was founded and continues to be led by people with disabilities and parents of children with disabilities, and it achieves social change by organizing and training at the grassroots level, crafting and promoting legislation and policy, and defending those policies in the courts.

DREDF identifies economic and social disenfranchisement of people with disabilities as the result of prejudice and discrimination rather than as an inevitable consequence of the physical and mental limitations imposed by disability. This worldview closely aligned DREDF with other civil rights struggles, thus leading to an invitation in 1981 to join the executive committee of the nation's largest coalition of civil rights groups, the Leadership Conference on Civil Rights (LCCR).

DREDF plays a central role in articulating the principles of disability rights law and developing and disseminating strategies for groundbreaking disability civil rights legislation and litigation. DREDF is best known for advocating successfully for federal civil rights laws, representing members of Congress and leading disability organizations in amicus curiae briefs in cases argued before the U.S. Supreme Court, and national grassroots training and empowerment for thousands of parents of children with disabilities and adults with disabilities.

DREDF laid the groundwork for enactment of the landmark 1990 Americans with Disabilities Act (ADA) by preserving and advancing its predecessor law, Section 504 of the 1973 Rehabilitation Act when it came under attack by the Reagan administration and in the courts in the early 1980s. Similarly, DREDF organized to preserve regulations implementing the Education for All Handicapped Children Act. DREDF is also credited with playing leading roles in the passage of the ADA and other groundbreaking laws such as the Handicapped Children's Protection Act of 1986, the Civil Rights Restoration Act of 1987, and the IDEA Amendments Act of 1997.

In 1987, DREDF established the Disability Rights Clinical Legal Education Program and began teaching disability rights law at the University of California, Berkeley, Boalt Hall School of Law and supervising law students in the practice of law. DREDF litigation seeks not only to enforce existing laws but also to clarify and advance disability rights through the pursuit of law reform cases, such as by filing the first full-inclusion special education case that went to the U.S. Supreme Court, *Holland v. Sacramento City Unified School District* (1994).

Since 1990, DREDF has worked internationally in 17 countries with advocates who seek assistance in the development of law and policy reform strategies. Ongoing future challenges include restoring, sustaining, and preserving the ADA from further erosion in the courts, and meaningful enforcement of IDEA. As DREDF works in coalition with racial, economic, and environmental justice groups, future challenges will broaden the reach of DREDF's expertise to key areas such as equitable and accessible health care services.

—Julia Epstein

See also Activism; Advocacy; Advocacy, International; Disability Law: United States; Disability Policy: United States; Justice.

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DISABILITY RIGHTS OF CHILDREN

See Children with Disabilities, Rights of

DISABILITY STUDIES

DISABILITY STUDIES AND DISABILITY RIGHTS

Disability studies functions as the theoretical arm of disability rights movements. As an interdisciplinary field of study and scholarship, disability studies analyzes the meanings attributed to human corporeal, sensory, and cognitive differences. Participants examine the role that disability serves in expressive traditions, scientific research, and social science applications. They study the status of disabled persons, often by attending to exclusionary scholarly models and professional structures. Interestingly, a key aspect of disability studies has involved focusing on the privilege that accrues to nondisabled persons within built environments. Implicitly, then, researchers question the ethics of inbuilt social exclusions by tracing out their origins. As a result, they track down many historical "genealogies" of practices and attitudes concerning disabled persons.

In seeking to understand the variety of interpretations that make disability an evident facet of human diversity, the field includes many methodologies such as quantitative assessment, qualitative interpretation, critical analysis, and historical genealogies. Nonetheless, because disability studies marks a departure from fields of knowledge and professional training that may have sustained exclusionary practices and mandated social shame, participants in disability studies primarily engage in efforts to reevaluate the implications of traditional approaches to disability. New scholarship proposes research topics that allow disability perspectives to emerge. As a result, the experiences that infuse life with a disability are valued for insights that can be culled for innovative strategies to assist new generations of disabled persons. Such disability perspectives bring to the forefront of cultural commentary a body of insight previously marginalized within many universities during an era of scholarship in which eugenics ideas prevailed.

It should be emphasized that disability studies initiatives, research projects, and curricula have been developed worldwide, with formations primarily in global urban centers and wealthy nation-states. This entry, however, will be limited to the United States, and to an extent, Canada, the United Kingdom, and Australia. Disability studies takes place when groups of committed advocates, activists, and scholars pursue work locally to make the persistence of disability exclusions across a variety of regional and global contexts better understood, documented, and interpreted. Only very recently, during the last decade of the twentieth century, did disability studies begin to be more generally recognized as an area of academic inquiry, while the moniker "disability studies" came into usage during the1980s. The new term sought to differentiate its concern with the well-being of disabled persons from what one scholar has termed the "disability business." The disability business was perceived as a megalithic operation of management interests and government surveys that were frequently answerable to the goals of nondisabled persons at the expense of their disabled clients, family members, or neighbors.

At present, disability studies consists of a nascent, yet rapidly expanding scholarship that draws researchers from across a diversity of academic fields. Most universities have been inaccessible to disabled persons; as a consequence, scholars in disability studies observe the ways in which curricular ideas also suffer from this central exclusion, taking as a given that disability experiences offer a substantial vantage upon human existence. Because aspects of fields of study may reiterate the perpetuation of "able-ist" bias, disability studies can sometimes involve a rejection of habits, methods, and undertakings of universities in the past in their assumptions about bodies and capacities. Thus, disability studies also entails studying the myriad ways that traditional fields have been willing to study their topic from a distance without embracing the insights and critical perspectives of disabled persons concerning their own predicament. The distinction entails making claims for critical insights to be gained by partaking of disability-based experiences, knowledge, and lifestyles.

Disability studies scholars distinguish their undertaking as "new" in order to mark a distance from the viewpoint of modern eugenics that sought to "improve human stock." At the beginning of the twentieth century, such an enterprise targeted the eradication of disabilities from human populations. Not only are many events and public spaces of modern life organized by policies that effectively segregate persons with disabilities from a civic mainstream, but traditional responses to disabled persons, termed the "study of disability" as opposed to "disability studies," also see disabled persons as clients, informants, or research objects to be treated, managed, regulated, controlled, and investigated. So not only must social barriers to the inclusion of disabled persons be broken down, as disability rights proclaims, but the sources for misperceptions about disability experiences need to be redressed. These objectives require studies of discourse, and of the etiologies and histories of the definitions of pathology and aberration, in addition to study of the histories of the development of environments and communication modes that privilege some players and exclude others.

Universities, such as renowned Stanford University, whose first president David Starr Jordan promoted eugenics ideas about the obvious inferiority of disabled persons' lives and bodies, may not be perceived as immediately welcoming of disability perspectives. Recently, for example, Princeton University garnered international press coverage for hiring eugenics theorist Peter Singer. Singer argues not only that parents should decide whether disabled infants should be killed at birth but also that adult disabled persons have no evaluative criteria to contribute to a discussion over the value of a life lived by a disabled infant. Able-ist biases in top-flight universities, from their physical plant specifications to their presumptions about body qualifications, make them chilly places for disabled persons. Many note how ideas for gas chambers, first developed as a means to ease the difficulty for health practitioners in administering lethal injections, were developed within academic settings and with demonstration project methodologies. When Harriet McBryde Johnson, a disability rights lawyer and noted disability rights commentator, visited Princeton for a series of forums with Peter Singer, she reflected on the ethical conundrum such a visit provokes. On the way out, she thought about her "brothers and sisters," the 14 arrested protestors for Not Dead Yet, who "were here before me and behaved far more appropriately than I am doing." Johnson's statement recalls that of Virginia Woolf, who, when invited to speak at an Oxford college, still could not access the Bodleian Library to review a manuscript on the basis of her gender. "And I thought how it was better to be locked out than to be locked in," Woolf commented with a similar ambivalence.

Just as they were previously closed to the participation of women or as they discriminated against members of racial or ethnic groups, universities have not immediately embraced the influx of "out" disabled persons into their hallowed halls. As a result, many well-worn ideas and representational practices await critical reexamination with the supposition that patterns of interpretation likely uphold unrecognized investments concerning the inferiority of disabled persons. Research conducted to endorse ideas about eugenic segregation, the sterilization of those assessed as "feebleminded" or hereditarily deficient, or prevention of disabled persons on the premise of the social burden they present simply support oppressive disability ideologies of a previous, yet not quite antiquated, era. Old-school disability research may verify reasons that disabled persons should be excluded from public forums and civic roles. Furthermore, many technologies have been developed as means for containing unruly bodies and punishing the disruptions associated with bodies that "deviate" from the normal.

A key issue for disability studies, then, has been to determine the extent to which newer professionals who work within these frameworks can update disciplinary practices to make their research feasible for progressive disability goals. Similar questions had been asked about psychiatry, for example, after Holocaust genocide and medical experimentation implicated practitioners who had been schooled in the field and proceeded to generate from it violent medical interventions on disabled children and adults. Were premises in the field corrupting or did these perverse practices simply represent a complete aberration from mandated formats of investigation and hence only reflect violent impulses in the practitioners themselves? A similar revolutionary questioning guides disability studies as it surveys the current state of the university and interrogates fields such as behavioral and abnormal psychology for their routine support of evaluation practices designed to condemn disabled persons for their differences.

Scholarship in disability studies affords a unique and divergent vantage point from the paradigms that sustain traditional study, management, and interventions. For example, disability studies research would interview clients not to determine who would make the best fit for counseling or special education services, but to find the unique worldview that disabled persons have imbibed as a result of their marginalized social predicament. Those who endure demeaning cultural practices can often best assess the sources and mechanisms of their operation.

Following the advent of disability studies in the 1980s, many academic approaches toward disability were routinely put to the side as simply too "medical" in nature. What the first generation of scholars meant by this criticism of a "medical model" was that the research upheld an exclusively interventionist and individualized approach to disabled bodies. All insufficiency appeared localized within the dysfunctional body itself. A medical model approach proceeds on the assumption that the only valuable knowledge concerning disabilities would need to be directed toward curing, concealing, or fixing bodies so that individuals could be made to "pass" as normal. For a first generation of disability studies scholars, cure approaches reinforced social ideas that impaired bodies should be rejected. At the very least, these scholars focus on social barriers that disabled persons face and leave aside fields that pay attention to the repair of impaired bodies.

Importantly, the limitations of a medical model that early disability studies references may itself have little relation to actual practitioners of medicine. Instead, concepts of a "medical model" refer to the social premise, frequently held outside of medicine, that disability requires referral to the purview of medical practitioners. Several disability studies scholars have shown how factions of physicians in the American Medical Association initially resisted the idea that insurance decisions should be assigned to clinical assessments. Nonetheless, legislatures in Germany and the United States, for instance, decided that physicians would function as the gatekeepers for disability verification. They thus inaugurated a class of medical authorizers to diagnose and certify the validity of all disability claims. This professional gate-keeping, the practice of which often divides disabled people from the services they need, has become one of the foremost obstacles addressed by disability studies today—particularly in countries that lack universal health care systems such as the United States.

This system of evaluation requires disabled persons to endlessly submit to professional gazing to qualify for social supports. But the enforcers of this policy, that is now a habit of thought in many Western countries, may trickle down to the shoe store clerk who will not sell a shoe to a person with lower-limb muscle spasticity prior to obtaining a doctor's note. In an increasingly bureaucratized social state, the medical model has left disabled persons frequently vulnerable to the whims of general practitioners in spite of the fact that such professionals may have little knowledge about the condition in question. Consequently, one often finds practitioners invested with the power to assess patients for the purpose of qualifying for benefits, supports, and general consumer services such as airline travel or equipment.

In contrast, a rights era of disability studies endorses a cross-disability and nonspecialized approach to meaningful inclusion for disabled persons. Subsequently, as this entry observes, disability studies will ask for the modification of practices that are premised on privileging some bodies and excluding others.

Prior to the rights-based disability platform of the 1960s, a focus on disability in society entailed advocating for charitable contribution and safekeeping for persons with particular kinds—even "brand names"—of disabilities. For instance, mid-nineteenth-century institutions governed their populations so that they housed only the least severe. This ensured patient success and further supported ideas behind the rejuvenating mission of cures in benevolent nature. A return to the community for each institutionalized individual formed a key objective. More difficult disabilities were left to the family where they sometimes received local support in the form of outdoor relief or made up a large percentage of those housed in indoor relief efforts such as almshouses. A widely accepted international theory of disability at this time, established by the French educator Eduoard Séguin, argued that those diagnosed as idiots suffered from a weak will. Training schools sought to correct this insufficiency—or at least ameliorate it—by subjecting disabled individuals within their charge to extensive rituals of personal hygiene tasks of rote repetition. Patients found themselves locked into an inflexible regimen of care and engaging in tasks that demanded concentration for extended periods of time. In cultivating such habits, training institutions aimed to improve a "defective" internal landscape by targeting the external body as a site of personal management.

From the 1920s onward, rehabilitation era disability professionals emphasized the acquisition of personal adjustments and skills that could enable a disabled person to survive in a society that was not built to accommodate them. In the United States, France, and Germany, for example, special schools that aimed to "salvage" human beings by educating the physically weak emerged in urban centers. These schools for "crippled children" pre-date legislation for disabled children that provides rights for a free and appropriate formal education (prior to 1974, 80 percent of disabled children did not have access to a formal education). Federal mandates in the United States continue to update this effort at social inclusion and the necessity of public education for schoolchildren with differing bodies, minds, and emotional habits alongside all others in a "least restrictive" environment.

In the 1920s, evolving from hospital schools, and offering an alternative to segregated warehousing, special schools for children with physical disabilities offered a curriculum that included rehabilitation services; in-house dentistry; occupational, physical, and speech therapies; Franklin Delano Roosevelt (FDR) era swimming pools; and a variety of wheeled transport and home-styled modification devices—all within the confines of a one-stop educational facility. Special schools explained their mission as a matter of "salvaging" the educable from the disability mix that had simply been consigned to training schools and workshop labor under the expansive eugenics era category of "feebleminded."

In this mold, special schools accompany the expansion and professional credentialing enterprise of other helping industries, in addition to nursing. Participants at schools for handicapped children also underwent continual assessments in specialized quadrants of the schools, for example, physical, emotional, dental, personal hygiene, and small and large motor control. But like rehabilitation medicine itself, special schools also sought distance from medical environments and fix-it approaches to disability. They too critiqued a "medical" approach in favor of education and rehabilitation. It is important to differentiate the agonistic distancing of professional service industries from medical approaches and the medical model critiques of disability studies. Unlike professionals who advocate for rehabilitation as a solution to a problem presented by disabled persons, disability studies represents the social and material predicament of disabled persons as a matter of inclusion, recognition, and social change. Furthermore, disability attends to the environmental resistance to inclusion—attitudes and the enforcement of normative expectations upon bodies—as opposed to individual adjustments.

Disability studies, uniquely, must put the status and experience of disabled persons prior to its own success as a professional operation. Thus, whereas rehabilitation and a rehabilitation movement could oppose disability rights in favor of principles of intervention, service, and care, disability studies aims to place the perspectives of the objects of scrutiny and remediation front and center to its concerns. One is reminded that even in the closing of the most inhumane institutions, a variety of interests will come forth to oppose such efforts: Care worker unions will protest out of a desire to keep their jobs in a specialized field; family members will often ally themselves with care workers and claim that the work of keeping a disabled person at home lacks sufficient social supports to be feasible; local businesses catering to institutional living complain that their economic livelihood will be undermined; nearby neighborhoods will resist under the argument that "freeing the inmates" poses threats to everyone's well-being. Yet disabled persons themselves, on the verge of emancipation, offer up ambivalent and less certain opinions. Few yearn to keep institutions open in that they represent sites of state-sponsored incarceration, but neither does it seem appropriate to look forward to life where one may be viewed as a persistent burden, economic drain, and social misfit. Scholars in disability studies seek to expand on the limited choices offered to disabled persons to live meaningful lives by redressing the social constraints that continue to underwrite such hostile public beliefs. Rather than individual insufficiency, disability studies aims its critique at the material social conditions—such as poverty, unemployment, and disability insurance restrictions on wage earning—that produce abject dependency.

Historically, populations of dependents have found themselves concentrated in poor houses, workshops, and almshouses with others who cannot effectively sell their labor in a competitive market rife with prejudice toward functional and aesthetic differences. One function of this lumping of the unemployable was the development of large bin categories of disabilities; such classification strategies emerged in the mid-twentieth century—an era dominated by rehabilitation and charity model approaches. Bin categories include "muscular dystrophy," a label that represents more than 37 manifestly different etiologies of neuromuscular disorders, or "cerebral palsy," a general term for hugely divergent muscular rigidities. Etiological clusters, such as paralyzed veterans or people with epilepsy, receive attention and management from agencies designed to attend to their lesser social opportunities. Thus, children with vision impairments might be sent to a blind school to acquire different skills such as Braille along with white cane techniques or canine companion assistance. Deaf children might be channeled to a deaf school where they acquire sign language or vocalization skills in the press to access regular educational curriculum. Multiply disabled children, those who have been projected to be low achieving by means of newly minted evaluation tools such as intelligence tests, and ranging from those termed "retarded" to those negotiating cultural barriers or nonstandard literacy, undergo institutional referral and placement throughout the twentieth century. A substantial number of infants and children with all kinds of disabilities continue to be abandoned and placed as "wards of the state." Individuals located within such sweeping categorizations represent not only disabled people, but rather the fallout from modern standardization practices that prove inflexible and unduly narrow when it comes to the rote expectations of all bodies within capitalism.

While pointing out the permeability of these categories of human differences, disability studies reassesses the historical solutions that have been arrived at in terms of placement, tracking, and a deterministic foreclosure on social possibilities. Yet the advent of the field has also been theorized as developing from experiences that issue from clustering together kinds of bodies that share designations of deviance. Collectivities can better foment collective action for improved social situations. Strongholds for initiatives in disability rights have come from collectivities of individuals who may have endured segregation at one time and now resist oppressive protocols. In other words, disability studies is also linked in history to the predominance of kinds of disabled living and the social opportunities afforded to highly particular groups. These include veterans groups, who sometimes claimed exclusive rights to remediation services but also precipitated the development of technologies such as power wheelchairs and curb cuts that benefited others. Not only did a post-polio president, FDR, seek to include disabled citizens as beneficiaries of services for disabled veterans, but in the late 1940s, disabled Canadian veteran John Counsell formed the Canadian Paraplegic Association, an advocacy group that demanded the supply of accessible cars outfitted with hand controls to all who could use them. Furthermore, in the 1960s "person first" advocates sought to upgrade social awareness by interrogating the linguistic implications of referring to persons with disabilities as handicapped, crippled, or disabled. In Britain during the early 1970s, the Union of the Physically Impaired Against Segregation (UPIAS) was formed as a coalition among those who had fought to escape confinement in nursing homes. The members of this organization may have been the first to formulate what would come to be recognized as the "social model of disability": one that viewed impediments as the product of social rather individual liabilities. UPIAS (1974/1975) put forth mandates about the social nature of disability experience that merit repeating:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation, in every area of life, such as education, work, mobility, and housing.

Likewise, the 1990s saw the rise of disability groups comprised of former poster children who critiqued the proliferation of telethons for those with muscular dystrophy and other disabilities and tendering the exhibition of disabled bodies as pity-ridden social capital for raising research and cure funding.

These efforts all paralleled various other civil rights agendas seeking to redress the invisibility experienced by devalued lives. Such movements shared a key strategy: to place distance between their own bodies and the belief that lack of success could be attributed to biologically located deficiencies.

INSTITUTIONALIZING DISABILITY STUDIES

As further evidence of political piggy-backing by various civil rights agendas, one witnesses a surge of interest in disability studies research and scholarship immediately following the passage of legislative initiatives such as the Americans with Disabilities Act in 1990 in the United States. As a result of this legislation and that which came before it (Section 504 of the Rehabilitation Act in the 1970s), a new generation of disabled students made their way to universities. Yet, despite the implementation of policies, codes, and mandates for inclusion, college students with disabilities often found themselves involved in highly individual struggles with able-ist barriers in the pursuit of their own education. After all, laws may exist but that does not mean that institutions and professions comprehend the barriers that their own fields of operation have put into play. This generation, the inheritors of legislation and ideas about the social nature of disability, committed itself to bringing the insights gleaned from struggles for disability rights into every avenue of social organization and thought. As many in disability studies have put it: "If disability studies didn't come along I would have had to invent it."

Put quite simply, many younger disabled persons became attuned to the fact that disability studies offered them further grounds for social theorizing and policy action toward their own predicaments. Disability studies affords students with disabilities a basis for asserting the right to accessible classrooms, libraries, and laboratories that had previously seemed off-limits due to prohibitive scheduling, inaccessible locations, and discriminatory attitudes. This post-ADA generation of students with disabilities forced opportunities for advocacy regarding obstacles that many took for granted as inevitable barriers. Suddenly, excessive work hours, timed tests, small print, fluorescent lights, inadequate table heights, flights of stairs to stages for ceremonies, and expectations about presentable appearance appeared as unnecessary barriers that by design excluded many disabled persons.

In addition, disability studies allows students and researchers to examine the buried able-ist exclusions that inform research premises. The research that has ensued tackles issues such as objectivity in nondisabled research perspectives and pathologizing ideas about human variation that sometimes inform premises. For example, disability perspectives require us to rethink assumptions that a bus with high stairs represents a democratic and publicly available mass transit objective accomplished. Deaf studies, likewise, asks us to rethink assumptions about oral eloquence and the aesthetics of sound that condition so many of our daily encounters. And in a basic way, disability studies demands reconsideration of dubious general public educational requirements such as the expectation that children will be able to hop on one foot as a mandated qualification to graduate from kindergarten. Just as universal design asked that we think about the ways architectural exclusions get inserted into a built environment, so disability studies asks us to analyze the assumptions about normalcy that go into validating educational, business, and civic practices. The field of disability studies seeks to expose the ways that naturalized exclusions have seeped into every cranny of modern social life.

Nearly 100 disability studies courses are currently offered at colleges and universities, while many curricular and research plans continue apace. Universities offer degrees, concentrations, minors, or simply courses of study in disability studies. Examples include Canadian programs in disability studies at Ryerson University; a master of arts degree in Critical Disability Studies at York University; a concentration in disability studies for a master's or PhD in the Cultural Foundations of Education program at Syracuse University; undergraduate and interdisciplinary minors in disability studies at universities that include Ohio State University in Columbus, Ohio, and the University of California, Berkeley; and an interdisciplinary PhD in disability studies at the University of Illinois at Chicago.

In addition, a web search currently yielded more than 50 affiliated programs, centers, clusters, and research institutes at universities. University-affiliated centers crisscross the globe from the Centre for Developmental Disability Studies at the University of Sydney in New South Wales to the Program in Disability Studies at Rutgers University where coursework has been revised so as to include the topic of disability geography. As mentioned earlier, the Centre for Disability Studies at the University of Leeds has been principal in setting the agenda and commitments of disability studies globally by publishing a journal in disability studies and establishing a research track to accompany degrees at all levels. Faculty at Leeds assist in publishing the international journal *Disability & Society* and pilot the list serve on disability research known simply as "the UK Listserv" by international participants. In addition, the Center on Disability Studies at the University of Hawaii emphasizes cultural approaches to disability and maintains commitments to working with disability coalitions in the Pacific Rim. Organizers recently launched an online periodical titled the *Review of Disability Studies: An International Journal.* And the Centre for Research into Disability and Society in New South Wales offers PhD scholarships to enroll at Curtin University while Temple University has launched courses and a graduate certificate program in disability studies proper.

In the United States, disability studies originates with the formation of the Society for the Study of Chronic Illness and Disability in the early 1980s. Chair of the Sociology Department at Brandeis University, Irving K. Zola, began distributing a newsletter from his office that collected together and advertised new initiatives on behalf of disability as a social experience. The photocopied newsletter publication contained a letters column, featured book reviews, and opinion columns. Significantly, early issues feature Zola's review of Erving Goffman's *Stigma: Notes on the Management of Spoiled Identity* and thus inaugurated a discussion of the disability coordinates of self-perception and social interaction that continues to fuel one aspect of the field. Zola, and his family and colleague's newsletter, which gained library subscriptions and an international mailing list, eventually grew into the current online academic journal *Disability Studies Quarterly.*

In 1986, at the urging of its membership, and as the push for an Americans with Disabilities Act gained momentum, the Society for the Study of Chronic Illness, Impairment, and Disability (SCIID) changed its name to the Society for Disability Studies (SDS). Other methodological models also developed alongside the strict social model advanced by UPIAS. For instance, at this time and prior to the ADA, Harlan Hahn pioneered a minority group model of disability contending that disabled people represented a distinct minority. The effort to study and analyze disability as culture, one that gives impetus to unique institutions, art, and perspectives, arose from the minority model. In the United States, the claims of Deaf studies to emerge from a unique heritage and to constitute a linguistic minority influence the claims made on behalf of disability culture, crip culture, or simply subcultures. Pioneering studies of predominantly deaf communities in disparate locations such as Martha's Vineyard and Varna had shown the cultural variability of signed languages and regional differences in expectations about normalcy and self-expression. Deaf communal forms such as sign language, deaf poetry performance, and investments in the merits of segregated deaf communities all influence disability studies but conflict with many precepts. These surround questions of disability hierarchies, language facility, and discriminatory ideas about self-expression whether spoken or signed. Nonetheless, many counterdiscourses interrogate the premises of a dominant "normal" culture through the examination of developed subcultures, many geographically isolated or disenfranchised as pockets within urban spaces.

Increasingly, disability studies has found itself needing to emphasize diversity as a key factor in the social desirability of having disabled persons represented at universities and across educational forums. The emphasis on disability as a diversity category emerges from research efforts to find commonality in variation without losing the divergent vantage points that such conditions afford. Disability studies scholars have contended that just as race, gender, and sexual preference can be demonstrated as either neutral difference or as productive characteristics as opposed to tragic implications, disability itself comprises a form of embodiment artificially constructed as flawed. Yet alliances between multicultural agendas and disability studies efforts to include disability as part of human diversity education have been slow in coming. For instance, one initiative to allow disability to fulfill the multiculturalism requirement at Hunter College met with fierce opposition from race and gender scholars. Multiculturalism is beset by its own able-ist premises in having exceptionally high-achieving exemplars of one's ethnic or native traditions serve as singular justifications for cultural equality. Perhaps disability studies might inevitably discover that diversity as exemplified by multiculturalism can arrive with very narrow ideas about bodies in tow. Yet, at the same time, many scholars in these fields have embraced disability as a deepening of multicultural pedagogies.

As a new area of scholarship that has thus far resulted in a wealth of publications and collaborative projects, as opposed to university posts, disability studies bears much in common with other "identity" fields such as queer studies and gender studies. These fields of scholarly endeavor also feature an incredible output in scholarship and quality of thought while having received less in the way of material recognition such as degree-granting programs or funded faculty lines. The older industries of a "disability business" still largely hold the purse strings to disability undertakings. And these industries have been built up by means of a "charity model" that likely depicts disabled persons as incompetent and needy—a representation that is anathema to disability rights, which points out that the predicament of validating disabled persons as the "deserving poor" reinforces the idea of a natural state of unemployment and dependency for all disabled persons. Concepts of a charity model run deep. Ironically, practitioners of disability studies have been accused of "biting the hand that feeds them"—a criticism that upholds the idea of disabled persons as parasitic and ungrateful by comparison to the common lot of human beings.

In addition to curricular innovations, many access and accommodations offices have sprung up to manage new generations of disabled students who anticipate accommodation, as opposed to exclusion, from educational settings. These offices sometimes support a disability cultural mission and/or active disability support networks. Staff for disability offices may lack the authority that comes from having gained knowledge through a standard credentialing mechanism, such as that offered by special education or communication disorders under the auspices of a previous "disability business." A field offers credentials in an education that guarantees training in requisite areas and study in a centralized knowledge base. Access and disability awareness may be subsumed as components of occupational therapy or policy studies. Only disability studies forces a convergence of the historical study of social management, human rights categories, and access strategies as a matter of group survival—a mosaic approach that recognizes these aspects as mutually supportive and inevitably interwoven. At present, resident disability experts on campuses often represent homegrown and creative talent. Offices are staffed by individuals who share expertise in areas ranging from a judicial history of the ADA to experience in disability sports such as wheelchair basketball. One should also point to the cultural and academic sway exerted by two offices for disability services located at major state universities during the 1970s, University of California, Berkeley, and University of Illinois, Urbana–Champaign, as fulcrums for university accessibility plans based on the insights generated among disabled and nondisabled students who participate at those sites.

At present, many disability services offices at universities become sites where the interests of budget-conscious bureaucracies collide with the rights and goals of disabled persons. Services offices may need to enforce policies that test, retest, and validate impairments so that individuals may qualify, on a case-by-case basis, for "extra" services such as captioning, sign language interpreters, relocation of classes in accessible spaces, lighting modifications, and extra test-taking time. While the redesign of curriculum to meet accessibility differences is significant, even a new area opened up by technological possibilities to which faculty need to dedicate time and attention, disability services quickly become overburdened by the necessity of serving in all these capacities. In general, under state bureaucracies that operate many educational settings, it becomes easier for offices to test and evaluate students for disability status than to theorize the modifications necessary to promote an inclusive learning environment. Still, many have risen to the challenge of this multitasking necessity and offer content-based national conferences on the topic of disability studies among an array of disability issues necessarily bound up in working toward the maintenance of inclusive community forums.

It has been pointed out that disability studies first emerges alongside the insights obtained by participants in disability rights movements and activities during an era that fiercely advocates for deinstitutionalization. As a result, many scholars surface from a first generation of families who refused to institutionalize their disabled children and family members. Along with their traditional research plans, these scholars conduct research into the new experience of living at home with disabled persons and the reaction of a mainstream society to this new choice. In addition, in literary circles, authors such as the Japanese Nobel Prize winner Kenzaburo Oe are celebrated for their open and honest address of the efforts to live at home with disabled family members. Oe's autobiographical memoir, *A Personal Matter,* discusses the entirely altered coordination of household affairs that occurs as a result of living at home with his autistic, musically gifted son, Kikura. Oe's partner contributes to his books with watercolor portraits of family scenes.

The topic of living at home with disabled family members may have previously been the purview of talk show entertainment but not of academic study. One can clearly see from this approach that disability studies benefits from the insights of women's and gender studies that the personal is political. But also the personal is a matter for redress by professions. Professionalism itself, in its rebuke of any personal attributes from kinds of hairstyles to habits of facial expression, stands in the way of the integration of disabled persons' entrance into the workplace.

In addition to alternative family arrangements, many centers for independent living (CILs) have become cultural powerhouses for the talents and insights of disabled persons in the community. Several CILs have even formed their own research think tanks to rival the funding streams traditionally poured into legitimated university research locales. They sponsor events and training sessions to bring about disability awareness in the community and to enforce accessibility standards that remain little understood. CILs have sought to introduce universities to the rich field of disability studies proper. The Ohio-based Ability Center of Greater Toledo worked with representatives across an array of academic disciplines to endow a faculty position to chair a disability studies program at the University of Toledo. At the University of Illinois, Chicago, disabled students apply from across the globe in order to pursue work in disability studies at the master-of-science level. Many scholars in disability studies, facing a lack of pathways yet to be put into place in curricula and university recognition, may leave to ply their research and social insights in community education. Such an eventual exodus at the level of higher education, as has occurred at CILs, continues to perpetuate a separate location for the focus on social barriers to disability living. In short, such mini "brain drains" occur in newly minted academic programs because of a resistance to the ideas about disability emancipation held by those in traditional academic disciplines who consider disability to be their exclusive purview. At community centers, scholars who have now benefited from university coursework sponsor disability pride parades, promote projects on digital storytelling, and coordinate data banks on disability images, disability history archives, and autobiographical archives from movement participants and key leaders. This shift to CILs as alternative research and employment domains is also evidenced by their active cultivation of disability-based archives. For instance, instead of donating his papers to a university library, FDR historian and disability policy activist Hugh Gallagher left his papers with Toledo's Center for Independent Living.

RECENT RESEARCH TRENDS

Whereas clusters of professionals, previously charged with maintaining records and oversight of institutional warehousing, found themselves declared increasingly irrelevant, and since rapid-paced deinstitutionalization in the 1980s promoted community care initiatives, the traditional privilege accorded to expert oversight has been roundly rejected by disability studies. This rejection has occurred in the midst of active efforts to seek models self-governance and a reevaluation of the principles of guardianship.

Whether indigenously cultivated or generated from universities in the "first world" and translated to those societies deemed "less enlightened," disability studies scholars have increasingly found themselves participating in knowledge dissemination strategies as an effect of postcolonial contexts. Since many countries participated in cross-cultural comparisons of eugenic practices, disability studies has found it necessary to follow suit and use successes in one national milieu to pressure results in other cultures. Yet this situation of political cross-referencing often results in scholars from developed countries preaching to the "unconverted." Such power imbalances situate developing countries as less "modern" in comparison to industrial powers. In addition, they also find themselves promoting or imposing products and policies devised in contexts alien to specific disability needs of various global regions. Thus, one can find Western-manufactured wheelchairs running aground in geographies without paved roads, curb cuts, or nonurbanized environments. Finally, there are few opportunities offered by scholars in developed countries to participate in a reciprocal exchange of ideas about disability innovation. Thus, even disability studies has been caught up in reifying inequities on a global scale.

Consequently, the postmodern and international coordinates for disability studies analysis cannot be underestimated. While disabled persons have faced many barriers to higher education, access to discussions and materials on the Internet have shifted the terms by which individuals in diverse locations acquire interpretive skills about their home contexts. In other words, the Internet opened up participatory forums to a social group that had found schooling prohibitive and the negotiation of public environments frequently dangerous. In the public sharing that occurred on the Internet, disabled persons and disability advocates could share notes on disability predicaments globally while evaluating their own local sense of key obstacles to an equitable and inclusive society: public transportation; access to education; employment; stigma; and common prejudices about bodily, emotional, and mental differences. Likewise, these virtual communities encouraged individuals to swap bodily and social strategies for more successful navigations of hostile or indifferent environments. At present, online discussion groups pursue topics that range from social justice, bioethics, scholarship in the humanities, prosthetic supplementation, personal assistance concerns, and issues of sexuality as appropriate conversation topics for disability-based community. They have also generated a growing global sense of history that provides points for contrast and comparison between the cultural situations of disabled people.

New kinds of study modes and information transmission such as the development of digital media, availability of captioning techniques, keyboarding and voice recognition software have all played a part in getting formerly home-bound or segregated disabled persons into a more participatory cultural mix. Less expensive visual transmission modes such as digital video are making some of the more erased pockets of disability experiences available to the ways we imagine alternative human existences. Histories of institutionalization have shown us that disability oppression occurs not just in violent practices but also in their relegation behind walls, in confinement practices, and as a result of assumptions about bodies in clinics or institutions properly deemed "private." As a result, disability studies has helped to forward media as an powerful venue for accessing personal narratives and multiple voices. International film festivals in Australia, Russia, England, the Balkans, Toronto, and other sites have all sought to use digital formats as an opportunity to educate general populations and legislative agendas in their home countries.

Yet disability studies continues to face up to how inclusion occurs at the expense of the newly included subject. The classroom may be suddenly desegregated but nothing that disrupts the operation of business as usual can occur. Postcolonial studies, with its focus on the internalized oppression of the subaltern and the ultimate silencing of counterdiscourses, has proven integral to current trends in disability studies scholarship. Rather than repeat the error of turning disabled people into passive victims of inhumane social practices, for instance, disability studies has borrowed from theories of international resistance efforts to keep its own interpretive strategies relevant and less marginalizing in and of themselves. In doing so, disability studies—now christened "critical disability studies" by some to remind the field of its radical orientations—pursues analytical approaches based on insights gleaned from comparative disabilities, disability as a subcultural form of alliance, and even the internal fractures precipitated by the advent of disability hierarchies as manifest of more internal forms of social oppression.

Contemporary formations of disability studies analyses have also taken on cooperative research strategies to de-emphasize the singular nature of much scholarly work. As in women's studies and some social science-based research, one witnesses the rise of greater self-consciousness about issues of research interdependencies and the privileges that result in scholarly success based on individual genius models. One now regularly finds research attributed to coauthorship and collaborative research teams circulating in the published literature. Such efforts are not merely the fortuitous results of disciplinary practices, but rather an active effort to re-imagine the collaborative effort invested in research efforts.

For a time, participatory action research enjoyed popularity with disability studies. However, while it integrated disabled persons, they were left as informants but not essentially engaged in the more critical tasks of knowledge production. While disability studies generates new questions, projects, and politicized research agendas, the field must continue to be mindful of the fact that it also potentially replicates the exhaustion of research-based practices on disabled people's bodies. Even the most liberating research models run the risk of treating disabled persons' time and resources as readily and freely available to investigators.

One common future goal would be to offer real choices in collaboration and a legitimate role in the creation of research-based knowledge generation. Such efforts need to occur without the enforcement of exclusive, delimited contact on the part of research subjects who share conditions for example. Thus, disability studies is faced with the challenge of formulating new disability-based insights that engage dominant modes of thinking without simply reproducing traditionally oppressive modes of research conduct. Such an elusive objective continues to guide much current thinking in disability studies.

—Sharon L. Snyder

See also Anthropology; Bioethics; Body, Theories of; Education, College and University; Humanities; Models; Queer Disability Studies.

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DISABILITY STUDIES: AUSTRALIA

Disability studies has emerged as a growing area of academic research and professional education and training in Australia as it has in many other developed and developing countries (Green and Meekosha 2004; Meekosha 2004). This is a consequence of the rise of the disability movement and the more vocal demand for relevant curricula by disabled people and their allies. It also reflects the impact on universities of the Australian Disability Discrimination Act (1992), which covered issues of discrimination in education. The growing presence of people with disabilities in society—in particular their presence in the community following decades of deinstitutionalization—has further contributed to an awareness of the responsibilities of educational institutions to disabled citizens. In addition, the demonstrated failure of medical and individual pathology models of disability to explain and "liberate" people with disabilities from constraining and repressive modes of treatment has resulted in many alternative arguments for including disabled people in wider social relations.

However, disability studies remains fragmented with individual scholars scattered across universities and departments. These individuals may have little support from their colleagues, and the institutions demonstrate only a limited understanding of the growth of disability studies overseas. Disability studies as a discipline thus remains fragile in the Australian context, especially given a political climate of neoconservatism and a significant political backlash against minority agendas. The traditional interventionist disciplines such as special education, health sciences, occupational therapy, and rehabilitation have begun to use the language of disability studies, in effect rebadging their courses, without necessarily changing their individualized, medicalized approach or incorporating the ideas of the disability movement into their curricula. A similar phenomenon has been documented in the United States (Linton 1998). Other than the audits referred to below, there is currently no critical literature examining disability studies in Australia. Thus, in Australia we have not seen the growth of departments created around disability studies. Unlike in the United States (Thomson 2001), neither women's studies nor Australian studies has incorporated issues of disability. There is no scholarly journal catering specifically for disability studies, and we have yet to see any collections of readings in disability studies unlike the United Kingdom where there have been several (Shakespeare 1998; Barnes 1999; Barnes, Oliver, and Barton 2002), or the United States where collections in the humanities are widespread (Davis 1997; Snyder, Brueggemann, and Thomson 2002). Key Australian analyses of social movements continue to exclude any mention of the disability movement (see, e.g., Burgmann 2003).

An audit of 26 of 37 Australian universities undertaken in 1999 (Social Relations of Disability Research Network 1999) sought to document the extent and type of subjects addressing disability in a social context taught across various professional and disciplinary areas. No relevant subjects were found in seven of these universities. In those universities where there were subjects, the range of professional programs affected the likelihood of relevant subjects appearing—disability studies, rehabilitation studies, and special education courses were the most likely to have subjects that reflected social issues. It was rare to find any reference to disability studies or issues in general arts degrees or indeed to find a social analysis of disability in professions such as nursing or medicine (as discussed in Wilson 2000).

Most subjects about disability outside law and sociology reflected service delivery priorities and interventions relating to specific impairments, through an individualized perspective that focused on disabled persons and their experiences and relations with professionals. These subjects would clearly be seen as "not disability studies" as defined by Simi Linton (1998). However, there were a significant number of subjects that reviewed changes in social attitudesto disability, and the expansion of human rights approaches to disabled people.

In 2004, a follow-up audit (Green and Meekosha 2004) revealed that there has been an overall fall in subjects dealing with social dimensions on disability. In particular, Deakin University and University of New South Wales had lost a significant number of relevant subjects, perhaps a consequence of cutbacks in overall subject offerings in an increasingly financially constrained environment, or the moving on or retirement of specialist teachers with a commitment to this perspective.

On the other hand, there had been some promising improvements. Some professional programs that had not done so in the past, such as occupational therapy at Curtin University, had begun to identify the social dimensions of disability as an important component of study. Also, subjects exploring the social dimensions of disability were more evident—though still a rarity—in general arts degrees.

—Helen Meekosha

See also Disability Studies.

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DISABILITY SURVEYS

A survey is a method for collecting information about a population. The survey method has several components: a sample of persons that accurately represents the population; standard data collection procedures, including a standardized questionnaire; summary estimates of statistics for the population based on the information collected; and estimates of the sampling error of the statistics. A *disability* survey uses the survey method to collect information about disability. In some disability surveys, disability is the primary topic in the questionnaire; in others disability is a secondary topic.

THE VALUE OF DISABILITY SURVEYS

The main value of disability surveys is that they are relatively inexpensive, unobtrusive, and accurate. Disability statistics can be produced in other ways: in a census that enumerates *all* persons in a population, not just a sample, or in administrative records that include all members of a population, such as the medical care system for elderly people in the United States. However, producing statistics from censuses and administrative records systems is more expensive, more burdensome, or less accurate than producing them from surveys.

Surveys can produce a variety of useful disability statistics. One important use of disability statistics is to formulate and evaluate disability policy. Proponents and opponents of disability policies in employment and transportation use survey statistics in debate. Disability statistics are also used by manufacturers and distributors of disability-related products and services (e.g., assistive devices, disability insurance plans), as they plan for production, advertising, and sales. Scientific researchers use disability statistics to investigate the causes and consequences of disability.

DESIGN AND ANALYSIS OF DISABILITY SURVEYS

Samples for disability surveys are selected in several ways. In a *scientific* sample, the sample persons are selected at random with known probabilities of selection. A scientific sample can be selected from a preexisting list of persons; for instance, if most people have listed telephone numbers, a sample can be selected randomly from telephone directories. Also, a sample can be selected by randomly selecting residential areas, listing the addresses of dwellings in those areas, and then randomly selecting addresses from the list.

Samples for disability surveys may also be selected by establishing quotas for sample categories with selected characteristics. The quotas are set so that the resulting sample will have the same proportions of persons in each category as the population. For instance, if it is known from a census that 10 percent of a population is African American, then a sample of

1,000 persons would be designed to include 100 persons in that category. Data collectors contact people in the population until the quota for each of the categories has been achieved.

While all disability surveys use standardized data collection techniques, they may use different *modes* of data collection. Frequently used modes are face-to-face interview, telephone interview, and self-administered questionnaires distributed by postal mail. Many survey organizations have begun to use self-administered questionnaires distributed by electronic mail or postings on the World Wide Web. Modes differ in quality of data and cost of administration: Generally, face-to-face interviews yield better quality but cost more, while electronically distributed questionnaires yield poorer quality but cost less. To optimize data quality and costs, disability surveys may use combinations of modes.

Once disability data are collected from a sample, they are *weighted* to produce estimates of population statistics, and the sampling errors of the estimates are estimated. If the sample persons were selected with a known probability, the weight for producing estimates of population statistics is the inverse of the probability of selection. For instance, if the probability of selecting a particular case was one in a thousand (1/1000), then the weight for that case would be the inverse (1000/1), or one thousand. If the weights of all sample persons with a particular characteristic (e.g., mobility limitation) are added together, the sum is an estimate of the number of people in the population with that characteristic.

Sampling error is the variability in a population estimate that arises because it is based on a sample rather than a complete enumeration. It is often stated in this form: "It is estimated that 15.4 percent of the population has a disability, plus or minus 1.2 percent." If the sample was selected scientifically, statistical theory and computer software are available to estimate sampling error accurately. If the sample is not scientific, estimates of sampling error have a weaker theoretical basis and may be less accurate.

ILLUSTRATIONS OF APPROACHES TO SURVEYS

Two surveys will be described to illustrate approaches to disability surveys: Canada's Participation and Activity Limitation Survey (PALS) and the U.S. National Health Interview Survey on Disability (NHIS-D). PALS was conducted by Statistics Canada in 2001. It was a "post-censal" survey, meaning that the sample for PALS was selected from persons enumerated in the 2001 census; persons who were homeless or living in institutions were not included. The census included these questions: "(1) Does this person have any difficulty hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities? and (2) Does a physical condition or mental condition or health problem reduce the amount or the kind of activity this person can do?" The PALS sample was selected at random from persons who answered "yes" to either census question. At the beginning of the PALS interview, the census questions on disability were repeated, and then a series of disability screening questions were asked. If these questions elicited no report of disability, the case dropped from the sample. About 43,000 persons with disabilities were included in the sample, and they were interviewed by telephone.

The PALS questionnaire was consistent with the World Health Organization's International Classification of Functioning, Disability, and Health (ICF). The ICF definition of disability includes restrictions to participation in societal activities (e.g., school, work), limitations in personal activities (e.g., walking, talking), and impairments of body functions (e.g., hearing, seeing). The title of the survey—*Participation* and Activity Limitations—emphasizes this multiaxial definition. PALS' predecessor was the 1991 *Health* and Activity Limitations Survey (HALS). The title change reflects a trend toward a social rather than a medical definition of disability in surveys.

PALS estimated that 12.4 percent of the household population of Canada had a disability in 2001. The rate was 3.3 percent among children and youths (0–14 years) and 14.6 percent among adults (15 years and over).

In the United States, the NHIS-D was based on the annual National Health Interview Survey (NHIS). The NHIS uses a *clustered area probability sample*—small geographic areas are selected at random with probability proportionate to population size; survey staff then lists the addresses of dwellings in the sample areas, and small clusters of households are selected at random from the lists. Survey staff then visit sample households and conduct face-to-face interviews with members of sample families.

The first phase of the NHIS-D was a supplemental questionnaire to the NHIS in 1994 and 1995. In those years, more than 220,000 persons were included in the NHIS sample, and an extensive questionnaire module was administered to determine if they had any indication of disability. The definition of disability in the NHIS-D was not based on a single concept of disability; rather, it was based on a variety of disability definitions used in national programs and policies. In the second phase of the NHIS-D, persons identified in the first phase as having a disability were contacted, and a face-to-face interview on consequences of disability was conducted. About 36,000 persons (16 percent) were eligible for a second-phase interview, and about 33,000 interviews were completed. A variety of estimates of disability prevalence have been made using the NHIS-D, most falling in the range of 10 to 15 percent.

ISSUES, PROBLEMS, AND OPPORTUNITIES

A major issue in disability surveys is measuring disability. Disability is an inherently complex concept that is difficult to define and measure. When the paradigm for disability changed from medical to environmental, measurement became more difficult. Disability surveys have good measures of many impairments and simple activities, but they are only beginning to develop measures of complex activities and participation, and measures of environmental factors are still over the horizon.

Another problem is survey accessibility for respondents with disabilities. Conventional survey design assumes that sample persons are able-bodied, or that an able-bodied proxy respondent can accurately answer questions about a disabled sample person. These assumptions lead to standard survey practices that systematically exclude full participation in surveys by persons with disabilities, undermining the quality of disability survey data. Survey methodologists are now beginning to recognize and address this problem.

New information technology is creating opportunities for disability surveys by making it cost-effective to measure complex concepts (e.g., computerized adaptive testing) and to administer questionnaires in a variety of accessible formats (e.g., screen readers, voice recognition). On the other hand, some information technology is making it more difficult for surveys to yield complete interviews (e.g., telephone "caller ID," electronic mail filters).

—Gerry E. Hendershot

See also Consumer Satisfaction; Research; United Nations Disability Statistics.

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DISABLED PEOPLES' INTERNATIONAL

Established in 1981 in Canada, Disabled Peoples' International (DPI) is a leading international cross-disability organization of and directed by persons with disabilities working in human rights advocacy. Around the world, disabled people total approximately 600 million with 80 percent living in developing countries. They represent the diversity of all humanity. DPI recognizes this and works through building consensus on issues by gathering together to discuss them.

Each year, 135 National Assemblies meet to identify priorities for countries and regions of the world. The DPI World Council, made up of six representatives from each region, meets every two years to discuss disability in a global context at the World Summit. DPI's largest gatherings are World Assemblies, which are held every four years to develop a multiyear action plan. For example, at the most recent 2002 assembly, held in Sapporo, Japan, delegates from more than 100 countries came together and identified priority issues for immediate action. The result was the prioritization for a campaign for a UN Convention to protect the rights and dignity of persons with disabilities.

In addition to its main priority of human rights, DPI works in other important areas, among them sustainable livelihoods, independent living, and inclusive education. In recognition of DPI as an international authority on disability, the United Nations has conferred Special Consultative Status with the Economic and Social Council of the United Nations (ECOSOC). Through its work, DPI is committed to achieving full participation of all disabled people in society.

—Moira Horgan-Jones

See also Developing World; Disability Studies; Economic and Social Development.

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DISABLED PERSONS' FUNDAMENTAL LAW OF 1993 (JAPAN)

The Disabled Persons' Fundamental Law (DPFL) is one of 27 fundamental laws in Japan. Ranked between the Constitution of Japan and various substantive or procedural laws, a fundamental law stipulates basic principles in each policy area. The purpose of DPFL is to establish the fundamental principles regarding measures for persons with disabilities and designate the responsibilities of the national and local governments to comprehensively and systematically promote measures for persons with disabilities, and thereby to promote their independence and full participation in society.

DPFL was enacted in 1970 through an initiative of members of the Diet across party lines to establish better coordination between policy areas, such as education, employment, social welfare, and transportation. Major revision was made in 1993 reflecting a progress of guiding principles in disability policy that were deeply influenced by international movements, such as the International Year of Disabled Persons (1981) and the UN Decade of Disabled Persons (1983–1992). Lobbying from the disability community also played an important role in this amendment.

With the 1993 revision, DPFL now provides, among other things, that (1) "disabled persons" means persons whose daily or social life is substantially limited over the long term due to a physical, intellectual, or mental impairments (first official recognition of persons with mental illness as the target of disability services); (2) national and local governments are responsible for establishing a long-term development plan for disability services; and (3) persons with disabilities have a right to take part in the formulation of this plan. DPFL, however, is not well-known to general public. The disability community has asked to revise it to include the antidiscrimination principle.

—Hisao Sato

See also Experience of Disability: Japan.

DISABLED VETERANS

Killing and maiming are not only the unfortunate by-products of combat. They are crucial to war's very aims. Since the beginning of time, enemy armies have sought to develop ever more lethal weaponry to injure and eliminate the opposing force. Some soldiers recover from their wounds or recuperate from their diseases and are able to return to battle. They may eventually return home with little lasting physical damage. Others, who are not so fortunate, join the ranks of the permanently disabled. Of course, civilians as well as soldiers are injured in wars. However, the term *disabled veteran* is generally taken to encompass only those injured while in the military. Because most fighting forces have been disproportionately male, the term *disabled veteran* refers primarily to men.

Disabled veterans have always been war's most conspicuous legacy. From the earliest Stone Age conflicts to modern warfare, the human aftermath of war has been measured in decades, not months. At a fundamental level, disabled veterans of today's wars still share a great deal with their forbears two centuries ago. Both are forced to adapt to infirmities incurred as adults in the service of their country. The emotions they experience—pride, despair, fear, and anger among them—are common threads that link the American soldier disabled in the Iraq War to the disabled veterans of the Napoleonic campaigns. Both have needs that are, on the face of it, similar: medical care, a job, and, if they cannot work, some form of subsistence.

Yet, despite these important similarities, the way in which disabled veterans are treated and viewed has changed significantly over time. With the rise of the modern nation-state, the conscription of mass armies, and the development of welfare programs, disabled veterans became a subject of new concern to governments. They have been the targets of innovative social policies that have expanded the state's scope of responsibility, and the recipients of novel benefits that have taxed treasuries. Disabled veterans have proven an important constituency to be courted for states intent on establishing their patriotic concern for the fighting man and, in some cases, their legitimacy to govern. At various points in history, disabled veterans have become disruptive when their demands are not met. As a consequence, the lot of disabled veterans, though often difficult, has, in general, been superior to that of the civilian disabled. Especially since the twentieth century, disabled veterans in many countries have established a privileged place at the heart of the welfare state.

The treatment of disabled veterans has varied not only across history but also, in important ways, between countries. While the questions that the care of the disabled veteran raises are often similar—On what basis should pensions be awarded? What should be the role of voluntary organizations in their care? How should they be employed?—the answers that individual nations have offered differ dramatically. The solutions that countries have offered are a product, in the first instance, of national patterns of welfare provision. They reveal much about the relative weight accorded state versus charitable authorities, and the tendency to resort to compulsory versus voluntary means of enforcement. Care for the disabled also depends on public attitudes toward the armed forces, as well as feelings surrounding the particular war—and its resolution.

While soldiers have always been injured in wars, it was not until the wars of the nineteenth and twentieth centuries that disabled veterans existed in massive numbers and constituted a highly visible special category for attention. Research on the ancient world indicates how very differently disability was construed in a period in which many wounds were simply incurable. It does not appear, for instance, that the Greeks honored the wounded or disabled in speeches or special ceremonies. While Plutarch records that the Athenian state provided some support to men wounded in battle, these were likely payments to the indigent, rather than honoraria for service.

With the rise of the early modern state, from the sixteenth through the eighteenth centuries, came new attitudes toward the disabled. Some governments recognized the need to provide the disabled with statutory benefits so that they were not forced to rely on charity. To better raise a mass army, or so the logic went, the state had to prove its commitment to the injured man. Europe's first state system of benefits for rank-and-file disabled veterans was initiated by the English Parliament in 1593, which hoped by this measure to improve recruitment and reduce desertion. The first veterans' homes—France's Hôtel des Invalides (1633) and Britain's Chelsea Hospital (1685)—were founded in the following century to care for the aged and the disabled. Although the care that men received was superior, in most cases, to the treatment meted out in poor houses, these institutions, and those that followed such as Frederick the Great's Invalidenhaus in Berlin (1748), nonetheless distinguished sharply between officers and other ranks. In the Invalidenhaus, for example, officers were accorded sumptuous living quarters, complete with private gardens sheltered by high hedges, while ordinary soldiers had to settle for a room or two.

So long as armies remained professional fighting cadres, recruited or impressed for service, there was little incentive or need to equalize treatment across the ranks. Even those measures accorded by the state were not secure; within a few decades of the English Parliament's introduction of state-sponsored pensions, the benefit had been restricted to those disabled veterans incapable of work, and devolved on the individual counties. However, the idea of the nation in arms, pioneered by the French revolutionaries, made every citizen a potential soldier—and disabled veteran. Before the introduction of universal conscription, only a very small percentage of the population would have served in the military. In France, on the eve of the Revolution of 1789, the army numbered only 156,000 out of a total population of 29,100,000. In the U.S. Civil War, by contrast, the North mobilized 2,000,000 out of a total population of 32,000,000. From the nineteenth-century conflicts forward, the circle of those who would fight was dramatically expanded, even as the ability to inflict harm was magnified by technological advances in weaponry, such as the Gatling machine gun used in the Civil War and improved, recoilless artillery pieces.

The American Civil War, the bloodiest of the nineteenth-century conflicts, inaugurated a new age in warfare and in the history of disabled veterans. Scholars have called the Civil War the first "total war," by which they mean that the entire populace was mobilized: men in the field and noncombatants (women, children, and the aged) in supporting roles at home. By the war's end, 620,000 American lives had been lost—more than were killed on the U.S. side in the Korean and Vietnam Wars combined. Figures from the Union army indicate that the North alone had treated more than 7 million cases of disease and 250,000 wounds; 30,000 amputations were performed. As a consequence, after the Civil War, the U.S. federal government faced a veritable avalanche of claims. The government responded with a system of veterans' homes, preference in government hiring, land grants, free prosthetics, and above all else, pensions. Although southerners were not entitled to federal pensions (they were provided for, usually scantily, by state governments), the cost of pensions skyrocketed, as these entitlements were politicized by parties eager to court the veterans' vote. By the end of the nineteenth century, the federal pensions bill amounted to $150,000,000 a year, or 38 percent of the entire federal budget.

Although the European governments looked with horror on the rapidly escalating pensions bill in the United States, the Civil War would prove, in some senses, a trial run for the twentieth-century's two world wars. More men were mobilized to fight World War I than ever before in history. Both the total losses sustained and the rate of loss (calculated as a proportion of the mobilized populace) were unprecedented. More than 9.5 million soldiers died over a period of 52 months; on average, the war claimed the lives of 5,600 men every day that it continued. Twenty million men were severely wounded; 8 million veterans returned home permanently disabled. As a consequence of dramatically increased firepower, they had suffered some of the worst injuries ever seen. Shrapnel from the new exploding shells tore ragged paths through flesh and bone; poison gas (first used by the Germans in 1915 and quickly reciprocated by the British) seared eyes and lungs, creating the spectacle that the painter John Singer Sargent captured in his heartrending painting *Gassed*. Under the threat of constant shellfire and ubiquitous death, some men lost their minds. After months of exposure in rat-infested trenches, others contracted debilitating illnesses that eventually shortened their lives.

As firepower became more destructive, medicine's ability to mend bodies improved in tandem. As a consequence of sanitary innovations, World War I marked the first war in which injury, rather than disease, claimed the largest number of British casualties. Improvements in the delivery of medical services behind the lines, a host of surgical innovations (especially in orthopedics and in plastic surgery), and improvements in the treatment of infectious diseases ensured that more men returned home than ever before, swelling the ranks of the permanently disabled. Medical science's advances continued through the twentieth century. The widespread introduction of antibiotics during World War II (penicillin had been discovered in 1929) cut mortality rates in hospitals dramatically. It has been estimated that during World War II, 60,000 American, Canadian, and British soldiers survived a hospitalization that would have killed them two decades earlier.

More disabled veterans meant greater pressure on the states that had sent them to fight. World War I forced all of the belligerent nations to deal with disability on a scale never before experienced. The overwhelming numbers of casualties, combined with the widespread expectation that the war would be short, meant that none of the European states was prepared to deal with the problems that disabled men faced. All were forced to develop solutions amid wartime budgeting constraints and, in some instances (as in Russia and Germany), political turmoil. Some responses were common. Governments largely acknowledged the need to provide nationally funded pensions, even in those countries (such as Britain), where charitable organizations had, during the nineteenth century, played a leading role. In most countries, rehabilitation, training, and employment were also of central concern to the state, as officials sought to return men to the workforce. Integration into the labor market, rather than segregation in veterans' homes, was the call of the day.

Despite these commonalities, however, important differences remained in the treatment of disabled veterans after World War I. The cases of Britain and Germany indicate the range of government responses. While commentators in both countries agreed that it was the responsibility of the state, supplemented by the efforts of its citizenry, to provide for the disabled, British and German veterans fared very differently. In Britain, civil servants in the new Ministry of Pensions charged with their care sought to limit the state's obligations toward disabled veterans. Pensions assessments were based solely on the degree of physical disfigurement or illness and did not take account of a man's capacity to return to work. Successive British governments proved notably reluctant to institute programs that provided disabled men with a chance at gainful employment. As a consequence, the tasks of rehabilitation and employment were left largely to philanthropy and voluntary effort. In Germany, by contrast, state officials embraced the rehabilitation of the disabled as their foremost duty, and largely eliminated charities for the disabled. Pensions were intended to compensate men for the loss of earning capacity, as well as for the physical fact of disability. The Weimar Republic's National Pension Law (1920) accorded the disabled more than a right to pensions; they were also entitled to an occupational retraining course and free medical care for all service-related ailments. Under the Law of the Severely Disabled (1920), most employers were required to hire and to keep them. It was very difficult to fire a disabled man.

In general, most countries hewed closer to the German model than to the British and, in the aftermath of World War II (even in Britain), the tide had turned against predominantly voluntarist solutions to the needs of disabled veterans. The privileged position of veterans in relation to other categories of the disabled was well established. In Soviet Russia, for example, disabled veterans of World War II were entitled to privileges that distinguished them from the peacetime disabled: a free automobile (to be replaced every seven years), a gasoline subsidy, free public transportation, priority in housing, and the free installation of telephones. To a limited extent, the civilian disabled profited from wars' creation of an entirely new populace of disabled people. Medical advances made in connection with disabled veterans, such as new prosthetic devices, could be translated into improved care for the rest of the population. Some social legislation, such as Germany's Law of the Severely Disabled, was extended to peacetime disabled as well. However, in general, veterans jealously guarded their prerogatives, and protested vehemently against any attempt to integrate their care with other categories of the poor or disabled.

While disabled veterans throughout history had usually defined themselves as a group bound together by shared experiences, the massive numbers generated by the twentieth century's wars, and their favored place in the welfare state created new kinds of political organizations. The first mass veterans' associations dated to the late nineteenth century, with the Grand Army of the Republic (organized by Civil War veterans in the North) and the Kyffhauser Bund (founded by veterans of the Franco-Prussian War). These were mixed organizations of disabled and nondisabled veterans, of officers and enlisted men.

Although many of the veterans' associations founded in the twentieth century adhered to this model, with World War I also came the formation of organizations whose membership was restricted to war victims, defined as the disabled, their dependents, and the survivors of the dead. Some of these organizations, as in France, were nonpartisan, focused chiefly on securing improved benefits. Others, as in Germany, though ostensibly apolitical, were in fact deeply politicized along the spectrum of left to right; the country's largest war victims' organization, the National Association of Disabled Soldiers, Veterans, and War Dependents, enjoyed close ties to the Social Democratic Party, while one of its challengers, the Central Association of Disabled German Veterans and War Dependents, was thoroughly conservative. By 1919, there were seven national organizations of war victims in Germany, with a total membership, at the high point in 1921, of nearly 1.4 million. Through the 1920s, these organizations were involved in an increasingly bitter battle with their fellow citizens, whom they accused of neglecting them, and the state, which despite its innovative welfare programs, could not fully compensate veterans for their sacrifices. By the early 1930s, disabled veterans in Germany had become a constituency ripe for the picking by the Nazi Party. In Britain and France, by contrast, where veterans could take pride both in their victory, and in their fellow citizens' grateful response to soldiers' sacrifices, veterans remained bulwarks of the established order.

Throughout the twentieth century, disabled veterans came to occupy a position of great symbolic significance in the lands to which they returned. Not only were the disabled present in the greatest numbers ever seen, but they had become, in most countries, the state's favored wards, the subjects of costly and path-breaking social legislation. Where disabled veterans had once been isolated in institutions such as the Invalidenhaus, they were now, quite literally, more visible on the street, in the workplace, and even on the movie screen, in films such as the Academy award-winning *Best Years of Our Lives* (1946). Changing attitudes toward disability, both furthered by disabled veterans and reflected in their situation, meant that an injury sustained in battle no longer necessarily stripped a man of his expectations for a well-paying job, marriage, or a family.

Yet, at the same time, the public image of the disabled veteran has often been an ambivalent one. Societies have tended to treat all veterans with caution, as men who have endured the fire of battle, have killed, and perhaps still contain within them the potential for violence. Because they carry the scars of war on their body, disabled veterans have been seen as an exaggerated instance of the general phenomenon. The civilian populace's guilt toward the disabled has undoubtedly played a role in stigmatizing these men as unstable. In novels and films in which disabled veterans appear, images of pathos have coexisted with threatening visions of danger. With rare exceptions, the quotidian struggles of disabled veterans are seldom depicted.

—Deborah Cohen

See also Advocacy Movements: France; Advocacy Movements: Germany; Citizenship and Civil Rights; Veterans.

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DISCREDITED THERAPIES

Alternative or discredited therapies are those that exist outside the framework of professionally accepted remedies as determined by mainstream medical systems. While one could speak of allopathic medicine as an alternative system in eighteenth-century China, this entry considers the context to be contemporary Western medicine. Among those therapies generally considered alternative, for example, are acupuncture, magnet therapy, and many herbal remedies.

Nevertheless, it is important to recognize that alternative or discredited therapies can also become mainstream or accredited, while previously approved interventions can be later discredited. Applying leeches to remove a plethora of one of the four humors, for example, was a mainstay of conventional medicine from antiquity into the nineteenth century. In 1833, some 40 million leeches were imported into France for medical purposes. By the end of the century, leeching therapy was overturned with successive changes in medical theory and practice. Over the past two decades, however, leeches have found new roles in postoperative management for plastic and reconstructive surgery; they have reentered accredited use, although for different theoretical purposes. Thus, the designation of alternative is a moving target.

The term *alternative*, or discredited, therapy fundamentally exists on the sociological level with allocation of resources—mainstream/licit therapies have the support of, for example, governmentally endowed institutes or departments at major universities; the alternative intervention often exists as a grassroots enterprise. Nevertheless, popular alternative therapies can command enormous market forces, which at times can overturn the traditional domination of mainstream medicine. Such changes are often full of social controversy.

Alternative or discredited medicine in Western Europe and North America may be said to have begun with the rise of mainstream medicine. Defining the latter means defining the former as “the other” kind of practice. Thus, in the early Western Middle Ages, magicians and sorcerers offered an alternative means of healing often sought by people with chronic conditions when doctors trained in humoral medicine or Catholic healing interventions were unsuccessful. At times, the Church and the more formal physicians joined forces to limit the appeal of such magical healers. By the thirteenth century, after the invention of the medical schools within the newfangled universities, physicians, lay governmental authorities, and the Church established regulations requiring that medical practice be certified by a license granted only after examination by the university faculty. In 1322, an illiterate woman, Jacqueline Félicie de Almania, and four of her colleagues were tried and excommunicated for unlicensed practice in Paris by the Medical Faculty, despite witnesses asserting her salutary effect in the face of mainstream impotence. Similar examples exist for medieval Spain, Italy, and England.

As university medicine grew in authority and prestige, its physicians entered medical service in the courts of the powerful. By the sixteenth century, figures such as Paracelsus (ca. 1493–1541) could be chased out of town after town for offering medical care that did not fit into the confines of the now codified theory and practice of the universities. In the late eighteenth century, some therapies, such as mesmerism, enjoyed a period of wild enthusiasm only to be officially and permanently discredited by a panel of experts. Others, such as electrotherapeutics for conditions such as stroke and insanity, were used with initial enthusiasm, followed by a period of discredit and but are now being investigated again and used by biomedical scientists.

In the United States, the slow absorption of proprietary, freestanding medical schools into the universities delayed the process of a more consistent division between accepted and discredited therapies until the late nineteenth century. This process was enhanced by the acceptance of the scientific method into medicine, though that acceptance was highly variable both chronologically and geographically. By the beginning of the twentieth century, requirements of verifiable proof of efficacy began to limit the social penetration of alternative medicine and increased the lists of discredited therapies. The ongoing "successes" of scientific medicine, from aseptic and antiseptic surgery to anesthesia to antibiotics to immunomodulators, generated a popular perception that scientific medicine would eventually be able to cure most, if not all, conditions.

Coincident with the shift from the acute- to the chronic-disease model in the second half of the twentieth century, the slow gains with respect to cures for cancer, HIV, and other objects of "wars on disease," as well as the social revolutions of the 1960s and early 1970s, popular acceptance of non-biomedical/university therapies grew. By the 1990s, the groundswell of use of such treatments had grown to the point that reportedly 42.1 percent of American patients acknowledged using such therapies. The National Institutes of Health (NIH) created the Office of Alternative Medicine (OAM) in 1993, which became the current National Center for Complementary and Alternative Medicine (NCCAM) in 1998. Such an official endorsement for the field has blurred the distinction between mainstream and alternative therapies in their classic definition.

As different cultures with a less professionalized medical history endorse the Western biomedical model to a greater or lesser extent, the relationship between "alternative" and "discredited" therapies varies. In China, for example, traditional Chinese medicine (TCM) shares a relatively coequal status with allopathic medicine. In Brazil, prayer competes with native remedies and allopathy**.** In addition, sociological relationships established by professionalized markets can reverse as one moves across cultural boundaries. Thus, in the United States, different alternative remedies have been embraced by both higher and lower socioeconomic groups, whereas in China, the likelihood of a person choosing TCM over allopathy decreases as one ascends to higher socioeconomic statuses.

Conditions, which include chronically disabling features, can fall into those with gradual functional "deterioration," no change, or slow gains, after the model of cerebral palsy, cancer, and HIV. Thus, people with strokes, traumatic brain injuries, amputations, chronic pain, and many others have sought out alternative therapies when biomedical science has not helped. In this way, modern people with such chronic conditions echo their medieval predecessors who, frustrated with the mainstream healer, sought out magicians, sorcerers, and the nonlicensed healers. While the salubrious claims of these complementary healers have not always been proven by science, more intense investigation may prove many of them and so embrace them as accepted therapy.

In the United States, over the past decade, such market forces have pressured both the government and insurance companies to accept in part previously marginalized therapies. In addition, certain medical disciplines, physical medicine and rehabilitation (PM&R) among them, have traditionally employed alternative therapies, from hippotherapy to acupuncture, in advance of more traditional allopathic specialties, further blurring the boundaries between accepted and discredited.

—Walton O. Schalick III

See also Acupuncture; Complementary and Alternative Medicine; Health; Humors, Theory of.

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DISEASE

Disease is a pathological state of a part of an organism. Disease may be brought about by multiple causes such as genetic, infectious, or environmental factors. Distinct symptoms usually indicate the presence of disease.

The concept of disease is at the heart of biomedicine. The purpose of biomedicine, also referred to as allopathic medicine, is to diagnose and cure physical pathology. Historically, disease has been understood in different ways. Before the use of the scientific method and the rise of biomedicine, disease and its symptoms were usually attributed to spirits, witchcraft, humoral processes, or other causes in the social world. In contrast, biomedicine tends solely to consider organic causes and aspects of disease. Discoveries such as the germ theory of disease and the existence of entities such as viruses and bacteria did much to bolster this latter understanding. Discovering the root physical cause of the disease is considered essential to treating, curing, and preventing it. For example, if a patient has a bacterial infection, an antibacterial medication is given. When a medication like penicillin was discovered to fight the disease process, it changed the health outcomes of entire populations. Similarly, when it was discovered that diseases could be transferred by germs, handwashing became a common practice. This simple behavior changed obstetrical practice and reduced infant mortality rates when babies started to be delivered into clean hands. In addition to curative medications and behavioral changes, biomedicine has discovered vaccines that can prevent diseases that were otherwise disabling or deadly such as measles and diphtheria. Because of the power of the biomedical approach to disease, medical research continues to flourish with the promise of curing an increasing number of diseases.

Biomedicine has made staggering improvements to the prevention and treatment of a myriad of diseases. However, the emphasis in this type of medical system is on disease rather than health or well-being. *Allopathic* means “against suffering or disease” and overwhelmingly focuses on removing pathology rather than sustaining health. In this disease-focused system, a person is often stripped of psychosocial or spiritual aspects and effectively becomes a set of body parts to fix. While this emphasis on pathology is changing to encompass health promotion to some extent, the Western medical system is still predominantly one of crisis management. Other systems, such as several Eastern medical models, focus on regular practices to sustain health in addition to disease treatment.

Current controversy exists over whether some conditions should be considered diseases or not in allopathic medicine. For example, a long-standing area of disagreement is addictions. Alcoholism, once considered a moral failing, is increasingly thought of as a disease with genetic factors related to the malfunctioning of neurotransmitters. Many psychiatric disorders have also been redefined as diseases rather than bad behavior such as Tourette’s syndrome, eating disorders, and obsessive-compulsive disorder. For many in Western societies, having a troubling condition defined as a disease rather than a character flaw removes stigma and aids the solicitation of professional help.

Medical anthropologist Arthur Kleinman identified an important distinction between disease and illness. He argues that disease refers to the biological pathology as well as health care practitioners’ understanding of the pathology according to biomedical models. On the other hand, illness refers to a broader set of experiences around the disease including the patient’s and family’s subjective recognition, naming, and experience of the problem. Whereas disease is presented as acultural in a medical model,[1] illness includes the sociocultural context of a problem. The social and cultural components of the experience of a condition have been identified as crucial to the course of the condition. Therefore, medical sociologists and anthropologists point to the importance of examining the illness in addition to the disease, even in biomedical contexts. In the study of disability, several anthropologists such as Robert Edgerton, Benedicte Ingstad, and Susan Reynolds Whyte proved that cultural context makes a significant difference in the identification, experience, and outcome of a condition. The disease/illness distinction is also especially relevant as allopathic medicine expands transculturally and as heavy transnational immigration creates multicultural communities. In such cases, experiences of illness and disability as well as symptom reporting may vary greatly, and it is crucial that important cultural differences are not dismissed in the professional health care setting.

—Eileen Anderson-Fye

See also Anthropology; Health; Health Promotion; Medicine.

Note

1. Many have convincingly argued that even biological pathology is shaped by culture. For example, heart disease and obesity-related health problems have been found to vary in their prevalence depending on a diet common to a particular culture or region.

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DISPARITY

The term *health disparity* is widely used to indicate inequalities in health status and health care services, as it relates to minorities. For example, a disproportionately high number of people in certain ethnic and socioeconomic groups have illnesses such as heart disease, obesity, and cancer. In addition, observed differences exist between Hispanic Americans and the general population in the proportion of having a usual source of care. Ethical judgments of such inequalities (fair or unfair) depend largely on a person's perception of the reasonableness of the underlying reasons for the inequalities, such as differences in income and access to insurance. Other inequalities are often considered unfair when race is the main reason for inequalities. For example, research has shown that the race/ethnicity of a patient is the main factor that affects primary care physicians' decisions on specialist referral or the use of expensive treatment.

Racial disparity in health surfaced in 1985, when the U.S. Department of Health and Human Services issued the first comprehensive national minority health study, known as the Secretary's Task Force Report on Black and Minority Health. The task force focused on differences in mortality for six key areas between minorities and the white population (cancer, cardiovascular disease and stroke, cirrhosis, diabetes, homicide and unintentional injuries, and infant mortality that collectively accounted for more than 80 percent of the mortality from 1979 to 1981) and concluded that the difference in mortality was not acceptable. Following the report, federal and state governments created agencies, such as the Office of Minority Health, to address these issues of health disparity. However, comparisons of the findings in the 1985 report to information released in *Health, United States 1990* showed very little change in the health status of minority populations.

By 1998, studies indicated that racial disparity had not improved as much as hoped. The long-standing considerable differences in death rates for infant mortality, heart disease, cancer, and HIV/AIDS between minorities and whites made a compelling case for a federal response. Consequently, President Bill Clinton launched a initiative that set a national goal of eliminating disparities in six key areas by the year 2010: infant mortality, diabetes, cancer, heart disease, HIV/AIDS, and immunizations.

In 1999, Congress authorized the Institute of Medicine's (IOM) study on the prevalence and impact of ethnic bias. Unlike previous governmental studies, the IOM report, titled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, focused on quality of treatment by examining provider-patient clinical encounter itself rather than mortality or prevalence of diseases. The report documented the prevalence of lower-quality treatment of minority patients, and concluded that minorities received unequal treatment because they are, in fact, minorities.

Policy makers started to express concerns related to the sole focus on racial and ethnic minorities as opposed to a more generally defined population, such as those whose health care needs are not well met. Concerns led to addition of the definition of *health disparity population* into a new federal law, the Minority Health and Health Disparities Research and Education Act of 2000: A population can be designated as "a health disparity population if there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population."

Specification of certain segments of the population in the health disparity definition provides insight as to which segments are of greatest interest for policy makers. The National Healthcare Disparity Report, developed by the Agency for Healthcare Research and Quality (AHRQ) to meet the mandate by Public Law 106–129, the Healthcare Research and Quality Act of 1999, identified persons with disabilities and persons who use long-term care, among others, as priority populations worthy to track health care disparities. According to the U.S. Census (2000), nearly one in five persons, or 49.7 million people, had some type of long-lasting condition or disability. They represented 19.3 percent of the 257.2 million people who were age 5 and older in the civilian noninstitutionalized population.

Some disparities were documented based on national survey data, such as the Medicare Current Beneficiary Survey, the National Nursing Home Survey, and the National Home and Hospice Care Survey. However, other national survey data were not usable for reporting on racial/ethnic and socioeconomic disparities related to disability. Many data collections do not capture disability and, when collected, do not have adequate sample sizes of the disabled to examine racial/ethnic and socioeconomic disparities.

In general, the Medicare Current Beneficiary Survey (MCBS) findings indicated the presence of racial/ethnic and socioeconomic disparities in the quality of health care among disabled persons. According to the disabled elderly, the percent of persons who reported problems with the quality of care is higher among Asian and Pacific Islanders (11 percent) when compared with whites (4 percent), and higher among persons in poor households (6 percent) when compared with persons in high-income households (3 percent). Small sample sizes precluded assessment of disparities in the quality of health care among the disabled nonelderly. Similarly, access to care also indicates disparity among disabled persons. For example, among the disabled elderly, the percentage of persons with a problem getting to the doctor from their home was higher among Hispanics (16 percent) when compared with non-Hispanic whites (7 percent). In addition, there is an income gradient with this measure of physical access to a doctor: Persons in poor (11 percent), near-poor (9 percent), and middle-income (7 percent) households experienced more difficulty than persons in high-income households (4 percent).

The National Nursing Home Survey and the National Home and Hospice Care Survey data were used to examine racial, ethnic, and socioeconomic disparities in nursing home care. Within the survey data, differences in the management of pain and the receipt of rehabilitative services among nursing home residents were demonstrated. Significant disparities in influenza vaccination were not observed, but disparities in pneumococcal vaccination among some nursing home residents were present. Among persons ages 18 to 64, rates of nursing home discharges were higher among blacks (22 per 10,000 population) when compared with whites (16 per 10,000). In addition, when discharged from a nursing home, the percentage of persons who stabilized/recovered was lower among blacks (22 percent) than whites (34 percent).

Health disparities can be examined from the point of view of public health purposes. This approach follows the 1986 World Health Organization definition of health, which states, "Health is a state of complete physical, mental, and social well-being, and not merely the absence of disease or injury." *Healthy People 2010* and similar state initiatives have committed the nation to the goal of eliminating health disparities by 2010. *Healthy People 2010* defines health disparities as differences that occur not only by gender, race or ethnicity, education, or income but also by disability, geographic location, or sexual orientation. Of 28 focus areas that cover both health care and health status measures, the sixth focus area addresses disability and secondary conditions with one of three goals being the elimination of disparities between people with and without disabilities in the U.S. population.

The disparity findings suggest that people with disabilities tend to have lower rates of physical activity and higher rates of obesity. They tend to report more anxiety, pain, sleeplessness, and days of depression, and few days of vitality when compared to people without activity limitations. Health promotion activities are important for people experiencing a disability regardless of race or ethnic group, gender, or primary condition or diagnoses (e.g., major depression, arthritis, cerebral palsy, diabetes, spinal cord injury, or fetal alcohol syndrome).

A 2003 national survey that updates the Disability Supplement to the National Health Interview Survey (NHIS-D) conducted nearly 10 years ago examined health care use, costs, and access among people with disabilities. More than 33,000 households were contacted; 3,687 of which were identified as including a household member with a disability. According to the survey findings, people with disabilities are often confronted with socioeconomic and health-related disadvantages, compared to the rest of the general population. Commonly, disabled people, both mentally and physically, have lower incomes, are older in age, are more likely to be female, are more likely to be unemployed, and are often poorer in health. Thus, because of these disadvantages, people with disabilities are more likely to use the health care system exhaustively: (1) 90 percent of the sample reported employing physician services six months prior to the survey, (2) approximately 33 percent reported frequenting emergency room services six months prior to the survey, and (3) 90 percent reported taking at least one prescription drug on a daily basis. These numbers indicate higher health care use rates for people with disabilities when compared to the general U.S. adult population. Although those living with disabilities are often profound and intense users of health care services, they obtain these services much less regularly than is normally recommended.

The survey findings highlight barriers to care among the uninsured and those with gaps in coverage within persons with disabilities. For example, the uninsured were four times as likely to have postponed care because of cost when compared to those with insurance coverage. Also, the uninsured were three times as likely to go without needed supplies or medication. Those insured primarily by Medicaid were less likely to postpone care or go without necessary medication compared to those covered by Medicare or private insurance companies. In addition, the disabled, covered solely by Medicare, fared worse than people with private coverage (12 times as likely to postpone care, and 7 times as likely to forgo medication). The findings suggest that Medicaid provide the most important financial protections when compared to other sources of coverage such as Medicare and private insurance.

On the other hand, the Medicare Current Beneficiary Survey (MCBS) data allow comparison of health status between two groups of Medicare beneficiaries: the disabled under age 65 and the elderly population. In general, the survey concluded that disabled beneficiaries have poorer physical, mental, and functional levels than the elderly. The study also reported that the disabled were twice as likely to be in fair or poor health (59 vs. 23 percent), and twice as likely to have trouble performing one activity of daily living (44 vs. 26 percent) or instrumental activity of daily living (36 vs. 16 percent). The survey also noted that disabled persons bear heavier disease burdens and are more likely to report having three or more chronic conditions. Furthermore, the disabled are often poorer: They are more than twice as likely as seniors to live under the federal poverty level (45 vs. 20 percent); nearly 80 percent live on modest incomes under 200 percent of the poverty level. Mentally disabled beneficiaries are the most vulnerable: They are more likely to have incomes below poverty level.

Differences in health status and disposable income seem to lead to differences in health care utilization between the disabled under age 65 and the elderly Medicare beneficiaries. In 1998, the average number of prescriptions filled by disabled users (34) was much higher than for elderly prescription users (25). In addition, the disabled spend almost 50 percent more than the elderly on prescription spending ($1,284 vs. $841).

A recent Commonwealth Fund study singled out a vulnerable subgroup within persons with disabilities: Severely disabled persons enrolled in Social Security Disability Insurance (SSDI), waiting the mandated two-year waiting period before their Medicare coverage takes effect. Medicare provides coverage for individuals whose disabilities are severe and permanent enough, qualifying them for SSDI, even if they are not age 65 and older. However, unlike the elderly beneficiaries, federal law requires these individuals to wait two years after they receive SSDI before their Medicare coverage takes effect. Many of these individuals are no longer eligible for Medicaid when they receive SSDI payments that push them over the financial limits for Medicaid. Some may still be eligible for Medicaid benefits but are unaware of their potential eligibility. In 2002, a total of 1.2 million people with disabilities under age 65 were in the mandated two-year waiting period. About 400,000, or one-third, of all these individuals likely were estimated as uninsured. Thus, many, particularly those in the waiting period, report enormous problems: skipping medications, putting off needed care, feeling depressed and anxious about the future, and believing they were not in control of their own lives. The study findings call for eliminating the current Medicare two-year waiting period and beginning Medicare coverage concurrent with that of SSDI.

Mental disorders are disabling conditions. Former Surgeon General David Satcher's 2001 report on health disparities, titled *Mental Health: Culture, Race, and Ethnicity*, documents the existence of several disparities affecting mental health care of racial and ethnic minorities compared with whites: Minorities have less access to, and availability of, mental health services. Minorities are less likely to receive needed mental health services. Minorities in treatment often receive a poorer quality of mental health care. Minorities are underrepresented in mental health research.

Studies mentioned above tend to focus on disparity in access to care. We may need more research related to quality and outcomes in health care for the disabled. Another observation relating to the studies mentioned above involves little research on racial disparity relating to disability. With the exception of mental health, most disparity studies mentioned above do not report on racial/ethnic and socioeconomic disparities related to disability. Many survey data conducted or sponsored by federal agencies do not capture disability and, when collected, the definition of disability is often not consistent across data or over time. Even when disability status is captured, in many cases, the data do not provide adequate sample sizes of the disabled to examine racial/ethnic and socioeconomic disparities. The 2004 National Academy of Sciences' report, titled *Eliminating Health Disparities: Measurement and Data Needs*, recommended the use of state-based data such as vital records, administrative data from Medicaid and the State Children's Health Insurance Program, and data from registry systems for analyzing disparities in health and health care. Although those types of data provide information on race and ethnicity and socioeconomic status, disability information may not be available, limiting their use for studying racial and socioeconomic disparities relating to disability.

—Kyusuk Chung

See also Health Care and Disability; HIV/AIDS; Poverty; Race and Ethnicity; Socioeconomic Class.

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DISSOCIATIVE DISORDERS

Dissociative disorders are disturbances of normally integrated mental functions such as identity, memory, consciousness, or perceptions of environment. These can occur suddenly or gradually and may last a short time or become chronic. Dissociative phenomena, on the other hand, are seen in normal subjects and may result from hypnosis or a trance state. About 90 percent of the population is hypnotizable. Trance refers to altered state of mind during which a person performs uncommon physical feats, such as standing on one leg for hours or walking on a bed of nails. Dissociative phenomena have been recorded in the temples of Aesculapius in ancient Greece, in Native American culture, and among Indian monks. Dissociative phenomena can also be seen in various religious and cultural ceremonies internationally where the process of celebration induces a group dissociative phenomenon.

Dissociative disorders are usually psychopathological and include the following subtypes: dissociative amnesia, dissociative fugue, dissociative identity disorder, depersonalization disorder, and dissociative disorder not otherwise specified.

Dissociative amnesia is characterized by an inability to recall important personal information of stressful or traumatic nature. It may be *localized* (inability to recall events during a circumscribed time), *selective* (can recall only some aspects of an event), *continuous* (ongoing amnesia following a specific event), or *systematized* (inability to recall certain categories of events). Dissociative amnesia can occur at any age but is rare in children. Its incidence is higher in soldiers in combat. It is reversible, usually beginning and ending suddenly. Recurrences are not uncommon. Hypnosis and amobarbital interview may be helpful in retrieving lost memory.

Dissociative fugue presents as a sudden, unexpected travel away from home with inability to recall some or all of one's past. Onset is sudden, usually following severe psychosocial stressors. This state usually lasts for minutes to days, but may be prolonged for months. Although confusion may be present, most individuals appear quite intact and do not draw attention.

Dissociative identity disorder (formerly called multiple personality disorder) is characterized by the presence of two or more distinct personality states or identities that recurrently take control of the person's behavior. The patient may be unable to recall important personal information. This is a chronic and complex disorder, which may result from severe childhood abuse (physical, emotional, or sexual) or neglect. It is diagnosed three to nine times more frequently in adult females. It is more common among the first-degree biological relatives of patients with this disorder.

The person may have different personality states or identities, that is, the child, the angry person, the protector. Most patients are unaware of their disorder and may seek treatment for depression. Many patients receive other diagnoses prior to treatment and may not respond to medications. The transition ("switch") from one personality to another is usually quite sudden. The degree of impairment depends on the manner in which various personality states interact with each other. The switching is a vulnerable time. Patients may attempt suicide, mutilate themselves, or become violent toward others. Long-term psychodynamic psychotherapy using an integration approach is helpful.

Depersonalization disorder presents as recurrent episodes of depersonalization in which a person feels detached or estranged from one's self. He may feel as if he is an observer watching himself as if in a dream or movie. Reality testing remains intact. The prevalence of this disorder is unknown. It usually occurs in adolescence or adulthood. Most patients present with anxiety, panic, or depression. Clinical course may be chronic with recurrences following stressful events. Impairment is usually minimal and most patients function well, but some become incapacitated from fear of going insane.

Dissociative disorders not otherwise specified do not fit in any of the above categories. Ganser's syndrome (in which the person gives approximate answers) falls in this group.

—Surinder Nand

See also Psychiatric Disorders.

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DIVERSITY

Although *diversity* is a much overused term within multiculturalism, its potential for promoting social transformation—particularly with respect to disability—remains significant. At base the term suggests difference, or rather, the recognition and acceptance of difference; however, even this formulation does not adequately address the term's importance. Instead let us say that diversity represents not a point of acceptance but a stance toward the world that refuses to foreclose on the question of who counts among the ranks of humankind. Diversity, then, becomes a more active ethical position, available for adoption as opposed to a goal to be fulfilled.

This distinction is important at the outset because the overuse of *diversity* in contemporary politics and rhetoric has reduced the term's meaning to an objectively achievable goal. If we have human "differences" represented at any one point in time—African American, Jewish, women, gay—then we have achieved "diversity" and we can go on from there. Such a position cultivates certain forms of tokenism where the one stands in for the many and, as a consequence, the plurality of the many drops out. Pure efforts to operationalize diversity inevitably miss the point of the concept, and therefore, this entry sets out a philosophical overview of the term's important meanings.

Properly understood, then, *diversity* means a plurality of singularities working together toward collective understanding and action. The realization of diversity, which can never occur once and for all, must constantly be renewed and implies a recognition that beneath any collective banner those who comprise it must also retain their specificity. Consequently, diversity should not be viewed as a question of representation; particularly in the sense of one perspective effectively embodying a diverse whole. Instead, efforts to achieve diversity seek to avoid rhetorical efforts in the name of false unity. The goal is not a subsumption of differences beneath a singular identity—whether that identity be women, African Americans, disabled people, the working class—but rather a cultivation of shared participatory space where differences remain recognizable. Nor can diversity be adequately identified with more outdated political groupings of "the people," "the masses," "the proletariat." If this were so, and diversity functioned merely as another synonym for designations of group identity, the term's significance would prove much less consequential.

Diversity has come to stand in as an alternative form of identification—one that ultimately attempts to suspend the need for singular group identity overriding dynamic differences across populations. As Ernesto Laclau and Chantal Mouffe have pointed out, political formations coalescing beneath an identity (no matter how large the potential grouping) inevitably experience the fracturing of differences residing just below the surface of a unifying banner. One might say that efforts to unify a plurality of identities beneath a nodal point of belonging find themselves inevitably beset by the demands of diversity. The specificity of individual differences ultimately makes demands on the larger category charged with organizing shared modes of belonging. Conceived in this way diversity can be understood as a disruptive presence at work in all efforts at totalizing allegiance.

At the same time, diversity does not involve surrendering to relativism either. The existence of particularities among collective gatherings does not necessarily mean that organizing devolves into irredeemable difference. Philosophies of political organizing, as Michael Hardt and Antonio Negri point out, have often offered formulas that result in a false choice between unwieldy plurality or authoritarian singulars. Diversity's alternative philosophical gambit resides somewhere in between these extremes. Instead diversity focuses on forms of collective action taken in common among the individualities that comprise it. The effort of diversity is not to forge "unity" of identity based on a shared interest or essential quality, but rather to achieve an open process respectful of differences born of intellectual, social, geographic, and embodied experiences. While there is a defining nonallegiance to national boundaries, diversity actively recognizes the specificity of place and culture. Within this formula there is no need to negate local differences; rather the creativity of differences interacting with each other express the ideal of diversity. The conscious goal of diversity is to produce alternative routes of belonging that bypass more worn down points of group organization.

Yet this formulation is not without conflict. Nor is its achievement simple to pull off. One inevitably finds exclusions occurring even in the most "diverse" gatherings. Disability, for one, often finds a difficult time inserting itself into political efforts claiming to be diverse for a variety of reasons. First, modern liberation movements have traditionally sought to undermine social designations of inferiority by distancing themselves from criteria of "biologically based" insufficiencies. The contemporary history of women's weaker constitutions or biological racism, for instance, situates a population's inferiority as having a bodily basis. By way of refuting such ascriptions modern concepts of femininity and race have rightfully exposed the social underpinnings informing such beliefs. However, in the wake of these liberation formulas, disability functions as a remainder of true "inferiority" in that it continues to operate within the parameters of biology.

Furthermore, disabled participants in politicized identity movements have often found themselves left out of traditional activist practices. On the basis of inaccessibility that exists within political organizations—for example, lack of audio description and/or alternative print formats for people with visual impairments, lack of sign language interpreting and/or captioning for deaf participants, lack of physical accessibility for those with mobility impairments—disability itself has not been recognized as a legitimate constituency with issues in need of political redress. Thus, divisions often surface based on insensitivities in Leftist movements to the forms of marginalization that disabled people face. In addition, within disability groups one could also point out that lack of active recruitment of other marginal identities results in a failure of diversity among disability movements as well. Within this matrix of insensitivities, inadequate recognitions, and exclusionary practices little space is left for the exploration of the substantial overlaps that exist between disability, race, class, gender, queer, and other identities seeking political change. One basis for social claims of marginalization eclipse other equally pressing oppressions, and disability often finds itself holding the least status among competing discourses of social redress. Diversity and disability, it would seem, do not mix.

Thus, disability as diversity continues to function as oxymoronic. Disability and its intersections with other identities have not yet been adequately recognized as a cultural attribute with something to contribute to our understanding of social disenfranchisement, political organization, or collective well-being. In fact, disability often appears as the identity claim that will ultimately expose all identity claims as false. If people with disabilities who have obvious "things wrong with them" (or so goes this rationale) can also claim the political terrain of social constructivism, then all identity-based claims are in jeopardy. With the arrival of disability we have somehow reached the end point of identity politics because claims to social disenfranchisement based on prejudicial beliefs about inferior biologies must be disallowed from growing too sweeping (and, therefore, ludicrous). If disability gains recognition as a minority like any other, then it instantly metamorphoses into the largest minority group (some 20+ million in the United States alone). Difference becomes mere variation; disability threatens to re-biologize socially derived inequalities; minority status itself becomes a joke when one has to work in such large demographic quantities; and anyone could ultimately become a resident of minority landscapes. Claims to social justice become impossible, incoherent, and, ultimately, unwieldy.

Diversity undermines (or, depending on your point of view, exacerbates) such fears in that it endeavors to attribute differences differently. Differences are not so much based on one's possession of discrete characteristics (femininity, homosexuality, color, disability); rather, diversity seeks coalitions among those who use difference as a tool to analyze structural inequalities. Diversity is a shared methodological tool more than a static mode of being. Such an approach does not mean a rejection of biological and social identities. Instead, diversity cultivates a common-ness across previously segmented identities based on annunciations of common objectives. As a result, diversity cannot be achieved beforehand or a priori. It is a dynamic and ever-shifting product of politicized identity constituencies as they interact with each other to formulate and imagine another world where differences could be signified as wealth rather than lack.

In April 2005, for instance, the Perth Social Forum in Australia adopted the slogan "Another World Is Possible." A three-day symposium included environmentalists, feminists, aboriginal rights advocates, disability rights advocates, theorists of organizational behavior, anthropologists, Marxists, globalization philosophers, "slow food" proponents, and antiwar protestors. Diversity operated as the expressed goal in that participants were encouraged to pursue multiple activist interests without privileging any singular aspect of their identity interests. In other words, the inter- and intragroup efforts explicitly discouraged a single basis for belonging or legitimate activism. Instead, coteries of interests became the norm and participants found themselves teaching and being taught across a variety of perspectives. By the conclusion of the event, five key themes surfaced as interests identified "in common" among all attendees: the insufficiency of existing forms of political participation, the global ruination of environments (both natural and artificial), the continuing proliferation of poverty, increasingly narrowing criteria of meaningful human inclusion based on variation rather than homogeneity, and strong commitments to global peace agendas. These shared investments signaled not unity of identity but common political and social capacities among those gathered.

Critics of diversity might say that, inevitably, every identity group is formed on the basis of its exclusions—those who do not fit based on fetishized traits strategically reclaimed to counter mainstream devaluation. Diversity sets out to undo this limiting logic by inserting a more expansive formula for involvement. Even when a historical moment is dominated by a variety of unifying identity rubrics, diversity responds to the indefinite nature of dispersed networks—those intersected by myriad differences of race, class, gender, disability, age, sexuality, and cultural/geographic specificities. Because the multiple interests of the Perth Social Forum could still manage to define agendas in common based on the five themes identified above, one recognizes that diversity does not necessarily undermine the ability to exist in common. Diversity is not a devolution into incoherency; instead it seeks to transform the appearance of incoherency from the outside into an organizational strength. Consequently, diversity grapples openly with the need for alternative organizational strategies that do not cover over differences but rather cultivate them openly as desirable—a politics based on variation as a commonality of our embodied, political lives.

—Sharon L. Snyder and David T. Mitchell

See also Citizenship and Civil Rights; Democracy; Gender; Gender, International; Inclusion and Exclusion; Race and Ethnicity;

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DIX, DOROTHEA (1802–1887)

American social reformer

Dorothea Dix was a renowned social reformer and vocal advocate for the humane treatment of people with psychiatric disabilities. During her lifetime, Dix traveled extensively throughout the United States and abroad, visiting jails and almshouses to document the inhumane treatment of those with mental illness. She used these notes and observations to fight for the use of "moral treatment" in their care. Her reports regarding the treatment of those with severe mental illness were presented in numerous state legislatures, leading to the creation or enlargement of many hospitals designed specifically for the needs of this group. Dix believed that it was important to provide a place that focused specifically on assisting people with mental illness. She felt that the current system of care, one that focused on trying to address the needs of many disparate populations, including orphans, criminals, and paupers, was not specialized to adequately address of all these issues. Dix believed that a therapeutic setting, focusing on recovery, without restraint or confinement of patients, would be most helpful in restoring mental health.

Dix rose to prominence after submitting a petition to the Massachusetts General Court, titled the *Memorial to the Legislature of Massachusetts,* which documented the horrific conditions of people with mental illness living in confinement throughout the state. As a result, Massachusetts enlarged its state mental hospital to provide specialized treatment to low-income individuals with psychiatric disabilities. As an outcome of her successful efforts in Massachusetts, Dix became involved in conducting surveys and inspections of almshouses and prisons in other states, and she lobbied other legislatures to enact similar reform legislation. She played an instrumental role in the creation of 32 mental hospitals and became nationally known for her reform efforts.

Although Dorothea Dix was progressive in her views about psychiatric disability and specialized treatment for people with mental illness, she did not embrace reform in many other areas. As a woman, she did not feel that it was appropriate to engage in public speaking herself. So instead of addressing legislative bodies and other groups, she wrote speeches that were read on her behalf by prominent men who supported her efforts to create mental health care facilities. In addition, unlike many reformers and activists of the 1800s, she was not an abolitionist, and she maintained close ties with prominent slaveholder families. Some historians have argued that she was more effective in her advocacy of humane treatment for the mentally ill because she followed the strict social conventions of the time. She presented herself as a reluctant activist moved to action by the plight of people with mental illness. However, her conservative views in many areas have made her less appealing as a role model for subsequent generations that have rejected many of her beliefs.

Dix was born on April 4, 1802, in Hampden, Maine, a small village on the Massachusetts frontier. During her youth, there was significant tension within her family, particularly between her parents and grandparents. Dorothea's father lacked much of the ambition and drive that had characterized her grandfather's success. In addition, her father married a woman that his parents felt was beneath him. At age 12, Dix ran away from her parents and went to live with her grandmother in Boston. At 14, she moved in with the family of a prominent physician and became semi-independent from her family. While living with this family, Dix opened a private school. She continued to teach for the next 20 years, in various locations, at her grandmother's home and at the Female Monitorial School, and she also provided private tutoring. In addition, she published a number of books for children, including her most famous *Conversations on Common Things.*

Dix's focus on social reform was in part influenced by her strong commitment to the Unitarian faith. In the early 1820s, Dix began attending sermons every Sunday and Thursday, and focused her life increasingly around church lectures, sermons, and humanitarian projects. Dix seemed particularly influenced by the church's emphasis on the poor and unfortunate and its efforts to create a more socially just community. Dix regularly attended a Unitarian church led by William Ellery Channing, and over time developed a personal relationship with the pastor. Dix began tutoring his children and eventually began to accompany the family on summer trips and on a lengthy journey to the Caribbean.

During the late 1820s and the early 1830s, Dix developed significant health problems, including a chronic respiratory condition. In the winter of 1836, she experienced an episode of severe depression. Seeking rest and a change of scenery, she sailed for England in the spring. However, upon her arrival, her symptoms worsened and she became bedridden and despondent. Dix was taken in by a Unitarian philanthropist, William Rathbone II, and his wife, who were acquainted with William Ellery Channing. During her stay with the Rathbones, Dix continued to experience severe symptoms of depression, in addition to an episode of pneumonia. She consulted with William Rathbone and Oxford physicians regarding her symptoms. Dix was often confined to her room by chronic fatigue; however, she enjoyed frequent visits from the Rathbone family. Dix convalesced in England for a year and a half and, as she became stronger, she socialized increasingly with the numerous guests that visited the Rathbones. Through these interactions, Dix was probably exposed to the "reform movement of moral treatment" that was becoming increasingly popular in Europe. Upon receiving news of her grandmother's death, she returned to New England in the summer of 1837.

Dix's philosophy regarding treatment reform for individuals with mental illness was strongly influenced by the moral treatment movement. Originating at the York Retreat in England, this treatment focused on encouraging patients to use self-control instead of using physical and mechanical restraints. The York Retreat was a private hospital in which seven staff cared for 30 patients. Patients were expected to take part in daily activities, such as reading, writing, sewing, socializing, and gardening. Work also was considered an essential part of developing self-control. Exercise, warm baths, and a generous diet were believed to be important to calm and reassure patients. Privileges were granted to individuals who behaved in a desirable manner. This new philosophy emphasized that patients could be rehabilitated and cured, particularly if early treatment was provided.

During the nineteenth century, public hospitals provided treatment only for low-income individuals and those who had exhausted their financial resources. Hospitals were viewed as the option of last resort and were associated with moral degeneracy and poverty. In addition, hospitals exposed patients to contagious, infectious diseases such as sepsis. In general, families cared for members with physical and/or mental illnesses at home. The asylum movement sought to change the role of hospitals in American society. The movement focused on creating institutions that would provide specialized care in pleasant, homelike environments. The asylum movement subscribed to the belief that the increasing complexity, dislocation, and urbanization of American life had detrimental effects on people's physical and mental health. Asylums provided safe havens where people could recover from these effects.

Moral treatment in the asylums used a system of incentives and punishments to treat mental illness. Asylum staff developed an individualized regimen of various activities for each patient that included grooming, exercising, meeting with the physician, dining, recreation, educational activities, and some work activities. The regimen was changed as an individual's symptoms improved or declined. Individuals were discharged from the asylum when they no longer experienced symptoms of mental illness, exercised sufficient control over undesirable impulses, and demonstrated a determination to lead a productive life. Asylum superintendents would often send inquiries in the years following discharge to former patients to see how they were doing. Generally, hospital stays lasted a number of months while, for a smaller number of people, hospitalizations occurred for a period of years.

When Dorothea Dix returned to Boston, she met Samuel Gridley Howe, who encouraged her interest in humanitarian work at a local prison. Together, they worked on strategies to bring more public attention to the situation of people with severe mental illness. Dix began visiting jails and almshouses in Massachusetts, documenting what she found throughout the state. During her visits, she conducted a census of each institution's inmates with mental illness, documented their general condition, and intervened in particularly dire situations to alleviate suffering. She noted the availability of religious instruction and literature. Howe, who had recently been elected to the state legislature, encouraged Dix to summarize her findings in a petition to the legislature. Dix completed her petition, *Memorial to the Legislature of Massachusetts,* including the names and dates of the various places she had visited, for the opening session of the legislature, where it was presented on January 19, 1843.

In her *Memorial to the Legislature of Massachusetts,* Dix detailed graphic portraits of men and women living in filth; she described people living in "cages, closets, stalls, and pens!" who had been beaten and whipped. She gave case examples of individuals kept isolated in dark cellars, naked, and covered in human excrement. Many confined individuals had no clothing, heat, or furniture. Through the *Memorial,* Dix recommended legislative action to create asylums for those with severe mental illness. She advocated separating them from criminals, asserting that those with mental illness needed care, not punishment, and that by confining them in prisons, their conditions only worsened.

A pamphlet of the *Memorial* also was circulated throughout the state, causing considerable controversy, as some of the institutions included in her petition disputed her findings. However, a few prominent politicians and attorneys spoke out in her defense. As a result, Dix became increasingly influential and met with many legislators in an effort to lobby her cause. In the spring of 1843, the Massachusetts legislature allocated funds to greatly expand the State Mental Hospital at Worcester. Dix conducted similar investigations and engaged in lobbying efforts in other states, including New York, New Jersey, Pennsylvania, Kentucky, Illinois, Tennessee, Louisiana, Mississippi, North Carolina, Alabama, and Maryland. Her advice and assistance often was sought by state politicians because she was viewed as an objective outsider who could assess the plight of people with mental illness and provide guidance regarding legislation to address these concerns.

By the late 1840s, Dix focused on developing a national plan to address the treatment of people with mental illness. She created a federal memorial in which she described the plight of those with mental illness in various towns and villages throughout America. She argued that mental illness was increasing, and that other countries were experiencing similar problems. She focused on the potential for treatment to cure some individuals, and its ability to make those individuals whose conditions were thought to be "incurable" comfortable and socially useful. Her petition led to a bill proposing a federal land grant for 12,225,000 acres to be set aside as a public endowment. The income from this land was to be used to provide services for people with mental illness, as well as those who were blind, deaf, and mute. From 1848 to 1854, Dix continued to lobby for her plan, and the legislation was successfully passed by both the U.S. House and Senate. President Franklin Pierce, however, vetoed the bill and ended Dix's pursuit of securing funding for current and future state programs to address the needs of the people with mental illness. In a written defense of his action, Pierce stated that he did not want to establish a precedent in which the federal government was responsible for funding state programs.

Discouraged by the failure of her effort to provide a national endowment for treatment of mental illness, Dix returned to Europe. She traveled extensively to many countries, including England, Scotland, France, Austria, Italy, Greece, Turkey, Russia, Sweden, Denmark, Holland, Belgium, and Germany. During her two years there, Dix visited prisons and almshouses, again documenting her findings and advocating for reform.

When Dix returned to the United States, she continued to lobby and advocate on behalf of her cause. Within a few years of her return, the Civil War began. She was appointed superintendent of United States Army Nurses by President Abraham Lincoln. In this position, however, Dix was often in conflict with the Army Medical Bureau. She had difficulty adjusting to the bureaucracy and organizational structure of the military establishment. Since her previous work had been conducted more autonomously, she faced constant challenges to her authority. With Dix's reserved and distant manner, in addition to her unorthodox ways, many critics emerged, leading to a decline in her public image.

After the war, Dix again returned to advocacy work for people with psychiatric disabilities. However, she was disappointed to see that mental hospitals had become overcrowded, understaffed, and run down. Most of the facilities lacked adequate funding to provide the type of treatment originally envisioned by those advocating moral treatment. Many rural communities where asylums were located objected to funding treatment for predominately urban populations. In addition, the economic depression of 1857 and postwar depressions further depleted hospital funds. Asylum facilities were also strained by the huge influx of immigrants, who had few financial resources. These facilities became merely custodians of people with mental illness, not the therapeutic, tranquil environments for which she had fought.

Dorothea Dix died in 1887, at the age of 79. She is buried in Mount Auburn Cemetery in Cambridge, Massachusetts.

—Marie Hamilton, Judith A. Cook, and Jessica A. Jonikas

See also Activism; Depression; Institutionalization and Segregation; Mental Health; Psychiatry.

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DO NOT RESUSCITATE (DNR) ORDERS

Do not resuscitate (DNR) orders are advance medical directives that request that doctors do not attempt cardiopulmonary resuscitation (CPR) if a person's heart stops or the person stops breathing. A DNR order is then placed on the individual's medical chart, and sometimes a colored bracelet is also put on the person's wrist stating, "Do Not Resuscitate." In these cases, when the person's heart stops or the person stops breathing, doctors then abide by this directive, and the individual is likely to die in the hospital.

A DNR order may be applied before, during, or after a cardiac or respiratory arrest. Individuals may write their own advance directive, indicating a desire to have a DNR order placed on them, if they are considered rational and able to communicate their wishes in a clear manner.

A DNR order does not mean that no medical assistance will be given to the individual. For instance, emergency care and other health care providers may continue to administer oxygen, control bleeding, splint or immobilize, position for comfort, provide pain medication, and provide emotional support. However, they will not administer chest compressions, inset an artificial airway, defibrillate or cardiovert, or initiate cardiac monitoring.

DNR orders can be particularly controversial when the individual is incapable of expressing his or her own wishes, for instance, if the person is in a coma. In these circumstances, when the individual is unable to give informed consent, the authority to make such decisions passes to a surrogate decision maker, such as a legal guardian, spouse, or parent. Often there are conflicts between surrogate decision makers and other family members or friends who disagree about the treatment the individual would have wanted.

Doctors often discuss the need for DNR orders when a person has malignant cancer or a severe infection such as pneumonia, or if the person's kidneys do not work well. People who ask for a DNR order in these circumstances often express a desire to let nature take its course.

Although some doctors may raise the issue of DNR orders with people who are likely to become disabled, their use in these circumstances is far more controversial. It cannot automatically be assumed that because someone is disabled, or is likely to become disabled, that quality of life will automatically decrease, and it certainly cannot be assumed that disability is an automatic justification for a DNR order. Disability rights activists often campaign on this issue—they argue that it is wrong to suppose a person will have a lower quality of life simply because he or she is disabled—and condemn doctors who promote DNR orders as a reasonable medical response to disability.

Another issue that is of concern to disability activists is whether the person who is subject to the DNR order actually consents to this order. In some cases, it has been argued that an individual with a DNR order did not consent to such an order and did not even know that such treatment decisions had been made.

—Mark Sherry

See also Bioethics; Death; End-of-Life Care.

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DOCUMENTARY FILM

Since the beginnings of film, disabled people have been central subjects of the documentary genre. The evolution and subgenres of disability documentaries provide insight into shifting social attitudes toward people with impairments. In addition, different constituencies have used the documentary's association with empirical "objectivity" as a means to serve a variety of social and political ends. Disability documentary can be divided into the following subgenres: medical, eugenic, inspirational, and activist. Individual films tend to fall into one primary subgenre while exhibiting characteristics of others.

The medical subgenre can be traced to the earliest film technologies. Medical practitioners used film in the early twentieth century as a tool to document the symptoms of individuals with impairments for multiple purposes: archival, research, diagnostic, and educational. For instance, in addition to making multiframed images of normative walking, standing, and crouching movements, the pioneering photographer Eadweard Muybridge made chronophotographs of "abnormal" gait patterns in the United States during the 1870s. Audiences for these early films primarily consisted of the medical community and researchers, rather than the general public. Currently, this subgenre thrives in the form of films created as professional development material for medical and social service providers. These films provide information on matters ranging from the latest therapeutic techniques to understanding the daily obstacles faced by disabled people to updates on disability legislation. This subgenre also includes documentaries intended for general audiences. For example, popular, current-day versions of the medical subgenre have proliferated on television, showing the miracles of modern medicine to cure, or at least markedly improve, the lives of the ill and disabled. These documentaries contribute to the popular understanding of the medical model of disability, which casts disabled people as individual, pathological patients in need of medical care or cure.

The eugenic subgenre emerged in the late 1920s through the 1940s. Eugenicist documentary filmmakers created propaganda aimed at both the medical community and the general public to justify the treatment of people with a variety of impairments, including institutionalization and other forms of segregation, sterilization, and in the most extreme cases, euthanasia including medical murder. A notorious American example of such films is *Are You Fit to Marry?* (1928), which warned against allowing disabled children to grow, marry, and give birth to ever-more impaired progeny. The film functioned as a health propaganda film that drew direct equations between individual citizen's bodies and the health of the nation. In doing so, *Are You Fit to Marry?* popularized eugenics ideology and made it the responsibility of individuals and family to strictly police their reproductive fitness. Nazi propaganda films produced between 1935 and 1937 (with titles such as *Straying from the Path, Hereditarily Ill,* and *Sins of the Fathers*) promoted the sterilization of people with mental impairments or psychiatric labels. Furthermore, British films released after World War I such as *War Neuroses: Netley, 1917, Seale Military Hospital, 1918,* as well as U.S. propaganda films during World War II demonstrated modern applications of psychiatric therapeutic techniques deployed to integrate traumatized veterans back into society.

The eugenic subgenre in its most blatant form has mostly died out; however, elements can still be found on television documentaries exploring the ethical complexity of end-of-life issues, such as the Public Broadcasting Services' series titled *Before I Die: Medical Care and Personal Choices* (1997). In addition, a number of films recording decisions about medical surgery decisions surrounding conjoined twins have been released.

The inspirational subgenre documents the trials and tribulations of life as a disabled person, focusing on either the ability of the individual to overcome impairments or the tragic inability to do so. Such films are often created by nondisabled filmmakers and geared to a nondisabled general audience. These films focus on disabled people of notable or extraordinary accomplishments. These accomplishments are often attributed to individual courage and acts of great willpower. Such films include Jessica Yu's *Breathing Lessons: The Life and Work of Mark O'Brian* (1994). O'Brian, a poet and journalist, was an American polio survivor who lived 40 years in an iron lung. Susan Hannah Hadary and William A. Whiteford's *King Gimp* (1999), which documents 13 years in the life of Dan Keplinger, a young American painter with cerebral palsy, can also be included in this subgenre. While such films explore many facets of their subjects' lives—including their work, friendships, family lives, and romantic aspirations—they ultimately tend to cast such issues sentimentally, rather than politically. These works evoke easy emotions of sympathy, pity, tragedy, or triumph by unveiling how their protagonists strive to achieve beyond their presumed incapacities to produce art. In doing so, they portray disability as an individual phenomenon that is divorced from the wider struggles of disability civil rights agendas and often neglect the degree to which class status provides an enabling context for their accomplishments.

Often in direct contrast to the inspirational subgenre, the activist subgenre includes documentaries that explore the social and political dimensions of disabled people's lives and advocate, explicitly or implicitly, for systemic liberatory change. Early activist films, such as the controversial American film *Titicut Follies* (1967) by Frederick Wiseman, documented the abusive treatment of people with disabilities in criminal psychiatric institutions. More recent films continue this theme by exposing past and current atrocities against people with disabilities such as Mat Fraser's *Born Freak* (2002), Snyder and Mitchell's *A World without Bodies* (2002) and *Disability Takes on the Arts* (2004). Furthermore, activist films tend to situate their disabled subjects in community with one another rather than as products of independent genius. The Israeli film *Liebe Perla* (2000) exposes Nazi medical experiments on a short-statured Hungarian family. This history is unvieled as Perla, the only living survivor of this family, is assisted by Hannelore Witkofski (who was born in post-World War II Germany and is also short statured) in finding evidence about her family from Josef Mengele's gruesome "studies." Another example is the French film *Forbidden Maternity* (2002) by Diane Maroger. Maroger documents the transition to independent living of a couple with cerebral palsy, Nathalie and Bertrand. The film explores the couple's efforts to deal with the effects of childhood institutionalization, the lack of liberty available to those under disability guardianship laws, and Nathalie's forced sterilization approved by her mother. In all of these efforts, independent disability documentary filmmakers seek to expose a debilitating history as the source of their collective impediments.

The 1990s to the present day have witnessed an upsurge of activist films by and about people with disabilities. The focus on disability oppression as a human rights issue coincides with the passage of civil rights legislation such as the U.S. Americans with Disabilities Act (1990). These films also participate in the creation and dissemination of disability culture and disability arts. For example, David E. Simpson and Billy Golfus's film, *When Billy Broke His Head . . . And Other Tales of Wonder* (1994), documents Golfus's recovery from a traumatic brain injury. Endless medical and social service bureaucracies seemingly designed to keep people with disabilities a permanent underclass as well as debasing attitudes shared among nondisabled friends and family thwart Golfus's reentry into society. Golfus learns to navigate these obstacles through the discovery of the disability civil rights and culture movements in interviews and friendships with disabled leaders. Other examples include Mitchell and Snyder's documentary, *Vital Signs: Crip Culture Talks Back* (1995), which features leading scholars, artists, and activists with disabilities presenting myriad viewpoints on disability culture, civil rights, and the politics of representation. Whereas the inspirational subgenre often captures one exceptional individual's struggles for acceptance, new disability documentary cinema steers away from more singular tales of disability prowess in order to foreground the shared and sometimes contentious perspectives among those who comprise contemporary disability communities.

Increasingly, there has been a renaissance of disability documentary filmmaking from locations across the globe. Just in the past few years, an explosion of new works in this genre have been released. What characterizes these films as revolutionary is the degree to which they move from introductory lessons in the humanity of disabled people for predominantly nondisabled audiences to nuanced explorations into the intimacies of interdependent lives. Many of these works explore close relationships between disabled people and others, such as Martin Taylor's *Berocca* (UK, 2004), which details the experiences of a father with cerebral palsy with his son in northern England; South African filmmaker Shelley Barry's recent work such as *Whole–A Trinity of Being* (United States, 2004), which features an ode to a woman's tracheostomy site; the Korean documentary film *Turtle Sisters*, which details the efforts of a small group of disabled women trying to set up a viable living situation for themselves; and *The Silent Wedding* (Russia, 2004), which portrays deaf laborers in St. Petersburg making a bell that they will never hear ring. This brief catalog of works suggests the increasingly global scope of disabled people's rights movements seeking to use film as a medium for effecting social change.

—Carrie Sandahl and David T. Mitchell

See also Anthropology; Film; Humanities.

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DOPING IN PARALYMPIC SPORT

Doping is defined as the use of certain prohibited substances and methods intended to enhance and/or having the effect of enhancing athletic performance (as described in the World Anti-Doping Code Prohibited List). Use is considered to have occurred when there is evidence of the application, ingestion, injection, or consumption by any means whatsoever of any prohibited substance or method.

In Paralympic sport, the International Paralympic Committee (IPC) established the IPC Anti-Doping Code, in compliance with the general principles of the World Anti-Doping Code (WADC), to prevent—in the spirit of fair play—doping in sport for athletes with a disability. The code applies to the Paralympic Games and all competitions sanctioned by the IPC and to all sports practiced within the context of the Paralympic movement, including during preparation for competition. All participants (athletes and athlete support personnel) accept these rules as a condition of participation and are presumed to have agreed to comply with the code.

Doping control has been conducted at all Paralympic Games since 1988 and most World Championships organized by the IPC. Since 2004, and the introduction of the WADC, all IPC-sanctioned competitions are required to conduct doping control. In addition, the IPC conducts out-of-competition testing in cooperation with the World Anti-Doping Agency (WADA). In the event of an anti-doping rule violation, sanctions are applied, which include disqualification from competition, forfeiture of all medals, points, and prizes, and ineligibility from competition for a set period depending on the type of anti-doping rule violation and number of violations committed by an athlete.

The WADC Prohibited List is published and revised by the WADA. In recognition that there may be instances where athletes seek to use substances on the Prohibited List for therapeutic purposes, exemptions may be sought from the IPC Therapeutic Use Exemption Committee. Exemption is granted on the basis that an athlete would experience a significant impairment to health if the prohibited substance or method were withdrawn from the course of treatment and the athlete would gain no additional enhancement of performance other than that which might be anticipated by a return to a state of usual health following the treatment of a legitimate medical condition.

Doping control is conducted for two reasons, first, to protect athletes from the potentially harmful effects that some drugs may produce, and second, to ensure fair and ethical competition by preventing athletes from taking drugs in an attempt to increase performance.

—Andy Parkinson

See also Paralympics.

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DORRIS, MICHAEL AND REYNOLD ABEL ("ADAM")

(Michael, 1943–1997; Abel, 1968–1991)

American writer (Michael) and Native American fetal alcohol syndrome victim (Abel)

Michael Dorris was a young unmarried academic when he adopted three-year-old Abel, a Lakota Sioux child with apparent developmental delays. Abel Dorris was eventually diagnosed with the condition now called fetal alcohol syndrome (FAS). Michael Dorris's book about Abel's childhood and diagnosis, *The Broken Cord,* was an award-winning critical success, though its ethical and rhetorical dimensions remain troublesome to many. Abel Dorris died in New Hampshire in 1991, after being struck by a car. Michael Dorris also died in New Hampshire, nearly six years later, in the last of several suicide attempts. Michael Dorris's own struggles with depression, substance abuse, and abusive behavior were widely noted after his death. Michael Dorris's passionate activism toward prevention of FAS, especially among Native Americans, and posthumous revelations about his own mental illness, are perhaps as much a part of his legacy as his several novels and the Native American Studies Program he founded at Dartmouth College.

—Penny L. Richards

See also Fetal Alcohol Syndrome.

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DOWN SYNDROME

Down syndrome is the common name for a genetic anomaly, trisomy-21–nondisjunction of the 21st chromosome during meiosis, resulting in a zygote carrying an extra 21st chromosome. Down syndrome occurs in one out of every 600 to 800 live births, making it by far the most common form of chromosomal nondisjunction in the living human population.

Humans with Down syndrome have existed for at least as long as *Homo sapiens* and its immediate ancestors, but trisomy-21 was not identified until 1866, when British physician John Langdon Down associated it with phenotypical facial features such as epicanthal folds in the eyelids and flattened noses. Since these features can also be found in certain Asiatic populations, Down syndrome was for many decades referred to as "mongolism," and Langdon Down's discovery played a minor part in nineteenth-century debates over the question of evolutionary "polygenesis"—that is, the question of whether humans evolved from different ancestors corresponding to the different human "racial" subgroups (Down himself understood trisomy-21 to be evidence of human monogenesis). The genetic principles behind Down syndrome were not understood for nearly another century; until 1959, when French physician Jerome Lejeune identified the nondisjunction responsible for the syndrome, conventional wisdom held that Down syndrome was caused at some point in fetal development, and some researchers speculated that fetuses with "mongolism" were "throwbacks" to earlier stages of human evolutionary development.

Down syndrome is associated with mental retardation as well as a wide range of systemic health problems, ranging from congenital heart defects to childhood leukemia to a vastly increased risk of Alzheimer's disease in later life. In 1900, the life expectancy for people with Down syndrome was under 10 years, largely because of their increased susceptibility to infection; the discovery of antibiotics helped push the life expectancy beyond 20, and with the advent of open-heart surgery, saving innumerable children who would have died in infancy, the average life expectancy for people with Down syndrome increased to 55. The average quality of life for people with Down syndrome, at least in industrialized nations, has increased more dramatically still. Long considered ineducable "idiots" (when that term was considered to be a diagnosis rather than an insult) incapable of acquiring basic skills regarding speech and reading and therefore best consigned to mental institutions, people with Down syndrome have lately demonstrated significant capacities for learning and expression. It is no longer uncommon to find adolescents and young adults with Down syndrome graduating from high school, or older persons with Down syndrome working and living independently or in assisted-living environments involving other persons with developmental disabilities. At the same time, however, advances in prenatal fetal screening, combined with a widespread sense in the medical profession that "prevention" is superior to palliative care, have led many people to see Down syndrome as a human anomaly that is potentially eradicable, and whose eradication would be an unqualified benefit to the species as a whole. Accordingly, advocates for people with Down syndrome—and many people with Down syndrome themselves—have tended to applaud the social advances that have incorporated people with Down syndrome into the fabric of public life while remaining suspicious of new forms of eugenics that threaten to render those social advances moot.

—Michael Bérubé

See also Aging; Aging, International; Alzheimer's Disease; Community Living and Group Homes; Mental Retardation, History of.

Websites

A comprehensive guide to publications relevant to professionals, researchers, parents, and all persons with an interest in Down syndrome and/or people with Down syndrome, http://www.altonweb.com/cs/downsyndrome/index.htm

DRAMA AND PERFORMANCE

The discussion of disability in drama and performance can include widely varying, even diametrically opposed, types of representation: the literal representation of disability used toward metaphorical ends in canonical drama; plays, solo performances, and community-based theater projects created by disabled artists with disability themes at their core; and performance modalities created with a disability aesthetic in mind.

Drama and performance are vital and powerful parts of disability culture for several reasons. Disabled bodies have been on display in performance at several points throughout history. As sideshow freaks, mendicants, poster children, and medical subjects, disabled people's bodies have been deployed within highly specific kinds of spectacle and put on display in ways heavily circumscribed by the expectations of nondisabled audience members. The pervasive presence of disabled people in traditional dramatic literature is somewhat more complicated; while there are many examples of disabled characters that reinforce stereotypes, there are still other representations that simultaneously represent and resist traditional ways of understanding disability. The work of contemporary playwrights and performers from within disability culture, therefore, has been a powerful way in which the disability community has reclaimed and redefined disability identity in performance. At once influenced by and carrying forward the confrontational spirit of disability activism, these artists have placed the disability experience at the center of their work, claiming the public space of the stage as location to which they have a right of access, and within which they can confront the voyeuristic stare. The disabled performer can no longer be hidden or looked away from; because the stage allows this direct challenge to the traditional relationship between the disabled person and the nondisabled spectator, it is a particularly powerful place for disabled artists to give visibility and voice to the disability experience. Within the space of the theater, the disabled artist can perform the reality of disability, model new ways to imagine the place of disability within contemporary society, and posit disability as a catalyst for artistic creation. This last aspect, reflective of much recent thought, opens the way for disability to be the conduit toward a more general invigoration of theater and performance.

The disabled body has been as consistently on display in Western theater as it has in other literary and artistic genres. For example, Sophocles' play *Oedipus Rex,* William Shakespeare's *Richard III,* Tennessee Williams's *The Glass Menagerie,* and Margaret Edson's *Wit,* although spanning diverse eras and countries, all depend heavily on the presence of disabled bodies to motivate the action and to serve as metaphors. These examples likewise bookend a long dramatic tradition of using both moral and medical models of disability. According to the former model, the disabled body bears moral meaning: It can stand for extremes of evil or innocence, mark a tragic fate or punishment, underscore the mystical or all-knowing sensibilities of a character, embody the outcome of violence or neglect, inspire nondisabled characters to some personal transformation, or symbolize some internal foible or personal failing of a character. The latter model posits disability as a condition that is either cured or heroically overcome at best, and as tragic fate at worst.

The kinds of disability represented throughout theatrical history include a full range of cognitive and physical disabilities, and their depictions are historically contingent. It is important to remember this contingency in fully evaluating the representation of disability in canonical theater; some plays, while bound to the audience expectations of their times, have also been able to challenge simultaneously the moral and medical models of disability. For example, George Henry Boker's *Francesca da Rimini,* while in many ways a typical mid-nineteenth-century American melodrama, critiques the prejudice and pity directed at the humpbacked protagonist, even though he is finally the drama's villain. Plays have shown the intersection between disability and other identity categories; Tony Kushner's *Angels in America,* for example, shows how homophobia and the stigmatization of AIDS patients in 1980s America were intimately interwoven. Indeed, there have been periodic plays within traditional theater that have directly challenged stereotypical ideas about disability and identity, such as Mark Medoff's *Children of a Lesser God.* This does not mean that disability always intersects successfully with theater that purports to challenge social constructions. For example, although disability is a social construction like race and gender, some plays of political protest created by multicultural and feminist playwrights have distanced themselves from the stigma popularly associated with disability, instead using disability metaphorically to illustrate the destructive quality of social oppression. Yet in so doing, such plays reinscribe that oppression as it is enacted against disabled people.

Today, there is a vital and wide-ranging body of drama and performance coming from within disability culture, a tradition that traces its roots to the contemporary disability rights movement. As disability and theater scholar Victoria Ann Lewis (2000) points out, it is a wave of creativity that originated in "the rag-tag comedy troupes, the stand-up (or more accurately, sit-down) comics, the agit-prop collectives, and rowdy performance artists that were the inevitable camp-followers of the political activists and legislators who changed the social reality of disabled Americans" (p. 93). Disability in performance is no more a monolith than disability as an identity category; therefore, to consider disability in contemporary drama and performance is to consider the work of playwrights, community-based theater groups, monologists, performance artists, and dancers with a full range of visible and invisible disabilities. In using the disabled body as a subject of and catalyst for creative expression, these artists have aimed for goals such as creating solidarity through affirming the presence of disability culture, articulating emotions from sharp wit to righteous anger, relating specific experiences with disability, recounting disability history, promoting advocacy and activism, revealing the intersections of disability and other kinds of identity, and interrogating traditional ideas about normalcy and looking.

Among the earliest groups formally to place the disability experience at the heart of their creative endeavors were the National Theatre of the Deaf, established in 1967; the National Theatre Workshop for the Handicapped, begun in 1977 under the direction of Brother Rick Curry; and the Other Voices Project, founded at the Mark Taper Forum in 1982 under Lewis's direction. While representative of diverse performance goals and creative styles, these groups have been joined by others working along similar lines. For example, Wry Crips Disabled Women's Theater (Oakland, California), Actual Lives (Austin, Texas), and the DisAbility Project (St. Louis, Missouri) have created dialogues about disability within their own communities. Many individual playwrights from within disability culture have likewise written plays which address diverse subjects; among the best known of these is John Belluso, whose work includes *Gretty Good Time* and *The Body of Bourne.* Mike Ervin and Susan Nussbaum are likewise playwrights of note who have written about physical disability, while Willy Conley has created plays about Deaf culture. Perhaps the most prolific and multivaried work within disability culture has come from solo performers. Monologists such as David Roche and Mary Duffy have challenged the idea of the stare, and criticized the imposition of a disability identity on themselves that is pathologized or writ tragic. Still other performers have explored the intersection of disability with race; Lynn Manning's *Weights,* for example, recounts his life as a blind African American man. And artists such as Cheryl Marie Wade have lyrically portrayed disability pride in bodily difference. Building on that last element, dance artists such as Catherine Cole and dance companies including AXIS have used the movement of the disabled body as a means of expression that invites audiences to see disabilities, in the words of disability and theater scholar Carrie Sandahl, as "states of being that are in themselves *generative* and, once de-stigmatized, allow us to envision an enormous range of human variety—in terms of bodily, spatial, and social configurations" (p. 22).

That final point marks cutting-edge thinking in disability drama and performance, as artists and scholars currently explore the idea of a disability aesthetic that would lead to a more broad re-envisioning of theater; after all, as Sandahl observes, "just as the disabled body challenges widely held beliefs about what constitutes the human form, disability theatre poses similar challenges to the form that theatre itself takes." Deaf/West Theater, for example, mounted its production of the musical *Big River* on Broadway in 2003, in which it integrated American Sign Language completely into the visual landscape of the performance itself. In playing with different configurations of signers and speakers, and of Deaf and hearing actors, the production not only disrupted the hierarchical relationship between speaking and signing extant in society, but it created a kind of choreography for the musical in which actors' bodies—whether Deaf or not—expressed in new ways. This and other uses of a "disability aesthetic" in contemporary direction, playwriting, and performance of all kinds posit the possibility that through a disability perspective, a more general broadening of our culture's understanding of representation and performance might be accomplished. In this way, performance—and ideally, the society that it reflects—would be thus reinvigorated by disabled people claiming their rightful place on the stage.

—Ann M. Fox

See also Aesthetics; Dance; Disability Culture; Representations of Disability, History of.

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▣ DRUG ABUSE

See Substance Abuse

▣ DU PRÉ, JACQUELINE (1945–1987)

English musician

Jacqueline du Pré was born in Oxford, United Kingdom, on January 26, 1945, and died October 19, 1987, at age 42 She was diagnosed with multiple sclerosis (MS) in 1973.

Du Pré has been called the world's greatest cello player. At the height of her popularity, she worked with Sir John Barbirolli and the London Symphony Orchestra, Itzhak Perlman, Zubin Mehta, Pinchas Zuckerman, and Daniel Barenboim. Many music critics consider her interpretation of Elgar's *Cello Concerto in E Minor* to be the finest ever recorded. In 1967, she married Daniel Barenboim and in the glamour world of the 1960s, the couple achieved rock star iconic status. But her MS caused her much anxiety and grief. Her marriage with Barenboim collapsed as her condition deteriorated. In the public image, she was the ultimate beautiful disabled heroine touched by tragedy.

The film *Hilary & Jackie* is based on the book *A Genius in the Family* by du Pré's sister Hilary and her brother Piers. In the book, her decline into "madness" is chronicled, but people familiar with MS will instantly recognize the exhaustion, ambivalence toward work and career, depression, strange and numbing bodily sensations, lack of coordination, and incontinence. Thus, her life did have many tragic elements—the degeneration of her body confronted her continually with the loss of the powerful person she saw herself as being. Her life became a series of struggles in trying to retain her power, and as each element was eroded, she sought some other way to affirm herself. She was not a victim of MS but a passionate musician battling her impairments. These personal battles are as important for our understanding of disability as those more publicly known because they reveal her individual encounters with the realities of disabling societies—issues that received much less attention during her lifetime.

—Helen Meekosha

See also Multiple Sclerosis.

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▣ DÜRER, ALBRECHT (1471–1528)

German artist

Albrecht Dürer, born on May 21, 1471, was the third of 18 children born to Albrecht Dürer, a goldsmith who had moved to Nuremberg, Germany, from the

Kingdom of Hungary, and Barbara Holfer, the daughter of Albrecht Dürer the Elder's master. Albrecht Dürer the Younger became a highly celebrated artist in Germany and many of the contemporary German humanists were his friends. To demonstrate their respect, the Germans chose Dürer as the first artist to have a public monument erected in his name and the first artist to have his home and tomb restored. Over the centuries he also became internationally known, especially throughout Europe, in the United States, and in Russia.

During his education and training, Albrecht Dürer learned a number of skills that later became highly valuable to him. After attending a Nuremberg school for a few years, at the age of 13 he went into an apprenticeship with his goldsmith father. Later he completed an apprenticeship with Michael Wolgemut where he learned to design landscape backgrounds, panel painting, and the craft of woodcut illustrations.

Throughout his life, Dürer had significant contact to individuals with health problems and with disabilities. First, it is noteworthy that most of his siblings did not survive beyond the first few years of life. Second, his brother Albert suffered from severe arthritis after having worked in a mine for four years to support Albrecht's training and education. In honor of his brother Albert, who had forfeited his own dreams of becoming an artist to support Albrecht, Dürer painted *The Hands,* which later was renamed as *The Praying Hands.* Third, after his father's death, Dürer became the caregiver for his disabled and blind mother.

—Ingrid C. Hofmann

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DWARFISM

Dwarfism is a rare phenomenon that nevertheless seems to have occurred in every recorded human society, as evidenced by images and records from ancient Egypt, Greece, and Rome; Renaissance and Baroque Europe; the nineteenth-century freak show; and contemporary cinema. The role, status, and cultural representation of dwarfs have varied: While many have traditionally been employed as jesters, pages, or entertainers, others have been successful soldiers, diplomats, or even rulers. In the modern world, self-help groups or representative organizations tend to favor terms such as *restricted growth* (United Kingdom) or *little people* (United States) or *short stature* (Australia), rather than the word *dwarf.*

From a medical perspective, there are at least 200 separate forms of skeletal dysplasia, and short stature can also be a consequence of other syndromes. The most common cause of disproportionate short stature is achondroplasia, a dominant genetic condition involving a mutation in the FGFR3 gene that leads to the characteristic short arms and legs and different skull shape. Restricted growth affects approximately 1 in every 20,000 births, with around 60 percent occurring in average-height families. While rare forms of skeletal dysplasia are fatal, and in most others there can be medical complications such as sleep apnea and spinal stenosis, people with skeletal dysplasia do not usually experience intellectual impairment, shortened lifespans, or major health problems.

The growth of support groups and improving social acceptance has meant that most people with restricted growth now lead normal lives and achieve the same social goals as average-height people. For example, members of this community have worked as doctors, lawyers, politicians, businesspeople, academics, and teachers and in many other occupations. While the world is not configured well for people who average just over 4 feet, most environments can be negotiated independently.

Public fascination is perhaps the most debilitating problem for people with restricted growth. While making fun of other minorities is proscribed, laughter at the expense of dwarfs seems to remain socially acceptable. Traditional images of dwarfs—including the paintings of Velasquez and the Brother Grimm stories—are more dignified than the infantilized characters portrayed in Walt Disney's *Snow White and the Seven Dwarfs* and subsequent pantomimes.

Perhaps because of cultural devaluation, extensive limb lengthening (ELL) has been attractive to some families affected by skeletal dysplasia. Orthopedic surgeons can achieve increases of around 6 inches in height, using metal fixators on the legs, and sometimes the arms. The procedure is painful and expensive and immobilizes the patient for months or years during early adolescence. Controversy surrounds the practice, which is denounced by many adults with restricted growth. Human growth hormone (HGH) has also been prescribed to some affected children. While it brings on the growth spurt and changes the growth curve, there is doubt as to whether it contributes to any increase in adult height. Genetic screening is not viable for such a rare condition, and antenatal ultrasound rarely detects skeletal dysplasia in utero until the third trimester of pregnancy, which is too late for selective abortion in many jurisdictions. For these reasons, dwarfism will remain part of the human experience, and the emphasis should be on acceptance and inclusion.

—Tom Shakespeare

See also Folk Belief; History of Disability: Medieval West; Visibility and Invisibility.

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Restricted Growth Association (UK), http://www.rgaonline.org.uk/

DYBWAD, GUNNAR (1909–2001)

American (German-born) author and civil rights advocate

Gunnar Dybwad was born in Leipzig, Germany, on July 12, 1909, and received his doctor of laws degree in 1934 from the University of Halle in Germany. He also earned a degree from the New York School of Social Work in 1940. His career in special education and human services spanned eight decades. During that time, he was made a fellow in several prestigious professional organizations including the American Association on Mental Retardation, the American Sociological Association, the American Orthopsychiatric Association, and the American Public Health Association. He was also an honorary fellow in the American Academy of Pediatrics.

Dybwad published several books and monographs in the field of mental retardation. In addition, his work has been published in more than 20 journals including the *Journal of Rehabilitation*, *CHILDREN*, *International Rehabilitation Review*, *Policy Studies Review*, *Journal of Rehabilitation in Asia*, and *International Journal of Religious Education*.

He was executive director of the National Association for Retarded Children from 1957 to 1964, served as a consultant to President John F. Kennedy's Presidential Panel on Mental Retardation, and was an expert witness in several landmark court cases in educational rights and institutional abuse, including *Mills v. Board of Education* and *Wyatt v. Stickney*.

He and his wife Rosemary were instrumental in the formation of the International League of Societies for Persons with Mental Handicap, which later became Inclusion International. He was president of Inclusion International from 1978 to 1982.

Dybwad was twice recognized with honorary doctorates: first a doctor of humane letters from Temple University in 1977 and then doctor of public services from the University of Maryland.

Dybwad's academic career included professor of human development at Brandeis University from 1967 to 1974, visiting professor at Syracuse University, and visiting scholar at the Canadian Institute on Mental Retardation.

Dybwad was at the center of the development of thoughts that are now taken for granted: normalization, deinstitutionalization, inclusive schooling, self-advocacy, and self-determination. Considered by many to be the grandfather of the self-advocacy movement, Dybwad worked in support of self-advocacy literally until his death September 13, 2001, at age 92.

—Hank Bersani Jr.

See also Advocacy; Rosemary F. Dybwad.

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DYBWAD, ROSEMARY F.

(1910–1992)

American author and civil rights advocate

Rosemary F. Dybwad was born on May 12, 1910, in the town of Howe, Indiana. The daughter of a missionary, she spent her teen years in Manila, Philippines. She spent her college years in Oxford, Ohio, at Western College for Women where friendships with international students led her to apply for a fellowship with the Institute of International Education.

She was a graduate student in sociology at the University of Leipzig from 1931 to 1933. During those years, she met Gunnar Dybwad and in 1934 they were wed and returned to the United States briefly. In 1935, she entered the University of Hamburg, receiving her doctorate in 1936. In 1939, she gave birth to their son, Peter, and 1941 their daughter, Susan. She was as proud of her accomplishments as a mother as she was of her work as a scholar and an advocate.

When her husband became director of the National Association for Retarded Children in 1957, Rosemary volunteered to assist with the voluminous international correspondence as similar parent groups were forming all across the globe. She began an international newsletter and became a driving force in the establishment of the International League of Societies for Persons with Mental Handicap.

In 1964, Rosemary and Gunnar became codirectors on an international mental retardation project in Geneva, which took them as consultants to some 30 countries. Upon returning to the United States, she began publishing an international directory of mental retardation resources. The third and final edition was published in 1989.

In her later years, she was a tireless advocate, supporter of self-advocates, and social change agent, spending time on picket lines, in demonstrations, and writing and speaking in support of self-advocates and in opposition to segregation.

Rosemary F. Dybwad died of cancer in 1992. Her memory lives on in the Rosemary F. Dybwad International Fellowship Trust Inc., which supports international travel for scholars and self-advocates.

—Hank Bersani Jr.

See also Gunnar Dybwad.

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DYSARTHRIA

Dysarthria is primarily a medical term. It is used to describe speech that is difficult to produce and/or difficult to understand as the result of lesions or damage to the nerves that send messages to the muscles involved in speech production. This includes the muscles for articulation or pronunciation (such as lips, tongue, jaw) as well as the muscles controlling nasality, phonation, and respiration. The muscles may be weak, be uncoordinated, move slowly, or not move at all. People with dysarthria may also have difficulty swallowing.

People may be born with dysarthria (such as individuals with cerebral palsy or muscular dystrophy). It may also result from a stroke, brain injury, tumor, infection, or a progressive neuromotor disease, such as Lou Gehrig’s disease (amyotrophic lateral sclerosis; ALS), multiple sclerosis, or Parkinson’s disease.

Dysarthria can be characterized in many different ways depending on the extent and location of the lesion. It may be localized, affecting only one muscle or muscle group (such as only respiration) or it may be generalized affecting many components, respiration, nasality, and phonation as well as articulation. People with dysarthria may experience limited lip, tongue, and jaw movement, slurred speech, slow speech or rapid mumbled speech, soft or inaudible speech, breathiness, hoarseness, and drooling.

People with dysarthria (primarily adults with cerebral palsy) report that they are often mistaken for "retarded" or deaf. If someone is unable to understand them, they may walk away, talk loudly, or talk to others about them.

Some people with dysarthria choose therapy to learn compensatory strategies for improving swallowing, improving the functionality, intelligibility of their speech or to learn augmentative, alternative methods of communication. To improve the functionality, intelligibility of their speech, someone may learn to talk slower and more deliberately. Also, communication partners may learn listening strategies (e.g., choose a quiet place, let the person know what part of the message you understood and parts you need clarified). Some people choose to use communication aids. If someone has difficulty producing adequate volume for speech, he or she may benefit from a speech amplifier. To clarify speech, people may learn to use letter or word boards to introduce the topic they want to talk about and/or to point to the initial letter of each word they say as they speak. People unable to produce speech may also consider an electronic augmentative communication device with voice output so that they can communicate on the phone and talk to unfamiliar people.

—Patricia A. Politano

See also Augmentative Communication; Cerebellar Ataxia; Dysphagia; Speech and Language Pathology; Stroke.

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DYSLEXIA

Dyslexia is characterized by an unexpected difficulty in reading in children and adults who otherwise possess the intelligence, motivation, and schooling considered necessary for learning to read. Dyslexia is the common and most comprehensively studied of the learning disabilities (LD). The prevalence of dyslexia is now considered to range between 5 to 10 percent of the school-age population.

The cardinal signs of dyslexia observed in school-age children are an inaccurate and labored approach to decoding and reading words either in isolation or in text. For example, when asked to read aloud, most children with dyslexia display a labored approach to decoding ("sounding out") unfamiliar words. This laborious and slow approach to reading words makes it difficult to understand what is read. This is because the more time spent in reading words the less time can be dedicated to remembering what is read. Typically, in contrast to the difficulties experienced in decoding single words, individuals with dyslexia have adequate vocabulary and listening comprehension abilities. Indeed, one sign of dyslexia is that the individual who has difficulty comprehending what is read because of labored reading can understand the same material when it is read aloud by another person. Parents of dyslexics frequently report that although their child enjoys the opportunity to be read to, reading aloud to the parent or reading independently is resisted.

In contrast to conventional wisdom, individuals with dyslexia do not see letters and words "backwards." The letter reversals that are observed in some children below age six or seven reflect normal variations in development. Persistent difficulties reading words and text, with or without letter reversals, are caused primarily by circumscribed language difficulties rather than deficits in visual perception. Rather, dyslexics have difficulties developing an understanding that words, both spoken and written, can be segmented into smaller elements of sound. This ability is termed *phonemic awareness* and is an essential ability given that reading an alphabetic language (i.e., English) requires that the reader map or link printed symbols to sound.

Children at risk for dyslexia can be identified as early as five years of age. Kindergarten assessments that measure awareness of phonemes and other language skills, such as rhyming ability and the rapid naming of letters and numbers, are highly predictive of later reading difficulties. Family history is also important in the diagnosis of dyslexia. Approximately half the children with a parent with dyslexia will also have reading difficulties. However, the specific mechanisms by which genetic factors predispose someone to dyslexia are not clear.

Effective intervention programs for school-age children with dyslexia provide direct, explicit, and systematic instruction in phonemic awareness, phonics, reading fluency, vocabulary, and reading comprehension strategies and ample opportunities for writing and reading. The teacher's knowledge and experience in assessing and treating dyslexia are critical.

The treatment of dyslexia in students in high school, college, and graduate school is typically based on accommodation rather than remediation. College students with a childhood history of dyslexia frequently require extra time in reading and writing assignments as well as examinations. Other accommodations include the use of laptop computers with spelling checkers, tape recorders in the classroom, access to lecture notes, tutorial services, alternatives to multiple-choice tests, and a separate and quiet room for taking tests.

—G. Reid Lyon

See also Educational Assistive Technology; Learning Disability.

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DYSPHAGIA

Dysphagia, or difficulty swallowing, is a common condition with many etiologies, including stroke, neurological disorders, and cancer. Dysphagia may cause malnutrition, weight loss, dehydration, airway obstruction, or aspiration pneumonia, resulting in potentially serious morbidity or mortality. Dysphagia due to oral or pharyngeal dysfunction is often amenable to rehabilitation and is the focus of this discussion.

Swallowing requires activity of 31 muscles and 6 cranial nerves and must be coordinated with breathing, speaking, and mastication. For descriptive purposes, the process of swallowing is commonly divided into four phases: oral preparatory, oral propulsive, pharyngeal, and esophageal. The oral preparatory phase includes mastication and oral food transport. In the oral propulsive phase, the tongue squeezes the food against the palate, pushing it through the faucial pillars into the oropharynx. In the pharyngeal phase, the bolus is transported to the esophagus during a rapid sequence of events that includes tongue base retraction, soft palate elevation, pharyngeal constriction, hyolaryngeal elevation, laryngeal closure, and opening of the upper esophageal sphincter (UES). During the esophageal phase, the bolus is transported downward by a peristaltic wave; the lower esophageal sphincter relaxes, allowing the bolus to enter the stomach.

Clinical evaluation of swallowing requires a comprehensive history and physical examination that includes assessment of cognition, voice, speech, cranial nerves, oral sensory and motor function, respiration, and trial swallows. If esophageal dysphagia is suspected, a routine barium swallow or endoscopy is generally indicated. The videofluorographic swallowing study or VFSS (also known as the modified barium swallow) is the "gold standard" for assessment of oral/pharyngeal dysphagia. This study is typically performed jointly by a physician (usually a radiologist or a physiatrist) and a speech-language pathologist. The purpose of the VFSS is to evaluate the structure and function of the oral cavity and pharynx. If aspiration is noted, compensatory maneuvers to reduce or eliminate aspiration are tested empirically during the VFSS, to determine the circumstances for safe and efficient swallowing. Fiberoptic endoscopic evaluation of swallowing (FEES) is often used to assess swallowing when VFSS is not feasible. Although it is a sensitive method for detecting aspiration, the FEES is less useful than VFSS because it omits assessment of critical aspects of the swallow (e.g., tongue base retraction, opening of the UES).

Rehabilitation of swallowing disorders aims at eliminating aspiration, improving oral intake so it is safe and adequate to maintain hydration and nutrition, and improving sensory and motor function to optimize the strength and speed of the swallow mechanism. Therapeutic exercises may address deficits in flexibility, strength, and coordination of oral, pharyngeal, and laryngeal structures. Compensatory maneuvers such as alterations in head position, respiration, or food consistency may eliminate aspiration and improve swallow efficiency. Designing the rehabilitation program requires understanding the underlying cause of the dysphagia and its unique manifestations in the individual with dysphagia.

—Jeffrey B. Palmer and Judy Haynos

See also Neurological Impairments and Nervous Disorders; Stroke.

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CHRONOLOGY

1500 BCE Egypt: The Ebers Papyrus, a medical textbook, devotes an entire chapter to eye diseases. It also shows that deafness is well understood and that clinical knowledge has developed.

400 BCE Graeco-Anatolian Hippocratic writings coin the word e*pilepsy* for a convulsive condition they view as a disease rather than a possession or punishment. Today, it is estimated that more than 80 percent of the 40 million people who currently have epilepsy throughout the world have little access or no access to contemporary treatments.

300 BCE China: *The Yellow Emperor's Internal Classic* is the first text to outline acupuncture. Ordinances on emergency relief for the disabled date to the Han Dynasty, 206 BCE–AD 220. Fiscal and administrative disability classification date at least to the Tang Dynasty, 618–907.

1250–1350 High point of medieval medicalization during which theoretical explanations for conditions gain currency in Western Europe. Prior to this time, in the most general of terms, lay explanations held more sway, ranging from the superstitious to the spiritual to the vindictive. With the founding of the universities, medical theory, typified by the four humors, became more influential in governmental, legal, and elite social circles. Disabling conditions like epilepsy, strokes, and paralyses, as well as psychiatric conditions, increasingly fell under the social control of doctors.

1400 Turkey: Deaf people work in the Ottoman Court from the 15th to the 20th centuries. Sign language becomes a recognized means of communication among both hearing and deaf courtiers.

1593 England: The origins of disability as a social and political category emerge with the first state disability benefits being enacted by Parliament for those disabled in war.

1593 Europe and the United States: English Parliament initiates Europe's first national system of benefits for rank-and-file disabled veterans. The first veterans' homes—France's Hôtel des Invalides, Britain's Chelsea Hospital, and Frederick the Great's Invalidenhaus in Berlin—are established in 1633, 1685, and 1748, respectively. Following the American Civil War, the U.S. government responds with a system of homes, preferences in government hiring, land grants, free prosthetics, and pensions for disabled veterans (however, southern veterans were limited to usually scanty state pensions).

1601 England: The Poor Law is passed to provide family and community support for those unable to make a living for themselves.

1604 Laws on witchcraft in the colonies all evolve from a 1604 English Statute that makes "being a witch" punishable by death. During outbreaks of witch-hunting, the "different" body itself is targeted as a sign and symptom of one's confederation with demonic forces.

1697 England: The first English workhouse for people with mental and physical disabilities is established in Bristol in 1697.

1704 Bethlem Hospital in the United States has 130 residents housing the "furiously mad."

1714 Canada: The Bishop of Quebec opens the first building in Canada exclusively for the confinement of mentally disturbed individuals. It is adjacent to Quebec General Hospital.

1749 France and England: Denis Diderot pens one of the most influential treatises on the blind and education in his *Letter on the Blind* in which he argues that the blind can be educated. In 1784, Valentin Haüy opens the first school for the blind in Paris. He perfects a system of raised *letters* to enable the blind to read. In 1828, Louis Braille modifies a raised *dot* system invented by Charles Barbier, which is used today by blind persons to read and communicate. In 1847, William Moon, an Englishman, develops an embossed script based on Roman capitals that blind adults can learn to read in a few days. It is the first reading system for the blind to be widely adopted across the world, but because it is costly to print, the Braille system, which can be produced by blind individuals for themselves, overtakes Moon's system.

1755 France, the United States, and Germany: The Abbé Charles-Michel de l'Épée establishes the first state-supported school for the training of young deaf children, where he teaches sign language. The school serves as an inspiration for the establishment of other European schools and has a dramatic impact on social attitudes toward the deaf. In 1817, Thomas Gallaudet and Laurent Clerc establish the Asylum for the Deaf (now American School for the Deaf) in Hartford, Connecticut. Clerc imports the French sign system, which influences the makeup of contemporary American Sign Language (ASL). In 1778, Samuel Heinicke establishes a school in Leipzig, Germany, where the "oral method" is used.

1800 France: Victor of Aveyron, a "feral child" found in southern France, is brought to Paris. Jean Marc Gaspard Itard, a French physician, develops a systematic training program for the boy and works intensively with him for five years. Itard considered his attempt at educating Victor to be a failure because the boy did not learn to use a language. Nevertheless, Itard's disciples, including Edouard Séguin, Maria Montessori, and Alfred Binet, continue his work by establishing classes for children considered to be "mentally retarded."

1802 France: The world's first pediatric hospital, L'Hôpital des Enfants Malades, is founded.

1817 The American School for the Deaf is founded in Hartford, Connecticut. It is the first school for disabled children in the Western Hemisphere.

1817 James Parkinson, a London physician, describes what is to become known as Parkinson's disease.

1817 Thomas Gallaudet and Laurent Clerc open the American Asylum for the Education of the Deaf and Dumb in Hartford, Connecticut.

1828 Frenchman Louis Braille, blind from childhood, modifies a raised-dot system of code, one of the most important advances in blind education. It not only allows the blind to read at a much faster rate but also makes it possible for the blind to be teachers of the blind. UNESCO creates the World Braille Council in 1952.

1829 France: Louis Braille publishes an explanation of his embossed dot code.

1832 Samuel Gridley Howe is chosen to direct what is later to be called the Perkins School for the Blind in Boston. It becomes the model for schools around the nation. Laura Bridgman and Helen Keller attend Perkins. In 1837, Ohio establishes the first state-sponsored school for the blind.

1834 England: The English Poor Law Amendment stipulates five categories of those unable to work: children, the sick, the insane, defectives, and the aged and infirm. This sets the stage for the development of specialty institutions that isolate the disabled from the community.

1841 P. T. Barnum purchases Scudder's American Museum in New York City. This moment is considered to be the beginning of the "Golden Age" of freaks, which persists until the 1940s. The tension

between freaks and disability rights comes to a head in 1984, when disability rights activist Barbara Baskin successfully lobbies the New York State Fair to remove Sutton's Incredible Wonders of the World Sideshow, featuring a limbless man who performs as the "Frog Boy," from the midway.

1843 Due to the influence of Dorothea Dix, an American social reformer, the Massachusetts legislature allocates funds to greatly expand the State Mental Hospital at Worcester. Dix also plays an instrumental role in the creation of 32 mental hospitals and becomes nationally known for her reform efforts. By the late 1840s, Dix focuses on developing a national plan that addresses the treatment of people with mental illness.

1846 William Thomas Green Morton discovers anesthesia and in 1867 Joseph Lister provides a model for antisepsis. These new technologies play a central role in the future of aesthetic surgery as well as surgical intervention for every type of disability that calls for it. Penicillin is discovered in 1929, cutting mortality rates in hospitals dramatically.

1848 The North Carolina School for the Deaf begins the first publication for Deaf persons with its school newspaper, *The Deaf Mute.* First published in 1907, the *Matilda Ziegler Magazine for the Blind* is an ongoing Braille publication.

1848 Samuel Gridley Howe founds the first residential institution for people with mental retardation at the Perkins Institution in Boston.

1851 In the United States there are 77 residential institutions for children, 1,151 by 1910, and 1,613 by 1933. By the 1950s and 1960s, family members and politicians throughout Western Europe, Canada, and the United States push for the deinstitutionalization of people with disabilities.

1851 The first International Sanitary Conference is held in Paris, France, with 12 countries participating. It leads to the World Health Organization, the WHO, which formally comes into existence in 1948.

1857 Edward Miner Gallaudet, youngest son of Thomas Hopkins Gallaudet, establishes the Columbian Institution for the Instruction of the Deaf, Dumb, and Blind, located in Washington D.C. Its college division, eventually known as the National Deaf-Mute College, is the world's first institution of higher education for deaf people. Abraham Lincoln signs its charter on April 8, 1864; today it is known as Gallaudet University.

1857 English philosopher Herbert Spencer is first to use the expression "survival of the fittest." The application of his idea in combination with Charles Darwin's theories in his 1859 book, *The Origin of the Species,* is called Social Darwinism. It is widely accepted and promoted in Germany in the 1920s and leads Adolf Hitler to express prejudice against the weak, sick, and disabled.

1863 Louis Agassiz, a significant American naturalist, advocates the permanence of different races and worries about the "tenacious influences of physical disability" if races were mixed.

1864 Germany: Karl Ferdinand Klein, teacher for deaf-mutes, and Heinrich Ernst Stotzner are considered the founding fathers of the *training school,* which calls for schools to be created for less-capable children with the goal of improving their lot. Training schools remain in effect today, but critics maintain that there is an over-representation of socially and economically underprivileged students in this type of setting experiencing little academic success.

1868 Sweden: The Stockholm Deaf Club is the first recorded organization of people with disabilities.

1870 England and Wales: Education for children with disabilities begins when universal elementary education is first introduced around this time. From 1895 onward, schools for "defective" children spring up. In 1899, Alfred Eichholz, an inspector of special education, draws up key recommendations, which leave their mark on the historic 1994 Education Act legislation. In 1978, the Warnock report

introduces the term *special needs education,* which soon gains acceptance worldwide. With the 1994 UNESCO Salamanca Statement and Framework for Action on Special Needs Education, a major shift in organizing educational services for children with disabilities is confirmed internationally.

1876 ◆ Isaac Newton Kerlin, Edouard Séguin, and others establish the Association of Medical Officers of American Institutions for the Idiotic and Feeble-Minded Persons. Today, it is known as the American Association on Mental Retardation. Séguin, who staunchly believes in the educability of those with significant cognitive disabilities, is styled as "apostle to the idiots," by Pope Pius X, reflecting the attitude of the time.

1880 ◆ The United States National Association of the Deaf (NAD), the first organization of deaf or disabled people in the Western Hemisphere, is established. In 1964, the Registry of Interpreters for the Deaf (RID) is formed to establish a national body of professionals who are trained and certified to enable communication between deaf, signing persons and nondeaf, speaking persons.

1880 ◆ Helen Keller is born in Tuscumbia, Alabama. An illness at the age of 19 months leaves her totally deaf and blind. In 1887, Anne Sullivan, recently graduated from Perkins Institution for the Blind, joins the Keller household as Helen's teacher and remains Keller's companion for nearly 50 years. For many, Keller's story is the quintessential overcoming narrative.

1881 ◆ The Chicago City Council enacts the first American "ugly law" forbidding "any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself to public view."

1882 ◆ The first major federal immigration law in the United States, the Immigration Act of 1882, prohibits entry to "lunatics," "idiots," and persons likely to become unable to take care of themselves. Most of the restrictions that apply specifically to disability are removed from U.S. law in 1990. Today, disabled immigrants are still denied an entry visa if they are deemed "likely to become a public charge."

1887 ◆ Walter Fernald serves as superintendent of the Massachusetts School for the Feeble-Minded (now known as the Fernald Center) from 1887 to 1924. Unlike most of his colleagues, Fernald moderates some of his earlier extreme views and eventually develops one of the country's largest "parole" systems for moving institutional residents back into smaller, community-based residences.

1887 ◆ The American Orthopaedic Association is founded. German and British counterparts are founded in 1901 and 1918, respectively.

1895 ◆ The chiropractic profession is founded. This type of care is used to relieve musculoskeletal pain, one of the most common causes of disability.

1899 ◆ Maria Montessori and a colleague open the Scuola Magistrale Ortofrenica in Rome, an educational institute for disabled children and a training institute for instructors. Her method relies on the concept of sensory-based instruction as a means for developing intellectual competence. Her methods allow the child the greatest possible independence in order to foster his or her own development (the child's own inner "building plan").

1904 ◆ Sir Francis Galton, half first cousin of Charles Darwin, defines the term e*ugenics* (which he coined in 1883) in a paper he presents to the Sociological Society on May 16. He argues for planned breeding among the "best stock" of the human population, along with various methods to discourage or prevent breeding among the "worst stock." Galton also develops the idea for intelligence tests. The term *feeblemindedness* is defined as broadly as possible and is widely used by eugenic social reformers to conflate myriad social problems. Further naming, classification, and labeling provides eugenicists with a troubling rationale for treating people with coercion, disrespect, and profound inhumanity. Persons within the various categories of sub-normality become particularly vulnerable

to state-sanctioned segregation, institutional confinement, and enforced sterilization. Eugenics is widely practiced in Europe, the United States, and Canada, culminating in the systemic murder of more than 260,000 disabled people by the Nazis between 1939 and 1945. Today, the so-called new eugenics, known as "human genetics," appeals to the needs of the individual. Critics (some of the first in Germany), however, criticize individualistic eugenic approaches and disclose the connections between human genetics, national socialist racial hygiene, and eugenics.

1905 Alfred Binet and Theodore Simon publish the first intelligence scale, known as the Binet-Simon Test.

1908 The publication of Clifford Beers's *A Mind That Found Itself* initiates the mental health hygiene movement in the United States. Speaking out against mistreatment and neglect within the system, Beers establishes the Connecticut Committee of Mental Hygiene, which expands in 1909, becoming the National Committee for Mental Hygiene and is now known as the National Mental Health Association. In 1940 there are 419,000 patients in 181 state hospitals. In 1943, the patient-doctor ratio is 277:1, and by the mid-1950s in New York state alone, there are 93,000 inpatients. The Bazelon Center for Mental Health Law, founded in 1972 by a group of committed lawyers and professionals in mental health and mental retardation, attempt to improve mental health service provision through individual and class action suits. In 1980, a group of these lawyers form the National Association of Rights Protection and Advocacy (NARPA). One-third of its board of directors must identify themselves as current or former recipients of mental health care. The association is committed to the abolishment of all forced treatment.

1908 Pastor Ernst Jakob Christoffel establishes a home in Turkey for blind and otherwise disabled and orphaned children. This grows into Christoffel-Blindenmission (CBM), an independent aid organization of Christians of various denominations united to help disabled people in third world countries. Today, it supports more than 1,000 development projects in 108 countries. In 1999, CBM, other agencies, and the World Health Organization initiate VISION 2020: The Right to Sight, a global initiative for the elimination of avoidable blindness by the year 2020.

1909 Germany: The German Organization for the Care of Cripples is created as an umbrella organization for the care of the physically disabled. The Prussian Cripples' Care Law of 1920 for the first time provides a right to medical care and scholarly and occupational education for this group.

1912 Henry H. Goddard publishes *The Kadikak Family,* supports the beliefs of the eugenics movements, and helps create a climate of hysteria in which human rights abuse of the disabled, including institutionalization and forced sterilization, increases. In 1927, the U.S. Supreme Court, in *Buck v. Bell,* rules in favor of forced sterilization of people with disabilities, further fueling eugenics movements—the number of sterilizations increases.

1914 By this date, Sigmund Freud develops his most enduring influence on the study of disability, namely, the theory of psychosomatic illness in which a psychopathological flaw is given corporeal form as a symptom, thereby establishing the notion that people succumb to disease or disability because they feel guilty about past or present repressed desires.

1918 The Smith-Sears Veterans Rehabilitation Act passes, authorizing VR services for World War I veterans. In 1916, the National Defense Act marks the beginning of the U.S. government's supportive attitude toward rehabilitation. In 1920, the Smith-Fess Act marks the beginnings of the civilian VR program. The Social Security Act of 1935 establishes state-federal VR as a permanent program that can be discontinued only by an act of Congress.

1919 Edgar "Daddy" Allen establishes what becomes known as the National Society for Crippled Children. In the spring of 1934, the organizational launches its first Easter "seals" money-making campaign. Donors place seals on envelopes containing their contributions. The seal is so well-known that it

becomes part of the organization's official name. Today, Easter Seals assists more than one million children and adults with disabilities and their families annually through a nationwide network of more than 500 service sites. During the 1920s, Franklin D. Roosevelt inspires the March of Dimes.

1920 At about this time, the Shriners open hospitals for the care of crippled children. President Herbert Hoover establishes a "Children's Charter" in 1928 highlighting the need to attend to the needs of crippled children.

1921 Franklin D. Roosevelt contracts poliomyelitis. Despite damage to his legs (which makes him a wheelchair user) and deep depression, through enormous rehabilitative effort, he eventually re-enters politics and becomes president of the United States. His triumph over personal disability becomes legendary. Critics, however, fault him for choosing to minimize his disability in what is called his "splendid deception." He establishes a center for the treatment of polio patients in Warm Springs, Georgia, called the Georgia Warm Springs Foundation (1927), which hires medical specialists from Atlanta to direct orthopedics. In 1937, President Roosevelt becomes the prime mover behind the National Foundation for Infantile Paralysis Research.

1921 Mary L. McMillan (Molly) establishes the American Women's Physical Therapeutic Association, which is known today as the American Physical Therapy Association (APTA).

1921 The American Foundation for the Blind is established.

1921 Canada: Researchers isolate the hormone insulin. In 1922, Frederick Banting, Charles Best, J. B. Collip, and J.R.R. Macleod produce and test the pancreatic extract on people with diabetes, for which they are awarded a Nobel Prize. Insulin becomes a wonderful treatment for diabetes, but not a cure.

1921 France: Three historical waves of advocacy movements can be identified beginning with the National Federation of Injured Workers (FNAT) in 1921 and other organizations that focus essentially on the protection of rights. Another factor that stimulates advocacy groups in the first wave is the wounded veterans of World Wars I and II. A second wave dates from the period after World War II. Many advocacy groups form between 1950 and 1970, such as the Union of Associations of Parents of Maladjusted Children (UNAPEI) in 1960. A third wave finds a gradual emergence of three types of associations: those that run specialized facilities (for example, Living Upright, which, in 1970, leads to the creation of the first group living facility); those interested in trade unions; and those represented by user-advocate associations. Financing comes in large part from public funds, thereby creating a government-association partnership.

1922 The founding of Rehabilitation International sets the stage for the establishment of other international organizations of and for people with disabilities that link together throughout the world. Later international organizations include, among numerous others, the World Federation of the Deaf (1951), Inclusion International (1962), the International Association for the Scientific Study of Intellectual Disability (1964), Disabled Peoples' International (1981), and the International Disability Alliance (1999).

1925 The American Speech-Language-Hearing Association, today the American Academy of Speech Correction, is established to provide high-quality services for professionals in speech-language pathology, audiology, and speech and hearing science, and to advocate for people with communication disabilities.

1928 Charles Nicolle is the first deaf person to be awarded a Nobel Prize.

1929 Seeing Eye establishes the first dog guide school in the United States.

1930 The Veterans Administration is created to administer benefits, promote vocational rehabilitation, and return disabled veterans to civil employment. There is a record of provision for disabled veterans in the United States since the Revolutionary War and the Civil War. After World War I, three agencies administer veteran's benefits.

1932 ◆ Herbert A. Everest, a mining engineer with a disability, and Harry C. Jennings collaborate to design and patent the cross-frame wheelchair, which becomes the standard for the wheelchair industry that exists today. Developed during World War I, the first powered wheelchair appears, but doesn't gain popularity for another 30 years.

1935 ◆ President Franklin D. Roosevelt signs the Social Security Act of 1935 on August 14. Beginning in 1956, SSA amendments provide disability benefits.

1935 ◆ By 1935, in the United States more than 30 states pass laws allowing for the compulsory sterilization of those deemed genetically unfit in state and federal institutions. By 1970, more than 60,000 people are sterilized under these laws.

1935 ◆ As a result of being denied participation in the Works Progress Administration (WPA), six young people with disabilities hold a sit-in at the offices of New York City's Emergency Relief Bureau, demanding jobs in non-segregated environments and explicitly rejecting charity. The League of the Physically Handicapped is born out of this activism and operates in New York from 1935 to 1938. The League identifies social problems that remain issues today.

1935 ◆ Peer support in the United States is traced to the establishment of Alcoholics Anonymous in this year. Interest in peer support increases in the 1960s and is adopted by the disabled community. Movements, such as the Center for Independent Living, and groups, such as the National Spinal Cord Injury Association, make peer support one of their major activities.

1936 ◆ The American Academy of Physical Medicine & Rehabilitation is founded, leading to the approval of the American Board of Physical Medicine & Rehabilitation by the American Medical Association in 1947.

1937 ◆ The Fair Housing Act of 1937 passes with a mandate to assist the poor, a group that includes people with disabilities, by creating public housing. However, it is not until the Rehabilitation Act of 1973 that housing law specifically deals with discrimination faced by individuals with disabilities in housing programs that receive federal funding. The 1988 amendment to the Fair Housing Act of 1968 extends protection for people with disabilities beyond those of Section 504 of the Rehabilitation Act to include private housing.

1939 ◆ The Nazi regime institutes the Aktion T4 program in Germany. Children and, later, adults with disabilities are selectively killed both in hospitals and in special centers. The program was officially terminated by Adolf Hitler in August 1941, but practitioners "informally" continued it through a phase historians have called "wild euthanasia."

1940 ◆ State activists for the blind, including Jacobus Broek, come together in Wilkes-Barre, Pennsylvania, to charter the National Federation of the Blind (NFB). In 1957, the NFB publishes the first edition of the *Braille Monitor,* which is still in print today. In 1960, dissatisfied NFB members form the American Council of the Blind (ACB).

1940 ◆ Paul Strachan establishes the American Federation of the Physically Handicapped, the nation's first cross-disability, national political organization.

1942 ◆ The American Psychiatric Association develops a position statement in favor of the euthanasia of children classified as *idiots* and *imbeciles.*

1943 ◆ The LaFollette-Barden Act, also known as the Vocational Rehabilitation Amendments, adds physical rehabilitation to federally funded vocational rehabilitation programs.

1943 ◆ The United Nations is established on October 24 by 51 countries. The global Programme on the Disability is the lead program concerning disability. Many other types of programs, activities, and instruments include the 1975 Declaration on the Rights of Disabled Persons, the 1981 International Year of

Disabled Persons, the 1982 World Programme of Action Concerning Disabled Persons, the 1983–1992 UN Decade of Disabled Persons, and the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In 1988, the first UN Disability Database (DISTAT) publishes statistics from 63 national studies covering 55 countries and the 2001 publication presents 111 national studies from 78 countries, indicating a growing interest worldwide for the collection of usable data. In 2005, a UN Ad Hoc Committee continues to consider a Convention on the Rights of Disabled Persons that is a legally binding human rights instrument. Today the UN membership totals 191 countries.

1943 ◆ Sweden: In possibly the first reference to the concept of normalization, the most significant driving force in the ongoing closure of state-run or state-funded institutions for people with a disability is made by the Committee for the Partially Able-Bodied, established by the Swedish Government. Through the advocacy of people such as Niels Erik Bank-Mikkelsen, normalization, with its profound positive effect on the lives of people who were once removed and segregated from society, remains relevant today.

1944 ◆ Richard Hoover invents long white canes known as Hoover canes that are used by many blind people.

1944 ◆ The word *genocide* first appears in a book by a Polish lawyer Raphael Lemkin titled *Axis Rule in Occupied Europe* in which he describes Nazi Germany's practices but also seeks the adoption of legal restrictions so that genocide will not occur. In 1948, the United Nations adopts a declaration and then a convention on genocide that describe both against whom genocide might be directed and acts constituting genocide. Article 6 of the Rome Statute of the International Criminal Court (ICC), established in 2002, uses language identical to that in the UN convention to define genocide. More than 90 countries are parties to the ICC, but not the United States.

1945 ◆ President Harry Truman signs into law an annual National Employ the Handicapped Week. In 1952, it becomes the Presidents' Committee on Employment of the Physically Handicapped, a permanent organization, which reports to the President and Congress.

1945 ◆ Canada: Lyndhurst Lodge, the first specialized rehabilitation center for spinal cord injury (SCI) in the world, and the Canadian Paraplegic Association, the first association in the world administered by individuals with SCI, are established.

1946 ◆ The first chapter of what will become the United Cerebral Palsy Association, Inc. is established in New York City. It is chartered in 1949, and along with the Association for Retarded Children, it becomes a major force in the parents' movement of the 1950s.

1946 ◆ The National Mental Health Foundation is founded by attendants at state mental institutions who aim to expose abusive conditions. Their work is an early step toward deinstitutionalization.

1946 ◆ The National Institutes of Mental Health (NIMH) are founded in the United States.

1946 ◆ Europe: The European Union is founded on September 17 in Paris. It consistently shows its commitment to eliminating discrimination on many fronts through joint declarations, resolutions, directives, and action programs. With regard to disability, the European Union supports actions in favor of people with disabilities, principally in the form of European Social Fund interventions. Action programs aim at facilitating the exchange of information between member states and nongovernmental organizations with a view to identifying good practices, integrating people with disabilities into society, and raising awareness of related issues. The EU Council of Ministers Recommendation on the Employment of Disabled People (1986) calls on member states to "eliminate negative discrimination by reviewing laws, regulations and administrative provisions to ensure that they are not contrary to the principle of fair opportunity for disabled people." Further

steps are taken in 1996 when a communication on equality of opportunities for disabled people sets out a new European disability strategy that promotes a rights-based approach, rather than a welfare-type approach. This is strengthened in 1997 when the heads of state act to strengthen Article 13 of the European Community Charter of Fundamental Social Rights of Workers (1989), giving the European Community specific powers to take action to combat a broad spectrum of discrimination that includes disability.

1948 ◆ The National Paraplegia Foundation is established as the civilian branch of the Paralyzed Veterans of America.

1948 ◆ The World Health Organization is established. The WHO actively promotes human rights and the principle of equity in health among all people of the world, including persons with disabilities. Today it consists of 191 member states, but strives for universal membership. In 1980, the WHO publishes the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and issues a revised version in 2001, the International Classification of Functioning, Disability, and Health (ICF).

1948 ◆ The United Nations General Assembly adopts the "Universal Declaration of Human Rights," which promotes and affirms the fundamental rights to life, liberty, and security; to medical care and social services; and to the benefit from scientific progress and its uses.

1948 ◆ Sir Ludwig Guttmann organizes the first Stoke Mandeville (England) Games for the Paralysed, thus launching the Paralympic movement. The Games become international in 1952. In 1960, the first Paralympic Summer games are held in Rome and the first Paralympic Winter Games follow in 1976. The Paralympic Games are multi-disability, multi-sport competitions and have become the second-largest sporting event in the world, only after the Olympic Games.

1948 ◆ World War II bomber pilot and war hero Leonard Cheshire establishes what is to become the largest charitable supplier of services for disabled people in the United Kingdom. In the 1960s, the resistance of disabled people who live in one Leonard Cheshire home, Le Court, plays a major role in establishing the British disabled people's movement. In the late 1990s, the Leonard Cheshire organization establishes the Disabled People's Forum, which is run by disabled people and supports disabled people's involvement and empowerment.

1949 ◆ Timothy Nugent founds the National Wheelchair Basketball Association, and the first Annual Wheelchair Basketball Tournament takes place.

1949 ◆ Europe: The Council of Europe, an intergovernmental organization, is founded. Its activities cover all major issues facing European society other than defense. Human dignity, equal opportunities, independent living, and active participation in the life of the community form the heart of the Council of Europe's activities in relation to people with disabilities. The European Social Charter of 1961 and its revision in 1996 include specific wording and expand the rights of individuals with disabilities.

1950 ◆ The Social Security Amendments of 1950 provide federal-state aid to the permanently and totally disabled (APTD), which serves as a limited prototype for future Social Security assistance programs for disabled people.

1950 ◆ The National Mental Health Association is formed with the mission to continue 1908-advocate Clifford W. Beers's goals of "spreading tolerance and awareness, improving mental health services, preventing mental illness, and promoting mental health."

1950 ◆ The National Association for Retarded Children (NARC) is established by families in Minneapolis. It is the first and most powerful parent-driven human-services lobby in the nation to emerge in the 1950s.

1950 Amniocentesis is developed by a Uruguayan obstetrician. Later, advanced prenatal testing provides a battery of powerful medical tools to predict risk of disability and provide information to parents about their pregnancies.

1951 With the founding of the World Federation of the Deaf, the deaf community becomes international.

1953 Francis Crick and James Watson propose a three-dimensional structure for the DNA molecule. The paper they publish also gives clues to genetic mechanisms. Today, more than 6,000 monogenic disorders have been identified, and these affect approximately 1 in 200 live births.

1955 The polio vaccine, developed by Dr. Jonas Salk, becomes available, thus ending polio epidemics in the Western world. A new oral vaccine, developed by Dr. Albert B. Sabin, is approved for use in 1961.

1956 Social Security Disability Insurance (SSDI) becomes available through amendments to the Social Security Act of 1935 (SSA) for those aged 50–64. Other important amendments to SSA include the following: 1958: provides for dependents of disabled workers; 1960: removes age limit; 1965: Medicare and Medicaid provide benefits within the framework of the SSA (until 1977); 1967: provides benefits to widows and widowers over the age of 50; 1972: Supplemental Security Income (SSI) establishes a needs-based program for the aged, blind, and disabled; 1984: the Social Security Disability Reform Act responds to the complaints of hundreds of thousands of people whose disability benefits have been terminated; 1996: President Clinton signs the Personal Responsibility and Work Opportunity Reconciliation Act, making it more difficult for children to qualify as disabled for SSI purposes.

1959 The UN Declaration of the Rights of the Child is adopted; the UN Convention on the Rights of the Child is adopted in 1989. A central principle of both documents is access to education for all children including those with disabilities. In 1993, a related UN document, the Standard Rules for the Equalization of Opportunity, extends this to preschool children, and in 1994, UNESCO's Salamanca Statement and Framework for Action specifies the provision of special education for children with disabilities or learning difficulties. These documents constitute a universal bill of rights that can serve as a framework in the development of national policies worldwide.

1961 The American Council of the Blind is established.

1961 Europe: The European Social Charter (ESC) protects "the right of physically and mentally disabled persons to vocational training, rehabilitation and social resettlement." In 1996, it is revised, updated, and expanded to take account of social changes.

1961 Michel Foucault's work *The History of Madness in the Classical Age* becomes obligatory reading for those concerned with the archaeology of madness and its treatments. It continues to be an academic *rite de passage.*

1962 Battered child syndrome is defined. Researchers estimate that the incidence of maltreatment of children with disabilities is between 1.7 and 3.4 times greater than of children without disabilities.

1962 Russia: The Moscow Theater of Mime and Gesture is the first professional deaf theater in the world. It has been in continuous operation for more than 40 years and has staged more than 100 classic and modern plays.

1963 Congress enacts new legislation to ensure funding for a comprehensive program of research on mental retardation through the National Institute on Child Health & Human Development. In 1965, the Office of Economic Opportunity launches the Elementary and Secondary Education Act (ESEA), commonly known as Project Head Start. The goal is to prevent developmental disability by providing increased opportunities for disadvantaged children in the preschool years.

1963 The Developmentally Disabled Assistance and Bill of Rights Act (DD ACT) is authorized, with its last reauthorization in 1996. It focuses on individuals with developmental disabilities such as intellectual disability, autism, cerebral palsy, epilepsy, and hearing and visual impairments, among others.

1964 The Civil Rights Act is passed. It becomes the model for future disability rights legislation.

1964 France: L'Arche is established. By the beginning of the twentieth-first century, it includes more than 113 communities in 30 countries. "The Ark" is a distinctive style of community living, based on "core members" and "assistants," who view their commitment as sharing life *with* people with disabilities, rather than as caregivers.

1965 Newly enacted Medicare and Medicaid provide national health insurance for both elderly (over 65) and disabled persons.

1965 The Vocational Rehabilitation Amendments of 1965 are passed. They provide federal funds for the construction of rehabilitation centers and create the National Commission on Architectural Barriers to Rehabilitation of the Handicapped.

1965 The Autism Society of America is founded.

1967 Deaf actors establish the National Theatre of the Deaf (NTD). It is the world's first professional deaf theater company and the oldest continually producing touring theater company in the United States. Today, after almost 40 years, the NTD chronicles over 6,000 performances. The National Theatre Workshop for the Handicapped begins in 1977 and the Other Voices Project in 1982. These groups are among the earliest groups formally to place the disability experience at the heart of their creative endeavors.

1967 Heart transplantation is introduced. This technology is preceded by open-heart surgery developed in the 1950s and coronary bypass and internal pacemakers in the1960s. The Framingham Heart Study begins in 1948. It collects data over the next decades that help identify major risk factors contributors to heart disease.

1967 Paul Lemoine in France in 1967 and Kenneth Jones and David Smith in the United States in 1973 independently describe the condition fetal alcohol syndrome (FAS), which comprises a recognizable pattern of birth defects attributable to the adverse effects of maternal alcohol abuse during pregnancy.

1967 England: St. Christopher's Hospice in South London opens. It is the first attempt to develop a modern approach to hospice and palliative care.

1968 Congress enacts the Architectural Barriers Act. The ABA requires access to facilities designed, built, altered, or leased with federal funds.

1968 The Fair Housing Amendments to the Civil Rights Act of 1968 guarantees civil rights of people with disabilities in the residential setting. The amendments extend coverage of the fair housing laws to people with disabilities and establish accessible design and construction standards for all new multifamily housing built for first occupancy on or after March 13, 1991.

1968 Sweden: The origins of People First® go back to a meeting of parents of children with intellectual disabilities whose motto is "we speak for them." However, the people with disabilities in attendance wish to speak for themselves and start their own self-advocacy group. Similar groups quickly spread to England and Canada. The name People First is chosen at a conference held in Salem, Oregon, in 1974. People First is an international self-advocacy organization run by and for people with intellectual disabilities to work on civil and human rights issues.

1970 ◆ Landmark legal cases such as *Diana v. State Board of Education* (1970; Latino students) and *Larry P. v. Riles* (1971–1979; minority students) challenge biases inherent in standardized testing procedures used to identify students as eligible for special education. Both cases call into question the widespread use of "scientifically" objective measures to gauge intellectual ability. Today, despite reforms, a disproportionate number of students from racial, ethnic, and linguistic minorities continue to be placed in special education classes.

1970 ◆ Japan: The Disabled Persons' Fundamental Law (DPFL) becomes one of the 27 fundamental laws that stipulate basic principles in each policy area. Major revision takes place in 1993 reflecting a progress of guiding principles in disability policy that are deeply influenced by international movements such as the International Year of Disabled Persons (1981) and the UN Decade of Disabled Persons (1983–1992). Disability Studies as well as modern disability movements are born this same year, when members of Aoi Shiba, a group of people with cerebral palsy, protest publicly for the first time against sympathetic views toward the killing of disabled children by their parents. Aoi Shiba and other disability movements join in the establishment of Disabled Peoples' International in 1981. In 1986, the Rehabilitation Engineering Society of Japan (RESJA) is established. In 1992, disability movements in Japan initiate the Asian and Pacific Decade of Disabled Persons 1993 to 2002. The Japan Society for Disability Studies is established in 2003 and a unified national organization, Japan Disability Forum (JDF), is established in 2004.

1970 ◆ United Kingdom: The Chronically Sick and Disabled Persons Act (CSDPA) strengthens the provisions in the 1948 National Assistance Act (NAA). Later, the Disability Discrimination Acts of 1995 and 2005, together with the Disability Rights Commission Act of 1999, constitute the primary source of antidiscrimination legislation for disabled people.

1971 ◆ A U.S. District Court decision in *Wyatt v. Stickney* is the first important victory in the fight for deinstitutionalization.

1971 ◆ WGBH Public Television establishes the Caption Center, which provides captioned programming for deaf viewers.

1971 ◆ Gerontologist M. Powell Lawton defines *functional assessment* as any systematic attempt to objectively measure the level at which a person is functioning in a variety of domains. Over 30 years later, functional assessment, in combination with *outcomes analysis,* is considered one of the "basic sciences" of rehabilitation. In 1980, the World Health Organization proposes a series of definitions, which have a profound impact on the assessment of functional status and outcomes in rehabilitation. It is modified and revised in 1993 and 2001.

1971 ◆ The Declaration on the Rights of Mentally Retarded Persons (UN 1971), the Declaration on the Rights of Disabled Persons (UN 1975), and the World Programme of Action Concerning Disabled Persons (UN 1982) indicate the emergence of a global discourse of rights for disability.

1972 ◆ A group of people with disabilities (including Ed Roberts, John Hessler, and Hale Zukas), known as the Rolling Quads, living together in Berkeley, California, formally incorporate as the Center for Independent Living (CIL). This first CIL in the country becomes the model for Title VII of the Rehabilitation Act of 1973. In the late 1980s and early 1990s the group's advocacy efforts help pass the Americans with Disabilities Act (ADA). CILs are always controlled by disabled people. Accepted by most people as the birth of the modern independent living movement, the Berkeley concept migrates to other countries. In 1999, a global summit on independent living is held in Washington D.C. The summit brings together more than 70 countries. The Washington Declaration that comes out of the conference establishes a set of basic principles. In 1996, the Ed Roberts Campus, an international center and a service facility, is created in Berkeley, California, in memory of Edward V. Roberts, founder of the independent living concept.

1972 A young television reporter for the ABC network, Geraldo Rivera, is given a key to one of the wards at Willowbrook State School on Staten Island, New York. Established in the late 1930s as a state-of-the-art facility for the “mentally deficient,” by 1972, Willowbrook becomes a warehouse for the “socially undesirable” of New York City, with a substantial minority having no disability at all. The inhumane conditions deteriorate to the extent that a visitor remarks, “In Denmark we don’t let our cattle live this way.” Rivera’s exposé leads to a lawsuit that results in the Willowbrook Consent Decree of 1975, which creates a detailed system of monitoring and oversight of all residents living there at that time, to be met until the last of the “class clients,” as they are sometimes referred to, pass on. The property has since been sold to a college.

1972 Paul Hunt’s call for a consumer group to promote the views of actual and potential residents of institutional homes for the disabled in the United Kingdom results in the establishment of the Union of the Physically Impaired against Segregation (UPIAS). The group’s aim is to formulate and publicize plans for alternative forms of support in the community. Hunt is regarded by many disability activists as the founder of the modern disabled people’s movement.

1972 New Zealand: Three key pieces of legislation pass have long-term effects on the disabled community: the 1972 no-fault Accident Compensation Act that provides monetary compensation to victims based on level of impairment suffered; the 1975 Disabled Persons Community Welfare Act, giving assistance to disabled people, parents, and guardians, as well as voluntary associations; and the Human Rights Act of 1977, which does not include disability as a recognized grounds for discrimination. Today, disabled populations in New Zealand continue to fight to establish an identity as disabled people rather than a group needing “welfare.” One task is to promote legislation that includes disability as a group against whom discrimination is outlawed.

1973 The Rehabilitation Act of 1973 lays the foundation for the disability rights movement. Its Section 504 asserts that people with disabilities have equal rights that prevent discrimination based on their disability in programs or activities that receive federal funding. This is the first major nationwide antidiscriminatory legislation designed to protect disabled Americans. These rights are further protected with the landmark Americans with Disabilities Act (ADA) of 1990.

Section 501 of the Act requires affirmative action and nondiscrimination in employment by federal agencies of the executive branch. Section 502 creates the Access Board, which grows out of the 1965 National Commission on Architectural Barriers to Rehabilitation of the Handicapped. As a result of the commission’s June 1968 report, Congress enacts the Architectural Barriers Act (ABA). Section 503 requires that to receive certain government contracts, entities must demonstrate that they are taking affirmative action to employ people with disabilities. The enduring hallmark of the act, Section 504, provides that no otherwise qualified individual with a disability shall, solely by reason of his or her disability, be excluded from the participation in, denied the benefits of, or subjected to discrimination under any program or activity receiving federal funds. However, it would take five years of lobbying and protesting before the American Coalition of Citizens with Disabilities (ACCD) wins the release of regulations that allow Section 504 to be implemented.

The Act is in many ways the direct predecessor to the ADA. However, the primary focus is vocational training and rehabilitation, and over the next half-century, disability law and advocacy move from the medical (medical issues) and vocational (often a justification for welfare and benefits) models to a civil rights model, which seeks to remove the barriers that impede the full integration of people with disabilities into society.

1973 The term *mainstreaming* emerges within the educational jargon associated with the Education for All Handicapped Children Act (EHA), the early U.S. legislation subsequently reauthorized as the Individuals with Disabilities Act (IDEA) in 1990.

1973 Ronald Mace is the driving force behind the creation of the first accessible state building code in the United States (North Carolina, 1974) and in the drafting of national accessibility codes and

standards. He coins the term *universal design* to capture and promote his expanded philosophy of "design for all ages and abilities"—curb cuts being his favorite example.

1973 Washington D.C. introduces the first handicap parking stickers. The Federal-Aid Highway Act funds curb cuts.

1974 First Lady Betty Ford and investigative reporter Rose Kushner are diagnosed with breast cancer. They help break the public silence on this topic. In 1954, Terese Lasser begins Reach to Recovery, a program of volunteers who have previously undergone radical mastectomies who provide emotional support to hospitalized women who have just had the operation. Today, one in eight women is diagnosed with breast cancer during her lifetime.

1975 The Education for All Handicapped Children Act, the first separate federal legislation authorizing special education for children and youth, passes, due, in part, to the advocacy efforts of a group of parents. In 1990, it becomes known as the Individuals with Disabilities Education Act, or IDEA.

1975 The Developmentally Disabled Assistance and Bill of Rights Act, providing federal funds for programs that provide services for people with developmental disabilities, passes.

1975 The Association of Persons with Severe Handicaps (TASH) is founded. It calls for the end of aversive behavior modification and deinstitutionalization of people with disabilities.

1975 The UN General Assembly adopts the Declaration on the Rights of Disabled Persons, which states that all persons with disabilities have the same rights as other people. This document is not legally binding and can be attributed in part to a UN Ad Hoc Committee set up in 2001 to consider a Convention on the Rights of Disabled Persons that is legally binding.

1975 United Kindom: The Union of the Physically Impaired against Segregation (UPIAS) publishes a paper that redefines the term *disability,* which becomes known as the social model of disability as it radically transforms the way disabled people see themselves and their place in society.

1976 The Higher Education Act of 1965, which establishes grants for student support services aimed at fostering an institutional climate supportive of low-income and first-generation college students, is amended to include individuals with disabilities. In March 1978, the Association on Handicapped Student Service Programs in Post-Secondary Education is founded. It later becomes the Association on Higher Education and Disability (AHEAD).

1976 Sponsored by Ralph Nader's Center for the Study of Responsive Law, the Disability Rights Center is founded in Washington D.C.

1977 Protesting the federal government's delayed enactment of the rules and regulations for the implementation of the Rehabilitation Act of 1973, disabled activists on April 1 organize protests at the federal offices of the Department of Health and Human Services in various cities across the United States. In San Francisco, protesters hold the regional offices hostage for 28 days, gaining national attention and resulting in an agreement with federal officials for the rapid establishment of the rules and regulations to implement Section 504 of the Act.

1977 Max Cleland is appointed to head the U.S. Veterans Administration. He is the first severely disabled person to hold this post.

1977 S. Z. Nagi defines *disability* as an individual's performance of tasks and activities related to achievement of social roles—a distinct concept, different from *impairment*. It is further formalized with the introduction of the World Health Organization's International Classification of Impairments, Disabilities, and Handicaps in 1980 and further refined in 2001 in its International

Classification of Functioning, Disability, and Health. Nagi's model is used as the basis for the Americans with Disabilities Act, for almost all disability social policy in the United States, and for statistics at the United Nations and in Europe.

1978 ◆ The Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 and the Adoption Assistance and Child Welfare Act of 1980 promote the adoption of children with special needs, including disabilities.

1978 ◆ The Atlantis Community, the second independent living center in the country after Berkeley, is established in Denver, Colorado, in 1975. On July 5–6, 1978, twenty disabled activists from the Atlantis Community block buses with their wheelchairs and bodies and bring traffic to a standstill at a busy downtown intersection. This act of civil disobedience results in the American Disabled for Accessible Public Transit, the original name for the American Disabled for Attendant Programs Today, or ADAPT.

1978 ◆ Legislation creates the National Institute on Handicapped Research. In 1986, it is renamed the U.S. National Institute on Disability and Rehabilitation Research (NIDRR). Its mission is to contribute to the independence of persons of all ages who have disabilities. It is located in the Department of Education under the Office of Special Education and Rehabilitation Services.

1978 ◆ The World Health Organization starts to promote the concept of community-based rehabilitation (CBR) as a means of helping people with disabilities in the developing world. It emerges, in part, from the WHO primary health care campaign Health for All by the Year 2000. Around the same time, in Western countries, home-visiting programs in which a trained worker regularly visits the family to advise on ways of promoting child development become one of the success stories of modern disability services. Among the best-known programs are those based on a model originating in Portage, Wisconsin, and now used in many countries.

1978 ◆ England: The Warnock report introduces the term *special needs education.* It marks a major shift in organizing educational services for children with disabilities and results in the new conceptualization of special needs education. This change is confirmed internationally by the Salamanca Statement and Framework for Action on Special Needs Education at the UNESCO's Conference held in Salamanca in 1994. This theoretical shift is marked with the change of the term *integration* to *inclusion* or *inclusive education.*

1978 ◆ USSR: The Action Group to Defend the Rights of the Disabled is established to advocate for legal rights for Soviets with disabilities.

1979 ◆ The Disability Rights Education and Defense Fund (DREDF) establishes itself as a leading cross-disability civil rights law and policy center. It is founded by people with disabilities and parents of children with disabilities. Because its philosophy is closely aligned with other civil rights struggles, in 1981, DREDF is invited to join the executive committee of the national's largest coalition of civil rights groups, the Leadership Conference on Civil Rights. In 1987, DREDF establishes the Disability Rights Clinical Legal Education Program and begins teaching disability rights law at the University of California's Boalt Hall School of Law.

1979 ◆ The National Alliance for the Mentally Ill (NAMI) is founded. NAMI is an advocacy and education organization.

1979 ◆ Germany: The first Cripples' Group is founded as a cross-disability group with emancipatory aims. In an attempt to reinterpret disability in positive terms, the cofounders choose the term *Krüppel* over handicapped or disabled.

1979 ◆ Nicaragua: The Organization of the Revolutionary Disabled is set up in the wake of the Sandinista victory.

1980 ◆ The California Governor's Committee on Employment of People with Disabilities and entertainment and media industry professionals establish the Media Access Office (MAO).

1980 ◆ About the time Congress is considering passage of the ADA (1990), marketers begin to acknowledge the economic potential of the disabled community; consequently, the appearance of disabled characters in consumer goods advertising mushroom and ability-integrated advertising becomes much more commonplace. Organizations such as MAO and NOD (National Organization on Disability) provide advertising strategies and guidance.

1980 ◆ The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), an interdisciplinary association composed of individuals interested in technology and disability, is founded.

1980 ◆ The World Health Organization's International Classification of Impairments, Disabilities, and Handicaps (ICIDH), a groundbreaking, but controversial, classification system is tentatively released for trial purposes with the goal of uniform information collection worldwide. It has a negligible impact on disability statistics or data collection; however, researchers argue that it is a vast improvement over available tools. It is renamed and vastly revised in 2001.

1980 ◆ England: Graeae Theatre Group, composed of disabled actors, directors, and other theater professionals, is founded in London by Nabil Shaban and Richard Tomlinson. It takes its name from the the Graeae of Greek mythology, three gray-haired sisters who shared one eye and one tooth. Graeae's first production is *Sideshow*.

1980 ◆ Netherlands: The Liliane Foundation starts by assisting 14 children. In 2002, it helps 31,982 children spread over 80 countries. The Foundation's efforts are directed primarily toward children with disabilities living at home. Its aim is to have direct contact with the child within the home situation and to assist the personal growth and happiness of the child, thus providing "tailor-made" assistance.

1980 ◆ Taiwan: The Physically and Mentally Disabled Citizens Protection Law is promulgated. It guarantees legal rights for the disabled and creates a significant improvement in their welfare. Although most of the disabled people in Taiwan still struggle to earn their due respect, today, public awareness of this group is emerging gradually and significantly.

1980 ◆ United Kingdom and Europe: The Black Report (*Report of the Working Group on Inequalities in Health)* is published. Among other groups it targets disabled people for better conditions that lead to better health. The report does not find favor with the Conservative government, but begins to be implemented under the Labour government in 1997. With its central theme of equity, the report plays a central role in the shaping of the World Health Organization's Common Health Strategy of the European Region.

1981 ◆ The Reagan Administration begins to amend and revoke disability benefits, a policy that continues throughout his administration and leads several disabled people who are in despair over the loss of their benefits to commit suicide.

1981 ◆ Justin Dart, recognized as the founder of the Americans with Disabilities Act (ADA, 1990), is appointed to be vice-chair of the National Council on Disability. The council drafts a national policy on equal rights for disabled people; the document becomes the foundation of the ADA.

1981 ◆ The Committee on Personal Computers and the Handicapped is established in Illinois, an indicator of the disabled community's interest in information technology (IT) accessibility, but in order to stimulate the development of suitable products, activists lobby for legislative protections, which are included in the Americans with Disabilities Act of 1990. In 2000, a suit brought by the National Federation of the Blind against AOL is suspended when AOL agrees to make its software accessible by April 2001. The World Wide Web Accessibility Initiative (WAI) launches in 1997. It raises the level of awareness of disability accessibility issues within the Internet community, especially among those who design and implement web pages.

1981 ◆ The first reported cases of AIDS in the United States appear in June. Today, the World Health Organization estimates that worldwide, approximately 40 million people are living with HIV/AIDS; 22 million men, women, and children have died; and 14,000 new infections are contracted every day. Around the world, in the year 2003, the AIDS epidemic claims an estimated 3 million lives, and almost 5 million people acquire HIV, 700,000 of them children. Currently, 6 million people infected with HIV in the developing world are estimated to need access to antiretroviral therapy to survive, but only 400,000 have this access.

1981 ◆ Disabled Peoples' International (DPI) is officially founded at a meeting in Singapore. The establishment of such international organizations around this time represents the disability movement becoming a global social movement instead of a national one. DPI is directed by persons with disabilities working in human rights advocacy. It sponsors World Assemblies, which are held every four years to develop a multiyear action plan. The most recent one is held in 2002 in Sapporo, Japan, where delegates from more than 100 countries come together. A leading slogan for DPI and other disability groups, coined in the early 1990s, is "nothing about us without us."

1981 ◆ The International Year of Disabled Persons encourages governments to sponsor programs that assimilate people with disabilities into mainstream society. Despite the positive worldwide effects it has, the UN program also creates some angry activists with disabilities who protest against the charity approach officially adopted for the event. Consequently, the activists build their own infrastructure consisting of counseling and advocacy facilities as well as job creation programs.

1981 ◆ Australia: Australia's modern disability policy takes shape after the 1981 International Year of Disabled Persons. Examples: The 1980s see a shift away from institutional care; the Commonwealth Disability Service Act provides a framework for the provision of disability services; and in 1991, the federal Disability Reform Package maximizes the employment of disabled. In 1995, a legal decision represents a watershed in telecommunications policy for people with disabilities when a commission's inquiry finds the national carrier, Telstra, guilty of discrimination against people with severe hearing or speech impairments. The success of the action results in the Telecommunications Act of 1997, which includes new provisions for the deaf community.

1981 ◆ Mexico: The Program of Rehabilitation Organized by Disabled Youth of Western Mexico begins as a rural community-based rehabilitation program.

1981 ◆ Soweto: The Self Help Association of Paraplegics begins as an economic development project.

1981 ◆ United Kingdom: Disabled people set up the British Council of Disabled Persons (BCOPD), the United Kingdom's national organization of disabled people, to promote their full equality and participation in UK society.

1981 ◆ Zimbabwe: The National Council of Disabled Persons, initially registered as a welfare organization, becomes a national disability rights group.

1982 Disability Studies originates with the formation of the Society for the Study of Chronic Illness, Impairment, and Disability. In 1986, it officially changes its name to the Society for Disability Studies (SDS). Disability Studies is a critical field of study based in human and social science.

1982 *In re Infant Doe* (commonly known as the Baby Doe case) launches the debate as to whether parents or medical authorities should choose to let a disabled infant die rather than provide the necessary medical treatment and nourishment essential to sustain life. In response to this and other cases, the U.S. Department of Health and Human Services creates a rule maintaining it unlawful for any federally funded hospital to withhold medical treatment from disabled infants. In 1984, the U.S. Congress enacts the Child Abuse Amendments, which calls for the medical treatment of newborns with disabilities unless the child would die even with medical intervention. The issue makes it to the U.S. Supreme Court in 1986 with the *Bowen v. American Hospital Association* case. The Court holds that denying treatment to disabled infants does not constitute legally protected discrimination under Section 504 of the Rehabilitation Act and that hospitals and physicians are to implement the decision of the parents. The decision results in the passage of the Child Abuse Prevention and Treatment Act Amendments of 1984. In the year 2000, a scholar argues that the Amendments, presidential commission writings, and disability advocates "have all combined to ensure that most babies who can benefit from medical interventions do receive them."

1982 Disability Awareness in Action (DAA) and other groups such as the Disabled Peoples' International (DPI) and International Disability Alliance (IDA) are the driving force behind the globalization of disability issues through the World Program of Action (1982), the United Nations Standard Rules of Equalization of Opportunities for People with Disabilities (1993), the World Summit for Social Development (1995), and the Education for All Framework for Action (2000), as well as the current campaign to secure a UN convention on the rights of disabled people.

1982 The National Council on Independent Living (NCIL) is formed in the United States. It provides an excellent example of leadership for people with disabilities by people with disabilities.

1982 Canada: The Charter of Rights and Freedoms section of the Constitution provides protection to persons with disabilities.

1982 France: Handicap International is founded in Lyon. It is active in various areas associated with all the causes of handicaps, both traumatological (land mines, road accidents) and infectious (polio, leprosy). In the 1990s it begins working on mental disability issues as a result of experience with Romanian orphanages and the war in the Balkans. In 1992, Handicap International creates its first two mine clearance programs and in 1997 it is the joint winner of the Nobel Peace Prize for its leading role in the fight against landmines.

1983 Rights-based approaches to disability rapidly gain currency in many developing countries since the UN Decade of Disabled Persons, 1983–1992. UNESCAP's Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-Based Society for People with Disabilities in Asia and the Pacific sets the priorities for the extended Decade of Disabled Persons, 2003–2012.

1983 Access and accessibility are concepts discussed throughout the World Programme of Action Concerning Disabled Persons passed by the UN General Assembly. The General Assembly in 1993 passes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

1983 England: The first Covent Garden Day of Disabled Artists is held in London.

1983 Thailand: DPI-Thailand is established.

1984 The Access Board issues the "Minimum Guidelines and Requirements for Accessible Design," which today serves as the basis for enforceable design standards. The 1990 Americans with

Disabilities Act (ADA) expands the board's mandate to include developing the accessibility guidelines for facilities and transit vehicles. The Rehabilitation Act Amendments of 1998 give the Access Board additional responsibility for developing accessibility standards for electronic and information technology. In 2001, Section 508 of federal law establishes design standards for federal websites, making them accessible to individuals with disabilities.

1985 ◆ The U.S. Department of Health and Human Services issues the first comprehensive national minority health study, which shows racial disparity in health and concludes that the difference in mortality is not acceptable. In 1998, studies indicate that racial disparity has not improved as much as hoped; consequently, President Bill Clinton launches an initiative that sets a national goal of eliminating disparities in six key areas by the year 2010. Some of these areas include diseases and conditions considered to be disabling as well as life threatening.

1986 ◆ The Air Carrier Access Act (ACAA) passes. It requires the U.S. Department of Transportation to develop new regulations that ensure that disabled people are treated without discrimination in a way consistent with the safe carriage of all passengers. The relevant regulations, Air Carrier Access rules, are published in March 1990.

1986 ◆ The National Council on the Handicapped publishes its report *Toward Independence.* It recommends that "Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities" and suggests that the law be called "the Americans with Disabilities Act." In its 1988 follow-up report, *On the Threshold of Independence,* the council takes the somewhat unusual step of publishing its own draft of the ADA bill.

1986 ◆ The Equal Opportunities for Disabled Americans Act allows recipients of federal disability benefits to retain them even after they obtain work, thus removing a disincentive that keeps disabled people unemployed.

1986 ◆ Australia: The Disability Services Act provides that a person with disability has the right to achieve his or her individual capacity for physical, social, emotional, and intellectual development. In 1992, the Disability Discrimination Act supports nondiscrimination in education and training. It also makes it unlawful to discriminate in relation to access to premises, including public transportation.

1986 ◆ Canada: The Employment Equity Act mandates the institution of positive policies and practices to ensure that persons in designated groups, including persons with disabilities, achieve at least proportionate employment opportunities.

1986 ◆ England: The first issue of the magazine *Disability Arts in London* (DAIL) is produced in London.

1986 ◆ Southern Africa: The Southern Africa Federation of the Disabled is formed as a federation of nongovernmental organizations of disabled persons.

1988 ◆ The Technology Act (Technology-Related Assistance for Individuals with Disabilities Act of 1988 and its 1994 amendments), and, in 1998, the Assistive Technology Act (AT) provide financial assistance to states to support programs of technology-related assistance for individuals with disabilities of all ages. The1988 act defines *assistive technology* (AT). The Americans with Disabilities Act of 1990 prohibits discrimination against people with disabilities in employment, public institutions, commercial facilities, transportation, and telecommunications, which includes accessibility to all entrances, bathrooms, program areas, and parking spaces as well as interpreters for the deaf and Braille and large-print materials for the blind. The Telecommunications Act of 1996 requires the telecommunication industry to make equipment that will support transmission of information in forms accessible to people with disabilities including broadband and television program captioning. By 2000, approximately 10 percent of the U.S. population uses AT devices and/or modifications to their home, work, or school that allow them to participate in major life activities.

1988 ◆ Congress introduces a series of amendments to the Civil Rights Act of 1968, including a prohibition of housing discrimination against people with disabilities. These amendments are known as the Fair Housing Act Amendments of 1988.

1988 ◆ China: Deng Pufang, a wheelchair user and son of the late Chinese leader Deng Xiaoping, is the driving force behind a series of laws and programs initiated to improve life for the disabled. In 1984, he sets up the China Welfare Fund for Disabled Persons and, in 1988, the China Disabled Persons' Federation, which endeavors to improve public images of disabled people. Today, there are 60 million disabled people in China.

1989 ◆ The European Network on Independent Living (ENIL) is set up. It focuses on personal assistance as a key component of independent living.

1990 ◆ ADAPT, the American Disabled for Attendant Programs Today, originally called the American Disabled for Accessible Public Transit, continues to gain public awareness through tactics of civil disobedience until regulations are finally issued with the passage of the Americans with Disabilities Act (ADA).

The ADA passes, after ADAPT uses tactics of civil disobedience, in the tradition of other civil rights movements, in one of the largest disability rights protests to date (600 demonstrators), the "Wheels of Justice March," during which dozens of protesters throw themselves out of their wheelchairs and begin crawling up the 83 marble steps to the Capitol to deliver a scroll of the Declaration of Independence. The following day 150 ADAPT protesters lock wheelchairs together in the Capitol rotunda and engage in a sit-in until police carry them away one by one.

George H.W. Bush signs the ADA on July 26. It provides employment protections for qualifying persons with disability. It is the most prominent and comprehensive law prohibiting discrimination on the basis of disability in the United States, expanding the mandate of Section 504 of the Rehabilitation Act of 1973 to eliminate discrimination by prohibiting discrimination in employment, housing, public accommodations, education, and public services.

In June 2000, the National Council on Disability issues a report, *Promises to Keep: A decade of Federal Enforcement of the Americans with Disabilities Act,* which includes 104 specific recommendations for improvements to the ADA enforcement effort. On December 1, 2004, the council issues a final summary report, *Righting the ADA,* in order to address "a series of negative court decisions [that] is returning [Americans with disabilities] to 'second-class citizen' status that the Americans with Disabilities Act was supposed to remedy forever."

1990 ◆ The ADA requires public entities and businesses to provide effective communication to individuals with disabilities. Title IV of the ADA mandates that nationwide telecommunication systems be accessible to persons with speech or hearing disabilities. The Federal Communications Commission (FCC) requires relay services to be in place by July 26, 1993. The Telecommunications Act of 1996 adds provisions to the Communications Act of 1934 that requires manufactures and providers of telecommunications equipment and services to ensure accessibility to persons with disabilities. In 2000, President Bill Clinton establishes regulations governing the accessibility to people with disabilities of the electronic and information technology used within the federal government.

1990 ◆ The Individuals with Disabilities Education Act (IDEA) is enacted. It guarantees the right to free and appropriate education for children and youth with disabilities and focuses on higher expectations, mainstreaming students where possible, and an increased federal rule in ensuring equal educational opportunity for all students. IDEA requires schools to provide a free and appropriate public education to eligible children with disabilities. It also requires schools to develop an individualized education plan (IEP) for each child and placement in the least restrictive environment (LRE) for their education. IDEA is amended in 1997 and reauthorized again in 2004 as the Individuals with Disabilities Education Improvement Act.

1990 ◆ Legislation establishes the National Center for Medical Rehabilitation Research (NCMRR), whose mission is to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of persons with disabilities. It has primary responsibility for the U.S. Government's medical rehabilitation research that is supported by the National Institutes of Health (NIH).

1990 ◆ The World Declaration on Education for All (EFA) is adopted in Jomtien, Thailand, by more than 1,500 persons representing the international community. Article 23 of the UN Convention on the Rights of the Child states that disabled children have the right to a "full and decent life" and that member nations provide free education and training to disabled children whenever possible in order to provide the "fullest possible social integration and individual development." UNESCO is the lead UN organization for special needs education.

1990 ◆ Korea: The disability movement celebrates the passage of the Employment Promotion Act for People with Disabilities. The government imposes control over the disabled population in the 1960s and 1970s by forwarding institutionalization under the banner of "protection," promoting sterilization, and violating the rights of disabled people in general. The 1981 International Year of Disabled Persons influences the government, and new laws, such as the Welfare Law for Mentally and Physically Handicapped, are enacted, and the human rights of disabled people becomes the dominant rhetoric of the disability movement.

1990 ◆ United Kingdom: The National Disability Arts Forum is launched at the UK-OK Conference at Beaumont College in Lancashire, UK.

1991 ◆ The Resolution on Personal Assistance Services is passed at the International Personal Assistance Symposium. Personal assistance services are the most critical services for individuals. Critical aspects of these services are that they must be available up to 24 hours a day, 7 days a week, to people of all ages, and with access to governmental payments. In the United States alone, personal assistance services affect the lives of more than 9.6 million citizens with disabilities.

1991 ◆ Australia: The federal Disability Reform Package is introduced; the Disability Discrimination Act, which covers issues of discrimination in education, is enacted in 1992; and the Commonwealth Disability Strategy, designed to provide equal access to government services for people with disabilities, is first introduced in 1994 and then revised in 2000. During the 1990s similar discrimination legislation emerges in other countries, such as New Zealand's Human Rights Act, the U.K.'s Disability Discrimination Act, Israel's Disabled Persons Act, Canada's Human Rights Act, and India's Disabled Person's Act.

1991 ◆ China: The most important laws and initiatives reside in the 1991 Law on Protection of Disabled Persons and a series of National Work Programs for Disabled Persons (1988, 1991, 1996, 2001), which integrate disability into the government's Five-Year Plans. China participates heavily in the United Nations Decade of Disabled Persons, 1983–1992, and initiates the Asia Pacific Decade of the Disabled Persons, 1993–2002. China continues to collaborate with UN projects involving the disabled and will host the 2007 International Special Olympics in Shanghai.

1991 ◆ Serbia and Montenegro: From the 1960s to the 1980s, post–World War II Yugoslavia is lauded for being a socially advanced nonaligned nation, but the contemporary wars that decimate Yugoslavia begin in 1991, and today there are more than one million disabled citizens, refugees, and casualties due to the wars. Disabled people in Serbia and Montenegro (formally named the Federal Republic of Yugoslavia—FRY) are left with shattered pieces of the spent past with little hope for the near future. Although the FRY constitution prescribes special protection of disabled persons in accordance with legal provisions and Serbia is party to numerous UN documents and acts, a disabled expert in 2004 admits that discrimination against persons with disability in Serbia and Montenegro is a

long-term problem that people without disability tend to ignore. Two of the most effective advocacy groups making in-roads today are the Association of Students with Disabilities and the Center for Independent Living in Belgrade.

1992 ◆ The UN Economic and Social Commission of Asia and the Pacific (ESCAP) proclaims a 10-year program known as the Asian and Pacific Decade of Disabled Persons 1993–2002 with goals of full participation and equality for persons with disabilities.

1993 ◆ The United Nations publishes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which becomes the international legal standards for disability programs, laws, and policies. Although not legally enforceable this instrument sets an inclusive and antidiscriminatory standard that is used when national policies are developed. It marks a clear shift from the rehabilitation and prevention paradigm to the human rights perspective on disability.

1993 ◆ Slovak Republic: The Czech and Slovak Republics separate into two independent countries. They both join the European Union in 2004. In Slovakia, a large number of highly innovative and resourceful grassroots nongovernmental organizations emerge to address the human rights, quality-of-life, and independent living priorities of citizens with disabilities. They pursue this mission, however, with extremely limited resources and with varying degrees of support from a multiparty parliament.

1993 ◆ Sweden: The Independent Living Institute (ILI) is founded.

1994 ◆ Two networks, one for elderly persons and the other for persons with disabilities, join together to form the U.S. National Coalition on Aging and Disability. In following years, policy makers and advocates begin to see the benefits of merging some services.

1994 ◆ Germany: The disability rights movement is successful in using for its own aims the reform of the German constitution, which is made necessary by the reunification process. An amendment to the constitution forbids discrimination on the grounds of disability. Other such laws as the Rehabilitation of Participation Law (2001) and the Federal Equal Rights Law (2002) are formulated with the active contribution of disability rights activists, and in 2003, the official German program of the European Year of People with Disabilities is organized by a prominent activist.

1994 ◆ Sweden: The Swedish Disability Act (LSS) comes into force. It expands the 1985 Special Services Act. The LSS is also more ambitious than its predecessor, calling for "good living conditions" rather than just an "acceptable standard of living."

1995 ◆ The National Council on Disability, a federal agency, makes recommendations to the president and Congress on disability issues. Among other issues, it calls for the end to the use of aversives (techniques of behavior control such as restraints, isolation, and electric shocks) because they are abusive, dehumanizing, and psychologically and physically dangerous. Other organizations follow, such as the Autism National Committee in 1999, TASH in 2004, and the International Association for the Right to Effective Treatment in 2003.

1995 ◆ The Commission for Case Management Certification (CCMC) incorporates. Case management is a process of care planning and coordination of the services and resources used by people with disabilities and their families.

1995 ◆ Europe: The Association for the Advancement of Assistive Technology in Europe (AAATE) is founded as an interdisciplinary association devoted to increasing awareness, promoting research and development, and facilitating the exchange of information. AAATE is composed of more than 250 members from 19 countries. It interacts with sister organizations in North America, Japan, and Australia to advance assistive technology worldwide. The Tokushima Agreement, signed in 2000 by AAATE, the Rehabilitation Engineering and Assistive Technology Society of North America

(RESNA), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation and Assistive Technology Association (ARATA), promotes exchange of information and collaboration.

1995 ◆ United Kingdom: The campaign for antidiscrimination legislation begins in earnest with the emergence of the disability movement in the late 1970s. The Disability Discrimination Act of 1995 (DDA) together with the Disability Rights Commission Act of 1999 constitute the primary source of antidiscrimination legislation for disabled people in the United Kingdom. The Disability Discrimination Act 2005 extends the protection.

1996 ◆ There are 1.4 million fewer disabled older persons in the United States than would have been expected if the health status of older people had not improved since the early 1980s.

1996 ◆ Advocates for mental health parity such as the National Alliance for the Mentally Ill (NAMI; 1979) believe that mental illnesses are real illnesses and that health insurance and health plan coverage for treatment should be equal with coverage of treatment for all other illnesses. Due in part to advocacy, the Mental Health Parity Act becomes law in 1996. In 1999, mental illness ranks first in causing disabilities among many industrialized nations, including the United States, which experiences a loss of productivity in this year of $63 billion. In the United States, 5 to 7 percent of adults suffer from serious mental disorders and 5 to 9 percent of children suffer from serious emotional disturbances that severely disrupt their social, academic, and emotional functioning.

1996 ◆ Costa Rica: Approval of a law called Equal Opportunities for People with Disabilities is a turning point for the population with disabilities, which is among the most excluded sectors of society. The law is inspired in part by the United Nations Standard Rules on the Equalization of Opportunities for Disabled People (1993). Disability experience in Costa Rica is definitely transformed as a result of the mandates of this generic law, as people with disabilities and their families start to use this legal instrument as a strategy to empower themselves.

1996 ◆ Europe: Created in 1996, the European Disability Forum (EDF) is today the largest independent, trans-European organization that exists to represent disabled people in dialogue with the European Union (EU) and other European authorities. Its mission is to promote equal opportunities for disabled people and to ensure disabled citizens full access to fundamental and human rights through its active involvement in policy development and implementation in the EU. The EDF has national councils in 17 European countries and has 127 member organizations. The European Year of People with Disabilities 2003 is one of the EDF's most important campaigns.

1996 ◆ India: The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, becomes law. It is the first legislation for equal opportunities for disabled people. Prior to this, disabled persons receive services but not legal protection. Improvements in conditions begin in 1981 with the International Year of Disabled Persons. India is a signatory to the UN resolution of 1976 establishing it and is thereby committed to improving the lot of the disabled. The Lunacy Act of 1912 is repealed and the National Mental Health Act is passed in 1987. Nonetheless, with approximately 70 million disabled people residing in India (in a population of over a billion), the government does not include the domain of disability in the 2001 census, which reflects the attitudinal barriers in acknowledging the disabled identity.

1997 ◆ Government expenditures on behalf of persons with disabilities may total as much as $217.3 billion (taking into account the costs that would be expected among persons with disabilities in the absence of the disability), the equivalent of 2.6 percent of the gross domestic product in the United States for 1997.

1997 ◆ The landmark 1997 UNESCO Universal Declaration on the Human Genome and Human Rights frames the actual application of the new scientific developments raised by genetics. As a policy

statement, it provides the first signs that genetics will be applied in ways that maintain human rights. In 2003, the Council of Europe and the council's Steering Committee in Bioethics issue policy statements in a working document titled Application of Genetics for Health Purposes. In the case of gene therapy, in 1994, the Group of Advisors on the Ethical Implications of Biotechnology of the European Commission voices concern regarding equity, maintaining that all genetic services that are available for the entire population should be equally available for persons of disability. Today, UNESCO's Human Genome Organization's Ethics Committee, the World Health Organization, the Council of Europe, and consumer organizations such as Inclusion International, Rehabilitation International, and Disabled Peoples' International play major roles in translating genetic innovations into health service and public health fields, helping develop policies that focus on the general recognition, respect, and protection of the rights to which all people, whether disabled or nondisabled, are entitled. Concerns related to the possible undermining of human rights are expressed in 2003 when Disabled People's International demands a prohibition on compulsory genetic testing.

1997 ◆ Colombia: The General Act for People with Disabilities, also known as the Disability Act: Law for Opportunity, passes. The 2003–2006 National Plan of Attention to Persons with Disabilities estimates that 18 percent of the general population has some type of disability. Despite the existence of at least 37 disability-related legal policies (2001), the government provides limited spending on programs that protect the rights of people with disabilities, and the lack of enforcement of rights remains a major concern. Today's awareness efforts include marathons with the participation of the general population to raise money for educational programs for children with special needs, Special Olympics, new organizations such as the Colombian Association for the Development of People with Disabilities, and media awareness campaigns.

1998 ◆ President Bill Clinton issues an executive order ensuring that the federal government assumes the role of a model employer of adults with disabilities.

1998 ◆ President Clinton signs into law the Rehabilitation Act of 1973 Amendments. Section 508 requires that electronic and information technology (EIT), such as federal websites, telecommunications, software, and information kiosks, must be usable by persons with disabilities.

1998 ◆ Ireland: The Irish Employment Equality Act entitles all individuals, including disabled persons, equal treatment in training and employment opportunities. The Education Act of 1998 requires schools to provide education to students that is appropriate to their abilities and needs. The Education for Persons with Disabilities Bill passes in 2003. A Disability Bill published in 2001 fails to underpin a rights-based approach and is withdrawn amid a storm of protest in 2002; a redrafting of a new Disability Bill is suffering from continuing delays. Traditionally, Irish voluntary organizations play a reactionary role in the development of services for people with disabilities and a key role as pressure groups trying to keep disability issues on the political agenda.

1999 ◆ The National Center on Physical Activity and Disability (NCPAD) is established as an information and resource center that offers people with disabilities, caregivers, and professionals the latest information on fitness, recreation, and sports programs for people with disabilities.

1999 ◆ Established by a panel of experts brought together to evaluate the UN Standard Rules on the Equalization of Opportunities for Persons with Disability, the International Disability Alliance (IDA) encourages cross-disability collaboration and supports the participation of international disability organizations in the elaboration of a proposed UN convention on disability.

1999 ◆ England: The first disability film festival, Lifting the Lid, is held at the Lux Cinema in London.

2000 ◆ The National Telability Media Center collects documentation of 3,000+ newsletters, 200 magazines, 50 newspapers, 40 radio programs, and 40 television programs dedicated to disability in the United States alone. *The Ragged Edge, Mainstream* (Internet-based), and *Mouth* are examples of disability rights-focused publications.

2000 ◆ *Healthy People 2000,* the second edition of the Surgeon General's report on health promotion and disease prevention (the first edition published in 1979), includes some reference to the health and well-being of people with disabilities, but few data are available. In the mid-1990s, the U.S. Department of Health and Human Services begins a dialogue with the Centers for Disease Control and Prevention to include people with disabilities in the third edition, *Healthy People 2010.* The resulting report includes more than 100 objectives that include "people with disabilities" as a subpopulation for data gathering.

2000 ◆ The World Bank, increasingly concerned with how to include disabled persons in the economies and societies of developing nations, establishes an online clearinghouse to make documents concerning the disabled readily available to member nations and the general public and holds its first course on disability issues in 2004 in Guatemala.

2000 ◆ Africa: The African Decade of Persons with Disabilities, 2000–2009, is adopted by the Declaration of the Organization of African Unity. The African Network of Women with Disabilities (2001) and the community-based rehabilitation organization CBR Africa Network (CAN) are examples of the many activities that result from the African Decade.

2000 ◆ Brazil is one of the few countries to include an entire section on disability in its 2000 census. Results show that 14.5 percent of the population, roughly 24 million people, report having some form of disability, the poorest region, the northeast, reporting the highest percentage and the richest, in the south, the lowest. People with disabilities in the first half of the twentieth century have no voice or representation. In 1932, the first Pestalozzi Society, a community-based school for children with intellectual disabilities, is founded. By the end of the twentieth century, there are 146 Pestalozzi Societies and more than 1,700 chapters of the Association of Parents and Friends of the Exceptional. The first center for independent living is established in 1988 (CVI-RIO). In 1992 and 1995, CVI-RIO organizes two international conferences on disability issues called DefRio, out of which comes "Goals of the ILM," a document that delineates the basis for the independent living movement in Brazil; however, financial support is not provided by the government, creating a struggle for sustainability. Brazil has progressive policies toward disability. The constitution includes sections on the rights of people with disabilities, and laws have been passed with regard to accessibility, education, and employment.

2000 ◆ Europe: A European Community directive requires all member states to have introduced antidiscrimination laws in the fields of employment and training by the end of 2006. It seeks to establish a general framework for equal treatment in employment and occupation and to render unlawful discrimination based on, among other categories, disability. The European Union Charter of Fundamental Rights sets out in a single text, for the first time in the EU's history, the whole range of civil, political, economic, and social rights of European citizens. Disability is included in the general nondiscrimination clause (Article 21), but Article 26 specifically states that the Union recognizes and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community.

2000 ◆ The Human Genome Project (HGP), an international effort to specify the 3 billion pairs of genes that make up the DNA sequence of the entire human genome, produces its first draft in June 2000. Formally begun in October 1990, it is completed in 2003.

2001 President Clinton declares in Executive Order No. 13217 the commitment of the United States to community-based alternatives for individuals with disabilities. This ensures that the *Olmstead v. L.C.* decision (1999), which mandates the right for persons with disability to live in the least-restrictive setting with reasonable accommodations, is implemented in a timely manner. The executive order directs federal agencies to work together to tear down the barriers to community living.

2001 In the United States, census data indicate that only 48 percent of citizens 25 to 64 years old with severe disabilities have health insurance compared with 80 percent of individuals with nonservere disabilities and 82 percent of nondisabled Americans. Women with disabilities in general are more likely to live in poverty than men. Minorities with disabilities are more likely to live in poverty than nonminorities with disabilities. In 2003, in the United States, about 28 percent of children with disabilities live in poor families compared with 16 percent of all children.

2001 A UN Ad Hoc Committee begins discussions for a legally binding convention under the draft title Comprehensive and Integral Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Its fifth session is held in early 2005.

2001 A new World Health Organization classification of people with disabilities, the International Classification of Functioning, Disability, and Health (ICF), replaces the old International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The ICF definition shifts the focus from disability as an innate deficit ("medical model") to disability as constructed through the interaction between the individual and the environment ("social model"). This shift encourages a focus on the kinds and levels of interventions appropriate to the needs of individuals.

2001 UNESCO launches pilot education projects for disabled children in Cameroon, the Dominican Republic, Egypt, Ghana, India, Madagascar, Mauritius, Nicaragua, Paraguay, South Africa, Vietnam, and Yemen. The global initiative Education for All 2000 has as its primary millennium development goal universal education by the year 2015.

2002 The U.S. Supreme Court rules that executing persons with mental retardation is unconstitutional.

2002 Disabled Peoples' International's 2002 Sapporo Platform, developed by 3,000 delegates from more than 90 countries, urges members to take every opportunity to seek publicity and awareness in order to change negative images of disabled people.

2002 Canada: The Canadian International Development Bank announces the approval of the Canada-Russia Disability Program, a four-year $4 million project, focusing on education, disability studies, social work practice, social policy, and information dissemination.

2003 A national survey that updates the Disability Supplement to the 10-year-old National Health Interview Survey highlights barriers to care among the uninsured. The uninsured are four times as likely to postpone care and three times as likely to go without needed supplies.

2003 The National Association of Social Workers (NASW) issues a policy statement that discusses their core values with respect to working with people with disabilities, including self-determination, social justice, and dignity and worth of the person. The statement emphasizes that social workers are responsible to take action with people who have disabilities in advocating for their rights to fully participate in society.

2003 The Disability Awareness in Action (DAA) database contains a total of 1,910 reports of known abuse affecting nearly 2.5 million disabled people. In the area of education alone, it documents

118 cases affecting 768,205 people in 67 countries. Responding to this documentation and other reports, the United Nations Commission on Human Rights creates the Global Rights campaign to address human rights abuses. Disability rights organizations use this information to insist on a UN convention on the rights of disabled people that would be legally binding on nation-states.

2003 The International Association for the Study of Pain has more than 6,700 members, representing more than 100 countries and 60 disciplinary fields. Chronic pain is one of the leading causes of recurrent and permanent disability in the developed world today, yet less than 1 percent of the U.S. National Institutes of Health's budget supports research into mechanisms and management of pain. The U.S. Congress declares 2000–2010 the Decade of Pain Control and Research.

2004 The *Journal of Gene Medicine* (January) reports that 636 gene therapy clinical trials are completed or ongoing, involving 3,496 patients. The first gene therapy clinical trials begin in the early 1990s.

Today Seventy to eighty percent—approximately 400 million—of the world's disabled people (600 million, or 10 percent of the world's population) live in the developing world, and of the world's poorest of the poor, 20 to 25 percent are disabled. In most countries, 1 out of 10 persons has a disability. Many international efforts are under way to address poverty and disability, such as those of the Action on Disability Development and the Chronic Poverty Research Centre.

Today E-health is the use of emerging interactive telecommunications technologies such as the Internet, interactive TV, kiosks, personal digital assistants, CD-ROMs, and DVD-ROMs to facilitate health improvement and health care services, including those with disabilities. E-health relies on environments that use a variety of technologies that can compensate for the lack of sensory ability. Telerehabilitation is an example of services delivered information technology and telecommunication networks.

Today Celebrating difference is the mantra and visible manifestation of disability culture in all regions of the world.

SEARCHING FOR AND EVALUATING WEBSITES

Anne Armstrong

The Internet, or Web, provides a vast number of channels through which researchers can find information on virtually any subject. The expansiveness of the Web can be daunting to new researchers. On the other hand, researchers often assume that they have mastered the Web in its entirety when indeed they have merely scratched the surface in terms of the numbers of resources they have consulted and searches they have performed.

Because the field of disability studies is continually evolving and inherently multidisciplinary, Web searchers can draw on previously conducted research from disciplines within the humanities, social sciences, and health sciences. This guide aims to expose beginning researchers to a mixture of general and subject-specialized Web-based search tools, as well as strategies for performing sophisticated Web searches and criteria for evaluating websites. In addition to its broad subject coverage, the field of disability studies differs from most fields in that many researchers may themselves have disabilities affecting their ability to perform research on the Web. For this reason, this description concludes with an overview of accessibility issues on the Web and suggestions for further reading.

OVERVIEW OF WEB-BASED RESEARCH TOOLS

When approaching Web searching, researchers should be aware of the multitude of search tools available to them, in addition to the varying purposes of these tools. Many users approach Web searching with the assumption that "everything is in Google," but this is a limiting misconception. No single search engine contains everything on the Web. Furthermore, all search engines function differently and rank results differently. Therefore, sampling various search tools increases the comprehensiveness of results on any topic. This discussion outlines multiple types of search tools available on the Web and offers potential starting points for Internet research on issues related to disability studies, whether from a health sciences, social sciences, or humanities perspective.

The Web-based search tools outlined in this chapter include general search engines, subject-specialized search engines, directories, indexes, catalogs, and Listservs. It is important to note that different types of search tools cover different parts of the Web. The Web is composed of layers. The top layer is detectible by general search engines, while a deeper layer termed "the invisible Web" can be penetrated only by specialized search engines, indexes, and catalogs. Readers should be aware that because the Web is in a constant state of flux, currently available resources may become obsolete over time, and newer, more sophisticated search tools will undoubtedly evolve.

General Search Engines

Most people who have searched the Web are familiar with sites such as Google, HotBot, or Lycos, which allow them to enter a string of keywords into a search box to retrieve a list of relevant websites (see Table 1). These sites, referred to as search engines, search the Web by means of a program called a *spider* (also

Table 1 Selected General Search Engines

Name	*URL*
AltaVista	www.altavista.com
Excite	www.excite.com
GO	www.go.com
Google	www.google.com
HotBot	www.hotbot.com
Lycos	www.lycos.com
Yahoo!	www.yahoo.com

called a *robot* or *crawler*). Since search engines tend to index millions of websites, they are most useful for entering specific search terms rather than broad concepts such as disability studies.

While Web searchers tend to pick a favorite search engine and return to it repeatedly, it is important to note that different search engines produce varying results, and that a truly comprehensive Web searcher should compare the results of multiple search engines. The variation between search engines can be attributed to differences between the spiders fueling the search engines as well as differences in the level of indexing and the order in which results are ranked. While some search engines index the full text of documents, others may index only the first page, or merely the *meta-tags*, which are lines of code containing keywords. Web searchers should be aware that developers of websites may intentionally increase their usage of certain words or meta-tags to increase the prominence of their website among search results. This practice has been referred to as *spamdexing* and is most prevalent among the developers of commercial websites advertising products and services. Due to the constant fluctuation of the Web, no search engine is entirely up-to-date; results produced by identical searches can vary greatly from one day to the next, even when one is using the same search engine.

Subject-Specialized Search Engines

Subject-specialized search engines (also referred to as subject portals) developed by educational institutions, associations, government agencies, and corporate entities narrow the broad scope of the Web, providing a focused channel by which researchers can search for information when they have determined the discipline from which their topic stems. Examples of such search engines are listed in Table 2. While subject-specialized search engines index considerably fewer websites and documents than general search engines, the information contained within them has been preselected, ideally by experts within a given field. Many subject-specialized search engines expose searchers to parts of the "invisible Web" not indexed by general search engines. Subject-specialized search engines can ease the research process by whittling down the Web to a more manageable size. However, researchers who use them should take the time to view the criteria for selection of

Table 2 Examples of Subject-Specialized Search Engines

Name	*URL*	*Subject Coverage*
Center for International Rehabilitation Research Information and Exchange (CIRRIE)	http://cirrie.buffalo.edu	Rehabilitation research
FamilyDoctor.org	http://familydoctor.org	Health sciences
FirstGov	www.firstgov.gov	Government
Google's Uncle Sam	www.google.com/unclesam	Government
Health*Web*	www.healthweb.org	Health sciences
Mayo Clinic	www.mayoclinic.com	Health sciences
MedlinePlus	http://medlineplus.gov	Health sciences
National Center for the Dissemination of Disability Research (NCDDR)	www.ncddr.org	Disability studies
Social Science Information Gateway (SOSIG)	www.sosig.ac.uk	Social sciences
Thomas	http://thomas.loc.gov/	Legislative information
Voice of the Shuttle	http://vos.ucsb.edu	Humanities
*Web*MD	www.webmd.com	Health Sciences

information contained within them. This information is usually posted within online "help" or "about" pages on the home page.

Table 3 contains search tools that have been developed distinctly for the purpose of locating specialized search engines by subject.

Directories

Directories are hierarchically arranged subject guides composed of websites chosen by or recommended to editors of the directory (Table 4). Usually, directories follow a template in which major subject categories such as health, sciences, social sciences, or humanities are posted on the top-level page. Each of these links leads to lists of narrower subcategories. The links on the second level lead to narrower subcategories, and so on. A sample hierarchy from the directory created by Google (available at http://directory.google.com) lists the following subject breakdown: Society → Disabled → Disability studies.

Directories provide Web searchers with the ability to browse recommended resources in various subject areas without having to enter specific search terms. Other useful attributes of directories are that they often contain summaries and evaluations of websites.

Table 3 Resources for Finding Subject-Specialized Search Engines

Name	*URL*
CompletePlanet	www.completeplanet.com
Direct Search	www.freepint.com/gary/direct.htm
InfoMine	www.infomine.com
Invisible Web Directory	www.invisible-web.net
Librarians' Index to the Internet	www.lii.org
Search Engine Colossus	www.searchenginecolossus.com

Table 4 Selected Directories

Name	*URL*
eBlast	www.eblast.com
Google Directory[a]	http://directory.google.com
Internet Public Library	www.ipl.org
LookSmart	www.looksmart.com
Yahoo! Directory[a]	www.yahoo.com

[a] These sites contain both directories and general search engines.

Article Indexes

Article indexes allow researchers to search by topic for published articles in magazines and scholarly journals. Researchers could certainly locate journal and magazine articles using a freely available search engine such as Google, but they would merely be skimming the surface of what has been published. While the Web provides access to *more* content, it does not provide comprehensive access to research published in journal articles. Article indexes are for the expressed purpose of finding journal articles. With a few exceptions (such as PubMed, an article index of health sciences journals developed and maintained by the National Library of Medicine), article indexes are not freely available on the Web. Libraries purchase subscriptions to multiple article indexes covering a wide spectrum of disciplines. The indexes available through a given library are often dictated by the curriculum of the college or university that the library serves. Thus, large research institutions offer a greater number of specialized article indexes than smaller institutions and public libraries. Due to licensing agreements between article index providers and libraries, off-site access to indexes is usually limited to faculty and students of a college or university. However, there are many libraries that allow members of the public to use their article indexes from within the library. A local public library would be a good starting place for those not connected with academic or commercial organizations.

Since article indexes are proprietary products developed by companies for sale to libraries, they tend to offer specialized search features that are not always available on freely available search engines. These features include subject headings, thesauri, abstracts (summaries of articles), and frequently the full text of articles. Researchers should familiarize themselves with online tutorials, "help" screens, and "about" pages to increase the effectiveness of their searching.

Freely available article indexes relevant to disability studies include the following:

- PubMed: A product of the National Library of Medicine, which includes more than 14 million citations for biomedical articles dating back to the 1950s. URL: http://www.ncbi.nlm.nih.gov/entrez

- CIRRIE: Center for International Rehabilitation Research Information and Exchange, a database containing more than 24,000 citations of international research published from 1990 to the present. URL: http://cirrie.buffalo.edu

Catalogs

While researchers can search indexes to find articles on specific topics, they can search online catalogs to find books. Some catalogs list the books available at individual libraries, while others contain the holdings of multiple libraries and institutions. The individual catalogs of public libraries and universities are usually freely available on the Web. The most comprehensive catalog is called WorldCat, developed by an organization called OCLC (Online Computer Library Center). WorldCat lists books available at public and academic libraries throughout the world. Like most article indexes, WorldCat is not freely available on the Web and must be accessed through a library.

Listservs

Listservs are mailing lists on the Internet that facilitate online discussions on various subjects. They allow researchers within a given field to communicate about scholarly issues via email. People customarily sign up for Listservs by sending an e-mail to the Listserv address stating that they wish to subscribe. Several Listservs related to disability studies are listed in Table 5. In addition, Web searchers can perform a search on a database called tile.net to search for Listservs by topic.

Table 5 Disability Studies Listservs

Name	*URL*
ADA-LAW	http://listserv.nodak.edu/archives/ada-law.html
Disability-Research Discussion List	http://www.leeds.ac.uk/disability-studies/discuss.htm
Disability Studies at Yahoo.com	http://www.groups.yahoo.com/group/disabilitystudies
Disabled Student Services in Higher Education (DSSHE-L)	http://listserv.acsu.buffalo.edu/archives/dsshe-l.html
Women's International Linkage on Disability (D-WILD)	http://groups.yahoo.com/group/d-wild

SEARCH STRATEGIES

Since search capabilities vary from site to site, Web searchers should use online "help" screens and tutorials to learn search tips and strategies for improving their search results. Some search techniques common to several Web-based search tools are summarized below.

Quotation Marks

When entering a search, users should enter phrases in quotation marks to stipulate that they would like the results to contain a specific word combination and order. For instance, multiword concepts such as "disability studies," "adaptive technology," and "section 508" should be entered within quotation marks. Proper names can also be entered within quotation marks.

Truncation

Truncation symbols allow Web searchers to simultaneously search for multiple endings of a given word. For instance, assuming that the asterisk is the designated truncation symbol in a search engine, entering the word "impair*" would produce results including all forms of the word after the root, including "impair," "impaired," "impairment" and "impairments." In addition to adding truncation symbols to the end of words, users may also insert internal truncation symbols if there are potential variations for the spelling of the middle of a word. For instance, entering the word "colo*r" would simultaneously search for the words "color" and "colour." "Help" screens or "search tips" usually list the designated truncation symbol for a given database.

Boolean Logic

Developed by the English mathematician George Boole, Boolean logic is a mathematical framework that Web searchers can apply to broaden or refine their searches. There are three words, or *operators*, that Web searchers can use to combine their keywords to perform more complex searches: AND, OR, and NOT. The three Boolean operators are summarized below, along with potential applications. It is important to read the online "help" section of a database before performing a Boolean search, as Boolean searching does not work in all databases.

Using the Boolean Operator "AND"

Combining words with "AND" narrows a search, as the database retrieves only items that contain *all* the words entered. The second search example below will produce fewer results than the first, since there are three keywords that must appear within the content of each result.

"disability studies" AND theory
"disability studies" AND theory AND history

Using the Boolean Operator "OR"

Entering the term "OR" between keywords stipulates that any, but not all, of the words entered must appear within the search results. Using "OR" is a way of searching for synonyms or related terms when there are multiple words for the same concept. The example below shows how you could broaden your search if you wanted to search for multiple adaptive technology applications in a search engine. The second search example will potentially produce more results than the first, since there is an additional keyword that the results could include.

JAWS OR "Ruby OpenBook"
JAWS OR "Ruby OpenBook" or "window eyes"

Using the Boolean Operator "NOT"

Entering the Boolean operator "NOT" after a word stipulates that the word should not appear within the results. Using "NOT" in a search can be particularly useful if a word is frequently used in multiple contexts and you wish to eliminate results dealing with a particular topic. In the example below, the second search will ideally eliminate items relating to the state of New Mexico, given that the researcher is looking for information on legislation related to disabilities in the country of Mexico. The use of NOT can be too limiting. The second search would eliminate results that discussed both Mexico and New Mexico.

Disabilities AND legislation AND Mexico
Disabilities AND legislation AND Mexico NOT "new mexico"

Nesting

Nesting allows Web searchers to simultaneously search for multiple search terms relating to the same topic. The grouping of synonymous terms within parenthesis is referred to as nesting, as multiple terms relating to the same idea are clustered together as a single concept. When using nesting, the words within the parenthesis are connected by the Boolean operator "OR."

To find information about software for people who are visually impaired, search results are increased by using nesting to group multiple words for each facet of the topic:

(software or "adaptive technology") AND ("visually impaired" or blind)

Plus and Minus Signs

Most general search engines allow users to enter plus or minus signs before a particular word. Entering a plus sign before a word (e.g., +ADA) stipulates that the word must appear within the search results. A minus sign before a word (e.g.,–mobility) stipulates that the word should not appear within the results. Since some search engines also use plus and minus signs as substitutes for Boolean operators, it is important to view online "help" or "search tips."

Search Limits

Most search engines allow users to limit their results by date, language, or document type. Limiting capabilities vary from site to site and are customarily outlined in online "help" screens. In general, article indexes have more sophisticated limiting capabilities than search engines that are freely available on the Web.

EVALUATING WEBSITES

A researcher weighing the quality of a journal article faces a lesser challenge than a researcher considering a website as a potential resource. The publishing industry applies labels to periodicals of varying type: Scholarly journals, popular magazines, trade publications, and newspapers comprise the major categories. Articles submitted to scholarly journals undergo a peer review process by experts in a given field. If in doubt as to the suitability of journal for scholarly purposes, a researcher can consult a directory of periodicals such as *Ulrich's Periodicals Directory,* which indicates whether or not a journal is peer reviewed.

The fact that the Web has no comparable methods of control complicates the task of determining whether a website is appropriate for research purposes. While websites produced by certain types of agencies and organizations certainly undergo a form of *internal*

review, the Web is a free forum; people can post anything they want, and no one has the right to force to take it down if it fails to meet certain standards of quality or accuracy. To complicate the matter, inaccurate or inexpert information can hide like a wolf in the sheep's clothing of sophisticated graphics, layout, and design. The Web has no peer review process to ensure quality. While none of the evaluation criteria outlined below can provide the final word as to the suitability of a website for scholarly use, a researcher who searches the Web with multiple evaluation criteria in mind expedites the process of finding quality information.

Authorship

When determining the credibility of a website, researchers should use multiple techniques to determine the credentials of the author as well as the character of the organization hosting, or sponsoring, the site. If individuals are listed as authors, researchers should take steps to determine their credentials and reputation in the field by performing a search in a general search engine to find biographical information or other documents written about the author. This will also produce references to the author on the sites of other authors within a field. Researchers can also consult a number of biographical sources available at libraries, such as *Who's Who in the America* or sources tailored to particular fields of study, such as *Who's Who in Science and Engineering.*

Website addresses, or URLs (Uniform Resource Locators) can also provide hints as to author affiliations and potential bias. Personal websites are often hosted on commercial ISP (Internet Service Provider) Web servers such as aol.com, or geocites.com. URLs of personal websites often contain first or last names, as well as percent (%) or tilde (~) signs. While personal websites may contain authoritative information, researchers should question why the same content does not appear on a site sponsored by an educational or research organization.. Was the site created as a pastime or to serve as a forum for airing personal views? Or does the site reflect serious scholarship backed up by other credentials and research published in scholarly publications?

Every website URL ends with a *domain name*, usually a series of three letters preceded by a period. The domain name denotes the type of institution that hosts the website and can often provide clues as to the purpose or potential bias of a site. Common domain names include the following:

Educational sites: .edu
Government sites: .gov, .mil, or country codes (e.g., .uk = United Kingdom, .au = Australia, .do = Dominican Republic)
Nonprofit organization sites: .org
Commercial sites: .com

Most URLs contain multiple levels separated by slashes (e.g., http://www.nod.org/stats/). To learn more about the sponsor or publisher of a particular site, you can remove levels of the URL one by one to see where the site is hosted and determine the character of the sponsoring entity. For instance, if a site is hosted on the site of an association, viewing the mission statement on the home page of the association can provide clues as to the bias or purpose of the content. When judging the credentials of the publishing entity, researchers should look for contact information and institutional logos. In general, sites devoid of identifying information or contact numbers and addresses should raise suspicion.

Audience

When evaluating a site, researchers should determine whether the content succeeds in addressing the stated audience through tone and presentation. Sites for adults should not have a childlike appearance or tone. Likewise, sites may be deliberately overrun by technical language or jargon to confuse or mislead a particular audience. High-quality sites clearly define their intended purpose.

Currency

Medical research findings or population statistics may become obsolete at a faster rate than research in the humanities. Web researchers should check sites for copyright dates and the date of the last update. Broken links are a sign of neglect, as they may indicate that URLs have changed or become obsolete since the last update of the site. To verify the currency of information on a site, researchers should check for several sites covering the same subject matter.

Accuracy

Determining accuracy involves further research to ensure that the claims or findings on a site are substantiated by other sources. If a site presents original research, the methods of the research and instruments used should be clearly explained, as well as potential limitations of the research. If authors make claims or conclusions, they should cite their

sources, and these sources should be tracked down to ensure their existence and authenticity. Websites should contain a list of works cited or footnotes on par with any print book or article. Since websites sometimes include fabricated resources, and erroneous or incomplete citations, sources should be verified using library tools such as indexes and catalogs. Lists of works cited with multiple errors reflect irresponsible research. If a website contains links, the links should be checked. Researchers should be wary of websites populated by broken links or links to defunct websites.

Quality

In general, sites that are poorly organized or sloppy should be approached with caution. Shoddy design may point to further weaknesses. Poor grammar and spelling errors are also red flags.

Bias

While bias is not always a negative attribute, Web searchers should be cognizant of bias as the search for information. The bias of a website can be partially discerned by the domain name (as discussed above under "Authorship"). Commercial websites may be motivated by the goal to market a product or service. Nonprofit organizations may promote a political agenda. While bias may be clearly stated in mission statements and "about" pages, many websites deliberately shroud their bias. Thorough research involves consulting additional sources to determine the history and activities of a particular organization. If a site contains links to other sites, those links should be checked to discern the character and activities of the other organizations listed. If a site is sponsored by other organizations, researchers should consider the relationship between the sponsors and the creators of the site.

Special Considerations for Evaluating Health Information on the Web

The American Medical Association (AMA) has published "Guidelines for Medical and Health Information Sites on the Internet" outlining evaluation criteria for websites publishing health information, whether for consumers or health professionals. While these guidelines are technically enforced only on sites sponsored by the AMA or affiliated organizations, they could be applied to all sites containing health information. Many of these guidelines mirror the previously outlined criteria for evaluating all websites, but there are certain factors that are heavily emphasized in the AMA guidelines, including the importance of peer review by experts in the field, the importance of clearly identifying sources of funding, an explanation of the relationship between individual researchers and the institutions sponsoring the research, the importance of clearly stating the purpose and intended audience of a site, and the need to address the stated audience in a consistent and effective tone. Seven criteria for assessing the quality of health information on the Internet have been developed by the Health Summit Working Group (Health Information Technology Institute 1999).

Information on health-related websites should be verified by checking sources such as journal articles, books, and other websites. These measures are needed as health information on the Web frequently includes unsubstantiated claims.

OVERVIEW OF ACCESSIBILITY ISSUES ON THE WEB

Disability studies research is unique in that many scholars in the field have disabilities that may impact their ability to effectively search the Web. While in many ways the Web "evens the playing field" by making a vast number of resources available electronically, inaccessible design frequently places barriers on Web searchers with disabilities.

Principles of Web accessibility have been developed by the World Wide Web Consortium's (W3C) Web Accessibility Initiative (WAI). The WAI establishes guidelines for creating accessible websites, browsers, and authoring tools to increase the ease of use of the Web for users with disabilities. Multiple scenarios outlining potential challenges to Web searchers with disabilities are summarized in a W3C working draft titled "How People with Disabilities Use the Web" (2001). Among other scenarios, the document emphasizes that many Web searchers with cognitive or visual disabilities use OCR (optical character recognition) software, which reads Web page text and transmits the information to a speech synthesizer and/or refreshable Braille display. Many users with visual disabilities use text-based Internet browsers instead of standard graphical browsers. The successful use of these tools requires that images on websites be accompanied by descriptive text and *ALT tags*. ALT tags are textual labels that appear on the computer screen when a mouse moves over an image. Since visually impaired

Web searchers often enlarge Web-based text using screen magnification programs, Web designers must create pages with nonfixed font sizes that can be altered as necessary. These are only a few of the issues facing Web searchers with disabilities. Other population groups with disabilities discussed in the guidelines include individuals with cognitive disabilities, hearing impairment, and mobility-related disabilities. Readers should consult the WAI website for the complete guidelines (http://www.w3.org/WAI/).

To support the goals of WAI, an online tool called Bobby™ helps website developers test the accessibility of their sites and adhere to accessibility guidelines. By entering a URL into the Bobby website, a Web developer can generate a report outlining which features of the site need to be adjusted to make it "Bobby compliant" and adhere to both W3C accessibility guidelines and guidelines established by the U.S. government's Section 508, a 1998 amendment to the Rehabilitation Act requiring that all federal agencies make their electronic and information technology accessible to people with disabilities. Complete information about these guidelines can be found on the Section 508 website (www.section508.gov).

CONCLUSION

While "one-stop shopping" in Google may be tempting, there is no single search engine leading to everything on the Web. Comprehensive and effective research in disability studies involves consulting multiple search tools, including but not limited to general search engines, subject-specialized search engines, directories, and indexes. In addition to using multiple search tools, Web searchers should experiment with multiple search strategies to maximize the effectiveness of their searching. As there are no standards of quality on the Web, researchers should apply multiple evaluation criteria to every website, verifying that research findings posted on sites are supported by other sources. Web accessibility is a crucial component to disability studies, as the Web has the potential to deliver equal content to all users but frequently presents barriers to people with disabilities by failing to adhere to standards of accessible design. Researchers can develop an awareness of accessibility issues on the Web by familiarizing themselves with the standards outlined by W3C's Web Accessibility Initiative and Section 508.

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The Reader's Guide is provided to help readers locate entries and primary sources by topical category. It classifies the A–Z entries (Volumes I–IV) and primary source documents (Volume V) into twenty-five categories: Accessibility, Arts, Biographies, Children and Infants, Deafness and Deaf Culture, Disability Studies, Economics and Employment, Education, Ethical Issues, Experience of Disability, Health and Medicine, Health Care, History of Disability, Information Technology, Language of Disability, Law and Social Policy, Models, Organizations, Politics, Rehabilitation, Rehabilitative Engineering and Assistive Technology, Religion, Science, Sports, and Therapies. Some entries and documents may appear in more than one category.

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E

EARLY CHILDHOOD INTERVENTION

Early childhood intervention is defined by services for infants and young children to prevent or reduce disability and to promote their development and general well-being. It seeks to identify actual or potential risks for disability as soon as possible and initiate interventions to minimize limitations related to individual, social, and environmental factors. Early childhood intervention recognizes the central role of the family in the child's development and is based on the provision of individualized intervention for the child and family in the proximal environment. Interventions focus on reducing and/or removing physical, cognitive, emotional, social, and environmental barriers and promoting the child's growth, development, and health through stimulation and provision of support. Early childhood intervention builds on biomedical, behavioral, and social and educational research and requires the contributions of specialists from many disciplines. It is a complex and continually evolving field with broad, interdisciplinary involvement including psychologists, early childhood educators, social workers, pediatricians, nurses, child psychiatrists, physical and occupational therapists, speech and language pathologists, and professionals in public health and social policy.

Children with diagnosed conditions such as Down syndrome, autistic spectrum disorders, cerebral palsy, and communication disorders were initially the primary recipients of early childhood intervention. However, children with developmental delays and children with risk factors associated with low birth weight, disadvantaged environments, and neuromotor problems are increasingly likely to be served in early-intervention programs.

Early childhood intervention was established in the United States and in some countries in Europe in the 1970s. The interest for early childhood intervention is increasing around the world since it covers common issues that transcend national boundaries. Researchers, clinicians, parents, program developers, and policy makers from many countries contribute to the rapidly expanding knowledge base of early childhood intervention. The International Society for Early Intervention (ISEI) with members from 50 countries representing all continents, provides a forum for professionals to communicate about advances in the field of early intervention. In Europe, Eurlyaid (European Association on Early Intervention), a European working party of professionals and representatives of parent associations from more than 15 countries, is involved in promoting early intervention for children at risk or with developmental disabilities. The European Agency for Special Education is also involved in promoting early childhood intervention in Europe. There are national organizations working for early childhood intervention in many countries all around the world, for example, in Australia, India, Hong Kong, South Africa, and Russia.

The age of entry to the early childhood intervention services varies from country to country. In North

America, early childhood intervention covers the years from birth to three, whereas in Europe it covers the ages from birth to five or six. The form of early childhood intervention services provided varies as a function of the system of services existing in each country. In some countries, early childhood intervention is included in general health care and educational services for all children. In other countries, special programs for early childhood intervention are provided that may be center based, home based, hospital based, or a combination. Services may include identification, assessment, and the provision of direct intervention. Variability may be found in eligibility criteria and accessibility to early childhood intervention as well as the extent of involvement of parents in the intervention process.

The universal framework of early childhood intervention relies on recognition of the individuality of all children in terms of abilities and disabilities, and a comprehensive approach encompassing the child's health and well-being. It relies on the knowledge that children are born active and are ready to communicate and learn and that stimulating and responsive social and physical environments are essential for development. The growth of the field of early childhood intervention is influenced by the declarations of the United Nations and the World Health Organization (WHO). Key sources are the 1959 UN Declaration of Rights of the Child and the 1990 Convention of the Rights of the Child, where the responsibility of society to ensure children's health and development is underlined. Article 23 recognizes the importance of meeting needs of children with disability. WHO declarations serve as a premise for advocacy and legislative initiatives concerning health and disability. Parent associations have also to a great degree influenced the evolving field of early childhood intervention advocating the rights and needs of children with disability.

Early childhood intervention is influenced by theory and developmental science. Universal features include an ecological framework, a systems theory approach, a focus on the family and the proximal environment for intervention, individualization of services and supports, and a preventive perspective. An underlying assumption is that early intervention can prevent or reduce later manifestations of delay and disability. The ecological base and a family systems approach builds on the assumption that developmental problems must be addressed in the environmental context of the child. It focuses on interventions addressing the child, the family, and other proximal environments and intervention providers. A basic premise is that the unique and complex needs and resources of each child and family are met best by an interdisciplinary approach in collaboration with the family. A systems approach recognizes that the family and child are influenced by the world of work, the preschool, available services for health, and other major social systems. On the macro level, early childhood intervention is influenced by broader factors of laws, culture, attitudes, values, geography, and economy.

Developmental science has had a major influence on the philosophy and practices in early intervention. A fundamental assumption in child development literature is that the child is seen as active in constructing his or her world and that development occurs through the ongoing transactions over time between the child and his or her social and physical environment. Another foundation for early childhood intervention is the centrality of relations and of the environment in early development.

As research on early childhood intervention continues to evolve, a distinction has been made between first- and second-generation research. In first-generation research, focus has been on the child and methods to assess and intervene with the child's impairment and disability. In second-generation research, issues that are of value in the daily activities of children, families, other proximal environments, clinicians, and teachers are in focus broadening the scope of the discussion about assessment and intervention. Second-generation research addresses the questions about what intervention, for what child, under which circumstances, and with what desired outcomes?

The basic philosophy in early childhood intervention relies on a number of basic assumptions that define the essential elements in processes and outcomes of early childhood intervention. To reach the goal of preventing disabilities and promoting growth, development, and well-being of infants and young children, interventions must take individual differences into account. The focus for interventions is thus the child's health, development, and well-being in both assessment and intervention. To meet the goals of early childhood intervention, services must be designed that are personalized for the child and family as a unit and in their specific social and cultural context.

—Eva Björck-Åkesson and Mats Granlund

See also Children with Disabilities, Rights of; Developing World; Education and Disability; Infant Stimulation Programs.

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EASTER SEALS

Easter Seals has been helping individuals with disabilities and special needs, and their families, live better lives for more than 85 years. From child development centers to physical rehabilitation and job training for people with disabilities, Easter Seals offers a variety of services to help people with disabilities address life's challenges and achieve personal goals.

In 1907, Ohio businessman Edgar Allen lost his son in a streetcar accident. The lack of adequate medical services available to save his son prompted Allen to sell his business and begin a fund-raising campaign to build a hospital in his hometown of Elyria, Ohio. Through this new hospital, Allen was surprised to learn that children with disabilities were often hidden from public view. Inspired by this discovery, in 1919 Allen founded what became known as the National Society for Crippled Children, the first organization of its kind.

In the spring of 1934, the organization launched its first Easter "seals" campaign to raise money for its services. To show their support, donors placed the seals on envelopes and letters. Cleveland Plain Dealer cartoonist J. H. Donahey designed the first seal. Donahey based the design on a concept of simplicity because those served by the charity asked "simply for the right to live a normal life."

The lily—a symbol of spring—was officially incorporated as Easter Seals' logo in 1952 for its association with springtime, renewal, and new life, and it has appeared each year as part of a fund-raising campaign.

Public support for the Easter Seals' "seals" campaign triggered a nationwide expansion of the organization and a swell of grassroots efforts on behalf of people with disabilities. By 1967, the Easter Seals' seal was so well recognized that the organization formally adopted the name "Easter Seals."

Easter Seals assists more than 1 million children and adults with disabilities and their families annually through a nationwide network of more than 500 service sites. Each center provides high-quality, family-focused and innovative services tailored to meet the specific needs of the particular community it serves. In the United States, Easter Seals' services for children and adults with disabilities include medical rehabilitation, job training and employment, inclusive child care, adults and senior day care and in-home care, and camping and recreation programs.

Easter Seals also advocates for the passage of legislation to help people with disabilities achieve independence, including the Americans with Disabilities Act (ADA). At the core of the Easter Seals organization is a common passion for caring, shared by its 13,000 staff members and thousands of volunteers, and by those who support its mission.

See also Advocacy.

Websites

Easter Seals National Headquarters, http://www.easterseals.com/site/PageServer

EATING DISORDERS

Eating disorders (anorexia nervosa, bulimia nervosa, and binge eating disorder) have been identified by some clinicians as an emerging public health crisis. Rates of eating disorders are difficult to gauge because of underreporting and misdiagnosis, but the *DSM-IV-TR* (American Psychiatric Association 2001) estimates lifetime prevalence to be 0.5 percent for anorexia and 1–3 percent for bulimia, with data still being collected on the newly designated binge eating disorder. Over 90 percent of those affected by eating disorders are women. An estimated 20 percent of all college females actively struggle with either anorexia or bulimia.

Eating disorders have long been viewed as a "culture-bound syndrome," as they have been historically observed in white, upper-middle-class teenage girls in the United States. Eating disorders have often been interpreted as expressions of conflicted feminine identity in the wake of capitalist expansion and as the embodied representation of conflicting cultural discourses regarding individualism and dependency. Recent reports, however, note increasing rates of incidence in other ethnic groups, persons of diverse economic backgrounds, boys and men, and non-Western cultural contexts. This diversification of the "typical" profile, coupled with increases in reported cases, produces something of a conundrum. On the one hand, the appearance of eating disorders in such a wide range of people across the globe might seem to lend credence to studies suggesting a biological basis for the disorders. On the other hand, the apparent coincidence of these increases with the expanded reach of western cultural ideology suggests cultural factors as a precipitating factor.

Regardless of where one locates causation, the fact remains that individuals who suffer from eating disorders are significantly impaired in their abilities to care for themselves, to interact with others, and to pursue school or employment. Their bodies are often ravaged by the disorder, leaving their bones brittle and weak, their teeth fragile, their heart and other organs often permanently damaged. Given this, and the increasing numbers of people struggling with these illnesses, one might legitimately argue that eating disorders should be classified as a "disability," and their sufferers afforded all the rights and protections given to other disabled individuals.

But there is something perhaps unsettling about this, and it speaks to the precarious situating of eating disorders in the cultural and clinical landscape: Do eating disorders reflect individual pathology, or should they be understood as crystallizations of pathological cultural dynamics? Are eating disorders inevitable given the presence of certain causal factors, or do they reflect individual choices within a given social context? How one answers these questions has direct implications for where one places responsibility for these illnesses, and, consequently, how they are understood vis-à-vis other disabling conditions. Put another way, we might ask: Can and should we recognize a condition as a "disability" that in many ways—through its emphasis on self-control, efficiency, and personal achievement—makes manifest our most treasured social values?

In strict definitional terms, eating disorders do meet the criteria for "disability." In its biopsychosocial model of health and illness, the International Classification of Functioning, Disability, and Health (ICF) defines *disability* as an outcome of interactions between health conditions and contextual factors that involves dysfunctioning (given certain qualifiers) at one or more of the three levels of human functioning: body or body part, whole person, and whole person in context (World Health Organization 2001). Eating disorders in their active phases certainly impair an individual on each of these three levels in ways substantial enough to disrupt everyday life. The Americans with Disabilities Act of 1990 states that an individual is considered to have a disability if he or she has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment. Again, eating disorders (viewed either from the perspective of mental illness or from the perspective of their physical consequences) would easily meet these criteria. But while conditions such as attention deficit hyperactivity disorder (ADHD), schizophrenia, major depression, and bipolar disorder are legally recognized as disabling conditions worthy of accommodation, eating disorders are not. What makes eating disorders different? The aim of this entry is not to argue either for or against classifying eating disorders as a disability, but rather to briefly outline some of the issues at stake when a disabling condition unfolds within a social context that explicitly values many of the features of that condition.

Few would argue that a person who has schizophrenia or bipolar disorder would (and should) qualify as "disabled" according to these criteria. But many eating-disordered individuals do not, at first glance, appear to be substantially limited in their ability to function in society (at least those with anorexia nervosa or bulimia nervosa). (There has also been increasing pressure in recent years to classify obesity as a disability. See LeBesco 2004 and Braziel and LeBesco 2001 for discussions of this and related issues.) One reason for this is that, as noted above, the heightened self-control, anxiety about not being good enough, and ambivalence about overconsumption characteristic of eating disorders, while perhaps pathological in their extreme expressions, are nevertheless "in sync" with our cultural ideology in a way that hearing voices or staying in bed for a week are not. And it is perhaps more difficult to view a condition as disabling if it appears (on the surface at least) to garner significant social and cultural capital for the person involved. Girls often *do* get more positive attention when they are thin; physical fitness and attractiveness *are* often linked to success in the business world (see, e.g., Bordo 1995; Wolf 2002). Indeed, the social perks that can accompany the attainment of the slim, fit ideal can easily transform eating-disordered individuals into objects of envy rather than of sympathy. This situation is complicated by the recent rise of "pro-anorexic" websites with names such as "Emaciate me," "Little Baby Nothing," "Ana By Choice," "Anorexic wit' Attitude," and "Beautifully Insane," which insist that being anorexic is a "life choice" and an avenue for empowerment. This would seem to lend credence to the position that people with eating disorders *choose* to be sick, and, by extension, could just as easily choose to be well.

But such a position obscures the everyday, soul-wrenching struggle many eating-disordered individuals endure as they work to pull themselves, inch by excruciating inch, out of the depths of their illness. In the throes of an eating disorder, one does not feel pretty or popular or successful or powerful. On the contrary, one feels hollowed out, hopeless, emotionally decimated. And the most debilitating aspects of the illness do not entirely go away with recovery. For most eating-disordered people, food and eating always remain wrought with anxiety, one's body is always to some degree the enemy, and the temptation to return to eating-disordered behaviors (horrible as they are) swells in the face of periods of stress (see Hornbacher 1999 for a particularly gripping personal account of these issues). The "disability" of eating disorders, then (should we choose to call it that), is perhaps more elusive and subtle than other forms of disability, such as blindness or cerebral palsy. It is more like a sustained vulnerability than a physical limitation in functioning. And unlike these other conditions, accommodations cannot be made for the eating-disordered person. On the contrary, recovery often proceeds *in spite of* social interventions (with its contradictory passions for super-sizing food portions, on the one hand, and fad diets, liposuction, and 24-hour gyms, on the other) rather than because of them.

What *can* be gained from exploring eating disorders as a form of disability, however, is an increased awareness of the lifelong, everyday struggle those in recovery must face as they navigate cultural expectations of control, success, and achievement through the attainment of the perfect body. This might also lead us to a critical revisiting of the notion of disability as a condition that prevents full participation in society. In some cases, it seems, this full participation itself can be implicated in both the causes and consequences of what often becomes a lifelong battle.

—Rebecca Lester

See also Normality; Obesity; Osteoporosis.

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ECONOMIC ANALYSIS OF DISABILITY

Studies of the economic impact of disability have been conducted from the perspective of government and society at large. Government expenditures on behalf of persons with disabilities may total as much as $247 billion (in 1997 terms), with all but $4 billion due to medical care expenditures or disability transfer payments. The costs of disability from the perspective of society may be as much as $345 billion (in 1997 terms); even after taking into account the costs that would be expected among persons with disabilities in the absence of the disability, the costs may total as much as $217.3 billion (in 1997 terms), the equivalent of 2.6 percent of the gross domestic product (GDP) in the United States for that year.

METHODS OF COST OF DISABILITY STUDIES

Estimates of the economic impact of reduced health or functional status have been produced with regularity since the mid-1960s. Most have concerned the cost to society of the prevalent cases of individual medical conditions, but the methods have been adopted by those interested in estimating the impact of disability on the national economy. In these studies, analysts enumerate the resources consumed as a result of having a medical condition (or disability), encompassing the costs of procuring medical services (including assistive technology and personal assistance), labeled "direct costs," and those associated with reduced ability to participate in activities, labeled "indirect costs."

Indirect costs might include the wage losses incurred by those who would be expected to work in the absence of the disability or of their household members who reduced work to care for them. Indirect costs would also include the economic costs associated with reduced functioning in other spheres of activity, such as parenting, as well as the harder-to-measure costs associated with the psychological impact of not being able to function as well as one would like. A full accounting of the costs of disability, of course, might include some gains as well. On the tangible side, there is some evidence that persons with disabilities use fewer medical resources than expected because they learn to consume medical care more judiciously. Similarly, some persons with disabilities are actually able to find more remunerative work after the onset of their disabilities or are able to replace paid help in family roles such as child care because of their reduced work time. Finally, some report personal growth through the experience of having a disability and, thus, would not report psychological deficits, but the opposite.

There are two principal methods to assess the costs of illness or disability. The first, the human capital approach, was devised by Dorothy Rice and colleagues. The human capital approach provides estimates of the economic value of services or goods purchased to take care of oneself (principally medical care) as well as the economic value of losses to society when individuals function more poorly, principally, the wage losses of those who stop or reduce work effort and the equivalent in wages for those one would hire to replace other kinds of function, for example, the costs associated with paying someone else to do the tasks associated with being a homemaker.

In the other principal method, the willingness-to-pay approach, one accounts for the tangible and intangible impacts of lost function by asking respondents how much they would be willing to pay to forgo an illness or disability. As a practical matter, because the obstacles to implementing the willingness-to-pay approach are so numerous (including the fact that individuals have trouble completing the exercise of stating their willingness to pay, are far more willing to pay after the onset of illness or disability than before, and the amount they are willing to pay is proportional to income, suggesting that some lives are worth more than others), there are no cost-of-disability studies using this method.

Even among the studies using the human capital approach to estimate the cost of disability, most have enumerated the direct and indirect costs incurred by persons with disabilities, regardless of whether the disability status accounts for the costs, rather than estimating the actual economic impact of disability above and beyond what would be expected in the absence of the disability. (Table 3, below, provides summary estimates of the latter below.)

RESULTS OF PRIOR ANALYSES

Table 1 reviews the results of the principal studies of the economic impact of disability over the past several decades. The studies differ in their perspective (with some providing estimates of the costs to government; some to disability insurers, including those in government and the private sector; and some to society as a whole) and the range of costs enumerated (with some limited to medical care expenditures as well as those for disability-specific services such as rehabilitation, some to disability insurance benefits [called income transfers when provided by government], and others encompassing both). In addition, the studies differ in the populations studied—from all persons with disabilities to only those of working ages or only children. Moreover, the results of the studies using different perspectives cannot be compared. For example, studies of the costs of disability from the perspective of society would necessarily omit an enumeration of disability transfer payments to avoid double-counting the impact of lost wages.

The first comprehensive assessment of the economic impact of disability was completed by Berkowitz and Johnson in 1970 and concerned the magnitude of disability transfer payments by the federal government in 1967: $43 billion ($207 billion in 1997 dollars). Burkhauser and Haveman provided a thorough review of government and private disability expenditures in several years; Table 1 provides the estimates for the last year for which they have complete data, 1978. They reported that government and private disability expenditures totaled $82 billion in that year (or $202 billion in 1997 terms). Disability transfers, worker's compensation, and medical services comprised most of the total. Snook and Webster estimated the magnitude of disability transfer payments, by kind, for 1981. Social Security Disability Insurance payments totaled $17 billion, worker's compensation payments were $16 billion, while private disability payments amounted to $5 billion. In 1989, Berkowitz and Greene updated the earlier estimates for 1986, finding that disability transfers (including those from the private sector) were $87 billion (or $127 billion in 1997 terms). The real value is actually less than their earlier study due, in part, to differences in services and income transfers enumerated as well as errors in adjusting for inflation. In addition, medical care expenditures on behalf of persons with disabilities totaled $79 billion in 1986 ($116 billion in 1997 terms) while expenditures on disability-specific services amounted to $3 billion ($4 billion in 1997 terms). The total of government and private expenditures on behalf of persons with disabilities in 1986 of $169 billion amounted to 3.8 percent of the GDP for the United States in that year. More recently, Aarts and colleagues provided estimates of government disability expenditures. Although they provided the estimates in terms of the percentage of GDP, we have translated the figures into billions of dollars. In 1991, government disability expenditures totaled $45 billion, of which all but $3 billion was due to disability transfer payments.

Several analysts have calculated the magnitude of medical care expenditures for persons with disabilities in both the public and private sectors. In the first of these, Newacheck and McManus estimated that expenditures on behalf of children with disabilities totaled $2 billion in 1980, or $4 billion in 1997 terms.

Table 1 Prior Studies of the Costs of Disability

Study	*Publication Year*	*Perspective*	*Population Studied*	*Scope of Study*	*Findings Study Year*	*% GDP*	*Current $ (billions)*	*1997 $ (billions)*
Berkowitz, Johnson	1970	Government disability insurers	All persons with disabilities	Disability transfers	1967		43	207
Burkhauser, Haveman	1982	Government and private expenditures	All persons with disabilities	Disability transfers	1978		29	71
				Workers' compensation			9	21
				Medicaid/Medicare			43	106
				All other			1	3
				Total			82	202
Snook, Webster	1987	Government and private disability insurers	Working-age persons with disabilities	Social Security disability	1981		17	30
				Workers' compensation			16	28
				Private disability benefits			5	9
				Total			38	67
Newacheck, McManus	1988	Government and private expenditures	Children with disabilities	Medical care expenditures	1980		2	4
Berkowitz, Greene	1989	Government and private expenditures	Persons ages 18–64 with disabilities	Disability transfers	1986		87	127
				Medical care expenditures			79	116
				Disability services			3	4
				Total			169	247
Chirikos	1989	Society	All persons with disabilities	Direct costs	1980		91	177
				Indirect costs of persons with disabilities			68	132
				Indirect costs of family members of persons with disabilities			18	35
				Total			177	345
Rice, Laplante	1992	Government and private medical expenditures	All persons with disabilities	Persons with one limiting condition	1980		49	95
				Persons with two or more limiting conditions			14	27
				Total			63	123
Trupin, Rice, Max	1995	Government and private medical expenditures	All persons with disabilities	Out of pocket	1987		29	41
				Private insurance			42	59
				Public programs			80	113
				Other			6	8
				Total			157	222

Table 1 (Continued)

Study	*Publication Year*	*Perspective*	*Population Studied*	*Scope of Study*	*Findings Study Year*	*% GDP*	*Current $ (billions)*	*1997 $ (billions)*
Institute of Medicine	1997	Society	Persons ages 18–64 with disabilities	Indirect costs National Health Interview Survey—without adjustment	1994		159	172
				National Health			111	120
				Interview Survey—with adjustment			133	144
				Current Population Survey—without adjustment				
				Current Population Survey—with adjustment			93	101
Aarts, Burkhauser, De Jong	1998	Government disability expenditures	All persons with disabilities	Vocational rehabilitation[a]	1991	0.05	3	4
				Direct job subsidies[a]		–		
				Transfer payments[a]		0.70	42	49
				Total[a]		0.75	45	53

Note: Current year estimate updated to 1997 terms by the Consumer Price Index for all items.

a. Article states costs as percentage of gross domestic product (GDP). Transformed back to $billions by multiplying percentage GDP by 1991 GDP.

Table 2 Direct and Indirect Costs Incurred by Persons with Disabilities

	Mean ($)	*% of Direct*	*% of Indirect*	*% of Total*	*Sum (billions of $)*
Direct costs					
Office Based/Ambulatory Care	1,722	22		9	39.9
Inpatient/ER	3,691	47		19	85.5
Home Health	1,024	13		5	23.7
Prescriptions	991	13		5	23.0
Devices/Home Alterations	222	3		1	5.1
Other	178	2		1	4.1
Total	7,879	100		40	182.6
Indirect costs					
Loss of Employment	8,489		72	43	96.0
Earnings Losses among Employed	3,252		28	17	19.0
Total	11,741		100	60	115.0
Total	19,620				297.6

Source: Author's analysis of 1997 Medical Expenditures Panel Survey.

Similarly, Rice and LaPlante estimated that medical care expenditures for persons with disabilities of all ages for the year 1980 totaled $63 billion, or $123 billion in 1997 terms. Trupin and colleagues calculated the magnitude of medical care expenditures for persons with disabilities for 1987, by source of payment. Of the total expenditures of $157 billion ($222 billion in 1997 terms), out-of-pocket expenditures were $29 billion, private insurance paid for $42 billion, public insurance paid for $80 billion, while other sources paid for $6 billion.

In 1989, Chirikos made the first comprehensive assessment of the costs of disability from the perspective of society using data from 1980. He reported that direct costs for medical care and disability services amounted to $91 billion in that year, indirect costs due to lost wages of persons with disabilities were $68 billion, while indirect costs of lost income among family members were $18 billion, for a total of $177 billion ($345 billion in 1997 terms). Using these figures, the cost of disability to society was the equivalent of 6.3 percent of GDP for 1980. Since the Chirikos study was published, no similarly comprehensive estimates of the costs of disability have been completed. However, the Institute of Medicine provided estimates of the indirect costs associated with disability for 1994 using two different data sources with and without adjustment for differences between persons with and without disabilities in demographic and health characteristics. The institute estimated that the indirect costs associated with disability ranged from $93 to 159 billion ($101 to $172 billion in 1997 terms). Thus, despite the passage of time since the Chirikos study, his estimate and that of the Institute of Medicine of the indirect costs associated with disability were of similar magnitude.

RESULTS OF NEW ANALYSES

The authors of this entry have used the Medical Expenditures Panel Survey (MEPS) to develop estimates of the economic impact of musculoskeletal conditions, the subset including various forms of arthritis, and respiratory conditions. The MEPS, jointly administered by the Agency for Healthcare Research and Quality and National Center for Health Statistics, is an annual survey of medical care utilization and attendant costs and functional status among the U.S. noninstitutionalized population. In these prior studies, we have estimated the direct and indirect costs incurred by persons with the aforementioned medical conditions regardless of whether the condition in question was responsible for those costs. In addition, we have used regression techniques to estimate the increment in direct and indirect costs associated with the specific condition being studied.

In the analyses reported here, we replicate the methods of the prior studies to provide estimates of the direct and indirect costs incurred by persons with disabilities as well as of the increment in such costs specifically associated with disability for 1997. For the analyses, we defined *disability* as the presence of a limitation in work, household, or school activities or a limitation in social or recreational activities or the presence of confusion or memory loss, difficulty making decisions, or the need to have one's activities supervised by someone else for one's safety due to cognitive impairment. All told, about 23.2 million persons (8.6 percent of the noninstitutionalized population) met one or more of these criteria for disability, of whom about 10.2 million were men and 13.0 million were women.

Table 2 shows the distribution of all direct and indirect costs incurred by persons with disabilities, by kind. Overall, direct and indirect costs for persons with disabilities averaged $19,620 per case, for a total of $297.6 billion (the equivalent of 3.6 percent of the GDP for 1997). Of the $19,620 average, $7,879 per case, or $182.6 billion (40 percent of all costs) was associated with direct costs and the remainder, $11,741 per case, or $115.0 billion, with indirect costs. Lost wages among persons who had stopped working altogether was by far the single largest component of costs ($8,489 per case, or 43 percent), while inpatient or ER costs and lost wages among those still employed represented 19 and 17 percent of total costs, respectively. To put the 3.6 percent of GDP figure in perspective, the economy is said to be in a recession when the overall economy contracts by 1 percent or more for two consecutive quarters. So the economic impact of the direct and indirect costs incurred by persons with disabilities would have an effect of a severe and ongoing recession.

The results of the analysis of the increment in direct and indirect costs associated with disability indicate that most of the costs incurred by persons with disabilities are the result of the disability itself rather than the other characteristics of persons with disabilities (Table 3). Accordingly, total costs associated with disability averaged $16,113 per case, or $217.3 billion (2.6 percent of GDP for 1997). However, the increment is disproportionately attributable to indirect costs as a result of lost wages. Whereas 40 percent of all costs incurred by persons with disabilities were for direct costs, only 18 percent of the increment associated with disability was due to direct costs. Prevention of work disability, one of the principal goals of the Americans with Disabilities Act, is essential to limiting the economic impact of disability.

Table 3 Direct and Indirect Costs Associated with Disability

	Mean ($)	*Sum (billions of $)*	*% of Total*
Direct Costs			
Total	2,953	68.4	18
Indirect Costs			
Total	13,160	148.9	82
Total	16,113	217.3	100

Source: Author's analysis of 1997 Medical Expenditures Panel Survey.

Note: Direct costs estimated for all persons age 18 and older; indirect costs for all persons ages 18–64.

Interestingly, the increment in the earnings gap is larger than the raw earnings gap. The implication is that persons with disabilities earn more than expected on the basis of their disability and their other characteristics; the results are inconsistent with the charge that persons with disabilities may not persevere at work because of the availability of disability benefits.

—*Edward Yelin and Laura Trupin*

See also Disability Policy: United States; Financial Costs of Disability; Health Management Systems.

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ECONOMIC AND SOCIAL DEVELOPMENT

Disability is linked to development in a manner that is neither obvious nor well established. For instance, increased disability may be the result of advances in health signaling broad-based welfare improvements, or societies may be in such economic or political disorder that continued poverty or war conflict leads to a rise in the prevalence of disability. At the same time, disability seems to impede development through the constraints it places on individuals’ productivities and earning capacities. These complications combined with a dearth of comparable data may explain why the link between disability and development has been the subject of very little research in both the disability and development literatures. More attention has been granted to the link between disability and poverty, widely accepted as a vicious circle. The relation between development and disability may be understood as a two-way street, where development affects disability and vice versa. Disability and development are intertwined, and we seek to understand both strands of the relationship. The major part of this review explores aspects of the relationship at a macro level, while touching on micro- and policy-level links as well.

This entry is organized as follows. I first clarify the concepts of development and disability. The entry then analyzes the two-way relation between development and disability. At the micro level, the entry explains the vicious circle between poverty and disability. Finally, I review disability policies of international development agencies such as the United Nations and the World Bank.

TWO CONCEPTS: DEVELOPMENT AND DISABILITY

We all have intuitive notions of *development* and *disability*. Yet these two concepts are complex and cannot be used without clarifying their definitions and measurements. Development typically refers to the structural transformation from a subsistence economy to an urban industrial economy, and to the sustained rise in income and productivity that follows. The transformation takes place in various aspects of the economy and society, including in the structure of consumption, production, investment, and trade and in demographic trends and economic institutions. While development is typically understood in its narrow economic sense, it also has human and political dimensions. Human development is the process of expanding the education, health, and other conditions of human life. In its political sense, development refers to the process that provides individuals with improved civil rights and with the opportunity to determine who should govern. It refers to entitlements and institutions one usually associates with democracies.

In this broad sense, development refers to the enhancement of individuals' capabilities and freedoms. This concept of development is far more difficult to measure than the conventional economic view of development captured in the per capita gross domestic product (GDP), growth, or industrialization measures. However, several measures have been developed to capture this broader approach of development including the Human Development Index of the United Nations Development Programme (UNDP). *Development* is thus a multifaceted term. We understand it as a broad concept with economic, human, and political dimensions when we attempt to understand its link to disability.

Disability has proved to be a very controversial and complex concept to define and measure, and analyzing its definitional problems is beyond the scope of this entry. In brief, different conceptual models have been created to define disability. For instance, the medical model considers disability as a problem of the individual that is directly caused by a disease, an injury, or other health conditions and requires medical care in the form of treatment and rehabilitation. An individual with an impairment is considered disabled (where *impairment* is the term used for an individual's condition) irrespective of whether the person experiences limitations in his or her life activities. The medical model is usually opposed to the social model. Overall, the social model sees disability purely as a social construct and a human rights issue. Disability is not the attribute of the individual; rather it is created by the social environment and requires social change. In the social model, disability is generally understood as the result of social oppression, and this oppression can start in the form of poverty and later on lead to disability.

Recently, S. Mitra used A. K. Sen's capability approach that was developed to analyze concepts of the standard of living, poverty, and development in order to define disability. Here, disability is understood as a deprivation of capabilities where capabilities refer to practical opportunities. Disability occurs when an individual with an impairment is deprived of practical opportunities. Such deprivation may result from the interaction between the resources available to the person, personal characteristics (e.g., impairment, age, gender), and the environment (physical, social, cultural, political, economic). Poverty is a factor that, while interacting with the individual's characteristics and environment, may lead to disability.

The development and disability concepts may overlap depending on the approach we adopt to define each concept. Development and disability do not intersect when they are understood in their narrow economic and medical senses, respectively. However, if development is defined as a broad-based process that enhances human capabilities, then it may well intersect with disability. If we place ourselves in the social model where disability is a human rights issue, or if we adopt the capability approach where disability may be considered as a capability deprivation for persons with impairments, then development and disability are entwined. Clearly, if being disabled means being deprived of capabilities, reducing disability can be conceived as an integral part of the development process. Development can be considered as a process that, among other things, curbs disability by enhancing human capabilities. Development and disability are then two intrinsically linked concepts.

In the remainder of this entry, we leave the complexities of the relation between the concepts of disability and development. We use the term *disability* as a two-facet concept that refers to both disability and impairment, and we understand *impairment* as a physiological, mental, or anatomical loss. Instead, we focus on the dynamic relation between disability and development, and between disability and poverty: How does development affect disability prevalence? How does disability affect the development process? How does disability relate to poverty?

DEVELOPMENT AND DISABILITY: A TWO-WAY RELATION

There are four fundamental questions relating to the relationship between development and disability: (1) How does development affect the prevalence of disability? (2) How does development affect the distribution of disability within the population? (3) How does development impact the major causes of disability? and (4) How does disability impact development itself?

The Impact of Development on Disability Prevalence

To attempt to address the first question, we introduce the notion of disability transition. Disability transition is a concept that is meant to capture the changing pattern of disability as a country develops. As there is a "population transition" apparent in reduced birth and death rates, one may wonder if there is a "disability transition" that accompanies development. There is no definite answer to this question, whether at the theoretical or empirical level. There are mainly three theories about the link between the effect of increased life expectancy and changing morbidity associated with development on disability prevalence. The first one, and probably the most widely accepted theory, is that development leads to increased disability prevalence. The basic rationale is that the demographic and medical changes associated with development, increased longevity and survival from disabling accidents and conditions, lead to increased disability prevalence. Second, in what is often called the compression of morbidity theory, it is argued that with medical improvements, the proportion of life lived with a disability decreases and the prevalence of disability also decreases. A third theory predicts a reduction in severe disabilities through enhanced medical intervention and a rise in mild disabilities.

Is there any empirical evidence of a disability transition? While we realize that country-level estimates are not comparable because different definitions and methods are used, available disability rates seem to show a higher disability prevalence in developed countries than in developing countries. On the basis of United Nations data, for developed countries, disability rates are in the 14 to 20 percent range, while they are generally below 5 percent in developing countries. However, one needs to be very cautious when analyzing this apparent correlation between disability and development. Many factors, in particular those related to perception and measurement, contribute to higher prevalence rates in developed countries.

There are several types of factors related to development that may have an increasing or a decreasing impact on disability prevalence. First, there are factors related to demographic and health changes associated with development. For instance, improved survival rates from conditions causing illnesses and impairments would lead to an increase in disability prevalence, whereas an increase in prevention care would generally be expected to reduce disability prevalence. Second, there are aspects in the environment that would be affected by development and would in turn affect disability prevalence. Wars and political unrest are surely not limited to developing countries, but it is in the developing world that the effects are widely borne by populations, in particular through disabling injuries. It is also in developing countries with mass poverty that there are impairments resulting from inadequate nutrition and hazardous modes of living. Such impairments resulting from political unrest or poverty would be expected to decrease with development.

Third, there are factors related to the way impairments and disabilities are perceived and reported. These include increased knowledge and awareness of impairments, increased diagnosis and screening, medicalization of problems, change in perceived standard of good health, and eligibility to social benefits based on disability. All these factors lead to an increase in perceived disability and would therefore explain a higher reported disability prevalence in developed countries compared to developing countries.

Finally, fundamental differences in measuring instruments also affect prevalence estimates across developed and developing countries. Developed countries typically use disability screens that assess activity limitations, whereas developing countries tend to use impairment screens. Activity limitation screens generally lead to higher rates of reported disability than impairment screens. Indeed, individuals are more likely to identify activity restrictions because they immediately connect with daily experience, whereas an impairment may be only vaguely familiar and its nomenclature may be unknown.

The first two types of factors mentioned above indicate that some factors associated with development changes per se (medical, demographic, environmental changes) are expected to have a negative impact on disability prevalence, others a positive one. In contrast, factors related to perception and measurement all seem to have a positive association with development. Altogether, these factors probably argue in favor of higher reported disability rates in developed countries compared to developing countries. This analysis is consistent with the much higher rates of disability prevalence that we find in country-level estimates for developed countries versus developing countries.

However, this analysis and these country estimates are not consistent with global estimates of disability prevalence. The United Nations estimates that 10 percent of the worldwide population have a disability and that two-thirds live in developing countries. In 1984, the UN secretary general reported that an average of 20 to 25 percent of the population of developing countries is disabled. This number is likely to have increased because of wars and other forms of violence, inadequate medical care, and natural and other disasters. The empirical evidence on the impact of development on disability is thus inconclusive: The lack of comparable data across countries prevents us from providing any clear and supportive evidence to any of the theories on a disability transition.

The World Health Organization (WHO) has recently released the International Classification of Functioning, Disability, and Health (ICF), which should provide a more unified and standard framework for the recording of disability in the context of development if it is implemented successfully. It is astonishing that disability data have been rarely collected in the human development literature. Since 1990, as part of the Human Development Reports, UNDP reports annually on the health access and profile of populations as part of its human development indicators and for the compilation of a human development index. Health profile indicators include, among others, incidence of malaria, HIV/AIDS, tuberculosis, cigarette consumption, and access to nurses and physicians; rarely has it included data on the numbers of persons with disabilities. One exception is the Human Development Report of 1999.

Despite these limitations due to the dearth of comparable data, we can make some general statements regarding the distribution of disability by age and causes across developed and developing countries. The distribution of disability causes across developing and developed nations is well-known. Disabilities resulting from land mines and wars, tuberculosis, malaria, anemia, HIV/AIDS, and diarrheal diseases are more prevalent in developing countries, while disabilities resulting from road accidents, heart disease, and pulmonary diseases are typical of developed countries. The distribution of disability by age is also well established. In developing as in developed countries, age-specific disability rates and the severity of disablement increase with age. However, because in developed countries the elderly represent a larger share of the total population than in developing countries, disability seems to be more concentrated in older age groups. In addition, in developing countries, the proportion of disabled children is higher than in developed countries.

The Impact of Disability on Development

We tackle the last question that we set out at the beginning of this section, what are the implications of disability for the process of development? This relationship is typically thought to be negative. A large disabled population means that there is a lower supply of productive labor, leading to a reduction in income and production. However, this question is somewhat more subtle than appears at first glance. There are many ways in which disability can influence economic and social outcomes and development in particular, ways that will vary given a country's resource endowments and its social, cultural, and institutional environment.

Simple economic arguments suggest that disability worsens social and economic outcomes and impedes development. Indeed, disability places constraints on individuals' productivities and earnings capacities. As such, there is an economic loss attributable to disability, and the extent of this loss has been assessed in some countries. For instance, a study by Cooper and Rice found productivity losses due to disability amounting to 3.5 percent of the gross national product (GNP) of the United States. Of course, this economic loss associated with disability is reduced in countries that have effective vocational rehabilitation programs in place that promote the labor force participation of persons with disabilities.

The economic and social implications of disability are also apparent in public expenditures and disability-related sectors of the economy. This is mainly the case though in developed counties, where disability has given rise to specific markets in the health care, rehabilitation, insurance and legal fields, and where government disability expenditures tend to be significant. For instance, estimates of public expenditures on disability-related programs stand at about 5 percent of GDP for the Netherlands and Sweden, and 1.5 percent for the United Kingdom. The net impact of disability on the overall economy depends on how the loss in productivity and potential earnings compares to disability-related expenditures in the private markets and the public sector. In developing countries, because government expenditures and markets related to disability are very limited, the main economic implication of disability seems to be the economic loss from reduced productivity and earnings. Thus, while disability seems to hold back development through the economic loss it brings about, the impact of disability on this process evolves and becomes more complex as a country develops and establishes public policies and private markets related to disability.

The economic loss resulting from disability points toward the importance of prevention and employment policies as part of the development agenda as well as toward the link between disability and poverty at the micro level.

DISABILITY AND POVERTY

Poverty is the most visible characteristic of underdevelopment. There is little controversy nowadays over the fact that the fundamental purpose of development is poverty eradication. Hence, the relation between poverty and disability is an important consideration. If the relation between disability and development is complex and ambiguous, what can be said about that between disability and poverty?

Poverty and disability have been linked through a "vicious circle" that has been described in several sources. For instance, it has been described as a two-way relationship with disability contributing to an increased risk of poverty and vice versa, resulting in persons with disabilities being part of the poorest of the poor.

From Disability to Poverty

The fact that disability may lead to poverty is common sense. Disability places constraints on an individual's earnings capacity and adds costs related to the disability in terms of health care for instance. The economic well-being and poverty status of persons with disabilities has received limited attention in both developed and developing countries.

The few studies on the economic well-being of persons with disabilities in the United States have assessed trends in incomes whether from work or public benefits for persons with disabilities. However, such studies do not take into account the costs that may be associated with a disability at an individual or a household level. There is a need to assess the costs of a disability in terms of both forgone earnings and direct costs at the individual and household levels to gain a better insight into the poverty status or risk of such individuals and households. Such costs include medical expenses, equipment, adaptations to housing, and means of transportation and personal care. One study by Erb and Harris-White found, based on a village-level survey in southern India, that the direct cost of a chronic illness or an impairment in terms of equipment and treatment averaged three months of a person's income. This does not include forgone earnings due to an inability to work, nor the opportunity costs borne by other members of the household. The costs to caregivers, particularly in terms of forgone work earnings, are increasingly recognized and have been evaluated in the United Kingdom. The cost of personal care on the household may be more important in developing countries than in developed countries since the former generally do not offer income maintenance programs and other funded entitlements as the latter do. In developing countries, families are typically considered as being responsible for persons with disabilities. The direct costs of disabilities and the forgone earnings they entail warrant more research in developing countries. Assessments of such costs would allow researchers to evaluate if the minimum standard of living encapsulated in the poverty threshold is sufficient to meet the needs of persons with disabilities and would aid the formulation of poverty reduction strategies for persons with disabilities. An obstacle to such research is the lack of sources of reliable data on both disability and poverty in developing countries.

From Poverty to Disability

Poverty itself can be the catalyst of a disability; this is particularly the case in developing countries where disability largely results from preventable impairments associated with communicable, maternal, and perinatal diseases and injuries. Poor individuals and families do not have enough resources to satisfy their basic needs, and their sanitation and shelter are inadequate. They may contract some diseases, which, with a lack of access to health care, make them become disabled. Malnutrition in its various forms is a cause of disability for adults and children. Malnourished mothers have low-birth-weight babies who are more at risk of debilitating diseases than healthy babies. Malnourished children are also more prone to impaired intellectual development. UNICEF notes that the incidence and severity of disability are the greatest in countries at earlier stages of development as a consequence of factors that are mainly related to poverty.

Poverty and disability are also linked through the general level of awareness and education of the poor. Parental awareness, access to information, and maternal education have been found to have a great preventive effect. In addition, poverty and disability are linked through the working environment of the poor given that poor people tend to work in more risky physical environments.

While this link from poverty to disability is usually addressed in the context of developing countries, it does not disappear with development. For instance, empirical evidence on the association of poverty and poor health or disability is clear in the United States. The link between poverty and disability is expected though to be more pronounced in developing countries with mass poverty.

Overall, it is obvious that poverty and disability are strongly correlated. Poverty may influence disability and disability may influence poverty. Understanding such relationships is essential for the design of poverty reduction strategies.

INTERNATIONAL DEVELOPMENT AGENCIES

Despite the strong but complex link between disability and development, international development agencies have paid marginal attention to disability. The emphasis has generally been on prevention of impairments and rehabilitation with additional initiatives in data collection efforts and rights-based initiatives. The United Nations has taken the leadership in providing assistance in the field of disability and development. Several UN agencies support or operate community-based programs providing rehabilitation or vocational training programs. In 1982, the United Nations adopted the World Programme of Action Concerning Disabled Persons as a global strategy to prevent disability, promote rehabilitation, and provide for the full participation of persons with disabilities. In 1993, the United Nations introduced the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which are not legally enforceable but do set an inclusive and antidiscriminatory standard that is used when national policies are developed. There is currently a campaign by disability organizations to have a UN convention on the rights of persons with disabilities.

The lack of comparable data on disability is an obstacle to research on development and disability as well as for international organizations to form disability policies and to evaluate policies aimed at tackling both disability and poverty. In 1993, the World Bank developed the disability adjusted life year (DALY) to provide comparable data on the burden of disease and disability. The DALY was strongly criticized on various grounds, including that disability is considered as a burden on society and that disability is equated to disease without recognizing the numerous factors that lead to disability including environmental ones. The WHO has taken several initiatives to develop comparable data sources, the latest being the development of the ICF. In the ICF, functioning refers to body functions and structures, activities, and participation, while disability includes impairments, activity limitations, and participation restrictions. The ICF is a model of disability that offers a concrete classification system of individuals, and it is thus expected to provide comparable data across countries if it is implemented successfully.

Thus, there is a very limited record of disability work in prominent development organizations. We are very far from having a disability paradigm in the development field as there has been a health or gender paradigm in the recent past. It is encouraging to note though that a new Office of the Advisor on Disability and Development was created in 2002 at the World Bank as a result of which the disability dimension of poverty reduction programs is starting to receive some attention and several data collection and gathering efforts in relation to development are under way.

CONCLUSION

It is evident that there is a strong link between disability and development. Despite this, disability remains a marginal area of interest in development research and practice. Certainly, efforts to improve the quality and comparability of disability statistics will help clarify some of the complex relationships we have pointed out in this entry and demonstrate the importance and relevance of disability issues in the context of development.

—Sophie Mitra

See also Citizenship and Civil Rights; Developing World; Economic and Social Development, International; Poverty; United Nations; World Bank; World Health Organization.

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ECONOMIC AND SOCIAL DEVELOPMENT, INTERNATIONAL

"Disability" is a complex, global phenomenon. The number of persons with disabilities in the world is estimated to be 500 million. In most countries, at least 1 out of 10 persons has a disability with physical, mental, or sensory impairment (United Nations Enable 2004). What is disability? Though they are different, terms such as *functional impairment*, *disability*, and *handicap* often are used interchangeably. The World Health Organization (WHO) offered a comprehensive

International Classification of Functioning, Disability, and Health (ICF) as an operational standard (adopted by 191 member states of WHO) to facilitate policy development, economic analyses, and research uses involving disability (WHO 2002). ICF is complementary to WHO's International Classification of Diseases (ICD-10). ICF offers core classification on function, while ICD offers core classification of health condition and diagnosis. ICF is organized around body function and structure, individual activities and task participation, and environmental factors.

Countries gather data on disability and estimate prevalence rates. But due to differences in the concepts (or definitions) and methods used in collecting data on disability, prevalence rates are not comparable across countries. Differences in definition or method can lead to different prevalence rates even *within* a country. Inconsistency in definitions of disability can cause a problem in the administration of programs for persons with disabilities. For example, acknowledging this problem, Australia has been working toward national consistency in disability definition and data collection (Australian Institute of Health and Welfare 1997).

From a *traditional perspective,* many cultures associated disability with sin, shame, and feelings of guilt. Persons with disabilities were socially ostracized and excluded from participation in community activities. The presence of an impairment coupled with negative attitude and behavior of family and community led to rejection or isolation of children and adults. From a *medical perspective,* disability is regarded as a sickness or disease that can be cured through medical intervention. From a *humanitarian perspective,* disability is viewed as a function of the interaction between the individual with impairment and the environmental demands (cultural, social, architectural, and technological). From a *workforce perspective,* disability is viewed as a functional limitation preventing equal rights and full participation in an employment setting. Appropriate job accommodations may be used to increase the employability of persons with disabilities and create equal opportunities (Job Accommodation Network 2003).

Increasing numbers of persons with disabilities are linked to factors such as poverty, hunger, epidemics, violence, war, living conditions, illiteracy, health care, rural/urban geography, age shifts, accidents, natural disasters, environmental pollution, drug/alcohol abuse, and HIV/AIDS. The correlation between disability and poverty has been well established. In developing countries, 80 percent of persons with disabilities live in isolated rural areas and are extremely poor (Chaliand 2004). How a person responds to a disability depends on *intrinsic factors* such as the type/severity of impairments (e.g., diabetes, total blindness) and personal characteristics (e.g., gender, age, education, skills, interests) as well as *extrinsic factors* such as environmental variables (e.g., high unemployment area, dysfunctional family). Social, cultural, and economic disadvantages restrict access to health care, education, training, and employment. Progress in life expectancy and overall physical and mental fitness is related to contemporary social and cultural forces. Advancements in knowledge and practice in the areas of health care, technology, and management of economies have led to substantial improvement in physical fitness, mental health, and life expectancy.

Population and adult mortality rates for males and females for some of the developing and developed countries in different regions of the world are highlighted in Table 1. The WHO (2003) indicated that generally, the adult mortality rate for women in all of the countries (both developing and developed) is lower than the adult mortality rate for men. For example, in Zimbabwe, the adult mortality rate (AMR) for females (F) is 789 deaths per 100,000 in a year. For males (M), the AMR is 821. But the AMRs for men and women in developing countries are substantially higher compared to developed countries. For example, in Japan (Developed), the AMR (F) is 46, and in Cambodia (Developing) the AMR (F) is 298. The developing countries are, of course, at various levels of economic development. Much of their economic growth is linked to natural resources such as oil (e.g., Saudi Arabia, Libya), copper (e.g., Chile, Peru, Zaire, Zambia), and bauxite (e.g., Guinea, Guyana, Jamaica). Technologically developing nations of Asia, Africa, and Latin America generally are characterized as poor and with high rates of illiteracy, disease, and population growth. The technological and economic development promotes health, education, and quality of life of a nation and tends to reduce mortality rate.

Table 1 Population and Adult Mortality Rate (AMR) (Female and Male) in Developing and Developed Countries, by Region, 2002

Country	*Population (000)*	*AMR (F) (000)*	*AMR (M) (000)*
Africa *(Developing)*			
Zimbabwe	12,835	789	821
Swaziland	1,069	707	818
Botswana	1,770	745	786
Zambia	10,698	654	700
Burundi	6,602	563	692
Central African Republic	3,819	566	620
Mozambique	18,537	519	613
Namibia	1,961	529	605
Rwanda	8,272	474	605
South Africa	44,759	482	598
Angola	13,184	481	594
Democratic Republic of the Congo	51,201	449	585
Liberia	3,239	471	582
Tanzania	36,276	512	561
Uganda	25,004	431	505
Niger	11,544	443	497
Ethiopia	68,961	422	487
Chad	8,348	402	477
Congo	3,633	410	474
Ghana	20,471	303	354
Americas			
(Developed)			
United States	291,038	83	140
Cuba	11,271	89	138
Canada	31,271	58	95
(Developing)			
Haiti	8,218	438	493
Honduras	6,781	150	269
Bolivia	8,645	209	260
Bahamas	310	153	248
Brazil	176,257	136	246
Colombia	43,526	99	236
Peru	26,767	144	205
Uruguay	3,391	88	182
Venezuela	25,226	97	182
Argentina	37,981	90	177
Paraguay	5,740	120	171
Jamaica	2,627	121	162
Panama	3,064	84	146
Chile	15,613	67	134
Southeast Asia			
(Developing)			
Myanmar	48,852	236	335
Nepal	24,609	290	301
India	1,049,549	220	291
Thailand	62,193	153	279
Bangladesh	143,809	258	251
Indonesia	217,131	208	244

(Continued)

Table 1 (Continued)

Country	*Population (000)*	*AMR (F) (000)*	*AMR (M) (000)*
Sri Lanka	18,910	121	238
Republic of Korea	47,430	61	166
Europe			
(Developed)			
Russian Fed.	144,082	168	464
Ukraine	48,902	139	378
Latvia	2,329	118	327
Hungary	9,923	112	256
Azerbaijan	8,297	122	231
Bulgaria	7,965	97	219
Poland	38,622	82	204
Turkey	70,318	112	177
Albania	3,141	94	167
France	59,850	60	133
Spain	40,977	47	120
Germany	82,414	60	118
Greece	10,970	48	118
United Kingdom	59,068	67	107
Norway	4,514	60	100
Italy	57,482	49	96
Netherlands	16,067	65	94
Sweden	8,867	53	83
Eastern Mediterranean			
(Developing)			
Somalia	9,480	418	534
Afghanistan	22,930	413	494
Sudan	32,878	278	379
Yemen	19,315	228	286
Pakistan	149,911	201	227
Iran	68,070	132	213
Lebanon	3,596	139	201
Saudi Arabia	23,520	112	192
Jordan	5,329	121	191
Syria	17,381	127	190
Kuwait	2,443	63	81
Western Pacific			
(Developed)			
New Zealand	3,846	63	98
Japan	127,478	46	95
Australia	19,544	52	91
Singapore	4,183	53	90
(Developing)			
Cambodia	13,810	298	400
Philippines	78,580	133	258
Vietnam	80,278	129	200
Malaysia	23,965	106	192
China	1,302,307	104	165

Source: *World Health Report* (WHO 2003).

High mortality rates are associated with various types of diseases and injuries. The three major categories used by WHO are (I) Communicable Diseases, (II) Non-Communicable Conditions, and (III) Injuries (World Health Organization 2003). Table 2 shows the rankings for these three categories within each of the

Table 2 Ranking of Diseases, Conditions, and Injuries Associated with High Mortality Rates within the Three Major Categories Used by WHO, by Region, 2002

Disease/Condition/Injury	*Africa VHAM*	*Americas HAM*	*E-Medit. HAM*	*Europe HAM*	*S-E Asia HAM*	*W-Pacific LAM*
I. Communicable Diseases	**1**	**2**	**1**	**3**	**2**	**2**
HIV/AIDS	1	2	6	2	5	5
Diarrheal diseases	4	4	3	4	3	3
Childhood diseases	5	5	4	–	4	4
Malaria	2	–	5	–	6	6
Respiratory infections	3	1	1	1	1	1
Perinatal conditions	6	3	2	3	2	2
II. Non-Communicable Conditions	**2**	**1**	**2**	**1**	**1**	**1**
Malignant neoplasm	2	2	2	2	2	2
Cardiovascular diseases	1	1	1	1	1	1
Respiratory diseases	3	4	4	4	3	3
Digestive diseases	4	3	3	3	4	4
Diabetes	5	5	5	5	5	5
III. Injuries	**3**	**3**	**3**	**3**	**3**	**3**
Road traffic injuries	1	1.5	1	1.5	1	1
Violence	2	1.5	2	1.5	2	2

Source: *World Health Report* (WHO 2003).

Note: VHAM = very high adult mortality; HAM = high adult mortality; LAM = low adult mortality. The three major categories (I, II, and III) are ranked based on the number of deaths that occurred in each category in 2002 in various regions of the world. Within each major category, the diseases or health conditions that caused mortality are ranked based on the number of deaths that occurred in each region (1 = highest rank, 6 = lowest rank).

six regions of the world (Africa, Americas, Eastern Mediterranean, Europe, Southeast Asia, and Western Pacific). For example, Communicable Diseases ranked highest (no. 1) in Africa, ahead of Non-Communicable Conditions (no. 2), and Injuries (no. 3). Within each major category, diseases or injuries are listed as subcategories. For instance, in Africa, HIV/AIDS was the highest-ranking communicable disease (no. 1), followed by malaria (no. 2), respiratory infections (no. 3), diarrheal diseases (no. 4), childhood diseases (no. 5), and perinatal conditions (no. 6). Ranks within the regions based on Table 2 show that Communicable Diseases rank highest in Africa and Eastern Mediterranean, whereas Non-Communicable Conditions rank highest in Americas, Europe, Southeast Asia, and Western Pacific. Furthermore, HIV/AIDS is the greatest contributor to mortality in Africa, but HIV/AIDS is the smallest contributor to mortality in the Eastern Mediterranean region.

Though diabetes does not rank high as a major cause of deaths, diabetes has been rapidly increasing and having a great impact on adults of working age around the world, especially in the developing countries. In 2000, there were 171 million people with diabetes worldwide, and by 2030 this figure is expected to more than double (366 million), and most of this increase will occur in developing countries such as India and China. And a global partnership spearheaded by WHO, Rotary International, the U.S. Centers for Disease Control and Prevention (CDC), and UNICEF supports the efforts of national governments to eradicate polio. The partnership includes private foundations, donor governments (developed countries), and humanitarian and nongovernmental organizations (NGOs).

The WHO promotes collaboration among health, education, social, and labor sectors to ensure that persons with disabilities receive all available services to assist them in achieving equal opportunities. WHO encourages the involvement of persons with disabilities as an essential feature of all program areas (health, education, social, labor). WHO holds that empowerment of persons with disabilities in community-based rehabilitation is necessary to achieve full social integration within their communities. Many developing countries have taken important steps during the past 10 years. Recognizing that inclusion and integration of persons with disabilities into their communities can be achieved only through political and social action, many developing countries have enacted legislation to guarantee the rights of persons with disabilities. For example, in 1991, Thailand passed its first governmental act, the Rehabilitation of Disabled Person Act, focusing on the rights of people with disabilities (Constantine 2000). Philippines has legislation known as the Magna Carta for Disabled Persons. In 1995, Philippines partnered with the Danish Society of Polio and Accident Victims, and initiated projects establishing Therapeutic Activity Centers serving 5,700 children with disabilities. In 1991, Bangladesh established (1) the National Forum of Organizations Working with Disabled and (2) the National Council for the Blind, both under the Ministry of Health (Economic and Social Commission of Asia and the Pacific [ESCAP] 2002).

In 1992, the ESCAP proclaimed a 10-year program known as the Asian and Pacific Decade of Disabled Persons 1993–2002 (ESCAP 2002). The program adopted an agenda for action to achieve the goals of full participation and equality for persons with disabilities. The ESCAP agenda called for a multisectoral approach reflecting the following 12 policy categories: national coordination, legislation, information, public awareness, accessibility and communication, education, training and employment, prevention of causes of disability, rehabilitation (community-based rehabilitation, and health/social development), assistive devices, self-help organizations, and regional cooperation. The program has produced initiatives of good practice in the ESCAP region by governmental and nongovernmental agencies (self-help organizations of persons with disabilities). For example:

- Bangladesh and Cambodia focused particularly on increasing public awareness of disability issues and outreach.
- Hong Kong, China demonstrated that legislation is effective with a built-in implementation and enforcement mechanism.
- Malaysia illustrated that general public awareness of disability issues must be accompanied by specific action to achieve necessary change.
- India stressed that determination and continued advocacy were necessary to achieve accessibility, and a project in India showed that a firm commitment to the education of all children was essential (increased enrollment of children with disabilities from 8 in 1981 to 31,000 in 2000).
- Thailand demonstrated (1) how appropriate and adequate training to rural people with disabilities (blindness) can help reduce poverty, and (2) how practical capacity building for training on productive small enterprise activities (e.g., mushroom production) could offer both improved food security and income generation for people with disabilities.
- Philippines and Bangladesh (using local organizations) underscored the importance of community-based effort as an integral part of rehabilitation as well as prevention of disability.
- Vietnam established importance of training on issues of policy, decision making, and mobilization of a self-help group.

Rehabilitation of individuals with disabilities facilitates their participation in the global marketplace. As formal and informal communication among countries increase, attitudes toward people with disabilities, government policies on disability, and rehabilitation programs are acquiring commonalities across counties. Targeted legislation, adequate service delivery programs, appropriate professional preparation, and continuing research and development will promote economic and social independence, leading to better quality of life for all citizens of the global community.

—Ranjit K. Majumder, Sita Misra,
and Richard T. Walls

See also Developing World; Disability in Contemporary Africa; Disability in Contemporary India; Economic and Social Development; Globalization; Poverty; World Health Organization.

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ECONOMIC DECISION MAKING BY THE DISABLED

Disabled people face many difficult decisions about how to best cope with their disabilities and plan for the future. In recent decades, policy makers have become increasingly interested in understanding how such decisions are affected by public policy. Until the 1960s, disability was primarily viewed as a clinical concept. As the federal disability rolls expanded rapidly during the 1960s and 1970s, researchers began to consider disability more broadly as a partly behavioral phenomenon influenced by economic, psychological, and social factors. A purely clinical view of disability was decidedly inconsistent with large observed variation in work patterns and public program participation among disabled people with the same observed medical conditions and sociodemographic backgrounds.

Often one of the most difficult decisions confronting a disabled person involves whether to remain employed in the current job, change occupations, or withdraw from the labor force altogether. The timing of changes in employment status depends on a variety of considerations including the type and severity of the medical condition, its prognosis, and the possibility of employer accommodations to improve access. Employment outcomes also depend on tastes for continued employment (which may be influenced by pain or difficulty in commuting), savings, income support from family members, other private sources of income, and the extent to which monetary and in-kind public transfers might substitute for forgone labor earnings.

Given sufficiently unattractive labor market prospects, a disabled person may decide to apply for disability benefits. The two dominant federal disability programs in the United States are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). Participation in SSDI is comparable to early participation in the Social Security retirement program. After a five-month waiting period, eligible beneficiaries receive monthly cash payments equal to the retirement benefits they would receive if they were 65. After two years, SSDI beneficiaries gain access to Medicare; the value of these medical benefits varies substantially across recipients depending on their specific health conditions and private health insurance status. SSI is a means-tested program targeted to low-income aged, disabled, or blind people. In contrast to SSDI, there is no waiting period or work history requirement. Beneficiaries have immediate access to medical care through Medicaid.

Much academic attention has focused on estimating how a disabled person's choice whether to continue work or apply for disability benefits depends on policy parameters (e.g., benefit levels, award standards, waiting periods) and personal characteristics (e.g., age, occupation, medical conditions). Economic theory assumes that people will make choices that maximize their expected well-being, given their constraints. Statistical models based on this assumption attempt to quantify a disabled person's expected level of well-being under various scenarios. The methods recognize that decisions are made in an environment of imperfect information, including uncertainty about the evolution of the work limitation, the path of potential wages, the quality of leisure time, and the government's decision about whether to approve a disability application. The methods also recognize that while some important personal characteristics can be observed in the data (e.g., age and years of schooling), others are unobservable to the researcher (e.g., motivation, the severity of a condition, and potential discrimination). Empirical estimates obtained from these models have been used to assess the degree of work disincentives associated with various policies and to forecast the extent to which policy changes would affect economic decision making. Researchers generally agree about the directions but not the magnitudes of these policy effects.

—Brent Kreider

See also Decision Making; Disability Policy: United States; Job Retention.

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EDISON, THOMAS (1847–1931)

American inventor

Thomas Edison, the most prolific U.S. inventor, has appealed to the popular imagination since the late 1870s. Among the most enduring stories are those about Edison's lack of formal education. Generations of schoolchildren have learned these as object lessons in perseverance. In recent years, Edison's name has been used to encourage persons diagnosed with disabilities such as attention deficit hyperactivity disorder (ADHD) and dyslexia. Although there is no evidence that Edison, a prolific reader, was dyslexic, opinions are divided regarding ADHD. The affirmative case rests partly on his short school career, anecdotes about inattention and mischievousness, his restless creativity, and ability to work on several projects simultaneously. More likely is that economic hardship made it difficult for Edison's family to pay school fees; his mother, a former teacher, was manifestly capable and made use of the family's ample library. Edison's mind was distinctive and fecund, but there is no clear evidence of functional impairments, which an ADHD diagnosis requires. Rather, his combination of originality, energy, and learning through experience epitomizes the divergent thinking that psychologist Lucy Jo Palladino has termed "the Edison Trait."

Edison's hearing impairment was incontrovertible. Its origin is unclear; he seems to have recognized it as a youth and it grew progressively worse. When newspapers reported it in 1878 following his invention of the phonograph, Edison received many letters seeking advice and hearing aids, which he made some effort to develop. Even as normal conversation became more difficult, Edison remained sociable and enjoyed the theater, taking care to sit near the front. He had a lifetime love of poetry and music. In his 60s, he insisted on selecting artists and recordings for his phonograph business, to the company's detriment. He said that by biting into the wooden horn he could "hear better than anybody else" because the sound went directly to his inner ear, which had been "protected from the millions of noises that dim the hearing of ears that hear everything."

—Louis Carlat

See also Hearing Impairment.

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EDUCATION, COLLEGE AND UNIVERSITY

> *Indeed, attempting to fit the problem of discrimination against the handicapped into the model remedy for race discrimination is akin to fitting a square peg in a round hole.*
>
> *Garrity v. Gallen*, 522 F. Supp. 171, 206 (DNH, 1981)

> *Section 504 and the ADA should be welcomed for the opportunities they offer to postsecondary education for rewarding self-examination. No other set of laws so entreats academia to take its own temperature, examine its traditions, and thoughtfully deliberate about which of its standards are essential and which are merely unexamined habits.*
>
> Paul D. Grossman (2001)

Support for students with a disability in higher education has both a long and a short history, an approach-avoidance relationship that both reflects and shapes the views of the larger social milieu. In the latter half of the nineteenth century, a national philosophy of educational egalitarianism began to influence colleges and universities in the United States. This movement was reflected in the Morrill Acts of 1862 and 1890, which created the land grant colleges, increasing both the diversity of the student body and the fields of study available.

During this same period, the Columbia Institution for the Deaf, Dumb and Blind was founded in Washington, D.C., by William Kendal. Kendal hired Edward Miner Gallaudet (the son of Thomas Hopkins Gallaudet, who founded the first school for deaf students in the United States) as the first superintendent. By 1864, Congress authorized the Columbia Institution to grant college degrees. The following year, the nine blind students at the institution were transferred to the Maryland Institution for the Blind, and the Columbia Institution for the Deaf and Dumb became the National Deaf-Mute College by an act of Congress.

In 1866, the National Deaf-Mute College conferred its first bachelor's degree, 21 years later the first women were admitted, and 28 years later the name of the college was changed to Gallaudet College. During Gallaudet College's first 30 years, numerous elementary, secondary, and vocational "schools for the deaf" or "schools for the blind" were established but did not lead to the spread of specialized institutions at the postsecondary level as it had for colleges founded to educate African Americans.

At the beginning of the twentieth century, the first dozen historically black colleges and universities had been established. Gallaudet would stand unique until 1965 when the Rochester Institute for the Deaf was established by Congress. This was not because individuals with disabilities were attending "mainstream" institutions in large numbers; they were as unique to postsecondary education as Gallaudet and would remain so for most of the century.

War, or more precisely returning veterans, became one of the driving forces in U.S. disability policy. Legislation supporting disabled veterans returning after World War I combined with early vocational rehabilitation programs aimed at injured workers began to increase participation in higher education. In 1943, the inclusion of assistance to disabled veterans in the Vocational Rehabilitation Act and the passage of the GI Bill in 1944 significantly increased this trend.

Similar to the latter half of the nineteenth century, the second half of the twentieth century oversaw a period of rapid expansion and democratization in education. In 1954, *Brown v. Board of Education* mandated desegregation of public education. In addition, college enrollments increased, the community college system was established, and open admissions programs were begun. By 1965, the Higher Education Act established grants for student support services aimed at fostering an institutional climate supportive of the success of low-income and first-generation college students. Eleven years later, the act would be expanded to include individuals with disabilities.

Beginning with the increasing presence of disabled veterans on campuses, services for students with disabilities began to emerge. By 1948, the University of Illinois at Urbana–Champaign had a formal program for students with disabilities. In a speech at the 25th anniversary of the program, Timothy Nugent, its founder, stated:

> The University of Illinois was the ideal place to bring about the total rehabilitation and integration of individuals with disabilities with its varied academic, social, cultural opportunities and challenges along with the resources and research capabilities to give credence to what we were doing. It was difficult and took time but it was well worth the pain and suffering. Very few of the young people today would tolerate or endure what many of my early students went through but they knew that they were building for the future. Of all of our facilities and programs the most effective was the development and participation in normalized competitive sports. To the individual participant, it helped overcome self-consciousness and develop self-confidence. There were many common denominators in our sports programs and those of the general population that all people could understand, appreciate, and respect. They began to recognize the normalcy of those with disabilities—their desires, skills, competitiveness, and emotions. They were athletes, and good ones too! (LaMere and Labanowich 1984)

The University of Illinois at Urbana–Champaign was typical of a few dozen programs that emerged as a result of the GI Bill. This university in particular provides a good example because of its better than average documentation over the years. With an emphasis on wheelchair users, programs applied the vocational rehabilitation model to higher education. Such programs offered adapted sports, housing, and transportation. The program at Illinois and the program helped to found the National Wheelchair Basketball Association, established a service fraternity for students with disabilities (Delta Sigma Omicron), introduced curb cuts on campus, and had lift equipped fixed-route buses by 1952. A transitional living program for students with severe disabilities needing assistance in the performance of daily living activities was established in 1959, and a study-abroad program for university students with disabilities was in place by 1965.

About that time, another model was developing in California. In 1962, Ed Roberts, who used a wheelchair by day and respirator by night, wanted to attend University of California, Berkeley. After a series of meetings between Roberts, his mother, and the administration, Ed Roberts was allowed to move on campus but in the campus' health facility, Cowell Hospital, not the residence hall. Word of this spread and by the end of the 1960s there were a dozen students on the third-floor Cowell Hospital.

In 1969, the students began moving from the hospital to apartments on the south edge of the Berkeley campus. In the spirit of the 1960s, the students organized. Calling themselves the Rolling Quads the organization gave voice to student concerns, negotiated with the college administration, and proposed the formal establishment of services for disabled students.

In 1970, the students were awarded a federal Department of Education grant of $80,000, and the Physically Disabled Students' Program was established. Its first director was John Hessler, one of the original students living in Cowell Hospital. By 1986, the program had grown to approximately 350 students; today it employs 30 staff members and serves more than 850 students.

By the early 1970s, there were isolated programs serving students with disabilities. Gallaudet and the Rochester Institute for the Deaf, established by Congress, stood at one end of the spectrum; a few dozen programs similar to the University of Illinois at Urbana–Champaign might be seen as a midpoint; and a handful of programs that were student driven along the lines of the program at Berkeley stood at the other end. Beyond these exceptions at most of the 3,000 or so accredited colleges in the United States there were no structured supports for individuals with disabilities, and if participation was encouraged it was based on individual circumstances and advocacy. This was about to change.

The disability rights movement was taking shape. When the Rehabilitation Act of 1973 was passed it included Section 504, and for the first time civil rights were legislated for people with disabilities in the United States. Section 504 prohibits programs receiving federal funds, which includes most colleges and universities, from discriminating against otherwise qualified "handicapped" individuals. It would take five years of lobbying and protesting before the American Coalition of Citizens with Disabilities (ACCD) won the release of regulations that would allow Section 504 to be implemented.

The full impact of Section 504 on higher education is not the focus of this entry, but it is important to note that the regulations for Section 504, subpart E, specifically covered postsecondary education and required that postsecondary education operate its programs (specifically identifying recruitment, admissions, academics, housing, research, financial aid, counseling, physical education, athletics, transportation, and employment assistance) in a nondiscriminatory fashion.

It is also important to note that Section 504 required institutions to make academic adjustment (modifications to policy procedure and practice) and provide auxiliary aids and services to students to provide equitable access to their programs. These adjustments and aids, commonly referred to as reasonable accommodations, must be provided unless they fundamentally alter the program or service in which the student participates. Balancing these competing equities, the individual right to participate and maintain the essential nature of programs became a part of the role and fabric of disability services in higher education.

In 1975, the Education for All Handicapped Children Act (P.L. 94-142) was passed and established the right of children with disabilities to a free and appropriate education in the public school systems. This increased the number of college students with disabilities prepared for colleges.

In 1976, the Higher Education Act was amended to include students with disabilities as one of the eligible populations for Student Support Services grants. This provided funding for the growth in disability service programs across the country. In March 1978, the Association on Handicapped Student Service Programs in Post Secondary Education was founded, which later became the Association on Higher Education and Disability (AHEAD).

The passage of the Americans with Disabilities Act (ADA) in 1990 did not substantially alter higher education's legal obligation because nearly all colleges and universities receive federal funds. From the early 1980s to the early 1990s, there was a growth in the enrollment of students with disabilities. A survey of first-time freshmen at four-year institutions indicated approximately 1.8 percent in 1980 reported a disability. In 2000, over 6 percent reported having a disability. The largest growth has been in the number of students with learning and psychological disabilities.

Shifting demographics has affected services. Today, disability services offices divide their work between two sets of tasks: accommodations and services. As accommodation decision makers, they review students' disability-related needs, relying heavily on documentation for students with learning and other "nonvisible" disabilities, and determine accommodations appropriate to the students' needs. Typically, they arrange for the conversion of print material into accessible formats, advise on facilities' access issues, provide proctoring for modified test conditions (extended time, reduce distractions), and provide adaptive equipment. In addition, they may provide awareness and training to faculty and staff, provide advising and counseling to students, and host support groups and student organizations.

—L. Scott Lissner

See also Accessibility; Gallaudet University; Rehabilitation Act of 1973 (United States); Ed Roberts.

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EDUCATION, INTERNATIONAL

Education is universal and occurs wherever people interact and communicate with each other. Educational practice in all cultures and societies is a mirror reflecting the ways in which people relate to each other. While education may be a global occurrence, education systems are continuously shaped by local beliefs, customs, and history in diverse nations. The differing beliefs on educability remain deeply entrenched in the cultural values and attitudes of particular societies. Thus, the education of children with disabilities can best be understood if the precise historical and cultural contexts in which they are raised are well understood. Therefore, international perspectives on the education of persons with disabilities may focus on global issues, as the established universal values in education or on the diversity in education, fashioned by the prevailing principles and demands of various societies.

The manner in which societies exploit their distinct human resources is an acknowledgment and measure of the power of education. The education of persons with disabilities therefore provides a glimpse into the essential understanding of humanity as perceived by a particular culture. Schools are the vehicles that societies employ to advance their aims of education. The culture and philosophy of schools therefore reflects a view on education embedded in a particular historical and cultural context. The systems countries design, for educating their children with disabilities, characterizes their general outlook on the human character and spirit. Throughout history, children with disabilities have been regarded as nature's mistakes and cruelly neglected and often killed. Recently, better understanding of disabling conditions and more promising practices among practitioners have led to fruitful international exchanges and meaningful dialogue among professionals in this field.

Comparative special education attempts a description of similarities and differences in various systems and provisions engaged in the education of children and youths with disabilities. More recently, comparative approaches also examine trends in educational provision across the lifespan, including early education programs as well as adult education for persons with disabilities.

While comparative special education contrasts practices in various countries, international special education seeks to identify paradigms and models beyond the instructional practices in individual countries. More recently a global perspective as to the best methods for providing quality education for children with disabilities has developed alongside scientific enquiries into education in general. The international discourse on disability and education has been fashioned by the scientific community, on the one hand, and by international organizations, on the other.

Historically, educational services for people with disabilities developed from practices and traditions of the medical profession as well as the religious and charitable institutions. Today's international perspectives on education for persons with disabilities are more systems oriented and invite the education system to promote greater social cohesion, inclusive practices, and equitable access for all children and youths.

INTERNATIONAL PERSPECTIVES IN EDUCATION

International exchanges of views about good educational practices are often initiated by parents or professionals working with children with disabilities. Recommendations regarding the handling of complex and challenging situations as well as the most pragmatic methods for coping with everyday situations have cross-national legitimacy. Pioneer efforts are usually embraced by education systems once their intrinsic worth is established. Usually, such international exchanges tend to focus on specific issues such as the efficacy of "sensory training" or early intervention programs for children with specific disabilities. Other practices shared internationally are approaches to alternative and augmentative communication or ways in with children with cerebral palsy can be supported.

On the other hand, comparative special education does not concentrate on the individual successes of children, but rather on the achievements of the education system. These revolve around such issues as the types of provision in the various countries and their delivery systems. Comparative special education may entail simple descriptions of the manner in which states organize their education or present multidimensional facets of their pupils, resources, and attainments. The comparison of provision for children with disabilities in the various countries is not always straightforward because of the lack of precision in the definition of disability and limited information about the reasons for failure to join the regular schools.

A country's ability to integrate children with a hearing loss, for example, may be due to a wider definition of hearing impairment—leading to an overidentification, compared to procedures in other countries. Measures used for assessing the accomplishments of special education in various countries are the level of resource investment (attributes and qualifications of teachers, financial support, and the availability of auxiliary services), the quality of educational processes (assessment procedures, teaching practices, and team collaboration), and outcomes (academic performance, pupil and teacher satisfaction, personal well-being, and transition to work and other settings). The apparent differences between countries lead to cross-national collaboration, joint programs, and assistance to less developed countries. Some disadvantaged countries may have only insignificant provision; others may offer good facilities for the children of upper-class parents or those living in affluent urban districts, but have few services available to the poor in rural areas. Considerable sensitivity needs to be exercised in this exchange lest the superimposition of the donors' values on the recipient country undermines their trust and integrity of their own society.

An international discourse does not merely focus on educational practices in different countries, but is also concerned with theories and research results that underpin practices. Since the issues surrounding the education of persons with disabilities are so many-sided and complex, it is hardly surprising that a large variety of scientific workers (doctors, psychologists, sociologists, academics) and practitioners (teachers, therapists, social workers) are drawn to the study of disability. In its early years, the international dialogue centered on the educability of children with disabilities and methods to be applied to their education. The present discourse gives greater attention to societal and system transformations that may be necessary to ensure successful outcomes of education. Currently, there is a swing away from a medical model to a social model, which emphasizes the importance of social structures to support the independence and rights of people with disability. Presently, robust debates can be observed, particularly at international congresses when scientists and theoreticians freely exchange their respective views on burning issues of disability and education.

While academics base their position in accordance with their specific theoretical framework, international organizations pay more attention to changing practices according to their general mission. Recent emphasis on disability issues is also the result of a growing interest in human capital, lifelong learning, and understandably also in the education of persons with disabilities. Many major international governmental organizations initiating educational, economic, social, or cultural development are today concerned with issues about disabilities. Some of them have recently formed a common platform to discuss and coordinate their disparate endeavors with a view to reducing waste and overlap. The International Working Group on Disability and Development is one such initiative designed to coordinate the various internationally active organizations such as the Organization for Economic Cooperation and Development (OECD), the United Nations Educational, Scientific, and Cultural Organization (UNESCO), or the World Bank.

Nongovernmental organizations (NGOs) created by interest groups lobby strenuously to further their respective causes and make strong representation to governments. Several international NGOs unite national interest groups to further their objectives, such as Inclusion International and Rehabilitation International. The development and relevance of such international private bodies were facilitated by the United Nations when the organization conferred official status to international NGOs representing a relevant and substantial interest group.

DEVELOPMENT OF INTERNATIONALITY IN EDUCATION

Famous individuals have contributed to the theory and practice of educating children with disabilities across the centuries. In England, the writings of Charles Darwin may have influenced the view that only the fittest should survive. Indeed, Darwin's illustrious cousin Francis Galton, the geneticist, advocated the segregation and sterilization of children and adults with intellectual weaknesses. His contemptuous and callous description of even the mildly retarded as "polluters of the noble stock of humanity, too silly to take part in general society and easily amused with some trivial harmless occupation" relegated the disabled to institutions or asylums or placed in the care of hospitals or charitable organizations. Abroad in France and Italy, for example, a more optimistic view of the modifiability of human behavior was evidenced. The outstanding proponent of this view was enunciated by Jean Gaspard Itard, who rescued a "feral" so-called wild boy, Victor, found wandering in the forests of Aveyron in France. Itard designed and applied a systematic training program for the boy and made remarkable progress despite several vicissitudes. His disciples Edouard Séguin, Maria Montessori, and Alfred Binet continued his work by establishing classes for children with "mental retardation." Montessori, a doctor, recognized that the more effective "treatment" for such children was pedagogical, not medical. Today, most reformers accept the principle that through the promotion of education of persons with disabilities, critical insights into the makeup of a civilized society are discovered.

The philosophy underlying attempts to educate children with disabilities goes back several decades. It was, however, the influence of the English philosopher John Locke, who advanced the concept that knowledge was gained through the senses in his notable *Essay Concerning Human Understanding*, that aroused interest in the disabled. Jean-Jacques Rousseau emphasized that the "child's curiosity was the origin of learning" and that instruction should be based on its nature and not the demands of an artificial society. The climate of despair present in many countries of the nineteenth century was further improved by illustrious and legendary individuals and dedicated teachers such as Itard, Montessori, and Binet. They influenced educational practice for generations of children, by their practices and philosophy of teaching and interacting with children with disabilities. These individuals have in the past inspired parents and professionals and given them strong motivation to continue the quest for quality education. They are well-known internationally, having shaped our idea of education and changed restricted views people held on the educability of persons with disabilities. The story of Helen Keller and her devoted teacher Anne Sullivan has inspired countless parents, teachers, and professionals alike. However, it is necessary to avoid raising the hopes of parents and teachers when untested and bogus treatments and educational programs are advertised and marketed for parents and educationists. Rigor and scientific veracity are the watchwords to safeguard the welfare of this vulnerable group. The complex disorders of autism, cerebral palsy, hyperactivity, and other baffling conditions tend to be the targets of unfounded claims for effective treatment and cure.

Comparative special education began with contrasts between various state practices in dealing with persons with disabilities. In several countries, state institutions were founded in the late nineteenth and early twentieth centuries to care for the mentally ill or intellectually disabled. The regime in many cases was custodial, harsh, restrictive, and dismal. The isolation and lack of stimulation of the regime worsened the mental and emotional states of the "inmates" as they were referred to. These individuals were under the auspices of either health or social welfare departments/ministries. As a result of pressure exerted by professionals, parents, and other groups, the responsibility for such children was transferred to the ministry or department of education. Today, in all Western countries, the education of children with disabilities is the responsibility of education departments/ministries. However, in many developing countries the education of such children is still the under the authority of departments/ministries of social affairs or welfare.

It is of interest to learn that the earliest chair of special education in Europe was established at the University of Zurich in the 1920s and the first international conference on special education was held in Geneva in 1938. Since then, studies related to the education of children with disabilities have had contributions from general education, sociology, medicine, philosophy, and psychology. The international movement toward normalization occurring in the 1970s was led by Sweden and other Scandinavian countries. It spread to several Western countries making a deep impact on their education systems. For example in Italy, the antipsychiatry movement led by Franco Basaglia led to the rapid dismantling of special schools and the integration of most disabled children into the regular education system.

Today, there is a prevalent demand for increasing the number of children with disabilities to receive their schooling side by side with their nondisabled peers. This trend is now acknowledged and welcomed by the major education providers. It reflects a general world movement toward equity and educational opportunity for such a minority group. The growing conviction that all people have equal intrinsic value has permeated the thinking of those responsible for organizing and delivering educational services for children with disabilities.

In recent times, the recurring theme of "integration" has captured the attention of educationists, political activists, parents, and governments. This led to the promulgation of the Salamanca Statement and Framework for Action at the UNESCO conference in 1994, which invited all governments to embrace the philosophy of integration. More recently, the recurring theme of "inclusion" has captured the international attention of everyone working in the field. However, there is currently a major debate as to the efficacy of a particular form of social organization over another. The challenge facing the protagonists is to demonstrate that children with disabilities are meaningfully served in either the regular or special school system.

Critics of "segregated" (an unfair and pejorative term according to some) schooling claim that such placement denies children with disabilities the opportunities to access the full range of normal experiences and rich interactions available in the regular school. These strictures are strongly challenged, and it is argued that special education can and is offered in an array of integrated and special educational settings. In several countries, many segregated institutions for the education and well-being of children with disabilities were founded by parents or pioneers. These establishments often pioneered new and improved techniques and teaching methods for children who were deaf or visually impaired or had other disorders and maladies. With the spread of compulsory education, children with disabilities were now drawn into the sphere of the public education system and were in receipt of education as well as ancillary services. This might serve as a timely reminder that sensitivity toward local needs often serves the needs of children with disabilities preeminently.

Today, international scientific journals with interdisciplinary contributions help establish cross-national and international perspectives on issues affecting the education of children with disabilities. In addition, countries form alliances to tackle problems together. In Europe, for example, the education ministries of member countries have established a joint European Agency for Development of Special Needs Education. This agency serves as a platform for sharing and disseminating ideas and best practices in the member countries.

Today, many international organizations concerned with education still tend to ignore the specific circumstances of children with disabilities in their mainstream programs. For example, OECD's Programme for International Student Assessment (PISA) excludes children with functional disabilities from testing if the child's capacity to engage in a paper-and-pencil test on reading, mathematics, or science literacy is limited. Development projects of national and international donor organizations tend to focus on single issues, for example, health, women, children, or community-based rehabilitation. Recently, however, different organizations have met to discuss disability issues in depth and have tried to develop an integrated strategy to address complex issues of poverty or social exclusion. UNESCO's action plan on Education for All (EFA) was a response to the pressures exerted by various interest groups in including a specific flagship program on inclusive education.

SELECTED CASES

Tracing the developments of special education is a dynamic process, because changes are rapid and the literature on the subject has grown at an exponential level. This entry, however, deals with only the development in Western European countries. The advances in other countries as well as the developing nations is worthy of equal attention. Attitudes, values, and beliefs in all countries are undergoing dramatic transformations and the advent of preventive measures and early detection of disabling conditions as well as a renewed commitment on the part of society to remove the stigmas associated with disability have helped improve the circumstances of children and adults with disabilities. Countries vary in population and other demographic factors that can influence the practicalities of providing educational services.

Finland, for example, occupies the fifth-largest mass in Europe, but has a sparse population of about 5.2 million inhabitants and boasts a literacy rate of 100 percent—with one of the lowest rates of migration in Europe. In the past, children with disabilities were served by a variety of agencies and only recently has compulsory education for children with disabilities been guaranteed by law. Today, Finland is justly proud of making excellent educational provision for all categories of disability. The local communes and authorities are required to provide suitable education for pupils with disabilities. Recently, the movement for including all children with disabilities in the regular school has been adopted by the education and government authorities. There is a high level of cooperation between parents, teachers, and education agencies. Similarly, Norway has undergone considerable changes in the manner it offers education for pupils with special needs. In the past, the Norwegian authorities had a range of special schools as well as facilities that enabled children with milder disorders to be instructed in the regular school system. The country seeks to offer its services at the local level and has established a wide network of resources for teachers and pupils. These centers offer advice and short courses on a variety of topics related to the education of pupils with disabilities. Parents play a very significant role in planning and placement decisions affecting their children. Education for children with disabilities in the Nordic countries reflects the wish for good provision and equal treatment for everyone, a value embedded deeply in the framework of a Western democratic welfare state.

Education for children with disabilities in England and Wales began around 1870 when universal elementary education was first introduced in Britain. Children suffering from malnutrition or physical or intellectual disability were first identified in ordinary classes. Increasingly, children with poor sight, hearing, physical, and other ailments were recognized as different as teachers felt inadequate in instructing them. From 1895 onward, schools for "defective" children sprang up and a number of categories, mainly based on medical diagnoses, were employed to select children for placement in a variety of special schools. Many of these were run by religious or charitable organizations. In 1899, Alfred Eichholz, an inspector of special education, drew up key recommendations, which left their mark on the historic 1994 Education Act legislation. The next milestone for England was the publication of the Warnock report in 1978, drafted by a committee chaired by Baroness Warnock, the philosopher at Oxford University. In this report, the term *special needs education* was first introduced and soon gained acceptance worldwide. A decade later, the Education Reform Act was passed by Parliament. Meanwhile parents and professionals urged that the use of categories served the welfare of children poorly and argued that the education designed for nonhandicapped pupils should be available for children with disabilities. However, the Warnock Committee was anxious to point out that while supporting the concept and practice of "integration," they cautioned that integration must be accompanied by full resource support.

These short accounts illustrate diverse approaches to changes in educational practice in different countries. While countries can never copy practices in other countries, they may serve as inspiration and as a mirror to better identify potential problems and downfalls a system may be prone toward.

—Judith Hollenweger

See also Children with Disabilities, Rights of; Education, Primary and Secondary; Francis Galton; Jean Marc Gaspard Itard; Maria Montessori; Jean-Jacques Rousseau; Special Education.

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EDUCATION, PRIMARY AND SECONDARY

HISTORICAL OVERVIEW

Long before education systems became aware of issues surrounding disability, individuals responsible for providing health-oriented institutions became interested in the education of children and youths with disabilities. Nineteenth-century pioneers such as Jean Marc Gaspard Itard in France and Maria Montessori in Italy demonstrated through their work that education did make a difference to children with disabilities. Their work arose from an understanding that while the care offered by large institutions was essential for survival of their wards, education could make a significant difference to the lives of these children. The realization that children with disabilities could be educated was interrupted by the philosophies promoted by the eugenics movement before and during World War II. After the war, however, several professorships related to the education of children and youths with disabilities were established, thus heralding a new understanding that children with disabilities were not simply to be cared for but also educated. The charity perspective of saving the souls and possibly lives of persons with disabilities had yielded to the notion that education could make a difference to the children's development and quality of life.

In many cases, the parent's initiatives led to the establishment of institutions and services that competed with the existing institutions based either on charity or medical services. These private services often served groups that did not receive adequate or appropriate services offered by the state or existing organizations. This led to a very diverse range of services with a variety of methods, curricula, and equipment. These parent organizations played an important role nationally and internationally in persuading governments to improve their services and acknowledge that the needs of their children had to be taken seriously.

With the advent of social welfare states in Western countries, educational services for children gradually increased and a recognition grew that education was an entitlement rather than a charitable offering. Usually, departments of social welfare or social security assumed this responsibility and only later were these responsibilities transferred to education authorities. While in most Western countries education authorities assumed responsibility for children with disabilities, the services offered were not part of the general education system. A segregated educational service under the umbrella of regular education was organized based on the major functional problems or impairments of the child. Eligibility to the special education services was generally dependent on the severity of a particular disability.

In recent years, a progression from an eligibility-based to a rights-based approach became apparent not just by activists but also in legislation changes in some countries. This coincided with a move away from category-based services to an integrated provision in general education. International conventions and other international documents emphasized the rights of people with disabilities enshrined in such documents as the United Nations Standard Rules that urge nations to adequately address the educational needs of children with disabilities. It pays extra attention to the rights of girls, very young children, and children in impoverished families or communities. UNESCO's Dakar Action Plan describes the policy as "Education for All," which includes all children potentially excluded from participating in education, work, and social life. Whether these ideals can be translated into practice will become evident over the next decade.

COMPULSORY EDUCATION

In most countries, education is compulsory for all children at the primary and lower secondary levels (International Standard Classification of Education [ISCED] Levels 1 and 2). Many countries extend educational provision for children and youths with disabilities beyond compulsory schooling up to the age of 18 or even 21 years and offer special educational services for very young children. At the primary level of education, the focus is on basic reading, writing, and calculating skills as well as a general understanding of the world. The secondary level has a more discipline-oriented approach and may have an element for vocational and work skills preparation. Some students with disabilities follow a similar curriculum as their nondisabled peers and are given special assistance such as a sign language interpreter or information in Braille if needed. Others may follow a special curriculum that emphasizes the acquisition of life skills rather than academic skills.

The Organization for Economic Cooperation and Development (OECD) regularly compiles and publishes statistics and indicators in education. The OECD data on education reveal that depending on the country, the percentage of children in primary and lower secondary education who are identified as having a severe disability range from less than 1 percent to 5 percent of the school population. This variance is not primarily due to a difference in prevalence of disabilities, as more affluent countries tend to identify more children and youths as being "disabled" than poorer countries. The data reflect the manner in which countries allocate additional resources for the education of children. In some countries, the percentage of children receiving additional resources totals over one-third of the school population. This group includes not only children with disabilities but also children with learning or behavior difficulties as well as children and youths from disadvantaged backgrounds.

The diversity of student populations of today's schools has compelled education authorities to reconsider the traditional division between general and special education. With increasing numbers of children in need of special support, a reappraisal of the current policies is taking place in many countries with a view to ensuring effective and equitable uses of funds and resources.

Various countries and schools tend to offer diverse educational programs even to children with similar disabilities. These educational services could vary in terms of placement (i.e., integrated or segregated settings, day care or residential), function (preparation for an adult life in open society or a sheltered life in an institution), and content (regular or adapted curriculum, concentration on academic performance or life skills) as well as performance levels and range in intensity of support and training. A variety of professionals diagnosing the educational needs and the nature of therapy or special support may also be involved. These services may be school based or organized in centers that serve a particular region.

Education policies today are shifting from a content-oriented approach to a more standard-oriented one. The education authorities consider it more important to evaluate the competencies young people need to develop rather than insisting on the number of chemistry or geography lessons given. This coincides with a shift from judging education systems on input indicators to a general focus on outcomes. Thus, policy makers are more concerned with the abilities and achievements at the end of schooling rather than the amount of hours spent in school. This shift in perspectives has also led to a growing interest in the transition from school to work or employment. Young people seeking access to higher education, employment, and economic independence are perceived as important signs of the equity and effectiveness of compulsory education. The increased flexibility of school systems to respond to such changes could offer students with disabilities better opportunities for greater participation in education.

This development is reflected by the wide attention accorded to the OECD's Programme for International Student Assessment (PISA) in many countries. PISA claims to provide education systems better indication as to how well they have prepared their 15-year-old students for adult roles in their society and for lifelong learning. It measures the students' levels of reading literacy, mathematical literacy, and science literacy independent of a nation's curriculum or the specific contents of education in any given country. The results suggests that education systems with an integrative approach teaching all students together and focusing on their levels of competencies perform better than highly differentiated systems which direct students to different streams or programs.

CONCEPTUALIZING DISABILITY IN EDUCATION

The conceptualization of disability in education is reflected in the historical development of special educational services. Initially, an understanding as to what impact an impairment such as mental retardation or polio had on the development of a child was critical. Impairments were usually identified by a health professional in early life or following an injury or illness. Educational interventions were directed toward compensating or overcoming the impairment, generally focusing on children with sensory impairments and to a less extent, physical disabilities such as cerebral palsy. The emphasis of the compensatory approach was to ease or reverse the effects of a disability of the child. Functional approaches adopt a similar approach insofar as they also stress the disability or dysfunction of the child. While compensatory methods were more concerned with the overall development and well-being of children, functional approaches were mainly focused on learning in school. A functional approach to disability concentrates on a child's functioning in educational settings and relates mainly to behavior, learning, and interaction with others. Although problems with learning and behavior are often the result of complex interactions, functional like compensatory approaches focus on the diagnosis and intervention of the individual child. Many of the categories of disability currently employed in educational settings are based on the functional model.

The campaign launched by the disability advocates for equal rights and antidiscrimination legislation has had a considerable impact on accessibility, employment, and social security. But the rights-based approach to disability has had less of an impact on conceptualization of disabilities within primary and secondary education. The underlying premise that people with disabilities are a minority group implies that without barriers and discrimination, full participation in public life would be accomplished. This premise is not easily applicable to education. Accessibility to the full range of the curriculum is more complex. A right to be physically placed in a regular classroom does not necessarily ensure an equitable education. The minority model or rights-based approach may influence the overall policy to include all children within a single education system, but it has insignificant influence on the educational practice itself. Yet another concept of disability related to education is the social constructivist approach, which views disabilities not as a reality but rather a social phenomenon. It regards the school system or the social interactions occurring in schools as leading to the exclusion of children. Disability therefore is viewed as something that is created or constructed through the social processes inherent in the education system itself. The social constructivist model is helpful in understanding processes of diagnosis and disparities in the provision of services to children, but it has yet to establish its relevance to educational interventions and school practices.

It might help to view disability as a complex phenomenon with biological, psychological, and social aspects. Any conceptualization of disability in educational settings should take account of the fact that children are identified only if a mismatch between the expectations of the educator and the performance of the child becomes apparent. Attitudes and other factors in the environment need to be viewed as contributing to a disabling condition and therefore also as part of the intervention process. A multilevel approach that might lead to equitable access to the curriculum is of paramount importance.

EDUCATIONAL SERVICES

The primary concerns of educational systems center around the difficulties children and young people experience in accessing the curriculum as well as the issues of providing equitable education for all students. This has encouraged educational service providers to reappraise their policies toward education and learning.

Historically, in most countries, educational services for children with disabilities were developed separately from regular education system. Health professionals, parents or volunteers, and charitable organizations offered specialized services in special centers and schools. The groups catered to included those with mental retardation, blindness, deafness, and polio. These centers attracted workers who developed increased expertise in their respective disciplines, which led to greater improvements in services. Undoubtedly, such institutions provided opportunities for children unavailable in regular schools.

In the 1960s, a wider view of the term *disability* occurred, which resulted in the inclusion of children with behavior, learning, or social difficulties. As compulsory education extended to children with disabilities, services were organized under the umbrella of the education system. This resulted in a dual regular and special education system. In many countries, educational services still cater to specific categories of disabilities such as autism or dyslexia. They may also focus on associated aspects of disability categories such as communication, for example, through augmentative and alternative communication methods such as Bliss symbols or adapted computer technology.

A major shift in organizing educational services for children with disabilities was initiated in the late 1970s following the Warnock report. This resulted in the new conceptualization of special needs education. It assumed that while 2 percent of any given school population could be seen as disabled, about 20 percent constitute the larger group of children with special educational needs. Accordingly, special needs could be identified relative to communication, cognition and learning, behavior, emotional and social development, and sensory and/or physical functions. This change was confirmed internationally by the Salamanca Statement and Framework for Action on Special Needs Education, at the UNESCO's Conference held in Salamanca in 1994. Governments were urged to assume the responsibility for all children within the aegis of general education and abolish segregated settings. The integration of children into regular classrooms has been achieved to a greater or lesser extent in most Western countries, especially at the primary level of education. More recently, the trend has shifted from offering integrated services for individual children with special needs to the restructuring of education systems to better meet the needs of all children. This theoretical shift has been marked with the change of the term *integration* to *inclusion* or *inclusive education*. If and how this shift affects the everyday education of children with disabilities is yet to be seen.

In poorer countries where education is unavailable or not easily accessible for all, the issues are more basic. Children and youths with disabilities and especially girls and women with disabilities experience greater risk to being permanently excluded from learning and most aspects of adult life. Poverty is closely linked to disability and therefore increased exposure to social exclusion. UNESCO's initiative to ensure "Education for All" requires countries to increase the percentage of disadvantaged and disabled children and youth successfully participating in education. An effort is currently made by several international organizations to include issues of disability and education into their social development programs.

—Judith Hollenweger

See also Children with Disabilities, Rights of; Childhood, Youth, and Adolescence; Francis Galton; Jean Marc Gaspard Itard; Maria Montessori; Jean-Jacques Rousseau; Special Education.

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EDUCATION AND DISABILITY

EDUCATION AS A RIGHT OF ALL PERSONS

While public education is ideally a right of citizens in every society, universal access to schooling is only realized to varying degrees in countries around the world. In many countries, access to education is still denied or limited on the basis of gender, race, economic or social status, or disability. For individuals with disabilities, the right to education has been realized only in recent decades, a fact primarily true for individuals living in developed countries. As has been the case for girls and poor children in developing countries, most children with disabilities share the experience of being denied access to education. For these groups of children, education remains what it was in earlier times, a responsibility of the family. In societies where the families themselves are uneducated, the cycle of illiteracy and failure to realize individual potential is perpetuated.

Recognition of the right to education of all persons is relatively recent with international and national laws and legislation emerging only in the latter half of the twentieth century. At the international level, the first version of the UN Convention on the Rights of the Child was approved in 1959. Among the major principles in the convention is the right of the child to education. This right is inclusive of children with disabilities as defined in paragraph 23 of the convention. The right to education also is declared for children in the preschool years in another UN document published in 1993, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In 1994, the Salamanca Statement and Framework for Action provided further elaboration of the right to education by defining special education for children with disabilities or learning difficulties. In this context, it was emphasized that the educational approach should be child centered and based on the principle of inclusion in which children with disabilities are served as much as possible in the same settings as their chronological age-peers. For young children with disabilities, goals for education in the preschool years should focus on fostering the child's development and readiness for school.

Collectively, the UN Convention on the Rights of the Child, rule 6 of the UN Standard Rules on the Equalization of Opportunities, and the Salamanca Statement provide a summary of universal standards for equalization of educational opportunity for children and youths. As such, they represent a declaration not only of the child's protection from discrimination, abuse, neglect, denial of access, and illiteracy but also of the right to care, support, and education. These documents make the rights of children explicit, representing practices pertaining to the education of children with disabilities. While the scope of these declarations is universal, a review of policy and practice on an international level indicates substantial variability in regard to access to education for children with disabilities. In most developed countries, some level of commitment has been made to ensure the right of children with disabilities to education. However, in many, if not most developing countries, children with disabilities are denied access to education with groups of other underserved children.

In regard to access to education for children and youths with disabilities, policies and practices in the United States have often served as a model for other countries. In that context, this entry will describe the history and contemporary status of education for persons with disabilities in the United States recognizing that the situation in other countries may differ to varying degrees. In the United States, policies endorsing education for students with disabilities began in the early 1970s, with federal legislation to support free and appropriate education for persons with disabilities taking the form of Section 504 of the Rehabilitation Act of 1973. The intent of the act was to eliminate barriers that exclude persons with disabilities from educational institutions and other agencies in receipt of federal funds. The general focus of the Rehabilitation Act of 1973 was followed by the legislation directed to access to education for children with disabilities in the Education for all Handicapped Children Act (EHA) (P.L. 94–142) in 1975. This was a landmark law guaranteeing the right of all children with disabilities to education, specified under a zero-reject principle in which no child could be denied schooling. Eligibility for special education was based on meeting the criteria for defined disability categories. A comprehensive evaluation served as the basis for the development of the individualized education program (IEP), which provided the means and the goals for educational achievement of the child. An important element of the EHA was recognition of the central role of family participation in the education of their children with disabilities.

In 1994, a report was prepared for congress about effectiveness of the implementation of P.L. 94–142. The report concluded that special educational needs of America's (then 8 million) children with disabilities were not being fully met. Specifically, three major findings reflected the lack of effectiveness:

1. Special education programs lacked full equality of opportunity.
2. One million children were excluded entirely from the public school system.
3. Disability was not identified in many children with the result that many children needing services were not served.

In response to these limitations of special education, the U.S. Congress passed a revision of the EHA, which was renamed the Individuals with Disabilities Education Act (IDEA) in 1990. IDEA was amended in 1997 and reauthorized again in 2004 as the Individuals with Disabilities Education Improvement Act reaffirming the underlying premise of a free and appropriate education with major guiding principles as follows:

- Free, appropriate public education (FAPE) for all children with disabilities
- Appropriate evaluation
- IEPs for each child with appropriate assessment techniques
- Least restrictive environment
- Parent/student participation in decision making with regard to child's education
- Procedural safeguards to protect rights of children with disabilities

Although each amendment of IDEA since its inception has included revisions, IDEA has continued to provide educators and parents with the tools necessary to promote quality educational experiences that will lead children toward a productive adult life. The intent of IDEA is remedial, requiring provisions of programs and services in addition to programs already provided to persons without disabilities. These provisions include education, technical assistance for families and children, assistive technology, parent and professional training, and an array of related services. The committee responsible for special education has the responsibilities and authority to determine what services and to what extent services are required for the child with a disability. Although the provision of services is decentralized giving authority to individual states, each state is required to establish performance goals and standards consistent with the goals and standards for all children established by that state. The federal government maintains ultimate oversight of each state and controls the funding to ensure states comply with the federal mandate.

A HISTORICAL PERSPECTIVE

1800–1850

Within a historical context, the provision of educational opportunities for children with disabilities in the early nineteenth century took the form of establishing special schools for children with sensory impairments. The first schools for children who were deaf and blind in the United States were established in 1817 and 1832, respectively. A similar pattern of establishing special schools for these two groups also was found in other countries. By the middle of the nineteenth century, children were taken out of almshouses and family settings to be sent to "specialized" schools developed specifically for children with auditory or vision impairments or mental retardation. Segregated settings excluded children with physical disabilities. While the goal of placement in these special schools was to assist the individual with a disability to become a productive citizen, the prevailing societal values and conditions resulted in the fact that these institutions often became custodial facilities with poor quality services.

1850–1900

While schools had been established for basic education of children and youths who were deaf, higher education did not become available until the National Deaf Mute College was established on February 16, 1857, as the first school for the advanced education of individuals who were the deaf and hard-of-hearing. Now known as Gallaudet University, it was named after Thomas Hopkins Gallaudet, a notable figure in the advancement of education for the deaf and hard-of-hearing. An interesting historical fact is that for more than a century, leadership of Gallaudet was provided by a hearing administrator. With the selection of a new university president who was not a deaf individual, students expressed outrage, finding it patronizing, marginalizing, and inappropriate in the context of such an essential part of the Deaf community. Subsequent to the students' strike, the university was forced to hire a deaf president who could represent and relate to the deaf individuals enrolled in the university. This action represented a significant cultural and educational advance on behalf of the Deaf community.

Services for individuals with disabilities in the first half of the twentieth century continued to be largely institutional in nature with segregated schools and institutions providing all services on site. An important change, however, was emerging by the middle of the century with the growth of parent groups. The National Association for Retarded Children (NARC) in Minneapolis comprised of middle- and upper-class families was the first and most powerful parent-driven, human-services lobby in the nation to emerge in the early 1950s. The continued growth of parent advocacy for services for their family member with disabilities resulted in a climate of policy and legislative changes. In 1963, Congress enacted new legislation to ensure funding for a comprehensive program of research on mental retardation through National Institute on Child Health & Human Development. The premise of the legislation was to reframe mental retardation as a condition requiring services to promote health and development rather than a psychiatric problem to be treated.

Complementing the changing perspective on mental retardation was recognition of the link between disadvantage and developmental outcomes of cognitive and adaptive disabilities. The solution was to prevent developmental disability by the provision of increased educational opportunities for disadvantaged children in the preschool years. This approach was formalized with the passage of the Economic Opportunity Act in 1964 and the Elementary and Secondary Education Act (ESEA), commonly known as Project Head Start, in 1965.

A key indicator of the changing climate for persons with disabilities in the late 1960s and early 1970s was the abandonment of the concept of institutionalization. The President's Committee on Mental Retardation advanced a federal policy based on the principle of normalization contributing to the deinstitutionalization movement of institutions such as the Willowbrook State School in 1972. Paralleling deinstitutionalization was the need to establish a spectrum of community-based services to permit persons with developmental disabilities to reside in the community. For adults, this range included the development of halfway homes and intermediate care facilities (ICFs/MRs) to care for individuals with mental retardation outside of the institution. For children and youths with disabilities, there was an expansion of educational services culminating in 1975 with the passage of the Education for All Handicapped Children Act (P.L. 94–142) endorsing the right to a free and appropriate public education. A central element of FAPE was the design of an IEP plan based on the child's unique characteristics and needs. With preparation for independent living recognized as a right for the student with disabilities (*Board of Hendrick Hudson Central School District v. Rowley* [1982]), the provision of educational and community experiences to optimize the transition to the age of 21 years was included in the IEP (Clark and Lillie 2000).

CONTEMPORARY EDUCATION

Special education means specifically designed instruction to meet the unique needs of a child with a disability at no cost to the parent including instruction conducted in the classroom, home, hospital or institution, and other settings.

Early Intervention

The system of early intervention (EI) is primarily parent driven with case coordination provided through the county agency. For children 0 to 3 years of age identified as having a disability, an infant family/child education plan is developed, similar to an IEP, to ensure that children have access to appropriate community, educational, and related services. It is mandated that emphasis be placed on the natural, least restrictive, environment for provision and service coordination. Parents have the right to choose home- or center-based services. Typically, families prefer home-based services for younger children. The parent is usually the "coordinator" of home services, which may include related services of speech, physical, occupational, special education, vision, and services for deaf and hard-of-hearing.

Local School Boards of Education

Each local school board has the responsibility to locate and identify all children with disabilities who reside in the district, whether they are of preschool or school age. A register must be maintained by the committee responsible for special education and revised annually. In addition, school boards must adapt a written policy to ensure that children with disabilities have the opportunity to participate in programs to which they are entitled.

Preschool Education

The local education agency (LEA) is responsible for the provision of services and procedural safeguards for eligible children 3 to 5 years of age. Procedural safeguards include notice, consent, and the right to an impartial hearing. An IEP is developed by the committee responsible for preschool education through the local school district. There is a continuum of service options for the least restrictive environment, and services need not be provided in conjunction with a program at a facility approved or licensed by a government agency. Least restrictive options include itinerant services, or related services at home; itinerant services in a day care placement; integrated, certified preschool with nondisabled peers; or segregated, approved preschool. The focus of instruction for children of preschool age is typically developmental with remedial treatment techniques supporting the transition to kindergarten. To be eligible for services, the child is given a general label of "preschooler with a disability." The more restrictive the environment the greater the intensity of services including one-to-one instructional support and a full array of related services including physical, occupational, and speech therapy; psychological counseling; audiological or other medical services; and transportation.

Elementary and Secondary Education

The LEA is responsible for the provision of services and procedural safeguards for children 5 to 18 years of age, and under certain circumstances until the child reaches 21 years of age. There are specific disability categories used to ensure eligibility for services under IDEA. These 13 categories are as follows: autism, deafblindness, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, speech or language impairment, traumatic brain injury, visual impairment, and other health impairment. There is a continuum of services for the least restrictive environment that includes full inclusion through a segregated, private setting.

The No Child Left Behind Act of 2001 (P.L. 107–110) aims to improve the performance of America's primary and secondary schools by increasing the standards of accountability for states, school districts, and schools, as well as providing parents more flexibility in choosing which schools their children will attend.

The state-mandated curriculum is typically modified to meet the child's individual needs as outlined in the IEP. Remedial techniques and adaptations to instructional material may be made based on cognitive, sensory, or physical impairments. All children, regardless of disability, are required to participate in mandatory state assessments or specifically designed alternative assessments. The state maintains ultimate oversight of the program implementation, and related services may be provided within the classroom setting or in a separate setting in a small group or individual format. Most related services are provided 1 to 5 times per week in half-hour units of time per session.

Parents are members of the committee responsible for special education program team, which is responsible for developing, reviewing, and revising the IEP. The committee members are required to meet on an annual basis to review progress, plan future goals, and make recommendations.

A functional curriculum may be implemented in conjunction with the mandated academic curriculum for students who require such educational training. Vocational skill development begins around the 10th grade, or when the child turns 15 years old. In some cases, as deemed appropriate by the committee responsible for special education, children with severe disabilities are eligible for school until the age of

21 years and also may be entitled to full-day, summer school (30 days) at no cost to the parent.

Vocational/Work

LEA/committee responsible for special education are required to develop transitional plans for children with disabilities at age 15 that address adult transition including employment and living options. It is expected that other state/federal agencies with responsibilities related to vocational education, rehabilitation, and work force development be contacted to be part of transition planning for the child. Parents maintain a key role in assisting the committee responsible for special education in ensuring their child is prepared for adult life. Community leaders and business managers also are important individuals that need to be closely linked to the LEA as most students with disabilities find employment in their hometown. The School-to-Work Opportunities Act (P.L. 103–239) was created to help states and local schools better prepare non-college-bound students for work. The provision of the law provides dollars for the state, local school district, and business partnerships to develop and implement a combination of vocational education and on-the-job training for work subsequent to graduation.

APPROACHES

Certified Special Schools

Certified special schools are schools regulated through the state, which are under the same state/federal mandates as the public school system. They are considered the most restrictive environment typically with self-contained classrooms and limited interaction with normal peers. Most children placed in these highly specialized, segregated settings are severely, multiply disabled with either medical or behavioral conditions that preclude them from attending public school. The curriculum must be responsive to the state standards, and all children must complete mandated assessments or state-approved alternative assessments to ensure progress and state compliance. Instruction is usually intense in terms of teacher/staff ratio and in some cases one-to-one instruction may be necessary to ensure educational benefit from the program. It is always preferred that a child be placed in state and as close to the parents' home as possible.

Special Classes

This option is available when a child cannot be taught within a regular class environment. Most children attending special classes and not being mainstreamed into the regular class present with moderate to severe disabilities that can be disruptive to others, or the child may be deemed incapable of participating in the curriculum in a regular classroom setting. The committee responsible for special education has the responsibility to determine the least restrictive environment and the ratio of teachers to students, which is generally lower than that of the regular class. Each child's placement should be reassessed on an annual basis. The curriculum implemented must be responsive to the state standards and all children must participate in the mandated state assessments to ensure progress in the learning environment.

Mainstreaming/Inclusion

Inclusion in the regular classroom setting with appropriate peers with special instruction and related services as needed is considered the least restrictive environment and most ideal for the majority of children with disabilities. Some children participate fully in the regular class with special instructional techniques/modifications to assist in the learning process, while others participate partially in a mainstreamed format. Special education teachers and/or related service providers assist regular education teachers in designing appropriate teaching techniques to assist a child in meeting IEP goals as designed by the committee responsible for special education. Each child's needs for continued services must be evaluated annually.

FUTURE DIRECTIONS

Access to education by persons with disabilities has a short history in the United States and industrialized countries and is only beginning to evolve in other, less developed countries in the world. The priority for the future is first and foremost to translate the right of all persons with disabilities to a free and appropriate education into practice (UNESCO 1994). In the developing world, this right means creating legislation guaranteeing access for young children to early childhood intervention and special education for school-age students. An essential priority in this translation is education of parents regarding the rights of their child with disabilities to education. Associated priorities are teacher training and the development of curricula relevant to the academic and cultural standards of the country. The recent experience of India provides an encouraging example of the realization of the right to education. With the enactment of the Persons with Disabilities Act, India is committed to the provision of individualized education for children with disabilities through initiatives in teacher training, collaboration among government ministries, changing examination requirements, and involvement of nongovernmental organizations in implementation efforts (Sharma and Deppler 2005).

With fundamental building blocks for access to education in place in the United States and other industrialized countries, emerging directions focus on improvement of the effectiveness of instructional approaches and enhancing transition and continuity beyond the public school experience. While the IEP has been central to the concept of effective instruction for students with disabilities, the need to meet eligibility requirements as the basis for developing the IEP endorses a remedial rather than preventive approach and introduces a time lag in the initiation of services. While a categorical basis for special education eligibility has been challenged for some time (Hobbs 1973; Triano 2000), only limited alternatives have been explored at the level of individual states and assignment to one of 13 categories continues to be intrinsic to IDEA requirements. A priority for improving instruction is to identify means to initiate interventions earlier in the child's academic experience. To this end, the criteria for eligibility may need to be rethought for greater flexibility or consideration given to presumptive eligibility for young children. A second priority for improving effectiveness of instruction is to address the challenge of teaching children with severe and/or multiple disabilities. The unique and complex learning needs of this population require innovation in the nature and form of instructional approaches.

The transition from public school to the post-academic environment of work and independent living has been a significant concern in the field. Issues to be addressed include not only more individualized tailoring of instruction but also improving linkages with the community and the settings of work that the student with disabilities will enter. Fundamental to the transition to adult life is the process of the youth acquiring the rights under the IDEA and Section 504. Clarke and Lillie (2000) have identified steps in this process for transition planning and defined recommended actions for the student, family, the schools, and the community. In keeping with IDEA 2004, all transition planning needs to be consolidated by age 16 and requires a summary of the student's academic and functional performance at the receipt of a diploma or age 21. Finally, in the context of rapid societal changes, individuals with disabilities, like other persons, need continuing access to education across the lifetime. Such access could include existing methodologies of job coaching and on-site training, but also expand with new technologies using the computer for simulation and direct skill building. Education provides opportunities to learn and grow, essential to the quality of life of every individual.

—Theresa Hamlin and
Rune J. Simeonsson

See also Children with Disabilities, Rights of; Early Childhood Intervention; Individualized Education Program (IEP); Individuals with Disabilities Education Act of 1990 (United States); Race, Disability, and Special Education; Special Education.

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EDUCATIONAL ASSISTIVE TECHNOLOGY

Educational assistive technology (AT) can serve to both augment and replace function for students with disabilities at all levels of education. These functions can include reading, writing, speaking, walking, remembering, and other activities of daily living, but many barriers to acquisition of AT exist, including lack of funding. The Assistive Technology Act (AT Act) of 1998 provides a definition of AT: "Any item, piece of equipment, or product system, whether acquired commercially, off-the-shelf, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities."

The law includes in the definition of AT, those services that are necessary to implement AT solutions: "Any service that directly assists in the selection, acquisition, or use of an AT device including: evaluation and assessment; purchasing, leasing, or acquisition; selecting, designing, customizing, repairing; and training and technical assistance."

Although AT has the potential to enhance function for students with disabilities, 50 percent of all AT is abandoned within six months. To some extent, this is explained by developmental progress or changes in health or functional status (e.g., a student outgrows the wheelchair). However, it also appears that the failure to include active participation by the individual and family, individualize the process of matching the AT to the individual, include provisions for training the individual in use of the AT, and include a plan for maintaining and servicing the AT contribute to the high rate of abandonment. Most school-based AT specialists recommend a student-rather than technology-centered ecological approach to the evaluation of AT needs for students with disabilities where the interaction between the individual and the educational environment is stressed. AT evaluations are also best conducted by an interdisciplinary team, which must include the student and family representative and may include the teacher, speech pathologist, occupational and/or physical therapist, school psychologist, or other specialists. If the student is of an age where transition from school to work and the community should be considered, then representatives of the adult service system, such as a rehabilitation counselor, job coach, or even potential employers should be included to ensure that the AT considered can bridge the transition from school to work and life in the community.

CATEGORIES OF AT

AT can be described in terms of the function it serves. It is important to note that many AT devices can serve in more than one category.

Aids for activities of daily living. Enhancing independence with activities of daily living reduces the need for human educational aids in school and increases the student's autonomy. Aids for daily living include devices to assist in eating, toileting, personal hygiene, and medical management, which may be useful for students with limitations in mobility, dexterity, endurance, cognition, and support, for example, daily medication requirements. Educators may also become involved in enhancing the independence of the student at home where bath lifts and home modifications may be useful.

Augmentative and alternative communication. Augmentative and alternative communications (AAC) include electronic and nonelectronic devices and strategies that enhance communication for students with severe communication impairment accompanied by limited or no speech. Included here are strategies such as alphabet and picture boards and other "light" tech devices that play a prerecorded digital message when a button is activated. In the mid-level of technology, AAC includes portable devices that can generate speech or text listened to or read by the communication partner as the student types. On the high end of technology solutions are very sophisticated devices that may or may not have dynamic displays that the user selects, depending on context, and that employ symbols or codes that can be sequenced to form communicative outputs. Commonly used communications/expressions, such as greetings, can be stored for ready access. These systems require an extensive assessment of the full range of skills and abilities and, to be successful, must consider issues such as the level of and acquisition of literacy, training availability, environmental access, and support.

Computer access. In this category are the devices that assist with gaining access to the computer. These include modified keyboards, using voice recognition software, or various switches including "sip and puff," to activate on screen keyboards or even the use of Morse or another coded system. Also included in this category of interfaces are alternative pointing devices to replace mouse function, which may be activated by other parts of the body such as the feet or head including the infrared pointing devices. Output may be made accessible through screen enlargement software that makes the screen easier to read for a student with low vision, text-to-speech software that reads text from the screen to the student, or hardware that allow students who are blind to read the screen from a refreshable Braille display. There are also a variety of software applications, including those built into some operating systems and office packages, that can increase accessibility for students when the user enables them.

Environmental control systems. Environmental control systems are primarily electronic and enable students with limited mobility to control various appliances (TV, radio); operate security systems; open doors; turn lights, heat, and air conditioning off and on; open doors; flush toilets; and other routine actions. For example, a student might have access to a remote control device mounted on a wheelchair that when activated opens the bathroom door.

Seating and positioning. Certain accommodations to a wheelchair, task chair, or other seating system can provide greater body stability, trunk-head support, and eye-hand coordination; reduce pressure on skin, spasticity, and pain; and enhance function.

Wheelchairs and mobility aids. Many students may require aided ambulation including canes, various crutches, and walkers. Others may be able to propel manual wheelchairs, which are less expensive, more durable, and easier to transport. Other individuals may require three-wheeled scooters, which can be easily stowed but cannot be used by students who do not have adequate leg function and trunk support. Electric-powered wheelchairs provide independence in mobility for the appropriate student. They can be configured to provide position changes to protect skin and to accommodate computers, cell phones, and other devices that may be powered from the chair battery. Power chairs require special consideration for initial training, transport, and a backup plan for repair, maintenance, and insurance.

Aids for hearing impairment. There have been significant advances in devices to aid hearing for students with significant hearing impairments including programmable digital hearing aids and cochlear implants (Some people in the Deaf community oppose cochlear implants contending that it is an invasive procedure that could be avoided if deafness were not viewed as a condition that should be cured.) There are a variety of systems available for use in the classroom or for one-to-one conversation. These systems can either interact with the digital hearing aid or transmit to a set of headphones or earpiece worn by the user and may include infrared and FM loop systems. Other AT includes alarms that generate flashes or vibration to alert the student who is deaf to an emergency. Text pagers can allow transmission of emergency messages to deaf or hard-of-hearing students and text telephones (available in portable models) also enhance communication.

Learning disabilities. If students with writing disabilities are vocally fluent, voice recognition software may be useful. For other students with writing disabilities, word prediction software may allow them to identify and select the appropriate word from a list of possible choices. When the writing disability is mild, built-in spelling and grammar checkers may be helpful. For some students with reading disabilities, a plethora of software is available that combine text-to-speech output with colored highlighting of the text as it is read and a variety of other study aids. Here, it is necessary that the text be available in an electronic form. For students with memory difficulties, or deficits in executive functioning, prompts delivered as text pages to pagers or cell phones, calendars with alarms in personal digital assistants, watches with timers, and other readily available tools can help to reduce demand on memory or what is referred to as cognitive load.

Internet. The Internet itself can serve as AT. For students with limited mobility, or who are in fragile health, there may be times when access to the classroom is difficult. Because many elements of instruction, particularly in postsecondary education, are routinely available on the World Wide Web (WWW), students may be able to achieve an economy of energy by accessing an actual classroom, libraries, vast array of resources, discussion sections, peer reviews, and other academic programming from their homes. Also, the Internet renders communication barriers irrelevant and creates transparent bridges to the world of education and peers. Students who are blind can easily communicate with students who are deaf when web-based instruction is fully accessible. The potential for students with severe disabilities and concomitant health restrictions to fully participate in daily education regardless of medical status is limitless—we need only fulfill the promise of the technologies that are available to a digital society.

CONCLUSION

Educational AT can significantly enhance the performance of students with disabilities at all levels by augmenting or replacing function. Matching the AT with the student by incorporating an ongoing assessment of the student's changing needs and adapting to the resources and psychoeducational and psychosocial demands of the context with reference to other kinds of physical accommodations and learning styles is critical to maximizing successful AT use.

—Kurt L. Johnson and
Carol Cohen

See also Accessible Internet; Aids for Activities of Daily Living; Assistive Technology; Augmentative Communication; Computer Software Accessibility; Computer Technology; Environmental Control; Mobility Aids; Wheelchair; Wheelchair, Electric.

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▣ EDWARD THE CONFESSOR

(ca. 1005–1066)

English king

King Edward "the Confessor" was the penultimate king of the Anglo-Saxons (reigned 1042–1066), succeeded briefly by Harold, and then by the Norman, William the Conqueror. Edward's reign was distinguished by relative peace, concerns for succession of the childless king, and the early Normanization of the English church.

Edward's linkage with disability comes in two forms. The first, his reputed albinism, is dubiously supported by original sources. While later chroniclers of the twelfth and thirteenth centuries occasionally describe him as "white in his entire body," his only contemporary describer does not make such an observation. Even if he were an albino, the social consequences of such a pigmentary impairment would have been minimal in such an active and comparatively popular king.

Edward's more fixed association with disability is as the first of the European thaumaturgical kings. From Edward the Confessor through both the English and the French royalty came a tradition of the king's power to cure certain conditions by the touch of their hand—the royal touch. Cardinal among these was the "King's Evil," or scrofula/tuberculosis. King Edward, however, was also particularly well-known for healing blindness by touch.

King Edward was buried in Westminster Abbey and remains revered through accreted tradition as a "holy king." He was canonized in 1161 with a tradition of many healing miracles.

—Walton O. Schalick III

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E-HEALTH CARE/ TELEMEDICINE

E-health is the use of emerging interactive telecommunications technologies such as the Internet, interactive TV, kiosks, personal digital assistants, CD-ROMs, and DVD-ROMs to facilitate health improvement and health care services. Use of these specialized technologies is considered to be a type of "online" intervention strategy. An online strategy involves the use of electronic technology usually in the form of a computer. Often a health care intervention uses a mixture of online and the more traditional offline approach as the methods for delivery of information directed either to the patient and increasingly to the health care consumer.

The *Internet* is a public, international network of linked, decentralized computers linked by fiber optics and other networks that allows users to communicate with each other no matter what the location or time. The Internet provides access 24 hours a day, seven days a week—24/7. The Internet is used to transmit electronic mail, find information, and engage in person-to-person exchange of text, graphic, audio, video, and other data. *Interactive TV* also known as polycom provides both audio and visual transfer of a variety of information between two or more individuals at two or more locations in real time. *Kiosk* is a free-standing device, usually a computer, that provides interactive information to the user. Most information is provided through a series of interactive prompts on a touch tone screen. Kiosks can also be used to collect data and information from users. *Personal digital assistants* (PDAs) also known as handhelds or palm pilots are personal organizers that store thousands of bits of data including phone numbers, addresses, notes, and customized software. PDAs exchange, or synchronize, information with a full-sized computer. *CD-ROM* also known as a compact disk is a device that stores a variety of nondigital data. Some CD-ROMs can be used repeatedly (read/write) while others can only be used once to store and retrieve data. *DVD-ROM* also known as a digital video disk is similar to a CD-ROM but stores data digitally.

Telemedicine, also known as telepresence medicine, is a field where telecommunications and medicine interact. Telemedicine can be viewed as a subset of E-health because it makes use of the wide variety of interactive technologies that comprise E-health and has the goal of health improvement, usually through clinical intervention.

Disabled individuals often lack some sensory ability (sight, hearing, touch, taste and smell) that prevents them from fully participating in society. E-health relies on environments that use a variety of technologies that can compensate for the lack of sensory ability. For example, technology can be applied to the movements of the hands, fingers, shoulders, or face so that communication can be established between the individual, the computer system, and the person's environment. These adaptations have the potential to permit access for the disabled to the information society due to the less constraining environment of cyberspace compared to that imposed by the physical world. Likewise, telemedicine as an E-health strategy has the potential to improve patient–health care provider interaction and patient outcome through the increased ability to communicate on clinical and educational issues.

E-health and telemedicine have grown out of the need for health care systems and providers to document and track the health process and procedures performed on their patients, including the need for such documentation for reimbursement purposes by third parties such as insurance companies. Initially, providers kept paper records on the history and status of their patients. In the United States, during the 1970s and 1980s, spiraling health care costs led to the need for a systematic review of the number and types of procedures ordered for patients. This was known as utilization review. Often organizations external to the health care organization were responsible for utilization review. These organizations were known as management services organizations and they developed electronic tracking systems. This was the beginning of the transition from a paper-based system to an electronic-based system, which is known today as E-health. As E-health technologies continued to be developed, the field of telemedicine emerged. The field of medicine became interested in the application of telecommunications to improve the delivery and quality of patient care. Telemedicine first began in 1959 when X-ray images were transmitted across telephone lines.

CURRENT STATUS

E-health and telemedicine are designed to provide for effective exchange of health information among individuals and organizations within the community, usually in community-wide collaboratives known as electronic networks. Most E-health applications involve virtual environment technology, which is a system of technologies that allow the subject to explore and interact with computer-animated graphics. Other terms for virtual environment include *cyberspace*, *telepresence*, *mirror world*, *artificial reality*, *augmented reality*, *wrap-around compuvision*, and *synthetic environment*. In theory all five senses are involved in responding to an environment created by machine. The infrastructure needed to create the virtual environment includes computer networks, hardware, software, people, and management/quality assurance capacity.

Telemedicine can be used for remote consultation between physicians or between physician and patient regardless of geographic distance. Examples of telemedicine include remote diagnosis and surgery in which a specialist gives advice and assistance to a non-specialist during actual procedures such as in a remote location or an inaccessible environment. Some specialized uses of telemedicine include the following.

Teletriage—a specialized type of teleconsultation applied to military scenarios in which a military physician receives online health advice from a remote medical expert.

Telesurgery and telediagnostics—the local and remote physicians share the same virtual space with the patient and the normal and pathologic anatomy can be projected to the consulting physician while examining the patient.

Telecollaboration—the interactive exchange of audiovisual information or conferencing in real time between two or more participants. Several forms of telecollaboration exist including the telephone call, voice conferencing, video conferencing, pictoral information exchange, and data and/or document conferencing.

A major advantage of telemedicine is that it provides for a rapid linkage to remote "experts" who can help with patient care in underserved areas. Telemedicine facilitates the reality of providing a remote specialty consult from virtually any location within minutes. This provides greater expertise to the care of any individual patient. In addition, telemedicine is used to enhance the education of providers and patients through use of Internet-based interactives. Education is facilitated through the creation of telecommunication-linked classes providing interactive information on care and prevention to places where such information and expertise is not currently available. For example, a number of international telemedicine efforts are currently taking place in Indonesia, Africa, Japan, Korea, China, Europe, and the United States. The Telehealth Africa project between African and European hospital centers is working to transmit health-related diagnostic images. A weekly teleconferencing link collaborative between an American hospital and a Budapest institution on issues related to diagnosis of pediatric movement disabilities is also taking place.

For the most part, E-health and telemedicine have been developed and studied as tools and strategies for use at the health care provider level to improve the quality and cost of care and to improve patient safety within the health care system. Viewed from this perspective, patients are the passive recipients of improved outcomes rather than active participants in the health care delivery process. Increasingly, however, consumers not only have become educated consumers due to the availability of E-health and telemedicine but also have become the primary intended audience for E-health-related information and technology. There are benefits and barriers to both provider and consumer use of E-health and telemedicine.

BENEFITS

Provider level. Beneficial impacts of computer-supported decision making on physician performance and patient outcomes have been documented. These include the use of computerized drug ordering systems for physicians that can reduce adverse drug events through decision support systems. Similarly, automated computerized reminders can increase orders for recommended prevention interventions such as yearly physicals, mammograms, and prostate examinations. In more extreme situations, E-health has been used by emergency medical personnel and first responders for consultation during natural disasters and in military battlefield situations. In rural and remote areas, this technology has been used by primary care providers to provide consultations and/or second opinions for patients through direct linkage to urban-based specialists. Increasingly, E-health is being used as a distance education strategy for primary and continuing education. International collaborative initiatives such as the Cochrane Collaboration, which produces a majority of the world's evidence-based medicine recommendations, have also benefited from advances in E-health and telemedicine by making information readily available to health care professionals and consumers.

Consumer level. Consumers have also benefited from advances in E-health. Pharmacy needs and prescriptions can now be ordered online and delivered directly to the buyer. Consumer-oriented health information is now a large market niche for a variety of medical and health-related organizations. A majority of hospitals and other acute care institutions host web pages that detail their expertise and services. For those with disabilities who reside in the community, a variety of E-health-based strategies exist. These include telerehabilitation systems for poststroke patients. These systems not only monitor vital signs of the patient (i.e., blood pressure, pulse, temperature) but also permit direct provider-patient communication through audio or video conferencing linkages to gauge home-based progress. Another consumer-oriented application is telelearning, which combines education with self-managed behavioral interventions designed to improve quality of life. Adaptations for consumers with disabilities who cannot use the standard computer are currently under development.

BARRIERS

Provider level. Barriers to wider use of E-health by health care providers include lack of financial incentives and reimbursement to support its use widely within and across organizations. As is true with adoption of any new innovation, the process is slow and has been characterized as a sequence that moves from innovator/risk takers, early adoptors, mainstream users, to latecomers. Incorporating a new technology will have effects on workflow with the initial start-up likely to slow established processes down due to the learning curve needed to implement the new technology, followed by a more streamlined and routinized system, which should increase efficiency and productivity.

Other barriers to E-health technology include cost (e.g., hardware/software purchases, maintenance/upgrades) and the current "lack of standards" concerning the format and content of E-health information, particularly private patient health-related information, which has legal and economic implications for providers with regard to liability and malpractice insurance.

Consumer level. One of the largest barriers to widespread consumer use of E-health is often referred to as the *digital divide*. The digital divide can be defined as a basic lack of knowledge about the availability and familiarity with technology in general. While access to electronic communications is steadily increasing both in the developed and developing worlds, these increases are not uniform and disparities in availability and skill level in using these technologies are growing wider. Issues such as cost, literacy level, cultural appropriateness, and compliance with standards for those with disabilities (i.e., Americans with Disabilities Act) continue to be barriers in the use of E-health. For patients and consumers, issues such as protection of privacy and confidentiality and informed consent should be considered. Finally, related to the disabled in particular is the need to determine the ease of use and ergonomic issues related to the use of E-health.

In response to many of the issues raised by the exponential growth in E-health, the Institute of Medicine (IOM) issued a report in 2001 titled "Crossing the Quality Chasm." The report recommended that an information infrastructure be built that will support the following: health care delivery, consumer health, quality measurement and improvement, public accountability, clinical and health services research, and clinical education. Implementation of the recommendations of the IOM report will provide greater assurance that high quality standards are in place that will help to improve the health of many communities, including those with disabilities, that can benefit from new technology such as E-health and telemedicine.

—Karen E. Peters and
Michael L. Glasser

See also Accessible Internet; Health Care and Disability; Telerehabilitation.

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ELDERLY

See Aging; Aging, International; End-of-Life Care; Frailty; Hip Fracture; Osteoporosis

ELKIN, STANLEY (1930–1995)

American writer

One of America's most acclaimed twentieth-century writers, novelist Stanley Elkin lived and wrote with multiple sclerosis for 30 years. In 17 award-winning books, he developed a virtuoso prose style and a hilarious, provocative, humane "comedy of affliction" in

American life that reflected his adage: “The Book of Job is the only book.”

An early work, *The Franchiser*, published in 1976, employs paralysis as an ironic metaphor. Business visionary Ben Flesh hopes to “democratize” American wealth by spreading bright, identical franchises—Dunkin Donuts, KFC, Mister Softee—to the country’s underdeveloped corners. But “Flesh fails”—the entrepreneur is diagnosed with multiple sclerosis, his limbs grow dully indistinguishable (like franchises), and so MS turns Flesh into “Mister Softee”—a living parody of his plan to enrich America by homogenizing it.

In a 1993 novella, “Her Sense of Timing,” Elkin makes provocative dark comedy from the frustrations of dependent illness: A wheelchair-bound college professor’s wife leaves him suddenly, just before guests are to arrive for their annual faculty party. The plot pays ironic tribute to Elkin’s wife, who faithfully assisted him throughout his illness.

In *The Magic Kingdom*, from 1985, seven terminally ill children go on a last hurrah “dream holiday” to Disney World. The compelling, messy reality of sick children’s lives collides with the clean, efficient unreality of the Disney cartoon world. By turns hyperrealistic, fantastic, comic, and serious, the novel celebrates the shabby-but-wondrous condition of all embodied lives.

Elkin also wrote numerous Faulkner-styled essays about how art helps us prevail in the face of life’s—and the body’s—injustices: “As the old saying should go, as long as you’ve got your health you’ve got your naivete. I lost the one, I lost the other, and maybe that’s what led me toward revenge—a writer’s revenge, anyway, the revenge, I mean, of style.”

William Gass, novelist and critic, wrote that among Elkin’s achievements was “to disable disabilities by finding their use.”

—Tom Feigelson

See also Novel, The.

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EMERGING DISABILITIES

Our perspectives on disability are often framed by an implicit assumption that disability is an entity fixed in form and static in size. The term *emerging disabilities* was coined in the 1990s to focus attention on the changing nature of health risks in the United States and the possibility that these changes were affecting the composition of the disability population. Examples include the epidemic of drug-related gang violence, emergence of high-profile illnesses such as HIV infection, and growing awareness of the potential impact on disability of large-scale demographic transitions such as aging. The emerging disability concept can be seen as a working hypothesis about the impact of these trends on the size and character of the disability population.

Emerging disability is neither a discrete condition nor a group of diagnosable conditions. Rather, the term attempts to conceptually summarize different dynamics affecting the composition of the disability population: (1) changes in the economic or social environment that affect risk for disablement, (2) emergence of newly recognized conditions or sudden growth in the numbers of established disability conditions, and (3) changes in definitions that lead to the incorporation of conditions not traditionally thought of as part of the disability “universe.”

CHANGES ASSOCIATED WITH SHIFTING PATTERNS OF RISK

Understanding the impact of shifting cultural, demographic, or economic forces on disability populations is a major theme in emerging disability. The decade-long epidemic of firearm-related injury associated with gang violence and urban drug trafficking is a striking example of a disability shift embedded in the changing cultural circumstances of the 1980s. Data from spinal cord injury data systems reported violence-related injuries more than doubling from the 1970s to the early 1990s. Aging is an important example of change in disability populations caused by demographic forces since rates of severe disability are disproportionately represented among the elderly. With the anticipated rapid growth of the oldest population cohort—those age 85+ years—disability due to onset of later-life illnesses and impairments will become an increasingly important part of disability demographics. The shift in age distribution and its role as a risk factor for disability represents an unprecedented challenge to long-term care services, social welfare, and other health and support systems.

The role of economic forces is a central feature of emerging disability conceptions given the inextricable linkage of disability and poverty. Although the relationship is affected by age, education, and other demographic characteristics, two essential observations of disability and economic status are well established: first, that persons with disabilities are more likely to be economically marginalized, and second, that the poor are far more likely to be exposed to risks associated with disablement. The emerging disability framework considers this connection from the perspective of change, specifically, any changes in the structure of poverty. For example, the steady increase in income inequality since the 1960s signals a long-term change in the distribution of wealth in the United States—an expanding gap between rich and the poor, and greater concentration of poverty among families with young children. To the extent that impediments to childhood development are embedded in the conditions of poverty—lack of maternal and postnatal health care, malnutrition, and developmental deprivation, among other risks—emerging disability frames the trends in terms of the impact on the disability population.

CHANGES ASSOCIATED WITH NEW CONDITIONS/CHANGING ETIOLOGIES

A second form of change represented in the emerging disabilities concept is the recognition of new forms of impairments or unexpected increases in the incidence or prevalence of existing conditions. Examples of newly recognized conditions include chronic fatigue syndrome (CFS), multiple chemical sensitivity, and carpal tunnel syndrome. Conditions tend to be controversial because of an absence of standardized case definitions; consequently, estimates of the affected population tend to vary widely. Emerging disability also refers to familiar conditions or causes of disabilities that are undergoing a transformation in character or magnitude. Autism and attention deficit hyperactivity disorder (ADHD) are prototypical of the established condition becoming more prominent. Clinical service registries and school systems reported dramatic increases in the numbers of diagnosed children throughout the 1990s. However, the results of prevalence studies are contradictory and analysts fail to agree on whether the increases are real or merely an artifact of increased awareness and access to improved treatment options. Less contentious examples of increased prevalence among established conditions are spinal and brain cord injuries. With recent improvement in trauma care, survival rates for spinal cord and severe brain injury improved dramatically in recent decades. The form of injury is not new, but the increased likelihood of survival as well as the extension of lifespan because of improved posttrauma care creates new challenges for the systems of rehabilitation and support.

CHANGES ASSOCIATED WITH EXPANSION OF DISABILITY BOUNDARIES

A third emerging disability theme is the effect of conceptually broadening the disability universe by incorporating groups not traditionally served by the disability and rehabilitation field, such as persons with HIV infection, obesity, cancer, or other chronic illnesses. Expansion of the disability universe was first formalized in the 1990 Americans with Disabilities Act (ADA) in which *disability* was defined as a physical or mental impairment that substantially limits one or more major life activities, or as being regarded as having such an impairment. The qualifying phrase, "regarded as having an impairment," extended antidiscrimination provisions to those with conditions that did not directly affect performance, for example, the presence of disfigurement or obesity. Emerging disability extends the logic of expanded legal protections to encompass the potential role of traditional disability and rehabilitation service providers in addressing the needs of persons with conditions not typically associated with "disability" status. But expansion is problematic in that the linkage of label to disability is under increasing challenge in both our diagnostic theories and legal frameworks. In the new paradigms of disablement, disability is not an attribute of the person but rather a complex interaction of personal, environmental, political, and cultural considerations. The presence of impairment should not automatically be equated to disability status. Recent legal challenges seeking to restrict the scope of the ADA have also served to weaken the link between impairment and disability. In 1999, the U.S. Supreme Court ruled that impairments that can be corrected or do not substantially limit activities are not considered disabilities. Emerging disability is anchored in older, more medicalized paradigms of disability in its emphasis on reclassification of chronic conditions as disabilities and its focus on the causes and prevention of impairment. The effort to include these and similar groups of conditions highlight the ambiguities of defining a class of citizens as "disabled."

SUMMARY

Emerging disability is a conceptual amalgam of different dynamics affecting population change: changing demographics and etiologies, newly recognized impairments, and shifting boundaries for disability definition. Emerging disabilities is a useful conceptual tool for drawing attention to the dynamics of change in populations that may be the consequence of socioeconomic and cultural trends. It also serves to make more prominent public health concerns within the disability and rehabilitation fields by focusing on the epidemiology of impairment. The concept, however, has yet to gain widespread acceptance except as a broad and inconsistently applied umbrella term for unusual impairments. Perhaps a more fundamental challenge to the conceptual integrity of emerging disability comes from the new paradigms of disability that directly challenge disability definition based primarily on diagnostic categories. Contemporary disability definitions are increasingly nuanced. Until clear definitions and boundaries of impairment and disability are forthcoming (and there is debate whether that is achievable), the central utility of the emerging disability idea is to draw our attention to the reality of change and the fact that disability, however defined, is dynamic rather than static.

—*Glenn T. Fujiura*

See also Epidemiology; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Obesity.

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EMPLOYABILITY

Employability means the degree of possibility of finding or regaining employment. It can also denote an objective situation or a characteristic specific to an individual. In Europe, it was in the context of the great rise in unemployment at the end of the 1980s that the term took on its present meaning. This was accompanied by a shift in theoretical explanations of unemployment and in the measures taken to address it.

Until that time, employability had been a statistical concept, based on the average period of unemployment. It was an instrument to measure the workings of the labor market, which eliminated groups with objective characteristics such as age, sex, or qualifications. One could state from statistics, for example, that a given age cohort or that women, the disabled, or people with a certain level of education remained unemployed longer. For each of these categories, the chances of finding employment could be evaluated. Such tracking made it possible to better administer the flux of the unemployed, particularly by retraining them. This is employability in the "probabilistic" sense.

By the end of the 1980s, employability also denoted the medical and sociocultural obstacles encountered by job seekers. In other words, unemployment was no longer simply a question of vocational training; it was seen as linked, as cause or effect, to a desocialization, a destructuring of individuals. The solution to unemployment was sought in social qualifications, which could include such details as dressing correctly and arriving at work on time as well as having the necessary vocational credentials and references. From an objective, collective term, employability now designated an attribute of job seekers themselves, in fact, their only attribute, as the term "disabled" tends to do. Logically, then, attention to unemployment shifted toward attention to people, on whose behalf all sorts of social interventions, well beyond the vocational training of adults, had to be provided.

It was at this same turning point at the beginning of the 1990s that a new paradigm was introduced in Europe, along with a new term: the excluded. This term denotes the capability of maintaining oneself in the social fabric more than a capability for work. The job seeker is no longer simply one of the inactive; he or she becomes socially maladjusted, vocationally unfit, and, once again, one of the excluded.

Conceptual contours were becoming blurred from several perspectives. An individual's trajectory could move him or her from one status to another, according to which criteria were employed and to the interest of the stakeholders. Thus, we see the unemployed beginning to sign up for benefits previously reserved for disabled people or, inversely, disabled people finding, at least provisionally, greater satisfaction in being paid minimum wages that were primarily intended for job seekers. A second instance of blurred contours was on the level of interventions by social workers and counselors seeking to remedy unemployment.

Employability often becomes unemployability, as the lack becomes the focal point, thereby creating the category of the unemployable. The latter term is rather like a return to the old category of the able-bodied poor, that is, people who begged for lack of work but by virtue of their ablebodiedness were reproached, even condemned, as useless, lazy, or superfluous. But there is a growing confusion between the able-bodied without work and the disabled, whether the latter are themselves also without work or are prevented from working by their impairment. One confusion leads to another: Where does the distinction lie between the right to work and the duty to work? In countries with a welfare state, primarily in Europe, a distinction was established, on the one hand, between policies related to insurance, organized around the notion of salaried workers (social security), which covered the unemployed, and, on the other, policies of social assistance aimed at those who had difficulties in finding and retaining salaried work because of their individual characteristics(e.g., severely disabled people).

Even though things have never been so cut-and-dried—disabled workers are for the most part capable of work and there are many social assistance options available within the social security system—the fact remains that the expanded notion of employability, which includes notions of unemployable and of maladjusted, blurs employment policy. Indeed, new population groups that find themselves without work cannot be clearly identified as the able-bodied unemployed or as the disabled. The term employability leaves them between the two camps, sharing some of the characteristics of each. As a consequence, policy options drafted for their situation display neither a universalist vision, which would be that of integration policies focused on employment, nor an individualist vision, which would spring from social policy. It is into this interstice that the so-called insertion policies slip, producing a thick stratum of citizens who occupy a social substatus, always being inserted and disinserted.

In other words, the categories of employable and unemployable mask a variety of difficulties, for which there is now only a single remedy: minimal integration (some work, provisional and discontinuous, and some social networking effected by assistance and support measures). Such a minimum is self-perpetuating and creates a segment of the population whose stake is enduringly precarious.

—Henri-Jacques Stiker

See also Affirmative Businesses; Consumer-Run Businesses; Disability and Career Development; Employment; Job Retention.

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▣ EMPLOYMENT

Employment and disability; these two areas appear to be antithetical. Employment portrays gainful productive activity, while disability depicts inability to work or be employed due to impairment or limitations. With or without disability, work is an important aspect of life, a major role in adulthood. Sigmund Freud saw work as one of the basic requirements of human existence, and Erik Erikson indicated that work brings people a sense of selfhood. Inability to work not only hampers one's development in the life cycle but also brings damage to an individual's self-identity and worthiness.

Vocational psychologists suggest that employment has six functions. It provides income for daily living necessities such as food, clothing, and shelter. It regulates daily activities, allows for social interaction with others, and is a major determinant of one's social status. For the most part, one's social standing is determined by the perceived prestige of one's occupation and accomplishment at work. It gives a person an identity and provides content and meaning to life. In sum, work determines a person's worth and place in society, and it influences one's psychological identity and sense of well-being. Employment, however, is not readily available to all people, especially to those who have disabilities. Environmental barriers, societal prejudice, and functional limitations caused by disabilities often exclude people with disabilities from the world of work.

In the United States, attention to the employment of people with disabilities was heightened after World War I, responding to the postwar employment challenges faced by veterans. Subsequent development of vocational rehabilitation legislation and the state-federal vocational rehabilitation program extended services to all citizens with disabilities. Recent legislation, such as the Americans with Disabilities Act (ADA), is intended to ensure equal opportunity and nondiscriminatory practice in employment for people with disabilities. Despite passage of such legislation, obtaining and maintaining employment for people with disabilities remains a big challenge.

Employment Statistics of Persons with Disabilities

Employment rates among persons with disabilities vary depending on the measure of disability that is used. In a 1996 U.S. Census Bureau survey, about 11 percent of working-age Americans reported a "work disability" defined as having a health condition that limits the kind of work they can do. Among those reporting a work disability, about 20 percent are employed in a given week, compared to 75 percent of those not reporting a work disability.

If one uses the ADA's broader definition of disability involving major life activity limitations and functional impairments, it is estimated that there are 54 million Americans with disabilities. Of these, 29.5 million are of working age constituting 20 percent of the total working-age population. Under this broader definition, approximately 50 percent are employed in a given month, compared to 80 percent of working-age people without disabilities. The figure is much lower among those with severe disabilities, of whom only 25 percent are employed in a given month. More recent data from the U.S. Census Bureau (2002) show that 22.3 percent of people with disabilities between age 16 and 74 were employed, of which only 14.4 percent worked full-time. As expected, 25- to 34-year-olds have the highest employment rate (36.9 percent); the next group is 35- to 44-year-olds (30.2 percent) followed by those ages 45 to 54 (28.8 percent) and 16 to 24 (28.5 percent). Employment rate decreases as the person's age increases after age 55. There are similar employment patterns between workers with disabilities and those without disabilities. In general, women with disabilities are less likely than men with disabilities to be employed, and employment rates are especially lower among people with disabilities who are African American, older than 45, or who have never been to college.

The above data clearly indicate that persons with disabilities have difficulties in obtaining and retaining employment. When asked whether they are willing to work, most persons with disabilities would indicate so, but in fact only about 25 percent do actually work and most are on a part-time basis. Thus, the question is not, and never has been, whether people with disabilities are interested in working, but rather what is prohibiting their participation in the work force and what corrective action is required.

Earnings of Persons with Disabilities

Workers with disabilities earn lower wages than do nondisabled workers. It is estimated that people with disabilities earn 10–25 percent less on average than do comparable people without disabilities. A recent survey on earnings of recipients of state-federal vocational rehabilitation services show that the average hourly wage was $7.33 per hour (median $6), which increased to $9.62 (median $7.65) per hour three years after exiting from the vocational rehabilitation system. The lower employment rates and earnings of people with disabilities contribute to lower economic well-being. Including all sources of income, the median personal income of working-age people with disabilities is only 60 percent that of people without disabilities, suggesting that the various sources of disability income do not come close to making up for the loss of earned income. More important, about 19 percent of all people with disabilities live in poverty households, twice the estimated rate for people without disabilities (8.9 percent). While employment provides the means for a better standard of living, the lower earnings of workers with disabilities causes them to be more likely to live in poverty than employed workers without disabilities. Health insurance coverage, though, is very similar between people with and without disabilities, since greater Medicaid and Medicare coverage among people with disabilities mostly makes up for the lower levels of employer-provided health insurance. It is evident that employment is critical to the economic well-being of people with disabilities. However, many people with disabilities continue to suffer financially due to higher unemployment rates.

Barriers to Employment

While many speculate that the disability itself would be the main barrier to employment, the literature in disability and employment suggests otherwise. In most studies, disability accounts for only a small amount of the variance in employment. Barriers due to accessibility and discrimination appear to be the main and surmountable hurdles for employment among persons with disabilities. In general, there are three major types of barriers: environmental, societal, and personal.

Environmental barriers. Buildings with stairs at entrances and doors that are too narrow are obvious examples of architectural barriers to persons with physical disabilities. These barriers can be viewed as arbitrary limitations on equal opportunity when a person with a disability is qualified for a job but cannot take the job due to inaccessibility. The building itself is, in effect, an agent of discrimination. Other environmental barriers include limited access to public transportation and communication. The federal government has passed legislation to create barrier-free environments for people with disabilities. Under Section 502 of the Rehabilitation Act of 1973, the Architectural and Transportation Barriers Compliance Board was established to enforce the accessibility standards. The subsequent passage of the ADA further enforces equal opportunity and accessibility to employment. The ADA has been called the "Emancipation Proclamation" for people with disabilities. It prohibits discrimination in employment, public accommodations, government services, and telecommunications. It requires employers to make reasonable accommodations in the work environment so that a qualified worker with a disability can be employed. Incentives have been proposed for removal of barriers to encourage both public and private companies to become more accessible. Businesses that incur expenses in removing barriers, as is required under the ADA, may receive up to a $35,000 deduction for expenditures to remove architectural and transportation barriers to people with disabilities.

Societal barriers. A hidden but pervasive barrier to employment of people with disabilities is prejudice and discrimination. Society has certain beliefs or stereotypes of people who are different. Commonly expressed stereotypes about people with disabilities include pity, dependence, incompetence, and character weakness. Just because most people have knowledge of a set of stereotypes does not imply that they agree with them. In fact, many persons can recall stereotypes about different racial groups but do not agree that the stereotypes are valid. People who are prejudiced, on the other hand, concur with these negative stereotypes and generate negative emotional reactions as a result. A behavioral reaction of prejudice is discrimination. Discrimination toward people with disabilities includes outright intentional exclusion or relegation to lesser services, jobs, or other opportunities.

Formation of stereotypes and subsequent prejudice toward people with disabilities are often caused by misinformation or misconception. Misconception about specific disabilities, including presumptions about the cause of disability, often affect hiring recommendations. These unfounded myths and false assumptions are deeply, often subconsciously, rooted in many of us. Some of the myths about people with disabilities include the following:

- Increased insurance costs due to workers' compensation and higher accident rates
- Limited dependability and poor attendance records
- Low productivity
- Need for special accommodations and work arrangements
- Lack of acceptance by coworkers

Many of these myths can be disputed by facts. For instance, workers' compensation insurance rates are based on the hazardous nature of the work itself, the previous accident rate of the company, and the amount of resulting compensation and medical costs charged to the insurance carrier. Research evidence shows that employees with disabilities in general do not have higher accident rates than employees without disabilities. Also a long history of research findings rejects the assumptions that workers with disabilities have more problems than workers without disabilities in regard to absenteeism, productivity, and ability to perform the job. In addition, most work site accommodations cost nothing or less than $500, not the thousands of dollars most people believe. Specifically, about 50 percent of the reasonable accommodations cost nothing, 30 percent cost less than $500, 10 percent cost between $500 and $2,000 and 10 percent cost in excess of $2,000.

Personal barriers. Research evidence indicates that there is a correlation with certain personal characteristics and employment opportunities. In general, those who are employed tend to be younger, male, Caucasians, have more education, have previous work experience, and a physical disability. To understand the extent to which disability affects employment, one has to consider the disability in relation to the individual's physical, psychological, and vocational functioning. Questionable physical capacity becomes a significant concern in the consideration of types of employment for which the individual is otherwise psychologically and vocationally suited. The literature suggests that it would be a mistake to ignore the fairly consistent limitations associated with particular disabling conditions in relation to employment choices. Obvious examples are people who have ambulatory difficulties need accessible facilities (e.g., barrier-free buildings), those who have cognitive process problems need to consider jobs with less complexity, and people with disabling conditions exacerbated by stress should be aware of the stress levels associated with the job.

Psychological functioning, a significant employability factor, can either restrict or enhance the chance of employment. Maladaptive adjustment to disability such as denial or oversensitivity to one's disability could reduce employability. There is research evidence that suggests self-stigma could be one of the psychological barriers that people with disability need to overcome to be gainfully employed. Living in a culture that endorses prejudices about disabilities (e.g., people with disabilities are incompetent to hold anything but substandard jobs), people with disabilities may apply the prejudice to themselves (I am disabled so I must be unable to hold a regular job), resulting from diminished self-esteem (I am less of a respected person because of my disability) and subsequently report lowered self-efficacy (why try to get a job; someone like me is incapable of doing regular work). Turning this negative psychological force into a positive power would be beneficial to persons with disabilities in terms of adjustment to disability and enhancement of self-efficacy and self-esteem. Current emphasis on empowerment of persons with disabilities is a positive strategy to assist people with disabilities to address self-stigma issues.

For an individual to be employable, one has to possess necessary vocational skills and demonstrate appropriate behaviors. Due to limited work opportunities and consequent work history, persons with disabilities may not possess these necessary work behaviors and skills. Work adjustment training, a service provided through the state-federal vocational rehabilitation system, is designed to teach people the behaviors needed to fulfill employment requirements. Work adjustment training covers three major areas: job responsibility, task production, and social-vocational competence with strategies to enhance physical capacities, psychomotor skills, appropriate dress and grooming abilities, interpersonal and communicative skills, orientation to work practices, work habits, response to supervision, and getting along with coworkers.

It is obvious that persons with disabilities possess certain limitations that handicap their employability. The extent of handicap does, however, depend in large part on the complex interaction of the individual, the disability, environment, society, and culture. Rehabilitation psychologists have extensively studied this complex phenomenon and offer the following observations to help explain the effects of disability on employment.

- It is more important to focus on the functional limitations resulting from a disability and the individual's psychological reactions to those limitations than on diagnosis such as schizophrenia, mental retardation, or learning disabilities.
- It is easier to predict the source of disability to a tangible functioning and behavior (such as spinal injury to ambulatory problems) than intangible behaviors (such as learning potential, employability).
- There is a weak association between disability and personality. That is, there is no such thing as a "blind" personality or a "spinal cord" personality. Stereotypes or overgeneralization of disability results in prejudice and discrimination toward people with disabilities.
- Psychological factors are only a part of the equation in determining how one responds to disability. The importance of social or sociological factors must not be underestimated and negative societal attitudes serve to mask the rehabilitation and vocational potential of persons with disabilities.
- Persons with disabilities have the abilities to perform successfully in a large variety of employment functions and have demonstrated dependability and good performance on jobs.
- Employers' attitudes in hiring persons with disabilities are mixed. Among employers there is a discrepancy between reported intention to hire and actual hiring of persons with disabilities.

Strategies and Practice to Secure Employment

To compete with nondisabled workers, workers with disabilities need to have adequate job-seeking skills and abilities to secure employment. While some individuals with disabilities have sufficient job-seeking skills, many do not have preparation in the area. Studies show that a high percentage of persons with disabilities do not look for jobs frequently enough, most are unaware of techniques for securing and following up on job leads, most of them could not explain skills to employers, some have poor personal appearance or inappropriate mannerisms, and nearly all could not explain their handicapping condition. Inadequate job-seeking skills often limit persons with disabilities to entry-level, secondary labor market positions, which are commonly the last hired and first fired. Only with sufficient job-seeking skills can they reenter the workforce on their own initiative.

Some job seekers with disabilities may be unclear as to how their abilities and interests can best meet the needs of employers or be unable to conduct an extensive job search. Rehabilitation service intervention, such as job placement service, is necessary in assisting individuals with disabilities to secure employment by acting as information intermediary or broker between buyers and sellers of labor.

Job-seeking skill training. The goal of the training is to prepare persons with disabilities in job-seeking skills so that they can seek and secure employment. Common activities in the training include the following:

- How to find job leads
- Preparing personal resumes
- Filling out applications
- Role-playing job interviews
- Understanding hiring practices
- How to disclose disabilities

The Job Club strategy developed by Nathan Azrin and his colleagues is an effective approach in job-seeking skill training. Based on behavior theory, the Job Club uses multiple proven techniques to increase the individual's job-seeking capabilities, such as the buddy system, family support, role models, intense role-play practice of job interview, and practice in completing job applications. Club members meet daily in a small group format and follow up on job leads they have obtained from family, friends, other Job Club members, the phone directory, and previous employers. Members have a standardized script to use in making phone calls to employers, after which they receive reinforcement and feedback from their counselors and other club members as they complete calls and job interviews. Studies have demonstrated the positive results of job-seeking skill training and the Job Club.

Job placement. People with severe disabilities may require direct placement intervention and support to secure and maintain employment. Acquisition of employment for these individuals often requires the help of rehabilitation professionals such as rehabilitation counselors or job placement specialists who can both sell employers on hiring them and supply the necessary on-the-job support. Strategies that match the person to job requirements are used frequently to place persons with disabilities. Job matching considers the person's skills, abilities, interests, and needs. To facilitate a good job match, job analysis often is performed by studying the job demands such as physical demands, mental demands, job-related stress factors, characteristics of work environment, and existing and potential hazards. Job tenure occurs when the job meets the needs of the person and the person meets the demands of the job.

Another approach to job placement is partnership with employers, also known as demand-side job development. As proposed by job development professionals, demand-side job development provides services directly to employers that make the workplace more user friendly for people with disabilities and assists employers in meeting their personnel needs by hiring persons with disabilities. The demand-side model extends marketing away from sales and into consulting. To make job placement successful, rehabilitation professionals must provide counseling and consulting assistance to both individuals with disabilities and employers. This would prepare employers to be better able to make accommodations and train employees in accepting diversity through increasing demand for applicants with disabilities. Rehabilitation professionals enhance persons with disabilities' employment outcomes by functioning as consultants to employers in providing services such as human resources planning and filling "hard to fill" positions. In addition, they provide postemployment counseling and consulting to employees with disabilities and their supervisors to improve work performance, maintain employment, and enhance career advancement. Several national chains and franchises have been involved in providing employment opportunities to persons with disabilities through this partnership approach.

Assistive technology and accommodation in the workplace. In addition to the job placement strategies described above, assistive technology is used in the workplace. Assistive technology is an effective means to replace or extend a person's capacities to cope with different types of vocational and daily living demands. Technology can contribute to employment and social integration of individuals with disabilities through enhanced mobility, manipulative capabilities, and communication. A specific use of assistive technology in the workplace is job accommodations. Reasonable accommodation is a logical adjustment to a job and/or the work environment that enables a qualified person with a disability to perform the duties of that position. Accommodations in the workplace could include making existing facilities used by employees readily accessible to and usable by individuals with disabilities, job restructuring, use of part-time or modified schedules, reassignment to vacant positions, and acquisition or modification of equipment or devices. Examples of physical access job accommodation can be putting the job on the first floor, near the employee parking lot, or near the bathroom. Resource accessibility accommodation for a person with hearing impairment can be providing a notetaker or sign language interpreter; for a person with visual impairment, accommodation can be providing a reader or notetaker. Adaptive equipment accommodation includes "low tech" and "high tech" assistive devices. Examples for the person with arthritis or carpal tunnel syndrome can be providing a special pen/pencil holder; for those who have orthopedic problems by providing desk or chair modifications, speaker, and earphone on telephones. Accommodations for persons with visual impairment can be by providing a talking calculator or talking computer.

Job modification for persons with disabilities is based on the principle that modifications are made only to the job performance while maintaining the same job duties. A modification for a salesperson with energy or ambulation problems may be to do more telephone sales with fewer field appointments. A parking lot attendant with orthopedic problems perhaps could use a chair for sitting instead of standing throughout the day.

The Job Accommodation Network (JAN; 1–800–526–7234) is a resource available for information on employer accommodations. Before contacting JAN for information, it is necessary to have specific medical restrictions regarding the worker with disabilities, job duties that are precluded as results of the restrictions, and general information about the industry in which the job is located.

Future Employment Trend and Its Impact on Persons with Disabilities

The U.S. Department of Labor (DOL) unveiled its 10-year long-term forecast in 1998. In its forecast for the 10 years from 1996 to 2006, total employment will grow by 1.3 percent per year through 2006. After the September 11, 2001, terrorist attacks and subsequent two foreign wars, the U.S. economy suffered from a high unemployment rate and huge federal deficits. One could question the accuracy of DOL's long-term forecast considering the aftermath of 9/11. Nevertheless, trends and characteristics of future work force and job markets identified in the long-term forecast remain relevant and can affect future employment opportunities for persons with disabilities. While manufacturing employment is forecasted to continue its modest decline, employment in service-producing industries is expected to grow 2.9 percent per year, with employment in personnel supply services expanding by 4.3 percent per year and employment in computer and data processing services increasing at 7.6 percent per year. In terms of supply and demand in the workforce, DOL predicts that the supply of workers will increase by 1.1 percent annually, short of the 1.3 percent annual increase of employment. In translating the percentages to numbers, it is forecasted that through 2006, employers will increase their payrolls by 18.6 million workers, while the labor force is expected to grow by 14.9 million workers, creating a shortfall of 3.7 million workers. In short, labor markets are expected to remain tight in the next few years. Research evidence suggests that lower unemployment rates benefit low-wage earners more than high-wage earners. In general, low-wage earners usually are individuals with low skills and they tend to benefit from greater employment opportunities and higher wages when unemployment rates are low. Similarly, people with disabilities benefit from low unemployment rates.

The DOL's long-term forecast shows a variation in growth rates among industries. The fastest growing employment sector is personnel supply services, including temporary employment agencies. The food and beverage industry is the second fastest growing sector. State and local governments, including education, is the third fastest growing sector. Computer and data processing, health practitioner, and retail trade services make up the fourth, fifth, and sixth fastest growing sectors, respectively. Variations in job growth predictions underscore a growing dichotomy in labor demand between high-skilled, high-wage jobs and low-skilled, low-wage jobs. The dichotomy becomes clearer when the top 10 fastest growing occupations are compared. The top 10 fastest growing occupations through 2006 as reported by DOL are (1) cashiers; (2) system analysts; (3) general manager and top executives; (4) registered nurses; (5) salespersons; (6) truck drivers; (7) home health aides; (8) teacher's aides and assistants; (9) nursing aides, orderlies, and attendants; and (10) receptionists and information clerks. Low- and modest-skilled occupations such as cashiers, salespersons, and aides and attendants are usually low-paying jobs as compared to high-skilled and high-wage occupations such as system analysts, managers and CEOs, and registered nurses. As suggested by the literature, people with disabilities, especially those with severe and multiple disabilities, will fill many of the low-skilled and low-wage occupations such as retail salespersons, waitpersons, hotel workers, janitors, cashiers, hospital attendants and orderlies, nurse's aides, and security guards due to limited training or education. In addition, high-paid employment requires technical and professional education beyond high school, and high school graduates face a much harsher employment outlook today than 20 years ago. Lack of career advancement opportunities for people with disabilities is an expressed concern of vocational rehabilitation workers. For persons with disabilities to compete in the future job market, they need post-high school education and specialized vocational training.

Economists point out that as technology develops, especially in the area of information technology, globalization becomes the norm of modern society. Development of a global economy causes changes to the U.S. work force. The traditional ways of performing work no longer hold true. Future workers will require greater use of communication technologies and computer skills. They will be expected to make choices and decisions on their own and have abilities to handle multiple tasks and skills, and work as part of a team. It is likely that the future employment opportunities will be temporary and part-time, rather than permanent and full-time employment. Flexible work hours and job sharing will become more common. While most people with disabilities benefit from these new employment structures, some may find these changes challenging. For instance, persons with a psychiatric disability may find flexible hours difficult to handle.

In sum, while some people with disabilities have made gains in employment, they still remain at a disadvantage in many facets of the labor market. A range of employment opportunities will continue; however, the best jobs go to persons who are literate, can adapt to change, and continue to learn new skills.

—*Chow S. Lam*

See also Americans with Disabilities Act of 1990 (United States); Assistive Technology; Disability and Career Development; Employment, International; Employability; Job Retention; Vocational Rehabilitation.

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EMPLOYMENT, INTERNATIONAL

Employment is often considered to be work for which a person is paid. However, in many countries, work that provides sustenance does not also always provide a wage. Definitions of disability drawn from urban, industrialized settings that see disability primarily as an inability to work at a wage-paying job are problematic in the rural, nonindustrialized, and primarily agricultural economies found in developing countries. Nonwage work is an important source of sustenance for many people, both with and without impairments, in developing countries.

In developed countries, there is a large amount of research about people who have a "work disability"—that is, who have an impairment that limits the kind or amount of work they can do. However, that research—by definition—does not consider people who do not perceive themselves to have a work limitation, although they may actually have an impairment, and who are in fact working. Thus, results from this research do not apply to all workers with impairments. Although "objective" measures of disability are used as the basis for policies such as workers' compensation in the United States, they do not tell us about disability and work. For example, partial loss of a limb or a hearing impairment will qualify people for payments under workers' compensation, even if they can continue to work at their old jobs. One person with a severe impairment may be working, while another with a similar impairment may not—partially because of the types of training, skills, and job expectations they have.

When we put these two ideas together, we can see that there are four possible relationships between disability and work. These are shown in Table 1. These cells provide the organizing principle around which this entry is built.

Table 1

	Perceived impairment	
Type of work	*Work limiting*	*Not work limiting*
Wage	1	2
Nonwage	3	4

Cell 1: People who work in paid work and have an impairment that limits the kind or amount of work they can do.

This category of people has been extensively researched in the United States, Canada, and Western Europe, and the results tend to be fairly similar. People who are working despite having a work-limiting impairment, not surprisingly, earn less than workers without such an impairment, and they often feel that they are underemployed. In addition, they are more likely to be unemployed. (*Unemployed* means a person is actively looking for a job, but it does not refer to people who have given up looking or who have not yet started looking.) Because of this, one report on disability and employment in Canada states that "over 80% of disabled persons in Canada suffer from the 3 U's: unemployment, underemployment, and underutilization." In the United States, only about 30 percent of people of working age (ages 16–64) who have a work disability are even counted as being in the labor force (i.e., are either working or looking for work). In the United Kingdom, about one-third of disabled people of working age were at work in 1998.

In the United States in 1994–1995, men with nonsevere disabilities earned about 85 percent of the median salary of men without impairments; for women, the comparable percentage was about 82 percent. For persons with severe disabilities, the comparable percentages were 58 percent and 68 percent, respectively. (That women with and without impairments are more similar than men has been found in many different types of studies in the United States and is likely explained by the effects of occupational segregation by sex, which is strong and pervasive in the United States.)

Economic policies in many developed countries include support for segregated employment (Britain, Sweden, and the Netherlands) as well as incentives for employers to hire people with impairments. In addition, policies in all developed countries include some sort of social insurance system for workers with disabilities, which most have recently expanded to include nonworking people. Policies range from income assistance, as in the United States, to tax exemptions, as in Japan. These policies often offer disincentives to work, because the side benefits they offer, such as health insurance, cannot be duplicated in the lower-wage jobs that many people with impairments might be most likely to get. They are also sometimes seen by people with impairments as being given in exchange for exemption from benefits and obligations of citizenship.

Cell 2: People who work in paid work but do not have a perceived impairment that they perceive to limit the kind or amount of work they can do.

These people may have less severe impairments, or they may not, but in either case, they perceive their impairment as not limiting their work. Some research done on such people in the United States shows startlingly different results than does research related to people in Cell 1. For example, one study showed that workers with hearing or visual impairments earned higher wages than did workers of the same sex in the general population or with mobility or multiple impairments. These results showed that males had greater income than did females, while having an impairment, net of other differences, decreased income, and they showed that variables that have been strong predictors of incomes in many other studies are not consistently strong predictors of the wages of workers with impairments.

These results, which are so at odds with the preponderance of research results regarding people with work disabilities, support the notion that when the question is asked differently, the answers are also different. Thus, asking people who work *about* impairments they might have gives different results than asking people *if* they have a disability that limits their work. The latter group may be comprised of very different types of people, with very different types of jobs, than the former group. Workers with impairments are likely to be older (since the rate of impairment increases with age) and so more likely to have an established work history. As such, they are also more likely to be in a position to demand disability accommodations from their employer, since their expertise may have more value than the cost of the accommodations. Alternatively, some of these workers may be people who have earlier onset impairments but who overcame potentially disabling obstacles through the use of technology and or education. This is not to say that having an impairment has no effect on their work. Having an impairment *does* limit a person's occupational choices—although in the United States it is clear that gender is more limiting than is impairment.

This section has discussed research that comes from the United States only. But it is clear that similar research, which focuses on workers and only incidentally asks about impairments, needs to be done in other countries.

Cell 3: People who do not have a paid job and who have an impairment that limits the kind or amount of work they can do.

This situation may be more likely to occur in developing countries. However, in those countries, the percentage of people who actually hold wage-paying jobs is low and up to 80 percent of the population lives in rural areas. Unemployment rates as a proportion of people who *are in the work force* tend to be low. This is because people who cannot get wage-paying jobs do not spend huge amounts of time looking for work (nor do they spend that time drawing support payments such as unemployment, workers', or disability compensation, because most such countries do not provide such "social insurance").

Rather, people who cannot find wage work in developing countries have two choices: One is to work either in informal self-employment or informal paid employment, usually in cities; the other is to live in rural areas. Traditional examples of informal self-employment include selling cigarettes, souvenirs, toothbrushes, combs, toothpicks, or towels on the street. Begging, also an example, may entail walking around, sitting in a specific place, or visiting stores and asking for help. It could also include opening doors of cars in front of hotels or theaters, carrying baggage, or washing car windows, and requesting a small gratuity.

While people in Westernized countries tend to find the notion of begging or selling souvenirs to be morally or otherwise repugnant, the same reaction is not always true for people in other countries. For example, while the Hindu or Shinto religions may not explicitly view begging positively, helping beggars by giving money or food is seen as a charitable action which aids one's chances of a better life in the next world. (And, conversely, it is the duty of a disabled person to beg, to provide that opportunity for the person who is helping.) There is some indication that disabled people in developing countries are in fact beginning to object to the ways in which begging reinforces stereotypes and denies them the possibility of other types of employment.

Examples of informal paid employment could include working as a housekeeper, cook, gardener, or guard for a family. However, a person with an impairment may have difficulty finding work in this sector of the economy in developing countries. Such work is more likely either to involve physical labor (construction worker, gardener) or a certain level of education (housekeeper, ayah [nanny], or cook). This work is likely to be for people such as diplomats or employees of aid agencies who will need their employees to speak and possibly read some of their own language (often English, French, or Spanish). Since education is often not available to children with impairments in such countries, adults with early-onset impairments are quite unlikely to have these skills.

The picture of employment of persons with disabilities is quite different in rural villages in developing countries than in cities. In villages, people with impairments may be able to work within their family's farming or herding enterprises. While this will not provide a wage, it is likely to provide at least a minimum amount of food, clothing, and shelter. Physical, cognitive, or mental impairments *may* not prevent a person from fulfilling an economically productive role. (In fact, some scholars have suggested that industrialization had an important role in creating the notion of cognitive impairment.) For example, a person with a developmental impairment may be able to herd animals or carry water. Deafness might not prevent a person from working in fields or caring for animals. A blind person might be able to take care of children or grind spices. A person missing a leg might still be able to weave or stir porridge. (The diet in most African countries is based heavily on one type of starchy food. For example, in Zimbabwe, ground corn is made into *sadza*, while in Ghana, the staple food is *fufu*. Vegetables and/or meat and spices are cooked into sauces that can accompany these staple foods, which are often called porridge. Large parts of every day are spent in the preparation of staple foods as well as the accompanying foods.) In all of these examples, if nothing else, the person with a disability would be freeing another person to do other types of work.

There is a caveat to this discussion, however, related to gender role expectations. All societies have expectations about which sex does what type of work. Thus, if carrying water is expected to be done by women (which it frequently is), a deaf male either will not be expected to do that or he will be looked down upon (as being deviant) because he is doing "women's work." It is likely that many of the tasks that could be done by a person with a mobility impairment are usually done by females, since female gender roles tend to keep them closer to home than do male gender roles. This suggests that males in developing countries who have physical impairments may be at a greater disadvantage than are females.

In rural areas or small villages, it is likely that there is less difference between people with and without impairments than there is in developed countries. In developing countries, a larger proportion of the population exists at a subsistence level, whether or not they have impairments. People grow or produce much of what is needed for survival, and their village economy may not be based on cash but on informal exchange or reciprocity. They are most at a disadvantage in those parts of their society's economy that require cash, such as utilities (the provisions of gas, electricity, or telephone service), education, medical care, and transportation; in food, clothing, or housing, they may not be at a disadvantage if weather conditions are good for farming or herding. In such economies, people with impairments are frequently not worse off than people without impairments. They will not have cash, but they are likely to be supported by their families to the same extent that the families support themselves.

However, in developing countries, the impairment may interfere with noneconomic roles and thus may indirectly reduce economic status. Disability reduces the marriageability of women in many developing countries—and may even affect the marriageability of their siblings. This clearly affects their *economic status* in those societies, even though their *economic abilities* as such are not necessarily diminished.

Some of the initiatives that attempt to help people with impairments in developing countries focus on improving the possibilities for self-employment. These initiatives may include craft work done at home or sometimes in sheltered workshops. Zimbabwe had a very early example of this in the workshops set up by the Jairos Jiri organization.

Cell 4: People who do not have a paid job and who do not have an impairment that they perceive to limit the kind or amount of work they can do—although they do have an impairment.

People who have impairments that they do not define as work limiting in developed countries tend to be people for whom technology solves some problems posed by the impairment, who have enough education that they can find a job in an area in which the presence of a physical impairment is not in fact limiting, or who have a skill or talent that is so significant that it can overcome limitations posed by the impairment. Examples of these types of people include a person who has severe motor and speech impairments but who also has a computer that is programmed so that she can indicate words and the computer can "speak," a person who is deaf but who earns a Ph.D. and so can work as a college professor, and an opera singer who is blind but whose talent is recognized and nurtured despite her impairment.

One group of people quite likely to show up in this category in developed countries is women with impairments. Many women who believe that their impairments should not limit their work are, in fact, not working for wages. Rather, they are working as housewives. However, their work is not valued—it is not counted in economic statistics about national economies; it does not qualify them for pensions, disability support, or retirement income other than that derived from their husbands' work; and it does not qualify a woman for unemployment compensation if she should lose her "job" as a result of divorce.

In developing countries, however, people who have an impairment that they do not perceive to be work limiting and who do not have wage work are very similar to those people discussed with reference to Cell 3. They are people who are not part of the formal economy but who may be able to find many niches through which to support themselves. However, it is likely that this category of people is only beginning to exist in developing countries, since none of the developed country scenarios described above seems likely to occur in a developing country unless the person has a family with enormous wealth. Another reason why such scenarios are unlikely to occur in developing countries is that attitudes toward impairments are more negative and less accepting. Despite slogans such as "disability does not mean inability," which have appeared in several African countries, traditional cultures that equate disability with religious punishments still hold sway in many places. In addition, less developed countries are just beginning to adopt antidiscrimination legislation for people with impairments—even many developed countries are only beginning to make strides in this area. Thus, it would require an extremely unusual person in a developing country to have an impairment, not define it as work limiting, and be able to work.

This entry has shown that the relationships between employment and disability are not simple and are not universal. Rather, it has shown that more research needs to be done about these relationships in different types of economies.

—Sharon Barnartt

See also Begging; Charity; Developing World; Disability in Contemporary Africa; Disability in Contemporary China; Disability in Contemporary India; Employment; Employability; Family, International; Jiri, Jairos.

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EMPOWERMENT AND EMANCIPATION

Empowerment has become a key concept for disabled people and the disabled people's movement because of its associations with liberation and emancipation.

Disabled people's understandings of the idea highlight the essentially political nature of the concept and its focus on power and the redistribution of power. The idea of empowerment has also come to much wider prominence in recent years. This reflects broader interest in a concept that transcends conventional politics and ideology, addresses both the "personal" and the "political," and seeks to unite the two. Empowerment has become an important concept in public policy as well as personal living. It has become central in political, public, and social policy and educational, cultural, sexual, personal, and managerial discourses, as well as entering popular usage. This has been an international development. At the same time, there have also been growing concerns that the term has been reduced to jargon through overuse and lack of clarity.

The term *empowerment* can be used to refer to a process, a goal, or a combination of the two. While disabled people's definition of the term is closely connected with emancipation, this is not true of all interpretations placed upon it. There is little agreement about the definition of the term. Widespread concerns have been expressed about its meaning being diluted and distorted. But the contradictory and diverse meanings attached to empowerment say more about the complex origins of the idea than its practical or philosophical limitations. Inherent tensions in the concept are highlighted by its traditional dictionary definition, which is framed in terms of "licensing," "authorizing," or "giving power" to someone. The organization or individual "empowered" in this way is only an intermediary in the process, and the nature, extent, and goals of empowerment continue to be determined and circumscribed by the original powerholder.

Such a definition is far removed from the emancipatory interpretation of empowerment that has been placed on it by the disabled people's and other liberational and new social movements. It is helpful to remember that disabled people's discourse about empowerment is only one of a number of such discourses. In conventional terms, it is far from being the dominant one. The idea and practice of empowerment in relation to disability and disabled people can only be understood adequately in this broader context. The predominant discussions about empowerment in recent times have been consumerist and professional ones.

Many different strands can be identified in the development of the idea and usage of empowerment. There are self-help, liberational, professional, managerialist, and market models of empowerment. They are in complex relationship with each other. While there are overlaps between them, there are also important differences. Empowerment has become the site of key struggles over the nature and purpose of politics, policy, services, identity, and professional intervention. That is why its meanings are heavily contested and it is important to recognize its regulatory as well as liberatory potential.

The origins of modern discussions about empowerment are generally traced to the U.S. black civil rights movement of the 1950s and 1960s. They are also associated with theories and practices relating to feminist, (international) black liberation and radical politics of the 1960s and 1970s. Disabled people's discussions of empowerment are linked with these. Other key understandings of empowerment have subsequently developed, and disabled people's interest in empowerment needs to be considered in relation to these to avoid confusion. These approaches to empowerment—the popular, consumerist, and professional—all have had a bearing on the activities and debates of disabled people, but all have also been distinct from disabled people's own conceptualization of empowerment.

The most visible modern expression of the idea of empowerment is its adoption in popular culture. The word has now entered common usage. This is probably also the area where its use is most superficial. It has mainly been used to convey a sense of feeling good and powerful. It has increasingly been offered in this way in advertising, particularly to sell cosmetic, relaxation, and leisure products. Its lack of clear meaning has encouraged its being put to questionable uses. In the early 2000s, for example, an international pyramid selling scheme, called "Women Empowering Women," made headlines when many women lost their savings.

EMPOWERMENT, THE NEW RIGHT, AND PUBLIC PROVISION

Wider interest in the idea of empowerment toward the end of the twentieth century was associated with a political move to the right. This was characterized by a new enthusiasm for the private market in public policy and an increasing philosophical rejection of state intervention and provision. This shift in ideology extended to countries such as the United Kingdom, where there had been a strong tradition of large-scale state intervention and of collectivist state welfare.

The emergent political New Right highlighted the idea of empowerment. Its approach to empowerment was based on an individualistic consumerist model, which prioritized the market. The political New Right based its use of the term on its view of the state's capacity to meet individual needs as problematic and inferior to that of the market. It saw state services as inherently worse than market provision. Yet it also acknowledged that there might some policy areas where state services would continue to be needed, for example, for disadvantaged and impoverished groups. The New Right's understanding of empowerment was based on developing consumer rights, which would give citizens real and measurable powers over state services. "Customers" would have powers to make public services deliver the level and quality of services that the public felt were required. In this way, empowerment in public provision was offered as a parallel and complementary strategy to privatization. Arrangements for guarantees, regulation, and inspection were proposed to help ensure that "quality" standards were achieved. The political New Right conceived of empowerment in terms of equalizing the citizen's relationship with state provision. In the United Kingdom, for example, where this approach was particularly developed, it defined empowerment as increasing people's control over public services through "citizen's charters," "chartermarks," and government hotlines.

The political New Right's commitment to the market had long-term consequences for public services internationally, particularly health and welfare services. It gave direction to broader economic, social, and political pressures toward more consumerist and market-led approaches to public provision, particularly welfare provision. Traditional state welfare came in for criticism from both the political Left and Right for it paternalism, bureaucracy, centralization, inflexibility, and lack of responsiveness. A new welfare pluralist approach was pioneered in the United Kingdom with the advent of Thatcherism. This has had continuing effects on public service and welfare policies in Europe and beyond. It has been reinforced internationally by restrictions on public expenditure imposed by conventional approaches to and understandings of globalization. In the United Kingdom, this consumerist approach to policy was most coherently developed first in the field of social or "community care"—a key policy for disabled people.

Such community care reforms were explicitly concerned with changes in how and where disabled people and other service users received support, with an accent on them being able to live in their own homes and neighborhoods. However, they also actually heralded ideological changes that have had international significance. They entailed both a greater role for the market in the financing and supply of services and also the reframing of public provision to create "quasi-markets," where state and nonstate service providers operate in competition with each other. They highlighted a distinction between (public) purchasers and (private) providers. The rationale for this move was that the individual citizen/consumer would now have greater choice in health and welfare. This clearly had major ramifications for disabled people as a group historically denied choice and opportunities.

Empowerment became a core concept in such development. It was mainly understood in individual consumerist terms of the individual having voice, choice, and exit, that is to say, gaining opportunities to express their preferences, to choose from different services and service providers, and to go somewhere else if they don't like the service they receive. In practice, opportunities for choice and exit tend to be limited, particularly where people receive services on an involuntary basis, as is often the case for mental health service users, people with learning difficulties, and frail older people. Such arrangements have tended to be associated with charging, means testing, and with increasing restrictions on public expenditure, a tendency to increasingly restricted eligibility criteria. With an increasingly globalized sector of large multinational corporations as "care" suppliers and use of bulk contracts, it has also encouraged standardization of service, rather than customized provision.

Political interest in empowerment did not diminish with the waning of interest in the New Right. The realignment of left-of-center politics resulted in an increasing interest in reassessing relationships between state and market. One expression of this, which has had an international influence, extending to Europe, the United Kingdom, and United States, has been the development of ideas such as "the third way." Such remixes of market and state involvement have encouraged the development of ideas of empowerment that combine managerialist and consumerist elements.

THE PROFESSIONALIZATION OF EMPOWERMENT

Empowerment has become a key concept in public service professions particularly in health and social welfare. The concept has its longest history and has become most developed in social work and social care. The professional definition of empowerment sees professional intervention as the route to service users' empowerment. This is a strongly contested view. The concept of empowerment is now deeply ingrained in professional vocabulary, discussion, and practice. The most significant early developments in thinking about social work as empowerment came from the United States, highlighted by the writing of Barbara Solomon in the field of black empowerment. Professional interest in the concept has developed in European countries, such as the United Kingdom, in response to the new demands of the consumerist care market.

Empowerment has offered social care professions facing uncertainty and insecurity, new arguments for their own autonomy and consolidation, by emphasizing the prior need for their empowerment if they are to empower service users. Professionals, the argument goes, must be empowered if they are to empower service users. The concept of empowerment is also embraced enthusiastically as providing a new paradigm for practice, giving it fresh vitality, legitimacy, and credibility. Commentators such as Clare Evans and Mike Fisher argue that empowerment in social work and social care has largely been defined by professionals.

A liberatory and emancipatory rhetoric has been associated with such professional discourses on empowerment, as though the professional can play a key role in transformation for disabled people. Such workers are seen as having the potential to empower both individuals and groups. Some outside commentators, however, have also pointed to the regulatory as well as liberatory potential of such professional approaches to empowerment. Bearing in mind the social control role of professional social work, it is difficult to ignore this argument.

Professional approaches to empowerment have been particularly concerned with *personal* empowerment. Personal empowerment is concerned with people being able to develop new and different understandings of themselves and their world, so they are better equipped to respond to opportunities to take power. However, in professional welfare relationships, this can also mean working for change in people's attitudes and behavior consistent with the agendas, imperatives, and requirements of state agencies. Thus, empowerment becomes particularly concerned with people taking increased responsibility for managing their lives, relationships, and circumstances; to live in conformity with prevailing values and expectations; and to change in accordance with professionally set goals and norms. While this may be consistent with individual aspirations and self-determination, it cannot be assumed that the two are necessarily synonymous.

EMPOWERMENT AND DISABLED PEOPLE

Disability activists, however, have generally been suspicious of the idea that professionals can "empower" them. This is not least because such workers have historically been more often associated with structures, attitudes, and services that disabled people have seen as reinforcing their disempowerment. Disabled people have argued that professionals and service providers must learn to work in different ways and *stop* disempowering them. Many disabled people reject the idea that power can be "given" and see it as something that can only be *taken.* Two understandings of the role of professionals in relation to empowerment can thus be identified: first, the contested view that they can empower disabled people, and second, the idea that they can support disabled people to empower themselves, through the skills, resources, networks, and legitimacy that they can command. This latter view is consistent with the dominant view among disabled people that disabled people can only truly empower themselves.

Among disabled people, empowerment has tended to be understood through their understanding of *disempowerment.* The search for empowerment starts with the experience of disempowerment. This helps explain the significance that the idea of empowerment has among disabled people. They have wide experience of disempowerment through segregation, institutionalization, isolation, inferior educational opportunities, poverty, low income, and restrictions on opportunities and choice. For disability activists, empowerment means challenging their disempowerment, having more say in and control over their lives, being able to influence others and bring about change. The goal is greater autonomy and self-determination.

Empowerment is an inherently political concept and this is explicit in disabled people's understandings of the idea. These have focused on both personal and political empowerment. While professional interest in personal empowerment has tended to be concerned with encouraging change in individuals in conformity with state and service values and requirements, significantly different meanings have been placed on personal empowerment by disabled commentators. Here the aim is to alter disabled people's understandings of themselves and their situation as a basis for challenging and transforming both. Key elements toward achieving this are gaining new skills and knowledge and raising expectations, confidence, and self-esteem.

If the professional approach to personal empowerment is concerned with people accepting from outside the need to make change in themselves, disabled people's liberatory understanding of personal empowerment means having the chance to change your understandings of yourself and your situation.

A range of components are associated with empowerment. These include equal opportunities and access; access to advocacy and self-advocacy, to enable disabled people to speak and act for themselves; opportunities for personal development and to acquire new skills; participation, as fully as possible, in the range of activities in society available to nondisabled people and inclusion in the mainstream, rather than segregation in special institutions and services.

A key concept in achieving personal empowerment in the disabled people's and other liberatory and new social movements is consciousness-raising.

CONSCIOUSNESS-RAISING

Ideas of consciousness-raising are notably embodied in the writings and activities of Steve Biko in South Africa and Paulo Freire in South America. Freire has been described as the starting point for many liberationist and participatory approaches to empowerment, especially in the area of community work. Freire coined the term *conscientization*, the process by which oppressed people come to understand the causes of their oppression and to do something about it. Such approaches have been developed in many parts of the majority world by indigenous populations, communities, and their supporters.

There is a tension between these approaches to consciousness-raising and related professionalized, sometimes managerialist and top-down models adopted in community and international development. These tend to employ people without shared experience, often outsiders working for both government and nongovernmental organizations, who seek to involve and empower local disadvantaged groups and communities. They have raised concerns about the tyrannizing effects of supposedly participatory and empowering approaches to development. One initiative that has been associated with this approach has been the development of community-based rehabilitation (CBR) programs for disabled people in the majority world.

Raised consciousness involves an altered understanding of yourself (and others), based on a reinterpretation of your experience and identity. It entails a change in consciousness so that negative understandings of disability as an individualized, tragic (and blameworthy) medicalized condition are replaced by an awareness and understanding of disability as a social condition. Individuals are no longer the cause of "the problem." They are able to see what they have in common with other disabled people as well as how they are may be different from (as well as the same as) nondisabled people. They are able to see the social relations of their situation. They are able to question the legitimacy of their inferior treatment and status because they are disabled. They can resist external judgments that are discriminatory, as well as recognizing and questioning their own internalization of such judgments. Such altered understandings are liberating and provide a basis for taking collective action and seeking political change.

Consciousness-raising thus makes it possible to exert power. This connects closely with modern discussions about the meaning and nature of power. These have developed understandings of a view of power as relational, that is to say, based on the nature of relationships between people and organizations rather than a zero sum game where if one actor gains more power then it is because another loses it. In his influential discussion, Steven Lukes developed a "three dimensional" view of power that offered an analysis of why some people did not challenge their powerlessness, because of their inability to recognize or articulate their own interests. Thus, it is not enough for people to be offered power; they also have to be in a position to make use of it. This has traditionally been the situation of many disabled people, whose segregation and extreme powerlessness have frequently denied them the resources and opportunities to explore, reinterpret, and effectively challenge their disempowerment.

Three developments have supported and encouraged the self-empowerment of disabled people internationally: (1) the move to managerialist/consumerist models of public and social policy, (2) the development of the social model of disability, and (3) the development of new approaches to self-organization by disabled people.

CONSUMERIST/MANAGERIALIST MODELS OF PUBLIC AND SOCIAL POLICY

The managerialist/consumerist approaches to public policy and services that developed toward the end of the twentieth century brought with them very different understandings of empowerment and participation to those of the disabled people's movement. However, with their rhetoric of consumer choice and involvement, they provided a window of opportunity for the disabled people's movement and its related goals. The same was also true of the shift in public policy away from traditional institutionalization to the relocation and maintenance of disabled people in their own homes and neighborhoods. This provided opportunities for their integration, although it should also be remembered that it frequently created major problems through the failure to make adequate alternative provision. One particular consequence of this has been the imposition of additional restrictions on the rights of mental health service users who have been left without adequate or appropriate support in the community.

THE SOCIAL MODEL OF DISABILITY

The social model of disability provided a philosophical basis for raising the consciousness of disabled people. Traditionally in the West, disability has been understood in individualized terms as a problem of deficiency in the body, senses, or intellect. From the nineteenth century, this was overlaid with medical interpretations, which provided the dominant basis for both analyses and responses to disability. These were primarily based on a "treatment" model, which frequently equated disability with illness. This is still the dominant popular model of disability in the West.

The social model of disability developed by the disabled people's movement during the last quarter of the twentieth century drew a distinction between individual *impairment*—the (perceived) loss or deficiency of a limb or sense—and *disability*—the social response to such impairment. Disability was understood in terms of a negative social reaction, which manifested itself in prejudice and discrimination against disabled people and the operation of barriers to exclude them from mainstream life. While a dynamic discussion has developed among disabled people exploring the nature of disability and impairment and the relation between them, the social model remains the main model of interpretation developed by the disabled people's movement. It has provided the philosophical basis of the disabled people's movement. Efforts have also been made to extend its application to other groups, including people with learning difficulties and mental health service users/survivors. It has had a profound liberatory effect on many thousands of disabled people internationally. It has provided a coherent basis for consciousness-raising by offering disabled people an alternative way of understanding. It helps liberate them from a sense of blame, inferiority, personal responsibility, and pathology.

DISABLED PEOPLE'S SELF-ORGANIZATION

The social model of disability has also provided the philosophical basis for the self-organization of disabled people. The aims of disabled people's self-organization follow from the social model. They include seeking to increase the control they have over the support they require, overcoming discrimination that restricts their human and civil rights, and challenging the barriers that disable them in society. The effectiveness of its self-organization has been one of the distinct characteristics of the disabled people's movement. Traditionally in modern Western industrial societies, policies and services for disabled people have been developed and controlled by nondisabled people. They have also reflected their priorities and understandings of disability and disabled people. While the state has intervened systematically to make provision for disabled people since at least the establishment of the English Elizabethan poor law, charitable organizations have also played an important role in defining and providing for disabled people. This tradition has led disabled people to draw a distinction between organizations *for* and organizations *of* disabled people, which reflects their emphasis on and approach to self-organization. By *organizations for disabled people*, they mean those organizations operating in the field of disability that are controlled by nondisabled people. Disability policy and provision have predominantly been shaped by such organizations. The term *organizations of disabled people* has been used to signify those organizations that disabled people themselves control. Disabled people's self-organization has been based on the development of such independent organizations. The emerging organizations of disabled people met with strong opposition from traditional voluntary organizations for disabled people. There are now, however, a large and growing number of organizations of disabled people operating locally, nationally, and internationally. They are now found in North America, Europe, and the majority world.

The self-organization of disabled people has included both parliamentary and extra-parliamentary approaches to making change. There has been a concern with developing new ways of working that include people with impairments. This has extended to the development of new forms of direct action, as well as the development of disability culture, developing the body of disabled people's knowledge and providing user-led services through the development of centers for independent and inclusive living.

What also distinguishes the self-organization of disabled people is that it has tended to combine commitments to self-help and mutual aid with commitments to making broader social and political change. These twin aims help explain the centrality of the idea of empowerment within the disabled people's movement. This is because the idea of empowerment can be used to address issues of both personal and political change. In this way, it can provide a powerful conceptual framework for disabled people's aspirations for both.

Historically, there has often been a tendency to separate self-help and mutual aid from campaigning and political activity. Thus, the self-help tradition in empowerment has tended to be associated with (consensual) voluntary and charitable activity, rather than (conflict-based) political action. In contrast, disabled people's approach to self-organization has been based on an appreciation of the interrelation of the two activities. They have shared this approach with and learned from other new social movements, notably the women's, black people's, and gay men's, lesbians' and bisexuals' movements. The liberatory understanding of empowerment generally adopted by disability activists reunites the psychological and social elements of empowerment.

Disabled people's discourses have also highlighted both the individual and collective aspects of empowerment. Different commentators have placed different interpretations and emphases on the part each of these may play. Some, for example, have stressed the part that individuals' own reevaluation of themselves and their situation may play in leading them to become involved in collection action. In the mental health service user/psychiatric system survivor movement, for example, a particular emphasis has been placed on the part that support and self-help groups can play in encouraging people to get more actively involved with others.

A stronger strand, however, reflected in the writings of the British disability academic and activist Mike Oliver, sees empowerment as a collective process, whereby powerless people, by coming together with others, come to see and make more sense of their oppression and begin the process of challenging it, both within themselves and in the wider world. Self-organization becomes the means the means for both personal and political empowerment. Thus, the self-organization of disabled people has needed to address both. Just as there have been criticisms that the social model of disability has sometimes emphasized disability at the expense of addressing issues of impairment, so concerns have also been raised that disabled people's self-organization has sometimes inadequately addressed issues of personal empowerment because of the priority given to political change.

This has become a particular focus for discussion as efforts have increased to enable as wide a range of disabled people as possible to be included in the disabled people's movement. This includes, for example, people with learning difficulties, older disabled people, mental health service users, people who communicate differently, and people with chronic and life-limiting illnesses and conditions that are associated with impairment and disability. This has been linked with increasing pressures to address difference in terms of, for example, race, gender, sexuality, culture, and class. These developments have highlighted the need to support all disabled people to be able to exert power, acknowledging the particular personal and societal obstacles they may face.

The experience and activities of disabled people have highlighted that there are both individual and collective aspects to becoming empowered. Collective action can provide the basis for both personal and political empowerment. It provides an effective way of connecting the personal to the political, of making clear that the political is the personal and vice versa. Collective action among disabled people has also crucially been the basis for developing the philosophy, values, and goals of disabled people.

One large-scale initiative was taken in the United Kingdom (by an organization for disabled people) to support the self-empowerment of disabled people who were not involved in disabled people's organizations. This was based on a program of "empowerment training" developed and provided by experienced disabled trainers and offered to disabled people living in institutions as well as in their own homes. This was greatly valued by participants who reported the effects it had in raising their consciousness and understanding as disabled people. So far, however, it has not resulted in the organization involved changing its operation in line with service users' changed expectations and aspirations.

Research has been a major area of activity that disabled people have developed through self-organization. The disabled people's movement has equated much traditional research with broader structures of oppression and discrimination in society. The disability emancipatory research developed by disabled people highlights personal and political empowerment as key aims and has an explicit commitment to emancipation in its understanding of empowerment. Drawing on a social model of disability, it prioritizes a changed process of research production that aims to equalize relationships between researchers and research participants, as well as research primarily concerned with making change at both personal and social/political levels, rather than solely concerned with knowledge production. Such disability emancipatory research provides one of the bases for the development of disabled people's own discourse to challenge traditional, medicalized, individual understandings of disability.

—Peter Beresford

See also Activism; Advocacy; Politics; Politics, International.

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END-OF-LIFE CARE

End-of-life care generally refers to palliative care, care that affords relief, but not cure, to dying patients with no reasonable possibility of cure. End-of-life care becomes an increasingly important issue as Americans more often see patients neither improving nor acutely dying, alive but with a dwindling capacity to recover from their injury or illness. Chronic diseases—such as heart disease, cancer, and diabetes—are the leading causes of death and disability in the United States. These diseases account for 7 of every 10 deaths and affect the quality of life of 90 million Americans. Prior to World War II, deaths from these diseases were quick and mostly at home. Since then, advanced medical technology has prolonged the life of people with these diseases when they cannot be cured. Moreover, technology continues to turn acute disease into chronic disease. For example, in the early 1980s, the median life expectancy for AIDS was often less than one year but now it follows a chronic disease trajectory. Those living with serious chronic illness at the end of life generally show three types of trajectory of function and symptoms. Cancer patients generally experience a short period of obvious decline at the end. Prior to that, most cancer patients do not suffer from serious loss of daily basic functions. On the other hand, those dying with chronic organ system failures suffer from long-term disability, with a periodic acute phase during which symptoms are severe and death seems imminent, and then go into temporary remission. The third type of chronic disease is typical of an elderly population—osteoarthritis, osteoporosis, failure to thrive, and dementia, to name a few—and is characterized by self-care deficits and a slowly dwindling course to death. Generally, non-cancer diseases are characterized by long-term disability and an unpredictable timing of death, making end-of-life care for people with these diseases more difficult.

Advanced medical technology also shifted the place of death from home settings to acute care settings in the 1950s. Many of those dying with serious chronic diseases tend to die in the hospital attached to life-sustaining machines. A 1995 study reported on death in intensive care units (ICUs) in hospitals across the country: 38 percent of patients who died spent at least 10 days in an ICU, and 50 percent of conscious patients in the ICU reported moderate to severe pain at least half the time. In response to futile care and unnecessary suffering at the end of life, the hospice movement began in the mid-1960s to provide pain and symptom management in the patient's home where the vast majority of people choose to die. The focus of care is not on curative treatment, but rather the palliation of pain and symptoms through interventions designed to promote comfort and function.

Recognizing the value of hospice care, the National Hospice Reimbursement Act of 1983 created the Medicare Hospice Benefit (MHB) under Medicare Part

A (hospital insurance) of the Social Security Act, which became a permanent benefit in 1986. In addition, states were allowed to develop their own coverage for hospice programs under Medicaid. Currently, 43 states and the District of Columbia offer a hospice benefit to all individuals who qualify for Medicaid. Many private health insurance plans also provide hospice care. Because the scope of services varies by states and insurance plans, contact must be made directly with individual states or private insurance plans for information on hospice care coverage. The following discussion focuses mainly on MHB because the services to be covered under Medicaid/private insurance are essentially those for MHB. Information on MHB is mostly from the hospice section of Social Security Act.

Eligibility for MHB is fairly straightforward: The patient's attending physician and the hospice medical director must certify in writing that the patient is likely to die within six months. On the part of the patient, the patient must, for the duration of an election of hospice care, waive all rights to Medicare A payments for the following services: (1) any Medicare services that are related to the treatment of the terminal condition for which hospice care was elected or a related condition; (2) hospice care provided by a hospice other than the hospice designated by the individual (unless provided under arrangements made by the designated hospice). Upon admission, a written plan of care must be established by the attending physician, the medical director, and the hospice interdisciplinary group prior to providing care and the care provided to an individual must be in accordance with the plan. The plan must include an assessment of the individual's needs and identification of the services including the management of discomfort and symptom relief. It must state in detail the scope and frequency of services needed to meet the patient's and family's needs. The hospice must have an interdisciplinary group that includes at least the following individuals: a physician, a registered nurse, a social worker, and a pastoral or other counselor. The hospice must designate a registered nurse to coordinate the implementation of the plan of care for each patient.

MHB also specifies the standards of care that must be routinely provided directly by hospice employees or contracted staff if necessary. Four types of core services include nursing services, medical social services, physician services, and counseling services. The nursing care and services are provided by or under the supervision of a registered nurse. Medical social services must be provided by a qualified social worker under the direction of a physician. In addition to palliation and management of terminal illness and related conditions, physician employees of the hospice must also meet the general medical needs of the patients to the extent that these needs are not met by the attending physician. Counseling services must be available to both the individual and the family. Counseling includes bereavement counseling for the family, provided after the patient's death (up to one year), as well as dietary, spiritual, and any other counseling services for the individual and family provided while the individual is enrolled in the hospice. In addition to the core services, physical therapy, occupational therapy, and speech-language pathology must be available. Home health aide and homemaker services must be available and adequate in frequency to meet the needs of the patients. Medical supplies and appliances including drugs and biologicals must be provided as needed for the palliation and management of the terminal illness and related conditions.

MHB pays hospices capitated per diem for almost all services needed in a day to treat the patient. The per diem rate varies depending on the level of care: routine home care, continuous care, inpatient respite care, and general inpatient care. The day is counted as routine home care with the rate of $118.08 (as of October 2003 and regionally adjusted) when patients, residing within the home (or nursing facility), under the supervision of the hospice program, receive fewer than eight hours of care per day. Routine home care accounted for 95.1 percent of patient days in hospice care in 2002. A continuous home care day is when continuous nursing care is needed for 24 hours and can be provided for up to five days. It is furnished only during times of crisis and only as necessary to avoid transfer to a hospital usually as death nears. Continuous care accounted for only 0.9 percent of patient days in hospice care in 2002 and its rate ($689.18) is the highest, six times higher than routine home care. The third level of care, inpatient respite care, allows hospice patients to receive care in approved facilities on a short-term basis (no more than five days at a time) as respite for their caregivers. Inpatient respite care accounted for 0.2 percent of patient days in hospice care in 2002. Finally, general inpatient care permits patients to be admitted into approved facilities for pain control or acute/chronic symptom management that cannot be achieved in other settings. This form of care can be provided in a hospital, a hospice with its own inpatient facility, or a skilled nursing facility. General inpatient care days accounted for 3.8 percent of patient days in hospice care in 2002. The current national Medicare rate for general inpatient care is $525.28 (adjusted for regional wage differences).

The number of Medicare beneficiaries choosing hospice services has grown substantially during the past decade—579,801 beneficiaries enrolled in 2001, more than five times the number that elected hospice in 1991 (108,413). Cancer patients account for more than half of Medicare hospice users, but the most dramatic growth in use is among persons with other terminal conditions, such as heart disease, lung disease, stroke, or Alzheimer's disease. From 1992 to 1998, hospice enrollment by beneficiaries with cancer increased 91 percent, while enrollment among beneficiaries with all other conditions increased 338 percent. By 1998, about 43 percent of Medicare beneficiaries electing hospice had non-cancer diagnoses, compared with about 24 percent in 1992. This growing share of hospice enrollees with non-cancer diagnoses reflects the continuing legislative efforts to adjust the organization and financing of care to match distinguishably different trajectories of chronic diseases. The way benefit periods were organized in the original 1983 hospice legislation was geared toward cancer patients. Patients were allowed to elect hospice care during one of the three benefit periods: two 90-day periods followed by one 30-day period with a limit of a maximum of 210 benefit days. Given the concerns about the complexity of making a prognosis of six months or less for non-cancer patients, Congress later repealed the 210-day limit and replaced it with four benefit periods. It added the fourth benefit period of unlimited duration. At that time, however, beneficiaries could have no more than four benefit periods. The current benefit period system was structured by the Balanced Budget Act of 1997 (BBA). The act established unlimited coverage by changing the four hospice benefit periods to two 90-day periods, followed by an unlimited number of 60-day periods. However, the law also increased the number of times of certification. Under this act, all patients are initially admitted for a 90-day benefit period. At regulated intervals (90 days after initial enrollment, 180 days after initial enrollment, and then every 60 days, indefinitely), a patient must be recertified by the hospice medical director. Once recertified at the required intervals, the patient can stay in hospice care with no limitation. When patients cannot be recertified and have to be discharged because of a change in prognosis due to an improved clinical status or stability over a period of time, the hospice program assists in establishing appropriate follow-up care. When physical status worsens again enough to get recertified, they can elect hospice care again. Most important, patients have the right to return to active disease-modifying treatment during any benefit period, thereby relinquishing the hospice benefit and returning to the usual model of care. Patients who select this option are not penalized for this decision, and are readily welcomed back should they elect additional hospice care. The act also allows patients to change the current hospice provider once during each benefit period.

MHB assumes full financial responsibility for all medications related to the primary hospice diagnosis, for durable medical equipment (e.g., hospital beds, commodes, wheelchairs), and for the participation of staff. A hospice patient pays no more than $5 for each prescription drug and other similar products for pain relief and symptom control. A patient pays only 5 percent of the Medicare payment amount for inpatient respite care, wherein the inpatient hospital deductible under Medicare A ($876 in 2004) is the annual limit for respite copayments. Even though they must waive their rights to all other inpatient hospital, skilled nursing facility, and home health services for the terminal illness, beneficiaries may still be treated for other medical problems under the regular Medicare program. Even though the hospice team includes a physician, patients can continue to use their personal physician. Medicare will help pay for covered services provided by a physician not affiliated with the hospice if the patient is covered by Medicare

Medical Insurance (Part B). Also, if the patient has Part B, he or she can use all appropriate Medicare Part A and Part B benefits for the treatment of health problems unrelated to the life-limiting illness.

Despite a rapid increase in use of hospice care, only one of five hospice-appropriate deaths occurs while in hospice care. Advocates for hospice care cite two barriers among others to access to hospice care. One barrier is related to the focus of hospice care on home-centered care. Medicare does not pay for room and board if a patient lives in a nursing home or a hospice residential facility. Another barrier related to the nature of home-centered hospice care occurs when elderly people do not have caregivers to manage care at home and cannot be safely cared for by hospice in the home. Although some states have passed laws to establish inpatient hospice facilities to house those having no primary caregiver at home, the patients without caregivers may be unable to afford hospice care when Medicare does not cover home and board cost in a inpatient hospice facility. Some states including New York cover the room and board cost through Medicaid for hospice beneficiaries with low income, but the assistance program tends to have a sunset provision, reflecting the financial concerns about increasing Medicaid cost among states.

Another barrier to access to hospice care is related to uncertainty involved in certification of survival of six months or less. Physicians are often confused about how Medicare interprets its terminal illness requirement: Intermediaries in reviewing hospice claims use different guidelines from those used by hospice providers to determine eligibility of beneficiaries for hospice benefits. Physicians often delay certifying patients for hospice care. Sometimes even when the patient's conditions and clinical prognosis do not change, they refuse to recertify patients who do not die within the first six months of the initial certification. It is often difficult for beneficiaries and their advocates to convince physicians that hospice certification may well remain appropriate, that the beneficiary need not have died within six months for the hospice certification to have been legitimate, and that recertification should not result in a fraud claim. The delayed certification has resulted in a decrease in length of stay in hospice care, despite the increase in the number of beneficiaries. Thirty percent of all hospice recipients died within one week and 63 percent died within one month in the year 2000. A government report revealed an increase in the share of MHB users with very short stays over the past years: Beneficiaries using hospice care for one week or less accounted for 28 percent of all users in 1998, compared with 21 percent in 1992. The Centers for Medicare and Medicaid Services, the financing agency for hospice care, formally acknowledged the difficulty in prognosis, reducing the fear of fraud scrutiny among physicians. On the part of hospice care providers, there have been continuing efforts to develop the guidelines for certification based on specific functions and symptoms characteristic of near death for non-cancer diseases.

There has been a call to assist patients who are reluctant to elect hospice care because they do not know anything about it. They need to have their questions answered by a physician who specializes in end-of-life issues or a hospice representative. In response to the call, the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 provides provisions to permit physicians to refer terminally ill patients to a Medicare-certified hospice for consultation services that was not covered by Medicare. The provision applies on or after January 1, 2005. These consultation services include (1) assessing the beneficiary's need for pain and symptom management, including the individual's need for hospice care; (2) counseling the beneficiary with respect to end-of-life issues and care options; and (3) advising the beneficiary regarding advanced care planning.

Advanced care planning has been widely encouraged as a way of avoiding lingering deaths where the quality of life is poor and the patient cannot participate in decision making about continuing futile treatments to prolong life. Advance care planning, encouraged by a federal law, such as the Patient Self-Determination Act of 1991, generally involves two forms: living wills and durable power of attorney for health care. The former is a written document of wills that states the desire to not be kept alive by extraordinary or disproportionate medical interventions. Living wills become effective on the determination of terminal illness or imminent death, when the patient can no longer participate in decision making. Durable power of attorney for health care is to be distinguished from a living will in that it is a directive executed by a competent adult that appoints another individual to make medical treatment decisions on his or her behalf in the event that the person making the appointment loses decision-making capacity. The appointed surrogate is often referred to as the patient advocate, patient proxy, or patient representative. The laws governing the authority this individual does or does not have may vary from state to state and is dependent on the specific instructions of the document.

The Patient Self-Determination Act of 1991 requires health care organizations including hospice care providers (1) to inform patients of their right to complete an advance directive and (2) to document existing advance directives in patients' medical record. A significant increase in advance directives documentation in nursing home medical records was reported after the implementation of the act. Another study found that having a living will was associated with a lower probability of dying in a hospital for nursing home residents and people living in the community. However, many more studies cast doubt on the role of advance directives on definitive decisions to stop treatment in hospital: Only 47 percent of the physicians for the patients who preferred to avoid cardio-pulmonary resuscitation (CPR) knew that preference; 46 percent of do not resuscitate (DNR) orders were written late in the hospital stays—within two days of death. Studies reported a low level of physicians' compliance with patients' advance directives and a high level of reliance on their own clinical reasoning.

Hospice-appropriate deaths will increase. One of five Americans will be 65 or older by the year 2020. Advanced technology will increase the number of chronic diseases by turning acute disease to chronic disease. Advanced technology will prolong the life of those suffering from serious chronic diseases, probably increasing the difficulty in predicting the end of the life trajectory. Advanced technology will also prolong death, highlighting the need for physician and public education on advance care planning. Americans have generally made the choice to live as long as the quality of life is acceptable. As technology becomes more sophisticated, it is increasingly important for our aging population to indicate their wishes in advance about end-of-life care and what each person believes constitutes an acceptable quality of life. The quality of life standard, of course, differs from person to person. With life expectancy reaching well into the 90s in the foreseeable future, these decisions become critical in caring for our old-old, not only for their own personal dignity, but for the soaring health costs associated with life-prolonging technologies.

—Kyusuk Chung

See also Do Not Resuscitate (DNR) Orders; Palliative Care; Patients' Rights; Quality of Life.

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ENNS, HENRY (1943–2003)

Canadian (Ukrainian-born) activist

Henry Enns was a prominent leader in the disability rights and independent living movement in Canada, whose activities became international in scope through work with the United Nations and his leadership of the Disabled Peoples’ International organization. Enns was born in Ukraine and lived in Germany and Paraguay as a child, before settling in Manitoba, Canada, with his family. At the age of 15, Enns contracted rheumatoid arthritis, and gradually became increasingly interested in the issues facing people with physical disabilities. Throughout his adult life, Enns made notable contributions to the initiation and development of numerous disability rights organizations. In the early 1980s, Enns was a leader in the establishment and direction of some of the earliest independent living centers in both Ontario and Manitoba. From his base in Winnipeg, Enns became increasingly active in the 1980s and 1990s in the international disability rights movement. From 1990 to 1996, he served as executive director of Disabled Peoples’ International. At the time of his death, Enns was the executive director of the Canadian Centre on Disability Studies (1996–2002). He was the first non-U.S. citizen to receive the U.S. Presidential Service Award in 1992.

—*Zana Lutfiyya*

See also Canadian Centre on Disability Studies; Disabled Peoples’ International.

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ENVIRONMENTAL CONTROL

Environmental control is a branch of assistive technology that includes the use of adaptive devices to manipulate objects and of electronic devices that enable an individual with a disability to control other electronic devices in a home, school, or work setting.

Devices that may be used to manipulate objects can range from low-tech reachers to high-tech robots. The low-tech devices are often available through mail-order catalogs or through durable medical equipment vendors. The low-tech environmental control equipment can take the form of individual devices that assist with the performing of a specific task. For instance, a wire-frame buttoner can assist with dressing.

For some activities, environmental control equipment can include a range of devices. For meal preparation and eating, environmental control devices can include adapted cutting boards, pot-handle holders, plates with built-up edges, and powered eating aids. For reading, devices can include angled bookholders and powered page-turners. The level of technology appropriate for an individual with a disability is dependent on the person’s abilities, goals, support systems, and environment, among other factors.

Environmental control units (ECUs), sometimes referred to as electronic aids to daily living, are devices that enable the user to control devices such as lights, fans, radios, televisions, and powered door openers. The ECU may require direct selection of the controls or offer a scanning feature that lets the user control the device with one or two switches.

ECUs communicate with the devices being controlled through one of four methods: house wiring, ultrasonic signals, infrared signals, or radio frequency signals. House wiring may be used to transmit signals to the electrical outlets in the environment. Devices being controlled must be plugged into a module that receives the ECU’s signals and converts this information to control power to the device.

An ECU may use ultrasonic signals to communicate with the devices being controlled. Again, devices need to be plugged into a module that receives the signals and uses them to determine if power is to be provided or not. Ultrasonic systems are useful when the ECU and devices being controlled are in the same room, as the signals do not go through walls.

An ECU's transmitter may use infrared signals, again going to receiver modules that use the signals to determine whether power is provided to the device, or to determine the level of some settings (e.g., volume). Systems using infrared signals need to be located in the same room, as the signals will not go through walls, and some difficulty may be encountered if the system is used in direct sunlight.

ECUs that use radio frequency (RF) signals have the advantage of controlling devices throughout a home or work environment, as the signals go through walls. The system may need to be set to avoid interference from other RF devices, or by inadvertent control from another ECU.

—Glenn Hedman

See also Aids for Activities of Daily Living; Assistive Technology.

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▣ EPIDEMIOLOGY

The term *epidemiology* is derived from the Greek roots *epi* meaning on or upon, *demos* meaning the common people, and *logy* meaning the study of. Epidemiology is defined as the study of disease in human populations, their causes, and means of prevention. The term *disease* in the definition refers to a broad array of health and medical problems including disability, injury, and death.

Epidemiology differs from clinical medicine in a number of ways. It studies groups of people, not just individuals. Epidemiology also studies both well people and people with disease to identify the crucial differences between those who are stricken and those who are spared. These differences are compared to identify the underlying causes or etiologies of disease. While the goal of clinical medicine is to diminish pain, restore function, and bring the patient back to full health, the main goal of epidemiology is to understand the causes of disease in order to prevent them from occurring.

Epidemiology addresses many areas of public health. For example, it studies the natural history and prognosis of disease. It is used to measure the extent and burden of disease within communities, states, and nations. Epidemiology is also frequently used to evaluate therapeutic and preventive health measures, such as determining the effectiveness and safety of health screening programs, new drugs, and vaccines. Public policy makers, government agencies, health insurance companies, hospitals, physicians, and others increasingly rely on epidemiology as the foundation for making sound decisions to protect the public's health.

The field of epidemiology is highly interdisciplinary. It relies heavily on the concepts, knowledge, and theories of such disciplines as biology, pathology, and physiology in the health and biomedical sciences, as well as the disciplines of anthropology, psychology, and sociology in the behavioral and social sciences. Epidemiology is also very closely tied to the discipline of statistics, particularly biostatistics.

HISTORICAL DEVELOPMENT

Epidemiology is a relatively new science that emerged in the nineteenth century. However, its historical development spans thousands of years and is best described as slow and unsteady. Over the centuries, many individuals have contributed to the establishment of the modern field of epidemiology.

The first important individual was the Greek physician Hippocrates (428–347 BCE), who is traditionally regarded as the father of Western clinical medicine. Hippocrates wrote the first epidemiologic texts *Epidemic I*, *Epidemic III*, and *On Airs, Waters, and Places*. In these works, he was the first person to attempt to explain the occurrence of disease on a rational rather than a supernatural basis. Since Hippocrates recognized disease as a mass phenomenon as well as one affecting individuals, he is recognized as the first epidemiologist.

Another figure of importance was the English statistician John Graunt (1620–1674). Graunt was the first person to analyze the *Bills of Mortality*, which recorded the weekly count of births and deaths in London. In 1662, Graunt published the results of his findings in *Natural and Political Observations Made upon the Bills of Mortality*. He found that male births consistently outnumbered female births, yet males no longer outnumbered females by the time they reached their childbearing ages because males experienced higher mortality rates. Graunt also constructed the first life table, a statistical table that uses death rates of a cohort of persons to determine the group's average life expectancy.

James Lind (1716–1794), a Scottish naval surgeon, also helped establish epidemiology. Lind studied the great sea plague scurvy. On long naval voyages, scurvy often killed two-thirds of a ship's crew. To prevent scurvy, Lind conducted the first planned controlled clinical trial, supplementing the diet of a small number of sailors with fresh citrus fruit and lemon juice (the experimental group). He then compared the incidence of scurvy among these men to that of other sailors on the same ship who ate the normal vitamin-poor naval diet (the control group). Finding that citrus fruit prevented the disease, Lind recommended dietary changes for all sailors, which ultimately resulted in the eradication of scurvy from the British navy. Hence, British sailors are still referred to as "limeys."

Edward Jenner (1749–1823), a British surgeon who practiced medicine in the small village of Berkeley in Gloucestershire, England, observed that milkmaids who developed cowpox (a mild disease) never contracted the severe and often disfiguring and deadly disease smallpox. Using matter drawn from the lesions of cowpox on the hand of a milkmaid, Jenner performed the first vaccination. In time, the practice of vaccinating for the prevention of smallpox became widespread. Today, smallpox is the only disease to ever be totally eradicated from nature. And vaccination is a widely used method to prevent the occurrence of many diseases.

William Farr (1807–1883), a British physician who worked as the first compiler of scientific abstracts at the Registrar General's Office in London, helped shape England's vital statistics system. His most important contribution to epidemiology was the establishment of a sophisticated system for classifying the causes of death. This enabled the comparison, for the first time, of mortality rates among different demographic and occupational groups. Farr's classification system still forms the basis of the International Classification of Disease and Related Health Problems (ICD) that is in use today.

Another great pioneer in the field of epidemiology was John Snow (1813–1858). Snow, a contemporary of William Farr, was a well-respected London physician who specialized in obstetric anesthesiology. One of his patients was Queen Victoria, whom he assisted in the delivery of two of her children. Snow became interested in the cause and spread of cholera epidemics that periodically occurred in London. In 1854, when a severe cholera epidemic once again struck the city, Snow undertook an investigation. At the time, most physicians attributed the disease to miasma or "bad air" formed from decaying organic matter. Snow, however, held the radical view at the time that cholera was caused by drinking fecal-contaminated water. Snow started his investigation by plotting the geographic location of all cholera deaths in London. When he found a large number of deaths (more than 500 in a 10-day period) clustered around a public water hand-pump on Broad Street in the Soho District of west London, he informed the local authorities, along with his hunch as to the cause. Although the authorities were skeptical, the next day they had the pump disabled by removing its handle. Immediately, new cases of cholera started to dwindle, and then disappear. However, because cholera deaths were already declining in the city, Snow was unable to attribute the end of the outbreak directly to the removal of the pump handle.

Snow doggedly continued his investigation of cholera and conducted what he called his "Great Experiment." To conduct the "experiment," Snow painstakingly documented the cholera deaths (nearly 1,400) among the subscribers of London's two independent private water companies. The Southwark and Vauxhall Company (which supplied more than 40,000 homes) drew its water from the sewage-polluted lower Thames River, while the Lambeth Company (which supplied more than 25,000 homes) obtained its water farther upriver. Snow conclusively showed that the number and rate of cholera deaths were much higher for residents in homes served by the Southwark and Vauxhall Company, which supplied the polluted water. Using meticulously gathered data and the power of statistics, Snow brought about the beginning of the end of cholera in Britain. Because of his study methods and insight, Dr. John Snow is generally regarded as the father of modern epidemiology.

BASIC CONCEPTS AND TOOLS

Epidemiology has two fundamental assumptions. First, disease does not occur at random. Second, disease has causal and preventive factors.

Epidemiologists often use models to explain the occurrence of disease. One commonly used model views disease in terms of susceptibility and exposure factors. Specifically, for individuals to develop a disease they must be both susceptible to the disease and be exposed to it. For example, for a person to develop measles (rubeola), a highly infectious viral disease that was once very common among children, they must be both exposed to a person who is shedding the measles virus (an active case), and they must also be susceptible to measles by lacking immunity to it. Immunity to measles may be derived from either previously having the disease or from being vaccinated against it.

Another commonly used model, the epidemiologic triad, views the occurrence of disease as the balance among host, agent, and environment factors. The host is the actual or potential recipient or victim of the disease. Hosts have characteristics that either predispose them to, or protect them from, disease. These characteristics may be biological (e.g., age, sex, and degree of immunity), behavioral (e.g., habits, culture, and lifestyle), or social (e.g., attitudes, norms, and values). The agent is a factor whose presence or absence is necessary for a particular disease to occur. Agents may be biological (e.g., bacteria, fungi, and viruses), chemical (e.g., gases and toxic agents), nutritional (e.g., carbohydrates, fats, and food additives), or physical (e.g., electricity and ionizing radiation). The environment includes all external factors, other than the host and agent, that influence health. The environment may be categorized as the social environment (e.g., economic, legal, and political), the physical environment (e.g., precipitation, temperature, and weather conditions), or the biological environment (animals and plants). To illustrate the epidemiologic triad, consider a case of lung cancer. The host is the person who developed lung cancer. He or she may have had the habit of smoking for many years. The agent is the smoke, tars, and toxic chemicals contained in the tobacco. Environment may have been the workplace where smoking on the job was permitted, and cigarettes or other tobacco products were readily available.

Epidemiologists classify the type of disease cases and frequency of disease occurrence within a population as being either endemic or epidemic. Endemic is defined as the usual occurrence of a disease within a population. In contrast, an epidemic is a sudden and great increase in the occurrence of a disease within a population. It may also be the first occurrence of an entirely new disease. A special type of epidemic is the pandemic, which is a rapidly emerging outbreak of a disease that affects a wide range of geographically distributed populations. Many pandemics are worldwide in scope. To illustrate the three, a small number of people may have the flu (influenza) in a large city throughout the year and these would be endemic cases of the disease. In contrast, the number of people having the flu in the same city may increase enormously in the fall and these would be epidemic cases. Last, if a new variety of flu emerges and people throughout the world get sick from it they would be pandemic cases. An example of a pandemic is the great influenza epidemic of 1918, which spread throughout the world killing an estimated 20–40 million people.

Epidemiologists study the morbidity and mortality caused by acute and chronic diseases. Morbidity is defined as the state of illness, symptoms, or impairments produced by a disease, while mortality is death caused by a particular disease. Acute diseases are those that strike and disappear quickly, within a month or so (e.g., chicken pox, colds, and the flu), while chronic diseases are those that are long term or lifelong diseases, many of which are incurable (e.g., cancer, diabetes, and HIV/AIDS).

One of the most important tools of epidemiology is the use of morbidity and mortality rates. Epidemiologists use rates so that disease cases and deaths can be compared to the unit size of population. A rate is a special type of proportion that includes a specification of time, and the numerator of the proportion is included in the denominator. Rates can be expressed in any form that is convenient (e.g., per 100, per 1,000, per 10,000, and per 100,000). Infant mortality rates, for example, are typically expressed per 1,000 live births, while cancer rates are expressed per 100,000 population.

The following example illustrates the important role rates play in making epidemiological comparisons. Assume City A has 10 cases of a disease while City B has 50 cases. Although in terms of absolute numbers City B has five times more cases of the disease than City A, the differences may be due to the underlying population size of the two cities. To compare the occurrence of disease in the cities on a unit population basis, rates must be calculated. If City A has a population of 10,000, and City B has a population of 50,000, the disease rates per 1,000 people would be the same for both cities. City A's disease rate is (10/10,000) × 1,000 = 1.0 case per 1,000 population, and City B's disease rate is (50/50,000) × 1,000 = 1.0 case per 1,000 population.

Rates may be crude, specific, or adjusted. Crude rates use the total number of disease cases and the entire population in their calculations. For example, the above rates for City A and City B are crude disease rates. Specific rates differentiate cases and populations into age, sex, race, or other subgroups. For example, if the rates for City A and City B were for disease cases who were 25–34 years of age/the population in each city who were 25–34 years of age, the rates would be age-specific disease rates. Specific rates can be very detailed; age-sex-race-specific disease rates can be calculated (e.g., the number of disease cases who are African American males ages 25–34 years old/the population who are African American males ages 25–34 years old). Adjusted or standardized rates allow for comparison of populations with different characteristics. To calculate adjusted rates statistically constructed summary rates are used to remove age, sex, or race differences in populations. For example, in the United States the population of Florida (a state where many people go to retire) is much older than the population in Alaska, so it would be inappropriate to compare the mortality rates of the two states without adjusting for the differences in their age structures.

Epidemiologists use two types of rates to measure the occurrence of disease: incidence rates and prevalence rates. The incidence rate measures the rapidity at which new cases of a disease are occurring in a population over a period of time. The incidence rate is an important measure for evaluating disease control programs (if any) and has implications for the future problems of medical care. Specifically, the incidence rate is defined as the number of newly reported disease cases in a defined period/the population at the midperiod × 100, 1,000, 10,000, or 100,000. Epidemiologists in health departments, for example, study the incidence rates of HIV/AIDS to see if the disease is spreading and whether AIDS prevention programs are working.

The prevalence rate measures the total number of existing cases of a disease in a population at a given point of time (or sometimes a period of time, or even over a lifetime). The prevalence rate is a useful indicator of the burden of a disease on the medical and social systems of a geographic region. It is useful only for diseases of long duration (months or years). Specifically, the point prevalence rate is defined as the number of known cases of a disease at a given point in time/population at that time × 100, 1,000, 10,000, or 100,000. Epidemiologists at the World Health Organization (WHO), for example, use prevalence rates to determine the medical, economic, and social burden of AIDS in developing countries.

There is a relationship between incidence and prevalence rates. Prevalence rates vary directly with both the incidence and duration of disease. If the incidence of a disease is low, but the duration of the disease is long, such as with chronic diseases, the prevalence will be large in relation to the incidence. Conversely, if the prevalence of a disease is low because of short duration (due to recovery, migration, or death), prevalence will be small in relation to incidence.

SOURCES OF EPIDEMIOLOGICAL DATA

Epidemiologists use primary and secondary data sources to calculate rates and conduct studies. Primary data is the original data collected for a specific purpose by or for an investigator. For example, an epidemiologist may collect primary data by interviewing people who became ill after eating at a restaurant to identify which specific foods they ate. Collecting primary data is expensive and time consuming, and it usually is undertaken only when secondary data are not available. Secondary data are data collected for another purpose by other individuals or organizations. Examples of secondary data commonly used by epidemiologist include birth and death certificates, population census records, hospital and clinic patient medical records, data from disease registries, insurance claim forms and billing records, public health department case reports, and surveys of individuals and households.

An important source of secondary data is the Centers for Disease Control and Prevention (CDC). The CDC, which is an agency of the U.S. Department of Health and Human Services, consists of 12 centers, institutes, and offices. The various centers collect a wide array of epidemiological data on such areas as birth defects and developmental disabilities, chronic diseases, infectious diseases, injuries, occupational safety and health, and sexually transmitted diseases. Within the CDC, the National Center for Health Statistics (NCHS) conducts, publishes, and widely disseminates the results of numerous health surveys of individuals and health care organizations. Examples of NCHS surveys include the National Health Interview Survey, the National Health and Nutrition Examination Survey, the National Hospital Discharge Survey, and the National Nursing Home Survey.

DESCRIPTIVE AND ANALYTICAL EPIDEMIOLOGY

The field of epidemiology can be divided into two broad categories: descriptive epidemiology and analytical epidemiology. Descriptive epidemiology characterizes the distribution of disease within a population. It describes the person, place, and time characteristics of disease occurrence. It specifically asks the questions: Who is getting the disease? Where is the disease occurring? When is the disease occurring?

A typical example of descriptive epidemiology is an investigation of a food-borne epidemic at a local restaurant. To determine the cause of the outbreak, epidemiologists would investigate how many customers of the restaurant and what proportion or rate of all customers got sick (i.e., determine an attack rate). They would determine the demographic characteristics of those who got sick (i.e., age, sex, and race). They would also determine when the customers were at the restaurant (i.e., time of day, day of the week), and what specific foods they ate (i.e., items on the breakfast, lunch, or dinner menu). The epidemiologists would also work closely with a public health laboratory to test the existing foodstuffs to determine, if possible, what particular pathogen caused the disease. After determining the cause of the outbreak, the epidemiologists would make recommendations and/or mandate changes (i.e., requiring colder refrigeration, more hand washing by employees, or perhaps using higher cooking temperatures for foods) to the restaurant's management to prevent other outbreaks from occurring in the future.

Analytical epidemiology, on the other hand, tests hypotheses to determine if statistical associations exist between suspected causal factors and disease occurrence. It also tests the effectiveness and safety of therapeutic and medical interventions. To accomplish these tasks, analytical epidemiology uses four major types of research study designs: cross-sectional studies, case-control studies, cohort studies, and controlled clinical trials. Each of these types of studies has strengths and weaknesses.

Cross-sectional studies examine the relationship between disease and other variables of interest as they exist in defined populations at one particular time. For example, a cross-sectional study investigating whether residential exposure to the radioactive gas radon increases the risk of lung cancer may examine the level of radon gas in lung cancer patients' homes. Cross-sectional studies have the advantage of being inexpensive and simple to conduct. However, their main disadvantage is that they only establish associations at most, not causality.

Case-control studies start with people with a particular disease (cases) and a suitable control group without the disease and then compares the exposure of the cases and controls to the factor that is believed to have caused the disease. These types of studies are most useful for ascertaining the cause of rare events, such as rare cancers. For example, to determine whether the use of cellular telephones causes head cancers a group of head cancer patients (cases) would be compared to a group of individuals without head cancers (controls). The two groups would then be compared with respect to the proportion that used cellular telephones and their level of exposure (i.e., how many minutes they talked over the telephone per day). Case-control studies have the advantages of being quick to conduct and inexpensive, and they require only a small number of cases and controls. However, their main disadvantage is that they rely on recall, which may be biased, or records to determine exposure status.

Cohort studies are observational studies in which a defined group of people (the cohort) is followed over time and outcomes are compared for individuals who were exposed or not exposed to a factor at different levels. Cohorts can be assembled in the present and followed into the future (a concurrent cohort study) or identified from past records (a historical cohort study). An example of a cohort study is the Framingham Heart Disease Epidemiology Study. The Framingham study is the longest ongoing epidemiological study in the United States. Starting in 1948 with an original cohort of 5,200 adult volunteers from Framingham, Massachusetts, the study has followed the volunteers and their offspring to identify the risk factors associated with developing heart disease (e.g., cholesterol levels, smoking, obesity, and diabetes). To date, the results from this landmark cohort study have been published in more than 1,000 scientific papers. The main advantage of cohort studies is they can establish the timing and directionality of events. However, their main disadvantages are that they require large sample sizes and a long follow-up time, and they are not suitable for investigating rare diseases.

Controlled clinical trials are studies that test therapeutic drugs or other health or medical interventions to assess their effectiveness and safety. Controlled clinical trials compare the outcomes of new drugs or interventions given to an experimental group compared to another group (control) that does not receive the same drugs or interventions. To minimize bias, individuals involved in clinical trials may be randomly assigned to the experimental and control groups. For example, to determine whether a new drug to treat breast cancer is more effective than another drug, breast cancer patients would be assigned randomly into either an experimental group that would receive the new drug, or the control group that would receive the other drug. The outcomes of the two groups (e.g., number of remissions, and increase in survival time) would then be compared. In the United States, and many other countries, all new therapeutic drugs are subject to rigorous controlled clinical trials before they can be provided to the public. The main advantage of controlled clinical trials is they provide unbiased results. However, their main disadvantage is that they are very expensive to conduct.

SUMMARY AND CONCLUSION

During the past several decades, the field of epidemiology has greatly expanded in size, scope, and influence. The number of epidemiologists has grown rapidly along with epidemiology programs in schools of public health and medicine. Today, epidemiologists investigate the outbreaks of acute diseases such as food-borne epidemics. They also investigate the outbreaks of new emerging diseases such as SARS, and reemerging older diseases such as tuberculosis. At the same time, epidemiologists study the underlying causes of many chronic diseases such as cancer, heart disease, and stroke. They also study the causes of psychiatric disorders, substance abuse, and social problems such as violence. Since the recent terrorist attacks in the United States, Europe, and Japan, many epidemiologists are involved in planning and implementing health surveillance programs to detect and prevent possible bioterrorism attacks. Epidemiologists are also just beginning to examine the determinants of health at the molecular and genetic levels. They are studying how individual genes influence the risk of developing chronic conditions such as Alzheimer's disease. And epidemiologists are beginning to develop new molecular markers to improve the measurement of individually specific exposure and susceptibility factors.

—Ross M. Mullner

See also Acute and Chronic Conditions; Disability Surveys; Disease.

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EPILEPSIES, TEMPORAL LOBE

Epilepsy arising in some discrete location in the cerebral cortices is termed partial, or localization-related, epilepsy and named for the region of cortex from which it comes. It is further classified according to whether it does or does not, *at the onset of a seizure,* give rise to convulsive phenomena—involuntary movements that are rhythmical or sustained. Temporal lobe epilepsies (TLEs) are the most frequently encountered nonconvulsive localization-related epilepsies, although the typical staring with loss of touch from surroundings may at times "secondarily generalize" and become convulsive. The classical temporal lobe seizure consists of nearly motionless staring ("deambulation") and loss of touch with surroundings without generalization of the seizure ("complex" partial).

They are often preceded by an even more focal phenomenon termed an *aura* by Galen, who recognized some aspects of this type of seizure more than 1,800 years ago. Auras include difficult-to-describe internal sensations of which a person is aware and remembers: an epigastric "rising" sensation, unpleasant aroma or taste, auditory or visual hallucinations, strong memories, "forced thinking," and psychic symptoms. The temporal lobe is an important link in systems for olfaction, memory, emotion, feeding, fear, aggression, and sexual matters. "Psychic" auras include strange "dreamy states," fear, déjà-vu and other strong seeming recollections, fear and other alterations of emotion (ranging from despair to exhilaration), time, and space. These prominent phenomena account for the application of "psychomotor" to these seizures. Over time, TLE may be associated with deterioration of memory, alteration of personality, psychiatric symptoms (e.g., depression, anxiety, obsessive diary keeping, hyper-religiosity, self-loathing), and behavior problems. It is of interest to consider that Dostoyevsky's TLE may account in part for the traits he assigned to characters in his novels.

The ensuing *complex* loss of interaction for which the person is *amnestic* represents a spread of seizure activity from the initial focus. This phase may be accompanied by perseverative *automatisms.* These are relatively subtle patterned motor activities carried out without any clear purpose such as lip-smacking, spitting, silly laughter, quizzical facial expressions with seeming attempts to speak, page-turning, posturing of limbs, rubbing some part of the body, or picking at the air or clothing with fingers. The typical duration is in minutes, although a temporal nonconvulsive seizure may go on for many hours. Once it is longer than 5–10 minutes, it is termed psychomotor (or partial complex) status epilepticus. The spell may then terminate with somewhat confused resumption of activities, sometimes with transient loss of speech. TLE may "secondarily generalize," especially in children or untreated adults, giving rise to a generalized convulsive seizure, followed by prolonged sleep.

Galen's prescient recognition that odd and complex behaviors could be epileptic was not pursued to any great extent until the nineteenth century. In France, Calmeil (1824) revived the clinical description and Bouchet and Cazauvieilh (1825) identified some features of the most common pathology of TLE observing with partial correctness that the change was the result rather than the causes of epilepsy. Tissot's (1865) enlargement and classification of auras provided a foundation for Englishman Hughlings Jackson to provide a conceptual framework for epilepsies on the basis of recurrent clusters of phenomena that could derive from particular parts or all of the brain, assigning psychomotor seizures ("uncinate fits") to the temporal lobes and explaining the evolution from aura through dreamy state to generalized convulsion to spread of the epileptic discharge.

This concept proved very important in the neuroscientific view of brain function and provided the foundation for syndromic classification of the epilepsies, which would in time bear importantly on diagnosis, treatment, and prognostication. The focal electroencephalogram (EEG) changes of temporal lobe epilepsy were not detected until the 1930s, based on the pioneering work of Berger of Germany. Additional sophisticated subsequent clinical and pathological investigations have described a family of discrete subtypes of TLE, their natural histories, and treatment. There are now more than 10 valuable drugs employed in the treatment of TLE, only 3 of which were in use before the 1970s. Despite new drugs, TLE has remained a difficult type of epilepsy to manage.

Mesial temporal lobe epilepsy (MTLE) has proven to be one of the most common human epileptic syndromes. It is a highly drug resistant form of epilepsy that arises in the evolutionarily ancient anterior inner portions of the temporal lobe, the amygdala and hippocampus—the region whose pathology Cazauvieilh misinterpreted in 1825. Ounsted in the 1960s set in motion intense study of the biology of this condition. Techniques for the study of slices taken from this brain region were developed, along with increasingly sophisticated physiological studies that have defined MTLE as a focal degenerative condition. Despite various hypotheses about the origins of MTLE, it is not yet known why these regions of the brain are vulnerable. Although we know that the worsening of this form of epilepsy is typically due to seizure-related degenerative epileptic "remodeling," we do not know how the remodeling brings about this effect. The poor response of so many cases to drugs has provided the most important fostering influence on epilepsy surgery, the origins of which date back to work in Germany (Förster) and Canada (Penfield and Jasper) more than 60 years ago. Falconer greatly advanced and popularized temporal lobectomy in the 1960s. At least 80 percent of appropriately managed MTLE patients become seizure free with little or no surgical morbidity and arrest of the epilepsy-associated degeneration of memory and psychosocial disturbances.

EEG video monitoring, computed tomography (CT), magnetic resonance imaging (MRI), and single-photon-emission-computed tomography (SPECT) imaging, psychometric testing, and other techniques have greatly refined disease definitions and surgical planning. Non-MTLE temporal lobe epilepsies have also been identified including (1) "lesional" TLE (e.g., due to tumors, dysplasia, scars, vascular malformations) and (2) comparatively rare "neocortical" TLE arising on the lateral surface of the temporal lobe and marked clinically in some instances by speech arrest, eye movements, and focal twitching that help to set it apart from MTLE or lesional TLE. "Dual pathology" epilepsies occur sharing features of these three TLEs. Benign transient childhood epilepsy arising in the temporocentral region has also been described. Presurgical studies, surgical pathology, and outcomes have permitted localization to be fairly reliably ascertained on the basis of clinical features, since particular manifestations may arise from particular locations and propagate along set "preferential pathways."

Experimental studies of TLEs have provided information and techniques that have greatly enriched understanding not only of the pathophysiology of epilepsy, headache, movement disorders, and other neurological and psychiatric diseases but also of the brain's normal development and physiology. A complex and elegant system of neurotransmitters, receptors, membranes with electrical charge, and chemical pores provides explanations of how the "thinking" neurons work and how they interact with other cells within the nervous system and outside of it and importantly for treatment, how and where things go wrong and how they might be fixed.

—Robert S. Rust Jr.

See also Epilepsy; Neurological Impairments and Nervous Disorders.

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EPILEPSY

Epilepsy is the tendency to experience recurrent bouts of disturbed consciousness, sensation, or uncontrolled motor activities termed *convulsions*. It is the third most common primary, after migraine and depression, neurological condition. At least 1 in 25 people experience a seizure during their lifetime, while slightly less than 1 in 50 develop epilepsy (at least two seizures not explained by some controllable extrinsic influence). Since the beginning of time, it is likely that those with seizures and those witnessing them have struggled to deal with these strange and dramatic events that entail unpredictable loss of control, sometimes including bowel and bladder control, events that can engender shame and an anxious sense of vulnerability. Unmistakable descriptions of epileptic seizures in the ancient texts of China, India, and Babylonia ascribe them to "possession" by spirits—sometimes benevolent, other times demonic.

The ancient Graeco-Anatolian Hippocratic writings (ca. 400 BCE) coined the word *epilepsy* (επιλαμανειν or *epilamanein*) for a convulsive condition viewed as a disease rather than a possession or punishment—a potentially treatable disturbance of the equilibrium of the living organism. The view was not entirely enlightened. Seizures were associated with physical and mental imperfections with which Greek ideals were uncomfortable. In the second century CE, Galen recognized that there were disturbances of consciousness or behavior—nonconvulsive seizures—and that the onset of these or of convulsive seizures might be foretold by a strange sensation he termed *aura*.

Little further progress was made for 1,700 years, and indeed the stigmatizing view that seizures and associated physical or mental imperfections were somehow related to the concept of possession continued to be widely accepted until very recent times. In Christian doctrine arose the not uncontested view that the affliction of children with epilepsy and associated disabilities was judgment on the sins of parents, perhaps for having conceived a child on Sunday. It was recognized from ancient times, however, that epileptic swoons had afflicted such great men as Julius Caesar and possibly Alexander. Yet even here there remained uncertainty as to the boundary between madness and epilepsy, as well as a number of other neurological conditions. This, together with the absence of effective treatments, undoubtedly increased the degree to which epilepsy was feared and reviled. As of the end of the eighteenth century, better definitions began to be formulated and descriptions of transient and usually benign convulsions such as "teething fits" (probably febrile seizures) began to be described.

In the nineteenth century, French, English, and German neurologists and neuropathologists gradually compiled further descriptions of epileptic events. Based on this information and his own observations, the great English neurologist Hughlings Jackson formulated the concept that discrete brain lesions could give rise to particular epileptic manifestations; these, in turn, could predict the location of brain lesion. He also noted that the epileptic event could spread to contiguous areas. Jackson's colleague William Gowers explored the borderlands of epilepsy, enlarging the concept and defining some of its probable boundaries. Seizures and epilepsy came to be understood in the intellectual context that the nervous system was an organized collection of functional centers and interconnecting "wires" with, in part, an electrical function. The study of these relationships in individuals with epilepsy—ongoing to the present day—has made an enormous contribution to the study of the organization and function of the nervous system and to the diagnosis and management of epilepsy. Various treatments were developed, some very toxic, among which only bromides are now viewed as effective anticonvulsants. The agent had been chosen, however, in the effort to reduce prevalence of masturbation (viewed then and for the ensuing half century as a cause of epilepsy) in institutionalized patients. It improved epilepsy rather than the supposed etiology.

The twentieth century provided increasingly detailed clinical descriptions of epilepsies, their predisposing factors, and varied outcomes. Electroencephalography was added in the 1930s. Additional effective therapies were applied including treatments that remain valuable: phenobarbital (1909), the ketogenic diet (1924), and phenytoin (1937). A number of additional minor and some rather toxic anticonvulsants appeared in the next few decades. From the early twentieth century to the interwar period, patients with epilepsy faced a new challenge. Eugenicists hoping to improve the "gene pool" advocated and courts approved involuntary sterilization of some individuals with epilepsy, since the old and often incorrect notion that many were "feebleminded" persisted. More enlightened individuals opened epilepsy clinics devoted to the study and outpatient management of epileptic individuals, many of whom had found themselves in epilepsy "colonies."

Förster of Germany and Penfield and Jasper of Canada participated in the establishment of effective surgical techniques for management and even cure of epilepsy. In the 1960s, Dreifuss and others demonstrated the importance of long-term video/EEG monitoring of patients with epilepsy, data that they employed to systematically classify epilepsies into better refined syndromes as well as to explore related subjects such as conditions that look like epilepsy but are not (e.g., seizures, movement disorders) and the important topic of whether epilepsy is associated with violence. Additional "minor" medications, some of which carried serious potential side effects, were developed; since phenytoin, the past 30 years have been particularly fruitful, providing 10 new important and effective antiseizure medications. But surgery remains important, since some common categories of intractable epilepsies, such as temporal lobe epilepsy, are particularly suitable candidates for potential surgical cure.

By the 1970s, studies demonstrated that well-controlled seizures in children were often outgrown and that medications could be discontinued after several years of treatment. Long-term outcome studies defined with increasing precision these and other epileptic syndromes, some of which were inherited transient vulnerabilities, presenting at a particular age range and then resolving.

The development of imaging techniques, such as computed tomography (CT), magnetic resonance imaging (MRI), single-photon-emission-computed tomography (SPECT), and positron-emission tomography (PET) scanning, during the past 30 years elucidated structural causes of epilepsies, some requiring surgical management to be discerned. The development of many additional diagnostic interventions permitted other underlying conditions associated with epilepsy to be diagnosed and in many instances treated, thereby decreasing or eliminating the epilepsy that occurred secondarily.

Because of the development of experimental neurophysiology, particularly utilization of brain slices and sophisticated neurochemical and neurophysiological techniques, understanding of the pathophysiology of epilepsy has greatly advanced. A great deal is now known about the manner in which epilepsy may cause enlargement of an initial focus and unfavorably remodel an epileptic region of brain. It is as yet less certain how this process is initiated. It has also become clear that abnormalities in brain development underlie at least some epilepsies. Advances are also being made in defining the pathophysiology of heritable generalized and focal epilepsies, some of which resolve spontaneously. These studies, demonstrating overactivity and hypersynchrony of certain populations of neurons, have also revealed information of considerable importance concerning normal brain function and information pertinent to the understanding of nonepileptic conditions that also result from disturbances of specific neurotransmitters, membrane potentials, and ion channels. These studies help to explain the clinically observed relationships between epilepsy and sleep disturbances, movement disorders, migraine, and some psychiatric conditions.

Attention has been devoted to the understanding of relationships between seizures and conditions that may exacerbate them, such as sleep or lack of sleep, fever, menstrual flow, hyperventilation, and things that directly provoke what are termed *reflex* seizures—specific wavelengths and periodicity of repetitive flashing of lights or from such rare provocatives as certain tastes or even thoughts. Special attention has been devoted to epilepsy and pregnancy, from the vantage points of protection of fetuses from the effects of seizures or antiseizure medications and to the best management of epilepsy for the mother. These studies have discerned the importance of folate supplementation to prevent certain developmental deformities of the fetus that may occur if mother is being treated for epilepsy. Studies of great importance have been undertaken to understand and improve treatment of the sustained convulsive seizures, termed *status epilepticus*, a condition that may severely injure the brain or even prove fatal.

The evolving syndromic classification of epilepsies has permitted an increasing number of available therapies to be selected more intelligently and specifically. With such treatments, it has been proven to the satisfaction of all of the various state legislators that some restrictions on driving could be removed after treatment had achieved control for intervals of 6–12 months and that similar restoration of this important right could safely take place if individuals had remained seizure free for similar intervals after a resolved or adequately treated bout of epilepsy. Clinical experience also identified other important hazards for those with epilepsy, particularly the bathtub. Increasing knowledge of risks and natural history of the various forms of epilepsy together with the ability to tailor more effectively medical treatment to a specific syndrome rendered epilepsies increasingly predictable, alleviating fear and reducing the chance that individuals would experience embarrassment associated with public seizures. Public educational programs have also tried to foster greater understanding of epilepsy. Primary care physicians are educated concerning the recognition of unusual seizure types that require urgent treatment. These advances have greatly improved the lives of a very large number of individuals. Sadly, it is estimated that more than 80 percent of the 40 million people who currently have epilepsy throughout the world have access to few or none of these interventions.

The current approach to epilepsies entails excluding a wide variety of possible alternative diagnoses (including pseudoseizures) and then accurately characterizing the epilepsy syndrome. Electroencephalograms (EEGs) and other tests contribute to this otherwise clinical process. Epilepsies are categorized as to whether they are generalized (whole brain) or focal at onset and whether they are convulsive or nonconvulsive. Nonconvulsive or convulsive focal seizures are classified as to association with disturbance of consciousness (and therefore called *partial complex* or *psychomotor*). Convulsive elements include repetitive clonic movements or sustained tonic stiffening. Nonconvulsive elements of generalized seizures include typical and atypical absences, myoclonus, brief tonic activity, automatisms, and atonic (loss of tone) events. Atonic events may involve only part of the body or gradual incremental loss of tone or sudden and dramatic as in events termed *drop attacks*. Individual seizures may demonstrate evolution of one seizure type into another, most commonly to partial (simple or complex) to generalized convulsive. Some severe syndromes produce multiple seizure types.

Underlying identifiable causes are sought. A syndromic classification is then produced on the basis of the foregoing details and age. Provocative circumstances are identified and if possible alleviated, another anti-seizure medication is selected, and the dose systematically increased. If the drug proves ineffective or is not tolerated, it is replaced by another. In some instances combinations of drugs are employed. Perhaps 5 percent of all epilepsies are severe, intractable, often manifest several different types of seizures, and in some instances are associated with deterioration and even death, usually due to the underlying cause. Some of the most severe epilepsies have been reduced in prevalence because causative diseases have been eliminated or prevented by such things as dietary restriction. But for the majority of patients, epilepsies have minimal impact on their lives and those of their families. These and many patients who have temporarily troublesome epilepsy experience excellent control, resolution over time, or surgical cure of their epilepsies.

—Robert S. Rust Jr.

See also Epilepsies, Temporal Lobe; Hippocrates; History of Disability: Ancient West; History of Disability: Medieval West; Neurological Impairments and Nervous Disorders.

ESQUIROL, JEAN ETIENNE DOMINIQUE (1772–1840)

French physician

Jean Etienne Dominique Esquirol was a French alienist (a physician who studied "mental alienation," or insanity) who is best known for his attempts to facilitate a shift in early psychiatric practice from a taxonomy focus to a perspective favoring meticulous observation. A favorite student of Philippe Pinel, Esquirol succeeded his mentor at the Salpêtrière, continued to be an advocate of "moral treatment," and developed into an influential pioneer forwarding the idea that asylums were therapeutic mechanisms in themselves. Esquirol's vision of the institution as a place of recovery was based on the premise that isolation from an unhealthy environment was the first, and most crucial, step toward the restoration of "reason." While in many ways still a product of his era, Esquirol conversely attempted to move away from purgatives and bloodletting toward establishing individual relationships with patients; his "discussions" foreshadowed psychotherapeutic approaches in working with those with mental illness. Esquirol was a strong advocate for involving the state in the affairs of medicine—he was one of the originators of the 1838 French law that implemented a system of nationalized institutions. Quite famous in his day, Esquirol influenced a large number of students at the Salpêtrière with a series of lectures in psychiatry—possibly the first formal instruction in the youthful discipline. Looking back, perhaps his greatest accomplishment was his early endeavor at differentiating between insanity and mental retardation, which previously had been treated as one in the same.

—Steven D. Taff

See also Philippe Pinel.

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ETHICS

Ethics is a branch of philosophy concerned typically with the systematic treatment of issues of right and wrong, good and bad, virtue and vice. The terms *ethics* and *morality* or *moral philosophy* are interchangeable in common parlance, although sometimes ethics is used for the specific moral codes of groups or professions and morality (*mores*) is used for the ethical beliefs or customs of a culture. Morals in that sense can be the object of empirical studies and sociological theories, whereas ethics is a matter of analysis and argument.

In its classical phase (roughly up to the twentieth century), ethicists devised normative ethical systems or first principles and tried to justify them, with the practical aim of giving guidance on how one should live. During the first half of the twentieth century, influenced by the "linguistic turn" in philosophy, ethicists focused on the meaning and use of basic moral concepts, as well as "metaethical" issues such as whether (and how) ethical claims can be justified rationally, and whether differences in moral views among individuals or cultures entail that that universal ethics is impossible. On the defensive, ethicists tried to stave off subjectivist, relativist, and skeptic attempts to undermine ethics itself.

Arguably, moral skepticism and relativism have now run their course as plausible challenges to ethical theory. It is more common these days to believe that morality is universal and objective simply because we regularly, without qualms, grade, evaluate, praise, and blame others and ourselves. More fundamentally, our lives are defined by ethical impulses that are both mundane and universal: We feel gratitude to those who benefit us, sympathy with those in pain, and our sense of justice is offended when the guilty prosper or the innocent suffer. Building on this commonsense foundation, the most recent generation of ethicists have found the confidence to return to normative ethics and traditional questions of the good and the right, although seeing the need to respect cultural and other differences of moral opinion and to be wary of the effect of class, power, gender, racial, or ableist presumptions in mainstream ethical intuitions.

Since ethics concerns the values and actions of all human beings, ethics is relevant to the lives of people with disabilities. Like everyone else, people with disabilities, and their perceptions of themselves and the social world, are in part shaped by the moral climate in which they live. They use and rely on the basic concepts of ethics and have and express ethical impulses and judgments. This said, there are many particular ethical debates in which disability and the experience of people with disabilities are especially relevant, and some in which they play an important and salient role. Some of these specific issues are found at the interface of ethics, biology, and medicine, and of ethics, politics, and justice; in the field of bioethics and political philosophy. Increasingly, ethicists in and outside of these specialized areas have broadened or modified their analyses to include disability, or, as important, have reconsidered or challenged preconceived notions about disability that are found in classical or modern ethical writings.

The following three areas of ethical debate are examples of the kinds of linkages that have already been explored between disability and ethical concepts and theories, which should give the reader an idea both of what is already in the ethics literature and what the future holds for research at the interface of ethics and disability.

THE GOOD LIFE AND THE QUALITY OF LIFE

What makes a life worth living? What does it mean for a human life to go well? What is the "good life"? Given their antiquity and perseverance, these are arguably the central questions of ethics. A similar question (or perhaps the same question with a different spin) concerns the meaning of life, in the sense of what it is that makes life meaningful (and therefore valuable or good). Finally, and more recently, questions about the good life have been recast as questions about the value of life, about what constitutes human well-being. Arguably, the more ancient question about the good life focuses on the best way to live (or what kind of life one should lead in order to lead a good life), whereas the more recent value-of-life question widens the possible domain of evaluation to include, for example, the value that a person's life may have for other people, for the state, or for some other entity.

Traditionally, there are two general approaches to the good-life question: One can either posit an intrinsic value to human life itself, or else one can try to identify features of a person's life, or the living of it, that are components of the good life or are instrumental to bringing about something else that is, on its own, constitutive of a good life. The first approach offers little scope for expansion or explication: If life is intrinsically valuable, then the value of any particular life is unaffected by what happens in that life. That is, human life has intrinsic value, but there are no gradations or variation in that value. This has the important consequence that every human life has equal value. Most philosophers, however, take the opposing approach and argue that, even if life itself has some intrinsic value, lives are not equally and optimally good, since there is variation in the value, or as it is often put, the quality, of one's life.

The question then becomes, what are the components of life that affect its value or quality? On this question, philosophers from at least Aristotle (384–322 BCE) have had much to say. Aristotle himself surveyed the possibilities (fame, fortune, love and friendship, beauty, health, honor) and insisted that all these were good things, without which a life would not be good, but that in the end, the "good life" itself is what all of these good things help a person achieve, namely, a life of eudemonia—a sort of complete spiritual and intellectual happiness or satisfaction. Other philosophers have assessed the value of life in terms of more mundane, ubiquitous, and achievable experience. Jeremy Bentham (1748–1832) argued that in the end, the goodness or badness of a life was entirely a function of the extent of pleasure or pain that is experienced. Indeed, if one took into account the degree, extent, duration, and probability of the pleasures and pains experienced in a life, one could calculate the value of a life, thereby comparing the good-life outcomes of different kinds of lives a person might lead, or of the lives of different people.

As is well-known, Bentham and his more sophisticated follower, J. S. Mill (1806–1873), went on to develop a complex moral and political philosophy called utilitarianism, based on this relatively simple premise. In the century and a half since Mill wrote, utilitarianism has undergone a variety of refinements and revisions, to appeal to those with conceptions of goodness that go beyond pleasure, pain, satisfaction, and happiness, and to avoid such disturbing implications as the imperative to sacrifice an innocent person to appease a lynch mob or provide organs to several other people. What all these variations share is the evaluation of actions by their (expected) consequences, however defined; the broader approach is now referred to as "consequentialism," with act-utilitarianism—the appraisal of individual actions by the net utility they yield—merely one historically significant and conceptually simple variant.

Consequentialism retains the two features of utilitarianism that may have the most troubling implications for people with disabilities: the aggregation of the good found in the lives of separate individuals to make an overall outcome assessment—which tends to treat those individuals as mere sources or receptacles of goodness—and the commitment to maximizing whatever counts as good—which in effect places a higher value on those who directly or indirectly contribute more good to the total. Although some philosophers have attacked the aggregative and maximizing features of consequentialism head-on, others have tended to focus on the criteria for assessing outcomes as good or bad. We will touch on the former concern (which is dealt with at greater length in the "Justice" and "Health Resource Rationing" entries), but our focus here is on the latter: the relevance of impairment in assessing how well a life has gone or is likely to go.

Contemporary followers of Aristotle, such as Martha Nussbaum, reject pain and pleasure as a metric of well-being and tend to assess outcomes across people by their conformity to a pattern, such as equality, rather than by their aggregated magnitude. They argue that although there may be many kinds of life that qualify as valuable, still there are essential human "functional capabilities" (mobility, pleasure, happiness, cognition, play, health) without which the good life is unachievable. Because this approach relies on a conception of core or essential human goods, it is often called "essentialist." Whether one adopts Bentham's experiential approach or Aristotelian essentialism, the very endeavor to assess individual well-being, let alone to aggregate the results, is problematic for people with disabilities.

Since impairments are limitations of one capacity to perform actions, tasks, or social roles, and since they often cause pain, discomfort, or distress, is it inevitable on any definition of "good life" that the lives of people with disabilities are of less value? Are any of the "normal" or "standard" functional capacities of human beings essential to well-being, or are they only contingently related? Does severity of impairment matter? Is there a lower threshold of functional capacity below which a life lacks value, whatever else may be happening in the person's life? Are limitations in cognition or the senses more a threat to living a good life than limitations in mobility or strength; is a life of physical pain worse than a life of emotional distress? Does it make any sense to compare impairments in this manner, or to rank them with respect to their impact on the quality of a person's life? These are just some of the kinds of questions that arise when impairment is brought into the domain of moral value in the analysis of the value or quality of a human life.

It is true that classical and modern philosophers have often assumed without argument or discussion that all impairments substantially reduce quality of life. Similar assumptions of inherent inferiority have been made on racial, gender, and cultural or religious grounds. Still, the case of impairment may be different. Even if we rely on the modern conception of disability as an interaction between features of an individual's body or mind and the physical, social, and attitudinal environment, and insist that it is a person's environment, as well as or instead of his or her physical and mental differences, that account for the disability, still impairments have a reality that should not be ignored or glossed over. We may be confident that the lower quality of life of women is entirely the product of sexism, but it would be intellectually dishonest to insist either that chronic pain or severe depression has no effect on the value of a life or, worse yet, that the negative value of pain and depression is somehow "socially constructed."

There are very practical, indeed, life-or-death consequences of this realm of ethical debate for people with disabilities. If a fetus has a low quality of life because of congenital or acquired impairments, should that be a reason to abort it? Should we insist on prenatal screening to make sure that the children that are born are not disadvantaged from the beginning by a low quality of life? When there is a scarcity of medical resources, should it matter that one potential recipient is also disabled and so would not have as good an outcome as another recipient who is able-bodied? Should we make it easier for people with severe disabilities to kill themselves, or be euthanized, than it is for other people?

In light of these possible implications, some disability scholars have argued that the notions of "quality of life," the "good life," and "well-being" are dangerous nonsense. Some have insisted that what makes life valuable is entirely a matter for the individual—with or without a disability—to decide (so-called experts will inevitably judge lives with disabilities to be worse than individuals with those disabilities think they are). Such radical responses, however, create their own ethical issues. Eliminating the notions of the good life and quality of life from our ethical lexicon would eliminate important ethical dialogue: Surely we want to insist that it is ethically better to live free, to have our basic needs met, and to enjoy equal opportunities. We need to agree on what makes a life go well, what improves the quality of our lives, in order to better the lives of people and reduce what we all perceive as great, undeserved inequalities. What improves or devalues a life, moreover, is not merely subjective opinion: Not even saints or sages are infallible about what makes their lives go well. We may not want to leave it to "experts" to decide on the components of human well-being, but that does not mean that every individual must be the ultimate arbiter of his or her own good; it may be a matter for deliberation and consensus.

Perhaps a standard distinction in ethics may help here. Ethicists say that an experience, action, or state that is a candidate for a good and valuable thing is either intrinsically or instrumentally valuable. Something is intrinsically valuable if that experience, action, or state is valuable itself; instrumentally valuable if it tends to produce or cause something else that is intrinsically good. Now since impairments limit the activities we perform, we can ask whether common activities such as walking, reading, talking, and seeing are intrinsically or merely instrumentally valuable. If some or all of these activities were intrinsically valuable, then a life in which they cannot be adequately performed would lack an important source of value. Alternatively, though, we can maintain that these activities—indeed almost any activity—are merely means to the production of something ultimately valuable (perhaps the experience such as pleasure, satisfaction, or happiness). In that case, not being able to walk or speak need not limit the value of one's life as long as one can achieve the same ultimate end in other ways (e.g., by using a wheelchair or a communication device). In this manner, one could argue that impairments need not have an adverse effect on quality of life, as long as people with disabilities are given the resources they need to pursue alternative means.

This is an interesting moral argument, but it still needs more work. Some impairments do appear to involve the loss of something intrinsically valuable and irreplaceable. If one cannot see a painting, would having it described (say, by the artist herself) ever count as an equivalent means to the end of aesthetic enjoyment? Could we say that listening to a piece of music could produce the same kind and degree of aesthetic enjoyment as seeing the painting? Does this make any sense? Alternatively, could we argue that there are many different collections of activities that people do, each of which is intrinsically valuable (or else of sufficient instrumental value to produce the same degree and kind of intrinsic value) even though no two are identical? While one person cannot see and another has diminished intellectual capacity, with appropriate resources, training, or other facilitation, both their lives could be lived with equal value accruing from very different experiences. Certainly, these are interesting questions that might bring a more realistic understanding of the effect of impairments on well-being. But more work needs to be done to make them concrete and plausible. The onus of doing such work should not, however, rest exclusively on disability scholars. Arguably, the burden of developing a full account of human flourishing should fall on those who, in the absence of such an account, proclaim the lives of people with disabilities to be lacking in the requisites of well-being.

AUTONOMY, COMPETENCE, AND MENTAL DISABILITY

Some impairments affect mobility, others affect perception, fine hand motion, or communication. Still other impairments—those we call "mental impairments"—affect our abilities to make judgments, to reason, or to cope with the stresses of living. When mental illness or brain injury leaves individuals with very serious mental impairments, we may be tempted to say that these individuals lack the capacity to make decisions about themselves or others—a capacity often called "competence"—and others should make those decisions instead. Overriding the right of individuals to make decisions about themselves is a big step, and in many jurisdictions, the law put limits and restrictions on this form of paternalism.

The ethical significance of paternalism links to one of the central notions in the history of ethics: autonomy. Autonomy, or self-governance, was for Immanuel Kant (1724–1804) the foundation of ethics itself. Attempting to meet the challenge posed by David Hume (1711–1776) and others who claimed that reason played no role in ethics, Kant argued in effect that one cannot rationally act immorally, since to act within the bounds of reasons is, roughly, to treat others as you would have them treat you, or more formally, to act in accordance with a rule that you would will that everyone follow—that is, to act in accordance with what you could will as a universal law. Acting immorally, therefore, would in effect to irrationally demand that others act in the same immoral manner toward you. This so-called categorical imperative presumed that moral agents have the capacity to will to do things (indeed, Kant believed that the only truly good thing in the world was a good will). That meant that for Kant, ethics was rationally grounded in the human capacity to will actions, that is, to be autonomous moral agents.

The Kantian tradition is very strong in ethics, and is a source, among other things, of traditional liberal values, in particular, respect for the individual, for individual freedom, and finally, the recognition of individual moral rights (which, logically, apply only to moral agents). The ethical significance of autonomy, moreover, is reflected in the very foundations of our law: The fact, for example, that you can be convicted of a crime only if you have a "guilty mind" (mens rea) is another version of Kant's insistence that only agents with free will are autonomous and so morally responsible for their actions.

This Kantian view on the rational will as the source of human dignity is in one respect highly congenial to disability rights. It regards impairments of physical function, however severe, as contingent and morally insignificant features of the individual, and it opposes any attempt to value human lives on the basis of their productivity or utility. The Kantian injunction that people have worth, not a price, is often invoked to reject the whole project of allocating scarce resources on the basis of physical functioning. Yet at the same time, the Kantian premium on rationality leaves the moral status of individuals with cognitive impairments insecure.

The Kantian tradition underwrites the law of competence and mental illness, which in turn has consequences for disability. A person with a severe mental impairment may, if incompetent, lose his or her status as a moral agent, as a person with autonomy. Mental impairment can undermine what, in this ethical tradition, is absolutely fundamental to moral personhood. This creates a fundamental asymmetry between mental and physical disability. And Kant was well aware of this. He wrote that even if a person is severely physically impaired ("by a special disfavour of destiny or by the niggardly endowment of stepmotherly nature"), and can perform no actions, good or bad, the person will still be a moral agent as long as he or she has the mental capacity to will, that is, to intend to act.

The Kantian liberal ethical tradition is very influential, and a distinction between the physical and the mental is central to it. For those judged to have the mental capacity for practical reason and autonomy, it has been a source of important safeguards. For those who appear to lack that capacity, however, by virtue of mental impairment, it has been used to justify paternalism, as well as a wide range of social and professional practices involving the restraint, forced treatment, and other limitation of freedom. At the same time, the lack of ethical parity between mental and physical disability is hardly unique to Kantian morality. It is evident across modern society, and indeed, is sometimes played out within the disability rights movement itself.

DISABILITY AND THE LANGUAGE OF RIGHTS

The language of rights (human, civil, legal) has dominated the disability movement of the past couple of decades. The political fight for equality and antidiscrimination has been described as a battle for basic human rights. Although we often use the term freely and without much thought, morally speaking rights are vague entities. Probably because of the influence of the "natural rights" movement that dominated seventeenth-century political thought, we tend to speak of rights as if we were describing entitlements people have, rather than, more accurately, asserting a moral proposition about what entitlements people ought to have (but may not have in fact). The temptation, at least in the West, to find rights everywhere ("I have a right to smoke!") suggests that the concept is useful to us precisely because it is empty and vague. But this much seems to be logically required of a right: If it is true that a person has a right to something, then (a) there must be someone (institution or other social arrangement) who (b) has a moral duty to provide it. There is, moreover, an important logical limit to this duty, traditionally expressed by the Kantian maxim that "ought implies can"—namely, that one only has a duty to do something that one can actually do.

These simple, logical features of the concept lead directly to the vagueness of rights language. The United Nations Universal Declaration of Human Rights (1948) declares in Article 3 that "everyone has the right to life, liberty and security of person." But what does this right mean in concrete terms? How many resources can I demand if I truly need them to keep alive? And who has the duty to provide these to me? More troubling still, since everyone has the right to life, and since life-saving resources will always be finite, if not downright scarce, how do we determine whose right to life trumps someone else's when there are not enough resources to go around? And who has the duty to resolve this horrendous practical dilemma?

Given these and other worries, some ethicists have suggested that rights language is mostly rhetorical and not intended to have practical implications. Moral rights should be clearly distinguished from legal rights, which actually can get the job done. Even when they are abstractly expressed, legal rights are embedded within social practices and institutions whose job it is to interpret rights in specific circumstances and for specific individuals, and to transform the rhetoric of rights into precisely operationalized directives to the state or its agents. A legal right, in practical terms, is merely an entitlement to bring a legal action, to cite facts, and to make arguments before a tribunal that is both obliged to adjudicate one's claim and empowered to do something about it.

Some philosophers, most notably Karl Marx, have argued that moral and legal rights are individualistic, indeed egoistic, and so socially destructive. All our moral concern is focused on the demands of particular individuals, at the expense of the general good. In the liberal tradition, however, this is more or less what makes rights so attractive. The individual in a social setting needs rights to protect him or her from the egoistic demands of other individuals, the tyrannies of the majority, or the encroachments on freedom perpetuated by the state itself in its pursuit of what it sees as the common good.

The prospect that rights could protect individuals, or minority groups, against the majority was what attracted the disability movement to rights discourse. In the United States, especially, disability was characterized as mark of a minority subject to historic treatment of discrimination, stigma, and denial of opportunities. As a political strategy, characterizing people with disabilities as an oppressed minority—or more recently, as a social and cultural group—was a success. It is not as clear, however, whether this is the best strategy for the long term. There is the obvious difficulty of creating a "discrete and insular minority" (Americans with Disabilities Act of 1990) out of individuals whose impairments are highly diverse and whose experiences cannot be easily generalized. In addition, physical or mental functional limitations are highly dynamic, unlike race or gender, and, more important, are features of the human condition that everyone will experience over the course of his or her lifetime. The minority rights model that accepts the adversarial relationship and seeks to empower the weaker side conflicts with another, arguably more plausible, model of disability that sees it as a universal feature of humanity and that treats people with disabilities as having precisely the same human rights as everyone else.

It is unlikely that the politics of disability will soon abandon the language of rights. It is important, therefore, to be aware of the limitations of this language as an ethical discourse.

—Jerome E. Bickenbach and David Wasserman

See also Bioethics; Competence; Health Resource Rationing; Justice; Quality of Life.

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EUGENICS

A term coined in 1883 by the British scientist of heredity, Sir Francis Galton, *eugenics* was a movement devoted to "race improvement." Fueled by late-nineteenth and early-twentieth-century scientific advances in the identification and measurement of "defective mentality" (Mendelian genetics, human pedigree charts, intelligence testing), the eugenics movement sought to link social ills such as crime, prostitution, poverty, juvenile delinquency, and promiscuity to people with cognitive disabilities. To diminish instances of social "vice" and the prevalence of mental "defects," eugenicists extolled a wide range of restrictive social policies including marriage laws prohibiting unions of those diagnosed as feebleminded, epileptic, and insane; an expansion of lifelong incarceration in institutions for the feebleminded; laws that legalized state-sponsored sterilization programs; immigration restrictions on people with disabilities; widespread intelligence testing in public schools aimed at identifying feeblemindedness at the earliest possible age; and segregation of "backward" students in special or ungraded classrooms.

The eugenics invention of the category "feeblemindedness" moved from a general classification of "inferior" intellect to a tiered model of "defective" types: *idiots* referred to individuals with a mental age of two years or less, *imbeciles* represented those with an arrested mentality of three to seven years, and *morons* referred to those attaining a mental age of no more than 12 years of age. There were also classifications of varying degrees of backwardness for people occupying the intellectual cusp between "normal" and "feebleminded." Whereas the European construction of feeblemindedness tended to emphasize intellectual capacity, the U.S. definition recognized physical and sensory disabilities as visible bodily expressions of a feeblemindedness residing within.

Eugenics can be broken down into four specific historical stages: the early-nineteenth-century transition from familial and community responsibility for people with cognitive disabilities to a social and state problem, post–Civil War rhetoric that characterized feeblemindedness as a social burden to be alleviated through custodial institutional care, the promulgation during the first two decades of the twentieth century of an extreme version of feeblemindedness as a menace to society, and the post-1920 psychiatry-based mental hygiene movement that began to supplant eugenics with an emphasis on adaptation and adjustment through services that perpetuated segregation and that could be based in the institution or the community.

As an ideological practice cloaked in the empiricism of scientific research, eugenics was widely practiced in Europe, the United States, and Canada. Culminating in the systematic murder of more than 260,000 disabled people by the Nazis between 1939 and 1945, the eugenics movement gave birth to the contemporary forms of nearly every social and therapeutic discipline that attempts to treat and manage disabled people today: physical therapy, occupational therapy, social work, genetics, genetic counseling, special education, and community and applied psychology.

Beyond Europe and North America, eugenics also achieved global influence by exporting its practices to countries as varied as Africa, Mexico, India, Australia, Japan, Russia, and Israel. In many of these countries, eugenics was implemented with respect to distinct national and cultural contexts; for instance, Bolshevik eugenicists used family pedigree charts to demonstrate the degeneracy of czarist lines, Israel imported eugenics models to bolster arguments for a more robust Jewish citizenry, colonial Africa used eugenics as a rationale to solidify arguments about African inferiority and violent tribal practices such as female circumcision, and Japan sequestered its sensory feebleminded (deaf and blind) populations on islands.

—Sharon L. Snyder and
David T. Mitchell

See also Eugenics: Germany; Henry Herbert Goddard; Nazism; Sterilization.

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▣ EUGENICS: GERMANY

The theory of evolution developed by Charles Darwin and published in his book *The Origin of Species by Means of Natural Selection* (1859) can been seen as a starting point for eugenic thinking in Germany. Already during the 1860s, Ernst Haeckel (1834–1908), a German zoologist, spread Darwin's theory, although in a reduced form. Haeckel saw the concepts of adaptation to the environment, heredity, and struggle for life as essential elements of humankind's history. In public, Haeckel defended his position in numerous disputes and scripts. Mostly, representatives of confessional theories were against him, since Darwin's evolution theory stood in strict opposition to the biblical creation narrative. Haeckel's lectures "Natürliche Schöpfungsgeschichte" ("Natural History of Creation" 1868), written in a clear diction easily understood, had an overwhelming success. The book was published in 12 editions and translated in 25 languages.

With Haeckel as its pioneer, about the turn of the past century eugenics gained more significance in Germany. At 1900, a deep economic crisis combined with a distinctive retrogression of births took place. This situation inspired a fundamental criticism of civilization. It said that the birth decline happened only in the upper classes whereas the lower classes increased in large numbers. As a consequence, a successive degeneration of the German people was feared. One of the first German eugenics representative was Wilhelm Schallmeyer (1857–1919), who advocated for the degeneration theory in his book *Über die drohende körperliche Entartung des Kulturmenschen* (*About the Threatening Physical Degeneration of the Cultural Human Being*, 1891). Schallmeyer argued that under the influence of culture the quality of humankind was deteriorating. To stop this development, he demanded that hereditary biological registration, the population's instruction about hereditary processes, and barriers to marriage be employed. Besides Schallmeyer, the physician Alfred Ploetz (1860–1940) was important for the German eugenics movement. It was Ploetz who coined the term *Rassenhygiene* (racial hygiene) in 1895. This German term was used as a synonym for eugenics until the end of the Third Reich in 1945. In contrast to other countries, German eugenics allied itself under the term racial hygiene with the nationalist and anti-Semitic ideology of "race anthropology." This connection created the conditions for the specific German way of eugenics.

Ploetz, who originally sympathized with the social democrats, turned toward eugenics because he thought that with the "human race" existing in Germany at that time socialism could not be put into practice. He aimed at "racial welfare" by installing measures that should foster the procreation of many "high quality" descendants and simultaneously the weeding out of the so-called inferior parts of the population. Ploetz thought that the "Aryan race" was the best race in terms of culture. As members of the Aryan race he counted all peoples except "Negros." To him, Jews belonged to the Aryan race as well. In other words, Ploetz's position originally was not anti-Semitic.

Until the end of World War I (1914–1918), eugenic/racial hygiene was debated only by an academic minority. After the war, when the great numbers of casualties caused by the war battles became apparent, during inflation and the crisis of the welfare state, gradually eugenic ideas gained more and more influence within the political establishment of the Weimar Republic (1918–1933). In 1920, the Prussian Ministry of Welfare set up a committee for racial hygiene. In 1927, the German social democrats and the Catholic Centrum Party initiated the "Kaiser Wilhelm Society," whose institutes were to pursue scientific research. The Kaiser-Wilhelm-Institut für Anthropologie, menschliche Erblehre und Eugenik (Kaiser-Wilhelm Institute for Anthropology, Human Genetics and Eugenics) had the task to develop the scientific base for eugenic measures. The model for the Kaiser-Wilhelm Institute had been the Rockefeller Institute of Medicinal Research. Over the years, the German institutes gained such a good reputation among American science managers that they got funding until the United States entered World War II as a combatant in 1941. During the Weimar Republic, it seemed that German eugenics was just one part of the international eugenics movement. The Kaiser-Wilhelm Institute for eugenics was led by Hermann Muckermann (1877–1962), a Catholic priest having good connections with the Catholic Centrum Party. Muckermann had been developing his eugenic approach since 1917. At first, he pleaded for positive eugenic measures only. However, during his work at the Kaiser-Wilhelm Institute his position got radicalized; in 1929 he called for compulsory sterilization.

In general, during the Weimar Republic moderate eugenic positions were more influential than radical ones. A dispute between the social democrat Oda Olberg and Wilhelm Schallmeyer throws light on the socialist eugenic approach. Olberg shared Schallmeyer's opinion about the dangers of the population's degeneration, but she contradicted him in the causal analysis. For her, Schallmeyer was one-sided in primarily emphasizing genetic causes. Instead, Olberg saw the degeneration caused by the pauperization of the working class. Therefore, she pleaded for the improvement of the living conditions of the poor. Consequently, she saw a compatibility between eugenics and socialism whose common starting point was the orientation toward a strong state.

Besides the socialists, the middle-class women's liberation movement had also been open for eugenic positions since the beginning of the twentieth century. In 1905, Helene Stöcker (1869–1943) established the feminist Bund für Mutterschutz (League for the Protection of Motherhood). Stöcker stood up for a "new ethics" in sexuality and family planning. She pleaded for free sexuality in equal partnerships between men and women, but she argued against licentiousness and digression. Rather, the sexual partners were meant to use their liberty for a greater eugenic responsibility for their offspring. Of course, racial improvement was meant to be the result. In opposition to the mainstream racial hygiene approach, Helene Stöcker's position was individualistic. For example, she was against compulsory measures such as birth control and emphasized the human right to free decision. However, only "healthy" persons were meant to use this right. Patients with incurable and hereditary diseases were refused procreation. Concerning these people, Stöcker pleaded for restraint and compulsion. The women's liberation movement of which Helene Stöcker was a main spokeswoman accepted the degeneration thesis but saw their reasons in bad social and economic living conditions. In that respect, they joined the German socialists.

Before 1933, many parallels between the German eugenics and international approaches existed. A draft for a sterilization law, which was worked out by the Prussian ministry administration in 1932 was very similar to the laws that had been discussed or put into force in other countries. In this draft, sterilization was to be undertaken under the condition of the patient's agreement. Before 1933, even the German Society for Racial Hygiene was against compulsory sterilization without the patient's consent. However, it did not primarily have in mind the respect for the individual's right to physical integrity; instead it argued that too little about the hereditary traits of certain diseases was yet known. On the ground of the still insignificant hereditary knowledge the passing of compulsory legal measures was not seen as enforceable, especially in a democracy. With respect to the issue of compulsion, important differences between German eugenicists and their international colleagues did exist. Germans tended to be more radical in their positions. Owing to a weakly developed democratic culture in their country, they believed in state authority more than others. This belief was one factor why German eugenicists were susceptible to national socialism. Shortly after the Third Reich was established, they came to an agreement with the national socialist state. The state promised them to extend and promote genetic research; in turn, the eugenicists helped to legitimize racist policies and ideologies. During the 1930s, the registration of the supposedly racial and hereditary inferiors took place, and one result was the mass murdering of disabled people from 1939 onward.

After World War II (1939–1945), eugenics had a bad reputation all over the world. It especially lost its credit when as a consequence of the Nuremberg trials against Nazi leaders it got publicly known that in the concentration camps and hospitals scientific experiments with humans had taken place. But the end of the Third Reich did not mean the end of eugenic thinking. Instead, the scientific discipline got a new name and was called "human genetics." Many German eugenicists stayed in the background for some years but continued to dream of genetic enhancement, especially after James Watson and Francis Crick discovered the structure of the hereditary substance in 1953. During the 1950s and until the beginning of the 1960s, German eugenics/human genetics was internationally isolated. Nevertheless, despite history, former Nazi eugenicists managed to get appointments for the first professorial chairs in human genetics at German universities. For example, Otmar von Verschuer (1896–1969), who had been director of the Kaiser-Wilhelm Institute for eugenics during the Third Reich, got a professorship in human genetics at the University of Münster/Westphalia.

At the end of the 1960s, prenatal diagnostics was started in Germany. Since then, the second scientists' generation after the war gradually managed to acquire an international reputation again. When the first steps were taken to establish prenatal diagnostics in Germany, a eugenic argument was used. It was claimed that disabled children meant a burden both for their families as well as society in general. Cost-benefit analyses were undertaken to prove the efficiency of prenatal selection, called "primary prevention" in postwar Germany. The so-called new eugenics at present installed not only in Germany but all over the world certainly differs from the old conception as it is oriented toward individual autonomy and self-responsibility. In contrast to the early eugenics, which aimed at a population's enhancement, today's human genetics appeals to the needs of the individual. In Germany, disabled people have been among the first who criticized individualistic eugenic approaches and disclosed the connections between human genetics, national socialist racial hygiene, and eugenics.

—Volker van der Locht

See also Charles Darwin; Eugenics; Racial Hygiene (*Rassenhygiene*); T4 Program.

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EUROPE

See Council of Europe Disability Policy; Disability Law: Europe; European Commission Policy; European Disability Forum

EUROPEAN COMMISSION POLICY

The European Union is founded on the principles of liberty, democracy, respect for human rights, fundamental freedoms, and the rule of law. The right of individuals to equality before the law and to protection from discrimination is a fundamental right that is essential to the proper functioning of democratic societies. Equal treatment and nondiscrimination are fundamental to the principles for the achievement of the European Union's objectives of promoting economic and social progress and a high level of employment by increasing economic and social cohesion.

The European Union has long been involved in the promotion of equality on the grounds of gender and nationality. It has also consistently shown its commitment to eliminating other forms of discrimination through a variety of instruments—joint declarations, resolutions, directives, and action programs. The 1989 Community Charter of the Fundamental Social Rights of Workers recognized the importance of combating every form of discrimination in order to ensure equal treatment for all.

With regard to disability, the European Union has supported and implemented actions in favor of people with disabilities, principally in the form of European Social Fund interventions that finance training and support the integration of people with disabilities into the workplace. These measures were complemented in the early 1980s by a series of action programs (best known as the Helios Programmes) aimed at facilitating the exchange of information between member states and nongovernmental organizations (NGOs) with a view to identifying good practices, integrating people with disabilities into society. The action programs made an important contribution to raising awareness on the issues affecting people with disabilities and widening the agenda beyond simple financial assistance.

In addition to funding and awareness-raising measures, the EU Council of Ministers adopted nonbinding instruments—recommendations and resolutions—laying down principles concerning the integration of people with disabilities into mainstream employment or education. In particular, the Council Recommendation on the Employment of Disabled People calls on member states to "eliminate negative discrimination by reviewing laws, regulations and administrative provisions to ensure that they are not contrary to the principle of fair opportunity for disabled people."

A further step was taken when the European Commission issued in 1996 a communication on equality of opportunities for disabled people. This communication set out a new European disability strategy. The new policy framework attempted to move the agenda away from a so-called welfare type approach to disability issues and toward eliminating the barriers that prevent the realization of equal opportunity, full participation, and respect for difference. It provided details on discriminatory practices experienced by people with disabilities, held that these practices violated deemed various universal human rights, and affirmed that "the core right at stake is that of equality." This communication was subsequently endorsed by the Council of Ministers representing the member states. For the first time, there was a clear and shared commitment by the European Union and its member states to promote equal opportunities, to eliminate discrimination, and to recognize the rights of people with disabilities.

The new emphasis, often called the "rights-based approach," was no longer about conferring special treatment or measures on people with disabilities but was rather about ensuring that people with disabilities are given equal treatment and equal rights. Although the communication marked an important step toward the recognition of the rights of people with disabilities, the European Community's involvement was limited to encouraging the member states to fulfill the commitments they had made at the European level.

Despite this progress, the European institutions were often criticized for not going further and in particular for lacking a specific legal base to take action against discrimination on the grounds of disabilities.

This changed in Amsterdam, in June 1997, when the heads of state and government agreed to strengthen Europe's capacity to act in this area by introducing Article 13 of the treaty establishing the European Community, which gives the European Community specific powers to take action to combat discrimination based on sex, racial, or ethnic origin; religion or belief; disability; age; or sexual orientation. The inclusion in the treaty of a general nondiscrimination article covering, among other areas, disability has greatly improved the situation for persons with disabilities. Article 13 opened the way for the commission to propose legally binding measures to combat discrimination on the grounds, specifically, of disability.

The disability strategy that the European Community has developed since the mid-1990s finds its clearest expressions in Article 13. This groundbreaking provision endorses the shift from thinking about people with disabilities as passive recipients of charity to viewing them as active claimants of the right to be treated equally. The European Commission moved swiftly to implement the new treaty provisions. After a consultation period, in November 1999 two draft directives and an action program were adopted by the European Commission. The whole package was unanimously adopted in a record time by the council the following year.

The first directive, 2000/43/EC, prohibits discrimination on the grounds of racial and ethnic origin and prohibits discrimination in the fields of employment, education, social protection (including social security and health care), social advantages, and access to goods and services (including housing). The second directive, 2000/78/EC, prohibits discrimination in employment and occupation on the grounds of religion and belief, disability, age, and sexual orientation. Both directives prohibit discrimination in employment and occupation, defined as access to employment, self-employment and occupation, vocational guidance and training, employment and working conditions including dismissal and pay, and membership of organizations.

The directives prohibit any discrimination, direct or indirect, on all grounds mentioned. With regard to disability, the Equal Treatment in Employment Directive (2000/78/EC) requires major changes to existing rules in certain member states. Employers—public and private—will be obliged to accommodate the needs of people with disabilities to ensure that they have an equal opportunity to compete in the labor market. Failure to provide a reasonable accommodation in the workplace can constitute discrimination. In practical terms, such accommodation includes measures to adapt the workplace to people with disabilities, for example, adapting premises, equipment, and patterns of working time to facilitate their access to employment. The directive expands the concept of discrimination with respect to disability in that employers must not only refrain from discriminating but also take steps to accommodate people with disabilities in the workplace to ensure that they are treated equally.

The "reasonable accommodation" requirement in essence should ensure that there is a level playing field for people with disabilities in the employment sphere. The directive, and the obligations contained therein, challenges the equation according to which disability equates unfitness or incapacity. Indeed, it applies only to individuals who are competent, capable, and available to perform the essential functions of the post concerned without prejudice to the obligation to provide reasonable accommodation for people with disabilities. The concept of reasonable accommodation is the keystone of fighting discrimination on the grounds of disability. Reasonable accommodation is not a positive action left to the discretion of public or private operators but an obligation whose failure can constitute unfair discrimination.

The reasonable accommodation obligation necessitates a balancing act between the needs of the employer to conduct a profitable business and the aspirations of people with disabilities to enjoy equal employment opportunities. The obligation therefore does not apply to employers in all circumstances. The directive provides that an employer can deny a reasonable accommodation if it would impose a "disproportionate burden." The directive gives in that respect some guidance as to how to measure and assert the disproportionate burden: "to determine whether the measures in question give rise to a disproportionate burden, account should be taken in particular of the financial and other costs entailed, the scale and financial resources of the organisation or undertaking and the possibility of obtaining public funding or any other assistance."

The directive provides for positive action in that it acknowledges that the prohibition of discrimination should not be without prejudice to the maintenance or adoption of measures intended to prevent or compensate for disadvantages suffered by a group of persons of a particular religion or belief, disability, age, or sexual orientation.

The paradigm shift that has taken place at the European level—transforming needs of people with disabilities into rights—has spread across the international community. The debate around the need to develop a United Nations thematic convention on the rights of people with disabilities has clearly demonstrated the shortfalls of the existing international human rights instruments in relation to people with disabilities. The European Commission has signaled in a communication its full support toward the development of such a convention that would secure unequivocal protection for the fundamental human rights and freedoms of people with disabilities and acknowledge their legitimate membership in the international human rights system.

—Flaminia Bussacchini

See also Council of Europe Disability Policy; Disability Law: Europe.

Recommendations and Resolutions

Recommendation from the Commission to the Council in order to authorise the Commission to participate in the negotiations of an international legally binding instrument to promote and protect the rights and dignity of persons with disabilities SEC/2003/0116 final.

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Further Readings

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EUROPEAN DISABILITY FORUM

The European Disability Forum (EDF) was created in 1996 by its member organizations to defend issues of common concern to all disability groups and to be an independent and strong voice for disabled citizens in dialogue with the European Union (EU) and other European authorities. Its mission is to promote equal opportunities for disabled people and to protect their human rights.

EDF has 127 member organizations reflecting a broad geographic base and a wide range of concerns across the disability movement. Its membership currently includes 21 National Disability Councils: one from each of the EU member states, plus Iceland and Norway, Czech Republic, Estonia, Malta, and Slovenia. These national federations are independent organizations of disabled people, including all major impairment groups in each country; 96 organizations representing the various disability groups and interests in Europe and specialized by type of impairment or sector of activity, such as the European Blind Union and the European Union of the Deaf.

EDF's motto and basis for work is "nothing about disabled people without disabled people," as promoted by the Madrid Declaration. Therefore, its scope of work is very large, covering all EU areas of competence that can have an impact on people with disabilities' lives (e.g., employment, information society, social inclusion, transports, media, telecommunications).

One of EDF's most important campaigns was the European Year of People with Disabilities 2003, a proposal presented to the European Commission in 1999. The European Year marked the history of the European disability movement, providing the necessary impetus to advance the disability agenda in all EU member states and accession countries. The future challenge for EDF remains the adoption of a new disability-specific directive that will protect disabled people from discrimination in all fields of life, such as education, transports, information, and leisure. Ensuring that disabled people are able to benefit from the same rights and obligations as other citizens in the European Union will continue to be EDF's main goal; legal instruments to combat discrimination will remain the basis of its work.

—Helena González-Sancho Bodero

See also Disability Law: Europe.

EUTHANASIA

Both in conception and in practice, within and beyond disability communities, euthanasia provokes impassioned contentiousness. The word itself is derived from the Greek for "dying in a good way." How people of different persuasions react to the idea itself encapsulates the debate about practices variously labeled as "euthanasia."

To many people, such a notion is an oxymoron, for it is inconceivable to them that dying can ever be good. Many people therefore conclude that policies permitting euthanasia must be deceptively corrupt. The way that the practice is named is seen as a disingenuous attempt to pass off as instrumentally desirable an outcome that is intrinsically bad and that therefore should be avoided at all costs.

Many other people take a contrary view. To them, euthanasia is a commendable idea for making the best of a bad event that otherwise would be even worse. According to this very different understanding, death inevitably comes to all persons, but whether death occurs peacefully or is reached only through great suffering sometimes lies within our power to decide. In such cases, proponents of euthanasia argue, society owes its citizens at least the option of having a peaceful experience at the end of life instead of an anguished one.

In its broadest sense, euthanasia comprises any action intended to hasten death for the purpose of dispensing a merciful benefit. There are two different kinds of supposed beneficiaries. Euthanasia is said to benefit individuals by offering them death to relieve their suffering. Euthanasia also is said to benefit whoever is burdened by or otherwise disadvantageously implicated in the lives of the aforementioned sufferers. Thus, euthanasia divides populations into two classes of people: those who are supposed to benefit from their own quick deaths and those who are supposed to benefit from others' quick deaths.

Among the theoretically benevolent, but malignant in practice, ideas that have been applied to people with disabilities, euthanasia is one of the most prominent. Indeed, societal permission to commit acts of killing that might be labeled as, or lead to, euthanasia, and the frequency of such acts commonly are cited as evidence of societal disregard of the value of disabled people's lives. For example, although we commonly think of ourselves as mandated to provide nourishment to dependents, our sense of being obligated to do so seems to weaken to the extent that the dependent appears irremediably impaired. As a result, certain societies have condoned withholding nourishment from babies with certain congenital anomalies, people with profound traumatic brain injuries who are in the prime of life, and elderly people with dementia. The reasons for not nourishing them have been that their quality of life is inescapably inferior to individuals without impairments and that it is wrong to condemn them to the prolonged suffering occasioned by their deficits. This practice thus is fueled by societal presumptions that such people necessarily are very unhappy, absent sufficient research or other evidence that its empirical foundation is true.

SUFFERING WORSE THAN DEATH

The degree of suffering that qualifies as serious enough to call for hastening death is as controversial as every other aspect of euthanasia. We sometimes euthanize discarded pets simply because there is no one willing to care for them. Occasions of human suffering that people have thought grave enough to make death preferable include intractable or unceasing pain, hopeless illness, loss of control of bodily function, loss of dignity or autonomy, or becoming dependent or burdensome on others.

Culture and context affect whether or not persisting in any of these conditions is felt to be worse than dying. Of course, both cultural values and personal experience affect assessments of the badness of death. Islam, for instance, proclaims the sanctity of life and also holds that enduring unavoidable pain will be to an individual's credit in the hereafter, the real and enduring life. To take another example, Christian doctrine also usually is committed to the sanctity of life, and the doctrines of some versions of Christianity oppose any end-of-life intervention that reduces an individual's competency to repent in preparation for imminent death. To take a third and contrary example, Japanese Buddhism (but not other Buddhist sects) traditionally does not advance similar claims about sanctity of life and under certain circumstances tolerates or advises ritualized suicide, abortion, and euthanasia. And as a fourth example, Jehovah's Witnesses do not count life as of preeminent value; they forgo certain medical interventions prohibited by their scriptural doctrine even if the outcome of rejecting treatment will be death.

Personal experience also divides opinion on this subject. As a group, people with chronic impairments or long-standing disabilities are more likely than nondisabled people to consider pain, illness, and dependence as components of ordinary life rather than as reasons to hasten death. To many people with disabilities, therefore, the usual arguments about benevolently hastening death are impositions made from the perspective of the nondisabled majority. Those who hold this opinion presumably prefer to endure all unfortunate future alterations of their current state of life. Maintaining the security to continue living even if existence seems unbearable appears to them to be the best strategy for safeguarding that life itself.

There are many other people with disabilities, however, who are less disposed to relinquish control over their own fates. They want to command decision making about their own medical treatment and to retain authority over the degree of pain and suffering they must endure. For many, such self-determination or autonomy is central to achieving value in their lives. Consequently, to be forbidden to do so by a possibly overprotected state is of overriding repugnance to them. Maintaining the liberty to end life should existence become unbearable appears to them the best strategy for safeguarding the value of that life.

DEFINING EUTHANASIA

Voluntary, Nonvoluntary, Involuntary Death

Variables affect whether or not an act of hastening death genuinely is euthanasia. One variable has to do with whether the person whose death is at issue seeks such acceleration; if so, the expression *voluntary* euthanasia is used. *Nonvoluntary* and *involuntary* euthanasia are the other types, and in theory these are distinguishable. In the latter, the euthanized individual is competent to consent but does not, while in the former no capacity to consent exists.

Passive and Active Killing

A second variable has to do with whether death is accelerated by intervening or by failing to intervene. *Passive* euthanasia is the term applied to failing to provide, or withdrawing, necessary life support, so that a patient dies. *Active* euthanasia is the term applied to intervening by administering lethal medication or applying some other technique that ends life.

A related controversy concerning the boundaries of euthanasia regards the condition of the individuals who die. Some think that to hasten death on grounds of benevolence always is to euthanize, regardless of whether the patient's life already is slipping away. Others hold that euthanasia applies only where individuals would have lived but for being subjected to a fatal intervention.

Private, Professional, and Public Agency

The third significant variable involves the identity of death's agent. Whether or not a terminal intervention is called "euthanasia" may be affected by whether the means of death is self-administered, administered by a health care professional in the course of treatment, or administered by an individual who is not qualified to or charged with giving medical care. There is disagreement about who has the status to euthanize. From one perspective, parents who end the lives of their own disabled children should be described as having euthanized them. Another perspective, however, reserves agency in euthanasia for medical personnel, or for the state. The ground for being concerned with this distinction is the action of a parent in regard to a child who is disabled is morally different, in important ways, from the action of a medical professional or government agent in regard to a population that is disabled. For some people, however, this distinction is morally negligible.

DIVERSITY OF TERMINOLOGY

No Agreement

There is no agreement as to whether these variables should be addressed so as to broaden or narrow the kinds of cases that are counted as true instances of euthanasia. In some venues—for example, in the Netherlands—only voluntary self-executed and assisted deaths are termed euthanasia. There are other venues, such as the United States, where voluntarily assisted deaths usually are not called "euthanasia" and voluntary self-executed deaths never are. In the Netherlands, nonvoluntary deaths brought about for compassionate purposes are labeled as resulting from "life-terminating acts without explicit request," but in the United States some such nonvoluntary deaths may be the clearest examples of euthanasia.

In the Netherlands, both euthanasia (using the Dutch terminology, which entails voluntariness) and compassionate nonvoluntary life-termination have been deemed to be patients' rights. Physicians who facilitate their patients' exercise of these rights by dispensing euthanasia usually are shielded from punishment. In contrast, in the United States only voluntary passive dying is the right of the patient, made so because competent individuals are permitted to refuse treatment and thereby to reject life-supporting medical interventions. Voluntary active interventions to hasten death are called either mercy killings or assisted suicide, depending on whether the terminal intervention is executed by another party or is self-executed. All these open the U.S. agent or enabler of the death to prosecution, except that in the state of Oregon a patient within six months of death who is legally competent may obtain and self-administer a lethal prescription without triggering punishment for the physician.

Physician-Assisted Suicide as Euthanasia

Contention abounds about whether assisting disabled individuals who seek to self-execute their own deaths is nothing more than a camouflaged version of euthanasia. Physician-assisted suicide (PAS) is where the patient prefers self-administering the means to death over prolonged suffering from illness or injury, but also where procuring the means of death requires assistance from a physician. Some people believe that permitting physicians to facilitate disabled people's suicides is equivalent to killing them because, even when self-executed, such deaths are not really autonomous and therefore are not purely voluntary. They are prompted, it is said, by the disabled person's internalizing society's disparagement of disability. Other people believe it is simply a permissible implementation of people's exercise of the liberty to self-determine the time and manner of their deaths and that disabled people as a class are no more incompetent to enjoy such freedom than other people. Claims to such liberty are based on people's broader right to control when they will be subjected to medical intervention, a kind of freedom much cherished by many people with disabilities.

In the United States, physician assistance to a competent individual who self-determines to die and self-executes the activities needed to do so is suicide, not euthanasia, although opponents marshal the standard objections to euthanasia to combat permissiveness in regard to physician-assisted suicide. In the Netherlands, however, physician assistance in suicide is a form of euthanasia, with no moral difference drawn between a physician's providing a patient with a lethal prescription to be self-administered and administering a lethal dose to the patient. In opposition to U.S. practice, an equity argument with reference to people whose disability prevents them from self-administering is mounted in the Netherlands. This consistency of respect argument contends that physicians ought to accommodate patients who choose lethal drugs but whose conditions prevent self-administering them, as readily as they do nondisabled, as well as manually proficient disabled, individuals.

This argument is extended to people who are not able to give or refuse consent, fueling charges that physician-assisted suicide initiates a slippery slope that catapults a society into widespread practice of euthanasia. The thrust of the argument is that physicians ought to treat patients whose conditions prevent their making or communicating a wish to end their lives as benevolently as they do nondisabled and disabled individuals who are competent to consent to medical treatment. Therefore, in the Netherlands, physicians may end the lives of individuals who have not requested a hastened death but who, in the view of the physician, are or will suffer similarly to competent people who ask not to live. Ending the lives of neonates who almost certainly will not survive, or are dependent on intensive care and have a grim prognosis, or are not dependent on intensive care but are predicted to have a poor quality of life with sustained suffering, such as with severe spina bifida, is an accepted medical practice under the hospital policy known as the “Groningen Protocol.”

Withdrawing Life Support as Euthanasia

At the other end of the spectrum lies the hastening of death passively by refusing or withdrawing measures required to continue a patient’s life. Some people think of such actions as killing and therefore characterize them as euthanasia, whereas for others these are decisions to refrain from futile (and arrogant) prolonging of the natural conclusion of a life. For example, in nations under shari'a (Islamic religious law), to withhold nutrition from patients is to euthanize them and is unlawful, while in the United States to do so for a patient at the end of life, and with the patient’s or surrogate decision maker’s consent, is not euthanasia at all.

Further dispute occurs over what kinds of interventions are artificial. Some hold that providing nutrition is natural because we do so for humans too young to feed themselves but that mechanically effecting respiration is not so. Others contend that all medical intervention is artificial, while still others believe that our better natures categorically call for taking all measures to fend off death.

Such profound differences of view about the propriety of providing patients with perpetual life support explain the different treatment afforded Karen Quinlan and Terri Schiavo, who both were young women with brain damage resulting in a persistent vegetative state (PVS). Believing that she was being kept alive on a respirator in defiance of what nature decreed, Quinlan’s parents sued for the right to have her ventilation equipment removed. When doing so revealed she could breathe on her own, however, they maintained her nutrition and hydration using medical means because, they contended, parents have a natural duty to nourish their child. In contrast, Schiavo’s husband, who possessed the legal power to represent her wishes, rejected tube-feeding as being so artificial a route to nourishment as to occasion intolerable suffering. But Schiavo’s parents, joined by many disability advocates, contended that the overriding value lay in Terri’s continuing to live.

LOOKING BACK AT EUTHANASIA

Given such disparities of usage, not to mention profound differences in fundamental conceptualizations, beliefs, and values, it is impossible to say to what extent euthanasia is legally prohibited worldwide, and it is equally impossible to discover how widely it is either openly or surreptitiously practiced. There are, nevertheless, clear historical instances of programs and practices that euthanized people because they were physically or mentally anomalous and thereby were deemed to be disabled and unfit. The most often cited and clearest example is the Nazi program initiated in late 1939 that authorized certain physicians to put to an involuntary “merciful” death people who had been diagnosed with incurable illnesses or who could not conceal their impairments but who were far from dying of natural causes.

This euthanasia program was preceded, in 1933, by the Law for the Prevention of Progeny with Hereditary Diseases, among which were counted schizophrenia, bipolar disorder, epilepsy, Huntington’s disease, intellectual retardation, blindness, deafness, physical deformity, and alcoholism. Health care professionals were required to report anyone at risk of developing, or transmitting to progeny, these conditions. Almost 400,000 were sterilized. In 1935, the Marital Health Act forbade marriage between “healthy” people and carriers of “diseased” heredity. The latter were put on trial and then sterilized. The warrant was that citizens should be healthy to be productive and contribute to the social and economic well-being of the nation. Beginning in the previous century, Germans had enjoyed state-funded health and disability insurance, so keeping the population healthy also meant keeping down public spending.

The 1939 euthanasia program focused on the systematic killing of institutionalized individuals without their families’ knowledge. Some disabled people living in the community also were targeted, however. Questionnaires disguised as census documents were distributed to physicians and then used to find victims. Those euthanized (initially children and later adults) were mainly individuals with developmental disabilities, psychiatric illnesses, neurological impairments, genetic anomalies, and progressive diseases. As one

German clergyman of the period wrote: "Recently the inmates of old-age homes have also been included. The basis for this practice seems to be that in an efficient nation there should be no room for weak and frail people" (Letter from Dr. Wurm 1940). Opposition, especially from the clergy, led to the program's suspension in late 1941, but a year later it was reinstituted. Instead of transporting "unfit" individuals to be gassed, the unfit, who now included geriatric patients and bombing victims, died from withdrawal of nourishment or lethal injection at treatment clinics or residential institutions. An estimated 250,000 Germans with disabilities were killed by the euthanasia program.

There is no moral ambiguity about the case of the Nazi euthanasia program. Disabled people were exterminated against their interest and without their consent, under the guise of helping them, but actually to relieve and thereby benefit nondisabled people. Such moral clarity is not characteristic, however, of most contemporary cases in which permission for a merciful death is pursued through legal or legislative processes.

CONTEMPORARY CASES

There is a question about whether a sufficiently troublesome resemblance exists between the paradigmatically morally reprehensible Nazi euthanasia practice and instances in which disabled individuals ask courts to permit their obtaining assistance in ending their lives. In the United States, Larry McAfee, a respirator-dependent quadriplegic, successfully sought to shield the individual who manufactured a device permitting him to turn off his breathing support. Elizabeth Bouvia, whose cerebral palsy and arthritis led her to want to cease eating, obtained a court order to prevent nutrition's being forced on her. In Canada, Sue Rodriguez unsuccessfully petitioned to enable a physician to provide a device permitting her to self-administer a lethal dose when she believed her motor neuron disease (MND) had reached an intolerable stage. In the United Kingdom, 19-year-old "A. K.," a MND patient, won the right to have his ventilator removed when he became "locked in" and no longer able to communicate even by blinking. Another MND patient, Diane Pretty, was unable to acquire a legal shield against her husband's being prosecuted should he help her to kill herself.

In these cases, disabled plaintiffs, exercising autonomy, voluntarily sought death, sometimes by refusing life-supporting treatment, sometimes by obtaining physical assistance to execute a lethal act, sometimes by arranging to self-executing the lethal act. Thus, these cases seem to lie very far from the paradigmatic Nazi euthanasia program, where disabled people met death involuntarily and through active interventions by the hands of others. In all these cases, nevertheless, there were disability advocacy groups that opposed the disabled plaintiff's plan. These groups warned against a slide down a slippery slope toward the same societal presumptions that energized the Nazi euthanasia program.

First, they argued, only if prompted by presuming the worthlessness of disabled people's lives could courts find for the plaintiffs in these cases. But it is precisely such a view of the dispensability of this class of citizens that inspired the Nazi program. Furthermore, equal protection would be violated if courts found for these plaintiffs, given that starving or suffocating nondisabled people never is condoned.

Second, courts that create such law in particular cases endanger all the disabled. Law and public policy arguably have an expressivist function: Beyond their letter, they also can send messages of approbation or disapproval, respect or contempt. Excepting disabled people from prohibitions against killing thus may send powerfully broad messages about their inferiority.

Furthermore, these messages may depress disabled people's estimation of themselves, to the extent that some disability advocates report experiencing depression so profound as to have brought them to the brink of terminating their lives. In a society they know very well will reject them, newly disabled people are especially vulnerable to losing hope of having a satisfactory future life. Families or other caregivers who fear being burdened might intentionally or inadvertently induce their disabled dependents to relieve them if an easy death could be found without difficulty. Disabled people or their loved ones also may think of death as a cost-effective alternative to expensive care that prolongs their lives without improving the quality.

Related to this point are concerns about euthanasia's attractiveness as an instrument of cost control. Some disabled people believe that health care economics recommends using legal routes of causing death to remove patients and so reduce expense. It is unclear, however, whether eliminating the patients who are most readily removable this way serves the profit motive because at least some such patients—for instance, tube-fed geriatric patients—can be profit centers for custodial facilities. Nevertheless, a system to protect vulnerable patients from being sacrificed due to the cost of their care is unlikely to be effective because of the privacy that cloaks physician-patient interactions. It would be difficult to be confident that the patient's consent was voluntary and informed.

Third, the state is obligated to protect weak and vulnerable dependent people, such as the disabled commonly are. In the case of Diane Pretty, for example, the U.K. House of Lords ruled against a disabled woman seeking the right to kill herself on the grounds of the overriding public interest in protecting the weak and vulnerable. One lord remarked that it was impracticable for the law to attempt to distinguish between self-determining and vulnerable disabled people who are assisted in suicide. The U.S. Supreme Court has held that prohibiting assisting disabled people to end their own lives protects the poor, the elderly, disabled persons, the terminally ill, and persons in other vulnerable groups from indifference, prejudice, and psychological and financial pressure to end their lives and prevents a possible slide toward voluntary and perhaps even involuntary euthanasia.

LOOKING FORWARD: FEAR OF A SLIPPERY SLOPE

Two circumstances might prompt a slide toward a program of involuntary euthanasia such as the Nazis practiced. First, given the nature of physicians' access to patients, it might be difficult to prevent physicians from coercing patients into agreeing, or else fabricating patients' agreement, to end their lives. Second, given the nature of patients' reasons for ending their lives, it would be difficult to defend a prohibition against nonvoluntary euthanasia. Arguments for permitting competent disabled people to determine if they want to continue to live could be extrapolated to noncompetent people with similar illnesses or impairments. If a competent person finds living with a particular disability unendurable, courts might presume that incompetent people with similar disabilities would come to the same decision if they could.

Euthanasia policy therefore pits the interests of individual disabled citizens who prize self-determination against disabled people considered as a vulnerable group. A subset of the group of disabled people is especially dependent on strong paternalistic protections. Paternalistic policies, however, threaten opportunities for exercising choice by eliminating seemingly risky options for the group they are supposed to protect. There thus is a question about whether society is obligated to bar fully competent disabled individuals from an end they choose simply because of their membership in the disability classification. A related discussion addresses whether such self-sufficient disabled people are especially obligated to forego self-determination and under no circumstance seek to hasten death in order to safeguard their more vulnerable disabled peers.

POLICY IN THE NETHERLANDS

The developing freedom of ill and disabled people in the Netherlands to voluntarily end their lives increases the urgency of resolving these uncertainties. Until 1973, euthanasia courted prosecution and conviction in the Netherlands. In that year, a physician who had shortened her mother's agonized dying was put on trial but not punished. Courts then set guidelines for permissible medical intervention to hasten death: The patient must be suffering from a terminal illness, and the patient must request an immediate death.

Policy in the Netherlands has been influenced by the standard of community practice, by which is meant the prevailing consensus among physicians about the proper medical intervention once a diagnosis and/or prognosis is made. In 1984, the Dutch Royal Society of Medicine issued "rules of careful conduct" for euthanasia. Physicians had to inform the patient of the prognosis, consult the family (with the patient's permission), consult at least one other physician, keep written records, and obtain the consent of parents or guardian if the patient is a child. The boundaries set by these rules quickly proved elastic, however. In the following year, a court dropped the "terminal illness" requirement. A physician was not punished for assisting a young woman who did not wish to experience the struggle of living with nonremitting multiple sclerosis to end her life, even though her condition was not terminal.

The Dutch courts and the Royal Dutch Medical Association (KNMG) subsequently established new guidelines for physicians: (1) voluntariness—patients' request must be freely made, well-considered, and persistent; (2) unbearable suffering—patients' suffering cannot be relieved by any other means; and (3) consultation—attending physicians should consult with a colleague. If these guidelines are followed physicians will not be prosecuted. The KNMG chose a narrow definition: Officially, euthanasia is the ending of the life of one person with the help of another but at the first person's request.

Thus, in the Netherlands euthanasia is by definition always voluntary. But there is no punishment for ending the lives of babies with Down syndrome or spina bifida or adults in a persistent vegetative state. In fact, during the past decade, about half of the physician-assisted deaths in the Netherlands would be identified as nonvoluntary or involuntary euthanasia in most other legal systems.

This last observation recalls the danger of creating a slippery slope. Some people conclude that permitting Dutch physicians to perform voluntary euthanasia encourages them to perform nonvoluntary and involuntary euthanasia. Others say that that the data about these nonvoluntary and involuntary deaths merely document the results of a community practice that has long prevailed but only recently been revealed. There is no possibility of resolving this dispute scientifically, however, because the data are drawn from physicians' interpretive reports of their own and their patients' intentions. The Dutch experience therefore does not establish, but neither does it disprove, the inevitability of society's sliding from permitting a disabled person to freely choose to hasten death toward prescribing the deaths of entire disabled populations.

CONCLUSION

Current conflicts and confusions about what should be called euthanasia preclude a global approach to identifying the principles most beneficial to disabled people in regard to policies permitting or prohibiting the hastening of death. This state of affairs makes it difficult to develop evidence about how likely various medical practices and community standards are to evolve into a euthanasia program that mirrors the Nazis' purpose of purging disabled people from the population. Yet such careful study is crucial if we are to create safeguards for the disabled that do not cross the line into paternalism and violate their freedom of self-control.

—Anita Silvers

See also Death; Do Not Resuscitate (DNR) Orders; Ethics; Physician-Assisted Suicide; Suicide.

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EVALUATION IN EUROPE

See Disability Assessment/Evaluation, Europe

EVIDENCE-BASED MEDICINE

Evidence-based medicine (EBM) is a shorthand term for an approach to patient care in which decisions about the management of the individual patient are made by the clinician using his or her personal experience and expertise combined with use of the best-quality and most up-to-date scientific evidence. Summarized in this way, it may be thought that there is nothing about EBM to distinguish it from the main traditions that have dominated the science of health care provision for the past 200 or 300 years. While the degree of real originality of EBM is still disputed, it is beyond dispute that in the 1990s a powerful and cogent force swept through medicine, driven by articulate and forceful advocates for EBM, drawing largely on principles based in clinical epidemiology.

The enormous appeal of EBM stems from the very worrying and growing evidence that health services involve enormous and inexplicable variations between clinicians in the management of the same health problem. These variations are seldom explained by differences in either variations in patient characteristics or health care resources. Moreover, medical textbooks, far from instilling standard high-quality practice, have been shown to be major sources of error, producing misleading recommendations out of step with best available scientific research. For example, clear evidence from research about the benefits of intravenous thrombolytic therapy in acute myocardial infarction was available for many years before it appeared in any medical textbooks.

At the heart of EBM is the use of best possible evidence in diagnostic and treatment decisions where *best* is defined by a clear hierarchy of quality-of-study designs providing evidence. The most reliable evidence is generated by properly randomized, controlled trials (RCTs). Below such study designs are well-designed cohort or case-control analytic studies. Less reliable evidence can be obtained from multiple time series with or without the intervention. Least reliable of all, and therefore at the bottom of the hierarchy, is evidence in the form of the opinions of respected authorities, based on clinical experience, descriptive studies, and case reports, or reports of expert committees. Much debate has been provoked by the assertion by proponents of EBM that the RCT represents a gold standard method with all alternatives to varying degrees inferior. However, it is difficult to contest their basic argument that well-designed randomized controlled trials generally are least prone to biased estimates of treatment effects. In other words, if patients are properly randomized, estimates of benefits of an experimental intervention are less likely to be biased by, for example, differences in the pretreatment health status of patient groups or various other selection effects.

Increasingly, EBM emphasizes the central role of systematic reviews rather than individual trials. Where appropriate, systematic reviews of evidence result in a meta-analysis to produce an estimate of the net effect of an intervention across studies. Systematic reviews have their own sources of potential error and bias. For example, publication bias is one risk: Trials with a positive result are more likely to be published than trials showing no effect. As a result, the systematic review often needs to search the unpublished literature. Similarly, individual trials may not all be of similar quality in terms of how well they address risks of bias. A meta-analysis of the net benefits of an intervention across trials may need to omit or downplay the significance of poorer-quality trials.

One of the key developments in EBM was the foundation of the Cochrane Collaboration in 1993. Named after a British epidemiologist, Archie Cochrane, the Cochrane Collaboration is an international nonprofit and independent organization dedicated to making up-to-date, accurate information about the effects of health care readily available worldwide, particularly via its database of systematic reviews (the Cochrane Library).

EBM emphasizes five essential steps in the optimal clinical practice. First, the clinician identifies a clear clinical question arising out of the management of an individual patient, a question leading to a need for information. In the second step, he or she will identify the best source of evidence to address the need. Third, the evidence will then be critically appraised for its validity and applicability to the problem at hand. Fourth, the evidence will be combined with clinical experience and the patient's own preferences and values to determine an intervention. At the last step, the outcomes of the intervention in the patient are subsequently evaluated.

EBM began as a movement to improve individual patient care. Its principles are, however, just as relevant to many other aspects of health care. What are the optimal ways of delivering health care? What are the most effective ways of improving health professionals' practice? What are the most cost-effective methods of promoting healthy lifestyles of populations? It is commonly argued that all such questions are more effectively addressed by synthesis and meta-analysis of best available evidence. Some of the greatest returns from investment may arise from relatively simple interventions in resource-poor populations: hygiene-oriented interventions such as hand washing, nutritional supplements for children, and antibiotic prophylaxis for HIV. The need for randomized controlled trials and evidence-based practice in such global health challenges is enormous.

The initial impetus for EBM came from academic medicine, understandably advocating the application of applied health research to clinical practice. Strikingly, the financial, managerial, and ideological support for EBM of governments and other funders and providers has been of enormous importance in sustaining the movement. This support arises in general terms because of the attractive prospect of services being developed that are more appropriate and cost-effective for the population served. In more specific terms, EBM generates detailed guidelines and explicit protocols for the delivery of services, developments that in principle make it far easier to monitor and steer the performance of health professionals than was the case when professional decisions were essentially a "black box beyond scrutiny." The provision of unbiased information about effectiveness of interventions also has an obvious appeal to patient groups otherwise dependent on commercial or other biased sources of information and advice. EBM would seem an advantageous development for all stakeholders in health care.

Three major issues currently confront EBM: (1) technical and scientific issues regarding the foundations of EBM in RCTs, (2) political critiques, and (3) practical and organizational challenges of implementation. The initial momentum of EBM in some ways resembled the fervor of a religious movement; the current phase of development requires confrontation with many complex realities of health care.

The first complexity is the widely expressed argument that RCTs cannot provide a sufficient knowledge base for all problems in the delivery of health care. There are some important questions in health care that will never be resolved by RCTs for practical reasons. This may occur when adverse events to be avoided are so infrequent that trials would require impossibly large sample sizes or where the health outcomes are so far in the future that there would be major practical problems of maintaining a trial. A quite different problem is that many questions will not be addressed because of ethical concerns about conducting a RCT to address such questions, for example, in the field of critical care. There may also be political objections to the use of RCTs. For example, methods of funding and organizing primary care in the United Kingdom have repeatedly been introduced without a firm evidence base, their introduction being determined rather by political preferences and intuitions about change.

There is also a continuing and lively debate about whether RCTs have to be the gold standard in proving an evidence base for practice. Several studies have compared the results emerging from meta-analyses of RCTs with those obtained from observational studies such as cohort designs. The conclusion is often that although observational studies are more frequently prone to methodological failures to address bias, well-designed observational studies produce similar results to those obtained from RCTs.

Another important technical problem is the relevance of results from clinical trials and systematic reviews to decisions about individual patients. The research evidence is usually about the average effect of an intervention across all types of patients. The extent to which this average effect is applicable to patients with any given features of disease severity or comorbidity may be unclear, because the evidence from trials does not have sufficient power to analyze trends in subgroups. Where it has been possible to examine evidence in subgroups, for example, in drug and surgical treatments of stroke, it has become apparent that benefits do differ significantly according to patients' baseline characteristics. A related and more general criticism of evidence from RCTs is that trials tend to be performed on a rather narrow range of patients, for example, often patients with more favorable overall health status, so that generalization to more "typical" patients is difficult.

Although the scientific limits of RCTs are increasingly being identified and recognized, these limitations do not fundamentally flaw the basic principles of EBM. They may mean that trials and related studies will need to be increasingly large and complex to address information needs that arise in caring for individual patients.

A second challenge stems from political critiques. One powerful analysis of EBM argues that the movement represents a fundamental (and undesirable) erosion of professional autonomy of health professionals, especially medicine. Some observers argue that the reduction of clinical decisions to explicit guidelines and protocols results in the practice of "cookbook" medicine with all important decisions taken at much higher levels in the overall management of health care organizations. In turn, these higher-level priorities will be largely driven by business models of efficiency and cost control rather than the interests of patients. Such critiques view EBM as one of a number of managerially led developments that lead to the deprofessionalization of medicine, motivated either by the profit motives of business or government concerns to control costs of the welfare state. It is also argued that the significant investments by organizations such as the U.K. National Health Service (NHS) in bodies such as the Centre for Disseminations and Review and National Institute for Clinical Excellence (key bodies assessing the evidence base for health care interventions in the NHS) are the outcome of a conflict for power and resources won by statisticians, accountants, and economists over traditionally powerful groups such as the medical profession.

The political critique forces us to reflect on the broader significance of EBM and usefully draws attention to potentially harmful threats to responsible and professional clinical practice if reduced to mechanical implementation of guidelines. On the one hand, however, the scale, scope, and reality of such threats are probably exaggerated. Moreover, the political critique underplays the extent to which the overall goals of EBM are welcomed by practicing clinicians and overlooks the extent of collaboration of clinicians with statistical and other nonclinical disciplines in developing the scientific underpinnings of EBM.

The third and ultimately the most important issue surrounding EBM is whether it is an approach to medicine that is feasible to implement in practice. Studies from around the world, including Australia, Canada, New Zealand, and the United Kingdom, suggest that only a minority of clinicians report using evidence-based information sources such as the Cochrane Library. One survey found that only 4 percent of a sample of U.K. general practitioners had ever used the Cochrane database of systematic reviews to help in clinical decisions. Studies have identified a range of reasons for the relative lack of uptake. Many clinicians remain unaware of what constitute high-quality forms of evidence, still relying on traditional reviews and textbooks. Clinicians are often unaware of how to access systematic reviews. In some cases, their offices may simply lack appropriate Internet connections.

In general terms, research evidence suggests that although clinicians do express concerns about the threat to autonomy posed by what seems like guideline-governed medicine, they nevertheless welcome the emergence of EBM. There remain concerns about the importance of intuition, context, and judgment as important factors in the practice of medicine that are devalued by some versions of EBM. The view is also expressed that EBM may jeopardize the role of the doctor as therapist (the so-called placebo effect) regardless of specific interventions that he or she may use.

The biggest single barrier to uptake, however, is lack of time due to heavy workloads. Clinicians feel that it is unrealistic in clinical practice to seek out and appraise relevant scientific evidence to resolve clinical uncertainties. For this reason, the EBM movement has moved on from its original pure conception. Now it is argued that while some clinicians may be "doers" of EBM, in the sense of following all of the steps from problem identification through evidence searching and synthesizing to action and evaluation, they are likely to be outnumbered by two other important categories of clinician. First. there is the "user" of EBM who does make use of secondary reviews already made readily available. Probably even more important in the future is the "unconscious user." This clinician will work in an environment in which EBM-based cues, prompts, and advice will be made available in the course of routine practice without being actively sought by the clinician. To take an example, clinicians may receive specific relevant advice on an automated basis when they enter a prescription into an electronic system. There is very encouraging evidence that such automated prompts induce more appropriate use of prescribed drugs by the doctor.

EBM is now entering a more mature phase where the complexities of what constitutes good evidence are accepted and the difficulties of applying evidence to individual practice are acknowledged and addressed. Constant advances in information technology encourage optimism that feasible applications of EBM will emerge. One outstanding issue is relatively unexplored. Clinicians often identify patients' own views, preferences, and requests within the consultation as a further barrier to EBM, especially when they are in apparent conflict with best evidence. Ways of achieving the active inclusion of the patients' values in the EBM will represent the larger challenge to the evolution of this exciting paradigm.

—Ray Fitzpatrick

See also E-Health Care/Telemedicine; Medicine; Quality of Life.

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EVOLUTIONARY THEORY

The first half of the twentieth century was consistently characterized as an age where the eradication of disability was within Western science's grasp. Beliefs about the potential for eradicating disability need to be understood with respect to developments in evolutionary theory and the process by which "defective" human bodies were produced in the wake of Charles Darwin's revolutionary notions of natural selection. Briefly, Darwin's theory of species adaptation and diversification rested on three key principles that have great value for disability studies:

1. Most variation is for the good of the species.
2. Adaptation is random and gradual in nature.
3. Fortuitous variations are unpredictable given that shifting environments alone determine organismic viability.

As an important aside, Darwin disapproved of any human intervention efforts to control the process and direction of species variation.

Few theories have had a greater impact and been so misread as Charles Darwin's revolutionary analysis of the origins of the species. Rather than a divine presence overseeing and orchestrating the invention of nature and the organisms that comprise it, Darwin's evolutionary model premised that all organisms evolved from a shared origin and that differentiation is the product of adaptation over time produced by interactions with environmental forces. Previous theories of species development hinged on a belief in a mechanism of internal determinism that guided species toward increasing perfection. Darwin overturned these notions by positing that species development occurs through a haphazard process (termed *natural selection*) where some organismic characteristics prove accidentally fortuitous to certain environmental conditions. Thus, one of the major innovations of Darwinian theory rested on a debunking of an ideology of progress in species "advance" that undergirded Enlightenment thought.

What we often refer to as disabilities today are central to evolutionary theory. Such conditions have been represented as either a failure of adaptation (organismic regression to a prior primitive state) or as a site of potential species innovation. The intellectual history of evolutionary theory is multiple and vexed with respect to the meaning of mutation (those forms of organismic and species differentiation marked as "severe" or most atypical). Following Darwin's philosophical break with the formalist tradition (planned internal design toward perfection), as represented by debates between Geoffrey, Cuvier, Agassiz, and Owen and particularly in theories of gradualism developed by Darwin's primary mentor, geologist Charles Lyell, Darwinian theory's three central themes have been amended and/or extended but not toppled in the sense that the kernel of natural selection remains intact. The solidity of this theoretical foundation is surprising in spite of those who have made relentless challenges to all three key Darwinian domains.

Those who attacked Darwin's theories from the mid-nineteenth century onward included eugenicists such as Galton; the mutationists such as de Vries and Goldschmidt; the catastrophism of Kelvin and Malthus; the "hardening" of Darwinian thought that occurred during the modern synthesis (1937–1963) in the work of Simpson, Dobzhansky, and Mayr; the rise of modern genetic theories that try to locate adaptation exclusively at the molecular level; and finally, the contemporary macroevolutionary theories of Gould and others. The primary argument that has served as a catalyst for evolutionary theory is between those who argue for the excesses of mutancy as superfluous, and thus largely undesirable, deviancy and those who believe that organismic/species creativity originates at the "extremes" of special variation. This structuring dichotomy is the focus of the remainder of this entry as that which is most critical to ongoing evolutionary debates for disability research.

The saltationists argued against the validity of Darwinian natural selection based on limitations ("structural constraints") inherent in the germ plasm or organisms. Following the lead of Sir Francis Galton, eugenicists theorized that species differentiation occurs according to the laws of regression toward the mean where atypical features—both desirable ("genius") and undesirable ("idiocy")—tend to give way to the overreplication of traits considered average or typical across a species. Unlike Adolphe Quetelet, the Belgian statistician who viewed average characteristics as most desirable, Galton's fascination was exercised in favor of extreme points of deviation from the mean. By dismissing the critical principle of Darwinian gradualism as too slow and inefficient to adequately explain species development, the saltationists advocated directed breeding practices. Unlike Darwin, who argued for an Adam Smith-like laissez-faire attitude toward adaptation, saltationists-turned-eugenicists encouraged the practical application of Mendelian principles to state oversight of human reproduction. Eugenics promoted the adoption of public policies that would better ensure the transfer of "desirable" characteristics (i.e., intelligence, eye color, and other features primarily associated with Caucasian peoples), and discourage the passage of "undesirable" traits (i.e., feeblemindedness, epilepsy, blindness, deafness, congenital impairments, alcoholism, and ethnicity). In other words, saltationist theories encouraged direct intervention in the process of species evolution to artificially cultivate some traits at the expense of others in a nation's germ plasm.

Another aspect of the saltationist debate with Darwinism was the more promising development of mutation theory by the Dutch botanist Hugo de Vries in 1909. Like Galton, de Vries poured his energy and theoretical development into the interpretation of genetic "extremes" (those rarefied cases that comprised the right and left tails of the bell curve). Yet, whereas Galton viewed "deviation" as largely irrelevant to organismic adaptation in nature and across epochs, de Vries's "mutation theory" championed "deviancy" as the locale of species "creativity." As a mutationist who also paradoxically embraced Darwinian principles of natural selection, de Vries argued that the production of "giant" and "dwarf" forms of the *Oenothera* plant signaled the origin of a new variation in an otherwise doomed organismic homogeneity. Consequently, de Vries merged the two extant theories of evolutionism—Darwin's non-directed selectionism with Galton's saltational "facet-flipping" (the sudden appearance of a new organismic form)—in the articulation of one of the first DNA-like arguments of organismic invention. Mutation theory's penchant for rapid and dramatic change in the matter of a generation provided one of the first successful efforts to overturn Kelvin's arguments that the planet was too young to accommodate Darwinian investments in the single species hypothesis. In other words, genetic mutations (many of which are classified as today's congenital impairments) serve as catalysts for species differentiation over time.

DeVries's celebration of mutational principles continue to resonate not only in the much maligned formulation by Goldschmidt in 1940 of "hopeful monsters"—"a completely new anatomical construction" that emerges in "one step from such a change"—but also in more contemporary theories such as Gould and Eldridge's most original contribution to macroevolutionary theory called "punctuated equilibrium." While Darwin located adaptation exclusively at the organismic level, Galton moved down the evolutionary scale to the level of germ plasm, and de Vries's mutation theory manifested its most significant impact at the species level, punctuated equilibrium formalizes its theory of adaptation at the cladistic level (evolutionary branching at the level of multiple lineages). This theory is distinct from that of most contemporary geneticists who (like the saltationists before them) argue that the molecular scale determines outcomes at all levels above: organisms, species, clades. As a field that relies on narrative methodologies that include history and interpretations of the fossil record, macroevolutionary theory seeks to analyze the crucial dimension of adaptation as an expression of interactionism between species-individuals and environments. In doing so, evolutionary theory places itself in direct competition with genetic determinist models where the transfer of molecular materials across generations can presumably account for the majority of manifestations of species differentiation.

At stake in these arguments for current disability-based research is the overreliance on molecular analyses as deterministic of human forms perceived as "unacceptable" at the social level. In displacing a social process into the organic, one effectively seals off the complexity of social influences upon an object of study. By locating a gene (or now perhaps a protein) as the origin of "deviancy," geneticists perpetuate the fallacy of the early saltationists who believed that organisms were internally directed in a deterministic fashion. As a direct disciplinary descendant, contemporary genetics threatens to reproduce the value system that powered eugenical practices at the beginning of the twentieth century, namely, by misrecognizing the organism (rather than the messy interactional space that exists between individuals and society) as the appropriate arena of intervention. This is a critical site where social model approaches to disability can contribute to the growing theoretical base of evolutionary thought.

As with the field of ethics, the meaning of disability functions as the unacknowledged Other in evolutionary theory. The discourse provides significant materials to fuel further disability research efforts to transform impairment from a presumed inferiority into a system of adaptive responses that continue to guide the origins of the species.

—David T. Mitchell

See also Charles Darwin; Eugenics; Mutation Theory.

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EXERCISE AND PHYSICAL ACTIVITY

During the past 50 years, many scientific studies have examined the relationship between physical activity, exercise, and health. The results of these studies have demonstrated that physical activity and exercise have a significant and positive effect on health promotion, disease prevention, treatment of chronic illnesses, and rehabilitation of people with disabilities. At the same time, lack of physical activity or a sedentary lifestyle has been identified as an important risk factor for chronic diseases. Thus, governments and public health agencies have developed policies including recommendations to promote and maintain an active lifestyle. Furthermore, many professional organizations have included exercise as an integral part of various clinical therapeutic and rehabilitative protocols.

Physical activity can be defined as any activity that involves the neuromuscular system and results in energy expenditure. Physical activity can be classified into various categories including occupational, recreational, or sports-related based on the objectives of the activity and the environment in which it takes place. All categories of physical activity have been associated with positive health outcomes in a large number of studies conducted since the 1950s. Exercise, on the other hand, is a subset of physical activity that is planned, repetitive, and structured to improve the physical and psychological health of a person. Exercise can be classified based on the nature of the muscle action involved (static [when there is no joint movement] vs. dynamic), the physiological adaptations induced (aerobic, strengthening, flexibility, or stretching), or the clinical objective of the exercise program.

Many disabling conditions are associated with reductions in health-related fitness. A practical classification of exercise is based on the nature of the specific component of health-related fitness that the exercise program is targeting. The health-related components of fitness include flexibility, muscle strength, muscle endurance, cardiovascular endurance or aerobic capacity, and body composition (percentage body fat or lean body mass). In this context, the type of exercise chosen must be specific for the physiological or functional capacity that needs to be developed. Thus, when the objective is to increase muscle strength, a specific exercise prescription for strength (or resistance) training such as weightlifting is indicated. If the clinical need is to develop flexibility, then a stretching exercise program is recommended. For cardiovascular endurance, and to increase aerobic capacity, exercise programs that activate large muscle groups such as walking, swimming, cross-country skiing, dancing, and many other similar activities are more effective in obtaining the goal. Finally, both strengthening exercises as well as aerobic activities influence body composition in a positive way by reducing body fat and maintaining or increasing lean body mass.

It should be clear that the goals have to be defined first and that the exercise recommendations must be specific for the chosen goals. The process of setting goals, one of the central tenets in the practice of clinical rehabilitation, is guided by the nature of the disease or injury and the physiological or functional losses associated with it. For example, when an injury to the knee joint results in joint swelling and pain that requires immobilization in a brace to protect tissues from further injury, the range of motion of the joint may be reduced and muscle atrophy can develop. In this situation, a program of flexibility exercises is indicated to treat the joint loss of motion and a strengthening exercise is designed to prevent or restore the loss of muscle mass and strength. Joint contractures and muscle atrophy are examples of impairments that, if not treated, could lead to a permanent disability.

Exercise and physical activity have been shown to be effective in the primary prevention of several chronic diseases that are common causes of death and disability in many countries. For example, epidemiological studies show that physically active men and women have a lower incidence of coronary heart disease, stroke, hypertension, diabetes, obesity, breast cancer, colon cancer, and depression. The evidence is so strong that many professional organizations and public health officials have included exercise as an important component of their health promotion strategies and the World Health Organization has endorsed an international "physical activity day" to promote the benefits of physical activity.

Although primary prevention is important, exercise can also be used for secondary prevention after the disease has evolved to a clinically detectable condition. Patients who have already developed these diseases can benefit from exercise programs because the regular participation in such programs induces adaptations in almost every organ/system of the human body. Some of the physiological and metabolic adaptations to exercise that help in the treatment of these diseases are a reduction in body weight and fat, an increase in lean body mass, lowering of blood pressure at rest and during exercise, enhancement of cardiac function, improvement in peripheral circulation, proliferation of small blood vessels or capillaries, increase in HDL (or good) cholesterol, reduction in LDL (or bad) cholesterol, improved sensitivity to insulin, and increased tolerance for physical stressors.

Finally, patients in rehabilitation programs, for example, stroke survivors, patients recovering from heart surgery or myocardial infarction, patients with pulmonary disease, amputees, and many others can also benefit from exercise programs. In a rehabilitation setting, where disability is prevalent, exercise can be used to normalize the basic pathophysiology of the disease (e.g., carbohydrate metabolism in diabetics), limit impairment (e.g., by increasing motor control in the hemiplegic arm), and correct functional losses (e.g., with gait training in amputees). In other words, physical activity and exercise have been shown to be effective interventions at different points of the pathway to disability. Without offering a cure for a permanent impairment or an incurable chronic disease, exercise can enhance the functional capacity and quality of life of the person with a disability.

It should be noted that although the physiological adaptations to exercise training have received more attention, exercise has also been shown to have important psychological and mental benefits. People involved in regular exercise programs report lower levels of anxiety, reduced depression scores, higher levels of self-esteem, improved well-being, enhanced cognition, and higher tolerance to pain. More research is needed in this area but the scientific evidence in this respect is convincing.

When recommending exercise as an intervention to minimize tissue damage, limit impairment, enhance function, or reduce disability, it is important to be specific. Thus, an exercise program must de defined in terms of the type of exercise and its frequency (sessions per day or week), duration (number of minutes per session, number of sets and repetitions), and intensity (usually expressed relative to the maximal capacities of the person). Although general guidelines exist, more research is needed to define the optimal combination of these elements for different patient populations and for persons with different types of disabilities. Furthermore, many recommendations have been developed for healthy subjects without disabilities and it is not clear that the results of those studies can be extrapolated to all.

The type of exercise is defined by the goal (as mentioned above) and the other three elements (frequency, duration, intensity) are specific for each type of exercise. The selection of the type of exercise is also influenced by the nature of the disability, the personal preference of the individual, and the existing resources in the community to support the choice. In other words, if swimming is ideal, does the person have access to a swimming pool? Another important consideration is the equipment that may be needed to perform the exercise. A wide variety of options are commercially available and both home- and gym-based options can be considered. Considerable research has been done in this area to develop adapted equipment for the exerciser and the practice of sports modalities for people with disabilities. For example, persons with permanent disabilities such as amputations and spinal cord injuries can use special skis for downhill skiing and wheelchairs to play basketball and compete in track sports.

Exercise programs have to become part of the daily and weekly routines of the individual. If not practiced regularly, the benefits of exercise will be lost, usually over the course of several weeks or a few months. In general, flexibility exercises are practiced daily, strengthening exercises 3 or 4 times a week, and aerobic exercises almost all days of the week. Although each person may have to develop an individualized program, specific recommendations regarding duration and intensity have been published in many forms and are available for specific types of exercise.

In summary, physical activity and exercise can be effective in the prevention, treatment, and rehabilitation of disability. There are no reasons for persons with disabilities to avoid exercise.

—Walter R. Frontera

See also Health Promotion.

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EXHIBITION

The term *exhibition* is a very general way of describing public presentations of a wide variety of subjects, including art, goods, services, athleticism, and performance. In the context of nineteenth-century popular entertainments in the Western world, "exhibitions" were colossal, grand-scale displays of industry and commerce held in various metropolises on grounds constructed specifically for that purpose. The largest of these were known also as "International Expositions" or "World's Fairs," sponsored by leading citizens and supported with vast government grants. Generally speaking, these events resembled small, rapidly erected cities of massive, architecturally ornate buildings showcasing the greatest recent advances in scientific development. Inside the buildings, visitors could bear witness to the agricultural, commercial, cultural, and technological marvels of the day.

The exhibitions were also known for attracting entrepreneurial vendors, showmen, and cheap service providers who erected ramshackle restaurants, hotels, saloons, amusement booths, and fly-by-night dime museums in hasty conglomerations that attached themselves to the larger, more "official" fairgrounds. These side-exhibitions were known as "shantyvilles" and "dinkeytowns," and they provided a profitable environment for less respectable forms of entertainment. In this *demimonde,* certain persons with disabilities, unusual appearances, or special skills could profitably present themselves as freaks to an audience whose appetite for wondrous entertainment was already whetted.

The first such exhibition in the world was held in London in 1851 and had been so successful and profitable that it spawned American revivals as early as 1853, when an attempt was made to create a New York City World's Fair. This attempt proved abortive, however, despite the fact that the entrepreneur Phineas Taylor (P. T.) Barnum had been invited to the board of directors. In his memoirs, Barnum blames the failure of the event on the refusal of the other prudish, middle-class directors to incorporate popular entertainments (which included freaks as well as musical and dramatic presentations) into the program. Paris would hold World's Fairs in 1867, 1878, 1889, 1900, and 1937.

The next great American exhibition was the Philadelphia "Centennial Exhibition" of 1876, which commemorated the century since the signing of the Declaration of Independence. It operated under no prudish restrictions, and during the six months of its operation it hosted some 10 million visitors (one-fifth of the total population of the United States at the time). The shanteyville it spawned was a mile long and featured some of the most widely known freak performers who appeared as "traveling foreign curiosities." These included the "Wild Australian Children," the "Aztec Children," the "Man-Eating Feejees," and the very famous "Wild Men of Borneo." Freaks who appeared in the context of exhibitions cultivated a performance style that conventional freak performers of the dime museum or the carnival midway adopted with less frequency. This style was distinct in two ways: It was "exhibitive" rather than "performative," and it was "exoticized" rather than "aggrandized."

The freaks of the exhibitions focused less heavily on "performance" than traditional freaks, who habitually included presentations of virtuoso skill in, for instance, acting, acrobatics, contortion, comedy, recitation, impersonation, mental acumen, singing, playing of musical instruments, or craftwork. Exhibition freaks relied less heavily on performance and more strongly on merely appearing in an exoticized manner. This mode of performance required the freak to be understood as an exemplar of a foreign culture. Indeed, the exhibition of disabled persons in such fairs was often wholly conflated with the exhibition of "perfectly ordinary" members of exotic tribes. The exhibits usually wore ostensibly authentic costumes and conducted ostensibly authentic activities in ostensibly authentic backgrounds. It was often the case that the entirety of an exhibit was invented, the elements of the presentation bearing no real relationship whatsoever to actual foreign persons, artifacts, or settings. The great manager George Middleton related an incident where he had employed his roustabout Bill Jackson, an African American from New Jersey, to pretend to be a "Zulu Warrior." Jackson, dressed in a lionskin with a great shield and assegai and a bone in his hair, suffered acute embarrassment when a lady in the audience recognized him and called out his name. The Wild Men of Borneo, in addition, turned out to be brothers of Scandinavian descent from Ohio.

Audiences of the time would not have drawn great distinctions between the presentation of exotic, nonwhite persons and freaks; in the context of the exhibition, both were presented as "scientific" exhibits to "educate and uplift" the public and were associated very much with middle-class Yankee values of courage, thrift, common sense, piety, and patriotism.

—Michael M. Chemers

See also Body, Theories of; Chang and Eng Bunker; Freak Show.

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EXPERIENCE

Our aim is to situate the primary experience of the disabled person that wakens to a relation with the lived body, temporality, spatiality, lived speech and in relationship to "others." For to contemplate the experience of disability is to bracket the thing itself. It is to be concerned with phenomenology rather than ontology. In the discourse of disability studies, it is to be concerned with disability over impairment, and with social construction, politics, and self-image over biology. The experience of disability is properly fundamental to disability.

Phenomenology aims at description of the patterns of lived experience. It is a philosophical approach that incorporates the mathematical-scientific point of view while providing access to a primary realm of human experience that remains irreducible. Such experience cannot be understood as merely "subjective" or

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Note: Parts of this entry are taken from the authors' "The Phenomenology of Disability: Implications for Vocational Rehabilitation," William Roth and Richard Sugarman, *Rehabilitation Literature,* November/December (pp. 366–369), 1984.

psychological. Phenomenology cuts across the objective-subjective dimensions by which many view reality, and we maintain that a phenomenological perspective can bring important insights to disability that have eluded more traditionally "objective" social sciences.

The lived body maps out our temporal-spatial world through our movements and actions. The lived body is our own, one that experiences directly. It is not merely the residue of the anatomical body and conditions our being situated in a world with others. As Sugarman suggests, "near" and "far," "up" and "down" register as irreducible categories of corporeal existence. For the disabled person, these "directions" may present and raise questions that do not readily occur to others.

The experience of human temporality is measured by meaning and concern before it is calibrated by counting and calculation. This lived time is qualitative, heterogeneous, discontinuous, and purposive. Mathematical time is quantitative, homogeneous, and continuous. The reduction of lived time to mathematical time reduces the human subject to an object.

Recent discoveries, particularly by the French philosopher Emmanuel Levinas, show an irreducible exteriority that demonstrates an "otherness" prior to the distinction between social construct and biological condition. The relation between the other and the self has foundational implications for an ethic of disability. It is in the act of recovering from the encounter with the other that the self recognizes both his or her own subjectivity. This is the locus of responsibility of one for the other.

A philosophical deficit arises from our currently diminishing sense of primary experience. Able-bodied people are in a corresponding position to relearn perceptual experience from disabled people. As examples, the discontinuous character of lived time is punctuated for the disabled person. Waiting for the other person can become a commonplace personal and social experience for a disabled person. This kind of waiting is, or course, found in the everyday experience of the able-bodied as well. Indeed, often the disabled person inhabits the time of the other, perhaps experienced by the disabled person as waiting, anticipation, rejection, in any event, as disruption. For that matter, the disabled person often inhabits the space of the other and does so not as an intruder, but as captive. Even attempts to make space his or her own may be interpreted as confinement (i.e., the phrase "confined to a wheelchair"). The disabled person may simultaneously be apart from and mesh with the space and time of the other. This engagement of the disabled body with space and time, although not unique to disability, is particularly revealed in the experience of disability. With the accelerating pace of the workplace, the impatience fostered by an ever-increasing desire for instantaneous access to information, and an impatience with delayed gratification, the phenomenon of waiting and the virtue of patience are a diminishing part of postmodern industrial life. Indeed, expectations for maturation have left less time for children to act like children. It is possible to imagine social worlds where a disability is not disclosed as dysfunctional, deviant, or pathological. In such worlds, people would have different conceptions of disability and work that would make different demands on persons, whether disabled or not. If the structure of the work world is not necessary but contingent, then the significant message in an advanced technological society may be one of social artifact rather than social necessity. But frequently we regard the world of work as a natural order and try to adjust the disabled person to that world by education, medicine, counseling, placement, advising on the job, and so forth.

While everyone can potentially benefit from advances in information technology, the premature reduction of understanding to mere information benefits no one. Academic lectures now imitate the sound bites of televised news with the result that education itself may proceed in ways less than desirable. In fact, as Roth suggests, the disabled person paradoxically may have more to gain from the revolutions in computer technology than others. The necessity to modify or adapt computer equipment for disabled people returns us to the domain of the lived body and the primary experience of the senses. Using the ball of the foot to control a mouse refers the engineer back to the capacities of a foot that is guided by conscious intention. Intentional movement, understanding, attention, and waiting are all inescapable aspects of irreducible human experience.

Loneliness is a dominant category of contemporary postmodern experience that, as David Reisman showed in the 1950s, can be experienced in a crowd. However, being alone is quite different from loneliness. The impediments for disabled people, and here we include the ill, the sick, the aged, and the young as well, can bring about life-threatening circumstances as well as the desire for human companionship. The nature of such solitude depends on whether it is forced or optional, momentous or trivial, and contingent or noncontingent. Here we see the emerging of a foundation for an ethics where the disabled person performs the role of teacher rather than student. All infants need care, supervision, and nurture. There is an asymmetry involved in the obligation of the parent to the child. Consciousness emerges for the parent as a continuing responsibility for the child. In most cultures, the reciprocal obligation of a child to care for a parent does not bring with it either the same obligations or legal sanctions. This would suggest that there is a concession that is made to the irreversibility of aging. The awareness that our time and the time of the other are different for each of us may be more likely to be known in advance by those who are disabled. This sense that the other approaches us from without—exteriority—forces a doubling of consciousness where we experience ourselves as a body-subject. The first experience is one of positionality or proximity and therefore of a subjectivity.

The disabled person may experience lived time and space with a greater degree of discontinuity born of dependency than many an able-bodied counterpart. In this sense, the life of the disabled person is more likely to be folded into the urgencies, priorities, and concerns of the able-bodied. This creates a surplus suffering over and above physical impairment. Psychological consequences, the experience of depression in particular, may accompany such temporal marginalizing. However, what remains to be explored is the precise relation between pain and suffering, the self and other. It is a commonly held opinion that suffering can exist without physical pain. Such suffering may be understood as psychological, emotional, or spiritual. However, from a radically empirical point of view, it would appear that where there is suffering, it is experienced in a corporeal sense first as pain. Pain may be temporary, even fleeting, like stubbing one's toe or an insect bite. Furthermore, pain can be experienced without a consciousness of an expectation with respect to the source of the pain as being unfair or unjust. Suffering, however, requires pain experienced for a sufficient duration to be memorable. At the same time, suffering arises in relation to expectation and therefore in relation to the expectations of others as well. The element of surplus suffering for the impaired person is unnecessary and therefore, in the language of Levinas, useless suffering. Useless suffering refers to the arrogance that would rationalize the sufferings of the other, our friend or our neighbor.

If we wish to reflect on our own suffering and endow it with some deeper purpose or insert it within some eschatological scheme, we are perfectly free to do so. This rationalizing in the first person superimposes a kind of theodicy that, when applied to others, shows ethical obtuseness. The surplus suffering of others can be decreased and ameliorated. This is done by placing the other before ourselves. Levinas argues that "the only absolute value is the human possibility of giving the other priority over oneself." This, according to Levinas, is the responsibility that founds consciousness in relation to experience. Ethics, according to Levinas, begins with justifying our spontaneity in the presence of the other. What is assumed here is that the other approaches us with immanent demands that we are not free from obliging. There would seem no end to such responsibility. How then would the market place, the workplace, cohesive social groups, function?

It is the third party, the neighbor, who may be present or absent, near or far, a close family member or a stranger, who limits our responsibility so that the order of justice can be installed. In this way, there can be justice for us as well for others and neighbors. By responding to the other, we assume our responsibility as a body-subject. This temporal distance between ourselves and the other is lived in first instance as a responsibility for our passivity. This extreme vulnerability registers in the sensibility through which perception informs understanding.

In this entry, we adhere to what William James called a radical empiricism that brackets issues of essence, ontology, biology or, for that matter, any of the other issues that may or may not be hidden behind the naked fact of our experience. Yet the experience of social beings is different from that of monads. The population of the experiential world by self and others and its animation by the multitude of relationships among these is not only part of that from which issues the experience of impairment but also, more important, that from which issues the rich complexities of the social experience of disability.

It is only a beginning to note that disability is overwhelmingly social, that is, given by the interactions of the self and others. Of course, others are of enormous variety and complexity. It is in the spirit of suggesting such complexity that we offer a rough-and-ready taxonomy of the other. Others can be divided into friends and strangers. The experience of disability is likely to be different for a friend or a stranger, as is the experience of this experience by the disabled self. Sometimes an other moves from being a stranger to being a friend, and the experience of disability may change accordingly. Another distinction about others, whose primacy we shall not comment, is that between master and slave. This sheds its dialectical relationship and is reified in the writing of Nietzsche through Foucault into the postmodernists. Here it is power that constructs knowledge including, of course, knowledge of disability.

There has been much talk about the medical model of disability. However, in the experience of disability, medicine is reabsorbed from its position of dominance as indeed it has been trumped by other vectors of social power. Gliedman and Roth point out that it has become ever clearer that the medical model is only a special case of the social pathology model. It appears then that power constructs our social world, some even say our non-social world. Hence the question of power is important to our experience and disability and it will be necessary to speak truth to power even if that involves questioning the primacy of power itself. Such indeed has been the trajectory of modern phenomenology.

Another distinction of others can be made between the professional and layperson. Often the professional invents and deploys a power that may be predicated on illusion. Other professionals may share the illusion, and laypeople may share it as well and be humbled before it. When the layperson is disabled, such dynamics become part of his or her experience. However, people of privilege know full well that professionals work *for* them. This has become evident in modern American culture with the displacement of the professional by the entrepreneur. For example, Bill Gates did not finish college, and he hires professionals. This is only part of an ancient tradition.

There are countless other distinctions that can be made between others such as distinctions in gender, age, proximity, class, or ethnicity. All or any can change the experience of the disabled self. For example, whether the other is erotic or neutered and whether the other considers the disabled self, for after all selves are others to others, as erotic or neutered can profoundly effect their relation in being that is contingent on relationships with others.

Thus, the human world is composed of complex aggregations of others. Indeed, the experience of others can make of them bigots actively hostile to people with disabilities. Far more typically, however, they do not know. Such ignorance may issue from their limited experience with disabled people. Often ignorance, or misinformation, echoes through the world of the other through complex mechanisms of culture that include language, practice, education, the media, advertising, or the law. In good measure, the liberation of people with disabilities involves changing such mechanisms. At times, disabled people have been unduly rancorous insisting on notions like temporarily able-bodied. Such nomenclature is often the reflection of the experience of the disabled person. How then are we to adjudicate the truth of experience?

An examination of the experience of disability recognizes the rich complexity of the location of the disabled person in the social and political world. Of course, society is never a monolith; rather it is a collection of ever-shifting people and groups. Often the relationship between these collectivities and people can be subdivided into a sort of taxonomy such as sketched above. Sometimes this taxonomy would seem to express relations of power constructing local and less local meanings to disability. Sometimes these meanings overextend themselves, forcing their experience on people with disabilities and on others. One example is the medical model of disability, perhaps questionable itself, certainly questionable when used outside of medicine. Understanding the experience of disability can be magnified through the reciprocal experience of self and other. Indeed, it is not only the disabled person who must be concerned with the other, it is everyone, including others. A coherent explanation of the self, disabled and otherwise, is contingent on an examination of the other that transcends even the other as a source of much experience to the self.

Society, social agencies, social actors, and social scientists are governed by a rhetoric that implies a disabled person ought to adjust to the reality of disability and to the physical and social world. The disabled person who does not adjust is presumed to flirt with deviance and stigma. But there is another way to regard adjustment. Reckon that it might not be the disabled person who should adjust, but rather the social and physical world. The social world is composed of others. These others have certain ways they do things, beliefs and values they hold, and certain goals they desire. "Adjustment" expresses a relationship between a person and the environment. This relationship can expand or contract by changes in the person or environment or both.

Usually, we dwell on changes in the person. But corresponding possibilities of change elsewhere in the social structure exist, and we shall refer to them by the word *inversion*. Such terms as *work*, *education*, *productivity*, and *poverty* also express relationships between a person and the environment and are subject to inversion. If we are to understand and legitimate the experience of the disabled person, these terms must be explored with inversion in mind. The social structure is generally assumed to be natural and unchangeable. This is unjust both to society and the disabled person. Indeed, inversion involves not the adjustment of the disabled person to society but more frequently the adjustment of society to the disabled person—the complex reciprocities of adjustment reflecting back and forth through the mirrors of inversion.

Political and social reality is predicated on our experience. It is in the multitudinous reflections and refractions of countless others that a politics of experience is generated. Without the experience of disability, a politics of disability is arduous if not impossible. Stripped of experience, disability collapses into mere biology, bureaucratic case, or object of oppression. With experience the disabled body is activated and must be reckoned with. Of course, the sorts of politics that the experiencing disabled body can engage with are manifold ranging from exercising our bill of rights to voting, from communicating to organizing, from direct action to subtle pressure, from being constructed to constructive, from power to powerlessness, from freedom to servitude.

Perhaps special education, vocational rehabilitation, and other disability-dependent practices and professions exist to further the goals of professionals and an increasingly complex professional bureaucracy. It is possible that a system ostensibly serving a patient, person, or client primarily serves itself. Such inversion is a theoretical possibility and not a necessary fact. A society that discriminates does not know it erects barriers to disabled people and engages in unnecessary repression. This is particularly evident where society has generated a high degree of freedom from nature through technological mastery. The social and political construction of the disabled world by the able-bodied tends to disenfranchise and stigmatize persons with disabling conditions.

Embodiment, the lived body, discloses what a disability is. Disability is a difference in body orientation as well as appearance and anatomy. Or, to be more precise, disability is experienced as difference in the world inhabited by the lived body. It is, then, not only the body—which in most respects may be the same as a nondisabled body—but the way in which that body is informed by life, intentionality, will, intelligence, and other bodies that is decisive. A person with a disability is experienced as a person with a lived body that is different from the lived body of an able-bodied person. Body is a more interesting and fruitful notion than behavior, the sterile response to a stimulus. It is a more direct, tangible notion than that of action—we all are bodies, know what they are, and what they mean.

Sometimes the disabled person may resent being taken for a body, insisting rather that the real person lies within. Phenomenology suggests that the disabled person may be mistaken in this view. The proper relationship of the self to the body is not one of habitation, cohabitation, or possession, but is much stronger, approaching identity. Rather than "I am in my body," or “I own my body,” or “I and my body go through the world together,” it is more accurate to say, “I am my body.” From the phenomenological explorations of the lived body by Merleau-Ponty, Ricoeur, Sartre, Straus, Levinas, and others, we have learned that the phenomenon of embodiment holds the central place in understanding the meeting place between the “subjective” and “objective” poles of human experience, products of the division of “mind” and “body,” a dualism set in motion by Descartes.

The brain is part of our body. It is an organ of exquisite complexity whose very existence is prima facie evidence of the importance of bodies. Should one give brains attributes like consciousness and the ability to encounter the world with the rest of the body, much of our senses an extension of the brain, the requisite connection of the brain and the rest of the body become self-evident. The experience of our brains is a thorny issue, important nonetheless given the primacy of our brains and our brain’s connection to experience itself. At times, our brains function differently, and mental illness, cognitive irregularity, and even the nature of experience itself change. Our brains are connected to our motor functions, senses, memories, and most of the rest that makes us who we are. If multifaceted, our experience of our brains is important. Sometimes we refer to this experience as “mind” (Minsky).

Often it is not our brains we experience, but rather the actions that issue from them and our bodies. Thus, much of our experience with mental illness is the experience of our actions that mental illness causes and the responses that they elicit from others. We all have the experience of being conscious beings, conscious among other things of our actions. An account of the experience of disability must be one of our actions and brains both—or together. Many impairments derive from the human brain or the difficulties it may have in connecting with other parts of the body. Such impairments may include those of the senses, motor system, cognition, mood, and more. Often our experience of a disability includes our experience of impairment. Often our experience of the impairment is an experience of our brain as revealed to us by other parts of our body, the brain having no sensory neurology to reveal experience. With impairments most commonly attributed to the brain such as emotional, psychological, mood, thought, speech, and reading and writing, experience becomes of supreme importance, for it is our experience of these that brings them to our consciousness and our actions, which may occasion responses by others that refract them into disabilities.

The experience of disability by the disability-experiencing self and by the disability-experiencing other and society rubs up against the non-human world. The relationship between the human and non-human world has transmuted into one where people have or expect to have dominance over most of the non-human world. For example, architecture, systems of transportation, education, and production are part of the human environment, and the disabled person’s experience of them, perhaps hostile, perhaps inviting, is less experience of implacable nature than it is of human artifact. Usually, what human beings make could have been made otherwise. That it is not, and further that it is not even thought of being otherwise, suggests that the non-human environment is often constructed after the needs of some and not of all or even most. It is not surprising, then, that disabled people’s experience of the non-human environment may be painful. It also follows that such awkwardness may in fact be in the face of actions of some people, usually those described as having power. A disabled person’s experience of the human environment may be painful as well. Human organizations, bureaucracy, or culture may be experienced as painful by a disabled person. These are often in the service of those in power. Usually, people with disabilities are poor in power and therefore experience power as domination and oppression, rather than as empowerment and freedom.

When the disabled person desires to be accepted for what he or she truly is, rather than as a mere disabled body, that individual really protests against the obscure and tormenting construction of the disabled body by the able-bodied other. Such protest is in order; but if social oppression is internalized into a bifurcation of the disabled person and the body, insult is compounded.

The key to understanding the phenomenon of embodiment is intentionality. Only a dead body can be reduced to an anatomical object devoid of consciousness and subjectivity. From a purely naturalist or objectivist standpoint, a stillborn child may prove every bit as important to pathological examination as a child born living. The newborn infant moves with precognition to its mother's breast. There is, however, a significant difference between the intentionality of oriented movement and its accomplishment. Here the human experience of disability can be measured by the distance between the intention to grasp, stand, walk, or speak and the ability to do so. Subjectivity is given as embodiment. "Here" and "there," "up" and "down," "before" and "after" are inexplicable abstractions without reference to a world mapped out by an oriented body-subject. Embodiment conditions all spatial and temporal relations. It is embodiment that by engendering perspective compels us to have "experiences." Attempts to devalue human experience run up against the limiting condition of embodiment. Embodiment renders subjectivity universal, and thereby opens up the lifeworld for indefinite exploration.

In a posthumous retrospective, Merleau-Ponty summarized his own discoveries on the meaning of embodiment while pointing out new directions. For contemporary psychology and psychopathology, the body is no longer merely an object in the world under the purview of a separated spirit. "On the side of the subject, it is our *point of view on the world,* the place where the spirit takes on a certain physical and historical situation" (Merleau-Ponty 1964:5). Merleau-Ponty, Straus, and others have already explored cases of disoriented subjectivity arising from differing corporeality to shed light on the phenomenon of embodiment in general. More simply put, phenomenology has buttressed its case by making reference to disability.

The lived body is more, however, than a medium through which self-transparent thought would express itself without interference from its embodiment, and, therefore, its situated history. As Merleau-Ponty (1964:6) states, "The perceiving subject is not this absolute thinker; rather, it functions according to a natal pact between our body and the world, between ourselves and our body." The inner world, or human subjectivity, is rendered possible and knowable by the concrete experience of human embodiment. Disability, viewed from the perspective of functionality alone, is a limiting condition binding childhood to old age. It is discovered in childhood as the "I cannot yet" and in infirmity of age as "I can no longer." In an emerging world of potentially embodied technology, the nature of disability is arguably changing. Yet with existing technology able-bodied assembly-line workers are not unlike disabled people in contemporary society. By expressing knowledge as power, function, or utility innovations in technology can extend the reach of the able-bodied population as well as the disabled, and thereby close the unnecessary, socially constructed distance between the two groups.

To design programs and policies without understanding the experience of disabled persons does violence to their integrity and engenders their understanding of the world in terms of powerlessness, anger, and discrimination. The surplus suffering experienced by the disabled population is largely socially constructed and begs each of us to return to the sources of intimacy and human relations. The face-to-face encounter is preserved in the body's mutability. So, too, is the empathy and love for the one who is other, strange, different, and so rendered by virtue of his or her embodiment.

The precariousness of the able-body is a counterpart to its soundness, for neither the able-body nor the disabled body is dead. Both experience the dynamic of change and the body's incarnation of the will to self-assertion. Both have pasts, presents, and futures. Both are more alike than otherwise. There is, after all, a substantial measure of truth in the conception of the able-bodied person as a temporarily able-bodied person. If this truth is burdensome it is because it is so close to the able-bodied person and the able-bodied person has a stake in an able-bodied existence. To the extent that "negative attitudes" of the able-bodied population toward the disabled may be predicated on fear, it is not taken lightly. What appears as a fear of the unknown is more accurately fear of the known. And what is known although denied as real, its density making it unavoidable (or to be avoided at all costs), is that time and change are unavoidable and, therefore, disability is universal in its implications.

We are at a crossroads where disabled people inform us of the answer to our humanity: "Every incarnate subject is like an open notebook in which we do not yet know will be written." The meaning of humanity is open for both disabled persons and others. The latter should ground their encounters with disabled persons by keeping in mind how their own life-worlds were and are influenced by a complex social structure as well as by the possibilities of inversion. And finally—but not so since there is no finality here—the other must recognize his or her own subjectivity given as embodiment and the different subjectivities and experiences of different disabled people with different embodiments. He or she should never presume to know "what will be written," much less to write it. Assistance in the writing—by skill, teaching, counsel, wisdom, and by helping change the social order–is proper and honorable.

A decent society is measured by the way that people hold themselves responsible for the well-being of one another. The realization of social justice recognizes the asymmetrical relation between the other and the self. The experience of disability, or at least, to use Kant's term, "the possible experience," demonstrates the universal reach of ethical responsibility of one for the other. The social responsibility of one generation for another is enhanced with the recognition of the experience of finitude that disability brings. It also marks the achievement of a certain humanity when the framework of meaningful life and work is extended through refining the ethical obligations that elevate the social contract upon which societies are based. In this sense we are able to ground a policy of non-indifference towards the other as the starting point for further investigation into the experience of disability by inseparably linking it to the domain of ethics by which we measure the human within the order of things. Such an ethics begins with the other rather than the self and breaks with the dominant model of cultural and political imperialism that has dominated Western thinking since Hobbes. The idea of the one for the other is found not in the "State of Nature" as Rousseau thought; rather it begins with the capacity that we have to respond to and for the other.

It is the other who renders explanation philosophically intelligible. Explanation begins by turning towards a *someone* to whom such explanatory discourse can be made meaningful. In this way, to reason is to justify. Prior to discourse itself is the phenomenon of the expression that poses a question, asks something of us, and assigns to us a responsibility for responding. This experience of the expression coming from the other assigns us the possibility of recognizing subjectivity as our own, and therefore being inseparably bound up with an awareness of justice that we are called upon to perfect. This consciousness of the experience of a disability common to all serves as the prelude to any education.

—William Roth and
Richard Sugarman

See also Body, Theories of; Disability Culture; Disability Studies.

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EXPERIENCE OF DISABILITY: BRAZIL

Brazil is one of the few countries to include an entire section on disability in its census (2000). Results showed that 14.5 percent of the population, roughly 24 million people, reported having some form of disability. The poorest region, the northeast, reported the highest percentage of people with disabilities (16.8 percent) while the richest region, the southeast, reported the lowest percentage (13.1 percent).

HISTORY

In the first half of the twentieth century, people with disabilities in Brazil had no voice and no representation. They were either living in isolation with their families, or they were institutionalized. They were primarily studied, diagnosed, and "treated" by professionals such as medical doctors, psychiatrists, psychologists, and educators. In the years prior to World War II, Brazilian professionals viewed disability in three ways: a biomedical puzzle (to be solved using modern technology), an educational challenge, and a social problem. The professionals were divided as to whether disability, particularly intellectual disability, was primarily a biomedical or educational issue. As early as the mid-1800s, there were institutions for different types of disabilities—psychiatric hospitals, such Psychiatric Hospital Pedro II in Rio de Janeiro, and schools for the blind and deaf, such as the Imperial School for Blind Children, now called the National Benjamin Constant Institute, and the National Institute for the Education of the Deaf.

Much scholarly attention was focused on the physical and mental disabilities and illnesses of people living in rural poverty, especially those of African or mixed descent. However, due to Lamarkian-influenced eugenics theories, Brazilian professionals believed that improved health and social welfare would improve the genetic inheritance of these groups. Thus, the focus was not on institutionalization or sterilization of "pathological" populations, as was practiced in the United States and Europe, but rather efforts were primarily focused on improving public health and social welfare. However, laws were passed mandating prenuptual examinations that were specifically designed to deny marriage to people who were deaf or had intellectual disabilities.

Prior to the 1930s, educational programs for children with intellectual disabilities were located in psychiatric hospitals, and children who were blind and deaf were sent away to residential schools. In 1932, however, educator Helena Antipoff founded the first Pestalozzi Society—a community-based school for children with intellectual disabilities. In 1954, influenced by the Arc (formerly called National Association for Retarded Children/Citizens) movement in the United States, parents of children with intellectual disabilities opened the first APAE chapter (Associação de Pais e Amigos de Pessoas Excepcionais [Association of Parents and Friends of the Exceptional]). By the end of the twentieth century, there were 146 Pestalozzi Societies and more than 1,700 APAE chapters throughout Brazil. Many public and private schools currently strive to include children with disabilities, but issues such as proper teacher training and accessibility make inclusion a challenge.

Independent Living Movement in Brazil

After World War II, Brazilians with physical disabilities organized around sports and recreation clubs. There was no existing national public policy on disability. People with different types of disabilities did not have a unified group identity, nor were they represented as a group through the constitution or legislation. What opportunities and rights existed for people with disabilities were the result of isolated initiatives, mainly led by professionals and parents.

In the late 1970s, however, Brazil began to prepare for the International Year of Disabled Persons in 1981. By the early 1980s, there were hundreds of local organizations representing different disability groups. These groups began to work together, for the first time adopting a cross-disability perspective. People began to connect to the international disability rights movements and organized disabled people's councils in most Brazilian states and major cities. For the first time, there were people with different types of disabilities working together and representing themselves.

The experience of self-representation led to further initiatives in both advocacy and service provision.

The first center for independent living (CIL) in Brazil was founded in Rio de Janeiro, Brazil (CVI-RIO) in December of 1988. CVI-RIO was spearheaded by a group of activists with disabilities from the grassroots Brazilian disability rights movement. They differentiated themselves from preexisting advocacy organizations by offering services such as peer counseling, employment placement, and skills training. CVI-RIO established a new organizational model by adapting the philosophy and the services from the CILs in the "first world" to the Brazilian context. As the independent living (IL) philosophy spread throughout Brazil, the demand for personal services for people with disabilities quickly generated more than twenty new centers around the country, each adapted to meet specific needs of the communities in which they are located. In 1999, the National Council of ILCs (independent living centers) was established to ensure that organizations using the term *independent living* in their title adhered to the philosophies of the movement and provided services as well as advocacy.

Priorities of the Brazilian ILC include peer support, personal assistance, personal autonomy, information and assistance about civil rights, accessibility, technical assistance in development and counseling, ILCs led and staffed by people with disabilities, training for leadership, and professional training programs where none are offered by local or national organizations.

In 1992 and 1995, CVI-RIO organized, in partnership with other groups, two international conferences on disability issues called DefRio. Hundreds of participants from more than two dozen countries attended. During DefRio 95, participants drafted a document titled "Goals of the ILM." This document delineated the basis for the independent living movement (ILM) in Brazil, whose goals and objectives were applicable to current and future ILCs. Since financial support is not provided by the government, the ILCs struggle for sustainability through a variety of means, including grant writing, producing adaptive equipment, and acting as an employment placement service for people with disabilities. The employment placement services benefit from federal laws instituting a quota system that generates job-contract opportunities between companies and organizations of people with disabilities.

DISABILITY IN CULTURE AND POLITICS

Brazil has progressive policies toward disability. The Brazilian Constitution includes sections on the rights of people with disabilities and laws have been passed with regard to accessibility, education, and employment. The laws are enforced by the Office of the Public Defender on local, state, and national levels. Discrimination is penalized with prison and fines. This office, called Ministério Público, also promotes public awareness campaigns on legislation and civil rights of disabled people, among other minorities. They reach out, for instance, to big companies and pressure them to comply with employment regulations. As a result of the laws and partnerships to enforce them, individuals with disabilities are participating in the society in record numbers and the cultural impact is in proportion to this increased visibility.

On the national level, people with disabilities are elected to office in large enough numbers for there to be an association of national members of Congress with disabilities. Within the Secretary of Human Rights of the Ministry of Justice, there is a National Council on Disabilities and CORDE, the main Disability Office for the Inclusion of People with Disabilities. This office is responsible for the development of policies on social inclusion, protection of rights, and promotion of citizenship for people with disabilities.

Brazil is a Catholic country with a paternalistic structure of family relationships. In contrast to a cultural model where "independence" is achieved when adolescents or young adults leave their parents' home, Brazilian children often do not leave home until they get married, and may even return if the marriage ends in divorce. This homecoming is not necessarily dependence, but rather a form of interdependence reinforced by economic necessity. People with disabilities may not have the possibility to attain this type of "independence" and may rely completely on family to fill all their needs, while those without disabilities may have more opportunities to maintain autonomous spaces for themselves through their work, friendships, and romantic relationships. Although there is still a persistent lack of visibility and equal opportunities for people with disabilities to fully participate in society, there is more potential for IL than ever before in Brazilian history, due to Brazil's social development process as a whole and the progress made by the disability sector, specifically.

Through the disability rights movement and the support of the new laws and enforcing mechanisms, disability groups are taking important roles, both as advocates and service providers, to move the disability agenda forward. The IL concept is now beginning to be understood and spread all over the country: autonomy, empowerment, and self-determination as keys to a new human rights approach to inclusion and full participation.

—Pamela Block and
Rosangela Berman Bieler

See also Advocacy, International.

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Websites

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Brazilian Institute of Geography and Statistics (IBGE), www.ibge.gov.br

Coordenadoria Nacional para Integração da Pessoa Portadora de Deficiência (National Coordinator for People with Disabilities–CORDE), http://www.mj.gov.br/sedh/dpdh/dpdh.htm

CVI Brazil's Internet page, http://www.cvibrasil.hpg.ig.com.br/

SACI Network, www.saci.org.br

EXPERIENCE OF DISABILITY: CHINA

There are 60 million disabled people in China (includes sensory, physical, intellectual, and mental health impairments). Discrimination and disadvantage are daily experiences. Long-standing negative attitudes combine with structural barriers, making it harder for disabled people to attain personhood through work and marriage. In a country ambitious for economic and scientific progress, disabled people have to show they are not a liability.

Inevitably, given the scale of underdevelopment in many parts of China and the size of the population, there is limited state provision and heavy reliance on self and family. A series of laws and initiatives, led by the China Disabled Persons' Federation, have increased visibility and awareness and have affected hundreds of thousands of people, but the quality and availability of medical and support services vary widely, are heavily concentrated in large cities, and are accessed only by those with money and good social networks. There is growing demand from some city-resident parents of disabled children and educated disabled adults for services and opportunities; this has potential for positive change if helped to develop. Prospects are bleaker in parts of rural China where poverty is entrenched and disabled people fare worse.

ATTITUDES

Attitudes are changing, especially among urban élites, but there is extensive evidence of discrimination in all aspects of life. Confucian legacies of bodily difference as nonnormal persist, deepened by the construction of the active and productive body during the socialist Mao years, and the emphasis on economic growth and mobility since the 1980s. The language of disability is inscribed with notions of sickness, deficit, and worthlessness. Positive attempts to promote neutral terminology have yet to trickle down through China's social strata. Pejorative words are widely used, but less so face-to-face than in the past. Pity and disdain increase with the severity of impairment. Particular stigma attaches to intellectual impairment and mental illness, especially in urban areas where education and employment are markers of personal status and ability. People with congenital impairments (seen as evidence of wrongdoing or neglect in pregnancy, bringing particular shame on the mother) are treated more negatively than people with impairments acquired through illness, accident, or military service.

DISABLED CHILDREN

Since the economic reforms of the 1980s, families with disabled children have faced increased socioeconomic vulnerability and pressures. Former sources of (limited) support from work units or collectives have been eroded, particularly the practice of providing employment in the parents' work unit upon adulthood. The one-child policy and increased opportunities to make money for those with ability (*nengli*) have intensified parental hopes for their children, making diagnosis of childhood disability even more devastating.

Having a disabled child is seen as a major misfortune for the household as well as the child, whose own prospects for making a decent living, having a family life, and supporting parents in old age will generally be diminished. For the household, it signifies reduced productive labor, including from family members required to provide care; damaged social standing and perhaps damaged marriage prospects for nondisabled siblings; and increased costs of seeking medical treatment. Family and societal expectations to seek a cure are very high. The search begins locally, can last for years, and takes families far from their homes, with rural families traveling to the cities to get the best help they can afford. Parents take on additional jobs, sell their assets, and incur debts. Both Chinese and Western medicine are used, doctor-swapping is expected, and diagnoses of incurability may go ignored for years. Advertisements promising cures for deafness or paralysis add to the pressures, but a cure is seen as the best guarantee of averting the poverty that, as the saying goes, is bound to follow disability (*fengcan biqiong*).

Abandonment is illegal but still occurs for girls (nondisabled and disabled) and for disabled boys, despite permission to have a second child if the first child is disabled (the government also operates relaxed rules for domestic and foreign adoption of disabled children). The practice of keeping a disabled child hidden at home has reduced with increased educational opportunities (since 1994, schooling has been compulsory for disabled children). Notwithstanding, many parents are highly protective and may restrict the extent of interaction that their children, including adult children, have in the local community for fear of abuse or being taken advantage of. In urban and some rural areas, children with mild physical impairments access mainstream schools; children with visual or intellectual impairments and deaf children attend segregated schools or classes (Alison Callaway has done an insightful study of Chinese deaf children, their families, and education). In poorer areas, school is a luxury for parents, who may struggle to pay the fees, although some families prioritize education for their disabled child.

ADULT PERSONHOOD

Work and marriage are the central markers of personhood in China. How far disabled people attain these is often shaped by gender, impairment, and location.

Opportunities for mainstream employment are limited. Even the tiny number of high-achieving disabled graduates has encountered serious difficulties in getting a job, due to negative employer attitudes in a highly competitive labor market. Most state and private employers prefer to pay a fine than comply with the quota system of 1.6 percent disabled employees. There is evidence from welfare and commercial enterprises of disabled people on the payroll who have been paid to stay at home, often against the wishes of disabled people who want to work. Around 1 million disabled people work in social welfare enterprises (sheltered employment provided in factories or local workstations). However, a qualitative study by Pearson, Wong, and Pierini on the employment experiences of young adults with learning disabilities suggests that welfare enterprises are struggling despite tax relief (in Guangzhou Province a drop from 3,113 welfare enterprises in 1995 to 394 in 1999) and that low-waged, low-status work and phantom employment frustrate young people's ambitions to work and contribute to the family income, and thereby attain adult status.

In cities, more disabled people are becoming self-employed, perhaps assisted by vocational training, tax relief, and/or permission to buy a three-wheeled welfare-motorbike that can carry a passenger or goods. Often disabled people work in basic-level and stereotyped jobs (visually impaired masseurs or piano tuners, appliance repair, tailors, data entry, packing, cleaning). In poor rural areas, prospects are bleak for disabled adults whose impairment reduces their ability to do physical work or join the so-called floating population of 100 million migrant men and women who leave the countryside to find work in the cities and Special Economic Zones.

Economic self-reliance increases marriage prospects but is no guarantee. A complex hierarchy of attributes comes into play: gender, type and severity of impairment, whether impairment is congenital or acquired, residence (rural/urban), education, family status, and background. While Chinese men are more likely to be never married than Chinese women, the incidence of never-married disabled men is dramatically higher than among disabled women. Matthew Kohrman's analysis of the experiences of middle-aged men with a wobbly gait (mostly polio survivors) attributes this to the smaller gap perceived to exist between the female disabled body and dominant constructions of female personhood (at home, bringing up children), compared to that between the male disabled body and constructions of manhood (out of the house, mobile, active).

Hierarchies of normalcy intersect with gender, location, and education to shape what makes an appropriate match. For example, an urban disabled woman might be expected to marry a nondisabled man but he would probably be from the countryside with lower education. Deafness and intellectual impairment may be less stigmatizing in rural than urban areas, and for women than men, reflecting the different ways in which livings are earned and social status acquired. The process of marriage exclusion can be protracted and painful, particularly for disabled men. For disabled women, finding a (nondisabled) spouse may be easier but little is known about the quality of their marriages and incidence of domestic violence.

IMAGES AND IDENTITY

The China Disabled Persons' Federation has endeavored to improve public images of disabled people, showcasing entrepreneurs, athletes, and artists who have contributed to China's economy and international standing. There has been a proliferation of manuals, magazines, research, and creative writing, including by disabled people (Shi Tiesheng is one of China's most popular writers), and also films such as *Beautiful Mama* (1999) starring internationally acclaimed Gong Li as a divorced mother putting her deaf son through mainstream school. All challenge negative attitudes of disabled people as worthless (*canfei*). They also put ordinary disabled people under intense pressure to demonstrate their worth and aspire to be better than so-called healthy or normal people.

There are signs of shared identity among some strata of disabled people. Kohrman has written about identity and brotherhood among urban men with physical impairments; there is an emerging Deaf cultural community; there is increasing collective action among parents of disabled children, ready to set up support groups and services where permitted. The extent to which disabled people and families identify with the China Disabled Persons' Federation and the term *canji* (disabled) is likely to reflect what the individual can expect to gain. Parents may delay registering their child as disabled in case this restricts access to mainstream school. In contrast, growing numbers of disabled men register to get help with starting a business or a license to drive a three-wheeled welfare-motorbike. Some commentators are pessimistic about the scope for civil society and a grassroots disability movement in the People's Republic of China. Certainly, this is unlikely across much of China where basic needs preoccupy families and local governments, and where strong legacies of negative attitudes act against individuals and families acting to draw attention to themselves. But among urban élites, as domestic and international networks expand and as more disabled children finish school and college, supported by family and friends, there is cause for cautious optimism.

—Emma Stone

See also Advocacy, International; Confucius; Cultural Context of Disability; Disability in Contemporary China.

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China Disabled Persons' Federation, http://www.cdpf.org.cn/english

EXPERIENCE OF DISABILITY: COLOMBIA

Colombia is a country in South America, in the northwestern part of the continent, south of Panama. The capital and largest city of Colombia is Bogotá, with a population of about 7,000,000. In 2001, the total population of Colombia was reported at about 43,000,000, with 73 percent of the population living in urban areas. The majority of the country's population is young; 54 percent of the total (18 million people) under 18 years of age. Life expectancy at birth for the overall population is 72 years. It is estimated that about 95 percent of the population is Roman Catholic. Religion has played a critical role in how disability is perceived. Some view disability a punishment from God. Others see it as a challenge imposed by God to prove one's faith and courage. Children with disabilities are often hidden from public view, in part because of family members' shame, guilt, and lack of education about disabilities. This entry covers incidence of disability, current disability laws and policies, living conditions for people with disabilities, and current efforts to address disability concerns.

INCIDENCE OF DISABILITY

The 2003–2006 Plan Nacional de Atención a las Personas Con Discapacidad (National Plan of Attention to Persons with Disabilities) estimated that 18 percent of the general population has some type of disability. However, the government recognized the difficulty in having an accurate estimate due to the lack of adequate methods to conduct a census in rural areas and families displaced by violence and insurgency. It is also difficult to assess the characteristics of the homeless population. Moreover, there is a tendency for families experiencing shame not to report the presence of a family member with a disability. It is estimated that of those identified with a disability, 68 percent have sensory, physical, and/or cognitive impairment; the majority experience blindness, deafness, paralysis, and/or loss of limbs. It is estimated that 12 percent of people with disabilities are under 14 years old and 27.6 percent are over 60, and that over 60 percent of people with disabilities are males. Disability in the infant population is mostly due to prenatal, congenital, or infectious conditions. Young male adults also experience a high rate of disability, mostly associated with injuries, accidents, and the current violence and guerrilla war.

CURRENT LAWS AND POLICIES

In 1991, Colombia promulgated and passed into law a new constitution, which was intended to recognize and protect the rights of people with disabilities. The adoption of the new constitution provided a national policy in which people with disabilities had opportunities for social participation in the areas of education, communication, health, well-being, work, transportation, information, sociocultural development, and recreation and sports. Specific policies that were enacted included entitlement programs to assure benefits to eligible disabled individuals and discretionary grant-in-aid programs. In addition, supplementary financial assistance was approved to support specified activities for people with disabilities, and incentives (appropriations bills, tax legislation, and loans) are provided for covered entities to comply with the existing regulations regarding the rights of people with disabilities. Examples of these regulations include access to local and nationwide television channels, as well as access to sport activities through the Paralympic Federation. Much of the new constitution of 1991 focused on general rights and social and recreational programs with little or no emphasis in the areas of education, housing, employment, public accommodations, and transportation.

In 1997, the government passed the General Act for People with Disabilities also known as the Disability Act: Law for Opportunity, which includes five titles covering basic rights, education and rehabilitation, social welfare, accessibility, and transportation and communication. The implementation of these national policies is coordinated by the Ministry of Health and the year 2000 budget allocation was US$3.6 million. Yet many people with disabilities are not aware of the law, the national plan, or of their benefits. As of 2001, Colombia had 37 disability-related legal policies. The majority of these regulations are national civil rights statutes that provide people with disabilities with human rights and liberties, such as the protection against discrimination based on one's disability. Despite the existence of these laws, the government provides limited spending on programs that protect the rights of people with disabilities, and the lack of enforcement of disability rights is a major concern.

DAILY LIVING CONDITIONS

In the areas of daily living, people with disabilities face a number of barriers and challenges. People with disabilities are often marginalized in employment, education, and housing. Colombia has faced an economic crisis and guerrilla violence since the 1950s. These problems have led to an overall unemployment rate close to 25 percent as of 2003, the highest in its history. As a result, many young adults and families with small children sell goods on the streets. With such conditions, people with disabilities are not a priority when it comes to job placement, and as a result, 80 percent are unemployed. It is not unusual for individuals with physical disabilities to become street vendors.

In the area of education, access to free elementary education is available and much effort has been devoted to eliminating illiteracy. However, children with disabilities are often rejected by public and private schools resulting in a high rate of illiteracy. Forty percent of people with disabilities are illiterate. These rejections result from lack of accommodations, lack of accessibility, and lack of trained teachers to assist children with disabilities. Upper-class families with children with disabilities often send their children to expensive private segregated schools for children with special needs. A limited number of public educational centers are available for children with disabilities, and such centers often face funding problems.

Housing is an area in which people with disabilities face many challenges. In Colombia, public and private funds to remodel and accommodate homes to meet the needs of people with disabilities are not available. Most people with physical disabilities depend on family members to move around and to have their needs met.

In terms of welfare benefits, the only disabled people in Colombia who receive a pension are either military personnel who become disabled while on duty or insured workers who become disabled while on the job. No other individuals with disabilities receive pensions, social security, or health care coverage. There is no welfare system to assist them.

Accessibility around Colombian cities and small towns can also be challenging because many are more than 400 years old. Small rural villages and towns are not wheelchair accessible, since streets are often made of dirt, stones, or gravel. Furthermore, only people with disabilities who come from wealthy families have access to technology (e.g., adapted computers to communicate) and equipment (e.g., power wheelchairs) that they import, mostly from the United States.

Some efforts have been made to increase accessibility and mobility in the large urban areas such as

Bogotá. For instance, the new public transportation system, Trans Millennium, involves a system of rail buses that provides fully accessible transportation for people with physical disabilities including ramps and wide accessible entrances. This system is one of the first accessible transportation systems in Latin America. In large urban areas, most streets have curb cuts and most modern buildings have elevators.

CURRENT EFFORTS

Another component of the 2003–2006 National Plan of Attention to Persons with Disabilities has been to develop community awareness efforts throughout the country. These awareness efforts include marathons with the participation of the general population to raise money for educational programs for children with special needs, Special Olympics, new organizations such as ASCOPAR (Colombian Association for the Development of People with Disabilities), and media awareness campaigns to stop the use of negative language and characterization of people with disabilities. Some programs have gained national recognition such as Foundation Teletón, the Foundation for the Development of People with Disabilities, which sponsors rehabilitation and recreational programs for people with disabilities. DAVIDA (Give Life) was created by a mother of a child with a disability and provides comprehensive services for children with disabilities at one center.

Despite current laws and efforts to protect the rights of people with disabilities in Colombia, much remains to be done to further the implementation and enforcement of existing laws and policies.

—Yolanda Suarez-Balcazar
and Adriana Gonzalez

See also Advocacy, International; Poverty.

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Disability Act: Law for Opportunity, www.discapacidadcolombia.com

EXPERIENCE OF DISABILITY: COSTA RICA

As many other countries, Costa Rica has been influenced by the traditional, medical, and rehabilitation models that led societies to consider a disability as a “problem” and the person with disability as the cause of that problem. Those models reinforced the view of people with disabilities as dependent, ill, incompetent, limited, or even subnormal. The concept of being “normal” is a fallacy that still persists in the imagination of those who are not aware that being different is in fact being “normal.” The purpose of this entry is to share with the reader a descriptive analysis of the experience of living with a disability in Costa Rica.

During the past decade, the experience of disability in Costa Rica has been changing, an ongoing but slow process. Quantitative as well as qualitative changes have had an important impact on the public and private services offered by various sectors of the Costa Rican society such as education, health, employment, culture and recreational activities as well as the accessibility to information and communication. Considering living conditions from a human rights development perspective and the increasing participation of disabled people and their families’ organizations have contributed to these changes.

The social and economical context in which the majority of people with disability live in Costa Rica, in many cases conditions of extreme poverty, has influenced the quality of life of disabled people and is still limiting their access to services particularly in their own communities and in rural areas of the country. Furthermore, these economic limitations have definitely interfered with the efforts being made in terms of legislation and the promotion of human rights and opportunities. Despite all the actions taken to change attitudes and awareness about the needs of disabled people, experiencing disability in Costa Rica is closely related to and cannot be separated from economic and social development.

> After a half century of economic performance that was well above average for the region, Costa Rica has begun to experience a significant slowdown. The worsening economic situation is reflected in a stagnant poverty rate, which has remained constant at 21% over the last eight years, and an increasingly large gap in the distribution of income between rich and poor. (National Institute of Statistics and Census 1998)

According to the Ombudsman Office, the population with disabilities is among the most excluded sectors of Costa Rican society. Two surveys provide data about the general population and the percentage of disabled people. The Multipurpose Household Survey, conducted in 1998, reported that the population of the country totaled 3,340,909, of whom 261,371 persons, approximately 8 percent, had a disability. The National Census included for the first time information about disabled persons, and it reported that the total population was 3,810,179 and persons with a disability were approximately 5 percent of the general population. The difference in percentages was interpreted as methodological, since there are factors such as how disability is understood by the interviewers and who provides the information.

Based on the country’s economic conditions, there is no doubt that the social model, as it applies to disability experience in Costa Rica, inevitably leads us to concentrate on the priorities established by the government regarding social policies, the provision of additional funds to provide accessible services, and the inclusion of specific indicators related to disability experience as an effective measure to monitor the national development with regard to disabled people’s lives.

One of the turning points, during the past decade, was the approval of the Law 7600 in May 1996, called Equal Opportunities for People with Disabilities in Costa Rica. Before the existence of that law, there were already various projects presented by members of the General Legislative Assembly and the Costa Rican Parliament, and there was already a long list of demands presented by disabled people and their families at the Ombudsman Office, most of them related to lack of access to buildings, services, and educational accommodations.

The law was also inspired by the United Nations Standard Rules on the Equalization of Opportunities for Disabled People, published in 1993 by the United Nations and prepared by a group of experts who were people with disabilities themselves. The General Legislative Assembly in Costa Rica ratified this document. Even though the Costa Rican National Constitution guarantees the same rights to all Costa Rican citizens, it became obvious that these rights with regard to disabled citizens were not guaranteed on an equal basis with others.

Disability experience in Costa Rica has been definitely transformed in many areas as a result of the mandates of this generic law. There is no question about the fact that people with disabilities and their families in Costa Rica started to use this legal instrument as a strategy to empower themselves and to become aware of their rights as well as understanding the role of the state in accomplishing its responsibilities.

Education has been historically a priority for the Costa Rican government, and a significant part of the national budget is invested in education in general. Traditionally, as in many other countries disabled students have received their education in special schools. The first special school in San José was opened in 1940, and many young disabled people ended their education process in vocational training programs offered in sheltered workshops, some of them administered by nongovernmental organizations.

Even though access to educational programs was mainly offered in special settings, an increasing number of disabled students are attending regular primary and secondary schools as well as regular schools at the higher education level. According to the implementation of the law, support services have to be provided at all levels and modes of education, from early stimulation programs up to higher education. Support services include access to the curriculum as well as curriculum accommodations.

Experiencing disability in the Costa Rican educational context is still a continuous and great challenge for the national educational system, public and private. At present, one of the main educational barriers for young students and adults with disabilities seeking to finish their studies is the lack of professional resources, mainly educators who are trained specifically to teach students at the secondary or adult level. In a special report from the Ministry of Public Education, presented to the National Council of Rehabilitation and Special Education (CNREE), the national institution responsible for monitoring institutional progress in the field of disability, it was stated that "the model of teaching students with disability-related educational needs has shifted towards a new model that aims at providing schooling opportunities in less restricted environments" (Ministry of Public Education 2002). Presently, the diversity of programs in education include special schools, integrated classes in regular schools, and support services specialized in different disabilities. Teachers working in these services work together with the regular teachers so that the education program responds to the special educational needs of the students based on the regular curriculum.

The Statistical Department of the Ministry of Public Education indicated, based on growth rates in 2000–2001, that there were approximately 79,600 students with educational needs related to different disabilities attending regular classes in 2002. The majority of students with disabilities have access to regular education classrooms, but some are receiving their education in special classes located in regular schools or special schools. It was reported in 2002, by the Department of Special Education of the Ministry of Public Education, "Students with special educational needs comprise about 10.13% of the total number of students. Thus, out of a student population of 937,154, there are approximately 95,000 students with disabilities" (Ministry of Public Education 2002).

The transitional stage from education to work remains a challenge for professional training as well as for some nongovernmental organizations administrating sheltered workshops with a very low budget and little technical support. Systematic efforts have been made recently to provide access to technical education for young people to increase their competence at applying to jobs. For example, the National Institute for Learning (INA), which offers educational opportunities for all people in many regions of the country, has been putting into practice a variety of measures such as providing curriculum accommodations for people with intellectual disabilities who traditionally have been segregated from such programs.

Higher education for students with disabilities is mainly offered by public universities. Most disabled students are concentrated in public universities. Some private universities have started to introduce services for disabled students. There are four public universities that have been working together in a special committee to share experiences on accommodations and to prevent discrimination acts against students. Support services offered by these universities to students include sign language interpreters in classrooms, Braille printing, tutoring, text recording, note taking, and access to computers by training students on the use of text reading software, which is taught by a blind student. Deaf instructors offer courses on Costa Rican Sign Language (LESCO), and the national association monitors the quality of education for the deaf. It should be highlighted that during the past few years more disabled students have enrolled in various graduate programs, such as linguistics, law, project evaluation, and interdisciplinary disability studies.

Access to employment it is still a challenging experience for people with different disabilities, mainly for people with intellectual disabilities. Even though Law 7600 refers to specific measures to be taken by the Ministry of Labor, it has been very difficult to put them into practice. The ministry's national director of employment acts as a facilitator to contact potential employees, but this process seems to be very slow. It was reported by the Ombudsman Office (1999) that "only 15 disabled workers were hired." This office also promotes self-employment and the development of small businesses; however, people with disabilities often cannot meet loan requirements and therefore their opportunities are limited. The National Council on Rehabilitation and Special Education offers loans through a rotating fund so that people with disabilities can initiate their own businesses.

Recently, some positive actions have started to promote access to employment. A special unit was established to facilitate accessible conditions as an incentive to public institutions and the private sector so that they hire disabled employees. Some organizations of disabled people have estimated that the unemployment rate among this population is approximately 65 percent. This situation means that many disabled people and their families live in a constant struggle to survive and have limited participation in society.

Health services in Costa Rica are available through a public health system; a public institution, the Costa Rican Social Security Fund, also covers rehabilitation services. These are mainly offered by the National Rehabilitation Center (CENARE), a hospital located in San José, the capital of Costa Rica, and the National Psychiatric Hospital, which provides temporary and permanent services to people with mental disabilities.

General health services are available in regional hospitals and clinical settings, and recently there has been a new development, Comprehensive Health Care Units, called EBAIS, which have been located in urban as well as rural areas of the country and cover smaller communities. Some of these units are training their personnel to support disabled people in their communities.

Though there is a large coverage and access of people with disabilities to the general health system, rehabilitation services are not available at the community level and not all the infrastructure is accessible. Another important limitation of the system is the limited provision for technical aids and assistance devices, which according to Law 7600 should meet the requirements of disabled persons. In some cases, wheelchairs are provided by private organizations as part of a social welfare program, reinforcing the traditional view of disability and not as part of the obligations of the state or as a human right.

Other areas covered by the law include access to housing, buildings, transportation, information, communication, and recreational activities. The inclusion of accessibility as part of public life is a slow process. According to the law, new buildings have to be designed to meet accessibility requirements in order to obtain the construction permission given by the government. The concept of universal design is not yet incorporated into construction planning, and professionals working in this field are starting to be trained with regard to accessibility guidelines.

In some cases, accessibility is considered during the process of designing but is not well implemented or supervised by the government. Since San José and other regions of the country had not been planned to be accessible, it is still very common to find partially accessible places, where there are ramps to access the first floor but no elevators or accessible bathrooms. There is an increasing effort from the private sector to build accessible hotels and to offer accessible facilities in restaurants and shopping areas. A project provides guidelines to National Parks to have pathways and signals accessible for visitors.

Public transportation is starting to become accessible. The National Council on Rehabilitation and Special Education has negotiated with private enterprises and the Ministry of Public and Transport to start accessible services with a percentage of their units and routes and continue increasing these services until all buses are accessible. According to Law 7600, 10 percent of the taxis must be accessible. Many drivers who are interested in this kind of service have already obtained registered plates but are unable to obtain vehicles to operate because of their high cost. There is still much to be accomplished in terms of public transportation. Drivers should become aware of the needs of all people including persons with different disabilities and be trained on how to properly provide this kind of service.

As a general consideration, it becomes obvious that experiencing a disability in Costa Rica is relative to the living conditions and opportunities of all Costa Rican citizens. All the social and economical policies that affect the majority of people in this country have an impact on the quality of life of disabled persons. Nevertheless, the results during the past decade show systematic progress toward improving the living conditions of disabled people in Costa Rica and the continuing efforts toward including their particular needs, such as access to education, health, work, housing, transport, and recreation, as part of the national development planning. A crucial factor to accelerating this process is the pressure and participation of an organized movement of disabled people as a way of vindicating their human rights. Universities have an essential role in promoting access and supporting disabled students but also should educate all professionals with regard to their attitudes, knowledge, and skills necessary to develop an accessible society.

—Roxana Stupp Kupiec

See also Advocacy, International; Education, International; Housing: Law and Policy.

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EXPERIENCE OF DISABILITY: INDIA

The history of experiences of disabled people in India has never been recorded systematically. It would be unwise to generalize disability experiences because they are contextualized in a culture and region that is very diverse in a country the size of India. There is a dearth of historical investigation and resources. What little is available is archived in the interpretation of folk tales, mythology, special education, social welfare policy, and the Hindu and Islamic religious texts and other scriptures. An analytical study of these sources exhibits the following characteristics. First, in urban settings where it is being recognized that disability is an issue of development and rights, there has been a remarkable change in attitude toward disabled people. This change has come in the past 10 years, partially due to globalization and the self-help movement of disabled people. Second, Indian scholars tend to interpret disability experience in the context of mythology and other historical sources, viewing it as a result of as extreme neglect, past sins, or evil epitomized in the crooked body. Third, in the precolonial period the attitude of religious charity existed and care and welfare of disabled people were the responsibility of families, the state, and religious institutions. Fourth, archival evidence suggests that disabled people did not enjoy an equal status and were denied the opportunity of education and development. Attention to their education started with the emergence of Christian missionaries in the colonial period. Fifth, the level of acceptance, discrimination, and stigma varies with the type of disability, its onset, family's educational background, and also the region.

References to disability can be found in the two prominent mythological epics, *Ramayana* and *Mahabharata,* which form the basis of societal responses to disability and help in exploring the meaning of disability in India. A study of disabled characters in these texts demonstrates, on one hand, acceptance of disabled people in positions of power (although marginally); on the other hand, these images go a long way in perpetuating the idea of equating disability with evil, weakness, and inflicted as a form of punishment. In *Ramayana,* Manthra—Queen Kaikeyi's (consort of King Dasaratha) favorite maid—though hunchbacked, enjoyed an exalted status. However, she is held responsible for the exile of Lord Ram—heir to the throne after King Dasaratha—by her machinations. Another episode is that of Shurpanakha, the she-demon. She was Ravana's (the chief antagonist) sister who had eyes on Rama and wanted him for her husband. On sensing that Rama was not interested in her, she pounced on his wife Seeta, upon which his younger brother Lakshmana cut off her nose and ears and thus defaced her.

In *Mahabharata,* King Dhritrashtra of Hastinapur is blind. But he is a weak ruler and his status is used as a rubber stamp by his sons called *Kauravas.* The episode of Bhagwad Geeta (holy text of Hindus) in this epic sets the code of conduct for rulers to follow in their treatment of the disabled. It prescribes that people with visible disabilities such as being blind, crippled, or otherwise deformed, and especially the war veterans and their dependents, should be treated with sympathy and care. Bhagwad Geeta also establishes the rules for practicing charity and lays down the theory of good and bad karma (deed)—that disability is a result of moral sins committed in former life. It further prescribes the forms of charity—*artha* (money), *vidya* (education), and *abhaya* (courage). There is evidence that charity of *artha* was practiced generously but other forms of charity, that is, of education and courage, were rarely followed. It can be said that although disability was a social construct, it was not seen as such. It was perceived more as an economic problem and therefore remedies were provided in the form of charity. In this way, disability was intricately associated with poverty. The solution was seen more in terms of handing out doles rather than empowering them with education and other skills. The dictates of Manu—the ancient Hindu lawgiver—in his work Manusmriti, written between 200 BC and AD 2 and translated into English from Sanskrit in the colonial period, exhibit a dichotomy. On one hand, he lays out that those who are afflicted should be given food, clothing, and shelter, and be exempt from paying taxes; on the other hand, he refuses to give them the right to social equality since he deprives them from inheriting property and occupying any position in the decision making. In the rules for householder, he prescribes that he should "wed a female free from bodily defects." He treats physically and mentally disabled people, women, people of low caste, and aged at par with insects and dogs.

Thus, in ancient India, disability was believed to be a consequence of actions done in past or present life. This was corroborated even by the medical works such as *Charaka Samhita* (an authoritative book on the Indian system of medicine). The folk tales and ballads of Bengal, on the other hand, also hold mothers responsible for producing disabled babies. There is no evidence of the neglect of disabled people by the families, caste, and rulers; however, there definitely are images of blind beggars in folk tales and ballads. They also give evidence of blind people as talented musicians, singers, and poets. This has gone a long way in keeping the visually disabled out of the purview of other vocations. Even in independent India, the government jobs reserved for the blind in several states have been those of music teachers.

The position of disabled people improved in the reign of Maurya Dynasty between 322 and 299 BC. During this period, Buddhism and Jainism emerged as a powerful influence. They emphasized the virtues of nonviolence, charity, truth, purity, selfless service, and compassion to the disabled. For the first time, vocational rehabilitation for the disabled was looked at in ancient India. Kautilya, the prime minister of Chandragupta Maurya, wrote a manual for administrators and politicians called *Arthshastra,* where he called on them to employ dwarfs, the hunchbacked, and otherwise deformed people as political spies as well as secret agents in the royal palaces. In the reign of Ashoka, medical rehabilitation also started.

In medieval India, between the thirteenth and eighteenth centuries, the Mughal rulers continued with the practices set by their Hindu predecessors. They strictly adhered to the five *rukans* (duties) enshrined in the holy Qur'an, one of them being *zakat* (charity). As Mani describes,

> The forms that this charity took were: alms to the poor and the infirm: construction of mosques, rest-houses, erection of ponds, hospitals and orphanages. The Mughals had a special department with a head (sadr) to supervise charities and endowments. During the reign of Emperor Akbar, the benefits of such charitable institutions were extended to include even the non-Muslims.

The period of India's colonization by the British is seen by scholars as the beginning of the era of institutionalization of disabled. Prior to this there was no concept of educating and institutionalizing them and family was still the primary caregiver. It was seen more as an infringement and an attempt to break the traditional systems. They promoted a culture of custody rather than care. Special education institutions for the hearing and visually disabled were established in 1880s in Mumbai and Amritsar, respectively, by Roman Catholic missionaries. If, on one hand, the advent of colonial rule in India resulted in the creation of segregating environment for the disabled, on the other hand, it also helped in the formulation of welfare policy, which included disability. The first census of disabled people also commenced in this period—a practice that was discarded in the postcolonial period and restarted in 2001 after a lot of agitation.

The modern disability movement in India began in the early 1990s. The responses to disability by the government and society prior to this were more in terms of catering to the medical, rehabilitation, and welfare needs of disabled people. Disability groups had started organizing themselves and groups of visually disabled took the lead. They were successful in getting reservations for themselves in education and government employment, tax concessions, and travel concessions. Other disability groups also started demanding similar benefits and entitlements. Their demands were accepted, but they were more a piecemeal measure. They were not entitled to any benefits as a matter of right. Cross-disability groups started joining hands in the early 1990s to demand for a comprehensive disability rights legislation and protection of rights. After a prolonged struggle, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act was finally passed by the Indian Parliament in 1995. The enforcement of this act has brought some change in the experiences of and responses to various categories of disabled people in India, especially in the urban areas. According to a Cross-Cultural Applicability Study conducted in Bangalore, Chennai, and Delhi—three metropolitan cities of India with high rates of literacy—mental disability, HIV/AIDS, and substance abuse remain the most stigmatizing, and mobility impairment and blindness are the least stigmatizing. Provision of accommodations for the disabled in the physical environment—for example, by construction of ramps—is at a very basic stage. Awareness among the general public, judiciary, government, and disabled themselves regarding their rights is gradually increasing. Employment and accessibility are the crucial issues that are being raised today. Little attention has been paid to the issues of disabled women. Overall, though, Indians still see support to disabled as a matter of charity and an act of kindness rather than a development and human rights issue. In the absence of any substantial archival material, it is difficult to map the experiences of disabled people in India. However, it could indicate the areas of future research.

—Meenu Bhambhani

See also Disability in Contemporary India; Economic and Social Development, International; Education and Disability; Housing: Law and Policy; India, Impact of Gender in; India, Marriage and Disabled Women in.

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EXPERIENCE OF DISABILITY: IRELAND

PREVALENCE OF DISABILITY

Over the past 20 years, there have been repeated criticisms about the lack of reliable data on disability in Ireland. Since the late 1990s, the Irish Health Research Board (HRB) has undertaken the measurement of the numbers of people with intellectual disability and those with physical and sensory disability in Ireland. In 1995, the HRB began compiling the National Database of individuals with intellectual disability in the country. The HRB is also currently compiling the Physical and Sensory Disability Database, which will be used for planning developments and prioritizing service needs. A recent report shows that there were 26,668 people registered on the National Intellectual Disability Database in 2001, representing a prevalence rate of 7.35 per 1,000 of the population. The report noted that the total number with more severe levels of intellectual disability has grown by 31 percent since 1974 when the first census of this population was conducted. This increase is attributed to the general population increase over the period, improved standards of care, and an increase in the lifespan of people with intellectual disability.

The report also shows an increase in longevity in those with intellectual disability with those ages 55 years and older, who now represent 11.3 percent of all those with intellectual disability in Ireland. However, a most significant change is the large increase in those with disability currently in the ages 34–54 group. This cohort has now grown from 19 percent of the overall population of those with intellectual disability in 1974 to 32 percent of the overall population in 2000. The impact of this aging population of people with intellectual disability has major implications for service planning and provision. It is likely that data compiled on numbers of people with physical disabilities will show similar patterns of increased life expectancy.

NONGOVERNMENTAL ORGANIZATIONS IN SERVICE PROVISION

A unique aspect of the provision of services to disabled people and their families in Ireland is the major role played by voluntary (nongovernmental) organizations in the development of services for those with disability and their families. The growth of such organizations is often derived from the work of individuals, concerned groups, and religious orders trying to address gaps in state service provision. Other disability services have evolved from other medical services founded to respond to specific medical situations such as the tuberculosis epidemic of the 1940s and a serious outbreak of poliomyelitis in the late 1950s. Some voluntary organizations address the specific needs and issues of a single condition such as cystic fibrosis, muscular dystrophy, or multiple sclerosis. Fewer, larger organizations encompass a wider range of disabilities in their brief such as the Irish Wheelchair Organization for adults with a variety of physical conditions that impact on their mobility. Services for those with intellectual disability are also largely provided by voluntary organizations and are provided primarily on a geographic basis to individuals and their families.

Traditionally, Irish voluntary organizations have played both a pioneering and a reactionary role in the development of services for people with disabilities. They have also played a key role as pressure groups, trying to keep the issues of a particular condition or the situation of people with a range of disabilities on the political agenda. In the absence of state provision, they have played a major part in creating and providing a wide range of health and personal social services such as physiotherapy, occupational therapy, speech therapy, social work, family support, and respite care. Voluntary organizations rely on a combination of state funding and resources raised from fund-raising. Over time, state funding has become an increasingly significant factor in service provision, and the laissez-faire arrangements for such funding have been replaced by contractual agreements between the statutory payers and the voluntary providers in which the respective obligations of accountability and transparency are defined.

ACCOMMODATION

In Ireland, many of those with disability were traditionally cared for in residential facilities, but from the 1980s, Ireland has followed international trends in deinstitutionalization and community-based care. However, the ideal of care in the community in which those with disability can live a full, inclusive life, nurtured by those around them, has never been fully achieved and many disabled adults live long-term in the family home. The provision of home-based support services is underdeveloped and, as a result, parents still approach old age without the reassurance of alternate services when they can no longer take care of their child. From the viewpoint of disabled adults, scarcity of alternative accommodation can limit life choices and some may only leave home on foot of a crisis, primarily the illness or death of a parent. While respite provision and some supported independent living accommodation have been provided, they are inadequate to meet current needs.

EDUCATION

Education for people with disability in Ireland is provided in a mixture of mainstream and special schools. Over the past decade, the number of disabled children in mainstream education has increased while the numbers attending special schools has remained constant. In 1990, two landmark legal challenges were instigated that highlighted a lack of any education for children with severe and profound disability. The first of these, the *O'Donoghue* case (1994), resulted in many children with severe and profound intellectual disability being granted the right of a formal education for the first time. In the second (*Sinnott v. Minister for Education* [2001]), the Supreme Court held that the state's constitutional obligation to provide for free primary education ceased at the age of 18. Both of these cases attracted much public attention and pressurized the government into reviewing its education provision to disabled pupils. Many of these reviews have been integrated into aspects of the Education Act (1998) and the Education for Persons with Disabilities Bill (2003). The Education Act requires schools to provide education to students that is appropriate to their abilities and needs. It specifies that a school must use its available resources to ensure that the educational needs of all students, including those with disability or with other special needs, are identified and provided for. However, the level of actual provision leaves a gap between aspirations and reality and the paternalistic approach to the educational provision for people with disabilities has been attributed to the continuing dominance of the psychomedical model.

EMPLOYMENT

Since 1977, the Irish public sector has had a 3 percent quota program for people with disabilities, which has never been fully realized. This quota does not apply to the private sector where efforts to secure jobs for those with disability have concentrated on facilitating and encouraging employers to take them on voluntarily.

The Irish Employment Equality Act (1998) is based on the principle that all individuals are entitled to equal treatment in training and employment opportunities regardless of gender, marital status, family status, sexual orientation, religious, age, disability, race, or membership of the traveling community. The 2002 annual report for the Irish Equality Authority (Irish Equality Authority 2003) noted that that the number of employment equality claims brought by disabled people discriminated against by the public/semi-state sectors at the point of access to employment has been striking. The report notes that the effectiveness of the Employment Equality Act to deter such discriminatory behavior is hampered by the low fines that employers found in breach of the act can be asked to pay. Put simply, employers in public or semi-state organizations may prefer to pay the maximum fine of €12,700 ($12,000) at 2002 rates, rather than incur the expense of taking on a suitably qualified disabled person as an employee.

A more hopeful initiative in the area of employment and disability has been the development of supported employment programs for those with disability. These have been effective in the integration of people with disabilities into the open labor market. They are built on the principle of person-centered planning and have helped to place people with disabilities into jobs to which they are suited and that offer them personal fulfillment.

IRISH DISABILITY POLICY AND LEGISLATION

The *Report of the Commission on the Status of People with Disabilities: A Strategy for Equality* noted that people with disabilities were the neglected citizens of Ireland, many of them suffering intolerable conditions because of outdated social and economic policies and unthinking public attitudes. The report itself represented an important development as 60 percent of the membership of the Commission on the Status of People with Disabilities consisted of people with a variety of different disabilities, and carers. The result was a document that highlighted the multitude of problems facing those with a disability in Irish society, and it presents a number of policy measures to address them based on the fundamental concept of rights.

Recent European directives on employment and social inclusion have resulted in the development of new Irish equality legislation that encompasses people with disability. In addition, the period from 1998 onward has seen an unprecedented focus on the need for specific legislation on service development for people with disability. This was first addressed in the Disability Bill (2001) published on December 20, 2001. Many hoped that this new legislation would offer Irish disabled people and their families a rights-based piece of legislation on a par with the Americans with Disabilities Act. However, the bill was met with a storm of protest over the government's perceived failure to underpin the rights-based approach in the bill that had been advocated in the *Report of the Commission on the Status of People with Disabilities* (1996). Particular criticism was leveled at Section 47 of the bill, which purported to deny people with disabilities the right of appeal through the courts to seek improved services or judicial redress. A number of powerful advocacy groups organized a high-level publicity information campaign. This campaign, along with a growing sense of unease about the bill from the public in general, put pressure on the government to withdraw the bill on the evening of a mass meeting in Dublin in February 2002. An extensive consultation process with interested groups was then initiated in preparation for the redrafting of the bill. The redrafting of a new Disability Bill has suffered from continuing delays. However, any new legislation is unlikely to be full rights-based and may well be limited by that frequently used qualification that services are to be provided "where finance allows." This follows the tradition in Ireland of providing services for people with disabilities on a discretionary rather than mandatory basis.

—Bairbre Redmond and
Suzanne Quin

See also Disability Law: Europe.

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EXPERIENCE OF DISABILITY: JAPAN

Experiences of disability (*shogai* in Japanese) in Japan are as unique as those in other countries. Disability movements and disability studies in Japan have developed with the strong impact of Aoi Shiba, a group that raised fundamental and radical questions about disability and society. Disability movements in Japan are vocal and work closely with other Asian and Pacific as well as international movements.

RADICAL QUESTIONS ABOUT DISABILITY AND SOCIETY

A Murder in Yokohama in 1970

In one way, disability studies as well as modern disability movements in Japan were born when members of Aoi Shiba (*aoi shiba* literally means green grass), a group of people with cerebral palsy, made their views publicly heard in 1970. It was another murder. A mother killed her two-year-old daughter who had cerebral palsy. These killings of disabled people by their parents had been happening every year. When the murder was reported, the community was sympathetic to the mother. This was a usual response. Neighbors and members of the local family organization asked the court for leniency. More than 700 neighbors signed a petition expressing sympathy to the mother. The family organization protested the city government saying that since there were no institutions or support, there was no other choice but to kill disabled children whose right to life was denied by the society. This was to be just another murder of a disabled person and another typical response from the community.

But then, something unusual happened. Adults with cerebral palsy who were members of Aoi Shiba protested against these sympathetic views publicly for the first time. One leader of Aoi Shiba in Kanagawa Prefecture wrote in August 1970 that "in today's production-oriented society, people with cerebral palsy tend to be marginalized and their rights are denied. Even their life is not taken seriously" (Yamakita 1970:1).

Platform for Action

Then in October 1970, in the newsletter of Kanagawa Aoi Shiba, the four-point platform for action titled "We Act Like This" was announced as follows (author's translation):

- *We identify ourselves as people with cerebral palsy (CP).*

  We recognize our position as "an existence which should not exist," in the modern society. We believe that this recognition should be the starting point of our whole movement, and we act on this belief.

- *We assert ourselves aggressively.*

  When we identify ourselves as people with CP, we have a will to protect ourselves. We believe that a strong self-assertion is the only way to achieve self-protection, and we act on this belief.

- *We deny love and justice.*

  We condemn egoism held by love and justice. We believe that mutual understanding, accompanying the human observation, which arises from the denial of love and justice, means the true well-being, and we act on this belief.

- *We do not choose the way of problem solving.*

  We have learnt from our personal experiences that easy solutions to problems lead to dangerous compromises. We believe that an endless confrontation is the only course of action possible for us, and we act on this belief.

The following fifth point was added in 1975.

- *We deny able-bodied civilization.*

  We recognize that modern civilization has managed to sustain itself only by excluding us, people with CP. We believe that creation of our own culture through our movement and daily life leads to the condemnation of modern civilization, and we act on this belief.

Activities of Aoi Shiba

Throughout the 1970s, Aoi Shiba campaigned successfully against the revision of the Eugenics Protection Law of 1948, which was proposed to legalize abortion based on fetal impairments, protested against the mandatory segregated education, worked successfully against the national census on disability, moved against amniocentesis for the identification of fetal impairments at prefectural hospitals, and took to the street to stop inaccessible buses.

In addition to these visible actions, they claimed that "shogai was an indispensable part of their identity." Aoi Shiba also made an effort to create its own culture, as mentioned in the fifth point of the platform. Though they did not fully succeed in this project, they have at least managed to bring the "cultural revolution" permanently into the disability agenda.

Ideas and claims of Aoi Shiba have left a strong and lasting impact on disability activism and disability thinking, leading to the advancement of the independent living movement in Japan as well as to the later formation of *shogaigaku* (disability studies).

Aoi Shiba's fundamental objection to the production-oriented society led to the critical review of the U.S. Americans with Disabilities Act of 1990 (ADA), which had much impact in Japan. Though the majority welcomed this landmark antidiscrimination legislation across the Pacific, some did not agree with the overall emphasis of ADA on integration into the market.

Also, Aoi Shiba's criticisms against women's claim of right to self-determination over abortion in general sparked the initially bitter debate in the early 1970s and later led to some collaboration between the disability movement and the women's movement. Prenatal screening in Japan is not as widespread as in other industrialized countries, partly because of the disability movement, which was informed by Aoi Shiba.

NATIONAL, REGIONAL, AND INTERNATIONAL DEVELOPMENTS

Japanese movements, which included Aoi Shiba, joined the regional and international movements in the establishment of Disabled Peoples' International (DPI) in 1981, which was the International Year of Disabled Persons, organized by the United Nations. When the UN Decade of Disabled Persons came to an end in 1992, disability movements in Japan initiated the Asian and Pacific Decade of Disabled Persons from 1993 to 2002, declared by the Economic and Social Commission for Asia and the Pacific (ESCAP) to maintain the momentum created by the UN Decade nationally and regionally. The success of the Asian and Pacific Decade, owing largely to the efforts of regional and national nongovernmental disability organizations, promoted similar regional efforts in other regions, such as Africa and Europe.

International and regional work also served as a catalyst for the formation of a unified national organization, Japan Disability Forum (JDF), in October 2004. JDF, a loose umbrella organization, includes major organizations of disabled people and their allies and serves as the national representative organization. JDF, for instance, has regular dialogues with the government. JDF focuses on the following four major areas: (a) UN Convention on the Rights of Disabled People, (b) promotion of Asia and Pacific Disability Forum, (c) national disability plan, and (d) prohibition of discrimination against disabled people and the establishment of rights legislation. These are the priority areas for the movements in Japan.

DISABILITY STUDIES

In 1995, the intellectual impact of the deaf culture movement was keenly felt in Japan with the "Declaration of the Deaf Culture," by Harumi Kimura and Yasuhiro Ichida. By its emphasis on an independent culture as well as the denial of impairment and disability, this manifesto led to rethinking of impairment and disability not only in the context of the deaf/Deaf field but in the disability field in general.

Against this background, in 1999, "Invitation to Disability Studies," coedited by Jun Ishikawa and Osamu Nagase was published. This initiative resulted in the establishment of the Japan Society for Disability Studies in October 2003 at the University of Tokyo. Ishikawa, a blind professor at the University of Shizuoka, was elected the first president.

Disability studies in Japan, with its emphasis on disability as a form of discrimination as well as a meaningful way of living, has roots in Japan at least as far back as Aoi Shiba in the 1970s and today has a critical mass of people, disabled and nondisabled, who are committed to its development.

—Osamu Nagase

See also Advocacy, International; Housing: Law and Policy.

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EXPERIENCE OF DISABILITY: THE NETHERLANDS

Many terms and definitions in the area of disability, disablement, handicap, and invalidity exist. They vary depending on the aim, time in history, context, country, and the person who is using the terms and definitions, and it is important to explain the terms and definitions used. Because the World Health Assembly of the World Health Organization endorsed in 2001 the International Classification of Functioning, Disability, and Health (ICF) for international use and urged member states to use the ICF in research, surveillance, and reporting, in this entry we use the ICF terminology and definitions. The description of the situation of persons with disability in the Netherlands in 2002 is derived from the *Report on the Disabled* 2002. This report is published every two years at the request of the Ministry of Health, Welfare and Sport. Many persons with and without activity limitations (physical activity limitations or mental impairments) have been questioned on their situation in different population surveys.

TERMS AND DEFINITIONS

The ICF provides a framework and a standard language for the description of health and health-related states from different perspectives: the perspective of the body (body functions and structures) and the perspective of the individual and society (activities and participation). *Functioning* is the umbrella term encompassing body functions, structures, activities, and participation. *Disability* is the umbrella term for impairments, activity limitations, and participation restrictions. The ICF lists also environmental factors that interact with all of them as facilitators or barriers.

The ICF is to be seen as a supplement to the International Statistical Classification of Diseases and Related Health Problems (ICD-10), which includes morbidity and mortality causes and diagnoses. ICF and ICD are the core classifications of the Family of International Classifications of the World Health Organization (WHO-FIC).

In Figure 1 the relations between the components of the ICF in relation to the ICD domain are reflected. Table 1 shows the key terms and definitions derived from the ICF.

In the next paragraphs, we describe the disability situation in the Netherlands by using ICF terms. The information source is mainly dealing with disability in terms of participation (restrictions) by persons with activity limitations (physical activity limitations or mental impairments) and does not include the level of body function and structure (impairments) as such. It means that we present a short paragraph on the number of persons with activity limitations, a more extensive paragraph on participation (restrictions) in major life areas, and a paragraph on the use of existing services as facilitators by persons with activity limitations.

PERSONS WITH ACTIVITY LIMITATIONS

There are currently around 500,000 people living independently in the Netherlands with severe physical activity limitations, and around 1 million persons with moderate physical activity limitations, that is, people who have severe or moderate difficulty in carrying out day-to-day tasks relating to personal care, mobility, or household activities because of a health condition. In addition, there are around 9,000 people under the age of 65 living in residential facilities and 150,000 persons age 65 and older living in residential facilities because of severe or moderate physical activity limitations. There are more than 100,000 persons with mental impairments, roughly half of whom live in supported housing.

These people, excluding persons age 65 and older living in residential facilities, form the target group for Dutch government policy on disability. The core objective of this policy is to offer effective, high-quality support that is directed toward enabling the

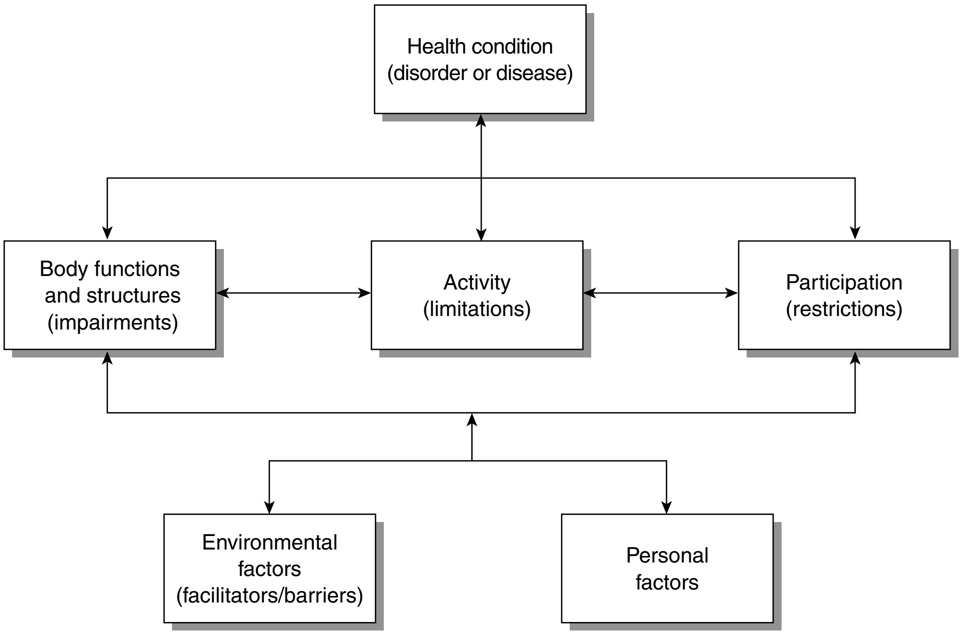

Figure 1 *Interactions between the Components of ICF*

persons with impairments and activity limitations to play a full part in society.

The next paragraphs describe the extent to which people with activity limitations (including those with physical activity limitations and with mental impairments) in the Netherlands participate in society in a wide range of major life areas (education, employment, economic life, recreation, and leisure) and how they make use of available facilitators (care and housing). The question of whether this participation and use is adequate is, however, difficult to answer, since there is no norm against which the participation of people with activity limitations can be measured. In the absence of such a norm, the social position of persons with activity limitations is consistently compared with that of people without activity limitations. Implicitly, this presupposes that both parts of the population ought to participate equally.

Participation in Major Life Areas

Education

Only a fragmentary picture is available of the school careers of people with physical activity limitations. Nothing is known about their participation in mainstream education, and they can only be partially identified from the records of the main special provisions (peripatetic support and special education). What is apparent is that pupils with moderate or severe activity limitations generally leave school with a lower level of achievement. This offers an important explanation for the relatively low participation of people with physical activity limitations in the labor market.

The amount of peripatetic support used in mainstream education has tripled since the early 1990s, and in special schools has increased by 40 percent. This growth is striking, since it is unlikely that the number of young people with activity limitations has risen so much faster over the period than the total number of young people (8 percent increase). The reasons for this growth in the take-up of provisions is not known. It may be that there was some underuse in the past, but it may also be that children with relatively slight activity limitations have begun making more use of these relatively "heavyweight" provisions.

It is also unclear to what extent people with mental impairments participate in mainstream education, though a clear trend can be seen whereby people with Down syndrome are increasingly participating in mainstream education: Today almost half of them

Table 1 ICF Key Terms and Definitions

Term	Definition
Body functions/impairments	Body functions are the physiological functions of body systems (including psychological functions). Impairments are problems in body function or structure such as a significant deviation or loss.
Body structures/impairments	Body structures are anatomical parts of the body such as organs, limbs, and their components. Impairments are problems in body function or structure such as a significant deviation or loss.
Activity/activity limitations	Activity is the execution of a task or action by an individual. Activity limitations are difficulties an individual may have in executing activities.
Participation/participation restrictions	Participation is involvement in a life situation. Participation restrictions are problems an individual may experience in involvement in life situations.
Environmental factors/facilitators/barriers	Environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives. Environmental factors may be a facilitator or a barrier.
Personal factors	Personal factors are the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states, such as: gender, race, age, fitness, lifestyle, habits, coping styles, social background, education, profession, past and current experience, overall behaviour pattern, character style, individual psychological assets, and other characteristics, all or any of which may play a role in disability in any level.
Functioning/disability	Functioning is the umbrella term encompassing body functions, structures, activities, and participation. Disability is the umbrella term for impairments, activity limitations, and participation restrictions.

Table 2 Disability in the Netherlands in 2002: Number of Persons with Activity Limitations (physical activity limitations and mental impairments)

Number of Persons	*abs 1,000*	*%*
Persons with		
severe physical activity limitations living independently	512	3.5
moderate physical activity limitations living independently	980	6.6
Persons aged below 65 living in residential facilities	9	0.06
Persons aged 65 or older living in residential facilities	150	1.0
Persons with mental impairments	103	0.7
Total persons with activity limitations	1,754	11.8

attend mainstream schools, at least for a few years. Strikingly, there has been an enormous increase in the size of the education sector for children with severe mental impairments, which has grown by 70 percent in the space of 10 years. There are no indications that the total number of children with mental impairments has grown so strongly.

One out of 10 persons with a physical activity limitation has at some time given up a course or been prevented from following a course because of their activity limitation. Almost all of them cite physical problems (pain, fatigue, absence due to illness or therapy) as the reason. They feel that adapted facilities (enlarged computer screens, adapted furniture) and the ability to follow lessons at their own pace are important conditions for their participation in education courses.

Employment

Physical activity limitations form a major obstacle to people's participation in the labor market. This is apparent from the fact that only 38 percent of people with activity limitations perform paid work, compared with 61 percent of the general population ages 15–64 years. The participation rate is even lower where people with activity limitations also have a low education level, are older, or are female.

A large body of new legislation and regulations has been implemented in the Netherlands in the past 10 years aimed at tightening up the rules on incapacity for work and encouraging more people with activity limitations to find employment. The results of these legislative changes have been disappointing: The proportion of persons with activity limitations performing paid work is still small and the number of people helped into jobs is only a fraction of the number who find employment by their own efforts.

People requiring more protection and support than the mainstream labor market can offer can seek admission to sheltered employment or day centers. Around the turn of the century, approximately 30,000 people with mental impairments were in sheltered employment and some 15,000 people were visiting a day facility for adults. Research among the users of these facilities suggests that the vast majority have a positive view of them, though around 10 percent of the parents/carers of the employees feel that the pressure of work in sheltered employment placements is too high, while roughly a third of the persons themselves would rather be carrying out activities other than those they are performing at present.

Economic Life

On average, 18- to 64-year-olds with severe physical activity limitations have a gross personal annual income that is more than €3,000 lower than that of those without physical activity limitations (€21,600 and €24,800 per annum, respectively). These income differentials occur largely because people with activity limitations participate in the labor market less frequently than people without activity limitations. At the household level, too, households in which (at least) one member has severe physical activity limitations have a lower income than households where no members have activity limitations (the difference is just under €2,000 per annum). People with mental impairments almost all have to live with a very low income.

Roughly 80 percent of people with physical activity limitations incur health-related expenses each year (e.g., for dentistry, nonprescription medicines, or their own contribution to home adaptations). These expenses average €750 per year, though can vary widely; for example, around 10 percent of persons with activity limitations spend more than €1,360 per year. It is not known what costs are incurred by people without activity limitations, and it is therefore not always possible to say that having an activity limitation necessarily leads to extra expenses.

Of people with physical activity limitations, 23 percent experience social deprivation. This means that financial reasons prevent them from doing or having a number of things that are necessary to function socially in the community (such as going out or inviting people for a meal).

Recreation and Leisure

People with an activity limitation participate in sports less often and also less frequently visit cultural or recreational amenities than people without activity limitations. The more serious the activity limitations, the greater the difference compared with people without activity limitations. The majority of people with an activity limitation see their own health status as the most important obstacle to leisure activities. They also cite the poor accessibility of buildings and problems with transport. People with severe physical activity limitations in particular are often unable to use public transport and are then forced to rely on adapted transport. Currently, around 860,000 transport provisions have been granted, almost half of which concern collective transport facilities. Local authorities are increasingly opting for collective transport; however, the fact that lots of people use these facilities does not mean that they are satisfied with them. The main complaints are that the transport often does not run on time and it is difficult to meet the requirement of asking for transport an hour before wishing to make a journey. This makes adapted transport relatively inflexible.

Roughly half of all adults with a mental impairment engage in leisure activities via an association or club. By far, the majority of these are associations that are used mainly by people with mental impairments. Around a third to 40 percent of people with mental impairments express a need to go out more. The main obstacle preventing them from doing so is lack of a suitable social network. Many are dependent on their family or carers from their residential facility, and as a result, the majority of people with mental impairments do not appear to be very socially integrated.

Use of Available Facilitators

Take-up of Care

In 1999, around 9 percent of households were receiving informal help with household tasks or personal care, while 8 percent were using private care facilities. Approximately 7 percent were receiving help from the home care services with household tasks or personal care. This figure is somewhat higher than in 1991 (5 percent). The increase is related to the fact that the number of people with disabilities has increased as the population ages. The average number of hours of care per client has, however, declined; approximately 40 percent of home care institutions ration the amount of care afforded to each client in order to be able to provide care to as many people as possible. These people receive an average of almost three hours per week less care than that for which they have an indication. More than a quarter of clients themselves feel that they receive too little care.

One of the biggest problems in the care sector is the waiting lists. In March 2001, there were around 30,000 people on the waiting list for home care services. Roughly 40 percent of them do, however, receive “bridging care” (i.e., another product or fewer hours than indicated).

Housing and Care

The vast majority of people with physical activity limitations live independently. The accessibility of their home is an important condition for their being able to do so. And yet 60 percent of those who have difficulty climbing stairs live in a home with a staircase (either indoors or in order to reach the front door). Only a small number (6 percent) have a stairlift.

A minority of people with moderate or severe physical activity limitations live in adapted housing, though the number of people with adapted homes increased by around 40 percent between 1995 and 1999. In many cases, these adaptations are carried out using grants pursuant to the Services for the Disabled Act (WVG): Each year 70,000 (in 1996) to 100,000 (in 1999) adaptations are approved the under the act.

Around 60 percent of the 80,000 adults with mental impairments live in supported housing units (total capacity: 17,500 places) or in a general institution for people with mental impairments (35,000 places). The capacity of these latter institutions increased by more than 30 percent between 1980 and 2000, and that of the supported housing units doubled over the same period. Those living independently or with their parents generally have less severe mental impairments, fewer physical limitations, and fewer behavioral problems than those living in institutions. In the Netherlands, as in other countries, the aim is to enable more people with mental impairments to live independently, with support where necessary.

CONCLUSIONS

An enormous amount of government policy has been implemented in recent years aimed at improving the living situation of people with activity limitations (including those with mental impairments) and increasing their participation in the community. These efforts have met with only partial success. To some extent, this is because the legislation brought in is still too new to expect its implementation to have had any impact yet. Where legislation has been in place for longer, as is the case with the WVG, for example, the picture is very mixed. Thanks to this act, a great many people with activity limitations have access to home adaptations, which enable them to continue living independently for longer. However, users are less positive in their views about the WVG provisions in the area of transport; whereas in the past people with activity limitations often received benefits for which they could pay for whatever form of transport they themselves chose, they are now often forced to rely on collective transport, which is characterized by a lack of flexibility.

The information presented in this entry reveals that the Netherlands is still not sufficiently accessible to people with activity limitations and so creates participation restrictions for them. This applies across a whole range of fields: education, the labor market, public buildings, people's own homes, public transport, care provision, voluntary work, and associational and club life. Although the government does pursue policy designed to improve this accessibility, the measures often have a nonobligatory character.

A minority of people with activity limitations in the Netherlands live in poverty, partly because of a lack of income from employment. Increasing the labor market participation of people with activity limitations ought therefore to be one of the central planks of government disability policy. As well as employment placement services, training and improving the school achievements of younger people with activity limitations are among the ways of achieving this.

Adults with mental impairments increasingly live independently in average neighborhoods. However, the expectation that this will enable them to play a greater part in the community is not being fulfilled; in practice this integration encounters numerous problems. For example, people living independently are found to play virtually no part in general social activities. People with mental impairments often lack a network of people with whom they can undertake activities; many of them remain dependent on their family or carers from a residential facility for this.

Living in an institution often causes people to become dependent on others and to have little autonomy. On the other hand, life in an institution does often result in an integral provision of diverse amenities, both residential and with respect to filling residents' days. This cohesion is lacking when people live independently.

Choosing between a residential facility and living independently is still too much a matter of choosing the lesser of two evils: In the former case people with mental impairments have too little autonomy, while in the second they are in danger in the present situation of losing quality of life.

—Marijke W. de Kleijn–de Vrankrijker
and Mirjam M. Y. de Klerk

See also Disability Law: Europe; Education, International; Employment; International Classification of Functioning, Disability, and Health; World Health Organization.

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EXPERIENCE OF DISABILITY: NEW ZEALAND

New Zealand is one of the most recently settled major land masses. Polynesian settlers arrived around AD 500–1300. The first European expedition to New Zealand was led by Abel Tasman in 1642. The name New Zealand comes from the initial Dutch settlers. Around the 1760s, Captain Cook started surveying the islands, which opened the way for trade and whaling expeditions. This led to the colonization of the islands predominantly by European settlers.

In 1840, a treaty (Treaty of Waitangi) was signed between Maori chiefs of New Zealand and a representative from Queen Victoria. This treaty promised complete chieftainship over resources. Today, the exact meaning of the treaty is being debated and it remains a source of resentment for both Maori and Pakeha (Europeans).

New Zealand became an independent dominion in 1907 and gained full independence from the United Kingdom in 1931. New Zealand is still a constitutional monarchy in the Commonwealth, although there is a growing movement to establish New Zealand as a republic. This change would also include shifting governmental representation from a governor-general appointed by the queen (on advice of the government in power) and a prime minister to a president.

New Zealand has two main islands (North and South Island) and a number of smaller islands. The total land mass area is 268,680 square kilometers, meaning that it is smaller than Japan or the United Kingdom and just slightly larger than the state of Colorado. New Zealand extends to 1,600 km through its main north-northeast axis.

Its closest neighbor is Australia, more than 2,000 km away to the west, with Antarctica to the south and Fiji, Samoa, and Tonga to the north. Due to New Zealand's isolation from other countries and the number of uninhabited islands that come under its jurisdiction, its economic zone is the world's fifth largest, totaling 4.2 million square kilometers.

Colonial life in New Zealand was tough with accidents more likely to cause death due to shock or loss of blood; nowadays people who experience an accident are more than likely to survive due to the advanced medicines and treatment available. However, in the 1800s a death of the breadwinner (usually a man) resulted in the family being destitute. Diseases such as whooping cough, measles, diphtheria, and poliomyelitis were also major causes of death or impairment. Alcohol also caused a fair amount of physical and psychological damage. Between 1863 and 1865, there were 42 admissions into an asylum in Dunedin and it was thought by the medical superintendent at the time that half of the admissions were the result of alcohol (450 out of 909).

One of the first pieces of legislation passed, the Lunatics Ordinance Act 1846, dealt with the issue of insanity and gave the right to detain or arrest those people who were deemed likely to cause danger to the general public. The first asylum was built in a suburb of Wellington and opened in 1854 with places for 10 people. This was followed in short time by a number of asylums throughout the country. Staff members at these facilities were appointed because of their ability to handle a large number of people rather than any skill in the area of working with or caring for people. In fact out of all the asylums opened only Auckland appointed a person with a medical background.

An early piece of legislation specifically affecting disabled people was the 1882 Imbecile Passengers' Act. The act required a bond from a ship's captain who brought into New Zealand anyone who was deemed to be a lunatic or someone who would become a burden by requiring charitable aid. The 1899 Immigration Act prohibited any immigrant that was seen to be an idiot or suffering from a disease to enter the country. Neither of these pieces of legislation was stringently enforced. The first piece of education legislation was passed in 1877 and introduced free and compulsory education; however, there was no acknowledgment of special education. The act did state that a temporary or permanent infirmity was grounds for exemption from attending school. Mother Aubert founded the Sisters of Compassion, which took in disabled children with spina bifida, Down syndrome, and a variety of other impairments. However, most of the institutional care provided in the late nineteenth and twentieth centuries was for people with mental illness.

Around the same time, the first institute for deaf and dumb people was established in Sumner near Christchurch in 1880. Instructions for deaf students were conducted orally because there was a ban placed on the use of sign language. It was not until 1979 that the ban was repealed.

While plans for the first asylum for blind people were made in 1874, the building was delayed due to the low numbers of people eligible for housing; at that time it was thought there were only about 12 people in the Auckland area with significant visual impairments. It was not until 1889–1891 that a school to teach blind children was established in Parnell. At that time, Parnell was an outlying suburb of Auckland and a difficult journey. The town was in the heart of the market gardening area, and funds were provided by a bequest from a strawberry grower who left $12,000 in 1905 (the sum is equivalent to $200,000 today). The building of the school started later that same year, was finished in 1907, and officially opened two years later. In present day, the Royal New Zealand Foundation of the Blind is in the heart of the city and a major landmark in the Parnell area. Individuals are housed in any of the original buildings.

At the start of the twentieth century in New Zealand, there was a feeling that the affairs of the country were historically linked to the United Kingdom. As a result, New Zealand eugenicists based many of their arguments on data and information received from England. In 1903, W. Chapple published *The Fertility of the Unfit*, in which he proposed that the increase in crime, destitute people, and insanity was the result of society being born of defective stock. The book was well received not only by the public but also by the chief justice of the time (Sir Robert Stout), who thought the work was excellent and helped to have the book published in the United Kingdom. According to Chapple, "the unfit" were those who, because of mental and physical disabilities, were unable to support themselves. This classification included criminals, paupers, and those who were defined as idiot, imbecile, lunatic, or alcoholic. When the New Zealand Society formed in the early twentieth century, it sought to directly replicate the London Eugenics Education Society. It was widely believed that New Zealanders were stronger and fitter than people from other countries; however, this perception was challenged when 57 percent of conscripts for World War I were rejected from serving.

A question in the census of New Zealand was framed to ask about infirmity in the household, in other words, to identify those people who were unable to work due to injury or illness. The question was withdrawn after the 1916 census, which identified 206 people as deaf and dumb, 566 as blind, 3,741 as lunatic, and another 777 as feebleminded. The reason for the question being dropped was a growing reluctance on the part of the population to acknowledge such impairments. The question was brought back into the census in 1996 and revealed that 20 percent of the population had some form of impairment. The elder population—those over age 60—had the greatest percentage of people with impairments.

In 1907, the Education Amendment Act was passed, which mandated the education of "defective" or epileptic children from the ages of 6 to 21. The minimum age for disabled adults in education today still stands at 21.

World War I resulted in New Zealand having a large number of returned servicemen in need of support due to the nature of their wounds. The government offered monetary compensation to these returned servicemen, and it was expected that the pension received would replace what the soldiers could have earned. The government offered no services to people, just monetary compensation. One of the returned servicemen was Clutha Mackenzie, who lost his sight at Gallipoli. Prior to enlisting, Clutha was on the board of the Auckland Institute for the Blind and it was through his lobbying that the government passed the Pensions Amendment Act in 1924, which introduced pensions only to blind people over age 21. It was not until a number of years later (1936) that pensions were offered to other impairment groups.

Also as a result of World War I, new procedures and organizations introduced in orthopedics and plastic surgery to returned servicemen were now offered to people with congenital disabilities. The war also had the effect of raising public awareness of people with mental illness—particularly in the form of neuroses—and this led to a halfway house and an outpatient's clinic being established. Finally, there was a need for more masseurs to treat wounded soldiers and this increase eventually resulted in the establishment of a Registration Act in 1920.

In 1925, a Royal Commission into the health of New Zealanders believed that the country was losing its colonial and pioneering energy. One of the committees of the commission, the Inquiry into Mental Defectives and Sexual Offenders committee, was the most openly eugenicist-minded committee in the Royal Commission. This committee also linked mental defectives and sexual offenders for the first time. Three years later, in 1928, the Mental Defectives Amendment Act was passed, and this led to the setup of the Eugenics Board, which was charged with compiling a register of people who were deemed to be mentally defective.

Templeton Farm was established in 1929 for the institutional care of people who were diagnosed as either imbecilic or feebleminded but without "psychotic complications." A number of people with physical impairments ended up in Templeton on the advice of doctors to their parents. These medical personnel during the early and middle part of the twentieth century advocated for the placement of children with disabilities in institutions.

In the early 1930s, New Zealand experienced another polio epidemic, which led to Alexander Gillies, a noted orthopedic surgeon, establishing the New Zealand Crippled Children Society (now known as NZCCS) in 1935. The organization was charged with helping the crippled child and in no way to usurp the local authorities or government obligations to those defined as "defective." The society sought to work in a supportive and cooperative way. During its formation, Lord Nuffield, who was visiting from the United Kingdom, donated £50,000 towards it establishment. Along similar lines, the Wilsons (one of the founders of the major morning newspaper, *The Herald*) donated a family home to assist in the rehabilitation of children under the age of 21 who were recovering from either illness or an operation.

World War II again added many veterans to the number of disabled people in New Zealand, and it was estimated in 1946 that 23,000 (or approximately 11 percent) of the returned servicemen and servicewomen were paid some form of pension. Again there were spin-offs with new technologies developed to treat wounded soldiers and these would again be used to treat the general public. Also occupational therapy became a professional career option for people who wanted to work with disabled people.

The 1940s brought two distinguished visitors to New Zealand; in 1947 Helen Keller visited on behalf of the Royal New Zealand Foundation for the Blind, and in 1948 Earl Carlson, a specialist in the treatment of people with cerebral palsy, recommended a facility be built for their care. This facility was duly completed in 1951 at Rotorua. In recognition of his influence, a school was named after Carlson in the Auckland area.

The postwar years brought about a view that people with disabilities deserved to have the same rights as other members of society. Through the Depression and war years New Zealand sought safeguards to prevent a repeat of eugenics in order to establish a fairer society so that the cause of the wars would not be in vain. In earlier years, an attempt was made to form an organization that represented the parents of children with intellectual disability called the After Care Association. While it did meet some of the needs of family members, parental voices still went unheard. In 1949, another attempt to bring about the first parent-driven association for children with intellectual disability was attempted. A group of 22 parents met on October 25, followed less than a month later by the establishment of the Intellectually Handicapped Children's Parents Association. The major focus of the group was to be a voice and support for those parents connected with people with an intellectual disability.

The 1950s saw the establishment of other specific-impairment groups, including the New Zealand Epilepsy Association and Hoehepa Homes (based on the Rudolph Steiner principles). Also in the 1950s, the first vaccinations of children against poliomyelitis took place. The Asthma Association was formed in 1962. The 1960s saw a settling-down period of single-impairment groups as efforts began to work with children, young adults, adults, and family members of people with impairments. A residential facility for blind children was established in the Auckland suburb of Manurewa and eventually children from this school were integrated with the local area schools.

The 1970s saw the introduction of three key pieces of legislation that would have long-term effects on the disabled community. In 1972, the Labour government passed the no-fault Accident Compensation Commission Act. This act gave people monetary compensation when they were a victim of an accident—no matter who was at fault. This monetary amount was based on the level of impairment suffered; the greater the level of impairment, the more compensation. This compensation was given only to people who gained their impairment from an accident after the introduction of the act in 1972. It did not and still does not apply to people who have the same level of impairment due to birth or illness.

In 1975, the Disabled Persons Community Welfare Act (DPCWA) was passed. The act gave assistance to disabled people, parents, and guardians, as well as voluntary associations. The act defined a *disabled person* as someone who has or suffers from any physical or mental disablement to a degree that the person is seriously limited in the extent to which he or she can participate in activities of everyday life. The DPCWA also introduced a program to give parents or guardians a chance to take up to four weeks of respite leave and have someone either come in and care for their child or send the child away to be cared for at either an organization or other type of facility.

The final act that had an impact on New Zealand's disability population was the passing of the Human Rights Act of 1977. This act made it illegal to discriminate on the grounds of gender, marital status, or religious or ethnic belief. Disability, however, was not included as a recognized grounds for discrimination.

The International Year of Disabled Persons was in 1981, and this saw a plethora of disabled people and organizations promoting disability issues. A telethon was held to celebrate the year, and it raised more than $6 million (New Zealand at that time had a population of just over 3 million people). In 1982, the Disabled Person's Assembly was formed to represent the voice of disabled persons. Its charter stipulated that the national executive committee had to have a majority of disabled people on the board.

CONCLUSION

New Zealand has grown from a small isolated island with strong ties to the United Kingdom. As has been shown, key events along the way have shaped the country's response to disabled people. What lies ahead for disabled populations will be more challenges as the community fights to establish an identity as disabled people rather than a group needing "welfare."

In fighting for this identity, what may happen is an explosion of smaller impairment groups as happened in the 1950s. This will lead to government departments having to contract to a large number of impairment groups rather than the "big four": CCS (provider of support and services to people with physical disabilities), IHC (provider of services to people with intellectual disabilities and their families), the Blind Foundation, and the Deaf Association. The first task will be to include disability as a group against whom discrimination is outlawed.

—Russell Vickery

See also Education, International; Eugenics; Housing: Law and Policy; Mental Illness.

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EXPERIENCE OF DISABILITY: SERBIA

Serbia is located in the central part of the Balkan Peninsula, on the most important route linking Europe and Asia, occupying an area of 88,361 square kilometers. Serbia is in the West European time zone (one hour ahead of Greenwich time).

The ethnic population of the Republic of Serbia is heterogeneous, a result of the country's turbulent past. The majority of the population of Serbia are Serbs, but another 37 ethnicities also live on its territory. All citizens have equal rights and responsibilities and enjoy full ethnic equality. The Constitution of the Republic of Serbia guarantees rights to minorities, in accordance with the highest international standards. The last 2002 census puts the population of Serbia (excluding Kosovo-Metohija) at 7,498,001, which is 92.3 percent of the population of the State Union of Serbia-Montenegro. The main religion of Serbia is Christian Orthodox.

GEOGRAPHIC INFLUENCES

This overview of rights for people with disabilities begins from a geographic perspective. This perspective is important because Serbia has shared similar experiences of disability with neighboring countries of Southeast Europe such as Croatia, Bosnia and Herzegovina, Serbia and Montenegro (Yugoslavia), Macedonia, Albania, Hungary, Bulgaria, Romania, and Moldova. All countries in this region had communist regimes in the past and poverty was widespread. These demographic factors significantly influenced the position of people with disabilities in the region.

As a research area of social importance, the topic of disability is poorly investigated. Internet resources are rare. This situation represents a problem for developing research on Serbia and people with disabilities, but at the same time, it also represents a challenge and an opportunity to make recommendations for future research.

Documents authored by the organization Disability Right Advocates (DRA; 2001) have proven both invisible and neglected. Yet one can find insights on the situation of people with disabilities in Central Europe spread throughout such reports. A summary of these analyses will occupy the bulk of this entry. Such documents present a starting point for research in this part of the world. Their analyses reflect global issues of disability oppression and deal with key perspectives and issues of importance for people with disabilities. They also present a special focus on the education of people with disabilities. The DRA report starts by describing the situation of people with disabilities in Central Europe:

> Indeed, although many of the nations of Central Europe stand poised to assume their places as essential political and economic partners with Western Europe, many are like third world countries in their treatment of people with disabilities. Thus, throughout Central Europe, very few people with disabilities have the opportunity to lead a full and independent life. As a group, disabled people are segregated and immobilized by pervasive architectural barriers. They are also poor, without necessary assistance or assistive devices, discriminated against, and lack sufficient information or governmental support to improve their situation. They suffer from massive unemployment and social, political, and economic exclusion. . . . Throughout the region, treatment of people with disabilities is also still dominated by the medical model and outmoded concepts of charity, pity and non-productivity.

One of the important facts about this part of the world is that people with disabilities are largely hidden from public view. Factors that contribute to this situation are widely held myths and prejudices that saturate the culture about disability as tragedy. These beliefs together with inadequate family supports for people with disabilities—families that often lack knowledge about disabilities and that are trapped in similar debasing ideas—form some of the core problems facing disabled people in these countries. The DRA (2001) explains this detrimental situation in the following manner: “In the past, disabled people were hidden by their family members and there is still considerable stigma attached to having a disabled child. . . . One result is the frequent institutionalization of the severely physically disabled, as well as developmentally disabled children and adults.” Furthermore, it is said that “the medical model for disabled people is still the dominant paradigm. The communist concept of the ideal citizen—a healthy manual worker—reinforced this negative image and labeled disabled people as misfits.”

The report also identifies prevalent myths about people with disabilities—myths that define common approaches toward this group. The first myth is that persons with disability cannot lead a productive life. This belief is identified as the “helplessness myth” and promotes ideas of extreme dependency as well as overall incapacity to contribute to society. The second myth, known as the “charity myth,” claims that philanthropy rather than organized institutional structures should deal with the “problem” of disabled people. The third myth (recognized in first contacts with policy makers in Serbia and other countries of the region) is the “costs myth.” According to this approach, disability costs too much and these countries cannot afford to spend their beleaguered budgets on the repair of disability issues.

The Association of Students with Disabilities of Serbia and Montenegro (ADS; 2004a) gives additional statements with regard to regional characteristics. These statements are mostly built from the valuable experiences of people with disabilities in the region, and therefore they have not yet attained the status of formal research insights:

Lack of political activities—It is very rare that one finds persons with disability as members of any national or local governments.

Architectural barriers—In most countries of the region, architectural barriers represent an impediment for people with disabilities. Lately, some regulations of accessibility for wheelchair users have been coming into use. Accessibility regulations for blind and other visually impaired people as well as people with hearing problems are extremely rare. Ineffective laws are the main reason for such situations, because such policies provide only mild sanctions at best against institutions that do not respect general accessibility regulations.

Inaccessibility of means of transportation—In the countries of Southeast Europe, regionally accessible public transportation usually does not exist. In big cities and capitals of the region, there are special means of transport for people with disabilities but these are often limited.

Employment—In Serbia and Montenegro, young people with disabilities are most frequently only fictively employed in a company and retire after only six months to two years, with the aim to gain a right to pensions. A pension thus acquired is very low and people with disabilities are once again dependent on the government and their families. When a vacancy exists, employers will invariably employ able-bodied workers in almost 100 percent of the cases. Such practices continue regardless of the qualifications that applicants with disability might have. An additional problem exists because few data on qualified young people with disabilities have been published. Companies willing to offer employment are, as a rule, inaccessible to persons with disabilities (due to a failure to implement accessible construction regulations). There is no legal obligation or stimulation by the government for solving this problem. This description is for the most part applicable to all countries in the region.

Personal assistant programs—A personal assistant initiative has been introduced in Hungary. The program is organized and carried out by a nongovernmental organization (NGO) motivated by a cooperative arrangement with the government. One of the ways this problem might be addressed in the region is civil service as an alternative to military service, and a number of organizations and individuals support this initiative. Currently, military service in the region is compulsory so that the introduction of a civil service requirement has yet to be adopted by most countries in the region.

Because Serbia is a small country, its politics have been greatly influenced through intersecting histories with neighboring countries. Consequently, the development of disability rights in Serbia could be studied from a regional perspective.

HISTORICAL PERSPECTIVE

What was the situation of disability rights in Serbia through history? Few written documents are available for study and thus analyses of disability in Serbian history are rare.

In a recent World Bank document titled *Poverty Reduction Strategy Paper for Serbia* (2004), a general history of Serbian social protection services is presented. It draws links between poverty and people with disabilities while also challenging the common practice of institutionalizing people with disabilities throughout Serbian history.

A first Serbian law for the protection of human rights for poor people was implemented in the thirteenth century by Saint Sava.

> In close cooperation with the civil authorities, the church was in charge of the creation of "honorable homes" for: the elderly, the poor, children deprived of parental care, foreigners etc. These homes had their administrative and managerial staff, as well as real estate and other assets that were bestowed upon them. The operation of these charitable institutions was closely monitored by the overseers, who were in charge of advocating for the poor, comforting the mourners, defending the abused etc. Among the vulnerable were also those with physical disabilities: the blind, deaf, mute, lame, etc. (World Bank 2004)

In the fourteenth century another piece of legislation was introduced:

> It is characteristic of the Law of Saint Sava that, apart from the material aspects of poverty, equal attention was paid to the legal protection and equality of all before the courts, regardless of their material status. This principle of universal legal equity was also included in the Law book of Tsar Dusan from the 14th century, which states: "Every washerwoman must be as free as the priest"; "a poor soul, who cannot represent herself at court, may send a representative to speak in her name." (World Bank 2004)

Such laws suggest an uneven history of the treatment of disabled people in the region. They also present possibilities for the existence of more humane efforts than recent history may present.

Yugoslavia after World War II

The filmmaker and disability rights activist Victor Pineda, in his research, *Disabled Yugoslavia—Integration and Disability in Serbia and Montenegro* (2003), tries to illustrate the situation of human rights and people with disabilities in Yugoslavia from 1940 to 1990. In addition, Pineda also examines the situation of disabled people in the second half of the twentieth-century incarnation of Yugoslavia as Serbia and Montenegro during the past decade. Pineda is fully aware that research and data on people with disabilities in Serbia and Montenegro are nearly nonexistent. Reports like his contribute to a better understanding of the situation of people with disabilities in this area.

From the 1960s to the 1980s, Yugoslavia was lauded for being a socially advanced nonaligned nation, providing respected national health and educational institutions for all members and ethnicities in its society. Today, a very different reality prevails due to the existence of more than 1 million disabled citizens, refugees, and casualties of the recent wars. Twenty years after this progressive period, disabled people in Serbia and Montenegro are left with shattered pieces of a spent past, and hardly a glimmer of hope for a brighter tomorrow.

Disability has been primarily treated in Yugoslavia, as well as in other communist countries, as a welfare "problem." Persons with disability needed, it was widely thought, the protection of the state, as they were unable to lead productive lives. Similarly, Pineda's (2003) report starts with an overview of the situation of people with disabilities in Yugoslavia between 1960 and 1980:

> Throughout the Federal Republic of Yugoslavia (FRY), associations of disabled people are impairment specific and their approach is based largely on a medical/charity approach. As in other communist or socialist countries, the disabled person is under the protection or care of a specialized state agency. This view is still very embedded in the health and social services and it continues to influence the way in which services are delivered today.

In contrast, Pineda provides access to the unique and rare citations of Yugoslav's longtime premier, Josip Broz Tito, speaking about people with disabilities in 1948, during a debate on the budget in Federal Assembly:

> Since 1945, 13,133 disabled ex-servicemen have completed different courses, schools or learnt various trades in their servicemen's centers while 29 thousand disabled ex-servicemen have found employment through their organization. The disabled ex-servicemen have undertaken the production of various prosthetic appliances and are today covering all their needs.

Furthermore, Pineda describes the financial support for people with disabilities through an analysis of "invalid relief benefits." (*Invalid* is the term used for persons with disability. It is interesting to note that disability terminology in Yugoslavia has remained largely unchanged with time. Lately, some more politicized disability organizations suggest changing such antiquated terminology.) From there, Pineda goes on to discuss Tito's views of government support for people with disabilities:

> Tito committed 74% of the total expenditures for social welfare to "invalid relief benefits." This included free medical examination and medicine in all health institutions, and entitled 13,000 disabled ex-servicemen (between 1945–1948) to visit and undergo treatment at different spas and seaside treatment centers. These centers were very popular and thousands of sick and injured people from each of the six republics in the federation would be allowed universal and free treatment and usage, regardless of religion or ethnicity.

However, significant financial government support ended by the end of the 1980s. It was at this time that the situation for people with disabilities started to dramatically change for the worse. The contemporary wars that have decimated Yugoslavia started in 1991. Later, Serbia and Montenegro (formerly part of Yugoslavia) faced enormous poverty and increasing numbers of refugees. For instance, poverty increased from 6 to 40 percent.

In its publication *Disability and Poverty in Literature* (2002), the World Bank addresses the health care situation in Yugoslavia after 1990. It states that Yugoslavia enjoyed relatively well-developed systems for health care, health insurance, social services, and education before 1990. Yet, due to the conflicts in Yugoslavia after 1990, such advanced programs have experienced radically decreasing resources. As a result, many conditions that would normally be treated regularly ended in chronic impairments for lack of treatment.

LEGAL PERSPECTIVES

The legal analysis of this section concerns disability issues in Serbia from reports by experts Damjan Tatic and Branka Pecanac, both persons with disabilities. *The Right of Disabled Persons to Higher Education* (Tatic 2000) gives an in-depth analysis of Serbian legislation pointing out that the Constitution of FRY (Federal Republic of Yugoslavia) prescribes special protection of disabled persons in accordance with legal provisions. Tatic lists all the international documents and acts for equal opportunities and human rights for people with disabilities, which Serbia has adopted: the Universal Declaration of Human Rights and the Covenant on Economic, Social and Cultural Rights, UN Convention on Rights of Children, and UN Standard Rules for Equalization of Opportunities Provided to Disabled Persons. According to the report, “Under the auspices of United Nations, two crucial acts for regulation of legal status of disabled persons had been adopted at the beginning of the last decade of the 20th century: UN Convention on Rights of Children and UN Standard Rules for Equalization of Opportunities Provided to Disabled Persons.”

Comments on the Draft of the Law against Discrimination of Persons with Disability (Pecanac 2004) explains that

> discrimination against persons with disability is a long term problem in our country, a problem in the face of which both professional public and community prefer to keep their eyes closed. The Draft of the Law against discrimination of persons with disability is a preliminary legal text treating this matter in full. The law is based on principles of sanctioning discrimination, respect of human rights and involvement in all spheres of social life on the bases of equality and also in all decision making processes about the rights and duties of persons with disability.

Pecanac recognized in the law one paragraph that is discriminatory: “organizing special forms of education for children and students with sensory and motor invalidity who cannot follow curricular activities in the usual way, as well as directing someone to special forms of education if this direction is based on categorization statement, is not to be considered discrimination.” Such a provision for segregation speaks to an unchanged perspective on people with disabilities after many years of legislation in Serbia. Pecanac reminds us about this continuing praxis in special schools and the ongoing segregation of children and youths with disabilities (this entry will address these issues in more detail later). She continues with an analysis of the recent introduction of a few government bodies that oversee issues of human and civil rights for people with disabilities, and again detects discrimination in the formulation of these bodies.

EDUCATION

One of the main topics of this overview is education because this creates a foundation for the movement of people with disabilities in any country.

DRA, in its report *Invisible and Neglected* (2001), includes a description of the educational system in Central Europe, including higher education for students with disabilities:

> In education for children and young adults with disabilities, Central Europe lags far behind most Western European countries. Not only are educational levels lower for people with disabilities but there is minimal, if any, educational integration. Virtually all of the universities and graduate schools, as well as research institutes, are not accessible to wheelchairs users or people with mobility limitations.

As in the Pecanac report, Pineda (2003) also includes a brief commentary on education systems for people with disabilities in Serbia and Montenegro.

> Public education at all levels is necessary to dispel the deeply rooted prejudice against children with

Table 1 Number of Students in Special Schools in Serbia, for the School Year 2000–2001

	Total number of students	*Boys*	*%*	*Girls*	*%*
Primary	7,560	4,488	59.37	3,072	40.63
Secondary	1,269	806	63.51	463	36.49
	8,829	5,294	59.96	3,535	40.04

> disabilities. Currently special schools exist for the blind, and deaf, these schools have existed for over 120 years. The newer special education schools were combined with medical treatment and rehabilitative centers in remote areas.

Likewise, the World Bank report *Poverty Reduction Strategy Paper for Serbia* (2004) includes an overview of the educational system for people with disabilities in Serbia. This document was made in cooperation with the Serbian Ministry of Social Affairs. One can notice outdated terminology such as "children with special needs" and a focus on special schools throughout the discussion:

> Children with special needs requiring long-term assistance due to irreversible disability account for approximately 7%-10% of the total student body. The majority of children with special needs are usually not covered by rehabilitation programmes until their enrolment to primary education,
>
> Pre-school education is organized in three forms:
>
> 1. Special pre-school groups in special schools;
> 2. Special development groups in regular pre-school institutions;
> 3. Pre-school education undertaken together with other children in the same pre-school group, without a special programme.
>
> Only 1% of pre-school children with special needs are covered by early childhood education and other preparatory programmes, whereas 22% of pre-school children in the general population are included in this form of education.
>
> The current education system for children with special needs is organised in three basic forms:
>
> 1. Special schools for children with mental, physical and sensory disorders and children with behavioral disorders (some 15% of children with special needs are enrolled in special schools);
> 2. Special classes in regular schools;
> 3. Classes in regular schools where children with special needs of all categories are educated together with other children, without special support.
>
> There are 85 special schools in Serbia, of which 5 are in the territory of Kosovo. Excluding Kosovo, the capacity of these institutions is 8,829 students. 61 schools are for mentally challenged children. In terms of organization and space, primary and secondary schools are normally located together. In 8 students' residences serving schools for children with visual and hearing disabilities, accommodation is provided for 480 students. The available data show that special schools do not fulfill their basic functions. They isolate children with special needs and do not prepare children for inclusion in regular life.

The document recognizes key problems in special education for children with disabilities including segregation and low-level education. The issue of low-level education is directly addressed in a later chapter of the report:

> The network of special schools and special classes in mainstream schools is not evenly distributed across the regions of Serbia. These schools are located in major cities so that rural children and children from small towns are separated from their families and placed in boarding facilities which are most often located with special schools.
>
> There are several problems related to the education of children with special needs:
>
> 1. There is no unified data concerning persons with special needs;
> 2. Only 30% of children with special needs who have completed primary school continue their education, in comparison to 79% of the total population.

Yet the editors of this document conclude in a positive way: "More efficient and greater inclusion of children with special needs in the education system, particularly in inclusive education, is necessary."

The ADS, mentioned earlier, is a nongovernment, nonpartisan, nonprofit organization, based in Belgrade, Serbia. The organization specifically addresses improvement of the position of young people and students with disability and their inclusion in society. ADS is an active organization, both locally and in the Southeast Europe region. ADS organized many successful and internationally recognized projects, such as international conferences, Southeast European Youth Network, media campaigns, counseling centers, summer schools, scholarship programs, youth employment services, legal regulations, and special transportation projects.

The ADS document *Higher Education for People with Disabilities in Serbia and Montenegro* (2004a) reviews the situation and position of students with disabilities by students with disabilities of Serbia. The report begins with a depiction of the legacy of former communist era regimes with regard to social engineering goals:

> The former government and communist regime of Serbia and Montenegro strived to establish a "perfect society" during the last decade of their governing. In such a society there was no room for people with disabilities.

The document further explains several steps that were taken to establish a so-called perfect society: considering disability as a medical category, existence and insistence on special schools, inadequacy of existing laws and regulations, and the dominance of charity media approaches.

Description of the "promotion" of special schools is especially interesting:

> The education process of children with disabilities mostly starts with diagnosing a disability. The physician suggests a special school in which a child with disability should commence her/his education (such as schools for visually impaired children).

Detailed description of programs and perspectives in special schools is stated: Curriculums of special schools are shortened, children with mental and physical disabilities are together in the classrooms, curriculums are adjusted to pupils with the highest degree of disability, children are segregated, and special schools have increasingly become boarding schools.

From here the document goes on to introduce a description of the higher education system for students with disabilities:

> Young people with disabilities find it extremely difficult to continue education at institutions for higher education. This further contributes to their isolation, and their choice of employment is limited to jobs they were trained for at special schools.

The text goes on to discuss obstacles for students with disabilities to obtain higher education, such as inaccessible buildings and programs, lack of accessible transportation, lack of personal assistance support programs, and lack of recognition of some types of disabilities in the country in general (such as some types of learning disabilities).

Apart from technical barriers, other more important and harder to reach objectives include the following:

- Laws and other legal regulations are not dealing with students with disabilities, or if they are, then they do not use the social model approach.
- Academic community and relevant institutions (including ministries of education, rectors' offices, students without disabilities, professors, university administrators and staff) do not have enough interest in and sensitivity to the rights and problems of students with disabilities.
- Students with disabilities are not sufficiently empowered and skilled to pursue their rights.

Report on Project: Promotion of Higher Education in Southeast Europe, by ADS (2004b), represents the first descriptive research on inclusive higher education in Serbia by disabled people. This document is not in the form of a research or scientific document, but rather a collection of observations and recommendations for improvement of human rights of young people and students with disabilities. It represents a unique, insider view on the topic of education for persons with disabilities and, in this way, provides an important and previously unavailable resource on the research of higher education for students with disabilities in Serbia.

The first part of the report deals with the overview of the situation in Serbia and with the accomplishment of results from the project:

> Students with disability in Serbia seldom take part in activities relating to changing their status in society. One of the basic characteristics of stigmatized groups, such as the group of young persons with disability, is that individuals that form it are isolated from society and withdrawn, with reduced social relations. They rarely have the opportunity to develop their social and intellectual abilities and skills.

In the second part of the report, one can find results of two surveys carried out in May and June of 2004, with students with disabilities at the University of Belgrade and the University of Nis.

The document also places a special emphasis on cases of privilege and discrimination by professors and colleagues as well as attitudes and needs of the interviewees regarding support and solutions. Adaptation of teaching styles is also addressed:

> Results demonstrate that in the situations when the teaching staff is prepared to make adaptations to fit the needs of students with disability, they mostly do it through flexible approach. Even when it comes to professors who are open to specificities of students with disabilities, there is still no idea about introducing learning/teaching aids and other means that would make studying easier for this population.

The second part of the survey emphasizes students with disabilities' motivation to pursue higher education. Finally, the last part of the report focuses on the analysis of legislation and policy related to the position of students with disabilities in Serbia, followed by proposals for policy change.

This document represents a first attempt to investigate the situation of students with disabilities in Serbia. At the same time, it is part of regional Southeast Europe initiatives for inclusive education for youths with disabilities. Additional research is absolutely needed as a follow-up to these insights.

DISABILITY MOVEMENT

After World War II, the first associations and groups of people with disabilities were established. Across the board, they were uniformly founded and organized according to types of medical diagnoses. These organizations were, and continue to be, largely funded by the federal government. Weak mutual cooperation between these organizations exists.

For years, these kinds of organizations worked to create an image of people with disabilities as persons in need of compassion and assistance. From the beginning of the period of crisis in 1990, and along with destabilization of the region and warfare, activities carried out by these associations basically consisted of delivering humanitarian aid and organizing charity events. As new, younger generations have taken up leading positions in some of these associations, they have endeavored to foster new attitudes and new ways for the associations to function. However, because such kinds of leadership shifts enact changes only at a slow rate, much has not changed in terms of the emphasis on charity.

In the past decade, a number of national government organizations have been founded with the intent to alter this situation. They mainly work with cross-disability principles in mind. The organizations have helped to introduce a new approach to disability problems by emphasizing a social model of disability with the stated purpose being the full integration of disabled persons into society.

In closing, Victor Pineda offers further perspective concerning the disability rights movement in Serbia:

> The nascent disability rights movement in Yugoslavia has already initiated small and successful changes and is shaping policy and public perception in line with the social model. This analysis recognizes that the circumstances of people with disabilities and prejudice they face are socially created phenomena and have little to do with the impairments of people with disabilities. This model sees the problem not as residing in the person with a disability, but as resulting from the structures, practices, and attitudes that prevent the individual from exercising his capabilities. . . . Overall there are over 40 active disability related organizations in Serbia and Montenegro, the great majority of these are primarily organized along single disability lines, and many are quite small, having an active membership of 25 or less. Two of the most active and organized voices in Serbia are the Association of Students with Disabilities, and the Center for Independent Living in Belgrade. These

> groups are claiming access and inclusion in an environment full of cultural, social and physical exclusion. In the new Democratic Serbia these proponents have passed laws, initiated media campaigns, and have been introducing a broader understanding of disability.

A new regional disability initiative, a project named Share SEE (Self-Help & Advocacy for Rights and Equal Opportunities South East Europe; http://www.share-see.org), could have outcomes not only for the Serbian disability movement but also for the whole region in general. The project promotes self-representation of people with disabilities, promotes cross-disability approaches, and advocates for changes in disability legislation in countries of the region.

Many positive signals are being transmitted that cooperation between cross-disability and social model organizations and the new government in Serbia is likely, particularly with the Ministry for Labor, Employment and Social Policy. Will this cooperation build foundations for changes in law, the inclusion of people with disabilities in civic events, and the establishment of equal opportunities for services that allow for inclusion to occur? The future for Serbian people with disabilities remains open to the possibilities for a new era of integration and access for all, but it remains to be seen how the country will ultimately respond.

CONCLUSION

Serbia, as well as other countries of the region, is in a state of transition. Laws are changing, the political situation is not stable, and minorities are at the end of legislators' priorities. This overview of the situation of people with disabilities in Serbia (and in the region of Southeast Europe) claims that future research is needed.

—Vladimir Cuk

See also Disability Law: Europe; Education, International; Employment.

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EXPERIENCE OF DISABILITY: SLOVAK REPUBLIC

The Slovak Republic/Slovakia is among the "newest" nations in Europe. The former Czechoslovakia gained independence from the Soviet Union in 1989 in a nonviolent process termed "the Velvet Revolution," and the Czech and Slovak Republics subsequently separated into two independent countries in 1993 in a nonviolent political process referred to as "the Velvet Divorce." Since gaining this two-phase independence, the Slovak Republic has faced much greater economic struggle and political instability than the Czech Republic, though in 2004 both countries made a major advancement toward "rejoining Europe" when they were granted entry into the European Union.

The Slovak Republic is a small, land-locked nation of fewer than 6 million people, bordered by Austria, the Czech Republic, Poland, Ukraine, and Hungary. With the exception of Austria, all of Slovakia's neighbors are also formerly communist nations that are undergoing transition to forms of democratic governance and free-market economies at varying speeds. Slovakia possesses a beautiful and largely rural landscape of heavily forested alpine regions, rustic villages, ski and trekking resorts, and farming regions. The capital city of Bratislava was largely overrun by communist era architecture, resulting in drab city blocks with the occasional enclave of preserved historic buildings. Architectural barriers to accessibility, however, are endemic, existing throughout urban and rural regions, pervading government, private, educational, and residential structures and public transportation systems.

As in many developed Western countries and other postcommunist countries in Central and Eastern Europe, the Slovak Republic population is aging, the birth rate is declining, the nature of illness is changing, and the pressure on limited public resources is rising (Kovic 2000). Health services are poorly equipped to address disability and chronic illness, as the health care infrastructure is largely based on a biomedical, acute care model (Holland 2003). While the current political climate is encouraging a greater percentage of the gross domestic product (GDP) to be dedicated to health care (Kovic 2000), there remains an emphasis on biomedical technology over community-based services, independent living, or prevention. Indeed, health care reform in the Slovak Republic has been referred to as "a case study in social policy immobility" (Lawson and Nemec 1998). Further complicating matters is a residual health care "gray market" system in which consumers pay out-of-pocket fees to health care professionals for clinical care. This gray market system not only serves to neutralize well-intended policy changes at the national level, but it also disadvantages those citizens who do not have significant private resources. Individuals and families with disabilities are disproportionately among these disadvantaged citizens, compounding health access difficulties.

Largely in response to the biomedical and custodial nature of services for people with disabilities, as well as some instances of severe human rights violations (Mental Disability Advocacy Center [MDAC] 2003), a large number of highly innovative and resourceful grassroots nongovernmental organizations (NGOs) have emerged to address the human rights, quality-of-life, and independent living priorities of citizens with disabilities in Slovakia. These grassroots NGOs have worked to fill existing gaps in community-based and independent living services by functioning outside of the confines of the sluggish, institutional, state-sponsored medical infrastructure. Many of the disability NGOs in Slovakia, often founded and led by citizens or families with disabilities, are actively promoting the independent living model and are challenging a long history of institutionalization of disabled people (Holland 2003). They pursue this mission, however, with extremely limited resources and with varying degrees of support for civil society organizations from a highly diverse and, at times, chaotic multiparty parliament.

Many of the disability NGOs in Slovakia are, like the broader national context, undergoing change and transition, and struggling with issues of identity. While some of the grassroots disability groups focus almost exclusively on service provision addressing complex activities of daily living, others have pursued a much more politicized human rights mission, challenging specific national policies and promoting political candidates who understand and support disability issues. This diversity among the disability organizations will ultimately constitute a strength, but at this stage of civil society development, the dramatic differences in missions among the groups can at times appear like lost opportunities for coordination.

The survival and strength of the disability NGOs in Slovakia, as well as in other transitioning countries in Central and Eastern Europe, will be critical for the independent living movement. The highly biomedically oriented, institutionalized, and custodial approach to disability, as reflected by the health care infrastructure, will likely change slowly. The remarkably resourceful grassroots disability NGOs in Slovakia, however, bear tremendous hope for disabled citizens there. It will be these disability NGOs that eventually direct necessary policy changes at the national level, while continuing their grassroots efforts to promote independent living in their communities.

—Daniel Holland and
Zuzana Ondriasova Gubrij

See also Disability Law: Europe.

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EXPERIENCE OF DISABILITY: SUB-SAHARAN AFRICA

Disability as a category of discourse is foreign to sub-Saharan African thought. Disability is fundamentally a Western category that should be understood as a result of historical developments between people and society, in particular between people and states. In developing an idea about the experience of disability in African societies, one tries to approximate African ideas and practices that have had impacts on their existence, the individual and social lives, the development of disability services and practices during colonial times, and postcolonial developments.

How do people experience disability in Africa? Are there particular cultural practices and beliefs that inform this experience? These are important, but perhaps a more fundamental question is: Do people experience "disability"? What is the history of this experience? This entry first explores the nature of the category of disability in Africa and then looks into specific realities of disability in Africa.

DISABILITY IN AFRICAN THOUGHT

It can be said that disability as a conglomerate concept that defines people with different physical, sensory, mental, or emotional deficiencies does not exist in sub-Saharan Africa. Words referring to the concept of handicap or disability simply do not exist in African languages. This finding refers to the complicated history in Western thought that gave rise to the emergence, growth, and historical transformations of disability as a category of thought. The globalization of this thought is both part of a history of industrialization and the creation of modern society, as well as of colonization. While disability identifies "lack of," "deficiency," African thought refers more positively to a striving toward "wholeness." Indeed, "whole" and "health" have the same meaning in certain African languages, such as Swahili. While a category of disability does not exist as a repository in African languages, it should be stated that concrete translations for physical disability (lame, crippled, blind, deaf) do exist. But there are equally specific categories of deviation from the ordinary that are part of the African experience. Most notably, extra-ordinary children are identified by their assumed supernatural power. Among the Songye of Congo and many other African peoples, the birth of particular children signifies something out of the ordinary. Twins, children who are believed to hold up the rain, children born with particular characteristics (with a hand on the cheek, born with feet first, with the umbilical cord, with teeth) are given specific names and respect, and they are surrounded with ritual behavior.

In the postcolonial era, which is characterized by a decline of the state order, some children are identified with supernatural powers. With the absence of a generalized category, such as disability or handicap, it should not be assumed that there has been no historical development in the development of terminology in African languages. Yet it can be determined that some terms not only have a large time depth but also that their meanings and connotations varied over time and regionally. A contemporary example of terminology development can be found in Swahili. Here, the term *kipofu* (blind) became rejected because of its placement in the class of nouns associated with "smallness." A replacement was devised through the term *msiona* (pl. *wasiona*), which literally means "the person(s) who does not see."

During the colonial period, some institutional settings, such as schools, medical centers, and vocational services, were developed. In many instances, they were merely copies of developments in the colonial center and initiatives of the colonizing country. In a few cases, there have also been initiatives during the colonial period by Africans themselves. For some, these initiatives were the result of study in the colonial center. For others, these initiatives were spurred by influences both in and out of the country. Inside some countries, the idea of self-help for Africans became prominent. The most remarkable of the latter are perhaps the initiatives of Jairos Jiri in southern Rhodesia, now Zimbabwe, because of its African initiative, aided by colonial and later international help, and its large national network of institutional development. For a long time, during the colonial period and beyond, Jairos Jiri furthered opportunities for disabled people through rehabilitation and vocational training programs.

But in general, it should be stated that disability was not an important priority during the colonial period. The postcolonial period was characterized by some attention to the plight of veterans from the liberation wars. More significant though is the growing influence of the United Nations, which culminated in the International Year of Disabled Persons in 1981. For some African countries, the international year meant the organization of a national survey as its most important activity. For the first time, disabled people were to be counted in the African context. In the following years, specialized agencies in the United Nations each developed programs in education, health, employment, and agriculture designed to affect the disability problem in Africa on both national and regional levels. In an effort to develop a concept of disability appropriate for developing countries, the World Health Organization took the lead when it launched the concept of community-based rehabilitation (CBR). Its impact was very important on the conceptualization of practices and services that were developed by other UN agencies and the work of nongovernmental organizations (NGOs). The impact in some countries was considerable, but in others it was rather limited. In many cases, these efforts were considered as generated from the outside, as postcolonial, "development," activities. In the context of the Organization of African Unity (OAU), a multilateral organization was created for the purpose of guiding the development of disability services and policy in Africa, namely, the African Rehabilitation Institute. It influence has, however, remained limited.

During the middle 1980s, self-help was being reinvented, but in the different context of global and postcolonial realities. On the global scene, human and civil rights became translated into a disability consciousness and liberation movement. It was geared against institutional development and rather toward the formation of membership organizations, although service development became also part of the agenda. The distinction between "organizations of" and "organizations for" disabled people became relevant. The development of this movement in Africa was an interesting mix between political realties, most notably the resistance to the apartheid system in South Africa, the political alignment of the so-called frontline states, and the continued global influence of UN organizations and international NGOs. Again, Zimbabwe, partly because of its lead in the frontline states movement, also showed great leadership in the development of disability-oriented membership organizations, such as the Southern African Federation of the Disabled (SAFOD). Such leadership also expanded and translated into enhanced leadership at the national scene through the representation of disabled people by disabled parliamentarians, on a more global scale, such as within the leadership of Disabled Peoples' International, and in the development of new regional initiatives, such as the African Decade of Persons with Disabilities.

The remainder of this entry explores some pertinent cultural themes relevant to the understanding of disability in African contexts.

WHY DISABLED?

Moral or religious model thinking aims at achieving an insight into the essence of phenomena. It attempts to develop links between individual, social, and religious behavior and the occurrence of disability. Traditional knowledge systems, such as taboos, sorcery and witchcraft, and knowledge of God are instruments in grounding the very reason for not being whole, for being disabled.

These systems take away the attention from the individual into the natural, social, and religious realms in which disability is embedded. It would be correct to say that African knowledge of disability is "embedded" in its seeking for links between the occurrence of disability and several world orders. Examples are the natural order (e.g., through the observance of practices related to food and those related to contact, such as sexual and gaze taboos), the social order (as this is regulated by links between social behavior and misfortune, e.g., through sorcery and witchcraft systems of belief, and marriage regulations), and the cosmological order, in which a distant, bifacial (i.e., both good and bad) God is central.

An embedded concept of disability appears to be more powerful in addressing questions of the nature of our lives, less geared to the practical solutions. Such a concept seeks for solutions to be found outside of the disabled individual, for example, in the correction of behavior or in the taking out of evil forces. In contemporary African societies, the proliferation of religious sects supports the retaining and transformation of an embedded knowledge.

INFANTICIDE AND AFRICAN BROTHERHOOD

The killing of disabled children at birth is a practice that has been both described and denounced by colonial administrators in Africa. Such practice was seen as incompatible with the development of modern society and therefore forbidden by law. Little attention, however, went into the analysis of ritual practices and belief systems that surrounded such killing. It can be said that the occurrence of a deformed child at birth was seen as a disturbance of the order that required the intervention of an authority beyond the head of a household. In certain cases, and perhaps already under the influence of colonial practices, a fine was charged because of causing such disturbance. It is important that a higher authority (not the father) be charged with conducting the killing and observing certain rules. These rules included that such a child could not be buried because it would pollute the earth. An exception is the burial in a termite mound, because its earth is already infertile. More common was the practice of throwing such a child in the river, in accordance with the belief that people not merely die but return to a place before they are once again born. The spirit of the child was to be respected, for example, by placing a small white chicken (a symbol of purification) around the neck or ankle of the child. The person charged with the killing further would have to send the child back and admonish God to send perfect children instead. Returning from the river, this person could never look back. Such practices put into better perspective the nature of the killing and would make it difficult to maintain the colonial argument that these were cases of murder.

In some West African cultures, the killing of disabled children is mediated by beliefs that surround "children of the snake." These beliefs stress the wrong-headed impression that people can have of each other: "While one may see a child, it could be a different creature." These beliefs emphasize the permeability of borders and the possibility of transformation between different creatures. It is possible to test whether a child is of the snake by practicing ritual behavior that enables one to see whether such a child will transform itself. In some cases, it legitimates abandoning a child as a test of seeing whether it belongs to the snake.

Diametrically opposed to such practices of restoring order, the notion of African brotherhood or solidarity is a theme that emphasizes tolerance and mutual help, also toward people who are deemed to be unfortunate. The basis of brotherhood is the clan or totem. The theme has been expanded in political discourse, such as in the Kenyan concept of *harambee*. In the modern context, however, notions of brotherhood have sometimes been criticized as working opposed to capital accumulation and economic development in general. It also appears that institutional development, such as in the case of the Jairos Jiri association, became reasons to forego African brotherhood. Moreover, colonial influence created the disabled beggar who, situated in the colonial city, is entitled to its spot in the street and request alms. The disabled beggar is equally supported in countries influenced by Islam, where almsgiving is a central pillar.

AFRICAN PROVERBS

In Bantu-speaking Africa, a major theme dominates the moral imperative toward disabled people, as it is communicated in proverbs. In the first part, these proverbs admonish "Not to laugh at disabled people." The admonishment can be found in many, if not all, Bantu languages, that is, spoken by sub-Saharan African people. It is a very direct statement, without much variation. The second part of the proverb has many variations, but the message is very similar: It is unsure what will happen to your own life. This is expressed by referring to God as creator, of both good and bad things that can happen. It can also be expressed by referring to certain possibilities of things to happen, thereby referring to some trade-off between different choices: If this does not happen, then something else could still happen.

These proverbs communicate that one has no control over one's destiny and that laughing at disabled people would be the worst way of challenging that destiny, worse than, for example, laughing at poor people. These proverbs relate to an existential insecurity, essentially not knowing what the future will bring, and cultivating that knowledge.

LOCAL AND GLOBAL DIMENSIONS OF DISABILITY

In contemporary Africa, disability can be associated with contagious diseases, emerging industrialization, and traffic accidents; civil war and genocide; and terrorism. For these local conditions, there have been numerous responses, from within and outside Africa. In the aftermath of colonial initiatives, local NGOs have developed services, followed by the input of international NGOs, and from the UN specialized agencies. First, some of these services were driven by charitable and medical services, and development took place in the context of "centers for physically handicapped people." Since 1976, CBR was formalized by the World Health Organization as the more appropriate strategy for meeting the needs of rehabilitation, compared to institution-based rehabilitation. The other specialized agencies, such as UNESCO and the International Labor Organization, followed with compatible strategies in the areas of education and employment. Integrated education and income-generating projects were launched. Throughout the 1980s, many initiatives in Africa were geared toward the integration of persons with disabilities in all sectors of society. An emerging disability movement that became especially prominent in southern Africa crossed these service-oriented approaches. Influenced by international meetings, disability leaders such as Joshua Malinga became prominent in the disability movement, both in their own country and at the international level. The organizations that characterized this emerging disability movement were characterized by their membership, not services. Eventually, by the end of the 1990s, attempts were made to find a meeting place between service provision and the disability movement.

—Patrick Devlieger

See also Disability in Contemporary Africa; Infanticide; Jiri, Jairos; World Health Organization.

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EXPERIENCE OF DISABILITY: TAIWAN

PRESENT SITUATION

Dignity has always been a major concern for disabled people in Taiwan. Most of them feel that they have been ignored and dishonored in every aspect of their lives, including the right to receive an education, to get a job, to have easy access to public places, and most of all, to live an independent life. In Taiwan, it was not until June 2, 1980, that the entire 26-article text of the Physically and Mentally Disabled Citizens Protection Law was promulgated, which was then completely modified to 65 articles in 1997. This law was passed to protect "the legal rights, interests, and livelihood of the disabled, secure their opportunity to participate in the social life fairly, consolidate the government and private resources, [and] plan and implement all measures of assistance and welfare." The law guarantees legal rights for the disabled and has significantly improved their welfare. The disabled persons referred to in the law are

> the people whose functions of participating in the society and engaging in the production activities are restricted or cannot be brought into full play due to physical or mental factors and who, after the process of examination and determination, are regarded as suffering one of [the] malfunctions which are in conformity with the grades regulated by the central competent authorities in charge of health and have received the handicap manuals.

The Ministry of Interior, Department (Bureau) of Social Affairs in the provincial government and the local governments are supposed to be in charge of all related affairs, such as welfare, nursery, services at home, medical treatment and rehabilitation, special education, vocational training, and employment services.

CULTURAL CONSTRUCT OF THE DISABLED IDENTITY

Before promulgation of the Physically and Mentally Disabled Citizens Protection Law, the disabled in Taiwan had gone through a very difficult period of time, and the disabled and their parents had to rely on themselves to take care of almost everything. The law helps solve many problems encountered by the individuals and their families. However, despite its well-intentioned plan and design, it still has limitations when put into practice, because the people who execute the regulations do not really care for the needs of the disabled. Indeed, given its 5,000-year cultural legacy, Chinese society is slow to react and care for the rights of underprivileged people. This negligence has its own history in Taiwan and speaks a lot about the human values that Chinese culture has nourished. With its long history, the Chinese should have more cultural assets that epitomize human values. However, when speaking of the rights and dignity of the disabled, Chinese society seems to head the other way.

To study and locate the source of the identity and stigmatization of the disabled in Chinese culture and to reveal old myths about disabilities, be they attitudinal, representational, or empirical, one may begin with a comprehensive understanding of the feudalist ideology, which is deeply embedded in Chinese culture. Given this ideology, the Chinese people are inculcated to respect only the privileged, the wealthy, and the powerful, and they look down on the underprivileged, who are often considered worthless and useless. Accordingly, disease is considered a taboo, a moral deficit, or a personal blemish, so the names of contagious or stigmatized diseases such as polio, cancer, and AIDS are not supposed to be mentioned directly. When a member in a family gets such a disease, the whole family will be discriminated against and considered morally inferior. In this situation, people might suspect that the family has done something evil or that their predecessors might have not accumulated enough merits to raise sound and healthy descendents.

Moreover, the Chinese people value family highly, and parents are responsible for continuing the strong lineage of a family. Children are supposed to honor their parents, so they will not be accused of disrespecting them. Thus, a family's value depends on its good genes or blood. Children are often considered extended egos of the parents, so a good and prosperous child can honor his or her parents by continuing the strong lineage of the family. Given this concept, a disabled child is therefore considered shameful and a burden to a family, as well as being a symbol of bad blood. The child is unwelcome because he or she cannot get married easily and is therefore unable to continue the lineage of the family. Raising children, earning enough income, maintaining a decent family, and showing filial piety all become impossible for a disabled child. Unfortunately, his inability to fulfill the family obligations marks him as less of a human.

Presently, Chinese and Taiwanese societies have changed greatly in terms of their treatment to the disabled, but most people still retain the same prejudices about them. These misconceptions make it harder for the disabled to find work. To help the disabled get minimum-wage jobs, the Taiwanese government deliberately offers them the job of selling lottery tickets. The government's intention is good, but the job system is still based on the biased understanding that the disabled cannot earn a decent living by their abilities and have to rely on the public's sympathy to buy lottery tickets. Sadly enough, misery and poverty seem to be the necessary outcome of a disabling condition.

GREATNESS PERSONIFIED

Given all the disadvantages, however, a disabled person can be redeemed by academic or worldly achievements, because the Chinese people, on the basis of either a feudal concept or Confucianism, think highly of scholars, officials, and successful people. If a disabled person overcomes his limitations by achieving something valued and recognized by Chinese society, such as scholarship, he or she will be treated differently and thus gain respect. Liu Hsia, for instance, is one of them. Liu contracted rheumatoid arthritis at the age of 12 and was confined to a wheelchair. She once jokingly called herself a "walking quadriplegic fossil" since she had been suffering from the disease for almost five decades. Her disease hindered her from receiving any formal school education, but she managed to study on her own and went on to establish herself as an acclaimed author under the pen name Hsing lin tsi, with a body of work of more than 30 books of essays, novels, autobiographies, and audio books. Most of her articles are inspirational, and she won the National Literature and Art Award in 1982. Liu's writing also earned her a commendation as one of Taiwan's 10 most outstanding women in 1980, and she used the award's NT$200,000 (US$5,700) in prize money to establish the Eden Social Welfare Foundation to take care of people who have disabilities. Many people adore her and are deeply inspired by her strong sense of humor and inspirational attitude toward life. For instance, Reverend Maurice Alwyn Sween III, an American missionary who has been residing in Taiwan for the past 15 years, once said that Liu often inspired him with fresh ideas. "Reading her articles helped me calm down, think deeply and remain clear minded toward the challenges in my life," said Sween. Indeed, she had a unique perspective, which encouraged people to hope and to never give up. In 2000, she was appointed as a presidential adviser. In 2003, Liu passed away at the age of 61 as the result of an accidental but fatal assault from her Indonesian maid.

In Taiwan, there are still many outstanding disabled people whose lives can always be a source of inspiration. In addition to Liu, Wu Shu-chen is another exceptional figure who has drawn attention to the human rights and dignity of the disabled. She is the first lady of President Chen Shui-bian. In 1985, while accompanying her husband to thank voters for their support, she was seriously injured after being run over by a truck. Her life was spared after multiple operations, but she has ever since been a wheelchair user. Despite her physical impairment, she was later elected as a legislator. Wu's experience in overcoming her trials further enhances her standing as not only a spokesperson for Taiwan's battle to win international recognition but also a role model for the disabled.

In addition to these extraordinary figures, most of the disabled people in Taiwan are still struggling to earn their due respect. At any rate, the disabled people's awareness is emerging gradually and significantly in Taiwan, and they are now able to fight against the able-bodied public's ideological projections and feudalist investments, which have accorded a common set of stigmatizing social values to disability and determined the treatment and positioning of the disabled people in society. With their arduous efforts, they hope that one day they can rewrite the history of the disabled in Taiwan and redefine the meaning of disability.

—Hsiao-yu Sun

See also Confucius; Experience of Disability: China.

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EXPLANATORY LEGITIMACY THEORY

Explanatory legitimacy theory builds on historical and current diversity analyses and debates. Within this framework, disability is defined as a contextually embedded, dynamic grand category of human diversity. Thus, who belongs and what responses are afforded to category members are based on differential, changing, and sometimes conflicting judgments about the value of explanations for diverse human phenomena. This approach to defining disability differs from previous schemes in which disability was determined by the presence of a medical condition that caused permanent limitations in one's daily function. For example, consider three individuals who use a three-wheeled cycle. The first is a child learning to ride a bike. The second is a woman who, because of balance challenges, uses a tricycle. The third is a man who delivers groceries in an urban neighborhood. Each individual engages in cycling activity using a tricycle but the explanation differs. According to explanatory legitimacy, none, one, two, or all may fit the category of disability or not and may engender different responses. Let us see how.

BACKGROUND AND THEORETICAL FOUNDATION

Looking back in history to civilizations that predated the emergence of industrialization, medical knowledge, and technological sophistication, the grand category of disability did not exist. Rather, the identification of, worth of, and community response to those who acted and appeared in ways that were considered to be atypical were inferred on the basis of context-embedded value judgments about attributed explanations for why individuals did not fit within conceptualizations of typical. And while definitions and responses have changed over time, contextually embedded values still form the basis for defining and analyzing disability. Thus, the influence of multiple factors (including but not limited to natural, chronological, spiritual, and intellectual trends) on value judgments is the key to understanding categorization, the legitimacy of individuals and groups who fit within a category, and the responses that are deemed legitimate for members.

In the twentieth and twenty-first centuries, three contextual factors—(a) economic productivity; (b) medical knowledge, technology, and professional authority; and (c) diversity—have had significant roles in definitions of what is typical, how phenomena that fall outside of the typical are explained, and the differential and complex determination of these explanations as legitimate disability status and response.

These factors have intersected to produce two overarching and hotly debated views of disability in the current literature: medical-diagnostic and constructed. Medical-diagnostic definitions locate disability within humans and define it as an anomalous medical condition of long-term or permanent duration. Thus, within this conceptualization, the domain of disability definition and response remains within the medical community. In opposition, however, to what was perceived as a pejorative, the constructed school of disability emerged. Within this broad theoretical category, disability is defined as a set of limitations imposed on individuals (with or even without diagnosed medical conditions) from external factors such as social, cultural, and other environmental influences. Both categories of thinking provide a forum for rich debate and intellectual dialogue. However, as the discourse expands and is applied to increasingly more fields of study and application, analysis of what disability is and is not calls for theoretical specificity that can address the complexity of disability within the larger context of human diversity.

THREE ELEMENTS OF EXPLANATORY LEGITIMACY

Explanatory legitimacy theory makes the distinctions among descriptive, explanatory, and the axiological or the legitimacy dimensions of the categorization of human diversity and identifies the relationships among these elements. Thus, similar to legitimacy-based analyses of other areas of human diversity, disability, defined and analyzed through the lens of explanatory legitimacy, is composed of the three interactive elements: description, explanation, and legitimacy.

Description

Description encompasses the full range of human activity (what people do and do not do and how they do what they do), appearance, and experience. Of particular importance to description is the statistical concept of the "norm." Developed by Belgian statistician Adolphe Quetelet in the late 1800s, "the normal man" was both *physically and morally normal.* Based on probability, the concept of normal translates into the most frequently occurring phenomena. Extremes are the "abnormal" and minimally occurring. Thus, common and frequent phenomena formed the basis for what we consider as normal and are the foundation of many theories and practices today regarding the acceptable limits of human description. Observation therefore turned to prescription and anyone exhibiting difference in activity, appearance, and/or experience was considered abnormal.

Because understanding and naming of what is normal are value based, use of terms such as *normal* does not provide the conceptual clarity sufficient for distinguishing description from axiology. Thus, in applying explanatory legitimacy to disability, the terms *typical* and *atypical* are used. They refer to magnitude rather than desirables.

Thus, description is conceptualized as two intersecting dimensions (typical/atypical and observable/reportable). Typical involves activity, appearance, and experience as most frequently occurring and expected in a specified context. Atypical refers to activity, appearance, and experience outside of what is considered to be typical.

Observable phenomena are activities and appearance that fall under the rubric of those that can be sensed and agreed on. Reportable phenomena are experiences that can be known through inference only.

Explanation

The second element of explanatory legitimacy is explanation. Applied to disability, explanation is the set of reasons for atypical doing, appearance, and experience. For example, what are described immediately above as the medical-diagnostic and constructed approaches are in our definitional taxonomy, explanations of doing, appearance, and experience across the lifespan. What is important to highlight with regard to the link between description and explanation is that explanation is always an inference. Because of the interpretative nature of explanation, this definitional element lends itself to debate and differential value judgment.

Legitimacy

The third and most important definitional element of explanatory legitimacy is legitimacy, which we suggest is composed of two subelements: judgment and response. Judgment refers to value assessments of competing groups on whether or not what one does throughout life (and thus what one does not do), how one looks, and the degree to which one's experiences fit within what is typical and are valid and acceptable explanations that are consistent with an all-too-often unspoken value set. Responses are the actions (both negative and positive) that are deemed appropriate by those rendering the value judgments. We have selected the term *legitimacy* to explicate the primacy of judgment about acceptability and worth in shaping differential definitions of disability and in determining individual, community, social group, and policy responses to those who fit within diverse disability classifications.

APPLICATION

Consider the following two examples.

Example 1

On the first day of their physics class, John and Jane both bring tape recorders for note taking. Dr. Joseph asks John and Jane to turn off the tape recorders, letting them both know that she does not allow students to tape her lectures. After class, John talks with Dr. Joseph indicating that he uses the tape recorder as an assistive device for a learning disability as recommended by disabled student services. Jane, however, tapes the lectures because she lives over an hour from the university and has a new infant who distracts her from reading at home. By taping lectures she is able to study in the car. In both cases, the observable atypical activity is tape recording a lecture when all other students are taking notes. John has a medical-diagnostic explanation and Jane has a social explanation for the atypical activity. For Dr. Joseph, only John's explanation legitimates him as a disability category member worthy of special response.

Example 2

Two women present in the emergency room with broken noses and bruises (description). Because Sue was injured in a fall after tripping on the shoes that her husband left on the floor (explanation), she is not considered to be a victim (illegitimacy as a victim). Heidi, who was assaulted by her partner (explanation), qualifies for legitimate victim status and is afforded the services and supports of the domestic violence system (legitimacy response). Knowing that Sue has very poor balance (explanation), her husband left the shoes on the floor purposively with intent to harm. On the basis of disability membership (disability legitimacy determination), Sue is tacitly and perhaps unintentionally denied credibility as a victim (victim illegitimacy determination) and thus is not met with access responses to services that may prevent further injury or even death (illegitimacy response).

Explanatory legitimacy is a theoretical framework that not only addresses a full range of analytic complexity but also provides guidance for related social action. Both examples highlight the link between explanatory legitimacy theory, universal ideology, and the action steps that derive there from. If responses to both students had been considered in terms of need rather than disability category membership, it is likely that Dr. Joseph would have expanded tape-recorded note taking as an option for all students. To the contrary, if the victim identification protocol had been universal in scope and focused on harm rather than inferred explanations for harm, disability membership would not have been met with exclusion.

In summary, explanatory legitimacy theory builds on a rich history of intellectual examination and debate. As a pluralistic theoretical framework, it locates disability within multiple discourses and provides theoretical clarity to pave the way for informed social action.

—Stephen French Gilson and
Elizabeth DePoy

See also Diversity; Models; Normality.

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F

FACILITATED COMMUNICATION

Facilitated communication training (FCT) is a strategy for teaching individuals with severe communication impairments to use communication aids with their hands.

> In facilitated communication training a communication partner (facilitator) helps the communication aid user overcome physical problems and develop functional movement patterns. The immediate aim in facilitated communication training is to allow the aid user to make choices and to communicate in a way that has been impossible previously. Practice using a communication aid such as a picture board, speech synthesizer, or keyboard in a functional manner is encouraged, to increase the user's physical skills and self-confidence and reduce dependency. As the student's skills and confidence increase the amount of facilitation is reduced. The ultimate goal is for students to be able to use the communication aid(s) of their choice independently.
>
> Facilitated communication training is a teaching strategy of particular relevance to individuals with severe speech impairments who can walk but have had difficulty acquiring handwriting and manual signing skills. Many such people are diagnosed as intellectually impaired and/or autistic. Through facilitated communication training numbers of these people have achieved functional communication, often revealing unexpected understanding and academic potential. (Crossley 1994)

Practices very much like facilitated communication had emerged from time to time around the world with particular people (e.g., Oppenheim 1973), but its development as a technique of general application dates from its rediscovery in Australia in 1975 by Rosemary Crossley and Anne McDonald and its adoption in the United States by Douglas Biklen. Crossley and Biklen also suggested that the high proportion of people previously regarded as intellectually impaired who had been enabled to communicate through facilitation cast considerable doubt on traditional views on the nature of the condition.

From the outset, FCT was surrounded by controversy. Many people continued to assert that the communications said to be coming from the person with communication impairment were in fact simply unconscious projections by the facilitator. An extensive bibliography deals with the conflicting studies on the validation of these communications. Two books of essays dealing with the controversy are Shane (1994) and Biklen and Cardinal (1997). Arguments became particularly pointed in the 1990s when many allegations of sexual abuse were made though facilitated communication. The method was condemned by the American Psychological Association in 1994 as a "controversial and unproved communicative procedure" and was described by one critic as "an unacceptable challenge to professional belief systems" (Shane 1993). Evidence of clients successfully achieving communication was condemned as anecdotal.

The debate continues, but differing epistemologies and presuppositions make it unlikely that any professional consensus will emerge. FCT continues to be used by a number of people around the world, assisted by the emerging evidence of increasing numbers of facilitated communication users who have graduated to independence. In the section on facilitated communication in the 1998 edition of their widely used textbook on augmentative and alternative communication, for example, Beukelman and Mirenda describe one long-term user:

> Sharisa Kochmeister is a person with autism who at one time had a measured IQ score somewhere between 10 and 15. . . . She does not speak. When she first began using facilitated communication (FC) several years ago to type on a keyboard, she required an FC facilitator to hold her hand or arm as she hunted for letters on a keyboard. No one thought she could read, write, or spell. She can now type independently (i.e., with no physical support) on a computer or type-writer.
>
> Sharisa joins a small group of people around the world who began communicating through FC and are now able to type either independently or with minimal, hand-on-shoulder support. There can be no doubt that, for them, FC "worked," in that it opened the door to communication for the first time. . . . We include FC here because of Sharisa . . . and others who now communicate fluently and independently, thanks to FC. For them, the controversy has ended. (p. 327)

—*Chris Borthwick*

See also Autism; Communication.

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FAIR HOUSING ACT AMENDMENTS OF 1988 (UNITED STATES)

Although not as well known as the Americans with Disabilities Act (ADA), the 1988 Fair Housing Amendments to the Civil Rights Act of 1968 (Fair Housing Act) guarantee civil rights of people with disabilities in the residential setting. The amendments extended coverage of the fair housing laws to people with disabilities and established accessible design and construction standards for all new multifamily housing built for first occupancy on or after March 13, 1991.

The Fair Housing Act, U.S. federal law that includes provisions for making all newly constructed multifamily housing accessible to a limited degree, covers the sale, rental, and financing of dwellings and other housing-related transactions. It prohibits discrimination based on color, national origin, religion, sex, familial status, and disability. Civil rights organizations are active in advocacy to promote the goals of the act and ensure its compliance. This includes monitoring and documenting cases of discrimination as well as legal action to obtain compliance.

By mandating adaptability (such that features of buildings that are not initially accessible can be made fully accessible with little effort and expense) and minimum accessibility in all new multifamily projects, this law was a major step toward achieving universal design in housing in the United States. But the amendments also ensured that residents with disabilities have a right to make accommodations to multifamily dwellings. Prior to the enactment of the law, the owners of buildings could prevent a tenant from adding a grab bar, widening a doorway, installing a ramp, or lowering cabinets, even if the tenant was willing to pay for the renovations. Not only did the amendments provide the legal means by which they could make modifications that they needed for accessibility, but they also require landlords to allow tenants to make changes to public parts of facilities, such as installing an automatic door opener at the entrance to a building or a ramp on the site. However, landlords can require the tenant not only to pay for the modifications but also to restore the areas modified back to their original condition when the tenant leaves.

Perhaps the most important feature of the Fair Housing Act amendments is the requirement that all new construction of multifamily buildings comply, unless covered by specific exceptions. *Multifamily* is defined as any building that has more than three dwelling units (although not including row houses). The act applies to housing finance both privately and publicly. Prior to the enactment of the act, only a few states had laws that required accessibility to dwelling units constructed with private funding. All dwelling units covered by the act must be accessible. Prior to the enactment of the act, accessible housing was generally provided by a small percentage of designated units. Thus, for new construction, the Fair Housing Act amendments introduced universal access to the multifamily housing industry.

To ensure compliance with the provisions of the act in new construction, the U.S. Department of Housing and Urban Development issued the Fair Housing Act Accessibility Guidelines (FHAAG). There are seven requirements in the guidelines:

1. An accessible building entrance on an accessible route
2. Accessible and usable public and common-use areas
3. Usable doors
4. An accessible route into and through the dwelling unit
5. Environmental controls in accessible locations
6. Reinforced walls for grab bars
7. Usable kitchens and bathrooms

Each of the seven requirements has specific technical design criteria that provide a basic level of accessibility. It is important to note that, as minimum design criteria, the FHAAG does not serve all the needs of people with severe disabilities, particularly inside the dwelling unit. The guidelines are also not as comprehensive and detailed as the ADA Accessibility Guidelines, but the latter do not have requirements specifically for dwelling units.

There are three important exceptions to Requirement 1. First, only the first-floor units in buildings that do not have elevators in housing built on steeply sloping sites are covered by the act. Second, there are exceptions for sites where accessibility is impractical due to the topography of the site (steep slopes). Third, another set of exceptions is allowed for unusual site characteristics such as location on a flood plain or coastal high-hazard area where building codes require floor levels of living areas to be a certain distance above grade.

Requirement 2 basically treats the shared areas of multifamily buildings and facilities like public buildings. This includes laundries, playgrounds, swimming pools, mailrooms, and other shared spaces. The FHAAG specifies the scope of accessibility to these spaces and references the ICC/ANSI A117.1 Standard, the model standard used to define minimum accessibility in the United States (American National Standards Institute 1998), for technical criteria. Only one entry to the dwelling unit is required to be accessible. And only one accessible path of travel is required. So, for example, a first-floor dwelling unit may have an accessible entrance to the front of the unit, but there may be stairs leading to a rear door.

Requirements 3 and 4 ensure that the circulation spaces inside the dwelling unit are accessible. The requirements do not preclude lowered or raised areas of rooms, but they do require that all rooms be on an accessible path. A major difference between other accessibility provisions in the United States and the FHAAG is that doors inside dwelling units are not required to have latch side clearances. This restricts usability for people who have limited reaching ability or large wheelchairs.

Requirements 5, 6, and 7 require a basic level of accessibility to the fixtures and equipment in the dwelling unit. This includes electrical switches and outlets, appliances, and plumbing fixtures. There are detailed requirements for access to bathrooms, ensuring privacy and independence. However, the requirements for the kitchen do not include knee clearances and lowered cabinets and counters. Bathroom requirements are also less generous than those required by the ADA, especially due to the lack of latch side requirements at doors and shorter grab bar allowances at toilets. Finally, the FHAAG does not require grab bars to be installed in any unit.

The guidelines produce dwelling units that are accessible at a basic level. The authors of the act and the regulations that support it consciously traded off the extent of accessibility required to obtain political support to cover a wider number of dwelling units. The guidelines, however, do incorporate features that allow the units to be easily adapted to an individual's specific needs. For example, Requirement 6 specifies that reinforcing must be installed in the walls of bathrooms to allow grab bars to be installed easily in the future, should they be needed by the current resident of a dwelling or some future resident. Furthermore, although the FHAAG does not specifically require it, there is an incentive for vanities to be removable or adaptable to allow the provision of knee space under a sink in the kitchen or bath. Both these measures save money by reducing expensive modification costs, and they provide added value to the design of the home.

The FHAAG does not substitute for other accessibility requirements in housing. For example, other federal accessibility laws still require 5 percent of dwelling units in federally financed housing projects to comply with the more stringent requirements of ICC/ANSI A117.1.

Housing designed to the guidelines is attractive to a wide variety of people, including people with chronic pain, temporary disabilities, visitors with a disability, and older people. Incorporating adaptability into the design also reduces the cost of making expensive modifications to accommodate an individual with a disability. This type of change is not limited to a new tenant moving in. Older people often need modifications to their dwellings to maintain independence. Disability can also occur to otherwise "healthy" people as a result of accident or disease.

Compliance with the Fair Housing Law, like the ADA, is a complaint-driven process. Initially, there was no local method of implementation in regulations. This situation is changing as the United States moves toward more uniformity in building codes. The 1999 version of the ICC/ANSI A117.1 Standard incorporated optional requirements for design of dwelling units that are essentially the same as the FHAAG. These requirements are now referenced in model construction codes that are adopted by the states and, increasingly, are being incorporated in state accessibility codes as they adopt the new model codes. In states that had more stringent requirements for housing, there is a concern that these modifications will reduce the level of accessibility provided.

While the guidelines are generally easy to implement, in comparison with the far more extensive ADA Accessibility Guidelines, information about the Fair Housing Law and its impact on new construction has not been nearly as easy to obtain as information about the ADA requirements. In fact, there is evidence that architects and builders are not very knowledgeable about the Fair Housing requirements. Builders, who prefer to construct the same design as much as possible, have made few changes in their designs to address compliance. The result has been the beginning of a wave of litigation by the U.S. Department of Justice to raise the profile of the law and ensure that the building industry understands that it must comply. Several cases have been either settled or are in the process of litigation. Settlements can include requirements to renovate common facilities, renovate units already constructed, provide opportunities for owners of condominiums to renovate their apartments if desired, and provide funding for other home modifications in the community if renovating the noncomplying units is infeasible.

—Edward Steinfeld

See also Accessibility Codes and Standards; Home Modification; Housing: Law and Policy.

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FAMILY

In a rapidly changing world, there is no longer an easy answer to the question "Who is the family?" Yet it is a profoundly important question for people with disabilities and their families. Governments around the world are committed to policies that support citizens with disabilities and their families, often under the banner of community care. But we know that most care in the community is care by the family, and that families "who care" save governments billions of dollars. Support and care between family members are the product of many forces—love, duty, obligation, reciprocity, altruism, custom—but it is a vital form of support that is primarily unpaid. As far as is known, it is also the norm in all societies. Who, then, is the family that takes on these responsibilities? How do families organize support of disabled relatives? How is this experienced? And what should families expect from governments to assist them in their endeavors?

WHO IS THE FAMILY?

Governments come and go but, taking a traditional view, the family as an institution is supposed to be a constant, even a stabilizing influence on society. In countries where major economic, political, and social changes have taken place, the family as an institution has endured but family structures, family forms, and the boundaries of families are being reshaped (Silva and Smart 1999). In many postindustrial societies, people are marrying later, having fewer children, and becoming parents later in life. Women are realizing improved educational opportunities, control over their fertility, and greater participation in paid employment. Changing demographics such as these will continue to affect the supply of people within families who are theoretically available to undertake caregiving responsibilities, but government policies can foster or restrain conditions that make this possible.

More significant than banner statistics about the family is the growing consensus that diverse patterns of family life exist. Perhaps the most major change in the concept of the family is that it can be represented in terms of the subjective meanings of intimate connections as well as formal, objective blood or marriage ties. This means that it is subjective experiences that can create ties between people living in separate households for part or all of the time, as well as people who choose to belong as a family.

What a family is can be closely linked to what it does, including, for example, support of disabled relatives, child care, sharing of resources and skills, and the meeting of demands and responsibilities. Within this context of changing definitions of *family*, there is little evidence to suggest an abandonment of commitment or obligation, much as those with more conservative views might argue. Newer family forms generate their own rules and norms to regulate exchanges and responsibilities so as to address the same commitments as other, more traditional, families. Though some of these arrangements are recognizable—families of choice, parenting across households, parenting by people with disabilities, single-parent families, and stepfamilies—many do not yet have names. Gene therapy and sperm donorship are making sure of that. Hence, there exists not solely one kind of family capable of producing moral, autonomous, caring citizens or of supporting in a sensitive manner family members with disabilities.

Values and beliefs that are culturally rooted, and long established, have a powerful influence in the setting of hierarchies of responsibility within families. Who ends up caring for whom therefore is likely to be a direct or indirect product of this. This may also affect who is defined as being part of the family and how help-seeking is negotiated. Currently, little is known about relationships between disabled people and their families from different ethnic and racial groups, especially outside of North America. Constructs of "the family" in developing countries, and how they organize their affairs, are likely to provide important lessons about effective ways of supporting disabled relatives, and how disabled people in turn can make valued contributions within the family and the community.

It is self-evident that "the family" is more than the sum of those individuals who live in the same home. Steady improvements in health and survival together with social and geographic mobility lead inevitably to the dispersal of families, though not necessarily to their fragmentation. More recent technologies such as the Internet, e-mail, and cell phones are means by which physical barriers to communication between family members can easily be accommodated, and responses to demands and crises dealt with. Indeed, these technologies represent one way in which care and support "from a distance" can be brought into play. By definition, they cannot replace requirements for more hands-on support and care where direct contact, intimacy, or constancy is necessary. This illustrates one of the fundamental divisions in how families fulfill their caregiving responsibilities toward those with disabilities or high support needs, that is, by accommodating responsibilities toward "caring for" persons while maintaining a commitment to "care about" them.

FAMILIES SUPPORTING DISABLED RELATIVES

Many ways of describing how families "do their caregiving" have been discussed in the literature. One of the more enduring approaches is to distinguish "caring for" from "caring about" responsibilities. Early social policy research tended to focus on caring-for responsibilities depicted largely in terms of highly personal care (e.g., helping someone with bathing, toileting, dressing) or homemaking (e.g., assisting with laundry, ironing, gardening). These activities can be regarded as task-based or *instrumental* in character, and clearly important as such. This is sometimes referred to as direct work. At the same time, families express how they care about their disabled children and relatives in other ways. These are rather less tangible, but no less important, and include things such as planning and anticipating, negotiating, problem solving, and case managing, all of which can be regarded as kinds of indirect care. With both direct and indirect care (caring for and caring about), there is typically an integral affective or emotional dimension reflecting the strength of ties that bind family members together.

Such ways of mapping how families express their support and care of children and relatives with disabilities dominate in the literature. They typically show that mothers are responsible for most direct care, with male partners playing a more secondary or even discretionary role. Indeed, it is the mothers who continue to occupy the role of what might be termed *primary caregivers*. In these regards, their commitments parallel those of mothers of nondisabled children. There is further evidence to suggest that when caregiving needs are most intensive or prolonged it is mothers who will be on the front line. At lower levels of caregiving intensity, contributions from male partners are more apparent. Gender divisions are not quite so clear-cut in relation to indirect care, not least because responsibilities do not fall so readily into the hands of any one person.

In relation to disabled children, grandparent support has been tacit but only recently formally studied in a systematic way. Maternal grandparents have been found to provide more support than paternal grandparents, grandmothers typically provide more support than grandfathers, and grandparents living closer to the family of the child with a disability seem to provide more support than those living farther away. Current research is exploring whether such support truly complements parent support and how it ameliorates or contributes to parental stress and adaptation. Support from siblings of the child with disabilities can similarly complement that of parents and may be particularly important at times when parents are under pressure. The impacts of such obligations on younger siblings, especially those of school age, require special attention given the formative stage of their own development.

Support and care within families are generally presumed to be positive in their effects, but this is not always so. The intent is one thing; the experience may be another. This makes it imperative to draw distinctions between motivations for caregiving, delivery of care, and the actual experience and outcomes of that care from the perspectives both of family members and disabled people in the family. Through careful and ethically sensitive research, representations of the views and experiences of disabled children about aspects of personal and family life are now emerging that will shed further light on supportive arrangements within families.

Family caregiving has also been studied with reference to its intended purposes with a focus on motivations and outcomes rather than tasks. Such research highlights caregiving that is anticipatory, preventive, and protective as well as supervisory and instrumental. Indeed, there is evidence to suggest that family caregivers tend to think more readily along these lines. This has the advantage of sensitizing those with responsibilities for supporting families to the goals to which families aspire, to what families achieve, or to what frustrates them along the way. It therefore shifts the focus from a purely process-based orientation to one that embraces both processes and outcomes.

A linked conceptualization sees disability and its consequences for families constructed from four dimensions: onset, course, outcome, and incapacity. The *onset* of a disability may be immediate or gradual, expected or unexpected, with the particular circumstances creating challenges and demands for families. The *course* of a disability may be progressive, constant, or relapsing/episodic. The character of the course therefore affects the ability to predict when and how supports need to be put in place. The *outcome* of a condition relates primarily to the expectation of death or shortened life expectancy, which may lead to the tendency to overprotection by families. *Incapacity* is the final dimension, characterized in five areas: cognitive, sensory, mobility, energy, and stigma. Different types of incapacity are seen as requiring differing responses from individuals and families, mediated in turn by values, expectations, and available coping resources. The four dimensions within this model are united by what has been called a "meta-characteristic," namely, predictability. Evidence suggests that families find it more difficult to deal with things when conditions remain less predictable. To some degree, this can be overcome by having access to good information about the onset, course, outcomes, and incapacities likely to be encountered.

These are examples of medical model thinking that views the person's disability as *the* challenge to be addressed or overcome. They do not fully explain oppressive forces that people with disabilities and their families face on a day-to-day basis. On the other hand, the social model redefines disability as the product of how the institutions of civil society exclude, disadvantage, or oppress people, rather than viewing impairment as a personal tragedy with the individual as victim. It addresses the lived experiences of people with disabilities and their families. Potentially, then, the social model has the capacity to see the interests of disabled people and their families as being united in a struggle to overcome the environmental roots of disadvantages that bar people from participating in community life on an equal footing with others. A critique of the social model is that impairment per se cannot and should not be marginalized on the grounds that it does in fact play an important part in their everyday experiences as disabled people.

EXPERIENCES OF FAMILY CARE

After many years of research about how families experience disability, most of the accounts are from the primary caregivers—principally, mothers of disabled children, spouses or partners of disabled adults, or children of older people with disabilities. Multiple accounts from different family members within studies are still rare, so controlled comparisons of the roles, reciprocities, experiences, and outcomes of supporting disabled relatives remain a priority for prospective research.

Family caregiving of children and relatives with disabilities is frequently portrayed as a stressful experience. Images of burdened or even burned-out family members who need respite from their caregiving roles continue to dominate the professional and academic literature. These perspectives depict family carers as being physically and emotionally stressed, with limitations placed on fulfilling social relationships, employment prospects, and quality of life. This view is based on a deficit model, which presumes that supporting someone with a disability must be burdensome or unduly challenging and that burden and challenge lead inevitably to negative experiences within the family. Nevertheless, there is a lot of evidence showing that perception of potential stressors and how these are appraised in relation to available personal coping resources are important keys to understanding how family members adapt to the pileup of demands they face.

Recent studies of parents with children with intellectual disabilities show that mothers tend to be more stressed than fathers by the behavior problems of the child, possibly because they are more involved in everyday direct caregiving, but that fathers can be more troubled by external factors such as other people's responses to or acceptance of the child. Many mediating factors have been identified in explaining such gender differences, but there is a general acknowledgment of the need for much further carefully designed research here.

Stereotypes are sometimes used to maintain an underlying pathological view of families. For example, it is still common within professional discourses to hear families being talked about as if they were responsible for the difficulties faced by their disabled relative. This is perhaps most prevalent in connection with parents of disabled children where the language of overprotection is commonly used. Similarly, the stress and burden families are presumed to face are sometimes linked to the idea that families are rather passive, unresourceful, and lacking in agency. Alternatively, in other accounts of family caregiving there is a tendency to view families as having agendas and needs that stand in opposition to those for whom they care, this perhaps being more common where disabled family members have reached adulthood with distinctive rights and claims of their own. Then there are families who are depicted as being frozen in time as a result of wanting to remember earlier times before they were engulfed by caregiving demands.

This type of imagery identifies caregiving, most of it undertaken by women, as a part of their oppression or marginalization, the proposed solutions to which appear to be a return to forms of residential or collective group home living by disabled people. This position has been criticized by disabled feminists for assuming that disability equates with dependency, and for also overlooking the voice and subjective experience of disabled people themselves, and what they contribute to collective well-being within the family and beyond.

More recently, there has been growing recognition of the wider complexities of family caregiving, including a fuller appreciation of its associated transformations and rewards. This, in turn, has been leading to a more positive view of how families accomplish their caregiving and of the capacity of families to learn, adapt, and overcome. In families with children and adults with intellectual disabilities, for example, there is undeniable evidence showing how the coping repertoires of families expand through experience. This evidence also shows how mastery increases though the growth of self-confidence and skills. As family members ascribe meaningfulness to their caregiving, the role and position of caregiving are often reevaluated in a positive way. Strengthened ties between the caregiver and the cared-for person are commonly reported arising from a fuller acknowledgment of the layers of reciprocities that bind people together. Love, coupled with the moralities of duty and obligation, is important here.

There is also experience suggesting that rewards and satisfactions accrue from overcoming everyday challenges. These can emerge from dealing successfully with matters that might seem mundane to third parties—helping to lift someone more efficiently, receiving a smile of acknowledgment from someone with a severe cognitive impairment—but they can also occur when families make breakthroughs, especially when their caregiving efforts give rise to a reevaluation of prognoses by doctors, as has happened quite frequently in families with disabled children.

Hence, despite what might at first appear to be multiple limitations in their daily lives as a result of caregiving, many families share hopeful visions and experiences, or what some have called profound personal growth, because of this experience. This "embrace of paradox" as it has been called is a perspective that acknowledges the frustrations, the sometimes dashed hopes, and the emotional troughs of caregiving experiences, but it also suggests the existence of a capacity to bounce back as a result of something more resilient that makes families what they are.

Identifying all the factors that appear to make some families, or some family members, more resilient than others when facing similar challenges remains an important topic for continuing research. Different theoretical starting points are assumed: some searching for personal qualities that make some individuals more resilient than others, while there is an alternative view that resilience should be viewed as a family-level construct. A number of different starting points have been suggested for further investigation here.

First, there is the theme of identifying capacity rather than incapacity within families. Families are often reminded by outsiders of their deficits rather than their competencies and expertise. Like disabled people, families are often reminded of their dependency status by formal organizations that continually check their eligibility for health or social care services. Newer service models are placing an emphasis on devolved systems of funding and decision making, including the introduction of direct-payment systems.

Second, there is growing evidence of the importance of the search for meaningfulness as a key to understanding successful coping and management. Families can be presented with many unexpected demands or find themselves doing their caregiving under nonnormative circumstances, for example, continuing to look after a disabled child for years beyond what they had predicted. Hence, they typically reframe the meaning of what they are doing, often by adapting their values and beliefs as they proceed. Such evidence can be found within the accounts of many older family caregivers.

Third, the ability of families to maintain a sense of control in difficult situations is a recurrent theme. Problems arise when matters that need control are beyond the direction of the family. This can implicate services as a prime culprit, for services that are designed to support families are often not available, are not synchronized with family routines and structures, are insensitive to family norms and rules, or else fail to involve families as partners when important decisions have to be made. These remain serious challenges for services in many countries.

Fourth, resilient family members need to be able to reaffirm their own sense of identity not only as caregivers but also as persons with important duties and obligations to themselves and to others. These families balance competing claims on their time and energy, giving rise to successful "boundary maintenance" or "border crossing" between their different identities. The role of culture and ethnicity in cementing, if not underpinning, the resilient qualities of families is not clear. Indeed, features of the "holding environment," that is, the social and cultural context in which families do their caregiving, are still being mapped. It is important to understand not only how these environments mold the dispositions and values that family members bring to their caregiving but also how the social networks to which they give rise shape the giving and receiving of care.

An important dimension of the family caregiving experience is the life course of the family. For family members, the life course sets the context for considering tensions around the uncertainties about future caregiving scenarios, maintaining a sense of control of environmental demands, and keeping a balance between the use of private and public time.

Particular tensions arise when individuals have to spend too much of their private time in caregiving when in fact they would prefer to use their time in other ways, private or public. The classic example is the conflict many families of working age face in balancing caregiving demands with employment. These opposing demands are less likely to clash if families can realize tax breaks, welfare payments, flexible working conditions, and job satisfaction, and disabled people can access inclusive education, suitable employment opportunities, or, as necessary, day care. Difficulties can arise for families when they become aware of growing discontinuities between the biological and psychological development of the disabled person. This is perhaps more typical when the disabled person has a cognitive impairment. It is often a signal that caregiving will have to take place "out of time," that is, beyond the point at which other families would normally end their caregiving. This perception of being out of sync with the rest of society represents another conflict for families, here between private time and social time.

While this is happening, families and disabled people have to manage their time and their activities within the calendars set by services and other institutions of society. With increasing plurality in the supply of services, for example, people with disabilities and their families are likely to encounter many transition points as they move between health, education, social care, employment, housing, and independent sector services during the course of their lives. Each transition is potentially very stressful since it usually heralds fresh ambiguities and a requirement to adapt to new service philosophies along with their accompanying rules and obligations.

Over the life course, families then are faced with an array of time demands generated by different personal and public calendars. How families manage such competing demands relates to their resilience and capacity, the "family-centeredness" of services, and the degree of continuity and predictability over the life course. How far this is possible given the destandardization and increasing individualization of the life course in postmodern societies remains to be seen.

ROLE RELATIONSHIPS WITH SERVICES

Families supporting either children or adults with disabilities have been described as having an ambiguous role relationship with services designed to help them. This ambivalence seems to be tied to the stereotypes of families described earlier that introduced family members as potential competitors for health and social care services, as well as allies of the disabled people they support. Four tacit models for understanding this ambivalence have been put forward: viewed by services as "resources," families would be maintained in their role as caregivers; viewed as "co-workers," they would attract greater recognition of their role from services; viewed as "co-clients," their needs are likely to be difficult to disentangle from those of their disabled relative; and finally, in the case of the "superseded" family caregiver, services would aim to replace or substitute them.

These are not fixed categories, and it is likely that over the life course family carers may well move between these roles as circumstances change, reflecting the accumulation of expertise, a preparedness to continue caregiving, and the emergence of the family caregiver's own needs. The implications of perceiving family caregivers in these contrasting ways are quite profound, for each category is associated with different sets of assumptions about what carers bring to their caregiving as well as what they might expect by way of support from services.

Service systems tend to view families largely as resources, and by various means seek to maintain them in their caregiving roles. This commitment seems to predominate over other functions, for example, those tied to enabling families to enhance caregiving enrichment, or supporting efforts by families to abrogate caregiving responsibilities without feelings of guilt when demands become too onerous. The agendas of services and families can therefore be dissimilar in significant respects.

For many years, there has been talk of professionals and services working in partnership with families, but often the rhetoric has not been matched by funding to plug gaps in family support services, by addressing imbalances in power relations, or by providing incentives for families to engage service systems in a more positive way. More recent policy initiatives in a number of countries are at last beginning to tackle these issues. System change at a number of levels is occurring to help make partnership work with families a reality. This change has entailed the following:

- A reorientation of professional activity from individualized casework to family systems approaches where reciprocities and individual autonomy within the family are respected
- A shift from the professional as expert to the family and disabled person as expert and potential case manager
- Adoption of a competency (or *salutogenic*) view of the family rather than a pathological view of the family
- An approach to assessment of family support needs that is committed to enabling families and disabled people to articulate their dreams and strengths
- Recognition that the solution to people's needs and problems is likely to be found by tapping the natural resources of the family and community with services acting as enabler, rather than by a reliance on services as the solution to everything
- Decision making that adopts a "non-zero-sum" approach, that is, where, as a result of consultation, there is the prospect of multiplying support, expertise, and knowledge that benefits all parties
- Delegation of decision-making responsibility and control of resources to people with disabilities and

families where this is feasible and, where not, to the point closest to them as possible
- A long-term view so that families can realize the kind of transitions that will occur over the lifespan and can plan for these
- New organizational forms that are more responsive, organic, and network driven rather than formal and bureaucratic
- Autobiographies and narratives based on the lives of people with disabilities and their families that act as testimonies to the values and principles to be respected in how they should be supported

—*Gordon Grant*

See also Caregiving; Child Care; Family, International; Social Networks.

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FAMILY, INTERNATIONAL

Internationally, the great majority of families caring for a disabled member live in the developing world. Life is hard for everyone, but these families often have a poorer quality of life due to the persisting stigma of disability in most cultures and the extra care demands that are placed particularly on the women of the family.

In the past two decades, three strategies have been effective in supporting these families: parent associations, home-based support, and income generation. Nonetheless, the obstacles to providing a better quality of life are formidable and their removal is dependent on a much larger agenda of political and economic advancement within and across nation-states. The primary lesson from the twentieth century is that it can be done. The challenge for this century is to make this a reality for most families with a disabled member.

WOMEN'S WORK

In all societies of the world, the task of child rearing and child caring falls mainly on women, usually mothers but also grandmothers and daughters. Mothers fulfill four main roles in relation to the disabled child or dependent adult: survival, intellectual development, socialization, and emotional support. (For convenience, the term *mother* is used throughout this entry.)

For many families in developing countries, their immediate need for survival is for food, clean water, sanitation, and basic health services. Unlike rich countries, the major causes of disability in these countries are childhood illnesses such as measles and cerebral malaria. Mothers have to keep the family fed and healthy.

Mothers and siblings promote intellectual development through the one-to-one attention in tasks such as feeding and dressing or through family games and activities. Often it is mothers who seek out nursery and school placements and assist with homework. With the disabled child, it is mothers who attend clinic appointments and who are expected to carry out recommended therapies at home.

In many cultures, it falls to mothers to socialize the child into the wider community, by bringing the child to family and community events such as religious ceremonies and celebrations and also by encouraging friendships with peers and relatives. Implicit in this is an inculcation of moral values and conduct.

Emotional support, in the form of close, sensitive, and loving relationships between mothers and children, will do much to foster their self-confidence and self-esteem, providing the child with a much needed sense of security and safety.

Mothers have to fulfill these roles alongside the other demands placed on them: working in farms or factories, coping with household chores, caring for aging parents, and being a wife. Most mothers manage all these roles despite the famines, wars, and poverty that beset many lives. A child with a disability may be the least of their worries and can even be a solace amid their woes.

The fact that most mothers and families cope is not to imply that it is natural or easy. The sacrifices are many, not least in terms of self-fulfillment and the poorer physical and mental health of these mothers, which has been evidenced in many different countries.

Yet despite attempts at finding other ways of bringing up a disabled child, the best alternative for families who are unable to care for a disabled member is undoubtedly to find another family. In Western countries, fostering and adoption rather than placement in children's homes and residential schools—no matter how well these institutions are staffed and resourced—has become a much sought after alternative. Professional workers are limited in their expertise and influence in the lives of children. Their essential role is to support families in their child-rearing and child-caring responsibilities. In the case of persons with disabilities, this may extend far into their adult years.

Yet research suggests that support from professionals is secondary to the support mothers receive from their partners and extended families. A disturbing trend internationally is the rise in the number of single parents caring for a disabled family member and the breakdown of extended family networks.

Support from neighbors and friends is more forthcoming too when the disabled person is accepted socially within the community. Particular emphasis is now placed on creating inclusive schools that are prepared to enroll all children, no matter their impairments.

PARENT ASSOCIATIONS

The perceived shame and disgrace of having a child with a disability are often keenly felt by families. Common explanations for the disability revolve around old superstitions and punishments for misdeeds, usually by the mother. Parents, individually and collectively, have been to the fore in challenging these beliefs. The pioneering parents tended to be better educated, articulate, affluent, and well connected in society. And although motivated to get the best for their child, they argued for a better deal for similarly affected families. Invariably, they came together with others to share experiences and to join forces in making their views known, and so parent associations were born. Although varying in size and sophistication, these associations commonly fulfill four main functions: providing parents with solidarity, information, advocacy, and services.

Solidarity

The heartache that comes from feeling alone with a problem can be assuaged by meeting others who have been through or are going through similar experiences. Membership can also boost parental self-confidence and help to create a sense of pride in having a child with a disability. This appears to be best fostered at a local level; hence, national associations work hard to instigate and sustain a network of branches throughout the country. Likewise, solidarity can also be nurtured internationally through worldwide organizations such as Inclusion International, which claims links with 20,000 associations of families and self-advocates.

Information

Parents bemoan the lack of information available to them even when they have access to a range of professionals. They need information that is tailored to their needs and concerns and presented in readily accessible ways. Parent associations often produce newsletters for their members; most organize meetings, conferences, and training events with invited speakers; some have telephone helplines; and other employ "parent advisers" or development workers to provide information and training for their members. The Internet is becoming a major information resource for parents in more affluent countries.

Advocacy

National associations play a vital role in speaking up for the rights of people with disabilities. They often organize events to profile issues of concern and to gain media interest. Delegations from the association may also meet government officials to press their case. Likewise, national association may support individual members as they confront local discrimination, such as school enrollment. Parent members can be trained to act as advocates and trainers of others.

The advocacy role is more effective if alliances are made with other organizations that share a common interest, most notably organizations of people with disabilities. In many countries, there is now some form of national disability council or forum that brings together all the disability organizations with a primary goal of advising and lobbying government.

Services

Parent associations through co-operative endeavors can offer services to their members. For example, parents may take turns in staffing a day care center so that other mothers can have time for other duties. Many associations have opened resource centers for their members where they can meet visiting specialists, obtain information, borrow toys and equipment, and attend income-generating activities. In more affluent countries, parent associations have started special schools, training workshops, and residential homes. These service initiatives are open to criticism, mainly on the grounds that it absolves communities and governments from investing in service provision and perpetuates a charitable ethos rather than a rights-based approach.

HOME-BASED SUPPORT

In Western countries, one of the success stories of modern disability services has been the advent of home-visiting programs in which a trained worker regularly visits the family to advise on ways of promoting the child's development. With experience, their role has widened considerably, often providing emotional support to mothers, giving advice on other family matters as well as acting as an advocate for the family. Among the best-known programs are those based on a model originating in the United States in Portage, Wisconsin, but now used in many other countries.

Around the same time, the World Health Organization started to promote the concept of community-based rehabilitation (CBR) as a means of helping people with disabilities in the developing world. Here too, a trained worker, who may be paid or unpaid, visits the person with a disability at home to show the families what they can do to help their disabled member and to offer the family support and encouragement. Although the evidence remains equivocal as to the impact such home-based programs have on the development of the person with disabilities, there is widespread agreement that they are valued highly by families. James Gallagher attributed this to "a new spirit of optimism and encouragement within the family," replacing the despair and feelings of hopelessness that usually flow from disability.

Home visitors are not a new concept. The extended family or "tribe" has often provided an adviser or confidante to new mothers with whom they can discuss their concerns. The home-visiting concept builds on this tradition by introducing the family to a person who has particular expertise or interest in the disability. However, cultures vary in their tolerance of an outsider becoming involved in family issues, and services must be sensitive to this when recruiting staff to act as home visitors.

Recruiting Home Visitors

Home visitors can be recruited from at least three different sources, and around the world, projects invariably use some combination of these. First, existing personnel are redeployed to act as home visitors. Teachers, therapists, and health workers have adopted this new style of working rather than solely seeing people in hospital clinics or disability centers.

Second, home visitors are paid employees who have been recruited and trained specifically for this role. Although the original idea was to recruit people from the community, in later years an increasing number of people with disabilities or parents of children with disabilities have successfully been employed as home visitors. This strategy not only gives much needed employment opportunities, but these individuals come with personal insights and motivation that can make them more effective and acceptable to families.

Volunteer workers form a third option. Some community services use family members as their primary workers, whereas other community programs have successfully recruited teachers and health workers, among others, to act as voluntary supporters for families. This is best exemplified in Brian O'Toole's work in Guyana.

However, the qualities that home visitors bring to the job, rather than the background from which they come, ultimately appear to contribute more to their effectiveness. In particular, it is important that home visitors do the following:

> *Empathize with the culture of the family.* Families are then more accepting and trusting of them.
>
> *Respond practically to the family's needs.* Parents should experience some immediate benefits from having a home visitor.
>
> *Try to involve all family members.* Grandparents, siblings, and cousins can all be recruited to assist with the child who has a disability.
>
> *Empower families to be decision makers.* They should share information and expertise freely with families so that they are empowered to make decisions and solve their problems.

Although the options for finding effective home visitors are available in most communities around the world, a great deal of effort needs to be expended on recruiting suitable persons because of the inevitable turnover that occurs with poorly paid or volunteer workers.

This approach of providing personal supports to families and people with disabilities is now widely accepted in developed countries as a means of giving carers extra help at home or short breaks from caring as well as enabling people with disabilities to live independently in what has become known as *supported living.*

RESPONDING TO POVERTY

All over the world, disabled people are more prevalent among poorer families. In more affluent countries, state pensions and social payments help to offset some of the consequences for families of having a disabled member, but this is not so in developing countries. Indeed, many of the so-called developing countries are in fact becoming poorer as they are beset with trade barriers, famine, civil wars, and diseases such as AIDS.

Malnutrition among mothers and infants is endemic in many developing countries. The economies of developing countries will never be able to sustain the levels of health care needed by persons with biological impairments. Infant mortality and increased morbidity will long continue to be featured in third world statistics.

The growth of industrialization and the drift to the cities has split families as fathers have sought employment away from the rural areas. Moreover, people with disabilities are more likely to be discriminated against by employers, or they risk exploitation with poor wages and substandard working conditions.

In many developing countries but especially in Africa, AIDS is taking a heavy toll on families, leaving many children orphaned and in the care of aging grandparents and relatives. Among these are teenagers and adults with disabilities who will require lifelong care but have no one to provide it. The full impact of this tragedy has yet to be felt and may never be fully known.

The option of moving away from the family home into other forms of care situations is an option for few people with disabilities in the developing world. Nursing homes, shared housing, or supported tenancies may be available but only for a few and for those families that can afford it. As medical advances have an impact on developing nations, increased longevity will surely result. Yet there are few provisions for the care of adults with disabilities who outlive their carers.

This depressing analysis had led some to question the wisdom of focusing intervention efforts solely on people with disabilities and family supports while ignoring the wider social context in which the recipients live. Rather, the solution they espouse is to empower communities to manage and direct their own development and in so doing to help all their members. This is new and radical thinking and for which Western style disability specialists have little experience.

Income Generation

Foremost is the need to instigate and sustain income generation initiatives for families and persons with disabilities because any member of the family who is not productive is then a drain on family resources. At a minimum, children with disabilities need to become self-reliant in their personal care and be able to undertake jobs around the home such as water fetching so that the family workload is shared and others are freed to earn an income.

It is better still if the young people can play a part in income generation perhaps by assisting on the family farm or business or by holding down a job with local employers. The latter option is becoming more of a reality in developed countries with the advent of supported employment programs in which a support worker trains the person with a disability on the job and remains available to offer support and guidance to employers and co-workers should problems arise. It is possible that similar programs could operate in developing countries, especially in urban areas and as industrialization advances.

Likewise, co-operatives have been established for disabled people or for mothers in which they generate the goods and services that will find a ready market in local communities, for example, the production of school uniforms and leather goods, basketry, and raising chickens.

Revolving loan and micro-credit programs have been used to provide the necessary capital to individuals and communities. The payments on the loans are used to help fund others to start similar schemes.

Community Development

Three basic tenets must underpin these and similar initiatives. First, change has to come from within families and communities. If imposed from outside these systems, it is unlikely to be sustained or to flourish.

Second, the leaders who will instigate and nurture new developments are already present in every community, but they need to be equipped with the skills and knowledge needed to function as effective leaders and given a vision of how things could improve for their community.

Third, development has to start with the present reality within communities and be shaped according to their needs; hence, there is no one universal "treatment" or approach that can be immediately applied across a nation.

Finally, these approaches will become fully successful only when society's attitude to disability is transformed from primarily a medical problem to a social issue, from a specialist concern to a community focus, and from a charitable ethos to an issue of human rights. This is starting to happen through government policies stimulated by the United Nations Standard Rules, but the transformation has to grow also at the grassroots level, and that is the bigger challenge.

Throughout human history, families have nurtured, supported, and loved their weaker members. This still remains the most cost-effective means of responding to the needs of disabled persons the world over.

—Roy McConkey

See also Caregiving; Child Care; Community-Based Rehabilitation; Developing World; Family; Global Inequities; Home Support; Poverty.

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FAMILY: LAW AND POLICY

The historical norm for individuals with disabilities was isolation and segregation from the rest of society. Due to the work of disability advocates, however, attitudes toward people with disabilities started changing from one of exclusion to one of integration. In the 1970s, the United Nations passed declarations that argued that people with disabilities have the right to full participation and nondiscrimination in their communities. By the end of the twentieth century, many nations created laws that protect individuals with disabilities by making discrimination illegal and protecting their right to full participation and integration in society.

This entry focuses on the relationship between the law and families that have children with disabilities. Two topics are pertinent. First is how the law can serve as a tool for families to protect their children's right to "live in the world" with the same rights and benefits as nondisabled children. What follows is a brief overview of nondiscriminatory laws, educational laws, and entitlement services that provide support and legal protection for families and their children with disabilities. After examining how the law protects a disabled child's right to integration and nondiscrimination, the second topic addressed is the controversial issue of whether a disabled infant has any right to live at all. In particular, the issue takes the form of a question of whether the law provides a right for parents to refuse necessary life-sustaining medical treatment and intervention.

NONDISCRIMINATION AND INCLUSION

Antidiscrimination legislation is a powerful tool for parents to prevent their child from social exclusion and isolation as a result of her or his disability. The earliest and most comprehensive antidiscrimination legislation emerged in the United States through Section 504 of the Rehabilitation Act (29 U.S.C. § 794) and the Americans with Disabilities Act (ADA) (42 U.S.C. § 12101–12213), which prohibit discrimination on the basis of disability. The statutes forbid discrimination based on invidious affirmative animus, and discrimination based on thoughtlessness, apathy, and stereotypes about disabled persons. The U.S. Congress found that individuals with disabilities are a "discrete and insular minority" who face restrictions and limitations "resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society" (42 U.S.C.A. § 12101(a)(7)). By prohibiting discrimination on the basis of disability, these two statutes were designed to ensure that disabled individuals have the same access to education, employment, goods, and services as the nondisabled.

Section 504 became law in 1973, and it was the first major nationwide antidiscriminatory legislation designed to protect disabled Americans. The purpose of Section 504 was to "firmly establish the right of . . . [disabled] Americans to dignity and self-respect as equal and contributing members of society, and to end the virtual isolation of millions of children and adults from society" (118 Cong. Rec. 32,310 (1972) (statement of Sen. Williams)). Section 504, however, was not the panacea to eliminate societal discrimination against disabled persons because its scope was limited to prohibiting discrimination by the U.S. government or any program or activity that receives federal financial assistance.

The ADA, which became effective on July 26, 1990, expanded Section 504's mandate to eliminate discrimination by prohibiting discrimination in employment, housing, public accommodations, education, and public services. It requires that

> no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases, (or leases to), or operates a place of public accommodation. (42 U.S.C. § 12182(a))

The ADA's purpose is "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities" (42 U.S.C. § 12101(b)(1)).

The ADA and Section 504 provide a framework that is designed to differentiate discriminatory from nondiscriminatory behavior toward individuals with disabilities. This legislation requires places of work, education, or transportation to make "reasonable accommodations" for individuals with disabilities that enable them to enjoy the same opportunities as the nondisabled. Reasonable accommodation essentially means that business and places that provide public services must make modifications in their programs and services that would provide disabled individuals the same benefits and privileges as the nondisabled. Failure to make a reasonable accommodation constitutes discrimination unless there is no way to accommodate the difference or it is an "undue hardship" to provide such accommodation. An undue hardship means that providing reasonable accommodations would require extreme difficulty or expense, which has to be proven on a case-by-case basis.

Similar antidiscrimination legislation emerged in other countries throughout the 1990s. Specifically, Australia's Disability Discrimination Act, New Zealand's Human Rights Act, the United Kingdom's Disability Discrimination Act, Israel's Disabled Persons Act, Canada's Human Rights Act, and India's Disabled Person's Act all prohibit discrimination against disabilities. In addition to nondiscriminatory legislation, there are other critically important legal tools for families to guarantee their disabled child's ability for full participation and integration in society, especially the Individuals with Disabilities Education Act (IDEA), which is designed to protect disabled children's right to education.

Education

In 1975, the IDEA was enacted to meet the educational needs of children with disabilities (20 U.S.C. §§ 1400–1485). The U.S. Congress found that more than 1 million children with disabilities were being excluded from public education, and 50 percent of all children with disabilities were not receiving appropriate education (42 U.S.C. § 1400(c)(2)). The purpose of the IDEA is to

> ensure that all children with disabilities have available . . . a free appropriate public education which emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living, to assure that the rights of children with disabilities and their parents or guardians are protected, to assist States and localities to provide for the education of all children with disabilities, and to assess and assure the effectiveness of efforts to educate children with disabilities. (42 U.S.C. § 1400(d)(1)–(3))

Protecting and improving disabled children's educational experience is necessary to "ensure equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities" (id.).

The purpose of the IDEA is to provide disabled children with an individualized education. Specifically, each disabled child must be educated in the least restrictive environment (LRE) appropriate to her or his needs. This means that a disabled child may be removed from the regular educational settings only when "the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" (34 C.F.R. § 300.550(b)(2)). Thus, the LRE then creates a presumption of integrating disabled children in their school environment.

The cornerstone of the IDEA is an individualized education program (IEP), which is a joint document between the disabled child's parents or guardians and school authorities. The IEP describes the child's abilities and needs and prescribes services to meet the individual needs of the child. An IEP must be formalized in a written program that contains information about the child's current level of educational performance, annual educational goals, specific services that the child will receive, and details concerning the extent of the child's involvement with regular educational programs.

In addition to protective laws for children with disabilities, many nations also have entitlement programs that provide services to families and their children with disabilities, which will be addressed next.

Entitlement Programs

The United States, as do many other countries, provides entitlement programs for families with disabilities. Entitlement programs can cover a wide range of different services from subsistence income, educational grants, and training for disabled individuals or their families. In the United States, for example, families that have disabled children may qualify (based on income and resources) for Supplemental Security Income, which entitles families to monetary assistance, and Medicaid health care coverage for their disabled child. Moreover, federal grants provide training for disabled individuals and their families. For example, under IDEA, grants provide support and information centers for parents of children with disabilities.

In the next section, this entry moves from discussing antidiscrimination protection and social support to examining whether parents have the right to refuse necessary life-sustaining medical treatment for their newborn.

DISABLED NEWBORNS

In the early 1980s, families, lawyers, bioethicists, and the courts were involved in a legal and moral battle over whether the parents of disabled children had the right to refuse medical treatment for their children. The legal question was whether parents or medical authorities could choose to let a disabled infant die rather than provide the child with necessary medical treatment or nourishment essential to sustain life. The following is a brief overview of this dispute, explaining how U.S. courts and the federal government tried to resolve this controversial issue.

In 1982, the debate started when the parents in a Bloomington, Indiana, family wanted to let their baby, who had Down syndrome and an esophageal blockage, die rather than receive lifesaving medical treatment after their doctor told them what their child's life would be like with his disabilities. The parents' decision, however, was challenged in the now famous *In re Infant Doe* case (commonly known as the Baby Doe case). The child's parents and doctors argued against corrective surgery because they believed a child with Down syndrome would have diminished quality of life—in essence, it would be better for the child to die than live with his specific disabilities. The court held that that the parents had a right to withhold treatment and ordered the hospital to comply with the parents' decision. A few days later, Baby Doe died from starvation.

Advocates of letting parents have the right to refuse medical treatment for disabled children had several rationales, which, generally, focused on sparing a life that they believed would suffer an exceptionally low quality of life. Adrienne Asch (2001) summarized the reasons for withholding treatment in the following:

> Rationales for withholding treatment focused on the physical suffering and pain of the potential treatments as well as the impairments themselves; the conviction that technology was being used to sustain children who would have short, painful, and miserable lives regardless of what was done for them; the anguish for parents who had to watch a child die slowly after enduring fruitless medical procedures; disappointment for parents who would not have the healthy child they expected and desired and might instead have to raise one who would always have disabling conditions; and believe that the millions of dollars spent for such treatments were better spent in other ways. (Pp. 303–304)

Disability rights advocates who opposed allowing parents to let disabled children die rejected arguments that disabled children have a low quality of life. A 1989 study by the U.S. Commission on Civil Rights supported disability rights advocates' arguments when it found that a majority of disabled Americans do not see themselves as having a poor quality of life and would not choose death over life (pp. 32–33). Disability advocates argued that disabled individuals had the right to receive treatment, and refusal constituted unlawful discrimination.

In response to *In re Infant Doe* and similar cases, the U.S. Department of Health and Human Services (DHHS) created a rule maintaining it unlawful for any federally funded hospital to withhold medical treatment from disabled infants. Hospitals and doctors challenged the DHHS decision in U.S. federal court. The issue of whether the federal government could require hospitals to treat disabled children despite the wishes of parents and medical providers finally made it to the U.S. Supreme Court in *Bowen v. American Hospital Association.* In 1986, the Supreme Court held that denying treatment to disabled infants did not constitute legally protected discrimination under Section 504 of the Rehabilitation Act. The Court argued that the hospital and physicians do not make treatment decisions for disabled newborns. Instead, hospitals and doctors implement the decision of the parents. If the parents do not want treatment for their child, then the hospital is not discriminating against the child. In essence, the Court held that for a hospital or doctor to discriminate against a disabled child, parents of the disabled infant would have to want medical treatment but the hospital and doctors would have to refuse treatment because the child is disabled.

Although the *Bowen* decision held that federally funded hospitals and doctors do not discriminate against disabled children when they refuse medical treatment in accordance with the parents' decisions, the U.S. Congress enacted the Child Abuse Amendments of 1984, which called for the medical treatment of newborns with disabilities unless the child would die even with medical intervention (42 U.S.C. §§ 5101–5106, 5111–5113, 5116 [1990]). Specifically, the amendment only allows medical treatment to be withheld if it would be "futile" or "merely prolong dying" (id.). The only remedy for violations under the statute, however, is loss of federal funds, which limits the statute's effectiveness.

Currently, the vast majority of disabled infants receive necessary medical support and care. Asch (2001) states that as of the year 2000, most newborns with Down syndrome and spina bifida and infants born with premature and low birth weight in the United States receive medical intervention (p. 305). Thus, she argues that the Child Abuse Amendments, presidential commission writings, and disability advocates "have all combined to ensure that most babies who can benefit from medical interventions do receive them" (p. 305).

CONCLUSION

The challenges in the legal relationships of families that have children with disabilities are ongoing. Antidiscrimination laws, educational laws, and entitlement services provide important tools for families to protect their disabled child's right to full participation in society. U.S. Supreme Court decisions, such as *Bowen v. American Hospital Association,* show how U.S. courts and the federal government have tried to resolve the controversial issue of whether parents have a legal right to withhold necessary life-sustaining medical treatment from their disabled newborns.

—*Jeffrey M. Brown*

See also Americans with Disabilities Act of 1990 (United States); Antidiscrimination Law, Judicial Interpretations; Bioethics; Children with Disabilities, Rights of; Down Syndrome; Individualized Education Program; Individuals with Disabilities Education Act of 1990 (United States).

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FindLaw, www.findlaw.com

National Counsel on Disability, http://www.ncd.gov

FEEBLEMINDEDNESS

By the early 1900s, *feebleminded* was widely used by eugenic social reformers and mental health professionals in England and the United States as an umbrella term referring to all degrees and types of "congenital defect." Upon its inception, this term attempted to replace earlier, more offensive categories such as moral and intellectual idiocy, but by uniting discrete social, medical, behavioral, and economic stigma under one name, the category provided dangerous interpretive flexibility. By 1915, the American Association for the Study of the Feeble-Minded defined the category broadly to include any person deemed "incapable of performing his duties as a member of society in the position of life to which he is born." Similarly, in England, the Royal Commission on the Care and Control of the Feebleminded defined a feebleminded person as incapable of competing on equal terms or of managing his or her affairs with "ordinary prudence."

Such wide-ranging classifications allowed eugenicists to conflate myriad social problems such as poverty, growing immigrant and nonwhite populations, unemployment, and criminality with purported medical and scientific diagnoses of cognitive impairment. In effect, influential eugenicists reductively explained complex cultural issues as part of a crisis brought on by a menacing and ever-expanding army of "subnormal" classes. As examples, Walter Fernald applied feeblemindedness to groups as diverse as the blind or cognitively impaired to those with poor social conduct. Harry Laughlin, an active proponent of sterilization and eradication policies, built on Henry Goddard's model to define "social inadequates" as those who failed chronically in maintaining themselves as "useful" citizens. Laughlin's inadequate classification brought together the criminal, poor, vagrant, physically and cognitively impaired, chronically ill, and visually and hearing impaired with the leprous, tuberculous, syphilitic, orphaned, and alcoholic. In this way, the process of diagnosing feeblemindedness became a simple project of locating disability, disease, moral impropriety, or economic dependency, and using these traits as evidence of mental deviance.

In an effort to further refine taxonomies of feeblemindedness, eugenicists designated specific subcategories such as the *idiot*, *imbecile*, and *moron* to reflect the range from lower to higher grades of mental defect. The introduction, maturation, and proliferation of mental testing during this period allowed eugenicists to attach particular mental ages to these categories. By 1920, these designations were solidified: Idiocy indicated a mental age up to two years; imbecility from three to seven years; and the moron category referred to those graded from 7 to 12 years. Goddard invented the term *moron* to designate those individuals most difficult to identify as mentally deficient because of their seeming normalcy. Many eugenicists considered such "borderline" individuals the greatest threat to social progress and reform.

The process of naming, labeling, and classifying individuals is inevitably a process of differentiation, and in the case of identifying feeblemindedness, it also provided eugenicists with a troubling rationale for treating people with coercion, disrespect, and profound inhumanity. Using ungrounded hereditarian arguments and misplaced medical diagnostics, anyone designated within these categories of subnormality became particularly vulnerable to state-sanctioned segregation, institutional confinement, and enforced sterilization. Once someone was *diagnosed* as feebleminded, this person was rhetorically constructed as a social menace or economic burden and represented by eugenicists as part of an urgent problem in need of eradication.

—*Michelle Jarman*

See also Biological Determinism; Eugenics; Walter Fernald; Henry Herbert Goddard; IQ; Mental Illness; Sterilization.

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FEMINISM

Feminism can be defined as a movement to achieve equality between men and women and to end male domination of society. It has its origins in the late eighteenth century when Enlightenment ideals of equality and individual freedom supported an emerging campaign to extend education, professional employment, and the vote to women. "Second wave" feminism, which dates from the late 1960s (by which time women's suffrage was well established in most industrialized countries), has sought to broaden the focus of attention to include women's position within the private sphere of domestic and family life. Fundamental to its approach is the distinction between *sex,* which is regarded as a biological characteristic rooted in nature, and *gender,* which is viewed as a social characteristic deriving from the meanings given to sexual differences by society. It is these socially assigned meanings that are seen as at the heart of women's subordinate position in society, and it is the transformation of society in relation to these meanings that is seen as liberating women from oppression and exploitation.

Feminism (or the women's movement) has much in common with the disability movement in terms of both its analytical position and its political activism. It has therefore been a source of some frustration to those who have links with both movements—most notably, disabled women and mothers of disabled children—that stronger alliances have not been forged between them. Indeed, it appears that neither movement has paid serious attention to the concerns of the other. Feminism, while increasingly recognizing difference and diversity among women, has largely overlooked disability with the result that it has at times argued in ways that have been detrimental to disabled women. The disability movement, traditionally dominated by men, has largely neglected gender and adopted an agenda predominantly concerned with participation in the public sphere. It has been left primarily to disabled women feminists, marginalized by both movements, to challenge their analyses and to work toward a more inclusive model that recognizes a common cause among all oppressed groups.

A number of very different strands have developed within feminism over the past 40 years, and while none has incorporated a disability perspective, proponents of many have offered their own analyses of disability. Liberal feminists, for example, have focused on inequality of rights and opportunities and have emphasized the need for legislation and education to challenge stereotypes and open up opportunities to all disadvantaged groups including women and disabled people. The latter group includes disabled women who are regarded as bearing a "double disadvantage." Marxist and socialist feminists have focused on women's class position within capitalism and their subordinate position within the family. They argue that equality of opportunity is not enough and call for a transformation of society to challenge the structures that create and perpetuate sexism, disability, and other forms of oppression. Radical feminists explain women's subordinate position in society as the product of patriarchy, a mode of social organization in which men have dominance and control over women, and advocate radical changes ranging from separate communities for men and women to androgeny. Radical feminism is also associated with standpoint epistemology, which recognizes women as having a particular position from which to speak. A similar standpoint positioning has been proposed with regard to disability, which would include the body of knowledge built up by disabled women and a recognition of the interdependence of disabled women's experiences, consciousness, and actions.

Feminists within the disability movement have also tried to take forward the analysis of disability by extending the social model of disability to incorporate impairment. The social model of disability views disability as a problem within society rather than within individuals with impairments. Drawing on the feminist principle that "the personal is political," feminists within the disability movement argue that by focusing exclusively on disabling barriers in the external environment, the social model of disability denies an important aspect of their experience. They stress the need for an analysis that encompasses all aspects of disability, including the experience of impairments and the problems to which they give rise that cannot be solved by social manipulation. These developments are highly contentious within the disability movement where an emphasis on impairments and the *differences* between disabled people is seen as potentially divisive and threatening to the movement as a whole.

While feminist analyses of disability have largely been welcomed by disabled women (and men), disabled women themselves rarely feature in mainstream feminist analyses. As a result, disabled women have argued that much of feminist analysis is of little relevance to, or even in conflict with, their interests and concerns *as women.* This is perhaps best illustrated in relation to two issues of central concern to women: reproductive rights and care in the community. With regard to the first, disabled women feminists point out that mainstream feminism has done much to liberate able-bodied women from the constraints of their roles as wives and mothers but has largely overlooked the way in which disabled women have been denied the possibility of ever fulfilling these roles. Within mainstream feminism, reproductive rights have been seen largely in terms of access to methods of birth control that enable women to make choices about and within motherhood. For disabled women, however, reproductive rights mean something quite different: in the context of discriminatory assumptions about the legitimacy of their desire for children and about their capacity to bear and raise them, reproductive rights mean acknowledgment of their right to have children should they wish to and provision of practical help to enable them to bring them up. Perhaps most contentious of all aspects of reproductive rights has been that of abortion. Feminists have traditionally argued for a woman's absolute right to choose to terminate a pregnancy when the fetus has an "abnormality" and have welcomed antenatal screening as a means through which women can gain further control over their own reproduction. Disabled women, by contrast, have been critical of prenatal screening and selective abortion, arguing that they devalue people with disabilities and that they are potentially a new form of eugenics.

Another key point of debate between mainstream feminism and disabled women has been in relation to community care. Those in the disability movement have welcomed the move away from residential care to care in the community for people with disabilities as a major advance toward greater social inclusion. Mainstream feminists, however, have challenged the development of community care, arguing that it depends largely on women's unpaid labor in the home. By increasing this burden, community care policies further exploit women and perpetuate their dependent role within the family. Disabled women feminists have criticized this analysis, pointing out that it is made exclusively from the point of view of the caregiver and casts the recipient of care as passive and dependent. It also fails to recognize that most recipients of care are themselves women and many have caring responsibilities of their own. It is because they have failed to integrate a disability perspective into their analysis, disabled women feminists argue, that their nondisabled sisters have argued in support of institutional forms of care, which disabled people oppose. It also explains their failure to recognize that the family could be the site of oppression for disabled people as well as women and to join with disabled people in seeking alternative ways of supporting them so they do not have to depend on unpaid care by their family. Feminist philosophers of the ethics of care offer an alternative to both these analyses, challenging the stress each places on autonomy and individualistic independence as aspirational ideals and emphasizing instead the values of caring solidarity and interdependence.

With the turn of the twenty-first century, both feminism and the disability movement have faced new challenges from the growing influence of postmodernism. Postmodernism has the potential to undermine both movements through challenging the principle of universal rights based on citizenship entitlements and through denying that either "women" or "disabled people" constitute a unitary or stable subject on which to base political actions. Despite this, postmodern feminism has developed as an influential strand within feminism, criticizing both the "grand narrative" of feminism and the extreme relativism of postmodernism. Ironically, perhaps, the emphasis that postmodern feminism places on the deconstruction of accepted categories (such as disabled), multiple identities, and the politics of difference may provide fertile ground for a more insightful—though local, contested, and provisional—understanding of disability issues than that provided by previous strands of feminist thinking.

—Mary Boulton

See also Gender; Gender, International; Reproductive Rights.

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FERAL CHILDREN

Before the seventeenth century, outside of myth and legend, only scattered and fragmented stories of feral or wild children appear in European history. Suddenly, during the 1600s, several accounts emerge; there are descriptions of a wolf boy in Germany and children abducted by bears in Poland; and, in 1644, the first story appears in English of John of Liège, a boy lost by his parents in the woods who took on animal-like behaviors to survive on his own for years. Early descriptions of such children detailed their nonhuman qualities: running on all fours, foraging and hunting for food, exceptional hearing, and absence of language. As several such children were rescued from the wild and brought back into human society, their continued animalistic behavior coupled with a seeming inability to master language fascinated philosophers, who began to wonder if such children actually belonged to a different species than the human family.

This question was taken up with great seriousness in the eighteenth and nineteenth centuries as science attempted to name, classify, and understand the intricacies of the natural world and human development. The most widely known feral child of the early eighteenth century was a boy found in Hanover in 1724. Peter the Wild Boy—as the famous Dr. Arbuthnot named him—became a fascination of the English royalty, living for the next few years both with King George I and the Prince of Wales. Like earlier children found in the wilderness, however, Peter's unbreakable silence and unique ability to survive much as an animal would compelled scientists to address this animal-human divide. Within a decade of Peter's discovery, Carl Linnæus, the hugely influential natural historian, actually included feral man, *homo ferens,* as one of six distinct human species. Notably, *ferens* is the only classification listing individuals—rather than whole races—as examples.

In the 1792 translation of Linnæus's *Natural Systems* into English, however, a note was added that such children were probably "idiots" who had been abandoned or had strayed from their families. It was this conflation of feral nature and disability that was taken up by Jean Marc Gaspard Itard in his project of civilizing one of the most famous cases in Europe, Victor of Aveyron, a wild boy caught in 1800 in the forests near Lacaune. Philippe Pinel, the foremost physician in France, dismissed Victor as an "idiot," but to Itard, the boy was a living artifact—an atavistic body on which to test Rousseau's notions of original perfection against a belief in language as the only means through which human identity could be forged. After several years of training, however, Victor was still unable to use language, a failure that further solidified an understanding of feral children as mentally "infantile" and "inferior."

In many ways, the systematic education, training, and confinement of cognitively disabled people in the nineteenth and early twentieth centuries drew on the legacy of "civilizing" projects taken up by teachers of feral children. Building on the techniques of Itard, for example, Eduoard Séguin promoted repetitious physical and mental training processes for "feeble-minded" children—training systems that were further developed by eugenicists in Europe and the United States. During the twentieth century, as psychologists endeavored to distinguish between behaviorism and biological nature, wild children—a designation including children in isolation as well as those who survived among animals—again seemed to provide a key to the puzzle. A pervasive assumption that such children are abandoned or confined by their parents because of apparent cognitive impairments remained entrenched until the later decades of the century.

Presently, most psychologists attribute the inability of such children to master language to their unique histories of survival outside of human society—as a behavioral mechanism specifically adapted to their environment and circumstances rather than a biological inability. Fascination with wild children, however, remains, and the fates of such children become deeply tied to the doctors, teachers, and caregivers, who, through measurement, diagnosis, training, and compassion, inevitably attempt to resocialize these children and return them to the fold of human interaction.

—Michelle Jarman

See also Jean Marc Gaspard Itard; Philippe Pinel; Eduoard Onesimus Séguin; Victor of Aveyron.

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FERNALD, WALTER (1859–1924)

American institution administrator

From the time of his appointment in 1887 to his death in 1924, Walter Fernald served as superintendent of what was then known as the Massachusetts School for the Feeble-Minded (now known as the Fernald Center). In this role as head of the first public asylum in America specifically created to house intellectually disabled people (started by Samuel Gridley Howe in 1848), Fernald became one of the most prominent institutional professionals in the United States, associated with a strong advocacy of institutional care of people with intellectual disabilities. He served two terms as president of the main professional organization in the area of intellectual disability (now called the American Association on Mental Retardation). For many years, Fernald wrote in aggressive terms about the "burden of the feeble-minded" on the rest of society, and he was an active proponent of involuntary sterilization just as eugenics laws were being passed by state legislatures throughout the country.

Unlike most of his colleagues, Fernald moderated some of his more extreme views by the end of his life. He became a supporter of community placement for many of those he previously characterized as part of a "parasitic, predatory class," eventually developing one of the country's largest "parole" systems for moving institutional residents back into smaller, community-based residences.

—Philip M. Ferguson

See also Biological Determinism; Eugenics; *Feeblemindedness*; IQ; Sterilization.

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FETAL ALCOHOL SYNDROME

Fetal alcohol syndrome (FAS) comprises a recognizable pattern of birth defects attributable to the adverse effects of maternal alcohol abuse during pregnancy. The condition was initially described independently by Paul Lemoine in France in 1967, and Kenneth Jones and David Smith in the United States in 1973. The observations of these investigators, later confirmed through animal model and human epidemiological research, constituted the first recognition that alcohol is a teratogen (a substance causing birth defects).

The full-blown disorder encompasses prenatal growth deficiency (persistent after birth), neurodevelopmental deficits, microcephaly (small head size), and a specific facial appearance, including small eye openings and an underdeveloped midface. Cardiac, renal, and skeletal anomalies may also be observed. Subsequently, a spectrum of disability was delineated accompanying prenatal alcohol exposure. Most accurately termed fetal alcohol spectrum disorders (FASD), the gamut of disability ranges from full FAS to neurodevelopmental deficits absent the other features of the syndrome. FASD is the most common environmentally induced cause of mental retardation in the world. Although the prevalence in the United States is generally quoted as 0.5–2.0 cases per thousand births, in some children in the Western Cape province of South Africa rates as high as 48 per thousand have been documented.

—*Kenneth Warrens*

See also Substance Abuse.

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FIBROMYALGIA

Fibromyalgia is a medical syndrome (constellation of symptoms) that is characterized by chronic widespread pain of at least six months' duration. In 1990, the American College of Rheumatology proposed criteria for diagnosis:

- Pain in the axial skeleton (pain in the region of the cervical or thoracic spine, anterior chest, or lower back)
- Pain above and below the waist
- Pain upon palpation in at least 11 or 18 paired tender points throughout the body. (Palpation is performed over the tender points with just enough pressure to just blanch the fingertip of the examining physician.)

SYMPTOMS

The most common symptoms that people with fibromyalgia experience are widespread pain, fatigue, sleep disturbance, and myalgias (muscle aches). There are several other syndromes that are commonly associated with fibromyalgia. These include migraine headaches, irritable bowel syndrome, interstitial cystitis (pain of the bladder region), depression, anxiety, and temporomandibular dysfunction (pain in the region of the jaw).

PHYSICAL EXAMINATION

The treating physician should perform a thorough general medical and neurological examination, which is generally normal. In addition, a complete examination of the musculoskeletal system should be done to evaluate for local overuse pain problems such as bursitis (inflammation of the bursa or fluid sac between bone and muscle), tendinitis, radiculopathy ("pinched nerve" or sciatica), and myofascial trigger points (areas of "muscle knots").

The examining physician should palpate the 18 paired tender points with approximately 4kg of pressure. This is just enough pressure to blanch the fingernail of the examiner. The patient will experience pain at these locations.

TREATMENT

Initial treatment includes patient education, pharmacologic treatment (medications), gentle exercise, and relaxation training. Pharmacologic management aims to normalize sleep patterns and diminish pain. Low doses of sedating antidepressants at bedtime (e.g., 10–25 milligrams of amitriptyline) can be helpful for sleep and pain. In addition, small doses of more stimulating antidepressants (e.g., fluoxetine) can be given in the morning to reduce pain and fatigue. The combination works better than either medication taken alone.

Pain may be relieved with simple analgesics such as acetominophen or ibuprofen. Tramadol is the next-line agent. Opioids (e.g., morphine) are rarely necessary. Adjunctive nonpharmacologic pain control methods include acupuncture, massage, and biofeedback.

REHABILITATION

Physical therapy is used to educate the patient on a stretching, gentle strengthening, and cardiovascular (aerobic) fitness program. This can improve fitness and function and decrease pain. Occupational therapy is incorporated to review ergonomics (efficient ways of performing tasks) of daily household and worksite activities. Task simplification, pacing, and maximization of function are emphasized.

Mental health professionals can be helpful in the rehabilitative phase to educate the patients in a mind-body stress reduction program. This provides the patient with positive coping strategies for living with chronic pain. Associated depression and anxiety may require evaluation and treatment by a psychiatrist.

FUNCTIONAL LIMITATIONS AND DISABILITY

Patients may be limited by both pain and fatigue. Patients also report cognitive dysfunction with difficulty in concentration, organization, and motivation. This has been termed "fibro fog." Approximately 25 percent of patients with fibromyalgia report themselves as disabled and are collecting some form of disability payments. Individuals are more likely to become disabled if they report higher pain scores, work at a job that requires heavy physical labor, have poor coping strategies and feel helpless, or are involved in litigation.

—*Joanne Borg-Stein*

See also Acupuncture; Myofascial Pain.

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Oregon Fibromyalgia Foundation, http://www.myalgia.com. This website is hosted by the Oregon Fibromyalgia Foundation, which was started in 1995 by Robert Bennett and Sharon Clark. It is a nonprofit academic organization that provides reliable and unbiased information to fibromyalgia patients and others.

FILM

The portrayal of disability on film shares traits with that of literature and drama. Disability in film has been disproportionately underrepresented at the same time that it has been excessively displayed. For the most part, disabled characters onscreen are minor figures, whose less-than-perfect bodies serve as a foil for the protagonist. In this way, characters portrayed as disabled perform the dual purpose of signifying a "lack" or character flaw to which more primary characters (and presumed-to-be-able-bodied audience members) might succumb, while at the same time disabled characters reestablish the wholesomeness and integrity of those key characters (and supposedly normative audience members).

In such films, disability figures as metaphorical emphasis for any moral impact in the films that directors wish to impart. Some notable examples include the unconscious character of Alicia (Leonor Watling) in Spanish filmmaker Pedro Almodóvar's *Hable con Ella* (*Talk to Her* [2001]) whose coma enables her nurse and suitor, Benigno (Javier Cámara), to sexually violate her body, or the title character of the independent U.S. film *Pumpkin* (2002), a young man (Hank Harris) with developmental and physical disabilities who comes to represent the undesirable "other" to sorority girl Carolyn (Christina Ricci). The mainstream Hollywood movie *At First Sight* (1998) features a blind character, Virgil (Val Kilmer), who struggles to adjust once he has *regained* his lost vision. This film ironically presents its character as doubly "challenged": first as a character who must relearn how to negotiate his changed environment and second as a living metaphor for the ills of the world that other characters "choose" not to see.

Alternatively, Dogme 95 (a Danish-based collective of film directors) member Lars von Trier's film *The Idiots* (1998) depicts characters who embody the physically normative, yet who perform as if they have cognitive disabilities in order to disrupt and disturb their conventional world. Independent Canadian filmmakers Shawna Dempsey and Lorri Millan, in their short video *The Headless Woman* (1998), display the circus freak not only as metaphoric of the contemporary status of women and especially lesbians but also to reveal the haven that the sideshow world has traditionally offered to people whose bodies and bodily desires did not always fit into societal ideals of "the norm." A small number of mainstream films embrace disabled characters as central to the plot, but that plot usually depends on a narrative of triumph, wherein the protagonist must "overcome" a physical impairment to fit into the normative nondisabled world. In such narratives, the protagonist strives for a victory of personal achievement and attitude, rather than one of making the world more disability-accessible or disability-centered. Examples include Susie Hendrix (Audrey Hepburn) in *Wait Until Dark* (1967), a character who has gone blind and must summon her limited resources to battle the crooks who threaten her, and Alice Culhane (Mary McDonnell) in *Passion Fish* (1992), whose accident has left her a wheelchair user and has also deprived her of her job as television soap opera star.

DISABILITY STUDIES FILM SCHOLARSHIP

Film scholarship on disability representation has followed the stages named by critics David Mitchell and Sharon Snyder in *Narrative Prosthesis: Disability and the Dependencies of Discourse.* Tom Shakespeare, Paul Longmore, and Paul Darke helped to initiate the field with articulations of what Mitchell and Snyder call the "negative imagery" school of disability film criticism. Martin Norden's *The Cinema of Isolation: A History of Physical Disability in the Movies* clarifies such disability critique in its categorization of such disability stereotypes. Norden's categories include the "Civilian Superstar," the "Comic Misadventurer," the "Elderly Dupe," the "High-Tech Guru," the "Noble Warrior," the "Obsessive Avenger," "Saintly Sage," the "Sweet Innocent," the "Techno Marvel," and the "Tragic Victim." He emphasizes the placement of these stereotypes in a number of films, especially those not predominantly focusing on disability.

The first collection of essays to explore the "fusion" of disability and film studies, 2001's *Screening Disability: Essays on Cinema and Disability,* edited by Anthony Enns and Christopher R. Smit, moves to what Mitchell and Snyder call the "social realist" school in an attempt to contextualize and confront the negative images that dominate cinematic representation. Mitchell and Snyder's own work in *Narrative Prosthesis* participates in a stage of disability criticism they have labeled "transgressive reappropriation," which demonstrates how disability representation can work against dominant modes of understanding power and can undermine typical portrayals of social dynamics. For example, in Atom Egoyan's *The Sweet Hereafter* (1997), the character of Nicole (Sarah Polley) openly plays on the effects of her disability to emphasize her newfound power over her sexually abusive father—rather than showcasing her recently acquired disability as an outward sign of a shameful secret. More recently, the Korean film *Oasis* (2002) depicts the "severely" disabled central character Gong-ju (Moon So-ri) forging an intimate link with a male character, Jong-du (Seol Kyeong-gu), who has sexually assaulted her. The characters' outcast status allows them a transgressive space in which to call into question societal assumptions about their personal lives.

SILENT ERA FILMS

With Charlie Chaplin's *His New Profession* (1915) and Tod Browning's *The Unknown* (1927) as perhaps the most prominent and famous examples, the silent era of film introduced a number of disability themes and patterns that continue to this day. For example, *Stella Maris* (1918) features Mary Pickford as a disabled avenger. Though this pattern continues throughout film history, it is important to note that the female avenger is less common than the male. D. W. Griffith's last successful film, *Orphans of the Storm* (1921), portrays a blind sister Louise (Dorothy Gish) dependent on her sighted sister Henrietta (Lillian Gish). The two sisters set out for Paris to seek a cure for Louise's condition and are both kidnapped in the process. King Vidor's *The Big Parade* (1925) introduces a visual standard for the portrayal of veterans who acquire disabilities in battle. *The Hunchback of Notre Dame* (1923) began a long tradition of adapting the novel for the screen and also marked Lon Chaney as a key actor in early disability roles, particularly in the horror genre.

HORROR FILMS

For many filmmakers and viewers, the image of disability and the horror genre are closely intertwined. In Hollywood, movies such as *Darkman I, II, and III* (1990, 1994, and 1996), the various versions of *Frankenstein* (1931, 1970, 1973, 1984, and 1992, among others), *Night of the Living Dead* (1931, 1994), *Terror in the Wax Museum* (1973), and the first of many *Halloween* films (beginning in 1978) exploit viewers' unease about screened versions of crippled, disfigured, or mentally disabled characters. Filmgoers' long association of disabled characters with evil (or at least as living within the realm of evil) reaches from the silent film era's *Hunchback of Notre Dame* (1919), *The Shock* (1923), and *Phantom of the Opera* (1925) to the new millennium's *X-Men* I and II (2000 and 2003), and *Hannibal* (2001). An influential film for directors, actors, and disability activists, the early "talkie" *Freaks* (1932) blasted into cinemas by presenting actual disabled actors as their disabled character counterparts. Both praised and reviled, *Freaks* director Tod Browning reinvented the horror genre at the same time that the ending of his film reinforces a horror-disability correlation.

A subcategory of the horror genre is the science fiction film, many of which began to surface in the late 1930s and return with significant consequences in the late 1980s and early 1990s. Set in a time markedly different from the present, sci-fi narratives invariably propose "alternative" bodily categories as abundant examples of the "norm" gone deviant. Some examples include the Mariner (Kevin Costner) in *Waterworld* (1995), where the proliferation of ocean miraculously encourages evolutionary changes onto the body, such as the main character's gills and webbed feet. Less "neutral" bodily transformations include the clichéd chemical and biological mutants that sci-fi films continue to offer. Examples range from *The Island of Dr. Moreau* (1933) to the tedious genetic-experiment-gone-amok of Ang Lee's *Hulk* (2003). In David Cronenberg's film *Dead Ringers* (1988), twin gynecologists Beverly and Elliot Mantle (both played by Jeremy Irons) liken themselves to the famous conjoined twins Chang and Eng. The twins indulge in sexual exploration while studying the genetically "mutant" body of medical patient Claire Niveau (Geneviève Bujold) at the same time as their attempts to claim individual lives descend into a medical nightmare.

WAR AND WAR VETERAN FILMS

Beginning with Thomas Edison's newsreels featuring war coverage (first projected in 1897), war veterans and characters who have been affected and impaired by war have played a large role in film history. Such documentary spots soon gave way to narrative features, beginning with *The Empty Sleeve* (also released as *Memories of Bygone Days* [1909]). This film participates in a long-standing tradition wherein disabled war veterans gain social value only when they can display triumph in a homecoming celebration of their geographically distant nationalist triumphs. U.S. war films made during or immediately following prominent international conflicts tend to valorize the positive symbolic potential of brave wounds. This pattern has resulted in waves of patriotic World War I films such as *For Valour* (1914), *I'm Glad My Boy Grew Up to Be a Soldier* (1915), and *Womanhood: The Glory of Nation* (1917). U.S. patriotism continued in post–World War II films such as *Thirty Seconds over Tokyo* (1944), *The Enchanted Cottage* (1944), and *Since You Went Away* (1944).

In part because of the large role played by television representation, making the horrors of war immediately available in American living rooms, the Korean, Vietnam, and Iraq (1991) conflicts have yielded many filmic depictions of veteran postwar experiences. Examples include *Coming Home* (1978), *Deer Hunter* (1978), and *Courage under Fire* (1996). A main concern for largely male disabled veterans featured prominently in such films is the type of sexual life they will be able to pursue, and, as a result, their subsequent (masculine) virility comes into question, a patent example being *Born on the Fourth of July* (1989).

Films made following major conflicts are more likely to question the cost of war, with *The Big Parade* (1925) providing an early example. After the glow of World War II conquest began to fade, U.S. filmmakers initiated film plots that questioned the ease of readjustment to ableist home environments. Prominent examples include *The Best Years of Our Lives* (1946), *The Men* (1950), and *Bright Victory* (1952). A film about life subsequent to World War II that contrasts such patriotism is Akira Kurosawa's *Hachigatsu no Kyoshikyoku* (*Rhapsody in August* [1990]), which depicts a character who survived the Nagasaki bombings. She retells (and relives) those days to her grandchildren, for whom the war is simply a long-ago ghost story.

CHILDREN'S FILMS

An often overlooked medium, films directed at children present an especially high number of disabled (or "afflicted") characters. Whether child audiences actually demand physically distinct characters, or whether filmmakers simply find such characters a convenient route through which to navigate the film's narrative and moral conclusions, a plethora of films reproduce disability stereotypes in the visual depictions of secondary characters. Even in a film such as *Toy Story* (1995) that offers a fantastical depiction of childhood imagination, the unavoidable "real world" invades owing to the minor character of the boy next door who destroys the toy-characters and then reconstructs them as "mutant" beings.

As is true of their literary counterparts, disabled characters appear on children's screen as either diabolical (e.g., Captain Hook in *Peter Pan* [most recently 2003] and *Hook* [1991] or Governor John Ratcliffe in *Pocahontas* [1995]) or delightfully benevolent and determined (e.g., the tin man in *The Wizard of Oz* [first made in 1939] or the beast in *Beauty and the Beast* [1946, 1991]). Quite often in children's movies, characters are represented as *both.* For example, in the *Harry Potter* (2001–2005) films, Harry has been injured and scarred for life, which is admirable, yet his nasty cousin, Dudley, is obese and constantly gorging himself. As well, a character such as the grinch (in *The Grinch* [2002]) is visually obvious as the villain, yet the very visual "difference" that sets such a character apart as evil indicates to the audience that such a character can be morally redeemed.

Children's movies also frequently feature the disability as a plot device that enables the action. For example, in *Mulan* (1998), the main character (voice-over by Ming-Na Wen) not only hides her gender in order to go to war to fight for her people, she also steals her father's papers in order to fake his identity. Had she not done this, the film implies, his disability injury from the previous war would have led to his likely death in battle.

CONCLUSION

Too frequently, written narratives and narrative films (especially but not exclusively dominant Hollywood productions) portray disabled characters as either pathetic victims (some examples include Blanche Hudson [Joan Crawford] in *Whatever Happened to Baby Jane?* [1962] and Tiny Tim in *Christmas Carol* [adapted for the screen several times between 1938 and now]), courageous heroes (Christy Brown [Daniel Day-Lewis] in *My Left Foot* [1989]), avenging villains (Quasimodo [Lon Chaney initiated the film role] in

Hunchback of Notre Dame [repeatedly adapted for film between 1923 and 2002]), or minor metaphorical glosses to a more important ableist central narrative (e.g., Warren Jensen Matthews [W. Earl Brown] and Tucker [Lee Evans] in *There's Something About Mary* [1998] and Ronny [Nicholas Cage] in *Moonstruck* [1987]). However, the history of cinematic depiction of disability both in Hollywood and elsewhere differs from that of literature and other representational arts in part because of techniques such as lighting, framing, and editing that control the gaze of the film audience. In addition, the film industry and its domination by Hollywood renders film a unique example of visually imposed normativity. Disability roles can be the focus of a movie (e.g., Sam, played by Sean Penn in *I Am Sam* [2002] or Helen Keller, played by Patty Duke in *The Miracle Worker* [1962]) or can be tangential to the main plot (e.g., a character who happens to be deaf, such as the brother character, David [played by David Bower], in *Four Weddings and a Funeral* [1994]).

Frequently, filmmakers use disability to portray a character as essentially evil, the character's disability serving as bodily signifier to inherently "flawed" human characteristic (e.g., Elijah Price [Samuel L. Jackson] in *Unbreakable* [2000] or Arliss Loveless [Kenneth Branagh] in *Wild, Wild West* [1999]). As Robert Bogdan (1988) says about the depiction of such characters (quoting his young son) in *Freak Show: Presenting Human Oddities for Amusement and Profit,* "If they look bad, then they are bad" (p. 6). Almost as frequently, filmmakers portray the opposite; rather than presenting villains whose disabilities display their essential evil, many films depict "ordinary heroes" whose disabilities—in and of themselves—transform them into noble and dignified "better than average" characters (e.g., Ben Affleck's blind and therefore extremely physically adept do-gooder lawyer, Matt Murdoch, in *Daredevil* [2003] or the tormented yet dignified John Merrick [John Hurt] in *The Elephant Man* [1980]).

Recently, independent and documentary films have begun to explore a more rounded or complex representation of disability onscreen. *What's Eating Gilbert Grape?* (1994), although still predominantly focused on main character Gilbert (Johnny Depp), depicts his brother (Leonardo DiCaprio), who has a developmental disability, and their extremely overweight and reclusive mother (Darlene Cates) as major players in the film's narrative. The documentary narrative *When Billy Broke His Head . . . And Other Tales of Wonder* (1994) humorously adopts a road-trip format while portraying Billy Golfus's attempts to rejoin the workforce with a brain injury; as well, David Mitchell and Sharon Snyder's short film *Vital Signs* (1995) situates disability as a provocative site of culture and performance. The two documentaries *Forbidden Maternity* (2002) and *Face to Face: The Schappell Twins* (1996) portray "Othered" lives from the point of view of the subjects'—rather than the expected viewers'—point of view. More and more, such films work to undermine clichéd presentations of disabled characters at the same time as they achieve grounds for further filmic narrative explorations.

—Sally Chivers and Nicole Markotic

See also Charles Albert "Tod" Browning; Documentary Film, Normality; Representations of Disability, History of.

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FINANCIAL COSTS OF DISABILITY

Examining financial costs of disabilities from a number of different perspectives having to do with actual and opportunity costs, presented by the disability, is the focus of this entry. Analysis of who pays the costs for the treatment of the disability must also be understood. This entry also looks at factors involved when a decision is made to no longer pay the financial costs associated with disability and the impact on the society in which the person with a disability lives. Consideration of the factors involved in conceptualizing the extent and impact of the financial costs of disabilities is a useful exercise in promoting an understanding of the impact of disabilities on the individual and society.

Understanding the financial costs of disability requires examination of actual and indirect costs. This is a complex task, since the term *disability* means different things in different cultures and countries, and sometimes means different things within a culture and country.

DISABILITY DEFINED

In the United States, for example, the term *disability* is defined in a variety of ways in different pieces of federal legislation. Disability, as defined in the Ticket to Work and Work Incentives Improvement Act (TWIIA), relates to functional limitations that determine a person's eligibility for national vocational rehabilitation services (TWIIA 2001). Under the Americans with Disabilities Act (ADA), a disability implies real or perceived impairment, which may result in some discriminatory activity (ADA 2001). Disability under the Social Security Act means the inability to engage in substantial gainful activity because of a medically diagnosable impairment (Social Security Act 2001).

Similar legal and cultural discrepancies exist in the way the term *disability* is defined or treated within and among other cultures. The dialogue about disability centers around the concept that an individual has a disability when he or she has diminished physical, mental, or emotional capacity(ies) when compared with the population in which he or she lives. For example, the World Health Organization (WHO) defines disability as the functional limitation(s) secondary to a mental, physical, or emotional impairment (WHO 1980). Although cultural norms vary, the standardized approach to defining this diminished functional capacity would be a standard deviation or more below the mean of that culture on that functional limitation. In many cases, cutoff points are defined by formalized testing to justify qualification for programming or services.

From a societal perspective, existence of diminished capacities associated with disabilities threatens the decision-making abilities of those who have them. Therefore, persons with disabilities, whether they are children, adolescents, or adults, (often) have a diminished capacity to make binding decisions in regard to their lives (financial or otherwise), which is consistent with their non-disability-related state of life.

ACTUAL COST

Because people with disabilities, by definition, have a limitation in physical, mental, or neurological capacity, an accommodation to that diminished capacity needs to be made. For example, the societal burden of accommodating and treating mental illness was estimated to be more than $170 billion in the United States alone in 1990 (Rupp, Gause, and Regier 1998). In the U.S. Social Security system, total maintenance support income for consumers with disabilities (both Supplemental Security Income [SSI] and Social Security Disability Insurance [SSDI]) is estimated at $7.3 billion of the $70 billion Social Security Administration budget, or roughly 10 percent of the U.S. taxpayers' contribution to the Social Security system (Garske, Williams, and Schiro-Geist 1999).

Substituting, replacing, or adding to the usual and customary way things are done in order to accommodate a person with a disability also has cost. Often, the real cost of accommodation is not monetary. Rather, the cost is in the thinking and planning process associated with creation of an appropriate appliance, therapy, or program that makes the accommodation functional. Application of the thought process can often be done with little cost. In returning a person with a disability to work, 90 percent of the accommodations required end up costing $500 or less (Geist and Calzaretta

1982). This cost can be borne by the employer or the potential employee or by some external benefactor such as the state/federal system of vocational rehabilitation in the United States.

Medical costs and therapeutic interventions are also borne by the person with a disability, his or her family, or society. In countries without national health care, this can become an overwhelming burden on the family system. To respond to this burden, persons with disabilities are often emancipated from their family situation to allow the shift in therapeutic intervention from the individual/family to societal responsibility.

In the United States, for example, the SSDI program evolved to an income maintenance program from the original concept of holding benefits consistent from the point of disability to the usual retirement age of 65+. SSI evolved in the 1970s as a general welfare program for adults. Benefits from this program have since been extended to include children with disabilities who have not contributed to the pension system to earn the benefits of this insurance-based system. The amount of maintenance provided for SSI recipients is subject to the generosity of the U.S. Congress.

In other countries, reliance on government support rarely guarantees an amount consistent with even a substandard level of gainful support. The expectation exists that some other part of society, usually the family, will help support the person with a disability who is not working. In some countries, persons with disabilities are considered “lucky” to have any kind of regular income maintenance, and the income maintenance payment itself becomes a disincentive to competitive employment.

Examination of disability cost extends beyond medical services. Persons with disabilities in many cultures and countries receive special vocational support and administrative services (Schiro-Geist 1992). Service delivery systems vary from centralized or decentralized depending on the size and structure of the country. The costs also vary greatly depending on the availability of other benefits such as free or low-cost educational services, attendant care, housing, and administrative costs. Analysis of international costs of nonmedical expenditures is hampered by inconsistent availability of data.

In addition to the more obvious physical disabilities, mental disabilities financially tax society. Individuals with mental disorders make up the largest single disability group in the United States. Services for this group absorb one-quarter of all federal disability funding. Provision of direct services for this population accounts for more than $69 billion in annual costs in the United States. Indirect costs such as social disruption and loss of productivity were estimated to account for an additional $78.5 billion annually. These direct and indirect costs include income maintenance, disability-related costs such as case management, rehabilitation service costs, and work-related cost containment. Although advances in treatment for mental health problems are being made, the amount spent on mental health research is disproportionately low when compared to other research in the life sciences (Rupp et al. 1998).

In Western countries, which will soon see the full effect of the aging baby boomer generation, the fear of disability-related costs looms large. There is limited discussion about the reality that this increased cost to society will also result in increased production of goods and services consistent with the increased need of the majority aging population.

When totaling the cost of disability, one should attend to the profit accrued by components of disability-based industries. The population of persons with disabilities requires a variety of drugs, appliances, therapies, and support to function. Producing these products and services is done at a profit. Vendors of products as well as service providers live and run their businesses based on the needs of people with disabilities, borne by themselves, their families, and society. This often overlooked contribution to the gross national product, created by the disabled community, is one to be reckoned within any national economy. Many people with disabilities report only limited income for fear of losing their maintenance payment. They contribute to the national economy of a country with the goods and services produced through their “shadow economy” of work products and services rendered but not reported and taxed. Economists can only estimate the value of this disability shadow economy related to disability for a country and assume it to be a major contribution. Removal of the costs and benefits connected with people who have disabilities would undoubtedly affect the productivity of the country.

OPPORTUNITY COST

In addition to the actual costs accrued for goods, services, and income maintenance, there are costs to the person with a disability, his or her family, and society. These include lost opportunity, time, status, and often diminished return on benefits. People with disabilities are prohibited from doing things that they want to do and families and society assume the responsibility to provide for (whether or not they want to) the functional limitations created by disabling conditions.

The perception exists that people with disabilities are a negative financial influence on society or weigh society down. This creates stigmatizing values. These values lead to the conclusion that the person with a disability creates a huge financial drain on society because things have to be done for them or to them and these costs would otherwise not accrue to society as a whole. This misperception may come from the lower socioeconomic position of many people with disabilities. If people with unlimited financial resources have someone do their laundry, clean their house, do their shopping, and even dress them, there is less stigmatization. The wealthy person commands respect in spite of being dependent on a host of people to maintain his or her status. When a person with a disability of lower means requires or uses the same services, however, that person is seen as a burden on society even if the person is paying for the services.

TERMINATION OF PAYMENT OF COST

Society, to contain the ever rising and inflating costs, often puts caps on direct and indirect costs. In countries with national health care policies, there are age limitations on treatment offered to persons with potentially terminal disabilities. Medicare, the major insurer for retired persons in the United States, has caps on the amount of payments made for a variety of medical problems. Some states in the United States are moving toward limitations on all but palliative care for persons over age 80. Persons with private insurance or unlimited personal resources can continue to access treatment and services that are limited in the public domain. This highlights the inequity of disability support for persons based on their socioeconomic status.

SUMMARY

Just as the term *disability* varies in definition across and within countries, so does an estimate of the financial cost of the disability vary depending on the perspective of the analyst. The costs of the disability can be seen as a negative drain on a society, especially if the society or culture views disability in a negative way. However, the financial costs connected to disability can also be perceived as a positive influence from the perspective of the disability industry as an active economy within the larger gross economy of a country.

—Chrisann Schiro-Geist and
Emer Dean Broadbent

See also Economic Analysis of Disability; Health Management Systems; Quality of Life.

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FINANCIAL PLANNING

See Economic Decision Making by the Disabled

FLEURY, VICTOR (1800–1856)

French author and school administrator

Victor Fleury was born in France and moved to St. Petersburg in 1817. He began as a teacher of the deaf and then became director of St. Petersburg School for the Deaf (1838–1856). He authored the book *Deaf-mutes* (1835), which described methods of instruction and analyzed sign language of the deaf.

—*Anna Komarova*

FOLK BELIEF

Folk beliefs are often cautionary tales that locate misfortune, accidents, and unexpected events in human causes, and people who seem different from others appear most frequently as these causes. Fairy tales and folklore recount the adventures of human beings with creatures who seem less or more than human: witches, nature spirits, fools, trolls, dead ancestors, speaking and singing animals, shape-shifters, zombies, ogres, giants, and dwarfs. Superstition holds that people with the evil eye harm with a glance, that hunchbacks bring good luck, and that diseased or deformed children are changelings substituted for a human child. Some figures of folk belief, of course, are neither less nor more than human. They are simply human beings who present some form of mental or physical disability. The creatures of folk belief include the seeing and hearing impaired; twins; people with achondroplasia, epilepsy, birthmarks, or birth defects; and those simply deemed more ugly than others by social convention.

Folk belief represents disability as a curse or punishment, a symbol of sin and disgrace in the family, or a sign of impending disaster, and people with disabilities are said to have malignant influence over other people or to possess magical powers. The world of folk belief is a world of human difference often explained to the detriment of disabled people.

The reliance of folk belief on disability is at once obvious and little discussed. Gods, cultural heroes, magical beings, and their adversaries bear marks of bodily and mental impairment that echo or exaggerate common disabilities. Divinities are routinely portrayed in folklore as possessing a surplus or deficit of organs. In Hindu folklore, gods have six faces; in China, three faces; in Jewish lore, five faces. Hindu and Chinese legends tell of gods with many eyes, while Tonga folk belief describes a god with eight mouths. In India, Tahiti, Hawaii, and Russia, divinities possess many heads, but they are legless or armless in Borneo. Irish and Greek legends describe one-legged and lame gods. A cultural hero of the Maori has different-colored eyes, while Irish legend pictures a hero with seven pupils in each eye. Oedipus has a clubfoot in Greek myth, and Balor of Ireland possesses an evil third eye. When gods or cultural heroes do not have a disability, they may pretend to have one for the purpose of humble disguise. In England and Ireland, fairies have unusually long ears or hair, or they might possess hairy bodies, a long tail, half a thumb, or red eyes. Changelings are recognized by large teeth, a thick neck or skull, and congenital disorders. Ogres are blind in Iceland and one-eyed in Ireland, while other minor villains of folklore present a broad variety of disabilities and bodily differences, including being one-eyed in Jewish, Irish, and Chinese superstition; toothless in India; and left-handed among the Inuit.

The most common superstitions attribute to ordinary people exceptional powers based on unusual characteristics. The evil eye, for example, is a folk superstition evident in nearly every world culture, both archaic and modern. It expresses the belief that certain people may pass illness, do harm, or cause accidents with a look. Those accused of possessing the evil eye are often disabled or distinguished physically or mentally in obvious ways. Eye disabilities such as lesions, corneal scars, and strabismus increase the chance of being accused of possessing the evil eye, as do squinting or red eyes. Eye color may also affect the possibility of being accused. In regions where an eye color is rare—for example, green eyes in the Middle East—that color is inevitably associated with the evil eye. The idea that an evil or envious eye that disapproves of wealth or beauty causes accidents, injuries, and disabilities is seen as the products of malignant wishes or curses. Moreover, the evil eye superstition explains that certain illnesses and deformities may be passed from person to person through the medium of the eyes. The cleft palate takes its common name, harelip, not only from its resemblance to the lips of the hare but also from the belief that a pregnant mother may pass the feature to her child if she sees the animal. Folk belief explains common birth defects as impressions passed to child from mother when she looks too intensely at her surroundings.

Many other folk beliefs are based on congenital disabilities, appearances deemed ugly, cognitive disabilities, or physical and mental characteristics uncommon to a given population. Scholars argue that people with epilepsy or catatonia provide the model for the belief in zombies in Haiti. A host of exaggerated beliefs surround the seeing impaired, often representing them as possessing magical or malignant influence. On the one hand, the blind are routinely said to possess second sight or clairvoyance, as in the case of the blind prophet Tiresias of Greek mythology. Folk beliefs also suppose the blind to be more impartial judges than other people because appearances do not deceive them. On the other hand, blindness symbolizes evil, sinfulness, ignorance, avarice, or self-delusion. Leviticus 21:18 forbids the blind from entering the temple, and Jewish legend calls Satan “the blind one.” Superstition holds that the evil eye produces blindness or that the blind may transmit their impairment if they accidentally look into the eyes of a sighted person.

In general, the appearance of disability foretells evil or impending disaster. Dwarfs are universally credited with malignant powers. Their lack of growth represents ignorance in Hindu myth, and they are often described by other folk traditions as jealous or miserly hoarders. Animals offered for sacrifice in Greek and Jewish belief must be unblemished, and the lame, blemished, or disfigured are often forbidden from appearing in places of worship. The birth of monsters signals the end of the world in Jewish mythology. In soothsaying, the birth of a child without nostrils portends that a country will enter a period of affliction, while the birth of a child without fingers prophesizes mass infertility. However, the presence of disability may also herald favorable times. Rubbing the back of a hunchback is thought to promise good fortune. Touching cripples or giving them alms ensures good luck.

Folk beliefs throughout the world characterize disability or deformity as a punishment for sinful or improper behavior. Blindness is characterized as God’s will or a punishment for promiscuity or immorality. In folk belief, people are often struck speechless as a punishment for misbehavior. In Ireland and Iceland, paralysis is a frequent punishment. Curses produce leprosy in India, loss of an eye in Ireland, and the head to drop off in the United States. They lead to stillbirths in India and sick children in Canada. In Ireland and the United States, monstrous births are a punishment for pride, while in China and Greece incest causes misshapen children. Folklore also attributes the forms of animals to misbehavior: The flounder was punished with a crooked mouth for discourteous speech; the crab has eyes in the back of its head and the hare a cleft lip as punishment for speaking rudely or out of turn.

Folk humor reserves a special place for disabled people. Folklore makes fun on many occasions of misunderstandings caused by deafness. It also recounts numerous stories about the blind leading the blind to ridiculous effect or about duping blind people for a good joke. The fool is a universal figure in the disability humor of folklore. Taking advantage of fools, duping them into injuring themselves, or laughing at their stupidity are recurring motifs in world mythology, showing that folk belief is preoccupied with mental as well as physical disability. Other human characteristics ridiculed by folk humor include long noses, stuttering and speech impediments, ugliness, lameness, fatness, and small stature. Folk belief provides a convincing catalogue of the human propensity to mock unusual people or to make them the butt of a joke.

People with disabilities would seem to have little in common with the creations of folk belief and superstition. The fantastic worlds of folklore are populated by mythological gods, witches, monsters, magical heroes, and supernatural villains such as the possessor of the evil eye. But the worlds of folk belief and human difference collide when the need to account for misfortune and accidents places blame on people who do not seem to fit the norms of appearance and ability dictated by society. It is a small step from the human diversity of disability to the supernatural differences of folklore, mythology, and superstition.

—Tobin Siebers

See also Changeling; Deformity; History of Disability: Medieval West; Norse Sagas.

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FOLLY LITERATURE

See Literature, Folly

FOOLS

The origin of fools is uncertain. During the Middle Ages and Renaissance, fools played various roles. They were merrymakers at court, had their own "fool-societies," and particularly played their roles during the time of carnival. At the end of the Middle Ages and in the beginning of Renaissance, literature often used foolishness as a metaphor to describe the radical changes taking place in religion, economy, politics, and culture.

In late medieval times, particularly at court, fools were separated into natural and artificial fools. To the latter, merrymakers and jesters such as the German Kunz von der Rosen, the Italian Gonnellas, or the French Brusquet belonged. They were expected to act in foolish ways to make people laugh. To fulfill this aim, they performed comic and obscene productions and mimicry. Artificial fools were laughed at and laughed with. In contrast, natural fools were only laughed at. They were objects of mockery, adoration, and, in later times, pity. From the perspective of disability studies, natural fools are the more interesting topic.

Until the Enlightenment, natural folly was understood as a mental difference that was congenital. It was perceived neither as a mental disease nor as a changeable condition of human being. Instead, mentally challenged people were interpreted as a category in their own right. According to the Dominican friar and theologian Thomas Aquinas (1225/27–1274), natural folly was not a sin but a natural disposition. Natural fools belonged to the "marvelous" human beings, as the fourteenth-century encyclopedist Konrad von Megenberg (1309–1374) put it in his *Buch der Natur* (*Book of Nature*).

Marvelous human beings were divided into two different groups: marvelous people and monstrous individuals. Marvelous people were thought to live at the "end of the world." It was assumed that they were different from the European type of mankind and formed their own cultures with their own rules and customs. Monstrous individuals, showing selective physical or mental deviations, were also regarded as marvels. These individuals were seen as divine beings whose purpose was to warn mankind about forthcoming evil events.

Within this categorization, natural fools did not belong to the group of marvelous people but to the one of monstrous individuals. Courts kept natural fools and made them live in special conditions. They were treated like children and often exposed to physical violence. They could be laughed at and were allowed to say nearly anything. They did not own property nor did they get any wages, as was the case with their artificial counterparts.

Written evidence about natural fools is rare. Few records only reveal nicknames or first names. Some bills are preserved, but they simply state the cost of clothes or, in some cases, the salary for the fool's waiter. In general, natural fools had to be looked after, since they were not held responsible for any damage they did. According to various laws such as the German *Sachsenspiegel*, fools and mentally ill people could not be judged. Any cost of damage caused by them had to be paid by their guardian (*Sachsenspiegel*, III, 3: "ouer rechten doren unde sinnelose lüde en scal men oc nicht richten. wenne se auer scadet ere uormünde scal dat geldene").

Outside the courts, people designated as natural fools lived with their families at home or sometimes in special institutions. In Germany, these institutions were named *Narrenhäuser* (fools' homes) or *Torenkisten* (fools' boxes). In these asylums, fools were locked away together with the mentally ill, drunkards, or men who visited whorehouses. These inhabitants were supposed to be dangerous to themselves or society and were therefore put away in special institutions. For admittance, a medical diagnosis was not required; therapy was not offered, either. If families could not afford to look after their temporarily or permanently mentally impaired members, they brought them to the *Narrenhaus* (fools' home). Fools from foreign towns were also kept in these asylums, but only for a short time before being sent home again. Towns even used ships to get rid of foreign fools. However, there never were any "ships of fools" aimlessly traveling around the country as the French philosopher Michel Foucault falsely described it in his book *Madness and Civilization*.

During the sixteenth century, natural fools were increasingly kept as "marvels of nature." In various courts, marvelous and miraculous objects such as precious stones, ostrich eggs, whale bones, and peculiar plants were collected. Even humans belonged to these "cabinets of curiosity." As marvelous objects they were not only thought to have material value but magic forces, too. Like the religious relics, which often were the basis of these collections, the objects represented their aristocratic possessor's power and uniqueness. At court, physically different people, such as dwarfs, giants, or people with dark or hirsute skin, were kept as living attractions. Natural fools were collected as well because of their different mental abilities. In contrast to the fifteenth century, they were no longer exclusively laughed at, but also adored, like the "folyshe Duke at Lancaster." He was the first natural fool taken by Henry VII (1457–1509) on his formal progress to Sittingbourne in 1492. Other natural fools also accompanied English kings on their formal progresses. This tradition was practiced until James I (1566–1625). The illustrated Triumph progress of the Holy Roman emperor and German king Maximilian I (1459–1519) at which artificial fools as well as natural fools were shown can serve as a further example of the fools' increasing value at the beginning of the sixteenth century. The emperor outlined his Triumph himself: He included not only pictures about his life and genealogy but also about his fools.

Natural fools were also used as presents. A natural fool named Sexton was given to Henry VIII (1491–1547) by Cardinal Wolsey in exchange for a ring. The fool was described as "for a nobleman's pleasure he is worth a thousand pounds." Details about his life are preserved because, like other fools, he was counted as part of the King's Privy Chamber. According to Cavendish's "Life and Death of Cardinal Wolsey," the fool himself did not want to be separated from his former possessor, Cardinal Wolsey. "Six tall yeomen" were needed "to conduct and convey the fool to the court."

During the sixteenth century, it was even discussed whether mocking natural fools should be prohibited. Paracelsus (1493/94–1541) among others believed that divine messages embodied by the fools could not be read if they were vexed. Fools such as the German Claus Narr were expected to show insight and prophecy. Natural fools belonging to the so-called monstrous individuals were seen as prodigies. Their behavior was interpreted as containing divine messages. However, in contrast to physically different "monstrous" individuals, it was said that the divine signs made by natural fools could not be seen from the outside. It is told that once Claus Narr divided a precious coat. His action was interpreted as a warning to the Saxon sovereigns not to divide their country. During the sixteenth century, insight and prophecy were no contradictions to mental diversity.

At the end of the eighteenth century, the exclusion of mentally impaired people from society—analyzed by Foucault in his book *Madness and Civilization*—also had an impact on natural fools. The Enlightenment saw natural folly declared a treatable mental sickness and the focus of medicine and pedagogy. Natural folly became an object of different scientific approaches and lost its marvelous characteristics.

—Ruth von Bernuth

See also Folk Belief; Literature, Folly.

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FOUCAULT, MICHEL

(1926–1984)

French philosopher

Michel Foucault’s work is immense, exploring extremely diverse fields, and it is read and commented on throughout the entire world. Here, only a few aspects that concern the sphere of disability will be reviewed. *The History of Madness in the Classical Age* (1961) inaugurated his major inquiries into the production of truths and bodies of knowledge but revealed less about the institutionalization of “disorders” (poverty, infirmity, madness, social marginality) than about the new relationship between reason and unreason, the creator of a radical madness and of the mad without remission. It would take a century and a half after the founding of the General Hospital by Louis XIV (1656) for madness to be considered curable (Philippe Pinel), and unreason came to be viewed as one more manifestation of the human mind. For all those concerned with the archaeology of madness and its treatments, Foucault’s book remains obligatory reading and an academic *rite de passage.* In 1974–1975, Foucault (1999) devoted his classes at the Collège de France to the “abnormal” (*les anormaux*): the monster, the incorrigible, and the onanist. As concerns monstrosity, his views are consistent with those of Georges Canguilhem, but for Foucault, it is essential to show that social categories no longer function, while disability, even when upsetting the natural order, still has its place in law. Yet it may be confused with monstrosity and so be exiled from the common social space.

—Henri-Jacques Stiker

See also Body, Theories of; Georges Canguilhem; Mental Illness.

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FRAILTY

The term *frail elderly* is accepted in the medical community to refer to a physically weak older person who is susceptible to disease. Geriatricians are trying to develop a working definition of frailty so that it relates to measurable physical attributes and functionality. Although debates continue about whether it is possible to diagnose “frailty,” the term serves to differentiate those older individuals who require specific care from those who appear to function without assistance and without impediment to their regular daily activities (as defined by the medical establishment). Although literary gerontologists such as Kathleen Woodward and Margaret Morganroth Gullette have argued that the elderly are mistakenly interpreted as always already weak and in decline from their youthful vibrant selves, the need within medical parlance for a distinguishing adjective indicates that “elderly” itself does not denote frailty. That is, it suggests that a robust late life is possible.

Given the diagnostic tests recently developed by Thomas M. Gill, however, the addition of the adjective *frail* also implies that physical disability in late life is a marker of weakness. Gill’s tests consist of asking patients to stand up from a chair without the assistance of one’s arms and to walk a measured distance at a normative pace. Of course, people with disabilities of all ages may score as frail under these tests when they do not really match the criteria geriatricians seek to measure. The attempt to measure frailty through physical function does not capture the impact of normal daily activities as desired by the geriatric community. Furthermore, while *frail elderly* is wielded selectively within the medical and gerontological communities, laypeople often assume *frail* and *old* to be interchangeable. The broader usage of the term and implications of frailty, such as referring to an older woman as a “little old lady,” support the findings of age scholars in the humanities and social sciences. As demonstrated in the well-known usage “Frailty, thy name is woman,” *frail* connotes delicacy, unreliability, and moral corruptibility capturing the ways in which people with “extraordinary” bodies are interpreted as socially suspect on a number of fronts. Although it has been interpreted as meaning physical fragility in contemporary contexts, frailty in this sense refers to the tendency of women to be unfaithful in love. The ascription of frailty to older people who essentially fail to remain young, then, fits into a long-standing context of depicting people with physical disabilities and nonnormative physical functionality as though they are immoral.

—Sally Chivers

See also Aging; Aging, International.

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The Program of All-inclusive Care for the Elderly (PACE):
National PACE Association, 801 N. Fairfax Street, Suite 309, Alexandria, VA 22314.
http://www.npaonline.org/
The Program of All-inclusive Care for the Elderly (PACE) model is centered around the belief that it is better for the well-being of seniors with chronic care needs and their families to be served in the community whenever possible.

FRANCE

See Advocacy Movements: France

FREAK SHOW

The term *freak* appears to be descended from the Old English word *frician,* to dance. *Freking*, for the medievals, was a form of cavorting, sudden movement, or capricious behavior. During the craze for scientific classification of the eighteenth century, as naturalists attempted to find specific categories for all life forms, organisms that failed to match a perceived species average were often referred to as *lusus naturae,* "cavorts" or "freaks of nature." In the early nineteenth century, certain naturalists toured Europe and America with examples of exotic or unique animals, charging admission to view their "cabinets of curiosities." Humans with bodies that were perceived to deviate significantly from an understood norm were often grouped with these *lusus naturae* shows, and so developed a variety of different performance genres that became collectively known as the freak show.

"Freak show" was a very general category that could refer to nontheatrical exhibits such as fetuses in jars ("pickled punks") or exotic or deformed animals as well as exhibitions of human "curiosities." In this context, *freak* was considered a relatively odious way of referring to humans, in performance or not, and was rarely used by professional performers or promoters until close to the end of the nineteenth century, after the death of Phineas Taylor (P. T.) Barnum (Barnum was never once known to use the term himself; see below). Favored alternatives were "raree show," "pit show," "kid show," and "ten-in-one."

Freak performers were present in America as early as 1738, but these freaks were not highly professionalized, and they appeared more often in the context of scientific lectures than theatrical performance, possibly as a means of evading colonial anti-theater laws. During the middle part of the nineteenth century, freaks gained great legitimacy, respectability, and profitability by performing their acts within the context of a new form of American entertainment known as the Dime Museum.

In 1835, Joice Heth, ostensibly a 161-year-old African American woman who had been the nurse of George Washington himself, was exhibited in the hall of a hotel in Bridgeport, Connecticut. She was a tremendous success, partially because of her flamboyant promotion, partially because her tales of Washington's youth were, reportedly, told with such integrity and intimacy that a controversy over her true identity was kept alive for decades. The controversy was resolved when an autopsy revealed she was merely 80, but Heth's fame only increased after her death. Skillful protestations of innocence on the part of her manager, P. T. Barnum, resulted in widespread publicity and interest.

Following his success with Heth, Barnum became a promoter of theatricals and the emerging variety entertainments. In 1841, Barnum purchased Scudder's American Museum on the corner of Broadway and Ann Street in downtown New York City; this moment is considered to be the beginning of the "Golden Age" of the freaks, which would persist until the 1940s. Among the human curiosities at the museum were the notorious and controversial Broadway actor Hervey Leach (also known as Hervio Nano), Mlle. Fanny (who turned out to be a perfectly normal orangutan), Native American and Chinese "families," giants such as Jane Campbell ("The largest Mountain of Human Flesh ever seen in the form of a woman"), a 220-pound four-year-old known as the Mammoth Infant, giantess Shakespearean actress and "sentimental soloist" Anna Swan, giant Captain Martin Bates, Isaac Sprague the "Living Skeleton," R. O. Wickware the "Living Phantom," a variety of dwarves, the famous "Albino Family," African Americans with vitiligo, the armless wonder S.K.G. Nellis, a cadre of sexually ambiguous persons such as bearded ladies and hermaphrodites, clairvoyants, "Lightning Calculators," and many, many others. Without question, the greatest of all the American Museum's stars was Charles Stratton, better known as General Tom Thumb. The General appeared not in the traditional "pit show" or "cabinet of curiosities" format but was celebrated around the world as a talented actor of highly theatrical, expensively produced melodramas, and appeared in performances before American presidents and industrial barons as well as the royal sovereigns of Europe and Asia.

By 1860, the human freak, appearing in the museum, on the legitimate stage, or in carnival sideshows (so named because they required a separate fee for entry from the main circus or carnival midway), had become one of the chief attractions for American audiences. A major moment in this period was the "Revolt of the Freaks" in 1898, when a collection of the 40 or so most famous freaks in the world staged a labor strike while on tour in London, demanding that the management of Barnum and Bailey's remove the term *freak* from promotional materials for their shows. A nationwide campaign to produce a new name was instigated, and the term *prodigies* was adopted by the "Council of Freaks." The intensity of this controversy reflected and magnified the popularity of freak shows, even though the whole event was probably nothing more than a publicity stunt.

In the middle of the twentieth century, the freak show began to suffer a major decline in popularity. Many factors combined to this decline; certainly the emergence of the medical model of disability, which replaced the freak show's narrative of wonder with one of pathology, made freak shows seem to be celebrations of disease, but advances in mechanical ride technology (rides were cheaper to run and more profitable than freak shows) and the rise of cinema and television were probably even more significant to ending the Golden Age of the freaks.

The use of the term *freak* did not diminish as freak shows became less prevalent in the latter part of the twentieth century, although its connotation suffered a sea change. The most common use of *freak* in modern American English refers to anything that appears in contrast to expectations, as in "a freak hailstorm," "a freak allergic reaction," or a person whose behavior is bizarre or unconventional, as in "an acid freak," or obsessive, as in "a computer freak." In the 1960s, the pejorative was appropriated by those who sought to celebrate an intentional rejection of conventional, conformist ideals by "Lettin' Your Freak Flag Fly." *Freak* entered American slang in the late 1970s with an undoubtedly positive spin: "Le Freak, C'est Chic," sang disco group Chic on a 1978 Atlantic Records hit to describe a joyful dance, while Rick James's "Superfreak" described a desirable woman in his 1981 funk album *Street Songs.* Nevertheless, *freak* continued to be applied pejoratively to disabled persons.

Freak show performance has a complicated relationship to disability; not all freaks were persons with disabilities, and activists of the disability rights movement have tended to avoid *freak* as a term of hatefulness. Eli Clare, activist and author of *Exile and Pride,* wrote: “Unlike *queer* and *crip,* [*freak*] has not been widely embraced in my communities. For me *freak* has a hurtful, scary edge; it takes *queer* and *cripple* one step too far; it doesn’t feel good or liberating.”

Two of the twentieth century’s most well-known professional carnival personalities, Priscilla the Monkey-Girl and Half-Girl Jeannie Tomaini, reported that they had “problems” with being referred to as *freaks.* The tension between freaks and disability rights came to a head in 1984, when disability rights activist Barbara Baskin successfully lobbied the New York State Fair to remove Sutton’s Incredible Wonders of the World Sideshow, featuring the beloved performer Otis Jordan (a limbless man who performed as the “Frog Boy”) from the midway.

More recently, however, activists have argued that the “Geek Love” mentality (referring to the title of the 1989 freak show novel by Katherine Dunn) is generating a desire even among “norms” to “freakify” themselves with piercings and tattoos. To the Geek Love advocates, the freak show signifies a celebration of human difference, which includes a politically motivated rejection of normality and conformity. Geek Love has, in fact, come to connote “disability pride” among certain disability activists.

In the twenty-first century, the freak show persists in America as part of the avant-garde underground circus movement. One chief practitioner is the highly regarded director and circus performer Jennifer Miller. Coney Island’s “Sideshow by the Sea” maintains the classic ten-in-one freak show approach and includes many forms of bizarre entertainment. Freak show imagery and history are also increasingly used in avant-garde performance, visual art, cinema, and music, notably including the 2004 HBO television series *Carnivàle* and the popular *Jim Rose’s Circus Sideshow.*

—Michael M. Chemers

See also Body, Theories of; Film.

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FREUD, SIGMUND
(1856–1939)

Austrian neurologist and psychoanalyst

Born in 1856 in a caul, an event that he believed guaranteed his future fame, Sigmund Freud invented psychoanalysis and established the direction of modern psychology. *The Interpretation of Dreams* (1900) elaborates his theories that the mind has both conscious and unconscious dimensions, that dreams seek the fulfillment of wishes, and that human beings are socialized under the pressure of an Oedipal triangle that places in conflict the desires of father, mother, and child. Freud devised the psychoanalytic session in which patients reveal the first thoughts that enter their mind as a mechanism for unlocking the unconscious basis of their mental problems. Freud’s most enduring influence on the study of disability was to develop the theory of psychosomatic illness in which a psychopathological flaw is given corporeal form as a symptom, thereby establishing the notion that people succumb to disease or disability because they feel guilty about past actions or repressed desires. In 1914, he further connected mental and physical states with the concept of narcissism, a pathology of self-love, whose theory also explains that bodily injuries prevent neurosis but make one susceptible to more serious narcissistic disorders such as megalomania or paranoia. Freud’s last theories divide the mind into the ego, id, and superego where the demands of the social world struggle with those of libido and conscience to determine the mental and physical health of the individual. Freud’s death in 1939 was physician-assisted by a dose of morphine to relieve suffering caused by cancer of the mouth.

—Tobin Siebers

See also Narcissistic Personality Disorder; Neurosis; Normality; Psychiatric Disorders; Psychiatry.

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FULLER, MARGARET (1810–1850)

American journalist

Margaret Fuller was an American journalist and Transcendentalist writer. Fuller's experience with disability was both personal and familial. She had chronic severe migraines of which her friend, Ralph Waldo Emerson, said, "She read and wrote in bed, and believed that she could understand anything better when she was ill. Pain acted like a girdle, to give tension to her powers." Her youngest brother, James Lloyd Fuller (b. 1826), had mental disabilities that seemed to combine elements of intellectual disability and mental illness—at the time he was called slow, lunatic, eccentric. When she left home for her writing career, she maintained a strong interest and responsibility for Lloyd's well-being, arranging jobs, clothing, and housing for him or sharing her own rooms with him during some periods. Margaret Fuller took a professional interest in disability as well. She wrote about the salutory effects of community living, with a romantic view of caregiving and resignation to one's fate as a moral opportunity and moral example to others. She wrote glowing reports from France about advances in education for people with developmental disabilities, and she described the Bloomingdale Asylum for the Insane in articles (1845–1846) for the *New York Daily Tribune.*

—Penny L. Richards

See also Progressive Era Women in Special Education.

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FUNCTIONAL ASSESSMENT

A gerontologist in Philadelphia, M. Powell Lawton, wrote in 1971 the first definition of *functional assessment*. He said that functional assessment was any systematic attempt to objectively measure the level at which a person is functioning in a variety of domains. Functional assessment, as a scientific endeavor, was slow to develop in rehabilitation. In fact, during the 1970s, most clinicians regarded functional assessment as an effort to measure the unmeasurable.

Substantial progress has been made in the past 30 years and functional assessment, in combination with outcomes analysis, is now considered one of the "basic sciences" of rehabilitation. Measurement of function is essential to the goals of rehabilitation, particularly medical rehabilitation. These goals are to monitor, support, and facilitate human performance and behavior, while considering environmental, structural, physiological, or psychological limitations. Functional assessment is a method for describing a person's abilities and limitations.

The essence of functional assessment is the measurement of a person's use of skills included in performing tasks necessary to daily living, leisure activities, vocational pursuits, social interactions, and other required behaviors. Information obtained from functional assessment is used to help formulate judgments as to how well essential skills are being used and to gauge the degree to which tasks are accomplished and social role expectations are met. Performance-based functional assessments take into account the social and physical contexts of the person. Measurement of functional abilities and outcomes must relate to real-life situations and settings.

Commonly, the emphases of rehabilitation programs include improving the functional status of individuals through a system of interdisciplinary interventions. Outcomes are determined by periodic reassessment of changes over time. The purposes of measurement are to make explicit the effectiveness, the efficiency, and the cost-effectiveness of the interventions. In this manner, outcomes of professional interventions of health care, rehabilitation, education, or psychological and social counseling may be described and monitored. Once outcomes become measurable, they become manageable.

The term *evidence-based practices* fits nicely with the idea of functional assessment and outcomes analysis as a basic science of rehabilitation. A scientific approach to assessing function and rehabilitation outcomes enhances national and international communications through use of a common language.

MEASURING FUNCTION AND ANALYZING OUTCOMES

Functional assessment and outcomes analysis require measurement. Measurement begins with understanding what is to be measured. This understanding must be grounded in theory and must be connected to a comprehensive model for identifying and then meeting the needs of the person being assessed. Each tool used in measurement must be designed and tested with respect to its purpose, practicality, construction, standardization, reliability, validity, responsiveness to change, feasibility for use, and meaningfulness in the clinical setting.

There are many difficulties in applying measurement principles to function and outcomes because the concepts to be evaluated relate to whole-person perceptions, attitudes, knowledge, or behaviors and are more often intangible (so-called latent traits) rather than tangible. For example, physical performance measured in terms of muscle strength, endurance, velocity of contraction, oxygen uptake, or even timed ambulation is much more tangible than measuring the ease or difficulty that a person as a whole experiences in tasks of daily living. Another example is the long-standing difficulty in measuring pain. Pain is a factor that often limits a person's ability to complete daily living activities, social interactions, and role participation.

Person variables are latent traits because they are hidden in the person; we can only infer them from observation of behaviors. These are just a sample because the person may generate a universe of behaviors, not simply mechanistic responses to external stimuli. One can infer that a person is "independent in daily life" by observing that he or she eats, dresses, or moves autonomously, but many other behaviors, if produced and observed or reported, might convey the same kind of information. This implies (a) discontinuity in the source data (we can only count discrete observations along a continuum); (b) nonlinearity of the counts (different behaviors do not represent the same amount of autonomy, despite being counted as "one more"); (c) more numerous behaviors replicate (and thus make more reliable) the observation that the variable is there, but do not necessarily reveal "more" of the variable; and (d) inhomogeneity of the error surrounding the observation (too easy or too difficult tasks for a given person provide very reproducible outcomes, whereas tasks "on target," despite being more informative, may end up in "pass" or "fail"). Thus, despite integer numbers, counts of observations represent a potentially poor surrogate of the intended measure. Recent developments of psychometrics, led by Rasch analysis (after the name of the Danish mathematician Georg Rasch), are at last shedding light on this fundamental challenge to functional assessment.

One technique for developing measures of tangible and intangible phenomena is through use of the Rasch mathematical model. Easily used software programs are now available to assist in the measurement process using the Rasch model. Rasch is described later, in the section titled "Uses of Functional Assessment."

Distinctions must be made between performance-based functional assessment, taking the social and physical contexts into account, and the conceptually simpler, more objective evaluation and measurement of functional capacity. Functional capacity assesses the person's performance under controlled circumstances, similar to judging optimal performance in laboratory conditions. These results may not reflect how the person performs in daily living activities in the "real world." Testing muscle strength and timed walking distance, as described above, are measures of functional capacity rather than of daily living activities.

There are many models for conceptualizing the attributes to be measured. Most emanate from the work of psychologist Abraham Maslow (1954), who evolved a hierarchy of needs to achieve self-actualization in order to live a fulfilling life. He understood that life's work was to systematically overcome barriers. At the base of Maslow's hierarchy lie needs for physical survival, and at progressively higher levels are satisfaction of needs for security, social interaction, and self-esteem. One derivation considers that the concepts to be measured are challenges to quality of daily living. In this model, the goal of fulfillment is achieved through balancing one's choices, options, and expectations (functional opportunities) with one's physical, cognitive, and emotional constraints (functional demands/barriers).

When opportunities and demands are not directly measurable in quantitative terms, then the underlying factors that either support or form barriers to health and functioning are often chosen for measurement. For example, functional opportunities that are supported by good health may be described and measured by assessing physical status, mental/emotional status, social interactions, role participation, and general well-being. On the other hand, functional demands/barriers may be described and measured by assessing pathophysiology, impairment, functional limitations, disability, and societal limitations (see definitions below).

As another example, motivation is felt to be an important underlying determinant of how well a person may cope with adversity, for instance, a chronic disease or disability. While not directly measurable, inferences may be made by measuring variables related to motivation, such as self-esteem, mood, or by analyzing the steps one follows in solving a problem or in developing a plan of action.

The World Health Organization (WHO; 1980) originally proposed a series of definitions that have had a profound impact on the assessment of functional status and outcomes in rehabilitation. The original WHO framework was modified in a National Institutes of Health, National Center for Medical Rehabilitation Research report published in 1993. This report included the following definitions that are widely used within rehabilitation:

> *Pathophysiology* is any interruption of, or interference with, normal physiological and developmental processes or structures.
>
> *Impairment* is any loss or abnormality at the organ or organ system level of the body.
>
> *Functional limitation* is any restriction or lack of ability to perform an action in the manner or within a range consistent with the purpose of an organ or organ system.
>
> *Disability* is any limitation in performing tasks, activities, and roles to levels expected with physical and social contexts.
>
> *Societal limitation* is any restriction attributable to social policy or barriers (structural or attitudinal) that limits fulfillment of roles or denies access to services and opportunities associated with full participation in society.

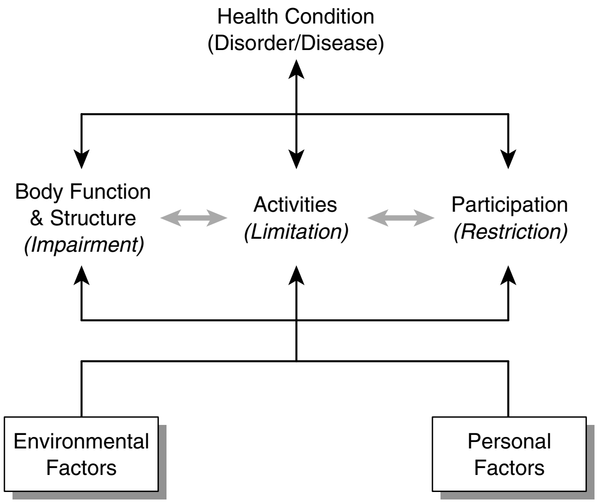

Figure 1 Interaction of Concepts
Source: World Health Organization (2001).

Recently, the WHO (2001) proposed a revised model referred to as the International Classification of Functioning, Disability, and Health. The components of this model are presented in Figure 1.

The dynamic evolution of disablement models illustrates that measurement of functional abilities and rehabilitation outcomes is an ongoing challenge in which researchers and clinicians attempt to disentangle complex nonlinear interactions that occur in real life, across many different variables. Yet measurement of each variable, itself, must be linear, that is, proportional to the quantity it is claimed to represent. Rehabilitation outcomes are multiple rather than singular. Assessment of "quality of life" requires use of measures that cover several aspects of functioning concurrently, yet cooperating in defining a unitary construct. This means that using a large number of instruments is not necessarily better than using a few well-chosen ones. As well, one must be vigilant that instruments are measuring accurately and succinctly. Johnston, Keith, and Hinderer (1992) have identified interdisciplinary standards and guidelines to foster improvement in development of functional assessment scales in rehabilitation. These standards and guidelines were compiled to counter the tendency to measure the "whole person" based on evaluation of severity of focal impairment alone.

The guidelines cover validity, reliability, clinical application, and program evaluation/quality improvement.

Validity includes three forms (content, predictive, and construct) and is the paramount criterion for choice and use of an instrument. Validity is regarded as the extent to which a test measures what it is intended to measure. Commonly, a "gold standard" is sought against which newer measures may be compared.

Reliability is the extent to which the data contain relevant information with a high signal-to-noise ratio versus irrelevant static and confusion, that is, sufficiently free of either random or systemic error. Repeatability indicates reliability. Agreement is the most stringent form of repeatability in which results of testing match across raters, time, or subjects. Agreement, however, may come also from the same bias affecting multiple observations (e.g., across raters or times). Internal consistency is another, perhaps even more stringent, form of reliability, demonstrating that all items are evaluating the same general construct. The more coherent the items are, the more they will be free from individual changes, independent from the shared construct, and thus, the scores will tend to be repeatable.

Clinical application means that users need to understand the scientific basis for the inferences they make from their clinical assessments and the boundaries of this knowledge.

Program evaluation/quality improvement involve application of measures to groups for purposes of ongoing review to systematically resolve identified problems and pursue opportunities to improve care and services, to accomplish accreditation, and to use evidence to support policy making. Wide variations in responses of individuals may reflect an instrument or measurement process that is not accurate or stable. Outcomes not only are dependent on the effectiveness of treatment but also depend on patterns of input, process, and conditions surrounding the treatment intervention. Good outcomes are the culmination of the combined effects of structure and process. Case-mix adjustments must be made to account for variations in severity or qualitative differences in the individuals being measured.

USES OF FUNCTIONAL ASSESSMENT

Using data from the Uniform Data System for Medical Rehabilitation, Margaret Stineman, associate professor, Rehabilitation Medicine, University of Pennsylvania, and colleagues (Stineman 1998; Stineman et al. 1994; Stineman et al. 1997) developed the FIM-FRG system to classify patients at the time of admission to inpatient rehabilitation. The FIM-FRG system was designed to facilitate prediction of length of stay and level of function that can be achieved during rehabilitation, and to compare outcomes between patients, having made case-mix adjustments. The classification system uses type of impairment, severity of disability using the FIMTM instrument (*Guide to the Uniform Data System* 1996) motor and cognitive measures, and for some groups, age. The IRF-PAI (Inpatient Rehabilitation Facility-Patient Assessment Instrument), developed for the U.S. Centers for Medicare and Medicaid Services (www.cms.hhs.gov) to use for prospective payment to rehabilitation hospitals, incorporates the FIMTM instrument, and has been used in the United States since January 2002.

In contrast to continuous linear measures (such as those for length and weight), item-response scales are most commonly used for functional assessment and outcome analysis. Scales are typically discontinuous-ordinal. The raw scores they provide are neither linear nor equal-interval, thus they should not be used in parametric statistical analyses. Interval measurement derived from raw scores through Rasch-based (Wright and Linacre 1989) transformation improves functional status analysis by providing unidimensionality and additivity. Unidimensionality means that items cooperate with each other as they progress in difficulty across a common range of performance, with each item adding a level of difficulty for the subjects. Unidimensionality also means that the abilities of the subjects can be located along the continuum defined by the items, according to common standard units. Additivity means that adding one more unit always increases the pool by the same amount, whatever the overall level of the measure.

Together, these two concepts of item difficulty and person ability being measured on the same linear metric are referred to as conjoint additivity. Conjoint additivity is achieved only if the measure is independent of the particular sample being tested, and of the particular set of items adopted. Therefore, Rasch-transformed measures, complying with the requirement of conjoint additivity, permit statistical validity and generalizability in comparing individuals on the basis of results using an aggregate rating and in comparing changes in ratings over time. The Rasch measurement model offers opportunities for comparing standardized expected values both for aggregate ratings and item responses when persons have problems that are relevant to the latent trait being measured.

Measures of function and outcome analysis are classified according to questions that they are intended to answer: (1) discriminative, (2) evaluative, or (3) predictive. The first task in using a measure is to identify levels of severity from low to high. The second task is to identify whether the value of the measure changes with changing severity. The third is to predict another parameter that is either concurrent, such as the cost of the treatment program or the value of a variable in the future, such as the likelihood of recovery.

A challenge that remains for the medical rehabilitation field to solve is the predictable relationship between the "dose" of rehabilitative services and the "response" of the person. In fact, depending on the problem and the treatment, rehabilitation outcomes may follow teaching-learning paradigms (e.g., in therapeutic exercises), in the same way that chemical dose-response dynamics (e.g., in chemical treatments for pain or spasticity) do.

When functional assessment is performed by observation of activities, it is very important to assure accuracy or intrarater and interrater reliability. This may be accomplished through several methods that include (1) testing competence of the assessors with an examination, (2) testing the results of the assessments with standard statistical studies of variance, and (3) Rasch modeling of the data testing for separability of persons and items and the fit of item responses to expected rating patterns. Assessors who are performing ratings through observation or interview need to receive training and then be tested to ensure their knowledge of the criteria for rating.

CONCLUSION

Feedback of the results of functional assessment and outcome analysis is extremely important (1) for clinicians to know whether they are "on track" and (2) for administrators to perform program planning and program evaluation and to make policy decisions responsibly. Accrediting bodies require functional assessment and outcome analysis as evidence of quality assurance. Accreditation agencies are also increasingly sensitive to feedback from the consumers of rehabilitation services. In the effort to measure quality of daily living, it has become important to use patient-centered questionnaires that gather the person's perspective, rather than attempt to infer this perspective from objective testing of body functions. The patient-centered approach to functional assessment and the evaluation of rehabilitation outcomes is consistent with the goals of medical rehabilitation and reflected in the motto "As we function, so shall we live!"

—Carl V. Granger,
Kenneth J. Ottenbacher, and Luigi Tesio

See also Evidence-Based Medicine; International Classification of Functioning, Disability, and Health (ICF/ICIDH).

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FUNCTIONAL MEASUREMENT

Functional measurement is a general term that describes the processes by which we collect information to evaluate disability and determine the need for vocational or rehabilitation services. On the surface, functional measurement may simply represent the act of determining a meaningful quantity of something. The term *functional* means purposeful or useful. Measurement refers to the process of determining a quantity or amount. However, the term takes on a special meaning in the context of disability and refers more specifically to the process of quantifying an individual's performance of particular tasks and activities in the context of specified social and physical environments. A preponderance of functional measurement is focused on the completion of tasks and activities that relate to work (specifically, to a particular job) or to caring for oneself. Thus, key tasks and environments that are most often the focus of functional measurement are *activities of daily living* (e.g., eating, dressing) completed in the home and specific job functions completed in the workplace. Another, though less emphasized, area of functional measurement involves getting around and using the community at large.

The reason for conducting functional measurements is to obtain a reliable and valid representation of how well an individual performs particular tasks or activities under certain circumstances. This task is complex, because people have a dynamic and personal relationship with the environments in which they inhabit. Therefore, the circumstances of any given performance involves many factors, including personal capabilities (knowledge, skills, abilities, and attitudes), the particular demands of the task that needs to be performed, and the setting in which the performance takes place. In practice, individual performance can be influenced by improving the person's capabilities (through accommodation or some other rehabilitation strategy), by altering the task to reduce or eliminate unnecessary demands, or by modifying the setting to remove environmental barriers. Rehabilitation and vocational specialists engaged in improving client performance and reducing disability use all of these strategies. Furthermore, the range of options is made known only through functional measurements that take into account the individual's capacities, the specific tasks to be performed, and the specific settings in which they take place.

HISTORICAL FOUNDATION

The concept of functional measurement has evolved over the past century as views toward compensation for injury and rehabilitation have become more sophisticated. In the first third of the twentieth century, disability was primarily considered a "defect with a cash value." Honored workers in the national economy (such as those in the military or civil service) were compensated for injuries that occurred on the job. At that time, assessment was limited to determination of impairment. The resulting compensation was rather crude involving a set cash payment for different types of impairments. For example, the loss of vision in one eye resulted in a different payment than did the loss of function in an arm.

Society continues to compensate workers for their injuries, although the method of calculating benefits has changed substantially. During the middle third of the twentieth century, we also began teaching injured workers to use and adapt residual capacities to work and reach their maximum vocational potential. This happened for a variety of reasons. However, the primary reason was the growing population now living with impairment due in part to the large numbers of casualties resulting from both World Wars and to increasing numbers of car accidents. Advances in medical science and technology resulted in people surviving injuries that previously resulted in death. The remarkable change in rehabilitation during this period was the acceptance of the holistic philosophy in rehabilitation. This philosophy held that the mind and body accomplish tasks in an integrated way. By implication, one cannot obtain a clear picture of the capacity to perform tasks or activities by measuring the functioning of body structures alone. Instead, the focus of assessment shifted to the "whole" person completing tasks and activities associated with daily living. According to Kessler (1970), the effective dynamic action of mind, body structure, and body function work as a single unit to complete tasks and achieve goals. During this period, there was a proliferation of functional assessment instruments that focused on the accomplishment of key activities of daily living, such as eating, dressing, and bathing.

The latter third of the twentieth century saw profound changes in rehabilitation. Advances in rehabilitation medicine led to improvements in the ability to remediate and improve patient capacity following injury or disease. However, just as important was the recognition that disability is "a form of inability or limitation in performing roles and tasks expected of an individual within a social environment" (Nagi 1977). In effect, Nagi defined disability as a distinct concept, one that is different from impairment. *Disability* is a socially derived term that refers to an individual's performance of tasks and activities related to achievement of social roles. The term *disability* was further formalized with the introduction of the World Health Organization's International Classification of Impairments, Disabilities, and Handicaps in 1980 and further refined in its International Classification of Functioning, Disability, and Health in 2001. As researchers and clinicians set about the task of "measuring" disability, the concept of functional measurement began to take shape.

PURPOSES OF FUNCTIONAL MEASUREMENT

There are two principal purposes for conducting functional measurements. One purpose is to facilitate reintegration back into one's living environment following injury, disease, or disorder. Rehabilitation or vocational specialists gather information about their client's home and work environments to discover ways to improve the individual's ability to complete important daily tasks. In this case, functional measurement refers to the collection of information to reflect the dynamic characteristics of the individual, including personal activities, capacities, environmental conditions, and needs. Together, this information is used strategically to plan for the individual's reintegration back into familiar work and living environments. Rehabilitation strategies can range from new surgery or therapy that is needed to improve the individual's personal capacity to remodeling the home to accommodate incapacity due to permanent impairment. Vocational strategies can range from retraining the individual to do a current or previous job to remodeling a previous work environment or training for a new vocational goal. All of these actions have the effect of reducing disability.

Analogous to this purpose is the concept of habilitation that concerns the integration, as opposed to reintegration, of an individual into increasingly demanding adult living situations or environments. Habilitation most often relates to the education of children and youths with disabilities. The goal is to reduce the potentially disabling effects of the increasing demands associated with adult living tasks and environmental settings through education. Functional measures provide a means for understanding educational needs.

The second purpose for conducting functional measurements is to facilitate decisions about access to relief under various laws. Functional measures provide critical information to the decision of whether a claimant meets the legal definition of disability, thereby making him or her eligible for benefits under the particular law. While the definitions are somewhat different under each law, they all require some functional measure of a claimant's ability to meet the demands of age-appropriate daily living requirements. For example, disability under the Social Security Administration (SSA) is narrowly defined and reserved only for individuals who cannot perform substantial gainful activity (i.e., SSA's term for work) now or in the foreseeable future. A determination of work disability, as it is sometimes called, leads to an award of monetary and health benefits to claimants who are disabled under the law. Given that the consequences of the decision for the individual and for society are costly, it is not surprising that disability determination under Social Security is a formal and often lengthy process involving careful assessment of a claimant's capacity for engaging in previous work or any work available in the national economy. If the impairment is severe and interferes with the completion of previous work requirements or the work requirements of any job found in the national economy, then the claimant is judged unable to engage in substantial gainful activity and is awarded benefits.

In all cases where a legal determination of disability is required, the decision is reached through a formal process of data collection and analysis. Functional measures are only a part of that process. For example, while the definition of disability is markedly different under the laws governing education and Social Security, both processes require that measures of impairment be collected before actual functional measures are collected. This makes sense, given that impairment is a prerequisite to disability.

Disability is sometimes "presumed" based on an assessment of impairment alone. In these cases, the impairment is considered so severe that it is not necessary to assess the environmental consequences of the impairment. In effect, it is already known. For example, individuals with Down syndrome who have a measured intelligence quotient in the low 50s are presumed to be disabled. This decision is based on accumulated knowledge that such persons will now (and in the future) face serious barriers to gaining control over their environment and will not be able to take on expected social roles. These individuals will largely require supervision in the conduct of daily living tasks and activities requiring higher levels of language, problem solving, and judgment.

MEASURES OF IMPAIRMENT

Functional measurement can be contrasted with measurement of impairment. Measurement of impairment is focused on a determination of the extent to which the body's structure or function deviates from that which is considered normal. In the International Classification of Functioning, Disability, and Health, examples of body structures include the nervous system (such as the brain and spinal cord), the eye, voice mechanisms (such as the nose, mouth, pharynx, and larynx), and structures related to movement (such as the head and neck, upper extremities, and lower extremities). Examples of body functions include mental functions (such as general functions of consciousness and intellect as well as specific functions such as memory and attention), sensory functions (such as taste and smell), and neuromuscular and movement-related functions (such as mobility and stability of joints and muscle power).

We may measure handgrip strength or range of motion associated with the shoulder, elbow, or wrists to determine the extent to which hand or arm function is impaired. The extent to which these measures deviate from normal measures, given age and sex, determines the existence of impairment.

Measurements for mental capacity or emotional development can be treated in a similar fashion. An individual's performance on a test of intelligence (IQ test) provides the information needed to determine the extent of mental impairment. Thus, measures such as the Stanford-Binet scale or Wechsler Adult Intelligence Scale (WAIS) yield information on the intellectual performance of an individual compared to "normal" intellectual performance. For many years, low IQ test performance was all that was necessary to "presume" disability for purposes of disability under SSA. However, these days IQ test performance is only part of the SSA disability determination process involving mental impairment. In recognition of the many skills and abilities that apply to successful work performance in one's environment, functional measures are now also required to supplement IQ testing in the determination of disability.

Functional measurement can also be contrasted with functional capacity evaluation (FCE). FCEs move a step closer to measures of a person's ability to perform daily tasks and activities. Even so, the measures remain focused on the individual as opposed to the relationship between the individual and the environment. FCEs assess individual performance on meaningful tasks, as does functional measurement. The purpose is to generalize to functional abilities that result from normal physical or mental development. Thus, FCEs require individuals to perform tasks that are specifically designed to measure limitations in physical ability (pushing/pulling, carrying, reaching, seeing, and hearing), neurobehavioral performance (walking, balance, and stamina), cognitive ability (oral or written language, memory, and problem solving), and interpersonal interaction (teamwork and responsibility). Performance on these "functional" abilities is then used to predict ability to engage in a previous job and meet daily living expectations. It is obvious that FCE is complementary to both measurement of impairment and to functional measurement. However, functional measurement is focused on the performance of actual job functions whereas measurement of impairment is focused on the extent of damage to a body structure or function, and FCE is focused on the effect of impairment on particular uses of the impaired body structure or function.

FUNCTIONAL MEASUREMENT METHODS

Functional measurement employs one or more methods of data collection. There are generally three types of methods for obtaining functional measures: (1) self-report methods, (2) structured performance rating methods, and (3) behavioral observations and situational assessment methods. Each method has its own unique use and characteristics.

Self-Report Methods

Self-report methods include checklists, rating scales, and inventories. The common characteristic among these types of instruments is that the data collection procedure involves obtaining the information directly from the individual who is the target of the assessment. They report on their own functioning. The individual affected is often considered to be the best source for information about his or her ability to function in familiar environments. Thus, self-reports are an efficient and direct way of obtaining reliable information. In addition, they can cover a wide range of topics and content. However, they are also subject to problems of validity since they are easily influenced by the desires of reporters who wish to appear more or less disabled, depending on the circumstances and the reinforcers apparent in consequences tied to the assessment. For these reasons, self-reports form only a small part of eligibility decisions associated with legal disability determination.

Self-report methods are used mainly in health care settings and in national surveys. In the health care setting, self-reports are often supplemented with clinical evaluations and judgments. For these reasons, their potential invalidity—due to "wishful" reporting—is less of an issue. Self-report is also the primary method for obtaining information in national surveys, since this method is the most efficient and cost-effective way of finding out about an individual's situation.

In some cases, another person, called a proxy, completes the self-report because the targeted individual may not be capable of reporting his or her own behavior due to weakness or fatigue or mental incompetence, for example. Proxy reports are most useful when the questions do not address personal feelings, opinions, or hypothetical situations. These types of questions lead to results that differ from the target individual's.

Structured Performance Ratings

Structured performance ratings include checklists, rating scales, and inventories completed by a trained evaluator. The notion behind structured performance ratings is that a trained evaluator provides objective evidence of performance. Typically, such persons include a physician, therapist, nurse, vocational assessor, or other service provider. The sources of information about the target individual might include observations, interviews, case histories, and tests. However, this implies that structured performance ratings are retrospective rating scales that provide judgments about performance observed in the past. While still subjective, structured performance ratings offer a more objective method for assessing target individual performance since the trained evaluator would have less incentive to skew the ratings.

The major limitation of structured performance ratings is the common context for making ratings. Evaluators may have insufficient information to arrive at a valid rating. This result could be due to ambiguous questions or bias. One way developers of such instruments confront this problem is to accept input only from evaluators who meet specified criteria—such as knowing the targeted individual for a certain period of time, or having observed the targeted individual in specific settings.

Behavioral Observations and Situational Assessments

Behavioral observations and situational assessments include observations of target individuals performing in natural or artificial environments. Behavioral observations typically focus on performance in natural settings, such as the individual's home, community, or workplace. Situational assessments are observations of performance in artificially constructed (situations) environments. Both methods provide a rich source of information about target individual performance. However, they are also time-consuming and costly. Their major limitation is the breadth with which one can generalize performance to a broader range of environments in which the target individual may find himself or herself. Another issue is that the episodic nature of some impairments does not lend well to these types of methods unless repeated trials can cover the length of time or period needed to obtain a complete picture of performance.

—William D. Frey

See also Activities of Daily Living (ADLs); Employability; Employment; Functional Assessment; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Vocational Rehabilitation.

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GAIT ANALYSIS

Twenty years ago, Gordon Rose, a pioneer in the field, suggested that the term *gait assessment* should be applied to the whole process of evaluating a patient's gait and that the term *gait analysis* be reserved for the high-tech component of gait evaluation. In the diagnostic triad of history, physical examination, and laboratory tests, gait analysis is a laboratory test. Historically, while Eadweard Muybridge (1830–1904) famously used sequential photographs to display gait in several species, gait laboratories were developed to support research into the biomechanics of human movement. The difficulty of the process limited the amount of data that could be processed and the sophistication of the models used to interpret the results. In the past few decades, gait analysis technology has improved significantly, resulting in a potential for wider clinical application. The development of powerful and inexpensive microcomputers has reduced the time and labor costs of gait analysis. Coincidentally, commercial vendors have developed standard packaged gait analysis systems that integrate the basic technologies required for gait analysis, motion capture, ground reaction force measurement, and muscle activity monitoring. Gait laboratories have developed a consistent set of parameters for describing gait and gait pathology.

At present, the most common clinical use of gait analysis is the assessment of spastic gait in patients with partial paralysis from an upper motor neuron pathology. Gait analysis allows one to understand the dynamic implications of a specific impairment, such as spasticity or weakness in a particular muscle group. Gait analysis helps the clinician determine those impairments and functional limitations that likely contribute to a walking disability. Probably no two sets of quantitative gait data from two individuals are the same, no matter how visually similar the individuals' gait disabilities appear. Logically, the optimal treatment for a given individual will be the one that addresses the impairments and functional limitations most contributory to that person's gait disability.

By defining causative impairments and functional limitations, gait analysis can focus and optimize rehabilitation treatment, including the prescription of specific exercises, electromyographic biofeedback, functional electrical stimulation, orthotics, and nerve or intramuscular blocks. In patients with upper motor neuron pathology, traditional static evaluations are not effective in measuring either functional muscle strength or spasticity. By identifying which muscle groups need strengthening (or electrical stimulation, or bracing) and which need relaxation (or stretching, or intramuscular neurolysis, or tendon lengthening), gait analysis can lead to optimal, methodical, and directed treatment.

Undoubtedly, gait analysis technology will continue to improve with developments in computer vision, artificial intelligence, computational methods, and computer power. In addition, models used to interpret gait analysis data will be refined and standardized. Ultimately, a clinician will likely be able to input kinetics measured with current gait analysis technology into a computerized robotic model that will produce a kinematic gait pattern, or mathematical description of the person's entire gait, that is similar to the individual's actual kinematic pattern. Changing the kinetic inputs in the robotic model could simulate rehabilitation, such as strengthening a particular muscle. The resulting modeled kinematics would help predict the kinematic changes to be expected if the patient were to undergo the treatment.

—Patrick O. Riley and D. Casey Kerrigan

See also Computer Technology; Paralysis.

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GALEN (129–CA. 199/216)

Greek physician and philosopher

Galen was a physician from Asia Minor who practiced on both gladiators and rulers, serving as physician to four emperors. He was also a philosopher and author who wrote more than 350 works in Greek on subjects ranging from anatomy to deontology, from philosophy to poetry, from pathology to therapy. He was a vigorous advocate of the tradition of Hippocrates but was equally eager to display his own innovative knowledge and investigations. In particular, Galen enhanced the concept of the four humors as a system of explanation for diseases.

At once arrogant and brilliant, Galen, through his texts and ideas, had a profound influence on elite Western medicine until the nineteenth century, although observations by anatomists and physiologists starting in the sixteenth century (e.g., those of Andreas Vesalius [1514–1564]) began to undercut the power of his ideas.

Galen's descriptions of disabling conditions ranged from fractures and paralyses to visual impairments and epilepsy, while his therapeutic interventions embraced dietary changes, fractured limb reductions, and bloodletting. He helped differentiate the trachea and the larynx, thus allowing speech disorders to be pathologized. Galen publicly demonstrated the function of the recurrent laryngeal nerve, which innervates the voice box. He cut the nerve in a squealing pig and thereby "removed" its voice, thus demonstrating both a refined physiological sensitivity and the use of impairment as a marker of physiological dysfunction. Galen's influence on disability, by way of medicine, is at once distant and profound.

—Walton O. Schalick III

See also History of Disability: Ancient West; Medicine.

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GALLAUDET UNIVERSITY

See Gallaudet, Edward Miner

GALLAUDET, EDWARD MINER (1837–1917)

American educator

Edward Miner Gallaudet, an influential nineteenth-century educator, was the founder of the world's first institution of higher education for deaf people. During his 46-year tenure as the head of the National Deaf-Mutes College (today known as Gallaudet University), Gallaudet was internationally renowned as the originator and chief proponent of the so-called combined method of educating deaf children, a method that stressed a combination of spoken-language training and the use of sign language in the classroom. A native user of American Sign Language (his mother was deaf), Gallaudet maintained lifelong connections with the American Deaf community largely through “his boys,” the Deaf male graduates of the college.

The youngest son of Thomas Hopkins Gallaudet, cofounder of American Deaf education, Gallaudet was born in Hartford, Connecticut, on February 5, 1837. After a stint as a teacher at the American School for the Deaf from 1855 to 1857, he was invited to establish a school for deaf children in the District of Columbia. The Columbian Institution for the Instruction of the Deaf, Dumb, and Blind was established on February 16, 1857, its college division charter signed by Abraham Lincoln on April 8, 1864. Gallaudet died in Hartford, Connecticut, on September 26, 1917, in the centennial year of the founding of American Deaf education.

—Joseph J. Murray

See also Deaf, History of the; Deaf Culture; Thomas Hopkins Gallaudet.

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GALLAUDET, THOMAS HOPKINS (1787–1851)

American educator

Thomas Hopkins Gallaudet was the cofounder of American Deaf education in 1817. A noted orator and evangelical Christian, Gallaudet used his considerable rhetorical skills to garner support from influential citizens and financial assistance from state legislatures for the then outlandish notion of educating Deaf people. Gallaudet held a lifelong interest in education and social reform, campaigning in areas as disparate as the common school movement, work with the mentally ill, and the abolition of slavery.

Gallaudet, born on December 10, 1787, became interested in the education of Deaf people after meeting Alice Cogswell, the Deaf daughter of a neighbor. With funding from Cogswell’s father and other prominent Connecticut citizens, Gallaudet traveled to Europe in 1815 to learn how to teach Deaf children. Dissatisfied by what he saw in British schools for Deaf people, Gallaudet was invited to visit a school in Paris. There, he received training from Deaf teachers Jean Massieu and Laurent Clerc. The latter accompanied Gallaudet back to Hartford in 1816 and helped him establish the first permanent school for the deaf in the United States in 1817, now known as the American School for the Deaf. Gallaudet served as the institution’s principal until 1830. Gallaudet and his wife, Sofia Fowler, a former pupil, had eight children, the eldest and youngest of whom continued their parents’ work with Deaf people. Gallaudet died on September 10, 1851.

—Joseph J. Murray

See also Deaf, History of the; Deaf Culture; Edward Miner Gallaudet.

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GALSWORTHY, JOHN E. (1867–1933)

English novelist and dramatist

Educated at Harrow and at New College, Oxford, and recipient of the 1932 Nobel Prize in literature, John Galsworthy is best remembered for his series of novels tracing the history of the upper-middle-class Forsyte family from the 1880s to the 1920s. Appointed to Britain's War Propaganda Bureau (WPB) in 1914, Galsworthy refused to encourage public hate of Germany, instead emphasizing support of men wounded and disabled in the conflict. To this end, he worked with the Red Cross in France at the Benevole Hospital for disabled soldiers, offered his family house as a convalescent home for recovering British soldiers, and chaired the executive committee of Kitchener House, a club for wounded sailors and soldiers. Galsworthy also published successful appeals on behalf of the Star and Garter Home for Disabled Sailors and Soldiers, contributed material to the *American Journal of Care for Cripples,* among many other publications, and wrote the foreword to the proceedings of the second Inter-Allied Conference on the After-Care of Disabled Men (1918). Additionally, he served as editor of *Recalled to Life,* later *Reveille,* a Ministry of Pensions journal designed to inform the general public of the welfare of disabled sailors and soldiers. Galsworthy resigned as editor following ministry disenchantment with the public indignation sparked by the publication. Galsworthy's collections *A Sheaf* (1916) and *Another Sheaf* (1917) contain articles he wrote specifically for the WPB.

—*Jeffrey S. Reznick*

See also Veterans; War.

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GALTON, FRANCIS (1822–1911)

English inventor, scientist, geographer, meteorologist, eugenicist

Francis Galton, inventor, scientist, explorer, and developer of eugenics, was born near Birmingham, England, on February 16, 1822. He entered medical school at King's College, London, in 1839 but subsequently left, in part owing to the urgings of his second cousin, Charles Darwin. Galton then entered Trinity College, Cambridge, to finish his medical degree; he graduated in 1844.

Inspired by Darwin's *Origin of Species,* Galton believed humankind could improve its physical and mental health through selective breeding, which he termed *eugenics.* Galton spent much of his later life conducting research on the physical and mental characteristics of Londoners in his anthropometric laboratory. He conducted studies on eminent men, twins, and adopted children to demonstrate the heritability of mental characteristics. Galton developed the idea for intelligence tests and the statistical methods of correlation and regression, which were used to verify the strength of heritable relationships.

Galton's eugenics ideas inspired many countries, including the United States, France, Sweden, and Germany to adopt racial hygiene movements, immigration restrictions, and forced sterilization laws. These activities resulted in the castration, vasectomy, salpingectomy (the tying of the fallopian tubes), and deaths of numerous individuals from diverse racial and ethnic backgrounds who suffered from physical and mental disabilities.

—Michael J. Root

See also Eugenics; Eugenics: Germany; Racial Hygiene *(Rassenhygiene).*

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GASTROINTESTINAL DISABILITIES

The gut is vital to the process of digestion and the processing of food into metabolic substrates necessary for energy, growth, and survival. In the medical model, functional failure results in disabilities ranging from mild to severe and may even be life threatening. In general, the gut comprises an entrance orifice, the mouth, and a lengthy hollow tube, the intestine; the mouth allows food to be masticated by the teeth and passed on for digestion and absorption in the intestine. The intestine includes first the esophagus (transit tube into the stomach) then the stomach (which secretes acid to kill ingested bacteria and also an enzyme, pepsin, to activate digestion), duodenum, and small bowel (jejunum and ileum), and finally the colon (cecum, right, left, and sigmoid) and rectum, which terminates at the anus for the elimination of feces. Most digestive products are absorbed into the portal venous system and thence metabolized by the liver, from where they enter the general circulation. Fats are absorbed in a similar fashion but conveyed via lymphatics and the thoracic duct directly into the circulation, bypassing the liver. The entire gut is supplied with blood by the celiac, superior, and inferior mesenteric arteries, which in turn give rise to the gastric, hepatic, and pancreatic vessels. Interference with either the arterial supply or venous drainage results in pain, bleeding, ischemia, and even bowel death. Medical evaluation of the gut is by endoscopy (upper or lower), barium studies, computerized axial tomography (CAT scan), and/or angiography; surgical evaluation is undertaken either by open operation (laparotomy) or closed visualization (laparoscopy)

Infection of the stomach with *H. Pylori* (bacteria) results in gastritis and peptic ulceration, although this can also be produced by excess acid production or agents such as alcohol and aspirin. Inflammation of the esophagus (esophagitis is caused by acid reflux) results in substantial pain and even difficulty in swallowing. Inflammation and ulcers of the esophagus, stomach, or duodenum may all result in bleeding, perforation, or stricture, with results ranging from discomfort to incapacitation and even death. The esophagus may also perforate after vomiting or during the medical procedure endoscopy. Inflammation of the small bowel (Crohn's disease) and colon (ulcerative colitis) is generically referred to as *inflammatory bowel disease;* its sequelae include bleeding, ulceration, and perforation, with symptoms ranging from pain and diarrhea to death. The cecum has a congenital diverticulum (the appendix) that often becomes infected (appendicitis) and requires surgical removal. The sigmoid colon with age develops other diverticuli that may become inflamed, bleed, or perforate, requiring either antibiotics or surgical therapy for treatment. The anus is commonly the site of dilated venous channels (hemorrhoids) that are problematic in terms of pain, prolapse, and bleeding. They may be removed by banding or surgical resection.

Cancers of the hollow viscera usually cause bleeding and block the lumen, resulting in obstruction and death if surgery is not undertaken to relieve the problem. They are most common in the colon, stomach, and esophagus but are rare in the small bowel. Surgical resection alone may not be adequate, as the tumors may spread either locally, to the liver, or elsewhere.

The accessory digestive organs, the pancreas and liver, drain their secretions (pancreatic juice and bile, respectively) into the duodenum via ducts, thus providing digestive enzymes and bile salts to facilitate absorption of carbohydrates, fats, and amino acids in the small bowel. The pancreas, in addition, secretes a hormone, insulin, into the blood from the islets of Langerhans that is necessary for glucose homeostasis. In certain conditions (chronic pancreatitis and islet cell dysfunction) lack of insulin secretion results in diabetes mellitus. Acute pancreatitis is usually due to alcohol or gallstones and causes an often uncontrollable inflammation of the pancreas that may result in death. Tumors of the pancreas are very malignant, present late, and even if removed usually lead to early death, although tumors of the endocrine pancreas are in general far more benign. The liver is susceptible to damage by viruses (hepatitis) and by alcohol and may become cirrhotic (fibrosed) leading to malfunction, jaundice (a yellow coloration of the skin and eyes), and the accumulation of fluid in the abdominal cavity (ascites). Bile is stored in the gallbladder before secretion during digestion, and gallstones often form, causing inflammation (cholycystitis) or even blockage of the bile duct and jaundice. Tumors of the liver are generally highly malignant and despite surgery are usually incurable.

In general, the organs of the gastrointestinal system are crucial to vital functions. Impairment of those functions leads to a variety of disabilities, as noted above, and their consequent handicaps under World Health Organization definitions. While many therapies exist, an enormous amount of work remains to be done through the collaboration of researchers, clinicians, and people with these impairments to improve their quality of life.

—Irvin M. Modlin

See also Diabetes.

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GENDER

Globally, persons with disabilities have historically experienced stigmatization and discrimination that continues to the present day. Evidence suggests that society views and stigmatizes persons with disabilities as second-class citizens, thus placing this group at risk for isolation beyond what may be caused by the disability itself. Among the many social divisions ascribed to individuals in a society is that of gender. It has been suggested that gender may play a role in the disenfranchisement that persons with disabilities experience in everyday life. Men with disabilities are often thought to be less masculine and weaker than nondisabled men. Likewise, disabled women are viewed as being less feminine and weaker than nondisabled women. It is important to view the role of gender in disability from both of these dichotomies (disabled/nondisabled and men/women) because evidence suggests that women with disabilities are at increased risk for poor health and social outcomes that go beyond placing them in "double jeopardy" as a result of sexism and disability bias.

Gender is often regarded as synonymous with sex differentiation, which posits that biologically and physiologically there are only two sexes, male and female. According to the World Health Organization, *sex* refers to the biological and physiological characteristics of male and female animals: genitalia, reproductive organs, chromosomal complement, and hormonal environment. However, transsexual individuals and those born with congenital anomalies such as ambiguous sex organs suggest that categorization of individuals by sex is not clearly differentiated. A broader interpretation of gender suggests that it is a culturally bound interpretation of biological differences. Again according to the World Health Organization, *gender* refers to the socially constructed roles, rights, responsibilities, possibilities, and limitations that, in a given society, are assigned to men and women. In sum, *gender* refers to what it means to be considered "masculine" and "feminine" in a given time and place. In this context, *gender* refers to a set of societal norms, roles, and behaviors that can be ascribed to individuals. For example, men are viewed as being more powerful than women and as exhibiting masculine traits, such as dominance and competitiveness, whereas women are viewed as exhibiting feminine traits, such as passiveness and nurturing. However, persons who are gay or lesbian, bisexual or transsexual provide evidence to suggest that the norms, roles, and behaviors associated with a particular gender cannot be universally applied. It is useful to consider both sex and gender concepts when addressing health and disability as a practice generally referred to as *gender awareness* or *consciousness.*

DISABILITY FRAMEWORK

Several conceptual frameworks related to the disabling process exist. Two of the most widely used disability taxonomies, those developed by Nagi (1969) and Wood (1975), suggest that there is both an individual role performance component and a social role performance component in the disabling process. In both the Nagi and Wood taxonomies, the "impairment" stage involves abnormality or loss of structure or function at the anatomical, physiological, mental, or emotional level of the individual. Such change requires medical intervention. As end points in the disabling process, Nagi views disability as limitation in the performance of socially defined roles within the larger societal environment. Similarly, Wood suggests that a handicap is a disadvantage that limits or prevents a normal role from being fulfilled. These taxonomies' "disability" and "handicap" stages both involve the notion of performance in a sociocultural context.

These distinctions are important because they parallel the two major sets of understandings of how persons with disabilities are viewed and stigmatized by society. When viewed as deviating from the "normal-bodied" norm, persons with disabilities become medicalized. When viewed as deviating from the "able-bodied" norm, persons with disabilities become second-class members of society.

In the social model of disability, disability is viewed as the discrimination against persons with disabilities that result from mainstream society's orientation toward "able-bodiedness." In this view, disability is a socially constructed phenomenon and those with disabilities find themselves socially oppressed. This is in contrast to more individually derived models in which those with disabilities must learn to cope and accept their status as having the individual and personal burden of disabilities that society views negatively.

The social model argues that two primary components reinforce the notion of disability as a societal negative: medicalization of disability and socioeconomic discrimination. Medicalization of disability can be seen as the ways in which the medical profession claims control of defining disability. Socioeconomic discrimination takes a variety of forms, including discrimination in employment and the strong relationship between poverty and disability. Ample evidence suggests that persons with disabilities worldwide experience multiple disparities in terms of social, economic, and health status compared with those who are not disabled. Specifically, these disparities are exhibited as greater rates of isolation and mental health impairments, higher rates of poverty and unemployment, and increased risk for premature mortality and morbidity.

THE GLOBAL BURDEN OF DISABILITY

According to the 1990 Global Burden of Disease project, a worldwide collaboration of researchers sponsored by WHO and the World Bank and based at the Harvard School of Public Health, several patterns may be seen in the global burden of disability:

- Disability plays a major role in influencing the overall health status of a population.
- The leading causes of death are substantially different from the leading causes of disability.
- Worldwide, almost half (49.4 percent) of all disability due to disease or injury occurs in the young adult age group (15–44 years), one-fifth (18.3 percent) occurs in the early childhood age group (0–4 years), and less than one-tenth (9.3 percent) of the disability burden is due to the incidence of disease or injury.
- The burden of psychiatric conditions has been underestimated.
- Of the 10 leading causes of disability (measured as years lived with a disability) 5 are psychiatric conditions: unipolar major depression, alcohol use, bipolar disorder, schizophrenia, and obsessive-compulsive disorder.
- There are differences by gender with regard to the leading causes of disability due to disease and injury.

Table 1 illustrates how the prevalence of disability differs by gender. The primary indicator used to analyze the burden of disease and injury by cause is years lived with disability (YLD). The 10 leading causes of

Table 1 Ten Leading Causes of Years Lived with Disability by Sex, 1990

Both Sexes			*Males*			*Females*		
Rank	*Disease or Injury*	*Cumulative %*	*Rank*	*Disease or Injury*	*Cumulative %*	*Rank*	*Disease or Injury*	*Cumulative %*
1	Unipolar major depression	10.7	1	Unipolar major depression	7.7	1	Unipolar major depression	13.8
2	Iron-deficiency anemia	15.4	2	Alcohol use	13.6	2	Iron-deficiency anemia	18.9
3	Falls	20.0	3	Falls	19.3	3	Falls	22.5
4	Alcohol use	23.4	4	Iron-deficiency anemia	23.5	4	Osteoarthritis	25.8
5	Chronic obstructive pulmonary disease	26.5	5	Chronic obstructive pulmonary disease	27.0	5	Bipolar disorder	28.8
6	Bipolar disorder	29.5	6	Bipolar disorder	30.1	6	Congenital anomalies	31.6
7	Congenital anomalies	32.3	7	Congenital anomalies	33.0	7	Chronic obstructive pulmonary disease	34.3
8	Osteoarthritis	35.1	8	Schizophrenia	35.7	8	Chlamydia	36.7
9	Schizophrenia	37.7	9	Road traffic accidents	38.2	9	Schizophrenia	39.2
10	Obsessive-compulsive disorders	39.9	10	Osteoarthritis	40.5	10	Obsessive-compulsive disorders	41.6

SOURCE: Adapted from Murray and Lopez (1996).

worldwide YLD account for nearly four-tenths (39.9 percent) of all YLD. As noted above, of these 10 causes, 5 are related to neuropsychiatric conditions (unipolar major depression, alcohol use, bipolar disorder, schizophrenia, and obsessive-compulsive disorder). Unipolar major depression accounts for 11 percent of all YLD worldwide. The other leading causes of YLD include anemia, falls, osteoarthritis, and chronic obstructive pulmonary disease (COPD).

When comparisons are made across gender, differences are also noted in YLD rank ordering and cause. For men, alcohol use (rank 2) and road traffic accidents (rank 9) are among the 10 leading causes of YLD worldwide. For women, anemia (rank 2) and chlamydia (rank 8) are leading causes of YLD globally. There are also differences in the rank ordering of the 10 leading causes of YLD by gender.

WOMEN AND DISABILITY

Most of the literature on gender and disability does not differentiate between women and men. Rather, the focus is on those with disability compared with those without disability. This is due, in part, to the societal stigma attached to those with disability as being "abnormal." This deviance from the norm has been the focus of most work in disability studies, and gender concerns have not been well investigated. Other barriers include social issues such as the feminization of poverty, abuse, violence, and sexual and reproductive rights. However, in recent years research examining the impact of gender on persons with disabilities has pointed to a relative decrease in status of women with disabilities compared with men with disabilities. Some examples:

- Disabled women are poorer than disabled men and are often heads of households.
- Disabled women have lower incomes than disabled men.
- Disabled women are at greater risk of sexual abuse than are nondisabled women.
- Women with disabilities are viewed as "asexual."
- Women with disabilities receive less education than do either nondisabled women or men with disabilities.
- Most disabled students are educated in segregation from students of the opposite sex.
- Women with disabilities have less access to "rehabilitation" services than do men with disabilities.
- There are differences between men with disabilities and women with disabilities in the rates and degrees of disability following heart attacks and strokes.

An estimated 300 million women and girls are disabled worldwide. A majority of these live in resource-poor or developing countries. Given that disability is a dynamic process, changes in gender differences among persons with disabilities can and will occur with increasing worldwide focus on women's rights. As a consequence, cultural taboos may lessen and more information will likely emerge about the disabilities resulting from such practices as female genital mutilation and domestic violence.

Although men and women with disabilities share many similarities, the literature suggests that women with disabilities are at a double disadvantage. This is manifested in a variety of ways, including disabled women's lower levels of participation in societal activities and lower levels of self-concept. In addition, the sociocultural aspects of being a disabled woman take the form of a variety of stigmas, including sexism and ableism.

Societal Participation

Compared with men with disabilities, women with disabilities are more likely to be isolated from general societal participation, including social relationships, education, and employment. This could be due to the general stigma society places on persons with disabilities. With regard to social relationships, compared with disabled and nondisabled men and nondisabled women, women with disabilities are more likely to remain single and, of those who marry, more likely to be divorced or separated. Similarly, women with disabilities are less likely to have children and to have significant relationships. These factors may result in forms of social isolation that may contribute to poorer general health among women with disabilities. Isolation may also be increased by the general lack of mobility due to disability.

With regard to education, women with disabilities are less likely to graduate from high school or to attend college for some period of time. In addition to the amount of education, differences may also exist in the content of the education received by women with disabilities. Comparison of employment rates between women with disabilities and other groups indicates that disabled women have lower rates of labor force participation, lower rates of full-time employment, and lower wage earnings.

Self-Concept

Women with disabilities generally have lower self-concepts than do men with disabilities. In particular, such women often feel the oppression of being disabled, the feeling that they cannot and should not engage in certain activities, and this is reflected in lower self-images and low levels of self-esteem. Such a poor self-concept may come from the woman's family members, who may place guilt on the disabled member as causing inconvenience or, conversely, may have an overprotective attitude toward the disabled woman.

Sociocultural Aspects

The sociocultural aspects of being a woman with a disability include stigma and discrimination. *Sexism* refers to the devalued status of women in comparison with men in society generally. Women are seen as childlike, passive, and dependent. Women with disabilities are often perceived as not being able to fulfill the variety of roles society places on women in general, such as mother, wife, and sexual partner. Likewise, society often views these women as not being physically attractive and thus as being relatively passive, nonsociable, uninteresting, and unintelligent. Needless to say, women of color who have disabilities can experience a third layer of bias. Clearly, women with disabilities bear a disproportionate share of stigma and discrimination from both internal (self) and external (society) perspectives.

The current global approach to addressing disability includes efforts not only to reduce the incidence and prevalence of disability but also to address the personal, economic, and social consequences of disability and thereby improve the quality of life for disabled individuals, their families, and society. Whatever specific strategies are developed in the future to address the issues related to disability worldwide, the process will be much enhanced by attention to the multiple influences that gender has on persons with disabilities.

—Karen E. Peters and Karin Opacich

See also Gender, International; India, Impact of Gender in; India, Marriage and Disabled Women in; Invalid Women.

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Women with DisAbilities, http://www.4women.gov/wwd/index.htm

GENDER, INTERNATIONAL

THE MEANING OF GENDER

> Gender is the structure of social relations that centres on the reproductive arena, and the sets of practices (governed by this structure) that bring reproductive distinctions between bodies into social processes. (Connell 2002:10)

Why do we need to understand about gender in disability studies? What is the relationship between gender and disability? How are men's and women's experiences of disability similar or different? Indeed, are gender and disability such different concepts given that women have been seen as deformed men and disability is often associated with femininity? In order to address these questions, we must examine the meaning of gender.

Gender is closely connected to sex, although there are different ideas about how sex is usually understood as relating to the biological and physiological body. The term *gender* is often understood to refer to the cultural interpretation of sexed bodies, embedded in the whole apparatus of a society's roles and norms. Thus, a sex/gender binary is set up parallel to that of nature/culture. Gender, as a relationship between sexes in societies, is usually seen as operating hierarchically, with men being more powerful and dominant, and women being less powerful and weaker. These power relations produce stereotypes of masculinity and femininity—traits and behavior that are expected of men and women (see further below). Role expectations of women as nurturers, men as breadwinners, and so on define approved ways to perform gender.

While the simple binary has been persuasive, insofar as there are two sexes involved in biological reproduction, we now know that there are more than two sexes—including transsexuals and people with congenitally ambiguous sex organs—and many ways of performing gender. Far from being a simple dichotomy, gender turns out to be a complicated and evolving realm of meaning making among people with sexed bodies. Gay, lesbian, and transgender individuals suggest the fluidity of these performances and their capacity to change over time and across societies.

Many of these questions go to the heart of understanding disability. The simple binaries have become complicated as we have learned more about the social construction of bodies and the biological influences on human behavior. Nature and culture, sex and gender, have their reflections (although not mirror images) in the distinctions between impairment and disability. The term *impairment* has been used to describe functional limitations accruing to an individual as a consequence of embodied differences, whereas *disability* has been used to refer to a system of social relations that limit an individual in the course of daily life. This simple binary, while heuristically useful, masks the interpenetration of the social and the biological. Gendered analysis of disability has been particularly valuable in demonstrating the web of social and biological factors that disable people, not just women. Gendered analyses address the processes through which both femininity and masculinity are constituted and the implications of these processes for people with impairments, thereby moving beyond the particular focus of feminism on the experiences of women.

THE GENDERED EXPERIENCE OF DISABILITY

Disabled people have often been represented as *without gender,* as *asexual* creatures, as freaks of nature, monstrous, the "Other" to the social norm. In this way it may be assumed that for disabled people gender has little bearing. Yet the image of disability may be intensified by gender—for women a sense of intensified passivity and helplessness, for men a corrupted masculinity generated by enforced dependence. Moreover, these images have real consequences in terms of education, employment, living arrangements, and personal relationships, victimization and abuse that then in turn reinforce the images in the public sphere. The gendered experience of disability reveals sustained patterns of difference between men and women. For people with disabilities gendering is conditional. Age of onset combined with the type of impairment leads to gender expectations.

Gendered studies of disability in Western industrialized nations reveal the following patterns of public and private dimensions. In the public arena:

- More women than men are classified as disabled, particularly as aging populations mean that larger proportions of the elderly are women with impairments.
- Disabled people are much more likely than nondisabled to live in poverty, and disabled women are likely to be poorer than disabled men, especially in developing countries, where women are often heads of households.
- Younger disabled women achieve lower educational outcomes than do men.
- Disabled women are less likely to be in the paid workforce than either men with disabilities or nondisabled women, and in general have lower incomes from employment.
- Women are less likely than men to have access to rehabilitation and to employment outcomes when they do receive rehabilitation.
- The age distribution for disabled women is different from that for disabled men (older versus younger).
- The types of impairments are different for women and men, with women more likely to experience degenerative conditions and men more likely to experience injury-related events.
- Disabled women are more likely than disabled men to experience public spaces as intimidating and dangerous.

In the private and familial arena, disabled women compare with disabled men in the following ways:

- Disabled women are more likely to be living on their own or in their parental families.
- Disabled women are more likely to be divorced and less likely to marry.
- Disabled women are more likely to face medical interventions to control their fertility.
- Disabled women are more likely to experience sexual violence in relationships and in institutions.

- Disabled women experience more extreme social categorization, being more likely to be seen either as hypersexual and uncontrollable or as desexualized and inert.

Moreover, in the developing world, gender patterns in relation to disability indicate the following:

- Poverty hits women and girls harder due to patriarchal property ownership structures.
- Aid is less likely to reach women and girls who are less able to compete in situations of scarcity.
- Disabled women are more vulnerable to domestic violence.
- Disabled girls are likely to find their access to education even more limited than that experienced by girls in general.
- Women disabled by war have few resources with which to survive.
- Disabled women who are sexually abused are likely to have few if any social supports or options.
- Disabled women are less likely to be accepted as refugees by industrially advanced countries (e.g., Australia prohibits the immigration of people with disabilities).

Gender has been widely used within the humanities and social sciences as both a means to categorize differences and an analytic concept to explain differences. In both the humanities and the social sciences, feminist disability studies have emerged partly as a result of attempts to explain gendered experience of disability and partly as a challenge to contemporary feminist theory on gender that fails to take account of disability, such as the work of Judith Butler.

THE PSYCHE AND GENDER

Disability has been used as a powerful metaphor in psychology, particularly as a means to assign to women the status of incomplete or deformed men. In addition, gender stereotypes have been used to characterize disabled people, particularly men, who have been presented as feminized and lacking masculine traits. These approaches have confused the conceptual difference between disability and gender.

Gendered analyses of disability have tried to move beyond these metaphors, to create a disciplined account of the impact on the gendered psyche of disabling social relations. Here four elements are presented: the development of the "normal" individual, the impact of disabling events, support for the survival of the disabled psyche, and strategies for normalization and social role valorization.

Psychological models of individual development are increasingly taking account of gender formation. As the psyche takes form, it develops a sense of self through interaction with others, one result of which is the defining of relations through the lens of gender. This process of identity formation contains a deeply embedded set of responses geared to the hierarchies of value in the able-bodied world. The identities that coalesce are thus both gendered and embodied, affected by the hormonal changes of growth and the social influences of role expectations, peer groups, family, and the wider society. For people with impairments, the reading of them from significant others and the wider society combines with the gendered nature of relations to differentiate them from the "normal" world. For instance, disabled girls may have their desires to be mothers supported by their gender role expectations but simultaneously denied by their disability status.

For people without impairments who experience disabling events later in life, their suddenly changed status creates major conflicts in their expectations and self-images that are reinforced by public perceptions of them as disabled. For instance, women may no longer be able to mother and thus may have their children taken from them in custody battles. Or men may have their masculinity denied and thus face struggles to sustain an affirmed identity. Whatever the situation, in such cases gender is centrally implicated.

Psychologists and social workers can provide support to people with impairments who are seeking to survive their disabilities. Approaches include adjustment and adaptation as key mechanisms of "coping" used in such support; these are themselves gender saturated. Assumptions of appropriate behavior, suitable outcomes, and role allocation reflect professional stereotypes and models, and are often dominated by medical model assumptions about the gendered body.

There is ample evidence that women with disabilities experience major psychosocial problems that remain largely neglected, including depression, stress, lowered self-esteem, and social isolation. Evidence also suggests that disabled women tend to be directed toward home-based activities, whereas disabled men are likely to be supported into more public and outward-looking opportunities.

People often recognize that disability can undermine masculinity, so many therapies assert traditional masculine identities—for example, encouraging disabled men to play wheelchair rugby. On those occasions when identity assertion occurs for women, it is likely to be about hyperfeminine self-presentation, such as makeup and grooming sessions.

With deinstitutionalization, there has been a growing emphasis on the social education of people with intellectual and developmental disabilities to support their living in the community. The primary orientation, *social role valorization* (SRV), uses a training approach to modify the behavior of people with impairments and thus reduce the disabling impact on them of social stereotypes. SRV adopts a "conservatism corollary" in its individual program plans, seeking to minimize the dissonance created for "normal" people by the presence in their midst of people with significant impairments and high support needs. This means, unfortunately, that training seeks to impose more traditional gender roles, and disabled people are drawn to perform these roles in order to reduce their visibility as stigmatized others.

While much of the professional practice concerned with the link between gender and disability occurs together within psychologically inflected professions, there is a wider social science involvement in the analysis of these questions.

CULTURE AND MEANING

Stereotypes are artifacts of culture that can be understood only through an exploration of their relations to each other in the cultural system. Gender stereotypes interact with disability stereotypes to constitute a deep matrix of gendered disability in every culture, developed within specific historical contexts and affecting those contexts over time. While language is the most analyzed site for the examination of both gender and disability, they interact in many other cultural locations as well—such as in cinema, television, fiction, clothing, body language, and gesture. Thus, cultures sustain the social relations of gendered disability in constant reiterations of stereotypes and expectations.

Put simply, disabled men are expected to behave and express their being differently than disabled women in all cultures, although the manner of these expressions is culturally specific. It is likely, however, that the hierarchies of power—usually male over female, able-bodied over disabled—will set the cultural parameters. In most cultures, too, the subordinate groups are not passive, but have developed strategies of resistance and self-affirmation.

Ironically, the interaction of stereotypes can generate resistance that consists of an embracing of stereotypes—for example, disabled women may be perceived as inappropriate mothers and only have status as receivers of care by others, so their resistance may consist of asserting a desire for a traditional female caregiver role in relation to their own children. Disabled men who are not able to behave in stereotypically competitive masculine ways may adopt a variety of strategies to cope with the stigma they experience from others, such as redefining masculinity as financial autonomy rather than physical prowess, building physical strength in areas of physical capacity (the "supercrip" phenomenon), or creating alternative masculine identities that stress personhood rather than gender roles.

Disabled men and women narrate their experiences in significantly gendered terms, with both the content and styles reflecting the ways in which gender expectations are modulated by disability status. Illness narratives are mobilized to make sense of the experiences, which are in each case centered on the impact on sexual identity, sexual relationships, and gender opportunities. Riessman-Kohler (2003), who has examined masculinity and multiple sclerosis, points to the breakdown of traditional marriage relationships when partners cannot cope with the disease state. She reflects on the importance of moving beyond the analytic binary of male/female sexual identities. She also reveals the analytic binary of able-bodied/disabled, which she argues can force descriptions of experiences into either/or categories rather than allow sensitivity to a complex range of responses and attitudes. When some men find themselves unable to perform masculine roles (including employment) and resent their decreasing capacity to be independent, self-sufficient, and self-determining, they explore their sexuality and widen their definition of gender identity to include more feminine and bisexual components.

THE SOCIAL REALM

Sociological accounts of gender and disability stress the systemic nature of the social order and its reinforcement of powerful social institutions and their capacity to enact and impose definitions and allocate resources. For disability the most central institutions remain those associated with the medical profession, rehabilitation, and social support. Many other institutions also reproduce patterns of gendered discrimination—such as education, employment, and transport. One of the most potent patterns of discrimination is found in the area of access to and use of public space.

Both gender and disability have traditionally been seen as products of biology. Gender as a result of biology has been thought to determine all manner of social behaviors on the part of men and women. In a similar way, disability as biology has been seen as determining disabled people's choices and behaviors. In the 1970s, feminists attempted to differentiate gender from sex (the social from the biological) to counter the argument that women are naturally inferior and weak. So, too, disability theorists have attempted to separate disability from impairment (the social from the biological).

But it is no longer adequate to separate the social from the biological in this dichotomous way. The social relations of gender and the social relations of disability are now viewed as much more complex and nuanced. The social model of disability has demonstrated that wider power relations (e.g., class relations in capitalist societies) significantly affect the pattern of disability disadvantage, making disability survival into a lottery critically affected by individuals' income and other material resources. Because the model draws on political economy, it emphasizes political and economic processes that generate disabling environments.

For instance, scholars who have analyzed the medical establishment's uses of individualizing and victim-focused ideologies and technologies have argued that disability is devalued because disabled individuals have little economic worth. Rehabilitation is thus geared to prospective productivity. But this ignores the differences between men and women in their economic situations. In order to understand the differential outcomes for men and women, a gendered model that incorporates patriarchal structures into class structures is absolutely crucial.

Lorber (2000) has shown that while social action around disability issues has benefited both women and men, women with disabilities are less likely than men with disabilities to be economically self-supporting or to have spouses to care for them. These patterns, together with conventional norms of femininity, have hindered disabled women's quest for independence. Women thus confront major obstacles not only in relation to overcoming disabling environments, but also in achieving outcomes equal to those of men who are similarly disabled.

—Helen Meekosha

See also Gender; India, Impact of Gender in; India, Marriage and Disabled Women in; Invalid Women.

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GENE THERAPY

Gene therapy is the treatment or prevention of disease through the alteration (through addition or deletion) of genetic material in human cells, tissues, or organs. The term *gene therapy* is also used to describe the manipulation of genetic information already within the cells for the same purpose. However, at present most of the available technology relates to the addition of new genetic information, and many researchers prefer to use the term *gene transfer* rather than *gene therapy* to reflect the fact that the purpose of this work is not always therapeutic. Throughout this entry, however, the term *gene therapy* is used in reference to processes aimed at both the treatment and the prevention of disease.

There are two types of gene therapy: somatic and germ line. Somatic gene therapy modifies any cells except reproductive cells (i.e., sperm and ova). The aim of this modification is to treat or prevent disease in the individual. Many such treatments are temporary, as the genetic material is not permanently integrated into the cell. Germ line gene therapy modifies reproductive or "germ" cells. This includes modification of sperm or ova and altering the DNA in a fertilized egg. The aim of this treatment is to affect the individual who will develop from the reproductive cells or embryo, together with that individual's descendants. However, germ line modifications may also be carried out as part of the therapy for an existing subject, the modification of the germ cells being an inevitable part of the genetic modification overall.

Various possible approaches to gene therapy have been identified. Where a faulty gene exists, a normal gene could be introduced. Alternatively, the faulty gene could be repaired. Another possibility would be to introduce a gene to "switch off" the faulty gene. Gene therapy has also been seen as a way to treat disease rather than to correct inherited disorders. For example, genes that generate specific toxins could be introduced into diseased cells (such as cancer cells) to kill them. It might be possible to engineer resistance to both cancer and HIV/AIDS through gene therapy. If so, such modifications would be both therapeutic and enhancing, since humans are not naturally resistant to cancer or to AIDS. If such modifications affect the germ line, they would also constitute permanent enhancements.

Gene therapy first entered clinical trials (i.e., trials in humans) in the early 1990s. As of January 2004, according to the *Journal of Gene Medicine* clinical trial database, 636 gene therapy clinical trials had either been completed or were ongoing or pending. These trials involve 3,496 patients, the majority of whom are in the United States. The majority have been or are being directed at the treatment of cancer (63 percent) as well as genetic conditions (12 percent) and vascular conditions (8 percent).

ISSUES

Gene therapy raises several social, ethical, and legal issues, including those discussed below.

Playing God

Some objections to gene therapy are based on the view that humans should not "play God" and interfere in the natural order. In response, it may be argued that we already seek to frustrate the course of nature through medicine, whether by using treatments such as antibiotics or preventive measures such as vaccination. If we accept these practices, we cannot consider it wrong to interfere with nature. Viruses, bacteria, and genetic mutations are perfectly natural, after all.

Writing from a theological standpoint, Ronald Cole-Turner (1993) has argued that genetic engineering may be justified where it is consistent with the purposes of God as creator.

Safety

Some critics are particularly concerned about the safety of germ line gene therapy, because any harm caused by this treatment could be passed to successive generations. However, given that any benefits will also be passed on indefinitely, if the probability of the magnitude of possible harms can be brought to an acceptable level, germ line therapy would be both hugely beneficial and highly cost-effective. Concerns about safety (together with other ethical concerns) have been reflected in public policy. In the United Kingdom, the Gene Therapy Advisory Council, which scrutinizes proposals for gene therapy research, will not yet consider proposals for germ line gene therapy research. Similarly, the Recombinant DNA Advisory Committee, which scrutinizes research proposals seeking federal funding in the United States, has stated that it "will not at present entertain proposals for germ line alterations."

Although the successful use of somatic gene therapy has been reported, trials have also shown associated risks. In 1999, a U.S. teenager, Jesse Gelsinger, died after taking part in a trial. In 2000, a group of French researchers announced that they had successfully used gene therapy to treat two infants suffering from severe combined immune deficiency (X-SCID). The researchers treated 11 patients, 2 of whom are reported to have developed a leukemia-like illness. This highlights one of the difficulties foreseen in relation to somatic gene therapy. Vectors may be used to transport correctly functioning genes into the patient's cells. These vectors, which are often viruses, are inserted either through placement into cells that have been taken out of the patient's body *(ex vivo)* or through placement directly into the body *(in vivo).* However, this process may cause mutations that can lead to diseases such as leukemia. Although the viruses are "disabled" so that they cannot replicate, the patient may suffer an immune response, as was the likely cause of Jesse Gelsinger's death. Concern has also been expressed that there is a risk that even the use of somatic gene therapy may affect germ cells. Nevertheless, where gene therapy could be lifesaving or remove oppressively burdensome conditions, and where the alternative is death or severe disability, many would argue that it is ethically justified in spite of such risks, for the risks are to be borne by the subject who would suffer the risks of denial of therapy.

The Introduction of Eugenics?

In addition to safety, another concern has been whether the use of gene therapy is a form of eugenics. Although one can scarcely use the word *eugenics* without invoking events that took place in Europe during the twentieth century, the concept is nonetheless profoundly ambiguous, admitting of both benign and malign interpretations.

Adopting the definition of the adjective *eugenic* as "pertaining or adapted to the production of fine offspring," John Harris (1993:178) has argued that gene therapy is eugenic, but that this in itself is not morally significant. We can consider a scenario in which a woman has had five of her eggs fertilized in vitro and, following usual medical practice, then has two or three implanted. If preimplantation screening reveals that two of the embryos possess disabilities, would it be right to implant these two embryos rather than the others? If we consider it would be wrong to implant the "disabled" embryos, this suggests that disability is something we do not desire and have good reason to reject. It suggests that disability can be identified as "a physical or mental condition we have a strong rational preference not to be in" and a condition that is "harmed" (Harris 1993:180). This approach avoids the task of defining disability by reference to a "normal" human being. Furthermore, it provides an explanation of disability that can be applied to the "potentially self-conscious" (Harris 1993:181) such as embryos and also the temporarily unconscious. It is not based on the subjective viewpoint of the individual or of the future individual concerned.

Thus, according to this approach, gene therapy is eugenic, but it is the treatment parents should adopt when it will avoid disability for their child (on the assumption that the procedure is safe). However, although parents may harm their child by not preventing avoidable disability, this approach does not state that parents should be compelled to adopt such treatment. Furthermore, to argue that parents should seek to avoid harming their children is not to discriminate against the disabled.

Some observers, such as Solveig Magnus Reindal (2000), have challenged this view of disability. Reindal refers to the distinction between impairment and disability, noting that the fact that an individual has an impairment does not necessarily mean he or she is disabled. Reindal propounds a "social model" of disability, which does not deny the fact that impairments exist but asserts that whether or not impairment leads to disablement depends on numerous other factors, such as the individual's view of the situation, social norms, and societal attitudes. Reindal is critical of "medical models" of disability such as that espoused by Harris. By focusing solely on impairment, Reindal argues, those who are unimpaired are led to make judgments about whether an impaired life is worth living. With reference to gene therapy, she holds that if a medical model is used in debate, those who are disabled will view such discussions as "eugenics in disguise." Such "biological determinist understandings" were, she argues, the foundation of sterilization laws passed in the 1930s. In Bill Albert's (2003) view, gene therapy not only legitimates the medical model of disability but also raises hope that research will lead to new treatments, which is followed by disappointment when these do not materialize.

Enhancement

Debate has also focused on whether gene therapy should be used to enhance individuals. Some enhancements might mirror the effects of other medical interventions currently in use. For example, if it were possible to use gene therapy to generate antibodies to infections such as HIV, this would be an enhancement similar to that provided by vaccination against diseases such as tetanus.

Eventually it may become possible to enhance, or at least alter, attributes other than health, such as height, behavior, and intelligence. However, it is acknowledged that many traits, even if found to have a genetic basis, are likely to be determined by complex interactions among perhaps many genes together with environmental factors. Gene therapy aimed at modifying such traits, even if it were to become possible, lies many years away. However, debate has focused on where the boundary should be drawn between acceptable and unacceptable enhancement, if indeed such a boundary can be defined. Even if it were generally agreed that an appropriate boundary would lie between "disease" and "disorder," there would remain the issue of how these terms are to be defined.

Individual Choice

Some observers have argued that if it were possible to do so, individuals should be permitted to use gene therapy for enhancements. For example, Jonathan Glover (1984) considers that it would be acceptable for individuals to improve their intellectual functioning even if theirs is currently in the "normal" range. In contrast, LeRoy Walters and Julie Gage Palmer (1997) consider it acceptable to use genetic enhancements to enable functioning within the "normal" range, but see further enhancement as more problematic, particularly given issues surrounding resource allocation (see below).

Parental Choice

Further issues arise in relation to the extent to which parents should be entitled to make enhancement choices on behalf of their children or future children. Walters and Palmer consider the issue of parents choosing intellectual enhancement for their children and express concern that this might present opportunities for a new form of child abuse. However, they accept that it might be appropriate for parents to seek some intellectual enhancement for their children; they note also that boundaries might need to be set to limit parental discretion in this area.

John Robertson (1996) considers this issue from the viewpoint of the principle of procreative liberty. He asserts that as reproductive decisions are so important, society has a sound moral basis for ensuring that these decisions are respected. In particular, he highlights the role of the law in this area. In relation to the selection or control of the characteristics of future offspring, he considers that two questions will need to be addressed. First is the question of whether the characteristic is central to the decision to procreate; only if it is should the law uphold procreative liberty. Second, the extent of any harms that would flow from a policy allowing selection must be considered. In the context of the nontherapeutic enhancement of traits such as intelligence, Robertson argues that even if such decisions do not fall within procreative liberty, they might be argued to fall within the parental right to rear the child after birth. As he points out, the law already enables parents to influence their children's development after birth by sending them to tutors, orthodontists, and so on.

A final issue relates to whether parents should be entitled to choose treatments for their children that will affect future generations. An argument frequently made in this regard is that if the technology were to exist to make the alteration in the first place, the technology needed to reverse the process would also likely be available.

Justice

Resource Allocation

It is widely acknowledged that gene therapy technology will initially be very costly. Given that treatments cannot be provided to all those who might want to receive them, this raises long-standing debates concerning issues of justice and political theory. A libertarian approach, as espoused by Robert Nozick (1974), would suggest that access to such treatments should be based on free-market principles. In other words, those who can afford them should be entitled to them (although Nozick does foresee the need for some restrictions). Alternatively, if justice is viewed in terms of equality for all individuals, then access to treatment should be available to all on an equal basis. However, although there is no agreement as to how this principle should be applied in practice, it is clear that it would be unethical to deny therapies to some unless and until they can be provided for all. The development and availability of new and effective therapies cannot wait on agreement as to just principles of distribution.

Benefit

Additional questions relating to justice arise even if we resolve the problems associated with the allocation of treatment. Once such treatments have been allocated, classes of people may develop who are in stronger positions than others in certain respects. For example, individuals who have received therapy to slow down the aging process may be more attractive as employees, given their longer life expectancy.

Changing Humanity

Francis Fukuyama (2002) asserts that developments in biotechnology, such as gene therapy, have the potential to alter human nature and so lead us into a "posthuman" era. He therefore urges the establishment of regulation to ensure that we are not driven by technological progress to abandon values we might wish to protect. In contrast, Gregory Stock (2003) sees the potential to re-create ourselves as an expression of our humanity and argues that this process should be subject to minimal regulation.

Gene therapy is a new technology, and as yet it is unclear to what extent the expectations surrounding it will be fulfilled. It raises many of the same issues that are already under discussion in the larger health care arena, such as how limited resources should be allocated. It also raises specific issues linked to the possibility of affecting future generations and the consequences that might result.

—Catherine Stanton and John Harris

See also Eugenics; Genetic Counseling; Genetics; Genetics and Disabilities: Social and Ethical Dilemmas.

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GENETIC COUNSELING

Genetic counseling is a process of communication in which a specially trained professional, often but not always a doctor or nurse, meets with an individual, couple, or family to provide information about a genetic condition that has affected the individual, couple, or family or may do so in the future.

The 1940s saw the establishment of genetic counseling clinics in both the United States and Great Britain. Initially, the purposes of these clinics were to aid in the delivery of eugenics policies and to control population growth among specific ethnic groups. The purpose of the clinical practice of genetic counseling has now changed considerably, and such counseling is available in most developed countries. The focus of modern genetic counseling is to provide people with balanced information and nondirective support so that they can make informed decisions regarding issues related to genetics. The expansion of genetic knowledge and improvement of diagnostic techniques has led to an expansion in the profession since the late 1990s, and professional courses in genetic counseling are taught worldwide.

WHO RECEIVES GENETIC COUNSELING AND WHY?

Genetic counseling should be an integral part of genetic testing at the points of the life cycle discussed below.

During Pregnancy Planning

Couples who are planning pregnancies often seek the assistance of genetic counselors when one or both of the partners themselves, one or more of their existing children, or other family members are already affected by genetic conditions. Members of ethnic communities in which recessive genetic conditions are particularly prevalent also frequently seek genetic counseling during pregnancy planning. The genetic counselor gathers relevant information from the counselees to assess their risk of passing on a particular condition to the next generation. DNA testing (e.g., from a blood sample) is often required for a clear diagnosis.

During Pregnancy

In developed countries, it is now routine for pregnant women, especially those over 35 years old, to be offered some form of genetic testing. Noninvasive screening tests such as ultrasound or serum screening, conducted between 10 and 20 weeks of pregnancy, can provide information about whether the fetus is developing normally or is at increased risk (greater than 1 in 250) of being affected by a chromosomal condition (e.g., Down syndrome) or neural tube defect (e.g., spina bifida). Usually, these tests allow counselors to provide risk estimates, not conclusive results. Diagnostic tests such as amniocentesis or chorionic villus sampling (CVS) are performed after a positive screen result to obtain accurate results for chromosomal conditions such as Down syndrome. However, these tests also carry some risk of miscarriage (approximately 1 percent). Population pregnancy screening can identify only a limited number of common genetic conditions; most genetic conditions are rare and difficult to detect.

If a diagnostic test reveals a positive result (i.e., that the fetus is affected by a genetic condition), the woman must decide whether to terminate the pregnancy or continue with it and give birth to a disabled child. At this point, it is essential that the woman receives unbiased and accurate information about the relevant condition and feels supported in making the right decision for her.

Most women who undergo screening or testing in pregnancy will receive genetic counseling in some form, possibly from a midwife, general practice physician, or obstetrician rather than an individual who specializes in genetic counseling. Such counseling may be cursory and directive, sometimes even eugenic. Both before and after testing, a woman should have access to the services of a trained genetic counselor to ensure that she can make genuinely informed decisions and be confident that she has made the right ones, as terminating a wanted pregnancy can be as distressing as giving birth to a disabled child. Because the screening procedures used today are often noninvasive, and because many times full information on her options is not readily available, a woman may end up drifting into a situation in which she is forced to make a difficult choice about termination, whereas if she had been fully informed up front, she may have declined to embark on the "antenatal testing conveyer belt."

Childhood

Most babies in the developed world undergo genetic screening within the first 72 hours of life, through blood taken from a heel prick (Guthrie test). The blood is screened for a number of genetic conditions for which early detection and intervention can offer increased chances of effective management; these may include cystic fibrosis and phenylketonuria as well as rarer metabolic conditions. Although hospitals seek parental consent prior to taking an infant's blood, no formal genetic counseling is provided unless it is requested or a positive result is found. Frequently new mothers are unaware that the tests are being done, or, if they are aware, give very little consideration to what such tests could disclose.

Families and individuals who are directly affected by genetic conditions may also seek genetic counseling. They may want to gain more information about particular conditions and why those conditions affect them, to explore the specific ways in which genetic conditions affect them, to seek advice about managing their conditions, and/or to meet others who are similarly affected. Many genetic counselors specialize in certain groups of genetic conditions, such as bone dysplasias and metabolic conditions. Such counselors tend to be very familiar with the day-to-day effects of living with particular genetic conditions and can help individuals to find appropriate support groups.

Adulthood

One of the largest growth areas in genetic testing is that of predictive testing—that is, testing aimed at determining whether a person is at risk of developing a late-onset genetic condition (e.g., Huntington's disease, some forms of cancer) or has a genetic predisposition to a common disease (e.g., heart disease). Before individuals begin the predictive testing process, genetic counseling is advisable. Discovering that one is going to develop an incurable late-onset disease such as Huntington's can be highly traumatic. Individuals in affected families may not wish to know their status if there is nothing they can do to avoid their fate. Even when preventive action is possible—for example, mastectomy to minimize the risk of breast cancer—this knowledge itself can be traumatic. Also, some recommended preventive actions may be hard for individuals to comply with (e.g., behavioral or dietary changes). There is evidence that many individuals have difficulty understanding risk percentages: Without the benefit of counseling, some may underestimate their risk; alternatively, some individuals who receive diagnoses of genetic conditions may believe they are facing an unavoidable fate even though preventive action may be effective.

WHAT HAPPENS IN A GENETICS COUNSELING SESSION?

A typical genetics counseling session starts with the professional's ascertaining what it is that the counselee (usually called the *proband*) expects or wants to get out of the session. The professional spends a large proportion of the initial session taking the proband's pedigree, or recording the proband's family tree.

A pedigree usually includes the names, birth dates, ages, and causes of death and brief medical histories of the proband's family members over three or more generations. The pedigree may assist the counselor in calculating the likelihood of the proband's being affected by a genetic condition or passing it on to future generations. A geneticist may also physically examine the proband during the first session. Once all of the relevant information has been collected, the proband, counselors, and anyone else who may be present (e.g., family members, partners, other medical professionals) discuss the implications. This is the time when the proband asks questions and receives explanations from the counselor. Often, a clear diagnosis cannot be given based on the pedigree and a physical examination. In such a case, the counselee may be sent for follow-up diagnostic testing (e.g., blood tests, X-rays, MRI). Following a genetic counseling session, the counselor usually sends the counselee a letter documenting what was discussed during the session, giving details of the relevant genetic condition, and providing information about available support services and how to follow up the session.

WHAT ARE THE ISSUES FROM A DISABILITY PERSPECTIVE?

Many within the disability rights movement view the medical advances being made in genetics as a "return to the eugenic past"; they find the concept of genetic counseling confronting, inappropriate, and part of an eradication process. Societal investment in diagnostic technology and screening programs sends a message that disability is a major problem that should be prevented at all costs. The language of "risk," "abnormality," "burden," and "medical tragedy" is prejudicial to disabled people and ignores the high quality of life that many disabled people achieve. From this perspective, genetic counselors are implementers of eugenic policies, despite their professional rhetoric of supporting individual choice.

For individuals who are affected by genetic conditions, the process of genetic counseling can be a confronting experience. The aim of genetic counseling sessions for disabled persons should be exactly the same as for individuals without disabilities. But disabled persons who choose not to have children with the same conditions as theirs may feel that they are somehow "validating" society's view or belief that their own lives are not valuable or worth living. Deciding whether or not to take the risk of passing on a genetic condition can be challenging to a disabled person's sense of self, raising problematic emotions. A good genetic counselor should be able to provide such a client with accurate, balanced, and understandable information; help the counselee to explore his or her feelings about possible outcomes; and, most important, support the counselee through whatever choice he or she makes.

Since the 1990s, genetic counselors' stated aspiration to provide nondirective counseling has been debated, and some observers have questioned whether nondirective counseling is achievable. They argue that the language in which counselors present risks and the information they provide about disability are bound to influence counselees' decision making. In practice, counselees often look to genetic counselors for direction, asking, in essence, "What would you do in this situation?" Genetic counselors have to be able to support those they counsel whatever they decide; thus counselors need to have a heightened awareness of their own prejudices and moral stands on issues surrounding genetics and, more specifically, disability.

—Caroline Bowditch

See also Genetics; Genetics and Disabilities: Social and Ethical Dilemmas.

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GENETICS

The science of genetics has an increasingly powerful influence on contemporary ideas about the causes of disability and how impairment might be cured or—perhaps more controversially—prevented. It is important to be clear from the outset that "genetics" is no longer restricted to the ways in which characteristics, including impairments and chronic disease, are inherited. With the development of sophisticated molecular techniques, geneticists today are equally interested in uncovering the genetic bases for all the biological processes that keep organisms going and that, if disrupted, can contribute to disease or disability. This entry gives a brief outline of some key genetic concepts and goes on to discuss the relationship between genes and disease, the contribution of the Human Genome Project to genetic knowledge, recent developments in genetic medicine, and some issues in genetics that are of particular relevance to disability.

SOME KEY GENETIC CONCEPTS

As the study of the transmission of characteristics between generations, genetics has existed for more than 100 years. The early history of the discipline was dominated by attempts to understand *patterns* of inheritance while at the same time trying to identify the *mechanism* through which characteristics are transmitted. It was not until the 1940s that the chemical deoxyribonucleic acid (DNA) was conclusively shown to play a key role in heredity, and not until 1953 that a plausible three-dimensional structure for the DNA molecule was proposed. As Francis Crick and James Watson noted in the paper publishing this result, the structure of DNA also gave clues to genetic mechanisms. Over the next few decades, enormous effort was devoted to unraveling the fundamentals of gene action.

According to the simplest model of gene action (and it should be noted that even among biologists there is disagreement over the details and scope of models of gene action), genes give rise to proteins in a series of steps. The DNA sequence of a gene specifies ("codes for") the production of a related type of molecule, messenger RNA, which in turn specifies the sequence of constituent amino acids in a protein. Proteins play a number of diverse and crucial roles in the development and maintenance of an organism, forming structural components (e.g., the constituents of muscle), enzymes that regulate biochemical pathways, and components of the hormonal signaling systems of the body.

Although we often speak casually of a "gene for" a disease, as in the "cystic fibrosis gene" or the "Huntington's disease gene," this is a shorthand that can be misleading. Genes are not *there* to cause disorders; rather, disorders arise when changes (or mutations) in genes alter the production of proteins required by the organism. So the "cystic fibrosis gene" encodes a protein that transports ions across cell membranes. It is mutant forms of this protein that do not perform their transport function adequately and result in the condition called cystic fibrosis. Similarly, the commonest form of hereditary hearing impairment in European and American populations results from mutations in the cx26 gene, the unmutated form of which specifies the production of a gap junction protein, connexin 26.

GENETIC DISORDERS

Single-gene, or *monogenic,* disorders are caused by mutations in the DNA sequence of just one gene. More than 6,000 monogenic disorders have been identified, and these affect approximately 1 in 200 live births. They include some of the best known and most studied genetic disorders, such as cystic fibrosis (CF), sickle-cell anemia, achondroplasia, and Huntington's disease (HD).

Monogenic disorders may show *dominant*, *recessive,* or *sex-linked* inheritance. People who inherit only one copy of a mutated gene are described as *heterozygous* for that gene, whereas those with two copies are *homozygous.* Where a condition is dominantly inherited (e.g., achondroplasia, HD), a person need inherit only one copy of the mutated gene in order for the condition to be apparent (that is, for the *genotype,* or genetic constitution, to be expressed in the *phenotype*). For recessive disorders, inheritance of two copies—that is, one from each parent—is necessary; a heterozygote will usually be phenotypically normal but be a carrier, and so can still transmit the mutated gene to his or her children. Probably the best known example of a recessive genetic disease is CF. In sex-linked disorders, the abnormal gene is on one or other of the so-called sex chromosomes, and this often means the condition occurs only in males. Sex-linked conditions include fragile X syndrome and Duchenne muscular dystrophy.

Geneticists and genetic counselors often show what seems to be a disproportionate interest in vanishingly rare monogenic disorders. This is because these disorders are relatively easy to diagnose and usually have straightforward inheritance patterns, so the inheritance may have been well characterized by classical genetics even before the relevant gene was identified. Nevertheless, it is now thought that most conditions of medical interest are *polygenic,* with numerous genes making greater or lesser contributions to the phenotype, alongside environmental factors such as diet and exposure to pollutants. Tracking the inheritance patterns of these disorders is difficult unless the gene loci have already been identified. Examples of conditions for which some of the genes involved have been tentatively identified include breast cancer, heart disease, asthma, and diabetes.

Mitochondrial disorders are much rarer genetic conditions caused by mutations in the DNA carried by mitochondria, small organelles that are found in cells and that carry their own tiny pieces of DNA.

In addition to genetic conditions there are *chromosome disorders*. These are larger-scale abnormalities in which entire chromosomes may be lost or duplicated, or show major structural changes (such as translocations). Probably the best known chromosomal disorder is trisomy 21, or Down syndrome, in which the affected person's cells contain three copies of chromosome 21 instead of the usual two.

THE HUMAN GENOME PROJECT

The Human Genome Project (HGP), an international effort to specify the 3 billion base pairs that make up the DNA sequence of the entire human genome, produced its first draft in June 2000. A key rationale for the massive investment of money and effort in the HGP is that the more we know about gene sequences, the more we will understand—and be able to prevent—disease and disability. Even at this early stage, the genome sequence has thrown up some interesting observations. For instance, only about 5 percent of the entire genome seems to contain sequences that actually do code for proteins, while the function of the remaining 95 percent remains unknown.

Nevertheless, it has rapidly become clear that the expanding knowledge of human genomic sequences will, at first, do no more than enable us to diagnose more genetic variations. The number of loci being linked to disorders is growing day by day, and this straightforward increase in diagnostic ability is coming onstream well before the genome sequence has provided much in the way of greater understanding of the complex developmental pathways that lead from gene to phenotype. Any possible therapeutic interventions lie even further in the future.

GENOTYPE, GENE ACTION, AND PHENOTYPE

Genetics' understanding of the route from gene to living organism is still very limited. The earliest and simplest model (the Central Dogma) held that DNA makes RNA makes protein, makes a particular phenotype. Thus, a given DNA sequence straightforwardly determines the final appearance of a characteristic. Mounting experimental evidence has shown that, although broadly correct, this model is inadequate. For example, it is clear that the molecular structure of genes is more complex than was once thought. There may be ambiguity about which DNA sequence elements in reality form a gene, multiple proteins can be produced from a single gene, and the protein product can be regulated in unexpected ways. Furthermore, molecular biologists now realize that genes in a genome interact with each other, and with the nongenetic aspects of the whole organism, such that facile extrapolation from experimental setup to the living individual may be misleading. And finally, the environmental context may also interact with the genetic constitution to produce the resulting phenotype in ways that are not predictable.

Equally, since any given protein can be implicated in a host of physiological functions, many genes are *pleiotropic*—mutations in them will have numerous phenotypic effects. This is why many genetic disorders are classed as syndromes identified by characteristic constellations of signs and symptoms. For example, genes such as cx26 have been identified where mutation leads to hearing impairment, but there are also many genetic disorders that *include* hearing impairment among other features. Whether we consider the relevant genes to be primarily to do with hearing impairment or primarily associated with one of the other characteristics will depend more on our point of view than on the biology of the gene.

What all this means is that genetic determinism, the idea that the characteristics of individuals (and, in the extreme, their whole lives) are determined exclusively by their genes, must be abandoned. At the clinical level, it means that even for well-characterized genetic lesions it is rarely possible to predict exactly what the phenotypic consequences will be for each individual. In terms of disability, it means that the story is not as simple as "reading off" an impairment from a gene sequence, let alone understanding how that impairment will be experienced as disability. It is salutary to remember this when evaluating claims that the sequencing of the human genome will *by itself* increase our understanding of disability and illness.

GENETIC VARIATION

Perhaps the most provocative observation of the HGP is the sheer amount of variation between different people's genomes (known as *genetic polymorphism*). Each individual's genome differs slightly from everybody else's, and moreover everybody's genome carries a number of polymorphisms that have no phenotypic consequence, either because the change for some reason does not affect the production of a gene product or because the mutation is recessive and is compensated for by the normal copy inherited from the other parent.

According to standard evolutionary theory, this high degree of genetic variation is necessary to provide the raw material for adaptation to changes in selective environmental pressures. Any group of organisms, however currently well adapted they are to their habitat, needs to contain a reservoir of phenotypic diversity so that if things change (the environment gets hotter or wetter, food becomes scarcer, a new predator comes along), some individuals will find themselves flourishing better under the new conditions. Randomly generated genetic variation helps provide this diversity. Some of the variation will be extreme, producing phenotypes that would be regarded as impairment or disabling under any circumstances; examples here might be osteogenesis imperfecta (brittle bone syndrome) and Gaucher's disease. But even in some cases of apparently harmful mutations, there may be hidden advantages. Although both sickle-cell anemia and CF are disadvantageous, often painful, and life-shortening diseases for homozygotes, there is evidence that sickle-cell heterozygotes (carriers of one copy of the mutant gene) have greater resistance than noncarriers to malaria, and CF carriers have similar improved resistance to cholera.

GENETIC CAUSES OF DISABILITY

A focus on genetics tends to obscure the fact that a relatively small proportion of impairment is directly attributable to genetic causes. It is notoriously difficult to estimate the number of disabled people in any given population because of international differences in definitions of disability and in the methods used to collect the data, and these factors also make it impossible to compare the causes of disability across countries. However, the U.K. 1991 census gives a figure of 12.2 percent for the proportion of people with disabilities (Office of Population Censuses and Surveys 1993). Of this total, perhaps 10 percent may be directly attributable to monogenic disorders. Another, unknown but still probably rather small, percentage will be disabled by polygenic conditions such as heart disease or diabetes and its complications. But it remains the case that *most* disability is caused by events that occur after birth: aging, illness, and trauma, including war.

The fact that we can identify the inheritance pattern or can do a genetic test tells us something about the strength of the genetic contribution to a condition, but it may not tell us very much about the most significant causes of that condition in real life or its severity or prevalence. Prenatal testing for Down syndrome has been widely available for many years in Europe and the United States, not because Down syndrome is the most devastating of all genetic disorders but because trisomy 21 is easy to detect by ultrasound and on a chromosome spread. Conversely, major depression, which according to many surveys is the condition with the most disabling global impact, has not been unequivocally linked to any gene loci and will probably turn out to have a multifactorial etiology. This is an important point, because it is tempting to assume that genetic knowledge is focused on (the most) severe or significant conditions, or that the existence of a genetic test reflects how severe the condition is, and this is not always true.

GENETIC MEDICINE

Until recently, genetic medicine was restricted to using classical genetic methods to study the transmission of familial disease and providing genetic counseling to affected individuals. The new genetics has not only made genetic diagnosis much more targeted and accurate, as more and more gene loci are identified, but has also opened up a range of novel interventions. Some of these are already part of clinical practice, whereas others are more or less likely to arrive in the foreseeable future. All have practical and ethical implications for the conceptualization of disability.

Prenatal screening has become standard antenatal practice in most parts of the developed world. To date, prenatal screening has relied on ultrasound scanning of the developing fetus, which detects only a few gross abnormalities, and examination of the fetal karyotype for chromosome disorders following amniocentesis or chorionic villus sampling. Again, as gene loci are identified it will become possible to test fetal genetic material specifically for genetic variations. And as with earlier forms of screening, if the test result is positive—that is, if an anomaly is detected—the question the parents then face is whether to terminate the pregnancy or not. Given that many more conditions will be diagnosable by genetic testing than by ultrasound or karyotyping, the number of affected pregnancies is predicted to increase. (Figures for the United Kingdom in 2000 indicate that about 1,760 of the total 175,542 legal terminations were performed solely because of fetal abnormality; Office for National Statistics 2001, Table 10.)

Preimplantation genetic diagnosis (PGD) is a technique that combines in vitro fertilization (IVF) with genetic diagnosis. After "test-tube" embryos are produced through IVF, they can be tested for the presence of disease-associated genes before a decision is made regarding whether or not to transfer them to the future mother's uterus to continue the pregnancy.

Both kinds of prenatal diagnosis are loaded with the same questions about what detecting the presence of a gene locus actually means for the life of the person who carries it (or will carry it if the pregnancy is continued to term or the embryo implanted). The ambiguities of the relationship between genotype and phenotype outlined above have to be borne in mind here. Other ethical questions are raised by carrier testing—where the embryo or fetus is heterozygous for a genetically recessive condition that, because it is recessive, will not directly harm the baby itself.

Genetic testing can also be done *postnatally,* in newborn babies, during childhood, or at any stage of adult life. The aim of this testing may be to *confirm a diagnosis* made on clinical grounds, perhaps to distinguish two similar disorders from each other, which may be necessary to provide the appropriate treatment or give the right prognosis. In other cases, postnatal genetic testing may be *presymptomatic.* Presymptomatic genetic testing may be offered for disorders that develop later in life, the best known example probably being Huntington's disease. HD is a late-onset autosomal dominant condition in which symptoms of neurological degeneration generally first appear when the individual is aged 40 or older. The gene responsible for HD produces an aberrant version of the protein huntingtin. Until it was identified, people who knew they were at risk of the disease could only wait to see if they developed symptoms. In 1983 the gene was located, and in 1993 it was cloned. Since then it has been possible for at-risk individuals to determine their genetic status—if they want to.

Moving beyond diagnosis, the identification of genes strongly associated with particular characteristics opens up the possibility of *gene therapy.* This involves removing an impairment by replacing a variant gene that plays a significant role in the development of the condition with a normally functioning gene. Numerous disorders are potentially treatable by gene therapy, including classic single-gene diseases such as CF and muscular dystrophy, but also more complex conditions such as diabetes, cancer, and AIDS. Although the idea behind it is straightforward, technically gene therapy is highly complicated. Among the problems that have to be overcome are delivering the gene to enough cells to be useful, to the right type of cell to correct the defect (e.g., into the epithelial lining of the respiratory tract to treat CF). The exogenous gene must be expressed as the right protein at the right time (which demands a good understanding of these processes) and must not interfere with the normal functioning of any other gene or cause a new clinical problem. Clinical trials of gene therapy began in the early 1990s and were successful in treating some rare blood disorders, but by the early years of the twenty-first century no form of gene therapy is in routine clinical use, and there is skepticism about whether the technical barriers will ever be overcome successfully enough to make it a practical clinical intervention.

A more realistic use of genetic information is *pharmacogenomics.* The idea here is to understand the genetics behind the physiological responses to medication. When people take a drug, most respond as expected, but a minority prove to be more sensitive or less sensitive, fail to respond at all, or show unusual or dangerous side effects. This variation can make treatment dangerous, time-consuming, and expensive; identifying which class of antihypertension drug a patient will respond best to, for example, is generally a matter of trial and error over weeks or months. Much, although not all, of the variation in individual response to drugs can be traced back to genetic differences, and the idea behind pharmacogenomics is to use genome data to identify which genetic compositions make people best or least suited to treatment with particular pharmaceuticals.

GENETICS, ETHICS, AND DISABILITY

Genetics is a discipline that has grown up in close association with medicine and with developmental biology, both of which make it conceptually relevant to thinking about disability. Moreover, advances in genetic medicine provide a range of new or foreseeable interventions in disability. Hence it can be argued that the ethics of genetics and disability are especially pertinent to each other. Over the years, writers in disability studies, disability activists, bioethicists, and others have raised concerns about all of the genetic medical technologies outlined above. Although the practical implications have received most attention so far, the impact of genetic thinking on disability ethics—and the impact of a disability perspective on genetic ethics—may have more subtle but equally far-reaching effects.

Prenatal genetic screening and PGD both raise the specter of what is frequently referred to as “eugenics,” although many scholars are not convinced that contemporary genetic selection is directly comparable with the well-characterized eugenics movement of the twentieth century. The disability critique suggests that selection against fetuses or embryos on the grounds that they have detectable impairments is based on unexamined prejudices about living with genetic disorders. These prejudices are encouraged by societal unwillingness to accommodate to disability and by a model of disability that sees it as a biomedical (and currently genetic) issue. The expressivist argument claims that selecting against fetuses and embryos with genetic disorders sends out a negative message to disabled people, and to society as a whole, about the value of disabled lives. Similar arguments might be made about any form of therapy, in that removing an impairment could be interpreted as a message that the person is more acceptable without the impairment than with it. But therapy does not involve the same existential life-or-death moral choices that are clearly part of prenatal genetic screening or PGD. Postnatal genetic testing may exacerbate the existing marginalization of disabled and chronically ill people, generating a new underclass of people and families with genetically detectable disorders who may be discriminated against in health or life insurance, employment, education, or other areas—even when they are presymptomatic. Pharmacogenomics has been criticized for threatening the same on a grander scale in which whole groups of people are marginalized because their genetic constitutions make them less attractive to pharmaceutical companies interested in developing drugs targeted at the profitable majority.

Lurking behind the regulation of the practice of genetic medicine, however, are wider ethical issues that extend beyond the topic of disability as such. Trying to set limits to prenatal screening or to gene therapy means taking a closer look at some fundamental but often unexamined community beliefs about the goodness of choosing the kind of people we want to have, the value of choice in general, and whether human diversity has any moral or metaphysical meaning. This set of questions in turn links to a discussion of the contemporary significance of human genetic data: how genetics' scientific authority confirms sequence data as the most fundamental description of an organism and whether the current dominance of genetics is impoverishing our repertoire of culturally available models of what it is to be a human being. The ethical dimension of genetics will necessarily focus on the proximate, practical applications, but it will become increasingly necessary to consider the broader moral background as well.

WHAT DOES GENETICS HAVE TO SAY ABOUT DISABILITY?

There is no doubt that genes make a contribution to many illnesses and disabilities, but the level of that contribution, and exactly how gene action interacts with environmental and social factors, is likely to be different for every condition. For some, the genetic influence is overwhelmingly strong, and here genetics can offer an understanding of pathology and, potentially, therapy. For others, genetic knowledge will never do more than offer a partial insight into the etiology, and nongenetic interventions (changing working conditions, for example) are likely to remain the most effective.

The disability rights movement has often been skeptical of or hostile toward genetics. The major concrete objection is that genetic diagnostic technologies will be abused for eugenic ends. But genetic science has also been condemned as just another way of locating the source of disability in an individual's deviation from the (genetic) norm, simply acting to reinforce the undesirable methodological and political individualism of the medical model of disability.

Genetics certainly has the potential to do this, alongside an equally worrying potential to divert attention and resources away from any nongenetic etiologies or to encourage the misclassification of all forms of genetic variation as pathological. Arguably, these potential misuses are not inevitable. They will depend on the social and economic climates in which genetic knowledge is put to use. It is just as conceivable that the information about human genomes generated by the HGP can radically and positively destabilize some entrenched assumptions about norms, normality, and deviation. As described earlier, the HGP provides material evidence of the huge degree of interindividual genetic variation, with many apparently "normal" people identified as the unwitting bearers of highly atypical genetic sequences. The implication of this is that in genetic terms, any line running from normality to defect, or normal to abnormal, is a continuum along which the cutoff points are determined by the needs of human groups rather than by biology. Extreme variations would impair or disable under any circumstances, but for others the point along the continuum where "variation" becomes "impairment" is dependent on environmental, cultural, and social factors. So, for example, many people with genetic short stature claim that they are chiefly disabled by society's inability to accommodate to their size. As another example, the effect of a genetic variation that reduces reading ability (there is evidence for a genetic component in dyslexia) is unlikely to have been experienced as problematic in preliterate societies. By this interpretation, genetics supports the radical consensus within disability studies that disability cannot be theorized as a fixed, stable dichotomous category. The model in which there are two groups of people, one with "the" normal genome and the other made up of people with deviations from that genetic norm, is no longer tenable, and it is genetic knowledge that makes its abandonment necessary.

—Jackie Leach Scully

See also Bioethics; Biological Determinism; Ethics; Eugenics; Gene Therapy; Genetic Counseling; Genetics and Disabilities: Social and Ethical Dilemmas; Health; Medicine; Sterilization.

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GENETICS AND DISABILITIES: SOCIAL AND ETHICAL DILEMMAS

The scientific community has made enormous strides in the knowledge of genetics since the landmark discovery of the double-helical structure of DNA more than 50 years ago. While the promises of genomic medicine are manifold, the coming decades of genetics and biotechnological developments will undoubtedly raise social and ethical concerns that may undermine the human rights of people with disabilities.

Inclusion International, a nongovernmental organization representing agencies from more than 115 countries and promoting the inclusion of persons with intellectual disabilities, has articulated the fear that genetic data, although anticipated to do much good, may also lead to discrimination. Also, this organization argues that developments in genetics could be used in ways that restrict rather than enhance the rights and choices of people with disabilities and their families.

This entry examines the social, ethical, and policy implications arising from developments in genetics against the backdrop of four core ethical principles that are emphasized in much of the discussion about disability and human rights. These principles are as follows: justice (every person has the right to have access to services and to develop to his or her full potential), nondiscrimination (every person has the right to be respected for who he or she is, and to live as an equal citizen), diversity (every person has the right not to be judged on the basis of notions of perfection and normality), and autonomy (every person has the right to make his or her own decisions and to participate in decisions that will have an impact on his or her life). In light of the social and ethical issues raised by genetics and biotechnology, this entry presents a selection of ethical norms emanating from such international and regional bodies as the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), the Council of Europe, as well as other documents from nongovernmental organizations.

The suspicion that people with disabilities and their representatives entertain toward genetic technology can be explained by the discrimination they have historically faced. This anxiety is notably exacerbated by past eugenic abuses in which it was deemed appropriate and desirable to sterilize those considered unacceptably different. Moreover, during the 1920s and 1930s, two Canadian provinces implemented laws that allowed for the sterilization of mentally disabled persons; these laws, which led to the undue restriction of the rights of people with disabilities, were not repealed until the late 1970s.

DEFINITION OF DISABILITY

Over time, approaches to disability have evolved. Initially, disability was considered within an individual framework. This focus on the individual was promoted by what is commonly known as the medical or rehabilitation model of disability. The next generation of approaches focused on society—that is, on the social, economic, policy, and legal conditions that lead to disability. This paradigm shifted the emphasis to culture and environmental factors. More recently, the model adopted has been based on human rights, which is a powerful framework from which to defend and protect persons with disabilities from genetic discrimination.

For the purposes of this entry, a broad-based definition of disability is adopted, a definition that encompasses the WHO 2001 International Classification of Functioning, Disability, and Health. This definition views the etiology of health conditions as neutral and reflects the interactive relationship between health conditions and the contextual factors of the environment and the individuals.

ETHICAL PRINCIPLES AND INTERNATIONAL POLICIES

Overall, human genetics concerns figure prominently in statements issued by international and regional health- and culture-related organizations. Some of the policy documents of such organizations specifically mention disability. Furthermore, in response to advances in human genetics and biotechnology, a number of governmental and nongovernmental organizations at the international and regional levels have taken an interest in addressing genetics within a human rights framework. A broad consensus of remarkable consistency is emerging. It addresses four ethical principles: justice, nondiscrimination, diversity, and autonomy.

A starting point for the discussion about ethical principles is the 1948 Universal Declaration of Human Rights, which promotes and affirms the fundamental rights to life, liberty, and security (Article 3); to medical care and social services (Article 25[1]); and to the benefit from scientific progress and its uses (Article 27[1]). The WHO, notably in its 2001 International Classification of Functioning, Disability, and Health, focuses on social and environmental barriers and on the rights to which people with disabilities are entitled. Nevertheless, developments in genetics raise particular new concerns that need to be addressed. The landmark 1997 UNESCO Universal Declaration on the Human Genome and Human Rights frames the actual application of the new scientific developments raised by genetics. A core principle of the UNESCO declaration is respect for human dignity; the declaration promotes a perspective based on the basic rights to justice, nondiscrimination, diversity, and autonomy. As a policy statement it provides the first signs that genetics will be applied in ways that maintain human rights. Even though most of the documents under review here do not expressly address disability, they can be interpreted as implicitly applying to disabled individuals, as most of them address the "new" genetics, either tacitly or explicitly.

Justice

The principle of justice implies the obligation to distribute benefits and risks equally. Genetics and biotechnology may harm people with disabilities by classifying and possibly devaluing people who are different and treating them as deviations from the norm. In the extreme, some believe that preventing the birth of a disabled child following preimplantation genetic diagnosis (PGD) or prenatal testing is a rejection of people affected by the specific genetic disorders tested for. However, others argue that it is not rejection of the individual per se but of the disorder. There are other ways, not limited to persons with disabilities, in which genetics and biotechnology can breach the principle of justice. For example, physicians' lack of awareness of the need for genetic referral and consumer lack of knowledge of genetic services might also lead to inequality of availability and accessibility to genetic services and care for all citizens.

Justice and International Policies

Internationally, many guidelines, although not specifically addressing persons with disabilities, consider that all humans, regardless of differences, are entitled to access to medical and genetic developments. Foremost in this area, UNESCO's 1997 Universal Declaration on the Human Genome and Human Rights specifically addresses the principle of justice in Article 12(a), stating that advances in biology, genetics, and medicine concerning the human genome shall be made available to all, with due regard to the dignity and human rights of each individual. Article 12(b) of the declaration recommends that research (including applications in biology, genetics, and medicine) concerning the human genome shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole. In other words, equitable access to care, services, treatments, and research findings in the field of genetics is a fundamental human right of individuals and, where applicable, of groups of people.

The Council of Europe and the council's Steering Committee in Bioethics, concerned with genetic developments, have issued policy statements of general relevance to persons with disabilities. The council's 2003 working document Application of Genetics for Health Purposes recommends equitable access to preventive, diagnostic, and therapeutic genetic services (Article 10). Also, its 1997 Convention on Human Rights and Biomedicine holds that screening must be made available to all (Article 3). The binding force of the convention depends on its being signed and ratified by the council's member states. Furthermore, each ratifying member country may adapt these obligations with regard to its own health needs and resources.

In the case of gene therapy, in 1994 the Group of Advisors on the Ethical Implications of Biotechnology of the European Commission (GAEIBE) voiced concern regarding equity. It recommended that within the European Union appropriate measures should be taken to ensure equal access to gene therapy. With regard to prenatal diagnosis (PND), the GAEIBE (1996) agrees that all genetic services that are available for the entire population should be equally available for persons with disabilities. The GAEIBE specifically mentions that prenatal diagnosis should not discriminate against people with disabilities or those who do not terminate a pregnancy. This organization expresses two concerns regarding the application of genetic tests to persons with disabilities: First, people who test positive for genetic mutations have a variable likelihood of developing the disorder in question; and second, it is difficult to define the severity of disorders. In view of these concerns, the GAEIBE concludes that it is inappropriate to generate a list of disorders that qualify for prenatal genetic diagnosis.

Finally, Inclusion International (2003) stresses that genetic research must not lead to the reduction or suppression of opportunities for health and social services, education, employment, leisure, or citizenship responsibilities for people with disabilities.

Nondiscrimination

Issues related to genetic discrimination by insurers, employers, and educators are of major concern to many persons with disabilities. There is some evidence, admittedly anecdotal, that genetic information is being used or could be used to deny access to life or health insurance and employment. Advances in genetics may have major financial implications for people seeking health insurance, especially in countries that do not have universal health care funding. Moreover, in such countries employers may use genetic information to maximize their economic benefits by denying jobs to people with particular genetic profiles. This serious concern merely aggravates the already widespread discrimination that people with disabilities face. If genetic testing is increasingly successful in predicting genetic susceptibility, even those with "future" disabilities may suffer in the present.

The issue of discrimination is not limited to employers and insurers. Some individuals might be denied fertility treatment or adoption rights in light of past mental illnesses. There is also a fear that genetic information will lead to stigmatization and have a negative impact on disabled people's rights to accept or refuse medical treatment and to reproduce according to their own wishes.

PGD and genetic screening raise similar concerns of discrimination. Whereas testing for very rare monogenic conditions such as Tay-Sachs disease and Huntington's disease is generally accepted, testing for less "severe" diseases is more controversial, especially if the results may determine whether a fetus will be aborted or not. In some situations, and in order to increase their chances, couples with disabilities may request PGD to select embryos without hereditary conditions such as deafness, achondroplasia, or intellectual disabilities; such couples may also wish to have children who have the same disabilities they do.

"Wrongful life" lawsuits are seen as inherently discriminatory toward persons with disabilities. The Perruche case, which urged France to modify its health law policy, is an example of the concern. The case concerned a boy who was born deaf and severely disabled due to the rubella his mother contracted while pregnant. The boy claimed damages from doctors who, because of laboratory negligence, did not diagnose the mother's rubella. Even though medical negligence was proven, this ruling offended people with disabilities who felt the decision implied that disabled people were not worthy of life. The Perruche lawsuit is just one of a number of similar suits that have suggested that disabilities are injuries worthy of compensation.

Issues concerning discrimination are likely to intensify and become more widespread, particularly if research succeeds in linking genes to behavior, intelligence, and personality traits. The topics of the genetics of mental disorders and behavioral genetics are sensitive, controversial, and complex, and research in these areas may rekindle the old debate between nature and nurture and serve as a basis for discrimination and stigmatization, as suggested by the Nuffield Council on Bioethics (2002).

Nondiscrimination and International Policies

Overall, there are strong indications that key international organizations, through their policies and guidelines, promote the principle of nondiscrimination based on genetic information. Generally, these organizations' statements avoid singling out persons with disabilities; rather, they promote collective human rights irrespective of race, ethnicity, gender, or physical or mental characteristics.

Mention should be made of two influential United Nations documents specific to genetics. The UNESCO Universal Declaration on the Human Genome and Human Rights states that people should not be excluded because of certain genetic characteristics and that no one should be subjected to discrimination based on genetic characteristics. In the International Declaration on Human Genetic Data, the United Nations proposes that genetic data should not be used for discriminatory purposes or in any way that will stigmatize a group. The declaration also states that there should be no unauthorized disclosure of genetic data to third parties (e.g., insurers, employers, and educational institutions).

The World Health Organization explicitly recommends adopting language that is sensitive and nonpejorative; terms such as *mentally retarded* and *defective fetus* are absolutely unacceptable. At the regional level, the Council of Europe prohibits any form of discrimination on grounds of genetic heritage in its Convention on Human Rights and Biomedicine.

The Council for International Organizations of Medical Sciences has developed ethical guidelines for biomedical research in which the organization recognizes behavioral genetics as a very sensitive area and recommends that behavioral geneticists publish their research findings in a manner that is respectful of the interests of all concerned.

Finally, although an emphasis on nondiscrimination toward all individuals and populations is a core ethical principle, and seen as a collective right, many organizations still explicitly recognize a need for the special protection of persons with disabilities. For instance, the European Parliament highlights disability in its Charter of Fundamental Rights. Under the terms of Article 21.1, any discrimination based on any ground such as genetic features and disability shall be prohibited.

Diversity

Respecting diversity entails valuing and accepting a wide variety of human characteristics, including disabilities ranging from the relatively mild (such as ectodactyly, or partial fusion of fingers or toes) to the very severe (such as Huntington's disease). Many observers fear that genomics will menace human diversity. Some persons with disabilities feel their rights are threatened by genetic advances such as PGD and prenatal testing and screening. Disabled Peoples' International (DPI) and a number of nongovernmental organizations within the disability community have voiced concerns that these reproductive technologies challenge the principle that all individuals have equal value and deserve respect.

In medical circles, the word *serious* is often used to differentiate disorders. Studies suggest that among professionals, interpretations differ concerning the “seriousness” of various conditions, including cleft lip/palate, hereditary deafness, diabetes, Huntington’s disease, cystic fibrosis, sickle-cell anemia, Down syndrome, and bipolar disorder. Such divergent interpretations raise difficult ethical questions because individuals, families, and medical professionals may perceive the seriousness of particular genetic conditions very differently.

Currently, PGD is offered when there is a high risk of a “serious” genetic disorder. Further developments in genetics may change what is considered a serious disorder and what is perceived as falling within the range of normal. DPI has noted that the field of genetics is threatening to undermine the rights of persons with disabilities because only a few genetic conditions are so severe as to make living unbearable. The organization points out that the views of people living with disabilities have not been heard.

Finally, there is also a concern that developments in genetics will allow policy makers to increasingly treat disability as a medical problem and conceivably overlook policies that advance the integration of people with disabilities into society by adapting the environment to the needs of these individuals. Over the past 20 years, the social model of disability, which emphasizes the role society plays in the experience of disability, has achieved legitimacy. However, with developments in genetics and biotechnology, the disability community fears a rekindling of the medical/biological model of disability, which places genetic factors at the forefront and overlooks environmental, social, political, and economic factors.

Diversity and International Policies

UNESCO’s Universal Declaration on the Human Genome and Human Rights asserts every individual’s right to dignity and human rights regardless of genetic characteristics (Article 2). Similarly, in its Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services, the WHO recognizes the need to respect human diversity and minority groups.

In a similar vein, the GAEIBE maintains that in light of the current controversies raised by germ line therapy and the actual state of the art, germ line therapy on humans is not currently considered ethical.

Regarding the complex interplay among several societal factors, the WHO’s International Classification of Functioning, Disability, and Health serves as a focal point for addressing the importance of the interactions among physical, social, economic, environmental, and genetic factors.

Autonomy

The right of persons with disabilities to participate in decisions affecting their lives is central to the principle of autonomy. However, in addressing the needs of persons with disabilities, two problems emerge: First, it is often presumed that persons with intellectual/mental disabilities lack the capacity to make their own decisions, and second, there is a tendency to make choices for competent disabled adults and their families because they are often seen as vulnerable and thus in need of protection, their choices are not perceived as appropriate, or the public sometimes has low expectations of them.

A distinction is generally made between care and research. Research requires more stringent conditions in terms of justification, disclosure, and consent. Research should be undertaken with and personal health services administered to human beings only as long as the persons involved are given exhaustive background information that will enable them to make informed decisions about whether or not to participate in research or clinical care (e.g., on the risks and benefits of participation, alternatives to the testing, treatability of the disorder). Some individuals may interpret the simple offering of prenatal screening or genetic testing as a suggestion that such screening or testing is necessary, desirable, and in their “best interest.” Also, it has been argued that if parents refuse prenatal tests they may later be made to feel guilty or blamed if their child is born with a disability.

Another important ethical issue is the need to involve the public and to provide forums in which the community can participate in identifying needs, setting priorities, and making decisions involving health services and medical research. Persons with disabilities feel they have a great deal to offer in this respect because they are most affected by and aware of the issues associated with their conditions. The phrase “Nothing about us without us,” originated in the early 1990s by disability rights activists, is today a widely recognized motto for people with disabilities who want to take a full and active role in their care as well as at all levels of decision making in matters concerning their lives.

Autonomy and International Policies

Two core issues concerning autonomy are addressed by international policies: The first is consent, a principle at the foundation of any ethical research and health service; the second is the right to participate and be involved in policy decisions that have an impact on services and research.

UNESCO’s Universal Declaration on the Human Genome and Human Rights recognizes the importance of informed consent, stating that in all cases, the prior, free, and informed consent of research participants shall be obtained. Obtaining meaningful informed consent from people with disabilities who are participating in genetic research raises challenges. There is an ongoing debate about the adequacy of the safeguards currently in place to protect disabled participants. The UNESCO declaration tries to strike a balance between the need to protect individual rights and the need to ensure freedom of research, primarily in relation to genetic information. Article 5(a) of the declaration states that research, treatment, and diagnosis should be made only following an assessment of the potential risks and benefits of performing these research activities and should adhere to a national standard.

As a health service, genetic testing of incapacitated adults also raises special concerns. The UNESCO declaration requires that the testing of an incapacitated adult be done only on the basis of that person’s best interest. Article 5 of the declaration states that if, according to the law, a person does not have the capacity to consent, research affecting his or her genome may be carried out only for his or her direct benefit, subject to the authorization and protective conditions prescribed by law. The Council of Europe’s Steering Committee in Bioethics recommends that testing should be permitted on an incompetent person only if certain safeguards and the following conditions are met:

- The purpose of the test is to allow the family member or members to obtain important preventive, diagnostic, or therapeutic health benefit, or to allow them to make an informed choice with respect to procreation.
- The implementation of such test is essential to obtain the benefit envisaged.
- The importance of the benefit foreseen has been independently assessed.
- The risks and burden of the intervention, and risks to private life that may arise from the collection, processing, or communication of the results of the test, are minimal for the person who is to undertake the test.
- The person undergoing the test does not object.
- The authorization of the person’s representative, or an authority or a person or body provided for by law, has been given.
- If the person tested has expressed the wish not to be informed of the result of the test, this wish shall be observed.

During the prenatal period, the GAEIBE recommends that no prenatal genetic testing be imposed by law, by public health services, or by any other institution or person. Tests should be done only at the request of the woman or couple after they have been fully informed through genetic counseling.

Regarding population-based genetic screening, Inclusion International stresses the importance of every individual’s having the choice to opt into or out of genetic (population) screening. This organization also suggests that a disabled person should not be pressured either tacitly or explicitly to undergo genetic testing and that the disabled person and his or her parents or other personal caregivers should be allowed to refuse to receive any test results.

Recognizing the need for public participation, internationally, agencies such as the WHO, UNESCO, and their advocates are vocal about the importance of providing people with the means to play a greater role in policy development with regard to genetic research. Responding to this need, the WHO (1997), in a report on ethical issues in medical genetics, stresses the necessity for close cooperation between medical professionals and patients' organizations. In a research context, a similar participatory approach is promoted by the Human Genome Organization's Ethics Committee (1996), which recommends that consultation should precede the recruitment of participants and should continue throughout the research.

In addition, recognizing the double discrimination experienced by women with disabilities, Rehabilitation International (1997) demands that the concerns and input of disabled women and girls be heard clearly in all debates and policies concerning genetic engineering, bioethics, prosthetic design, and human engineering, with regard notably to cochlear implants, abortion on grounds of disability, assisted suicide, and other eugenic practices.

SUMMARY

While the promises of genomic medicine are manifold, the coming decades of advances in genetics and biotechnological developments will undoubtedly raise social and ethical concerns with regard to the human rights of people with disabilities. The rights of disabled people that may be violated include the right of each individual to develop according to his or her potential, the right to equality and respect for each individual, the right to be valued in positive terms and not solely based on notions of perfection and normality, and the right of each individual to make his or her own life choices and to have a voice in discussions that shape and define genetics policies.

UNESCO's Universal Declaration on the Human Genome and Human Rights remains a pivotal document because it lays down general principles and provides a framework for addressing a complementary approach between human rights and medical sciences. The World Health Organization, the Council of Europe, and consumer organizations such as Inclusion International and Disabled Peoples' International also play major roles in translating genetic innovations into the health service and public health fields. Current policies have adopted an all-encompassing approach, focusing on the general recognition, respect, and protection of the rights to which all people, whether disabled or nondisabled, are entitled.

—Denise Avard and Clémentine Sallée

See also Bioethics; Ethics; Eugenics; Gene Therapy; Genetic Counseling; Genetics.

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GENNARO, ALDO (?–1987)

Chilean-Australian theater and dance director

> *Institutions suppress individual creativity; creativity is our tool to keep growing.*
>
> —Aldo Gennaro (in the film *Stepping Out*, 1980)

Aldo Gennaro was born in Chile, where as a young man he became an Augustinian priest in his quest for "spiritual energy." One manifestation of Gennaro's subsequent attainment of this energy came after he migrated to Sydney, Australia, when as a dancer and director, he worked with young people with Down syndrome from the Lorna Hodgkinson Sunshine Home on a dance theater project. The project emerged from the activity therapy center that Gennaro had established at the home. He saw the body as "an instrument of communication" and developed a "language of gestures" with the group that enhanced the young people's ability to communicate through dance.

In the first piece developed by the dance group, one of the performers took the role of the Clown. This offended some observers, who felt that the young man was somehow being mocked. But he himself insisted: "Yes, I can be a clown. There is nothing to be ashamed of to be a clown, not because I am Downs Syndrome, and when I go in the street people look at me funny . . . . I can be a clown. I can laugh from inside and invite you to laugh with us."

During the preparation of the group's major dance piece, which was eventually performed at the Sydney Opera House, Gennaro developed a special relationship with the group. In an interview given shortly before his death of an AIDS-related illness in 1987, he described this as "the first time I experienced real love in my life, unconditional love." The dance piece made an enormous impact. One critic described it as a "marvelous, colourful, creative, vibrant performance." The piece reached a far wider audience when Chris Noonan (who later directed *Babe*) made a documentary film about the group's dance project. The film, *Stepping Out,* was released in 1980; it was shown throughout the world and won 14 major awards.

—John Brotherton

See also Dance; Down Syndrome; Drama and Performance.

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GENOCIDE

This entry describes the disability-genocide nexus. Conceptions of genocide are distinguished, and practices that may accompany genocide and historical examples are described. Little has been written about the disability-genocide nexus, except for the Nazi example, although more is written about disability-related topics that can accompany genocide, such as eugenics, euthanasia, and famine. Genocide has legal, political, anthropological, and moral aspects, and this entry seeks to capture all of these.

The relationship between genocide and disability depends on how disability is defined. Weapons tipped with depleted uranium and posttraumatic stress disorder in Kosovo and spirit injuries in Rwanda have major individual and social consequences that may or may not be classified as disabilities.

Two approaches to identifying genocide are described below. The order is not hierarchical; thus the legal definitions mentioned first resulted from popular debate, which is mentioned second.

EVOLVING ATTEMPTS TO PREVENT AND PUNISH THE PRACTICE OF GENOCIDE

I. Limited Conceptions

The term *genocide* has multiple definitions. As with *disability,* definitions are not neutral; rather, they serve to spotlight or obscure particular practices. Each definition calls attention to particular aspects of what is done in a genocide and to whom it is done. Depending on one's definition, there may either be many instances of genocide or very few.

The word *genocide* first appeared in Polish lawyer Raphael Lemkin's 1944 book *Axis Rule in Occupied Europe.* Lemkin combined the Greek *genos* (race, tribe) with the Latin *cide* (killing). He was describing Nazi Germany's practices, but also sought the adoption of legal restrictions so that genocide would not recur. After that book's publication, Lemkin discussed genocide in a 1946 article in the *American Scholar,* in a 1947 article in the *American Journal of International Law,* and elsewhere. Lemkin's definition for the term was simple: "the destruction of a nation or ethnic group." Lemkin identified political, social, cultural, economic, biological, physical, religious, and moral dimensions of genocide. These included practices such as "racial discrimination in feeding" and "endangering of health," both often sources of disablement and death. In Lemkin's definition, "destruction" was not equivalent to "killing." Instead, it could mean measures such as prevention of births, endangering of health, and discrimination in feeding.

Earlier, in 1933, in an essay titled "Acts Constituting a General (Transnational) Danger Considered as Offences against the Law of Nations," which extended a report presented to the Fifth Conference for the Unification of Penal Law in Madrid, Lemkin proposed a multilateral convention making the extermination of human groups an international crime. The crime Lemkin identified in 1933, "Acts of Barbarity," would be a subject of a later convention under another name, genocide.

In the wake of the Nazi genocide, the United Nations adopted first a declaration and then a convention on genocide. Article 2 of the 1948 UN Convention on the Prevention and Punishment of the Crime of Genocide describes both against whom genocide might be directed and acts constituting genocide: "Genocide means any of the following acts committed with intent to destroy, in whole or in part, a national, ethnical, racial or religious group." The convention goes on to specify a set of acts that can constitute genocide: "(a) Killing members of the group; (b) Causing serious bodily or mental harm to members of the group; (c) Deliberately inflicting on the group conditions of life calculated to bring about its physical destruction in whole or in part; (d) Imposing measures intended to prevent births within the group; (e) Forcibly transferring children of the group to another group."

People with disabilities (PWDs) do not literally qualify as "the group." The disability community, however, is especially vulnerable to practices such as forced resettlement, famine, and diversion of resources that may be part of genocides. Prosecution of violators of rights of PWDs, specifically, has been for war crimes or crimes against humanity, but not genocide. People prosecuted for genocide under the UN convention have been violators of PWDs' rights, but the evidence has been anecdotal rather than gathered by prosecutors who were focused on the disability-genocide nexus.

Cases brought under the UN convention have run into procedural difficulties. Even with a limited conception, governments have been reluctant to cede the identification of genocide to international institutions. Article 9 of the convention provides for the resolution of disputes by the International Court of Justice in the Hague. However, many parties to the convention, including the United States, conditioned their ratifications by taking exception to this article.

Language identical to that in the UN convention is used to define genocide in Article 6 of the Rome Statute of the International Criminal Court (ICC). The ICC became a reality in 2002, and more than 90 countries, from Afghanistan to Zambia (but not the United States), are parties.

The Rome Statute contains provisions for the prosecution of many crimes against PWDs. Before destruction reaches the level of "genocide," there may be matters receiving the ICC's attention. Article 7, on "crimes against humanity," includes many offenses that have given rise to genocide (with great consequences for PWDs), among them deportation in paragraph 7(1)(d) and enforced sterilization in 7(1)(g). Similarly, Article 8, on "war crimes," includes enforced sterilization, unlawful deportation, biological experiments (as a form of torture or inhumane treatment), intentional starvation, and medical or scientific experiments. Some instances qualify as war crimes and could be the basis of prosecutions. But other instances would not; for instance, mutilation or experiments on occupied populations might be "justified by the medical, dental or hospital treatment of the person concerned."

Under Article 30 of the Rome Statute, prosecution requires that the material elements of a crime were committed "with intent and knowledge." That a defendant "must have known" or "should have known" is not sufficient. So the elimination of groups cannot be prosecuted as genocide unless it was intended.

The prohibition of genocide is fundamental in international law, and even where states have not consented to prohibition by written treaty, they are bound to obey the prohibition as a peremptory norm of international law (*jus cogens;* literally, constraining law). Leaders and scholars therefore often attempt to distinguish mass killings (sometimes permitted as self-defense or humanitarian intervention) from genocide (always prohibited).

II. Conceptions Challenging the Limits

Jus cogens has changed over time, so the public struggle over concepts such as genocide may eventually be reflected in law. Raising narrow definitional arguments is a strategy of genocide deniers, countered by advocates who insist that genocide be confronted.

In the 1948 UN Genocide Convention, limit to four types of groups was chosen over interpretations that might have added linguistic, political, or economic groups. "Political and other groups" were mentioned in a 1946 draft resolution, one that came from the drafting committee of the United Nations General Assembly's Sixth Committee, but later were excluded. Like the ICC, the International Criminal Tribunal on Rwanda (ICTR) used the fourfold enumeration, but it held that "all 'stable' groups, constituted in a permanent fashion and membership of which is determined by birth," should be included. By these criteria, some groups of PWDs would be included, but others would not.

Anthropological Conceptions

Alexander Hinton (2002) and others have followed the ICTR's example in calling for a broad definition of genocide, even suggesting that disabled people might be a "stable group." They contend that the essence of genocidal practices is "otherness," based on race or ethnicity in some contexts, but based on sexual orientation, gender, disability, political, or economic status in others. Genocidal circumstances may make group membership less stable, for instance, because of many people becoming newly disabled.

Other Conceptions

Cultures, advocacy organizations, and countries have sometimes adopted less exclusive conceptions of genocide. The use of cochlear implants has been described as "cultural genocide" directed at Deaf culture. Many opponents of forced institutionalization and involuntary practices of psychiatric drugging describe the practices as "genocidal." Philosopher Jean-Paul Sartre persuaded the nongovernmental Bertrand Russell Tribunal that the Vietnam War was "genocidal." The Spanish statute under which former Chilean dictator Augusto Pinochet was indicted included "political groups." French and Belgian approaches to defining genocide also include nonexhaustive lists of groups.

Users of broader conceptions of genocide apply the term to bring public focus to humanitarian issues faced in the present and future, not just the past. Users of narrower conceptions contend that this dilutes attention to important instances of genocide that must not be repeated.

PAST AND PRESENT PRACTICES REFLECTING THE DISABILITY-GENOCIDE NEXUS

Once "genocide" entered public discussion, it was applied to many practices and cases, some of which are described below. The disability-genocide nexus is seldom mentioned by observers, usually because they ignore it rather than because it does not exist.

Practices That Illustrate the Nexus

Many past and present practices reflect the disability-genocide nexus. If not part of genocide, they may constitute crimes against humanity or war crimes under the Rome Statute. Often, however, they have been accepted practices not just by prosecuted genociders, but by the prosecutors.

Eugenics was an important part of the Nazi genocide, but it was explicitly practiced in the United States and is advocated by many policy makers today. Thinking about eugenics intensified in the nineteenth century. In 1883, Francis Galton, a cousin of Charles Darwin, defined eugenics as "the science of improving the stock." That intention was invoked in efforts common in the twentieth century, including bans on marriage, sterilization, and rationing of scarce resources.

Advocates of euthanasia sometimes make eugenic arguments. PWDs are especially likely to be targeted as "worthy of death" as they were during the Nazi genocide.

Weaponry used to perpetrate and respond to genocide will mean that many people will become PWDs. Elaborate new weapons may help genociders, but they are not necessary to it. New and old forms of weaponry will kill many PWDs but will also make PWDs of other formerly nondisabled people. In Rwanda the machete killed many people but made amputees of others. Land mines are used both by perpetrators of genocide and by counterforces. Depleted uranium on modern weapons and posttraumatic stress disorder are two more reflections on the disability-genocide nexus.

Food is a common weapon in genocides, sometimes the primary weapon. Deprivation of food kills many people; it may also mean disability. For some people who are already disabled, the struggle for food, either where genocide is being practiced or in refugee camps, may mean death. Malnutrition's consequences for learning are great, even where the ultimate message is one of human resilience.

Historical Examples

The case most written about by far is the Nazi Holocaust. The Holocaust included practices of eugenics and euthanasia—labeled "child's play" compared to what followed by historian Daniel Goldhagen. Henry Friedlander (1995), Hugh Gallagher (1990), and others present a compelling contrary view that the actions against PWDs were central to the Nazi genocide. The techniques later used in the death camps were perfected in killings of disabled people.

A German law enacted on July 14, 1933, allegedly to prevent "hereditarily sick offspring" was the basis for sterilizations, initially voluntary, later mandatory. Many disabled people were killed in T-4, a project named for the street of its location, Tiergartenstrasse, that began in 1939 and ended in 1941. Others were "selected" at concentration camps as unlikely to be useful for arduous forced labor. The 14F13 program operated during most of World War II, and occupying forces found that killings of disabled people continued throughout the war.

Imprecise criteria resulted in hundreds of thousands of killings (about 250,000 PWDs). "Mental patients" describes some victims, but certainly not all; some had epilepsy, others were blind or deaf, and still others were killed for offenses such as bed-wetting.

Although each genocide has unique aspects, each can be compared and contrasted with others. The following 10 propositions explore the disability-genocide nexus. Each is more applicable to some genocides than others. (Earlier iterations of this list appear in Blaser 2001, 2002.)

1. PWDs may be selected as direct targets by a genocidal regime.
2. The earliest effects of genocide are likely to be felt by PWDs.
3. Genocidal movements' or regimes' perspectives on medicine may have disproportionate effects on PWDs.
4. Genocidal movements' or regimes' diversion of resources to carry out genocide may have disproportionate effects on PWDs.
5. Genocidal movements' or regimes' minimizing of contacts with other governments and nongovernmental organizations may have disproportionate effects on PWDs.
6. PWDs are disproportionately affected by genocide (in comparison with the nondisabled population).
7. Genociders may increase numbers of PWDs in the furtherance of genocide.
8. International organizations and intermediate national organizations may assist PWDs.
9. The "survivor syndrome" that is a result of genocide reflects the continuing relevance of disability.
10. Regimes following genocidal regimes are unlikely to deal successfully with issues affecting PWDs.

Cambodia in the late 1970s provides illustrative comparisons. The prosthetic devices used by many PWDs were identified as indicating ties to the West and therefore as bases for killing. Observers noted that people found near hospitals were targets for killing, all the easier if they were mobility impaired. Medical supplies were scarce, and temporary disabilities became permanent ones. In some cases, death resulted. Aid from humanitarian organizations was suspect, to the detriment of PWDs.

As in the Cambodian genocide, in 1994 Rwanda, ideology took precedence over human needs. In Rwanda it was a vaguely defined ideology of "Hutu power," where the more numerous Hutu destroyed many of the Tutsi minority. Early targets included institutions such as schools and hospitals that housed disabled people. Some people who survived lost limbs from machete attacks. Wing and Johnson (2002) suggest that genocide survivors are disproportionately women, many of them disabled. They also note the importance of including "disability" in the equality clause of Rwanda's postgenocide constitution.

Genocides were common in the twentieth century, and the term also applies to prior and later practices. The conquest of indigenous peoples and their lands, the status of Armenians in Turkey, the status of Kosovar Albanians in 1979, and the widespread use of sanctions are cases in which the consequences of "genocide" were felt disproportionately by PWDs. Contemporary practices of forced institutionalization and euthanasia include characteristics of past acts widely acknowledged as genocidal.

—Arthur Blaser

See also Eugenics; Euthanasia; United Nations.

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GEOGRAPHY AND DISABILITY

In its most common understanding, geography can be defined as the science of the earth's physical features, resources, climate, and population. From a broader perspective, geography is also the study of landscapes. Landscapes include spaces that can be classified as either environmental (natural) or human (built). Each type of space has important implications for persons with disabilities. Space plays a critical role in the lived experience of persons with disabilities because space is directly tied to accessibility and mobility. Therefore, space can be used to enable or disable persons with disabilities. Landscapes can have real (objective) or perceived (subjective) barriers for persons with disabilities. Thus, for persons with disabilities who may already experience social segregation, the presence of physical barriers due to space may further contribute to marginalization and lack of full integration into the community. These circumstances contribute to health disparity and inequity present in society worldwide.

Space is considered to be a social phenomenon that is influenced by the interactions of people, organizations, and systems in a historical process. As new landscapes are produced, those with power in that particular social structure are able to decide who will be advantaged and who will be disadvantaged. Therefore, the ability of persons with disabilities to participate in or influence decision makers has profound implications for how space will be built or altered to have a positive impact on people with disabilities.

Space is produced both naturally and socially. *Natural space* refers to geographic features such as mountains, rivers, oceans, and deserts. The ability of persons with disabilities to negotiate natural space is an important topic. It is often the case that the natural environment may pose obstacles for persons with disabilities; for example, those who are blind or physically disabled may have difficulty mountain climbing or skiing. In recent times, human guides and specially designed equipment have become available that permit disabled persons access to and mobility within natural environments. Similarly, innovations and alternations to the natural environment from engineering, architecture, and urban planning have increased access to and mobility in the natural environment. Physical change to the natural environment through human intervention is often referred to as the *built* environment.

A second way to view geography and its implications for disability is as social space. *Social space* is defined as nature that has been transformed through human practice. Human social space can be thought of as being physically produced (e.g., construction of a school)—the built environment—and socially produced (e.g., interaction between students and teachers in a classroom). In this sense, social space is viewed as the interaction of both a process (educational interaction) and an outcome (a building). It is important to note that environmental or natural space also plays a role in the creation of human social space (e.g., the construction of cities and towns near a river). Likewise, human creation of "built" space may also alter natural space so as to create a new environmental space that is oppressive to some groups such as those with disabilities (e.g., the lack of wheelchair-accessible street curbs in a city). When geography is viewed as a social phenomenon, several policy implications arise.

POLICY IMPLICATIONS

Employment

The experience of physically disabled persons is socialized in different times and in different places. Historically it has been shown that in capitalist-oriented Western societies, landscapes have been built that have a tendency to desocialize or marginalize persons with disabilities. This phenomenon has been characterized as the production of landscapes of exclusion. One example of this exclusion is the creation of sheltered workshops worldwide. Sheltered workshops often exclude disabled persons from mainstream employment opportunities and the work is often low paying and conducted under harsh conditions. In this regard, sheltered workshops have been viewed as places of exploitation and marginalization. Progressive social policies that view sheltered workshops as a source of production within the larger economy are needed, such as those in Germany, where federal policy mandates the employment of a certain proportion of disabled people in the country's large firms. Because research shows that poverty due to "work" disability is associated with geography, it is important for policy makers to consider the economic implications of the geography of disability.

Community Integration

Historically in Western societies, the disabled have often been isolated and institutionalized in hospitals, asylums, and other forms of sheltered housing. With the movement toward deinstitutionalization in the mid-1970s in the United States, persons with disabilities were transitioned to community-based forms of social care. This change in landscape, brought about by social policy, has implications for geography and disability. Most notable have been studies of community and neighborhood resistance to relocation of persons with mental and physical disabilities into their areas. This resistance has been termed "not in my backyard," or NIMBYism. Social policy directed at the deinstitutionalized has often resulted in poverty and social isolation, including increases in the numbers of homeless.

Incorporating a broader understanding of geography that includes not only attention to natural and built landscapes but also social spaces will help to create places that are more inclusive of persons with disabilities.

—Karen E. Peters

See also Accessibility; Accessibility Codes and Standards.

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GEORGENS, JAN DANIEL (1823–1886)

German educator

Jan Daniel Georgens, a typical "restless worker," was born on June 12, 1823, in Bad Dürkheim, Germany.

He visited a teacher seminar and quickly became interested in the *Volksschule* (elementary school), which he regarded as the central educational institution for the nation. Beginning in 1844, he worked as a teacher in various locations. In 1848, the year of the failed German revolution, he founded a girls' grammar school in Worms, and two years later, the first south German nursery school in Baden-Baden. He had close contact with Friedrich Fröbel (1782–1852), the founder of *Kindergarten* (German nursery schools). In 1852, Georgens went to Vienna, where he accepted a private tutoring position for four years.

In 1856, Georgens developed a plan to erect the Institution for Special Education in Vienna. Together with the author Jeanne Marie von Gayette (1817–1895)—his future second wife—and the pedagogue Heinrich Deinhardt (1821–1880), whom he most likely met in Weimar while visiting the German *Idiotenanstalten* (institutions for the feebleminded), Georgens was able to open the private Heilpflege- und Erziehungsanstalt Levana (Remedial and Educational Institution Levana) a year later in Vienna. The institution focused its efforts on children of the noble and middle classes but also had a few openings for needy children. "Normal" children as well as the "infirm" and "degenerate" were accepted. Levana was conceived as a pedagogical model institution. It had a department for infant care and general and occupational training facilities as well as a Gesunden- und Krankenabteilung (Healthy and Ill Division) for up to 30 children. In 1857, the institution was relocated to the Liesing castle near Vienna. Due to low demand, the institution had to abandon the castle in 1859 and occupy a smaller building near Vienna. The ultimate end of the entire enterprise came during the mid-1860s. Numerous factors—including personal conflicts, lack of organizational experience, unprofessional business practices, and lack of governmental and private support—contributed to the failure of this reform-pedagogical experiment.

One permanent outcome of these years was an extensive two-volume publication that covered the theoretical foundations of special education as a scientific discipline. The dual-authored publication, which was titled *Die Heilpaedagogik. Mit besonderer Berücksichtigung der Idiotie und der Idiotenanstalten* (*Pedagogy of Special Education: With Special Consideration of Idiocy and Institutions for the Feebleminded*), was published in 1861 and 1863 in Leipzig. After that period, Georgens and his wife lived in Switzerland, Nuremberg, and Berlin. Georgens involved himself in other educational projects and worked professionally and politically with the Allgemeinen Deutschen Lehrerversammlung (Public German Teachers' Association). At the same time, he devoted himself more extensively to literary activities. He died on November 9, 1886, in Bad Doberan on the Baltic Sea.

—Anne Waldschmidt

See also Heinrich Marianus Deinhardt.

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GERMAN TRAINING SCHOOLS (*HILFSSCHULEN*)

The concept of the training school emerged during the last third of the nineteenth century in Germany. It was designed for the so-called feebleminded, who were excluded from the elementary school system. The foundations of the concept cannot be detached from industrialization, because of its nature as a practical training school (*Erziehungsschule*). The training school was intended not as a model of "normal" education, but rather as one of occupational training for a predominantly proletariat clientele.

Karl Ferdinand Klein (1814–1868)—a teacher for deaf-mutes—and Heinrich Ernst Stötzner (1832–1910) are considered the founding fathers of the training school. In a memorandum written in 1864, Stötzner called for the establishment of this new school system:

> In all of the large cities, people ought to create schools for less capable children, with the goal of taking individuals—who would on the whole otherwise become burdens of the state—and training them, by appropriate personnel and through relevant instruction methods, in order to create useful and productive members of society (quoted in Klink 1966:55).

The main argument of the founders of the training school was that elementary schools must be relieved of the strain associated with educating less gifted children. Having no elaborate diagnostic instruments at their disposal, the school's administrators maintained that a person should be considered "feebleminded" if he or she remained unsuccessful in the elementary school for two years. The so-established categorization of "feeblemindedness" was then certified by additional doctors who served as consultants and fixed within the personal learning curves of individual students. The concept of feeblemindedness—which was borrowed from psychopathology—served to legitimate a new pedagogical institution and profession.

Through the establishment of the Verband der Hilfsschullehrer Deutschlands (Association of German Training Schools' Teachers) in 1898, the training school gained enormous attention: In 1893, there were 110 special classes in 32 cities in Germany, with a total of approximately 2,300 students. By 1911, the number of classes had increased to 1,544, with approximately 33,000 students.

In spite of further expansion in following years, the training school system first experienced formal recognition during the period of German fascism through the Allgemeine Anordnung für die Hilfsschulen (General Order for Training Schools) in 1938. Even opponents of the National Socialist state protected the position of the training school by claiming that the productivity of their clientele would be useful for the armament industry and again that the training schools relieved strain on the elementary school system. In addition, the training schools saw themselves as holding tanks with respect to the sterilization law and participated in the selection of the "uneducable" (*Nicht-Bildungsfähige*), who fell victim to the so-called Euthanasia program between 1939 and 1945.

After 1945, a restoration of the previous training school system emerged in West and East Germany. In the Federal Republic of Germany the newly founded (as of 1949) Verband Deutscher Hilfsschulen (Association of German Training Schools) published a 1954 memorandum that appealed to the Deutsche Städtetag (German Congress of Municipal and Local Authorities) to proceed with haste to reconstruct and extend the Special School System *(Sonderschulwesen).* This memorandum stimulated the *Gutachten zur Ordnung des Sonderschulwesens* (*Report of the Rules of the Special School System*) of 1960, published by the Kultusministerkonferenz (Commission of the School Ministers of West German Federal States). This report explained that, in addition to the training school, other types of special schools (e.g., for children with sensory, speech, and physical disabilities; the sick; and those with behavior problems) were also elements of the German education system. At the beginning of the 1960s, the Special School for the Cognitively Disabled was added. Likewise in the 1960s, the classical training school successfully renamed itself Sonderschule für Lernbehinderte (Special School for the Learning Disabled).

Modern critics of the Special School for the Learning Disabled in Germany focused on the high overrepresentation of socially and economically underprivileged students in this type of school, such as children with immigrant backgrounds. Another area of criticism was that the relatively low achievement level was not, on average, being raised through small classes and individualized instruction methods. In this respect, the Special School for the Learning Disabled proves to be a significant component of the selective German educational system.

—Vera Moser

See also Education, International; Education and Disability.

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GERMANY

See Advocacy Movements: Germany; Disability Law: Germany; Eugenics: Germany

ARNOLD GESELL

(1880–1961)

American physician and psychologist

Arnold Gesell is best known for pioneering work in child development and as the founder of the Yale Child Development Clinic. Gesell was born and raised in Wisconsin, completing a Ph.D. in psychology at Clark University in 1906 and an M.D. at Yale in 1915.

When Gesell started his investigations into child development, he was most interested in the child with disabilities. Like Edouard Séguin and others before him, Gesell was fascinated by the pathological as it reflected on the normal, particularly in the form of a feral child discovered in the early twentieth century. Nevertheless, most of his work was concerned with describing the "normal child." A number of his publications caught the eye of James Angell, then president of Yale University, who orchestrated Gesell's move to New Haven. The Child Development Clinic, institutionally, began in the Yale Psychology Department but later moved to the Medical School and the Department of Pediatrics. Gesell received funding from the General Education Board of the Rockefeller Foundation as well as the help of Abraham Flexner. Eventually, Gesell and his work split, with the Child Development Clinic remaining at the Yale University Medical School (to this day) and another group creating the private Gesell Institute in New Haven. At times, these two institutions vie for the mantle of successor to Gesell's work.

Gesell was one of the first child developmentalists to use quantitative measures as tools for assessment throughout the continuum of childhood. He also extensively employed film and photographs to illustrate his arguments. He created orderly sequences of developmental stages to explain maturation of the child, resulting in the Gesell Development Schedules, which describe a child's motor, language, adaptive, and social responses to a variety of stimuli and produce a "developmental quotient" (DQ) suggesting a child's proximity to a "normal" child of the same age.

Into the central decades of the twentieth century, Gesell assumed a position as doyen of child development in the public mind. The author of many books, Gesell popularized his ideas of normal development through a series of lay guides. Middle-class mothers in particular found his work appealing, bringing his books with them when they visited their children's pediatricians. He helped standardize issues around developmental expectations in the minds of the public as well as in the minds of pediatricians, psychologists, and educators. Into the second half of the century, his ideas were overshadowed by more "environmental" developmentalists such as Jean Piaget.

—*Walton O. Schalick III*

See also Edouard Onesimus Séguin.

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GILMAN, CHARLOTTE PERKINS

(1860–1935)

American writer and feminist theorist

Charlotte Perkins Gilman's childhood was spent in poverty after her father essentially abandoned the family. Her own first marriage was an unhappy one and ended in divorce. These early experiences were instrumental in forming Gilman's theoretical approach to feminism—expressed most fully in her 1898 classic work *Women and Economics,* which stripped away romantic notions about the family and called for society to view domestic duties as social responsibilities.

Gilman's personal experience with what she described as long-standing melancholia—what today would be called major depression—led her to write the short story "The Yellow Wallpaper," which has endured as a feminist and disability classic and has been the subject of wide critical commentary. Gilman herself had been advised by a leading medical specialist to "live as domestic a life . . . as possible" and "never to touch pen, brush, or pencil again." She reported that following this advice brought her "so near the borderline of utter mental ruin that I could see over" (Gilman 1913). In "The Yellow Wallpaper" she transmutes these experiences into powerful and disturbing fiction.

In addition to writing other fictional and theoretical works, Gilman also lectured widely and was one of the founders of the Women's Peace Party.

—Anne Finger

See also Depression; Feminism.

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GLOBAL INEQUITIES

Numerous historical, economic, political, and cultural factors and forces have contributed to significant inequalities in the lives of disabled persons worldwide. These include inaccessible or uneven geographies; underdevelopment; globalization; the strengthening of state structures and surveillance mechanisms; the imposition of Western-style rehabilitation models; warfare; a burgeoning refugee population; indigenous values, categories, and practices; and cultural representations that circulate through art, film, literature, the media, and theater. These factors and forces are refracted through the lenses of race, class, gender, and sexual orientation, creating multiple and intersecting marginality and invisibility for some. Nonetheless, an emerging and expanding global disability rights movement is currently seeking recognition from national and international bodies, demanding that disability rights be recognized as human rights.

Approximately 80 percent of all disabled people live in the majority world (third world). James Charlton (1998) argues that the imbalance between the minority world (first world) and the majority world needs to be placed in the context of world-systems theory. This theory purports that wealth inequities between these spheres emerged as formerly colonized countries were forced to remold their economies to meet the demands of the West. Leaving these countries resource poor has produced disability by generating inadequate food supplies, unsanitary living conditions, and unsafe working conditions. It has also stripped these countries of the assets necessary to guarantee disabled citizens integration and self-determination, contributing to underdevelopment and a sense of internalized oppression for some disabled people. This pattern of underdevelopment has been exacerbated by globalization processes that support unfair trade policies propelled by profit-seeking capitalists promoting a world open-market economy. The pattern is also bolstered by structural adjustment policies devised by the World Bank that require debtor nations to repay loans at the cost of undercutting basic safety nets, health care, education, and employment opportunities and training. These policies further disenfranchise already disenfranchised disabled populations. Additionally, these policy restrictions and stipulations perpetuate paternalistic models of development, silencing majority world voices that the minority world needs to hear.

Benedicte Ingstad and Susan Reynolds Whyte (1995) have published an edited collection that examines disability in cross-cultural perspective. The volume outlines criteria for such comparisons, including mind/body understandings, concepts of personhood, and values that determine an individual's social worth. Ingstad and Whyte have been criticized for failing to focus on social oppression exposed by considerations of political economy and for failing to account for the subjective experiences of disabled embodiment captured by phenomenological approaches. Nonetheless, their work is useful in that it serves to remind us that universal theories of oppression may obscure the diverse responses that specific cultures have had to disability, reinforcing misbegotten assumptions about the superior humanitarian impulses of the West.

Following on the work of Henri Stiker, Ingstad and Whyte's work reveals that there is a movement in many majority world countries to adopt Euro-American-style institutions and government procedures, often an artifact of colonialism. This style rests on the premise that equality equates with sameness, supporting uniform legal codes and uniform bodies and suppressing or replacing local or populist interpretations and practices even when they are beneficial to the disabled. Although there is a trend toward community-based rehabilitation (CBR), this appears to be driven more by cost concerns than by a desire to reimagine criteria for social belonging, encouraging input from disabled people themselves.

Matthew Kohrman (2003) offers an interesting ethnographic example of the ironies of a majority world country's struggles to establish criteria to determine eligibility for disability services and rights, placing his research in the context of modernity's nation-building projects. He conducted research in China on a state-run institution, the Disabled Persons' Federation. Founded in 1988 by Deng Pufang, Deng Xiaoping's eldest son, himself paralyzed in an attempted suicide during the Cultural Revolution, the Federation has attempted to redeem the moral status of the Communist Party by demonstrating its concern for China's most vulnerable citizens. Moreover, the state and the Federation have striven to prove to the rest of the world that China is deserving of first world status by devising statistical surveys that identify and count disabled people and by developing criteria for disability based on biomedical definitions.

The ironies are at least threefold. First, the criteria sometimes confuse and exclude persons applying for eligibility because they fail to consider functional limitations as imposed by disabling environments and because they ignore more fluid local categories. Second, government officials initially omitted mental illness because of its cultural associations with destabilizing social structures until pressure was brought from psychiatric elites who argued that recognizing mental illness is a mark of advanced civilization. Third, China established its goal for the total number of disabled to be located on the basis of a worldwide statistic of 10 percent first put forward by Rehabilitation International and then adopted by the United Nations. The statistic was not derived from rigorous evidence, but was meant to impress relevant national and international bodies that the magnitude of disability suggested that it was a pressing concern deserving immediate attention. However, when Chinese statisticians fell short of the 10 percent quota, they felt that they had lost face and embarked on another statistical count. Thus, unfortunately, the desire to be accepted as modern may actually draw energy away from more creative problem-solving forums that enable distinct nations to arrive at unique solutions.

Contemporary warfare, with its "advanced" strategies and technologies of death and destruction, serves as another catalyst for global inequality. The consequences of warfare are not random but intentional, such that "spoiled" and displaced bodies are evidence of the power of the victors over the vanquished, creating injuries and amputations that societies are unprepared for and generating refugees unhinged from familiar arrangements, social networks, and modes of survival. International policies, such as the 1997 Land Mines Treaty, set the tone for "fairness" in war, while reconstruction efforts are often hampered by a lack of consideration for disabled citizens. Modern nation-states also insist on preparedness for war, placing an emphasis on physical fitness as a requirement for full citizenship. Those who return from war may be classified as heroes or martyrs, potentially generating a two-tier system, with nonmilitary disabled citizens on the bottom rung of the social ladder.

John Hockenberry, a one-time reporter for National Public Radio, was stationed in Israel/Palestine during the first Intifada (Palestinian uprising that took place during the late 1980s). In his memoir titled *Moving Violations* (1995), he notes the enormous discrepancies he found between the conditions of the Israeli and Palestinian war wounded. The Israelis had lightweight, high-tech wheelchairs and were distributed vans with special government-issued license plates.

Elevated to the status of hero, they maneuvered their wheelchairs with militaristic confidence. Paralyzed Palestinians, on the other hand, were sequestered in rehabilitation hospitals, hopelessly awaiting the promise of cure in some other country. Reintegration into society was not a viable option for most, both because the role of martyr precluded a return to "normal" life and because old equipment, grinding poverty, and inaccessible terrain made it difficult for these individuals to return to their hometowns or villages.

Gender inequalities are another important factor to be taken into consideration in the analysis of global inequalities. Disabled girls and women are often the targets of various forms of violence, have their reproductive rights violated, are kept more sequestered than males, and are less likely than their male counterparts to have access to education and employment opportunities. Anita Ghai (2001) reports that disabled girls are particularly vulnerable in India for the reasons stated above. However, Ghai also notes, in an interesting twist, that disabled sons are thought to be a threat to "lineage capital" (a term borrowed from Emma Stone 2001), a form of capital that consists of the ability to fulfill expected family obligations, resulting in greater attention being paid to their rehabilitation needs.

Additionally, the voices of disabled women and girls may be dismissed and discounted, contributing further to a sense of nonpersonhood and invisibility. Veena Das and Renu Addlakha (2001) discuss the case of a woman in Delhi who was diagnosed with chronic schizophrenia and placed in a state-subsidized hospital. While there, she attempted to express concerns about her mistreatment by her husband and mother-in-law but was ignored because anything that she said was attributed to her "madness." In this case, the patriarchal structures of the state and the domestic spheres served to reinforce this woman's status as persona non grata.

Both disabled males and disabled females may be looked upon as lessening marriage opportunities for their siblings or otherwise symbolically polluting the kinship domain. Das and Addlakha recount the story of an Indian female born with a major facial blemish whose relatives wanted her quickly married off to a person of lower social standing as a means of containing the threat that she posed to their extended domestic circle. In this instance, her parents were her allies, ensuring that she acquired some education and allowing her to wait to get married until she found a suitable match. Such a stance necessitated that the parents be cut off from an ongoing relationship with their relatives. However, because they were a Punjabi family, displaced by the 1947 Partition between Pakistan and India, wartime conditions actually denaturalized taken-for-granted social arrangements. Moreover, when the woman married, she and her husband were able to take advantage of civil marriage statutes passed after India gained its independence from the British; this case provides an example of state policy helping to carve out new domestic practices that may prove beneficial to disabled citizens.

Finally, changing conventions of cultural representations of disability in art, film, literature, the media, and theater may create ruptures in ways of looking at and thinking about disability. Disrupting established narrative patterns by no means automatically undercuts entrenched inequalities, because old inequalities often resurface in new guise, sometimes rendering the processes of detection and interpretation multifaceted and opaque. Take the case in China of Liu Zheng's collection of photographs titled "My Countrymen." Before Mao Tse-tung's death in 1976, Chinese artists were expected to depict images of an idealized socialist society in which citizens were hardworking, physically fit, and mentally stable. Various genres of art have surfaced in the post-Mao era, some of which focus on unmasking the "reality" obscured by this ideal, and Liu Zheng's work falls within one such genre. Zheng photographs various categories of people living on the margins of society, including disabled people. While these categories may be reminiscent of Erving Goffman's typology of social stigma, as Wu Hung (2001) points out, there are aspects of Zheng's work that might strike one as disturbing. His juxtaposition of photos of disabled people with cadavers suggests an equation of disability with decay rather than a liminality that excites creativity or the forging of new norms. Zheng claims that as someone alienated from Chinese society, he feels an affinity with those photographs. However, even if these photos are aesthetically and empathically rendered, it still remains unclear as to whether they can be construed as progressive.

In recent decades disability rights activism has been sweeping the globe, confronting myriad inequalities. Global disability activism may be overlooked because of stereotypes that equate activism with fitness and the majority world with dependency and a passive femininity, making the pairing of disability and third world appear redundant. Activism may pose specific challenges for the disabled. In Canada, Vera Chouinard (1999) reports, a women's activist group was formed in 1977 called the Disabled Women's Network (DAWN). This organization made an effort to extend itself to women who had originally been excluded from the women's movement (people of color, immigrants, lesbians) in order to formulate broad-based objectives. Nevertheless, group members were faced with multiple constraints, such as lack of transportation, inability to afford the cost of conferences, inaccessibility of places in which to meet and places in which to stage protests, and uneven access to computer technology. Such obstacles, of course, are likely to be magnified in majority world countries, but as Anita Ghai recounts, even the urban slums of India are beginning to give rise to parental groups fighting for the rights of their disabled children and disabled people advocating for their own concerns. Moreover, as Chouinard points out, disabled activists in late-industrial societies are not necessarily guaranteed a voice because their bodies are often seen as lacking or contaminating corporate capital.

One of the benefits of globalization has been the circulation of information about global disability activism such that disabled activists can learn from each other and form coalitions. As with the minority world women's movement, however, disabled activists from first world countries need to exercise caution to avoid imposing their priorities and strategies on majority world activists who may face different conditions and political structures. It is equally important that the elites of majority world countries not be the sole decision makers regarding what discrimination and access issues are to be raised with local, national, and international bodies. A case in point is the Philippines, where a disabled talk-show host launched a campaign against disabled people in carnival freak shows. These entertainers protested his actions, noting that they preferred this form of employment to sheltered workshops, the only alternative supported by government officials for poor, disabled Filipinos.

This case underscores the importance of demanding economic and social rights and not simply focusing on individual civil rights. International disability rights assemblies, such as Disabled Peoples' International and representatives from the World Institute on Disability, have been working with the Union Nations to establish a convention that will recognize disability rights as human rights. Such a convention could prove useful to nations interested in developing their own policies and methods of implementation concerning disabled people. While such a convention would raise international awareness of disability issues, the process and outcome are also fraught with problems. For example, underscoring economic rights incites resistance from some minority world countries that benefit from the underdevelopment of the majority world. Additionally, there are problems with enforcing the stipulations of such a convention once it is forged and with ensuring broad-based input, including the most disenfranchised, into deciding the process of implementation.

—Sumi Colligan

See also Advocacy, International; Economic and Social Development, International; Employment, International.

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GLOBALIZATION

Globalization is a process of change whereby local conditions or entities succeed in crossing national borders and reaching all over the world. Often associated with changes in global dimensions of politics, economics, and cultural practices, globalization is characterized by tensions, contradictions, and unequal power relations. Different regions of the world are at once implicated in multiple overlapping processes of many different globalizations. The globalization of disability issues constitutes one among many globalizations that simultaneously interact with, conflict, and relate to other globalizations. For example, economic dimensions of globalization conflict with disabled people's goals of social justice and equity when competition and deregulation processes involved in market economies exclude people with disabilities from full participation in society. Other major dimensions and processes of globalization that are pertinent to disability include the following: (a) the rapid spread of democracy and push for universal human rights, (b) technologies and the processes of communication and knowledge exchange, (c) social-political dimensions of education and the processes of changing negative beliefs and attitudes toward disability, and (d) health dimensions that produce processes of access to services and applications of medical research. These four broad areas constitute the major focus of disability in relation to globalization.

ECONOMIC DIMENSIONS OF GLOBALIZATION

With its intimate links to capitalization, globalization contains tendencies toward deregulation, decentralization, and privatization. These tendencies are most often associated with economic policies and practices of transnational corporations (TNCs), which exert pressures on industrialized states to shape events and decisions in developing countries. Currently, the top 200 TNCs have wealth equivalent to 28.3 percent of the world's gross national product, and five industrialized countries hold 90 percent ownership of these 200. Further, all industrialized states together comprise only 19 percent of the world's population yet control 71 percent of global trade in goods and services.

At the same time, 80 percent of the world's 600 million disabled people live in developing countries, yet these countries expend 20 percent of the world's health care moneys. Disability is also widely recognized as inextricably linked to poverty. The World Bank estimates that disabled people account for as many as 25 percent of the world's poorest. What is meant by *poor?* Half of the world's 6 billion people live on the equivalent of less than two U.S. dollars a day, and 40 percent of the people in Africa live on less than one U.S. dollar a day. Conditions linked to poverty, such as limited access to health care, food, education, and shelter, in addition to hazardous working conditions, increase the risk of disability. Impairments often lead to exclusion, unemployment, and further poverty, in turn creating and increasing the numbers of disabled people with impairments. The high unemployment rates of disabled people and their subsequent poverty is exacerbated by their countries' debts and privatization policies.

Global pressures for efficiency and competition in deregulated and privatized market economies have created conditions under which disabled people suffer greatly. First, free-market ideologies, by their very nature, create winners and losers, and inequalities are justified in terms of their contribution to economic growth. Second, because deregulation has weakened nation-states' ability to intervene and provide "safety nets," disabled people have lost income maintenance programs. Further, economic structural adjustment programs imposed by donor agencies such as the International Monetary Fund have been geared toward debt repayment. As a result, these programs have forced governments to reduce education and social services that are critical for disabled people in order to pay off these debts. Third, economic policies and interpretations of individual "rights" are increasingly in the hands of unelected technocrats in TNCs, whose interests are profits, not social justice, social responsibility, or equality.

On the positive side, the push to increase productivity, economics, and labor market participation rates has produced a global agenda for education reform, poverty reductions, and increased social responsibility. For example, the World Summit's Program of Action (1982) formally acknowledges conditions of poverty as a prima facie cause of disability. Further, one of the principal goals of the Program of Action is to ensure that society acknowledges and responds to the consequences of disability by securing the legal rights of the individual and by making the physical and social environment accessible. The Program of Action, ratified by 155 countries and in its fourth cycle of five-year review, now requires progress reports as well as resources and funding solutions to ensure access and equity for disabled people.

It is predicted that by the year 2025, the number of disabled people worldwide will have risen from the current 600 million to 900 million. The causes behind this projection can be directly linked to globalization and its effects. Global agendas are clearly driven by economic goals linked to development. These goals hold both a danger and a promise for the future of disabled people. On the one hand, the needs of large numbers of disabled people, coupled with an urgent need for economic development, have led many countries to focus on untapped sources of development by increasing the numbers of disabled people in the workplace. On the negative side, this focus on economic development and disabled people as workplace commodities has led to greater intolerance toward those disabled people who cannot work.

TECHNOLOGIES OF GLOBALIZATION AND UNIVERSAL HUMAN RIGHTS

Globalization has also produced positive benefits in the area of technological advances. Technologies of globalization, such as the Internet and advanced communication systems, have brought disabled people together to document and focus attention on the plight of disabled people and to insist on universal human rights. For example, Disability Awareness in Action (DAA) is an international coalition of the organizations Disabled Peoples' International (DPI), IMPACT, Inclusion International, and the World Federation for the Deaf. Largely linked through Internet communication, DAA has documented evidence of human rights abuses in 28 of the 30 articles of substantive rights contained in the Universal Declaration of Human Rights. As of March 2003, the DAA database contained a total of 1,910 reports of abuse affecting a known 2,466,348 disabled people. These abuses are widespread. For example, in the area of education alone, DAA has documented 118 cases affecting 768,205 people in 67 countries of the world.

Responding to this documentation and other reports, the United Nations Commission on Human Rights created the Global Rights campaign to address human rights abuses. Disability rights organizations such as the International Disability Alliance (IDA) have used this information to insist on a UN Convention on the Rights of Disabled People that would be legally binding on nation-states. The IDA's member organizations include DPI, Inclusion International, Rehabilitation International, the World Blind Union, the World Federation of the Deaf, the World Federation of Deaf-Blind, and the World Network of Users and Survivors of Psychiatry. DPI alone, as an international network of disabled people, works with organizations in 158 countries around the world.

The push for a universal declaration to address basic human rights of disabled people globally carries with it some problems and tensions. The primary tension is in the differences between the situation of disabled people in more advanced industrialized countries and the situations of those in poorer developing countries. More than three-fourths of the world's disability population struggles for the right to life. One-fourth of the population fights for quality of life—often framed in terms of choices, access, and equal opportunity. To many disabled people in developing countries, such quality-of-life issues often seem to be empty slogans because they fail to recognize issues of privilege, power, and control. The push for human rights and self-determination assumes that disabled people have autonomy and a real capacity for choice. Many disabled women and children around the world simply do not have this status or capability. Their lack of food and basic education also affects their ability to advocate for themselves—either individually or collectively.

Some disability scholars and advocates argue that laws regarding equal opportunity do not automatically or even probably lead to improved standards of living, nor do they necessarily lead to social change or change in economic policies. For example, in the United States, 14 years after passage of the Americans with Disabilities Act, unemployment of disabled people remains virtually at the same level as before the law went into effect.

On the other hand, many believe that these programs, declarations, and conventions constitute a universal moral imperative, bring human rights to center stage, and along with it, the right of the international community to intervene in specific countries to protect these rights. The work of DPI, IDA, DAA, and others has been the driving force behind the globalization of disability issues through the World Program of Action (1982), the United Nations Standard Rules on Equalization of Opportunities for People with Disabilities (1993), the World Summit for Social Development (1995), and the Education for All Framework for Action (2000) as well as the current campaign to secure a UN convention on the rights of disabled people.

In addition to human rights implications, the role of information and communication technologies in disseminating information in a knowledge-based economy carries with it social and political implications. Prominent among these implications is the issue of bridging the digital divide between haves and have-nots in different regions of the world.

SOCIAL-POLITICAL DIMENSIONS OF GLOBALIZATION

In a globalized world, strategies that recognize interactions among rights, culture, and political-economic policies become imperative. For example, decisions to allocate resources for education and health services may reveal more about societal beliefs or government priorities than they do about a given country's ability to fund these services.

Education is widely recognized as inextricably linked to development. In response, UNESCO in particular has launched a global inclusive education project to increase the number of disabled children and youth who have access to education as well as opportunities for participation in quality education. In 2001, UNESCO launched pilot projects in Cameroon, Dominican Republic, Egypt, Ghana, India, Madagascar, Mauritius, Nicaragua, Paraguay, South Africa, Vietnam, and Yemen. The global initiative, Education for All 2000, has as its primary millennium development goal universal education by the year 2015. Advocates as well as governmental bodies differ on the subject of the nature and extent of inclusion for people with disabilities. For example, many countries still offer segregated educational experiences for certain populations of disabled children and youth, such as for blind, deaf, and deaf-blind individuals. However, all agree on the importance of education, not only as a basic human right, but as a primary source of individual and collective enhancement and development.

In reaction to globalization, age-old prejudices have also been reawakened, to the detriment of disabled people. For example, many nation-states are pushing for a return to traditional cultural practices to stem the tide of globalization, which is seen as a threat to tradition. Some Islamic states, for example, have reasserted that amputation for theft and stoning to death for marital infidelity are central to Qur'anic law, which overrides human rights declarations pertaining to cruel and unusual punishment.

Both the Declarations of Asia and the Pacific and the Africa Decade of Disabled People list as key objectives the fostering of positive attitudes toward disability and the challenging of traditional practices and beliefs detrimental to disabled people. For international disability organizations, a primary goal is not only educating children and youth, but educating civil society as well as political and governmental representatives. Disabled Peoples' International's 2002 Sapporo Platform, developed by 3,000 delegates from more than 90 countries, urges members to take every opportunity to seek publicity and awareness in order to change negative images of disabled people. Inclusion International and virtually every recent declaration (such as those of the African Decade and the Asia and Pacific Decade) list social-political agendas on which global partnerships to promote good government and full participation of disabled citizens are prominent goals.

HEALTH DIMENSIONS OF GLOBALIZATION

The new universe of disability is shifting and expanding. The shift is evident in the new World Health Organization classification of people with disabilities. In 2001, the new International Classification of Functioning, Disability, and Health (ICF) replaced the old International Classification of Impairments, Disabilities, and Handicaps (ICIDH-2). The new ICF was developed using a process of consensus involving both developed and developing countries. Basically, the ICF organizes disability along two dimensions: functioning and disability (including body functions/structures and activities/participation in society). This ICF definition shifts the focus from disability as an innate deficit to disability as constructed through the interaction between the individual and the environment. This shift encourages a focus on the kinds and levels of interventions appropriate to the needs of individuals within specific contexts and is consistent with the social model of disability that is upheld by disability rights organizations. The ICF distinctions are seen as particularly important in many developing countries, where personhood often depends more on social identity and fulfilling family obligations than on individual ability.

The expanding nature of disability is apparent in proposals to include persons with active, acute conditions such as HIV/AIDS under the rubric of disability. Prevention of these conditions has become an important public policy goal worldwide and introduces a need to reconsider the conceptual basis and terminology associated with disability. For example, including HIV/AIDS in definitions of disability challenges the thinking of disability advocates who have sought to separate notions of disability from disease.

Forces of globalization are also apparent in the area of rehabilitation and health-related services in the changing of language, such as the shift from the term *barrier-free design* to *universal design. Accessibility* used to refer mainly to the built environment, but new dimensions encompassed in the concept of universal design now include age-related factors, gender, culture, social context, levels of decision making, and control over major life activities. Guidelines for planning and design based on principles of universal design are now available in such disparate locations as Lebanon, Malta, and Peru.

Finally, global advances in medical research, genetics, and biotechnology have implications for people with disabilities. Genetic research has many practical applications to health care. Inclusion International (a nongovernmental advocacy organization on behalf of people with intellectual disabilities) recognizes that genetic research can be beneficial but also argues that it may undermine human rights and has implications for autonomy and informed decision making. As an example of these concerns, a formal policy statement issued in 2003 by Disabled Peoples' International demands a prohibition on compulsory genetic testing. The policy also demands prohibition of pressure on women to terminate pregnancies when their unborn children are considered likely to become disabled. As these organizations note, advances in genetic research and its applications may substantially alter the global diversity that disability offers human society.

CHALLENGES FOR THE FUTURE

To address economic, technological, social-political, and health dimensions of globalization simultaneously, a growing number of people with disabilities, professionals working in disability fields, and disabled people's organizations are developing a form of disability politics referred to as a *twin-track approach.* In such an approach, disability issues are included as a crosscutting theme in all poverty reduction work, rather than as a "special issue" or convention. At the same time, local issues particular to a specific culture, context, or disability group are attended to. For example, Bangladesh used a twin-track approach to improve the situation of people with leprosy. To overcome the stigma of leprosy, health education for the society as a whole was coupled with socioeconomic rehabilitation of people with leprosy. This approach makes the assumption that removing prejudice (through education) facilitates early detection and prevention.

Another example of a twin-track approach is found in the work of disabled people's organizations in the Slovak Republic. The organizations collaborated to provide community-based services for persons with disabilities at the same time they created a database on the health care needs of disabled persons and undertook intensive education of the Parliamentary Commission for Health and Social Affairs. This twin-track approach assumes that rights in and of themselves do not equal or produce justice. In other words, social justice requires economic justice, and political democracy requires economic democracy.

The small but growing number of disability scholars and those working in disability professions who advocate the twin-track approach point us in a promising direction for the future. First, in terms of legal/policy issues, the choice may not be between a social welfare state and market economies, but a hybrid of what has been termed a *radical democratic socialism*. In this hybrid one type of politics can facilitate the other. Second, some disability advocates and scholars recommend that all of us who are concerned about global disability issues, as a collective, develop a "politics of hope." The critical task of such a politics of hope would be to develop not only universal human rights laws and conventions but also context-specific tactics or strategies for their implementation. Further, hope involves the recognition of the unacceptable nature of certain negative conditions and relations of globalization, coupled with a desire for change and the conviction that change is possible.

Because of the complex interactions among dimensions and processes of globalization, what is desperately needed is concerted action to bridge the economic, digital, and other divides between people with disabilities in different regions of the world. Ultimately, the advancement of people with disabilities in the twenty-first century and beyond requires a globalized agenda for action that addresses universal rights but at the same time is sensitive to particular historical, political, cultural, and economic conditions.

—Susan J. Peters

See also Advocacy, International; Economic and Social Development, International; Employment, International.

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GODDARD, HENRY HERBERT (1866–1957)

American psychologist and educator

Henry Herbert Goddard was born in Vassalboro, Maine, and graduated from Haverford College in 1887. In 1899, he finished a Ph.D. from Clark University under G. Stanley Hall. In 1906, he became the director of the Vineland (New Jersey) Training School for the Feeble-Minded. Eventually receiving funding from the wealthy soap manufacturer Samuel Fels, Goddard carried out research and writing at Vineland that would gain him national notoriety. Between 1908 and 1910, he introduced an American version of the Binet and Simon intelligence test. At the 1910 annual meeting of the American Association for the Study of the Feeble-Minded, he coined the term *moron* to identify so-called high-grade imbeciles. In addition to intelligence testing and classification, Goddard's interests included eugenics. In regular communications with America's leading eugenicists, Goddard's writings reflected the linkage of intelligence, "feeblemindedness," criminality, and heredity—all prominent aspects of what Goddard (and others) called the "menace of the feebleminded." Among his writings are *The Kallikak Family: A Study in the Heredity of Feeble-Mindedness* (1912) and *Feeble-Mindedness: Its Causes and Consequences* (1914). In 1918, Goddard assumed the leadership of the Ohio State Bureau of Juvenile Research, and from 1922 to 1938 he was professor of psychology at the Ohio State University.

The definitive biography of Goddard is Leila Zenderland's *Measuring Minds: Henry Herbert Goddard and the Origins of American Intelligence Testing* (1998).

—*James W. Trent*

See also Developmental Disabilities; Eugenics; Mental Retardation, History of.

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GOETHE, JOHANN WOLFGANG VON (1749–1832)

German poet, playwright, and novelist

Johann Wolfgang von Goethe was born on August 28, 1749, in Frankfurt am Main, Germany, and died on March 22, 1832, in Weimar. He was the central figure of the classical period of German literature and was knighted in 1782. He wanted to study philology and history, but as an obedient son he followed his father's orders and studied jurisprudence in Leipzig and Strasbourg. Beginning in 1771, Goethe practiced law in Frankfurt. His first historical drama *Götz von Berlichingen mit der eisernen Hand (Götz von Berlichingen with the Iron Hand)* was published in 1773. A year later he published the epistolary novel *Die Leiden des jungen Werthers (The Sufferings of Young Werther),* which was enthusiastically received and made him famous. In 1775, Goethe moved to Weimar at the invitation of Duke Carl August. There, in 1779, he became the head of the highest finance authority. Between 1786 and 1788, Goethe made the famous trip to Italy that accounted for his transformation to writing classical epics. In 1788, he met fellow author Friedrich Schiller (1759–1805) and, despite their different perspectives, these two important representatives of the classical period of German literature developed a productive creative friendship. Goethe's long-term relationship with Christiane Vulpius (1765–1816), a member of the working class with whom he had a son (August, 1789–1830), created a scandal in the distinguished and aristocratic city of Weimar. By this time, Goethe had completed his major body of literature, and therefore important works such as *Wilhelm Meister's Lehrjahre (Wilhelm Meister's Apprenticeship), Faust I,* and *Die Wahlverwandtschaften (Elective Affinities)* had already appeared when he published his scientific study *Farbenlehre (Color Theory)* in 1810. Goethe considered this study his principal work; however, this claim met with much disapproval.

Goethe's contemporaries described him as a disciplined, stately man, although they often deplored his crooked teeth; he was, however, often ill. For example, he suffered a heavy hemorrhage due to tuberculosis as a student. He also had chronic kidney disease as well as facial neurosis, and in 1823 he suffered his first cardiac infarction. Sometimes people speak of Goethe's "healthy depression." He himself argued that misfortunes and sufferings form human beings. In his comprehensive, collection of 400 poems, *West-östlicher Divan (West-Eastern Divan)*, from 1819, he states:

> Wenn der schwer Gedrückte klagt:
> Hilfe, Hoffnung sei versagt,
> Bleibet heilsam fort und fort
> Immer noch ein freundlich Wort.
>
> [Should the one oppressed bewail:
> That both help and hope must fail,
> Remedy that's still preferred
> Is an ever-friendly word.]
>
> From "Hikmet Nameh: Buch der Sprüche"
> ["Hikmet Nameh: Book of Proverbs"]

—*Christian Mürner*

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GRAMSCI, ANTONIO

(1891–1937)

Italian politician and theorist

Antonio Gramsci was a revolutionary from a poor Sardinian family who cofounded the Italian Communist Party in 1921 and inspired the Eurocommunist movement after 1945. His writings stress civil society, culture, praxis, and the struggle for intellectual "hegemony"—by which ideas become accepted as "normality" or are challenged.

Gramsci had a spinal deformity and never grew to average stature. As a child, he was strapped into a harness and suspended from the roof of a barn to "straighten him out." His impairment excluded him from military service, hence he became prominent in the Italian workers' movement in 1917 after other leaders were either mobilized or arrested. Elected to Parliament, he gave speeches that commanded attention for their content, not their force.

In 1926, Gramsci was arrested by the Fascists. At his trial, the prosecutor said, "We must prevent this brain from functioning for twenty years" (quoted in Fiori 1970:24). Although imprisonment segregated him from politics and ruined his health, it did not stop him from producing seminal Marxist analyses of history and culture in the form of the *Prison Notebooks,* which were later smuggled out of his cell. Gramsci's idea of the "organic intellectual" who expresses and defines the will of a movement still has resonance within disability studies.

—*Tom Shakespeare*

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GREEK AMPUTEES AT PERSEPOLIS

See Amputees at Persepolis

GROUP THERAPY

The concept of group therapy covers a wide range of therapeutic (mainly verbal) activities in which people gather in professionally led groups to ameliorate suffering caused by psychological or somatic problems or difficult social circumstances. The field has multiple origins, and current theory and practice integrate material from different disciplines, including psychiatry, psychology, sociology, education, social work, and organizational theory.

Therapy groups have been used in medicine in a systematic way since the beginning of the twentieth century. Joseph Pratt, a Boston internist, is considered to be one of the pioneers, as he in 1905 gathered his tuberculosis patients in groups to teach them behavior and home-care measures he thought were crucial for the cure of their illness.

Therapy groups can be distinguished according to a number of different characteristics, including the following: They may make therapeutic use of the specific forces created by the group situation (dynamic, process-oriented groups) or they may use the group setting primarily as a time-saving device to deliver a message to several persons at the same time (didactic groups), they may be time limited or long-term, they may be closed or open for new members, and they may be homogeneous (e.g., only women, elders, or alcoholics) or heterogeneous (both sexes, different diagnoses, different ages). Group therapy may be the only treatment offered for a certain disorder, or it may be given in combination with other forms of treatment, such as medication or individual psychotherapy. It is also offered in many different settings, such as during hospitalization, in outpatient clinics, or in private practice. Most forms of group therapy involve a small group (6–10) of participants led by one or two therapists.

During the past few decades a wide array of self-help groups have appeared. These groups, which are based on principles of social support and mutual validation, may be very useful for patients and their families alike. Although such groups do not provide group therapy in a strict sense, they provide considerable benefit and reduce the amount of disability associated with chronic illness.

The goals of group therapy vary greatly and are related to the types of problems and levels of psychopathology of group participants (e.g., personality change, reduction in destructive drinking, improvement of social skills, learning to live with a chronic mental or somatic illness, or working through traumas). The effectiveness of group therapy for a wide range of different psychiatric/psychological disturbances has been documented through clinical experience and empirical research and can be summarized as follows: Group therapy is as effective as individual therapy for many conditions; group therapy based on cognitive behavioral theory may be most effective for specific disorders (e.g., social phobia), but for most disorders the empirical evidence for differential efficacy among various theoretical approaches (psychoanalytic, interpersonal, psychodrama) is not convincing. One reason for the current lack of clarity is that long-term (usually psychoanalytic) group therapy has been studied far less than short-term therapy.

—Steinar Lorentzen

See also Psychiatric Disorders; Psychology.

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GUGGENBÜHL, JOHAN JACOB (1816–1863)

German-Swiss physician

Johan Jacob Guggenbühl was, during his lifetime, one of the best-known men of science in Europe and America. In 1840, he opened a medico-pedagogical asylum for cretins on the Abendberg overlooking the village of Interlaken in the Bernese Alps of Switzerland. Combining an approach to education based on the senses, evangelical Protestant faith, and a spirit of experimentation in medical matters (dietetics, naturopathy, heliotherapy, electrotherapy), he was able to attract the support of physicians, educators, and philanthropists such as Father Grégoire Girard and Philippe-Emmanuel de Fellenberg. There were numerous visitors to the "holy mountain," fascinated as much by the beauties of nature as by the work of this "savior of the cretins" and as much by the professor's "system" as by the myth of the cretins' healing mountain.

The success met by Guggenbühl between 1840 and 1856, the date of the closure of "his" Abendberg, was equaled only by the doubts raised by this same success and the oblivion into which his pioneering work fell after his death in 1863. This neglect lasted until the rehabilitation of his reputation in 1905. Since that time, Guggenbühl has been recognized by history for the groundbreaker that he was: the founder of care for the mentally impaired in Switzerland, the precursor of medico-pedagogical treatment, and the pioneer of paedopsychiatry, even of sociotherapy.

—Henri-Jacques Stiker

See also Cretinism.

GUILLAIN-BARRÉ-STROHL SYNDROME

Guillain-Barré-Strohl syndrome (GBS) is the most commonly employed eponym for acute inflammatory demyelinating polyradiculoneuritis—inflammatory loss of the outer coating (myelin). It is termed *polyradiculoneuritis* because it tends to affect a large number and variety of nerve types. Peripheral nerves are all of the nerves that connect the central nervous system (brain and spinal cord) to the rest of the body. These nerves carry orders for motor movement or sensory information back to brain and spinal cord. They also send information back and forth to the brain and spinal cord that regulates the automatic functions of the body, such as muscle tone, balance, blood pressure, breathing, temperature regulation, reaction of pupils, bowel function, bladder function, and sexual function. Therefore, with the loss of myelin—and in severe cases the nerve fiber (axon) itself—these important functions may be disturbed or lost.

Occurring worldwide and in all seasons, GBS is the most common cause of acquired dysfunction of the peripheral nervous system, with 30,000 to 500,000 cases each year. It was not clinically recognized until Jean-Baptiste Landry of France gave the earliest systematic description in 1859 of the most common type, onset in the feet with ensuing ascending paralysis. Many decades later GBS was clearly set apart from poliomyelitis, a clinically similar condition. GBS, it would be discovered, is a disease of the peripheral nerves themselves and includes both motor and sensory dysfunction since both modalities are carried in peripheral nerves. It would also become clear that GBS tends to be symmetrical, to be more gradual in onset than poliomyelitis, and to have better recovery rates.

The names of Georges Guillain, Jean-Alexandre Barré, and André Strohl are commemorated in the name of the disease because their detailed description of it made the clinical distinction between GBS and poliomyelitis quite clear *and* because they described test findings that distinguished the two conditions. They found that protein concentration is elevated in spinal fluid in GBS as it is in polio, but that, unlike in polio, very few inflammatory white cells are found in the cerebrospinal fluid of GBS patients. This finding remains important in diagnosis of GBS to this day. The distinction of GBS from poliomyelitis was a very important contribution to the understanding of the hierarchical organization of the nervous system.

GBS is an acute autoimmune condition. A respiratory or gastrointestinal infection usually occurs days to weeks before the onset of GBS. This infection appears to cause the immune system to mount an attack against myelin by way of a protein target. One theory suggests that this occurs because of (a) the expression of a similar protein on the surface of that particular infecting organism and (b) the fact that the protein on the invading organism has been selected as the target of the immune response that is attempting to destroy the invading organism.

People who develop GBS may be more vulnerable to an autoimmune attack either because of the inheritance of an immunoregulatory weakness or because they have delayed development of an inherited protection against autoimmunity. A third possibility is that experiences such as early childhood infections help the immunoregulatory system to develop properly and that individuals without the right kinds of such experiences may be more vulnerable to autoimmunity. For unknown reasons, males are at greater risk for GBS than females. Stimuli other than infection may also provoke GBS; these include such things as immunizations, bee stings, pregnancy, malignancies, and even other kinds of autoimmune conditions, an important example of which is systemic lupus erythematosis.

In GBS, a complicated cascade of immune manifestations attacks patches of myelin along the course of these nerves and, by removing this important nerve covering (which is somewhat analogous to insulation), may severely disrupt transmission along the central part of the nerve, the axon (more closely analogous to an electrical wire). In the most common ascending form of GBS, this can cause loss of all motor and certain sensory functions, particularly those governing joint position sense, that are involved in finding one's way while walking in the dark. In severe cases of GBS, the axon itself may be injured by intense inflammation, the importance of which is that although the recovery from demyelination may be excellent, recovery from axonal injury often is not.

Weakness ascending from feet to higher locations is usually the earliest and most noticeable sign of GBS. Progression to maximal weakness generally takes less than four weeks, usually about 12 days, followed by a period termed the *plateau.* If disease ascends high enough in the trunk, it may imperil breathing. Tendon reflexes are usually lost. In addition to sensory loss, odd sensations called *paraesthesiae* develop in about 70 percent of cases. Unsteadiness develops in many cases, due to weakness and sensory abnormalities. There is usually no fever as GBS develops. Various automatic cardiovascular, gastrointestinal, urinary, sexual, sweating, and other functions are lost in 25 percent of cases, and in some these losses may not be recovered. Changes in blood pressure and heart rhythm are particularly serious and, together with loss of breathing, are the most important causes of death in GBS. Many patients experience mild to severe pain. Sophisticated electrophysiological tests that involve electrical stimulation of muscles are positive in 90–99 percent of GBS cases.

It is of the greatest importance that GBS patients be carefully monitored for the development of serious complications such as failure of breathing (20 percent of cases), swallowing, and blood pressure fluctuations. Skillful management must be provided to prevent serious consequences of such deficits. Even without such potentially dire events, support must be provided for other disabilities, including management of problems with bowel and bladder function and prevention, in bed-bound patients, of the development of bedsores. Emotional support is also quite important. The onset of recovery in GBS usually starts within two to four weeks of onset of the plateau. Most patients, particularly children, who have sufficient support recover well from GBS without other interventions. However, there are treatments aimed at correcting the autoimmune process itself. These include use of anti-inflammatory drugs and techniques to remove circulating immune complexes from plasma. Some of these appear to shorten the duration and perhaps the severity of the disease.

Recovery may be a long process during which carefully designed physical, occupational, and other therapies may be important and provision must be made for residual automatic functions, particularly bladder and bowel problems. Disappointingly, many patients whose recovery is otherwise excellent have residual urinary or sexual deficits. Once the individual is ambulating well, it still may require many months before a sense of fitness and loss of excessive fatigue are achieved. Individuals who have had significant axonal involvement recover even more slowly, although as many as half of these recover completely within a year. A small number of patients who are initially labeled GBS turn out to have a difficult-to-manage chronic and recurrent peripheral neuropathic condition termed *chronic inflammatory demyelinatig polyneuropathy.*

—Robert S. Rust Jr.

See also Polio.

▣ GUTTMANN, LUDWIG
(1899–1980)
German-English physician

Commonly known as "the founder of the Paralympic movement," Ludwig Guttmann was born in Upper Silesia, Germany, in 1899. He studied medicine and neurosurgery in Breslau and arrived in England as a refugee in 1939. As head of the Stoke Mandeville

Spinal Injuries Unit in Aylesbury from 1944 until 1966, he championed the concept of early treatment for injured servicemen in specialized spinal units and promoted the use of compulsory sport and physical activities as a form of rehabilitation, integration, and motivation.

Guttmann organized the first Stoke Mandeville Games for the Paralysed, held on July 28, 1948 (to coincide with the 1948 Olympic Games); that first event involved 16 competitors. The Games became international in 1952, and he founded the International Stoke Mandeville Games Federation (ISMGF), now the International Stoke Mandeville Wheelchair Sports Federation (ISMWSF). In 1960, the first Paralympic Summer Games were held in Rome following the Olympic Games, and the first Paralympic Winter Games followed in 1976.

Guttmann served as president of the International Sports Organization for the Disabled (ISOD) and as president of the International Medical Society of Paraplegia; he also founded the British Sports Association for the Disabled. Throughout his life, he worked to help integrate people with disabilities into society. Even after his retirement, he helped build facilities for athletes with disabilities. Among his many awards and honors, Guttmann was knighted in 1966.

—*Miriam Wilkens*

See also Sports and Disability.

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GUTZLAFF, AGNES

(CA. 1836–1869?)

Chinese missionary and educator

"Agnes Gutzlaff" was the name given by Carl and Mary Gutzlaff to one of several young blind Chinese girls, orphaned or abandoned, whom they adopted while in Macau in the 1830s. She was sent to London for formal education at the London Blind School, enrolling on January 3, 1842, at age five and a half. Agnes completed 13 years of education in London and shortly afterward returned to China as a missionary to teach blind people, almost certainly the earliest trained missionary with such a role. She joined Miss Aldersey at Ningpo in June 1856, learned the local language, and began teaching blind children and adults to read using materials first in Lucas's symbols and then in Moon's embossed script. After Miss Aldersey retired, Agnes moved to Shanghai, living and working there independently from 1862 until her death around 1869. "She worked hard, lived sparingly, and saved money, and at her death her property was left to found a hospital called by her name" (*Fortieth Report* 1878). The "Gutzlaff Hospital," in a back street of the English settlement in Shanghai, was a small, low-budget, general-purpose institution. It was later incorporated into St. Luke's Hospital.

—*Kumur B. Selim*

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[Letter from Agnes Gutzlaff, December 1858]. 1859. *Female Missionary Intelligencer* 2:96.

H

HANAWA, HOKIICHI (1746–1821)

Japanese bibliographer

Hokiichi Hanawa, the son of a humble farmer, lost his eyesight in early childhood. At age 13 or 14, he went to Edo (now Tokyo) and enrolled at a private school for blind youths, under Ametomi Kengyō. Hokiichi should have learned music and acupuncture, but it seems that he did not gain much proficiency in those skills. He succeeded in memorizing much Japanese classical literature under a famous teacher, Kamo no Mabuchi, who had just retired from active service. Later, Hokiichi became a notable professor of literature.

Hokiichi spent many years editing documents to compile the vast *Gunsho Ruijū* (*Classified Collection of Japanese Classics*) (1779–1819), in 530 volumes containing more than 1,200 books and documents. He was also obliged to raise funds over a long period to produce the collection from wooden printing blocks. Hokiichi is recognized as one of the founders of modern bibliographical work in Japan, setting high standards in a field that most people would have thought unsuitable for a blind person.

—Kumur B. Selim

See also Blind, History of the.

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HAND AND ARM MANIPULATION

Hand manipulation is the action of using the distal portion of the arm and involves skillful use of the hand and fingers on objects in the environment. It includes "dexterous grasp and release patterns, isolated finger movements, and coordinated in-hand manipulation patterns when interacting with task objects" (Fisher 2003:195). Hand manipulation is a skill that contributes to functional performance and enables an individual to perform activities of daily living.

Problems with hand manipulation may be observed as "difficulty manipulating task objects, limited dexterity or difficulty with in-hand manipulation" (Fisher 2003:195) and may cause disruption of task performance or result in inefficient use of time or increased effort. This may result in the individual adapting posture and position of the body in relation to the object being manipulated.

Hand and finger manipulation deficits can be managed by either improving the actual skill or by compensating for the impairment. Compensatory strategies might include the following:

> Change the demands of the task (e.g., restructuring the time spent on a task on any given instance).
>
> Modify the environment (e.g., the social environment can be modified so that another individual can perform those tasks that require manipulation).
>
> Use other parts of the body (e.g., using a mouth stick to type in the absence of adequate or lack of hand manipulation).

Provide adaptive equipment (e.g., splints and other orthotic devices, gadgets such as an electric can opener, and electronic equipment).

—*Supriya Sen and Kathy Preissner*

See also Assistive Technology.

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HANDICAP

The term *handicap* was used during the twentieth century to apply both to the impairments of individuals and to certain ways of evening the chances of success among contestants in sporting contests. With the rise of the disability rights movement in the past quarter of the century, the term's association with paternalistic attitudes toward disability has made *handicap* objectionable to many activists. Folk etymologies have grown up to explain why the term is offensive. It is often claimed that the original meaning of handicap referred to the fact that people with impairments could make a living only by begging, "cap in hand." This etymology is mistaken. The *Oxford English Dictionary*, the best etymological source on the English language, shows a much more interesting and complex history of the term.

Handicap originally referred to a sort of gambling game, practiced between the fourteenth and seventeenth centuries. One move in the game involved two contestants placing their hands in a cap and removing them at the same time, either open or closed (hence "hand in cap"). The game involved estimating the difference in value between two items. Some value (called the "boot" or "odds") was added to one item to make it equal in value to the other. During the seventeenth century, the technique of equaling the values of two items by addition of a boot was adopted in horse racing. A "handicap race" is one in which the faster horse carries extra weight. The game of golf adopted a system in which less skilled golfers were allowed to deduct strokes from their score, to be competitive with more skilled opponents. In horse racing and the gambling game, the term *handicap* referred to the game itself, not to the factor (the boot) that evened its outcomes. In golf, the handicap is a benefit for the less skilled, not a penalty on the more skilled.

In the late nineteenth century, the term came to be applied to disadvantages themselves, though not yet to impairments. The first recorded use with respect to impairments was in a 1915 poster labeled "the Handicapped Child."

Impairments were commonly called handicaps during the twentieth century, but the older sporting uses continued. In 1980, the World Health Organization (WHO) introduced another new definition according to which *handicap* referred not to an impairment itself but to the disadvantages that resulted from social discrimination against people with impairments. But by this time the term was distasteful to many. *Handicap* was offensive by association. The folk etymologies about "cap in hand" begging are mistaken, but they reflect a very real distrust of traditional attitudes toward disability.

Unfortunately, the loss of the term *handicap* creates a semantic vacuum in the American vocabulary of disability politics. British activists (unlike Americans) use the term *disability* to refer to what the WHO called *handicap:* the disadvantages caused by discriminatory treatment of people with impairments. They distinguish between impairments (biological conditions) and disability or disablement (the consequences of social arrangements). Americans use the term *disability* as a synonym of *impairment.* How do Americans refer to the social disadvantages? The 1980 WHO vocabulary had distinguished disability from handicap, the same distinction as the British but with different terminology. But because the term *handicap* was rejected as offensive, both in Britain and the United States, Americans are left without a simple term to designate the disadvantages that social arrangements create for people with impairments.

—*Ron Amundson*

See also *Cripple*; Impairment; International Classification of Functioning, Disability, and Health.

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HANDICAP INTERNATIONAL

Handicap International is an international nongovernmental solidarity organization, founded in 1982 in Lyon, France. The French section is at the origin of an international movement, with sections now existing in Belgium, Switzerland, Germany, Luxemburg, and the United Kingdom and representations in Denmark and the United States. Its goal is to ensure that people with a disability are able to regain their independence and their place in society, particularly in countries with difficult living conditions. The Blue Laces® are the symbol of this. The organization is active in various areas associated with all the causes of handicaps, both traumatological (e.g., land mines, road accidents) and infectious (e.g., polio, leprosy). Handicap International works especially in countries that are experiencing an acute or chronic crisis situation. Its activities are systematically based on a three-part approach: prevention, rehabilitation, and socioeconomic reintegration.

> *Prevention:* Preventing handicaps, for example, by mine clearance and removal of unexploded ordnance, road safety campaigns, and prevention of injuries caused by disabling diseases such as leprosy and polio
>
> *Rehabilitation:* Setting up centers for physical rehabilitation and rehabilitation and offering the required technical aids, physiotherapy, and rehabilitation programs
>
> *Reintegration:* Facilitating the reintegration of people with a handicap into their social environment by offering education and vocational training in a targeted way, promoting social reintegration, and improving the rights of people with a handicap

Handicap International works with local partners and government bodies within a contractual framework and helps them to take over the project after a specific period of time. Seventy percent of financial resources come from institutional funds and 30 percent from private donations.

Its activities began in 1982 when the first orthopedic centers opened in refugee camps in Cambodia, Thailand, Myanmar (formerly Burma), and Laos to help several thousand amputees. The use of simple and locally available materials is one of the major strengths that allows Handicap International to bring quick and efficient help and to train competent local teams. By 1986, the organization realized that providing artificial limbs is not enough, and consequently, it moved toward a more global approach to disability by creating networks of local educational workers and strengthening family and community groups.

By the beginning of the 1990s, the disability issue became enlarged to include people in situations of exclusion and vulnerability. Actions to prevent disability were undertaken. Handicap International started working on mental disability issues as a result of experiences with Romanian orphanages and the war in the Balkans. In 1992, the organization created its first two mine clearance programs in Cambodia and Kurdistan and took part in the creation of the international campaign to ban land mines.

The period 1993–1995 was characterized by the development of partnerships, both locally and internationally. National orthopedic and physiotherapy centers opened in various countries. Training leading to a degree was set up in Cambodia, Mozambique, and West Africa. Between 1996 and 2002, Handicap International took part in the development of national policies in favor of disabled people. In 1996, the organization received the Nansen Prize, the highest prize given by the UN High Commissioner for Refugees. A high point in its organizational history, the organization was the joint winner of the 1997 Nobel Peace Price for its leading role in the fight against land mines.

—Patrick Devlieger

See also Developing World; International Disability Organizations.

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Handicap International, http://www.handicap-international.org/english

HANSELMANN, HEINRICH

(1885–1960)

Swiss educator and author

The Swiss special education pedagogue Heinrich Hanselmann was born in Wald bei St. Peterszell

(St. Gallen). Hanselmann was based out of Zurich. There, he was a cofounder of the Heilpädagogische Seminar (Special Education Seminar) and took over the direction of this special education training center in 1924. At the same time, Hanselmann and his wife, Annie (née Heufemann), founded and ran the appropriately named Landerziehungsheim für Schwererziehbare und Entwicklungsgehemmte (State Home for the Education of the Learning and Developmentally Disabled) in Albisbrunn bei Hausen am Albis (Zurich). In 1930, a year after he published his chief work, *Einführung in die Heilpädagogik* (*Introduction to Special Education*), Hanselmann was promoted to Extraordinary Professor of Special Education at the University of Zurich. He held this position, which was the first of its kind in Europe, until 1950. He died in 1960 in Locarno (Ticino).

The concepts of special education or special education pedagogy and *inhibited development* (as a synonym for *disability*) go back to Hanselmann, concepts that are still customary to use in German special education theory. In addition, he stressed that we should consider the question "Who is normal?" before we can occupy ourselves with the objectives and goals of special education. Special education has to focus on the whole person. For example, it is wrong to describe visually or hearing-impaired people as "so-called normal, albeit without the visual or auditory senses."

Hanselmann tried to popularize his views on special education. He supervised a private office for educational and marriage counseling and wrote columns in popular magazines, despite the fact that such behavior irritated many of his professional colleagues. Hanselmann saw himself as an educator of the people, following the tradition of Johann Heinrich Pestalozzi (1746–1827). His writings were accessible to most readers and were therefore widely disseminated. They carried such titles as *Sorgenkinder, daheim und in der Schule* (*Problem Children, at Home and in School*) (1934) and *Vom Sinn des Leidens* (*Making Sense of Suffering*) (1934). Through such disciplinary transgressive actions, Hanselmann hoped to be able to abolish the "Inselhaftigkeit der Heilpädagogik" ("solitariness of special education"), which he criticized.

—*Christian Mürner*

See also Heinrich Marianus Deinhardt; Special Education.

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HATHAWAY, KATHARINE BUTLER (1890–1942)

American author

Katharine Butler Hathaway was born in Baltimore, Maryland. At the age of five, she contracted tuberculosis of the spine. To prevent the infection from causing any deformities, Hathaway spent the next 10 years of her life strapped to a stretcher. After being liberated at the age of 15 feeling that her incarceration was completely in vain due to a residual curvature, Hathaway and most of her family fell under the assumption that her deformity and resultant impairments would prevent her from ever gaining a "normal" life (i.e., getting married and having children). Yet, despite the unavoidable internalizations of societal stereotypes regarding disabled people, Hathaway's journeys as a single, disabled young woman proved a hidden benefit, which allowed her to throw herself into her creative writing and artistic endeavors.

The Little Locksmith: A Memoir, first published in 1943, reflects the internal conflicts of being a disabled woman. Struggling with her body's difference, Hathaway nevertheless feels blessed that it has granted her an independence few of her contemporary able-bodied women were allowed. Having lived during the height of the eugenics movement in the United States, Hathaway's memoir reflects her unease at being a disabled person when people with disabilities were so disposable. Yet she recognizes that her society tends to be very ignorant with respect to the lives of disabled people. Throughout *The Little Locksmith,* Hathaway is continually revising the assumptions surrounding disability, sexuality, and gender, allowing the memoir to become a mode of resistance and social redress with respect to disability. By presenting her “counterstory,” she helped to challenge the power of eugenic master narratives and the subsequent demise of the disabled body.

—Sara Vogt

See also Feminism; Sexuality.

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HAÜY, VALENTIN (1745–1822)

French pedagogue

Valentin Haüy devoted his life to the education of the blind and created the first school for the blind in Paris, which served as a model for the entire world.

The brother of the founder of crystallography, Valentin Haüy perfected a system of raised letters (and not dots, as in Braille). From his concern that the blind not be reduced to begging, in 1784 he opened, at his own expense, the first free school in Paris for blind young boys and girls. With the support of the Philanthropic Society, this school became the Institution for Blind Children. It was nationalized during the French Revolution, and in 1791, by the decree of the Constituent Assembly, became the National Institute for Blind Young People (INJA, Institut National des Jeunes Aveugles).

An important member of the Arsenal section during the Revolution, he was one of the leaders of the theophilanthropic movement under the Directory. This was a cult of natural religion devoted to “bringing hearts together by preaching mutual indulgence and forgiveness of all wrongs.” Disagreeing with the trends taken by the Institution, which was progressively losing its educational character to the detriment of professional activity, he preferred leaving his post in 1802. Soon afterwards, he left Paris to devote himself to the education of the blind and deaf-mute at the request of the Russian czar. He lived in Russia from 1806 to 1817. When passing through Berlin in 1806, he inspired the creation of the Berlin School for the Blind and founded a similar school in Saint Petersburg in 1808.

—Jean-François Ravaud

See also Blind, History of the; Denis Diderot; History of Disability: Early Modern West.

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HAY, WILLIAM (1695–1755)

English author

William Hay, author and member of the House of Commons as a loyal Whig from 1734 until his death, was arguably the first person in the history of English letters to claim disability as an identity in print. Attacked by smallpox as a young man, which left him both visually impaired and visibly scarred, a hunchback barely five feet high, Hay nevertheless insisted on accurate portraiture. His complete works contain a variety of political, religious, and belle-lettristic pieces, most important, “Deformity, An Essay” (1754), written in response to Francis Bacon’s influential “Of Deformity.” Fusing the scientific impulse to objectify “nature” with the premodern belief in disability as mark of divine punishment, Bacon argued that deformed persons, marked by nature, and “void of Natural affection, are “commonly even with nature” by acts of antisocial “revenge.” Removing deformity from the register of variable interpretation to that of scientific hypothesis, Bacon concluded, “It is good to consider of Deformity, not as a Sign, which is more Deceivable; But as a Cause, which seldom faileth of the Effect.” Hay contests Bacon’s theory by joining an alternative essayistic tradition of self-exposure practiced by his professed models, Michel de Montaigne and Alexander Pope, interpreting his deformity as a source of ineffable subjectivity and exemplary self-knowledge.

Balancing Christian stoicism with gentlemanly civility, he begins with a desire to "lay open my own Heart to the Reader" and concludes with the demand that his body be autopsied after death, "so that Mankind may be informed" of the effect of ingesting castile soap on bouts of the stone (kidney stone). Hay's deformity is a sign at the crossroads of literature and science; the ultimate evidence of his humanity is the clinical exposure of his body's interior in proof of a common disease.

—Helen Deutsch

See also Deformity; Alexander Pope.

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HEALTH

The concept of health is the most central concept in medicine and in the health sciences in general. Health is, indeed, the foremost goal of medicine (Pellegrino and Thomasma 1981; Callahan and Hanson 1999). Health also has a prominent position in many life contexts and is a crucial condition for maintaining and executing a profession, for enjoying leisure activities, and indeed, for living a good life in general. For example, health is a formal prerequisite for performing certain tasks or taking up certain occupations, such as that of soldier, police officer, or firefighter. More compelling is the place of mental health as a condition for moral and criminal culpability.

It is significant that, in modern secular society, health has gained an extremely high position in many people's value hierarchies. A Swedish group of researchers (Kallenberg, Bråkenhielm, and Larsson 1997) asked a representative sample of Swedes what are the highest values in their lives. A vast majority of these people put health at the top of their lists, which also contained such values as wealth, high social status, and good family relations. This social judgment can be contrasted with the ancient Platonian more restricted evaluation of health. According to Plato, it is an unsound condition in a society when people concentrate on their health and want to consult a physician anytime and about any question (*The Republic*).

Etymologically, health is connected with the idea of wholeness. This is evident in the verb *heal*, with the sense of regaining wholeness. The healthy person is a person who is whole in the sense of having all the properties that should pertain to a human being. Health has thus traditionally been viewed as an ideal notion, a notion of perfection that very few people, if any, can completely attain. Today, health also sometimes functions as an ideal notion. This is, indeed, the case with the formulation of health by the World Health Organization (WHO) in its initial declaration, published in 1948: "Health is a state of complete physical, mental and social well-being and not only the absence of disease or injury."

The notion of health is the object of scientific study from several points of view and within several disciplines. Besides research by those in medicine, public health, nursing, and other paramedical disciplines, other investigations are based in anthropology, psychology, sociology, and philosophy. In some of these disciplines, the focus is on a particular aspect of the notion: for example, in psychology, the experience of health and illness, and in anthropology and sociology, health and illness as factors of social importance. Philosophical analyses of health have often involved an attempt to formulate global definitions of the idea. Thus, in the following, many references will be taken from philosophical theories of health.

THE VARIETIES OF HEALTH

Health, thus, is a notion primarily applicable to a human being as a whole. On the other hand, there are more specific derivative notions. Ever since antiquity, and reinforced by the Cartesian distinction between body and mind, it has been natural to separate somatic health from mental health. The interpretations of mental health have varied over time. The ancient notion of mental health was closely connected to morality, whereby the mentally healthy person was a person who lived a virtuous life, but this idea has lost most, though not all, of its significance today. The idea of spiritual health is also current in the health sciences although it is not systematically recognized. Bernhard Häring (1987:154) is a leading spokesman for a notion of health including a spiritual dimension: “A comprehensive understanding of human health includes the greatest possible harmony of all of man’s forces and energies, the greatest possible spiritualization of man’s bodily aspect and the finest embodiment of the spiritual.”

The various categories of health have connections to each other. Sometimes bodily health has been given priority in the sense that it has been viewed as a prerequisite for mental health. Galen (AD 129–ca. 199/216) in some of his writings attempted to explain mental properties of the person in terms of specific mixtures of the bodily parts (Galen 1997). Consider also the ancient proverb: *mens sana in corpore sano* (a healthy mind in a healthy body). In the modern discussion about mental illness, one position, favored in particular by medical doctors, is that all mental illness has a somatic background, that is, all mental illnesses—if they exist at all—are basically somatic diseases (Szasz 1974). The customary view, however, also in Western medicine, is that a person can at the same time be somatically healthy and mentally ill, or vice versa.

HEALTH AS ABSENCE OF DISEASE

Although health is often described in nonmedical terms and with reference to nonmedical contexts, it has its primary place and function as a medical concept. Health in the medical arena is contrasted in particular with disease, but also with injury, defect, and disability. Culver and Gert (1982) have coined the term *malady* to cover the negative antipodes of health. In many medical contexts (Hesslow 1993), and in some philosophical reconstructions of the notion of health (Boorse 1977, 1997), health has been defined as the absence of diseases or the absence of maladies. The perfectly healthy person therefore is the person who does not have any diseases or maladies.

If one looks at the relationship between the concepts in this way, the burden of definition lies on the negative notions. Christopher Boorse (1997), for instance, defined disease in the following terms: “A disease is a type of internal state which is either an impairment of normal functional ability, i.e. a reduction of one or more functional abilities below typical efficiency, or a limitation on functional ability caused by environmental agents.” The notion of functional ability, in this theory, is in turn related to the person’s survival and reproduction, namely, his or her fitness. From this analysis follows that we need not use the notion of disease to define health. The same idea can be formulated in the following positive terms: A person is completely healthy if, and only if, all his or her organs function with at least typical efficiency (in relation to survival and reproduction).

This idea of natural function is similar to, but not identical with, the one proposed by Jerome Wakefield (1992 and later), where the platform for analysis is biological evolutionary theory. The natural function F of an organ is, according to this idea, the function for which it has been designed through evolution. This means that the species in question (e.g., the human being) has been able to reproduce through history with the genetic setup for the function F. This idea has been criticized partly because it relates the idea of health in the present context to developments in the past.

HEALTH, DISEASE, AND ILLNESS

In many contributions to the theory of health, a distinction is made between the concepts of disease and illness (Boorse 1975; Twaddle 1979; Fulford 1989). The general idea behind this distinction—although it has been made in different ways by different authors—is that a disease is a deranged process in the person’s body, whereas an illness is the person’s negative experiences, for instance, pain or anguish, as a result of the disease. In addition, some theories include disability in illness; see below. The distinction between disease and illness has proved useful in several contexts, including the clinical one (Hellström 1993), for separating the disease as a pathological phenomenon from its impact on the person as a whole. (For a criticism of the distinction between disease and illness, see Sundström 1987.)

HEALTH AS BALANCE

An extremely powerful idea in the history of medicine is the one that health is constituted by bodily and mental balance. The healthy person is a person in balance, normally meaning that different parts and different functions of the human body and mind interlock harmoniously and keep each other in check. The Hippocratic (428–347 BCE) and Galenic schools were the first Western schools to develop this idea in a sophisticated way. They stated that a healthy body is one where the primary properties (wet, dry, cold, hot) of the body balance each other. In the medieval schools, following Galen, this idea was popularized and formulated in terms of a balance between the four bodily humors: blood, phlegm, yellow bile, and black bile (cf. humoral pathology).

The idea of balance is strong in several non-Western medical traditions. The *yahurveda* tradition in India, for instance, declares that there are three humors acting in the body, the breath (*vata*), the bile (*pitta*), and the phlegm (*kapha*). The proportions of the three humors vary from person to person, and their actions vary according to the season, the environment, the lifestyle of the individual, and his or her diet. In good health, the humors are in equilibrium. Disease is the result of their imbalance (Singhal and Patterson 1993).

Balance is a powerful idea also in modern Western thought, in particular, within physiology. The idea is often recognized under the label of *homeostasis* (the Greek word for balance). Walter Cannon's (1871–1945) classical work on homeostasis (1932) described in detail how the various physiological functions of the body control each other and interact in feedback loops to prevent major disturbances.

The idea of balance or *equilibrium* (the Latin word for balance) has a rather different interpretation in the writings of Ingmar Pörn (1993). Here balance is a concept pertaining to the relationship between a person's abilities and his or her goals. The healthy person, according to Pörn, is the person who can realize his or her goals and thus retain a balance between abilities and goals (cf. health as ability, below).

HEALTH AS WELL-BEING

It is an important aspect of health that the body and mind are well, both in order and function. But we may ask for the criteria of such well-functioning. How do we know that the body and mind function well? When is the body in balance?

A traditional answer is that the person's subjective well-being is the ultimate criterion (Canguilhem 1978). Simply put, when a person feels well, then he or she is healthy. This statement certainly entails problems, since a person can feel well and still have a serious disease in its initial stage. The general idea can, however, be modified to cover this case too. The individual with a serious disease will sooner or later have negative experiences such as pain, fatigue, or anguish. Thus, the ultimate criterion of a person's health is his or her present or future well-being. (For a different approach suggesting that complete health is compatible with the existence of disease, see Nordenfelt 1995 and 2000.)

It is a difficult task to characterize the well-being constituting health. If one includes too much in the concept, there is a risk of identifying health with happiness. It is, indeed, a common accusation directed against the WHO definition that it falls into this trap. Health cannot reasonably be identical with complete physical, mental, and social well-being, many critics say. The absurd conclusion of this conception could be that all people who are not completely successful in life would be deemed unhealthy.

Some authors (Gadamer 1993; Leder 1990) have pointed out that phenomenological health (or health as experienced) tends to remain as a forgotten background. Health is in daily life hardly recognized at all by its subjects. People are reminded of their previous health first when it is being disrupted, when they experience the pain, nausea, or anguish of illness. Health is "felt" only under special circumstances, the major instance being after periods of illness when the person experiences relief in contrast to the previous suffering.

Thus, although well-being or absence of ill-being is an important trait in health, most modern positive characterizations of health have focused on other traits. One such trait is health as a condition for action, that is, ability.

HEALTH AS ABILITY

A number of authors in modern philosophy of health have emphasized the place of health as a foundation for achievement (Parsons 1972; Whitbeck 1981; Seedhouse 1986; Nordenfelt 1995; Fulford 1989). In fact, they argue, in partly different ways, that the dimension of ability/disability is the core dimension determining whether health or ill health is the case. A healthy person has the ability to do what he or she needs to do, and the unhealthy person is prevented from performing one or more of these actions. There is a connection between this conception and the one that illness entails suffering. Disability is often the result of feelings such as pain, fatigue, or nausea.

The formidable task for these theorists is to characterize the set of actions that a healthy person should be able to perform. Parsons (1972) and Whitbeck (1981) refer to the person's wants, that is, the healthy person's being able to do what he or she wants, Seedhouse (1986) to the person's conscious choices, and Fulford (1989) to such actions as could be classified as "ordinary doings." Nordenfelt settles for what he calls the person's vital goals. These goals need not be consciously chosen (babies and people with dementia have vital goals). The goals have the status as vital goals because they are states of being that are necessary conditions for the person's happiness in the long run. Health in Nordenfelt's theory is thus conceptually related to, but not identical with, happiness.

Although it is evident that health, as ordinarily understood, is connected with ability and ill health with disability, one may still doubt whether the dimension of ability/disability can remain the sole criterion of health/ill health. An important argument concerns those disabled people who are not ill, according to common understanding, and who do not consider themselves to be ill. These people are to be classified as unhealthy according to the ability theories of health.

One answer to this question (Nordenfelt 2001) is that disabled people (given that their disability is assessed in relation to their individual vital goals) are all unhealthy. However, they are not all ill and they do not all have diseases. Another answer, proposed by Fredrik Svenaeus (2000), is that there is a phenomenological difference between the disabled unhealthy person and the disabled healthy person. The unhealthy person has a feeling of not being "at home" with regard to his or her present state of body or mind. This feeling is not present in the case of the disabled in general.

HEALTH AND VALUE: NATURALISTS AND NORMATIVISTS

A crucial theoretical problem in the characterization of health is whether this notion is a scientific one. One can ask whether health and its opposites can be given a neutral, rather than value-laden, description, or whether it follows by necessity that health is to be characterized as a "good" bodily or mental state. Proponents of the former view are often called naturalists, whereas proponents of the latter view are often called normativists.

Different theorists have arrived at different conclusions with respect to this issue. Boorse (1977, 1997) claimed that there is a value-neutral definition of the basic notion of disease. Donald Broom (1993), who analyzed the notions of animal health and welfare, came to the same conclusion. Wakefield (1992) argued for the thesis that the notion of disease has two parts, one of which is value neutral, namely, the one that refers to the natural function of organs. The other part of the concept refers to the value-laden notion of harm. Most other theorists, however, think that the notion of health and its opposites are with necessity value laden. Some argue that these values are universal (Pellegrino and Thomasma 1981), others that the values determining the concepts of health and illness are connected to the background cultures (Engelhardt 1996). The physician/philosopher Georges Canguilhem (1978), who wrote one of the most significant treatises of human health and illness of the twentieth century, though he drew almost exclusively on medical data, came to the conclusion that health is an evaluative concept in a strong sense. The healthy organism, says Canguilhem, is not an organism whose functions are normal in a statistical sense. The healthy organism is one that is "normative," that is, one that is capable of adopting new norms in life.

One can discern further differences in the contention that the notion of health is value laden. Some theorists (e.g., Khushf 2001) claim that the notion is value laden in the strong sense that its descriptive content can vary over time. As a result of this, the only element common to an ancient and a modern concept of health is that health is a "good" state of a person's body or mind. Others, like the ability theorists above, would claim that there is a common descriptive content, namely, the fact that health has to do with a person's abilities but that one needs to make an evaluation in order to specify what aspect or level of ability is required for health.

HEALTH AND CULTURE RELATIVISM

If health is a value-laden concept, then, as we have seen, some would argue that there are differences in the interpretation of health between cultures both historically and geographically. It is important to note that these differences can be more or less profound.

The concepts of health can vary from culture to culture because there are fundamental differences in the basic philosophy of health and health care, as between Western medicine and traditional Chinese medicine or the traditional Indian ayurveda medicine. Western medicine, which is to a great extent based on a naturalistic philosophy of people, arrives easily at a naturalistic understanding of health, whereas oriental schools with a holistic understanding of people in a religious context derive a notion of health that incorporates forces and developments that are partly supernatural.

The ways of and reasons for ascribing health to people may, however, vary even if there is a basic common theory of health and disease. Consider a particular physiological state, the state of lactase deficiency, which has the status of disease in a Western country but not in most North African countries. Lactase deficiency causes, in combination with ordinary consumption of milk, diarrhea and abdominal pain. Thus, in Western countries where people ordinarily drink milk, lactase deficiency will typically lead to illness. Therefore, this state ought to be included in a list of diseases in these countries. In North Africa, however, people rarely drink milk. Therefore, lactase deficiency seldom leads to illness. Consequently, it would be misleading to consider lactase deficiency a disease in this part of the world.

What makes the difference between the Western and the African cultures in this example is not different concepts of health and disease. It is a question of different lifestyles and different environments.

HEALTH AND ILLNESS AS GENDER DEPENDENT

Some theorists contend that the way we define and in general look at health and health care is dependent on our gender (Oakley 1993). This difference is well reflected in the traditional health professions. The traditional doctor is a man who is basically concerned with the physical condition of his patients. He sees his primary task as being to cure the diseases of the patient by use of well-established treatments often in the form of surgery and drugs. The traditional nurse is a woman who is basically concerned with the general well-being of the patient. She sees her primary task as being to care for the person as a whole. Caring, for her, means above all "relating to the ill person as a whole person whose psyche is equally involved with her or his soma in the illness in question" (Oakley 1993:40).

HUMAN BEINGS VERSUS ANIMALS AND PLANTS

Health, disease, and the other central medical concepts are not used only in the human context. We ordinarily ascribe health and disease also to animals and plants. Do we then apply the same concept of health?

In this case, the answers differ. The naturalists, who relate health solely to survival and reproduction, can easily transpose their concept to the world of animals and plants. The same could hold for balance theorists. It is more problematic to use the idea of health as ability or, even more, the idea of health as well-being all over the world of animals and plants. This can serve as an argument in favor of the naturalistic account. On the other hand, it can be argued that there is an enormous difference between the human context and the context of other living entities. Human beings live in complex societies with complex demands and with a system of health care that is supposed to serve the demands. It is no wonder that the concept of human health has evolved in directions quite different from the concepts of health concerning animals and plants.

WORLD HEALTH ORGANIZATION CLASSIFICATION

The WHO has issued roughly every 10 years a version of the International Classification of Diseases, Injuries, and Causes of Death (ICD) (the latest version from 1992 having the changed title "International

Classification of Diseases and Related Conditions"). The purpose of this classification is to provide an international taxonomy and nomenclature for the whole range of diseases and injuries. In the present version, there are 17 classes of diseases and injuries. In addition to this, there is a special heading for external causes of injury and poisoning. This classification plays an important role in medical statistics, in particular the statistics of causes of death.

The ICD fails, however, to reflect the full range of problems that lead people to seek medical help. It stops short at the consequences of disease, such as disabilities and handicaps. The latter are factors that intrude on everyday life and are directly observable by the bearer himself or herself. To fulfill the need for a theory and classification of consequences of disease, the WHO issued a tentative proposal for such a classification in 1980. This was the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), renewed and finally accepted in 1993.

This classification is firmly placed in a health context. The key phenomena classified, impairments, disabilities, and handicaps, are viewed as typical consequences of diseases. This is clearly seen in the definition of the concepts. Disability, for instance, is defined in the following way: "In the context of health experience, a disability is any restriction or lack . . . of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO 1980:28).

As a result of extensive testing and investigation, the ICIDH was finally (in 2001) replaced by a completely new taxonomy. This is the recently adopted International Classification of Functioning, Disability, and Health (ICF). Here the notion of health and its negative counterparts play a different and somewhat diminished role. Health is mentioned as a relevant category, and the ICF proposes definitions for concepts such as health states, health domains, and health conditions. However, since the classification is intended for several uses outside health care, the notions of health and ill health do not play a crucial role in the construction of the classification.

—Lennart Nordenfelt

See also Georges Canguilhem; Galen; Health Promotion; Hippocrates; International Classification of Functioning, Disability, and Health (ICF/ICIDH).

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HEALTH CARE AND DISABILITY

The highest objectives of health care systems throughout the world can be framed within the context of the World Health Organization's (WHO) definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." The WHO Constitution (2004) further states that "enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being" and that "extension to all peoples of the benefits of medical, psychological and related knowledge is essential to the fullest attainment of health."

In addition to the obvious barriers created by issues of loss of mobility and communication deficits, research has established that individuals with disabilities have finance-related problems with access to health care. People with disabilities are more likely to put off or postpone medical care because they cannot afford it (28 vs. 12 percent in a recent U.S. survey). The same survey determined that persons with severe disabilities are almost four times more likely to cite lack of income as the number one reason why they were not able to get care when it was needed versus people with slight disabilities. Individuals with disabilities are four times more likely than people without disabilities to have special needs that are not covered by their health insurance. Meeting the health care objectives of the WHO faces steep barriers for persons with disabilities.

In the context of caring for persons with disabilities (e.g., physical, developmental, cognitive), health care providers' tasks can be described in the following distinct areas: physical access to health care, functional access to health care, fiscal access to health care, effective prevention of health care issues that create or worsen disabilities, effective intervention in the general health care needs of individuals who happen to have disabilities, effective provision of rehabilitation services to address the special needs of persons with disabilities, and equal employment opportunity for professionals with disabilities.

BACKGROUND

Since World War II, emerging social and scientific developments have improved the potential for individuals with disabilities and have had great impact on the provision of health care to this population. There are large, and growing, numbers of persons with disabilities in all parts of the world. While the consequences of disability vary throughout the world, variations in the health care available to persons with disabilities are the result of different socioeconomic circumstances and of the different provisions that nations make for the well-being of their citizens as well as the ignorance, neglect, superstition, and fear that greet such individuals throughout the world. Also, having disabilities is broadly associated with poverty, and poverty compounds the barriers to participation in the routine activities of the general population of a nation.

Since the 1960s, a new concept of addressing both the social and health issues associated with disabilities started to gain ground. The new thinking pointed to the correlation of the limitations experienced by those with disabilities, and the effect of the social and physical environment on those limitations. This thinking expanded during the UN Decade of Disabled Persons (1983–1992) to recognize the necessity of addressing both the individual needs (such as rehabilitation and technical aids) and the shortcomings of the society (various obstacles for participation). In 1975, the UN General Assembly adopted the Declaration on the Rights of Disabled Persons, which included a specific provision establishing the right to medical, psychological, and functional treatment.

In the United States, the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990 brought the force of the federal government into the effort to establish a clear and comprehensive prohibition of discrimination on the basis of disability.

The 1973 Rehabilitation Act, which covered all providers who were above a certain size and were receiving federal funds, was not as aggressively applied as it could have been and did not stretch to routinely extend the benefits of American health care to all persons with disabilities. Yet it did assert that in providing health, welfare, or other social services or benefits, a provider that is a recipient of federal health care dollars may not, on the basis of handicap,

> Deny a qualified handicapped person these benefits or services
>
> Afford a qualified handicapped person an opportunity to receive benefits or services that is not equal to that offered to nonhandicapped persons
>
> Provide a qualified handicapped person with benefits or services that are not as effective as the benefits or services provided to others
>
> Provide benefits or services in a manner that limits or has the effect of limiting the participation of qualified handicapped persons
>
> Provide different or separate benefits or services to handicapped persons except where necessary to provide qualified handicapped persons with benefits and services that are as effective as those provided to others.

In addition, the Rehabilitation Act mandated the use of assistive aids for those with impaired sensory, manual, or speaking skills, where necessary to afford such persons an equal opportunity to benefit from the service in question.

The ADA had significant impact on the provision of health care to persons with disabilities in the United States. The ADA continues to evolve through regulation and court decisions that extend the determination to make health care accessible to Americans with disabilities, and U.S. health care providers continue to evolve in their efforts to make health care seamlessly available to individuals with disabilities. Today, U.S. health care can be viewed as a leader in the effort to make health care services available to all regardless of disabilities. The effect of these changes in health care for the disabled can be described in several specific areas.

EQUITY: EQUAL ACCESS TO HEALTH CARE

The principle of equal rights implies that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies, and that all resources must be employed in such a way as to ensure that every individual has equal opportunity for participation. This also applies to the provision of health care services.

Physical Access

Most licensed health facilities in the United States are operated under state and local regulations (as well as accreditation rules) that require clinical facilities that are physically designed for accessibility in wheelchairs or carts. The ADA imposed new thinking that required wheelchair accessible entry to all public and common areas, accessibility to public toilets, barrier-free entry, and improvement of access and navigation for the visually impaired. Wheelchair lifts, automatic doors, power-assist examination tables, Braille labeling of elevator instructions, audible signals on elevators, and Braille directional signs are all commonplace in U.S. health care facilities today.

Functional Access

Simple physical access does not ensure that individuals with disabilities will be able to make use of health care services in any useful way. Visually and hearing-impaired individuals have long been left outside the mainstream of much routine activity. This barrier to full participation is even greater in times of medical crisis. Section 502 of the Rehabilitation Act covering providers of care as "public accommodations" mandated that adaptive devices and access to signing interpreters be available for hearing-impaired patients. Section 504 of the Rehabilitation Act regulates providers of health care as recipients of federal funds through the Medicare and Medicaid programs. Numerous court cases in the United States have served to define the underlying policy of functional access, and expand the application of it through the regulation of those providers that participate in such federally funded programs. Such cases not only have a direct regulatory impact but also serve to create a "community standard of care" that has great impact on potential financial liability in the courts if the provider of care is accused of harming the patient as a result of withholding these services.

Financial Access

Even in the presence of accessible facilities with appropriate functional adaptations to provide adequate care for persons with disabilities, ability to pay for that care may remain a significant barrier to service. The UN addresses financial support for assistive devices in its Rules on the Equalization of Opportunities for Persons with Disabilities. The rules specify "that this may mean assistive devices and equipment should be provided free of charge" or at a lowered price to ensure affordability. The U.S. Rehabilitation Act requires that communications assistance be provided at the expense of the health care provider. In the absence of a universal health care plan in the United States, many persons with disabilities would still be confronted with affordability barriers given the substantial portion of the population lacking private health insurance. Many of these persons are, however, covered under the U.S. Medicare and Medicaid health insurance programs by virtue of their defining disability.

Additional barriers have historically existed for employed and insurance-eligible individuals. Persons with chronic diseases and disabilities often found themselves confronted with rejection by insurers, or exclusion from coverage of their specific health problems. The passage of the Kennedy-Kassebaum Act of 1996 placed some limitations on the exclusions that insurance companies can impose on accepting coverage of employee group members.

One specific area of broad exclusion has been private insurance coverage for mental health needs. In the United States, mental and developmental disabilities remain largely overlooked problems. There is evidence indicating that such coverage is affordable and that substantial savings are possible in reduced medical costs, crime, homelessness, increased worker productivity, and increased employment taxes. Yet several efforts to create federal statute or regulation requiring parity of mental health coverage with existing somatic illness coverage have repeatedly failed to gain passage. As a result, significant barriers to obtaining such services remain.

EFFECTIVENESS

Health care aimed at the issues of persons with disabilities must pursue the same broad goals of health care for any population, with the added burden of addressing the specific risks of disability.

Prevention

The reduction in incidence of disabling diseases and injuries is the first goal for the health care system. The term *prevention* means action aimed at preventing the occurrence of physical, intellectual, psychiatric, or sensory impairments (primary prevention) or at preventing impairments from causing a permanent functional limitation or disability (secondary prevention).

Primary prevention may include many different types of action, such as primary health care, prenatal and postnatal care, education in nutrition, immunization campaigns against communicable diseases, genetic testing, measures to control endemic diseases, safety regulations, programs for the prevention of accidents in different environments including adaptation of workplaces to prevent occupational disabilities and diseases, and prevention of disability resulting from pollution of the environment or armed conflict.

Secondary prevention may include early detection of, and intervention in, potentially disabling diseases. It may also include the development of more sophisticated diagnostic and interventional techniques and technology to enable more successful reduction of adverse outcomes of chronic diseases and critical injuries.

Health Maintenance

Persons with disabilities may have special needs related to their disabling condition that can cause specific challenges to their continuing overall health and well-being. In addition, loss of mobility or ability to communicate effectively can increase the likelihood of secondary failures of health providers to manage the continuing health of such individuals. While there has been a trend toward the development of generalists or primary care specialists to improve the coordination of health care services for the general population, it may be argued that the special needs of populations with disabilities require special understanding to fruitfully provide such continuing care. Several special efforts have produced noteworthy results. There has been some demonstration that focused efforts to care for those with severe developmental disabilities can result in reduction of adverse outcomes and hospitalizations when compared to mainstreaming the care of such persons. Rehabilitation specialists delivering continuing care to disabled patients exhibit greater focus on the corollary problems of mobility loss (e.g., spasticity, decubiti, infection) that can lessen the quality of health.

Rehabilitation

The term *rehabilitation* refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric, and/or social functional levels, thus providing them with the tools to change their lives toward a higher level of independence. Rehabilitation may include measures to provide and/or restore functions or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of measures and activities from more basic and general rehabilitation to goal-oriented activities, for instance, vocational rehabilitation.

EFFICIENCY

Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment, and social services to maximize their ability to lead a productive life. Providers of health care cannot lose sight of the need to optimize the value of the provision of the care and to maximize the value of the outcome for an individual with disabilities. Certainly, keeping an individual within a local community and maximizing the possibility of a normal productive life is one of the needs that must be accommodated to achieve these goals.

Olmstead Decision

In the United States, several court decisions have served to define and expand expectations under the ADA. Key among these has been the court ruling known as the *Olmstead* decision, in which the U.S. Court of Appeals held that decisions regarding services and where they are provided must be made on the basis of the appropriateness for each particular individual and further that services should be provided in the most community-integrated setting possible. This and other cases have broadened the requirements to maintain the care of individuals with disabilities close to home and within the routine of a productive life. Largely applied to persons with mental disorders and developmental disabilities, the decisions have recently been applied to the deinstitutionalization of care for persons with spinal cord injury and other mobility deficits.

CONCLUSION

Health care has historically been driven by developments in technology and science. Health care for persons with disabilities brings to the formula the critical need for understanding the driving forces of ethics, philosophy, and social commitment. In this arena, the role of government regulation will surely play a continuing role.

—Benn Greenspan

See also Americans with Disabilities Act of 1990 (United States); Rehabilitation Act of 1973 (United States).

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HEALTH CARE SYSTEMS

In the early twenty-first century, the number of disabled persons continues to rise and their health care needs persist and multiply. At the same time, the health care systems they interact with are also constantly changing, reflecting responses to economic, political, and social forces. Those systems, composed of health care professionals (physicians, therapists, researchers), structural elements (hospitals, clinics, professional schools), and systems of payment for services (government, managed care organizations, insurers, voluntary organizations and other private sources) occur in different arrays, with subsequent differences in suitability and ease of access for persons with disabilities.

THE DISABLED AND MEDICAL CARE

Persons with disabilities depend on interaction with doctors and medical institutions. Even when well, the disabled must look to health care professionals for equipment, certification of disability and capability, rehabilitation or maintenance of status, eligibility for private and governmental supports, and entry to education and public services.

The professionals, however, are embedded in systems—both formal and implicit—that permit or constrain their abilities to perform effectively on behalf of their disabled clients. The systems in which they work and on which the disabled are dependent are the products of history, cultural norms and practices, national and local priorities, and legislative initiatives and rule, and these all determine the resources available to disabled persons.

Most people with disabilities are well, that is, not requiring acute medical care or interventions most of the time. The real continuing needs of the disabled in their everyday lives are for social and family supports, access to education and work, transportation, and living and working environments adapted to their disabilities; these are not areas in which health professionals necessarily have expertise or interest. Yet the dependence of disabled persons on medical and related systems for legitimation and entry to social and personal services requires that they understand and turn to the health care systems.

When problems are medical, the care of the disabled is rarely accomplished quickly; time required for their care is greater than that for nondisabled patients. Often physicians and other health care personnel are uncomfortable with patients with chronic problems that do not respond to acute care protocols. In addition, disabled persons often complain that medical professionals are eager to apply new and sophisticated technologies but overlook “low tech” interventions that might aid daily living.

While there has been significant movement in developed countries toward assessing the quality of medical care by looking at outcomes, almost all of the established outcomes and “best practice” protocols measure the success of acute illnesses and injuries. The desired outcomes for non-sick disabled persons are much less concrete and much more individual; even those who have degenerative diseases or periodic acute care needs spend most of their lives outside of hospitals and rehabilitation facilities. Thus, persons with disabilities do not fit well into either the standard treatments or the standard measures of quality used in acute care medicine.

HEALTH CARE SYSTEMS

Health care systems may be monolithic and governmentally structured, as in Canada, the Scandinavian countries, and the British National Health Service, or pluralistic and loosely organized, including both public and private sector components, as in the United States.

Systems begun in the 1980s organized around the concept of managed care at first offered great promise for comprehensive approaches for the disabled. However, the commercialization of such programs in the United States, with emphasis on cost containment and standardization of treatment, has led, in general, to disappointment for those with disabilities and chronic illness. Disabled persons often find their care needs are not met in health care programs and systems that depend on prescribed standards of care or “disease management” protocols for defined populations and illnesses. Wide variations in functional impairment and, thus, of the multiple health care services needed make generalizations about both services and reimbursement risky; each disabled person conforms only to a personal profile and, thus, challenges standardized programs of care. The service needs of most disabled people will continue for a lifetime; no defined period of treatment or financial coverage exists. Planners, policy makers, and insurers are reluctant to build or fund programs for individuals whose life expectancy, treatment duration, and intensity cannot be submitted to standard actuarial analysis, with predictable costs. State governmental forays into managed care in the Medicaid program in the United States have suffered from rising costs, often leading to restriction of the benefits and services most often needed by the disabled.

The training of health professionals, especially physicians, has not necessarily prepared them for the special needs of the disabled. The absence of such specific training puts physicians at a disadvantage in advocating for their patients in the health care systems. Medical care for the disabled often falls to the small group of physicians trained in physical medicine and rehabilitation, and a few generalists who choose to work with disabled and chronically ill patients. Within the medical care system, the disabled often confront fragmentation and lack of communication among medical specialists and between tertiary care centers, community agencies, and primary care physicians.

APPROACHES AND CHALLENGES

There are several promising alternatives that respond to the complex needs of the disabled and the inadequacies of acute care systems. Some centers have developed model comprehensive care programs with a case manager (really a care manager), whose responsibility is coordination and transmittal of information between medical professionals and community agencies on behalf of the patient and family. It is within such medical care programs that the disabled are likely to receive the most attentive and appropriate care. Unfortunately, this is not the dominant practice. Despite demonstrations that show improved outcomes, in both reductions in hospitalizations and in long-term costs of care, most medical organizations in the United States have not adopted the care manager model. Thus, disabled persons and their families or caretakers must de facto become their own care managers, an enterprise that can deplete already compromised reserves of energy, time, and funds.

In some states in the United States and in some countries (Sweden, the Netherlands), comprehensive programs for the disabled have grown out of integration of medical and social service programs; there are a few (usually academic) centers in the United States that have assembled such integrated approaches, using a combination of private, state, and federal funds.

Another trend that has benefited the disabled has been the growing practice of early discharge from hospital to long-term care at home and in the community. The home care movement has been propelled by a variety of factors, some well motivated, some suspect, including control of inpatient costs (the most expensive part of health care); improved technology allowing relatively complex interventions and treatments to be done in a home setting; recognition of the hazards of extended hospital stays (particularly infections), and acknowledgment of the psychological and social benefit of being in one's familiar surroundings. Where medical institutions and systems have extended their services and oversight into the home ("hospitals without walls"), there has been marked success in terms of recovery, maintenance of function, and patient and family satisfaction.

While there are clear benefits, home or independent care for the disabled and chronically ill creates new challenges for health care systems, many in previously unexplored territory. In choosing care at home, there is a transfer of responsibility and risk from the inpatient institution to the patient and family, which leads to important questions: What are the limits of the institution's (or health care system's) liability? What are the system's moral and legal responsibilities for adequate preparation and support of the home caretakers? Should the institution or system initiate a home care program in the face of inadequate continued funding and assistance from society and its formal (e.g., in the United States, local state and federal programs) and informal supports? Does the system's obligation to the patient and family end when they leave the hospital or rehabilitation facility?

The appropriate services for a disabled person at home may involve many agencies and organizations: physical, occupational, and speech therapies; vocational and educational services; the provision and maintenance of equipment and supplies; respite for caretakers; and modifications of the environment for accessibility and safety. Most of these are not attended to in traditional health care systems but (at least in the United States) are fragmented among many public and private agencies, a situation that demands constant initiative and vigilance from the caretakers, family, and the disabled persons themselves, adding to their already heavy logistical and psychological burdens. Advocates for the disabled note another paradox confounding home care: Both public and private insurance systems may pay for outsiders (e.g., nurses, therapists, attendants) to care for disabled persons at home or in school but do not recognize or reimburse for the large financial and emotional sacrifices made by family members when they perform the same tasks.

Some planners, looking from the perspective of system costs and pursuing efficient use of resources, propose the establishment of congregate facilities or the clustering of disabled persons around (or in) a central facility or a defined geographic area. Indeed, in larger cities with ample medical and social resources, one can imagine a virtual community of the disabled served by an organized system of care extending seamlessly from health care institutions to the communities and homes of the disabled. Pilot programs of this sort for the elderly, for children with continuing technological needs (e.g., ventilators), and for developmentally disabled children and adults have been successful. However, the initiative and continuing support for target populations has usually not come from health care systems, but from private or public service organizations. Such comprehensive approaches require sophisticated information and transportation systems, and a reservoir of professionals and support personnel. In rural areas and in small towns, such a network of services is difficult or impossible to construct, and disabled children and adults may have to travel great distances to engage with the needed health care and social services.

The development of congregate facilities for disabled individuals has been tried in several forms in Western Europe (e.g., Het Dorp in the Netherlands, a town of disabled individuals in which dedicated medical and social services are built around the daily lives and work of its residents). However, in the individualistic United States, the dominant philosophy is to support the integration of disabled individuals into everyday life. Many organizations (e.g., centers for independent living) work to connect individual disabled persons with accessible and appropriate health care and to find suitable living arrangements for them, including adapted housing.

For the more severely disabled who cannot live independently, there are several types of institutions that provide various programs of partial independence and sheltered workshops, some with permanent living arrangements. For those, the means of provision of health care services to clients vary; some have good working arrangements with local facilities, other negotiate on a case-by-case basis for adequate medical and health care services. Many of these organizations are private charities and work to mobilize additional available public funds (Medicaid, Social Security, Developmental Disability, Special Education) for their clients' health care and social service needs.

There is an understandable tension between philosophies promoting independent living and those supporting the various forms of congregate care. The greater efficiencies and access, especially to health care, gained by clustering disabled people is countered by restrictions on independence, social and physical mobility, and integration into the greater society. In the United States and other countries where geography and distance from centers of optimal medical care is a reality, those tradeoffs are sometimes seen as necessary. In more compact countries where medical care systems are regionalized (e.g., Sweden) and integrated with social service systems, the disabled may find less incentive to cluster around urban medical centers. Many disabled people say they find comfort and recognition in settings dedicated to people like themselves, with important psychological and social rewards. Especially for the majority who do not have continuous medical care needs, the real benefits deriving from congregate or clustered communities of the disabled may outweigh the potential benefits of independent living and the uncertainties about ongoing health care that go with it.

An encouraging trend has been the relatively recent development and growth of the specialty of geriatric medicine. The need for comprehensive care for the growing numbers of elderly persons, with and without disability, has brought attention to the need for integration of medical, social, and financial resources for all vulnerable populations. There are increasing numbers of demonstration projects and comprehensive programs for the elderly, from which models for the care of all disabled people, young and old, are emerging.

ISSUES IN FINANCING SERVICES

The ability to pay for medical services for the disabled in those countries without a comprehensive publicly funded universal health care system (most prominently, the United States) is very uncertain. Many of the services and therapies needed by the disabled are required for *maintenance* of present functional status, not for cure or even improvement of the primary causal illness or injury. Thus, they lie outside the benefits of most private insurance plans, and even of Medicare; they do not meet the criteria for "medical necessity." In the private insurance market, previously able-bodied persons who become disabled will usually find that their health insurance has a lifetime maximum benefit limit that can be quickly exhausted with high-cost medical procedures and specialized inpatient care. Those persons or their families must then seek support from public funds (Medicaid, Social Security) for continued access to medical care systems, some of which reject or refuse care to those supported by public funds. Because each state in the United States has different Medicaid, developmental disability, and special education programs, there is significant disparity in the services available across the country. This diversity of benefit packages sometimes leads disabled persons or their families to move from one state to another to improve their access to health care benefits.

Private insurance also limits access to coverage for "prior existing conditions"; such restrictions make it difficult or expensive to obtain private insurance (especially for those with congenital or early-acquired disabilities) and limit families' ability to relocate or change employment, where the change would require a new insurer.

While some advocates for the disabled have proposed that public and private funds available for their care be given directly to the patient or family, others are concerned that many families are not sufficiently informed or prepared to act in the disabled person's best interests. In addition, those disabled persons who are not part of a comprehensive medical care system may miss important therapeutic advances.

The future of disabled people in medical care systems is uncertain. It will be determined by the political and economic evolution of health care systems and will require vigilance and assertive participation of the disabled and their advocates.

—Arthur F. Kohrman and
Claire H. Kohrman

See also Health Care and Disability; Health Management Systems; Independent Living.

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HEALTH MANAGEMENT SYSTEMS

Management is an increasingly important component in the health and social care systems that provide services for people with disabilities. The rise of management science and specialist managers has coincided with a profound shift in the way organizations are run. Older forms of administration have been displaced by forms of active management that focus more clearly on economic efficiency, cost control, performance review, and accountability. Management thinking has influenced professional and policy networks so that it has been incorporated in the political, bureaucratic, and scientific discourses that affect health care organizations. The ranks of the specialist managers have been augmented by management-oriented physicians and other supporting experts. This has transformed the environment in which health professionals work and disabled people receive care.

Although there are cross-national variations in management philosophies and practices, differences appear to be diminishing as management science becomes a global phenomenon. In sociological terms, this may be linked to the spread of rational bureaucratic organization, which has helped to shape both private and public sector work. But from the 1980s onward, a new array of management technologies and practices emerged that made the micro-management of organizations more feasible. This has coincided with the creation of processes of regulation and control that permeate downward within organizations and introduce new forms of surveillance and accountability.

The management of health care affects disabled people in manifold ways. Aging populations and the increased burden of chronic illness in many countries mean that disability services have moved nearer the top of the policy agenda in both state and market-dominated health care systems. At the strategic level, senior managers play a leading role in planning the future shape of services and how consumers can access them. Planning decisions affect matters such as the volume and range of services, the degree of coordination of health and social care, the scope for patient choice, and how services are paid for. At the operational level, managers oversee the operation of the system, enforce the rules, and try to resolve emergent problems that arise in delivering services. Managers function as mediators or translators of policy fixed at a higher level in a public bureaucracy or corporation. Sometimes they actively shape policy as they adapt it in the course of implementation.

Much management work involves passing between high-level civil servants or corporate board members and the professional staff who provide frontline services. Managers liaise with professionals to determine the detailed procedures and practices that must be worked out as organizations are reformed and restructured. In many countries, better management systems have led to increased efficiency and also have provided a counterbalance to institutionalized professional power and the skewing of status and resources toward acute medicine. But this has also meant that managers are drawn into difficult decisions about priorities and the provision or nonprovision of services.

Precisely how managers undertake these tasks will depend on the nature of the health care system in which they work. There is a marked difference between a private market-based system, where managers remain at arms length from state regulators and work with owners or their representatives to determine corporate strategy, and a publicly funded/publicly provided system, where managers interact with civil servants and politicians to implement public policy.

The rise of management ideas is well illustrated by the global influence of U.S.-style managed care. The United States has a mixed, though mainly private, system comprising a range of organizations that purchase, provide, or coordinate health and social care services. *Managed care* is an umbrella term for a variety of systems and techniques used to control costs and quality. It typically involves review of patterns of utilization and the medical necessity of treatments, and the steering of patients toward certain providers and care pathways. Since the 1980s, against a background of rising health expenditures, there has been a drift away from traditional health insurance plans toward alternative products sold by managed care organizations (MCOs), such as health maintenance organizations. Some MCOs sought vertical integration by supplementing acute hospital provision with the buying up of outpatient clinics, nursing homes, home health care, and specialist psychiatric facilities, with the aim of creating large networks which could achieve economies of scale and force prices down. Largely for cost control and marketing reasons, other MCOs adopted the strategy of separating benefits for chronic illness or disability from the rest of their health plans. For example, mental illness, alcohol, and drug services were contracted out to specialist providers who would treat members who had purchased this coverage from the MCO. Because these arrangements often offered more limited benefits than indemnity insurance plans, they had the potential to reduce adverse selection and reduce costs.

Although MCOs have reduced the cost of health care, they have been criticized for limiting patient choice and excluding certain treatments from coverage. Managers play a key role in determining what plans will cover, and they consider issues such as cost and litigation risk alongside the question of the medical necessity of treatments. While research shows that denial of treatment for acute conditions is a relatively rare phenomenon in the United States, there are indications that exclusions may have more impact on people suffering from chronic illness and disability. For example, in a recent special issue of *Sociology of Health & Illness,* Gary Albrecht describes the constant battles faced by disabled people in securing access to desired forms of care, usually conducted via contact with middle managers in MCOs. Others have criticized the failure of specialist providers to liaise with cognate organizations and provide appropriate care networks. Recent efforts by some purchasing alliances to use buying muscle as a lever to drive up quality tend to focus on acute services and have so far had little impact on services for disabled people.

In a predominantly public service such as the British system, the role of managers centers more on the implementation and translation of government policy. The splitting of the National Health Service (NHS) into purchaser and provider divisions in 1991, together with the creation of a market in social care, led to significant changes in managerial roles. The interests of purchaser and provider organizations became more sharply differentiated, often leading to increased tensions between their respective managers.

Purchasing was regarded as part of a wider commissioning function, involving needs assessment and judgments about strategy and priorities, and better coordination between health and social services. Continued problems at the interface of health and social care have been partly blamed on continuing organizational barriers to collaboration, and an inability to move from communication at senior management level to effective team working on the ground. The heavy burden of work associated with the new system of contracting for clinical services resulted in growing numbers of managers, but along with new power came pressure to meet government-imposed "costs savings" and performance targets. Some commentators have argued that contracting became a financially driven exercise that paid insufficient attention to quality. There was also criticism from doctors who argued that managerial concentration on the key target of reduced surgical waiting times meant that clinical priority became less important than time on the waiting list.

The NHS reforms initially seemed set to improve the situation of people with disabilities because the quasi-market system was designed to end the system of historically based budgets, which had channeled money toward high-profile acute specialties and away from the so-called Cinderella services (long-stay hospitals and community services that had traditionally suffered from underfunding). However, in practice, spending patterns did not change as much as predicted, and there was little reallocation of resources to community and continuing care services that would meet the needs of disabled people. The concentration of spending on acute services was reinforced by the weight given by the government to surgical waiting times targets, and the way these were presented as a key indicator of the success of the reforms. Many district health authorities operated "exclusions" policies, usually formulated jointly by public health physicians and managers, which listed treatments that would not normally be purchased. This "postcode lottery" affected some high-cost drugs for disabling conditions, such as beta interferon for multiple sclerosis, anti-TNF medication for rheumatoid arthritis, Riluzole for motor neuron disease, and Memantine for Alzheimer's disease.

The Blair reforms introduced after 1997 marked a step away from the language of the market but retained the purchaser/provider split and the basic framework of service contracts. The burden of administration was reduced by a shift from annual to multiyear contracts. However, the government imposed new arrangements for "performance management" based on target setting and review, which increased providers' accountability for outcomes.

There were also new policies on "clinical governance," which aimed to achieve improvements in quality and safety. In practice, this involved the creation of clinical guidelines for a range of medical conditions, recommendations about whether new and controversial treatments should be provided on the NHS, and the development of a series of National Service Frameworks (NSFs), which defined expected care pathways for different condition groups. Several of these clinical guidelines affect disabling conditions such as chronic heart failure, chronic obstructive pulmonary disease (COPD), multiple sclerosis, diabetes, and "supportive and palliative care," and the NSFs include frameworks for older people, renal services, and diabetes. Sections of the British medical profession have helped shape these developments, but they go beyond professional self-regulation. Rather, they have emerged from a coalition of political, managerial, and professional groups, and they encapsulate a form of scientific/bureaucratic rationality that sets limits on the discretional decision making of individual professionals.

Although this short entry has focused on only two systems, most of the issues discussed have more general applicability. Converging trends in the health care systems of almost all developed countries ensure that management will continue to be a central component of disability services. Changing patterns of health and disease and the rising proportion of budgets directed toward chronic illness and disability must be considered alongside continuing technological advances and resource pressures. Disabled people will expect more, and it will be the management systems that are charged with finding ways of maximizing outputs for a given level of expenditure and placing limits on what a health or social care system can reasonably provide.

—David Hughes

See also Health Care Systems; Managed Care.

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HEALTH PROMOTION

Health promotion is defined as the process of enabling individuals to increase control over their health and to improve their quality of well-being by engaging in a socially, physically, and spiritually fulfilling life. This definition applies to people with and without disabilities. The process of achieving good health depends on the synergy of personal engagement and commitment, and a supportive environment that includes ample opportunities for maintaining and improving health.

Research has demonstrated that the more supportive an environment is in terms of access to quality health promotion (e.g., available transportation to obtain good medical care, close proximity to a grocery store that sells fresh fruits and vegetables, sidewalks to walk or push a wheelchair in the neighborhood), the more likely the person is to engage in these health-enhancing behaviors. The primary goal of health promotion is to empower people with disabilities to engage in their own successful health-promoting strategies with as minimal assistance as possible, and with the freedom to make choices appropriate to their needs and desires.

There is growing awareness in the public health community of the need for more knowledge and awareness of effective health promotion programs for persons with disabilities. Innovative strategies for improving health, preventing complications associated with a disabling condition, and adequately preparing individuals with disabilities to better understand their own health has emerged as an important public health priority. While people with disabilities account for only 17 percent of the noninstitutionalized population of the United States, they constitute 47 percent of total medical expenditures. On average, their medical expenditures are more than four times those of people without disabilities. Many health experts believe that access to quality health promotion programs can reduce medical costs while improving quality of life in persons with disabilities, who are generally underserved and vulnerable to the effects of poor health.

OVERVIEW OF HEALTH PROMOTION

Prevention of Secondary Conditions

The paradigm shift from disability prevention toward the prevention of secondary conditions is still a relatively new and emerging concept. One of the primary goals in disability and health is to encourage health professionals to become aware of the growing needs of people with physical, cognitive, and sensory disabilities. Another goal is to recognize that people with disabilities can achieve similar health benefits as the general population provided they have equal access to health promotion services/programs that are offered to the general community.

The term *prevention* has a different connotation for people with and without disabilities. For people without disabilities, primary prevention starts with a person being absent of disease and includes efforts to eliminate or reduce the risk of disease or disability. Although primary prevention of disabilities remains a high priority for public health agencies and intervention specialists, prevention of secondary conditions in people with disabilities is beginning to receive more attention. In people with disabilities, primary and secondary prevention include initiatives to prevent secondary conditions in addition to preventing conditions associated with poor health behaviors (e.g., smoking, physical inactivity, poor nutrition). The term *secondary conditions* relates to any physical, medical, cognitive, emotional, or psychosocial consequences of a primary disability. This may include weight gain or weight loss, pressure ulcers, pain, fatigue, advanced osteoporosis, depression, social isolation, orthopedic changes, and reduced physical function such as loss in aerobic capacity or strength. Secondary conditions have a tendency to exacerbate a primary disability and can limit physical and social independence and reduce participation in important health-enhancing behaviors such as employment and recreation.

Healthy People 2010

During the late 1970s, the United States began monitoring the health of the nation in its *Healthy People* agenda. The most recent document, *Healthy People 2010*, targets people with disabilities as a subgroup of the population. A chapter titled "Disability and Secondary Conditions" has been added to the document to reflect various health disparities found in people with disabilities. This document will serve as an important benchmark for supporting the development of health promotion initiatives for people with disabilities in the coming years.

Barriers to Health Promotion

People with disabilities often experience health disparities because of the many environmental barriers that they are confronted with when trying to improve their health, including poor physical access, societal attitudes, and lack of quality medical care. Research has demonstrated that the more supportive an environment is in terms of access to health-promoting behaviors, the more likely the person is to engage in these health-enhancing activities.

While there is substantial information on health promotion for the general population and for people with chronic conditions (e.g., diabetes, arthritis, asthma), much of this information does not provide important adaptations or modifications to be engaged in by individuals with physical, cognitive, or sensory disabilities. Barriers to health promotion for people with disabilities include inaccessible materials and programs, lack of transportation to get to an exercise facility, lack of financial resources to purchase healthy foods or medication, and lack of access to good medical care. Materials in standard curriculums or textbooks are, for the most part, not available in alternative formats (i.e., large print, audio), and information is often too generic for individuals with specific types of disabilities who may have several secondary conditions (i.e., pain, fatigue, urinary incontinence) and/or impairments (lack of vision/hearing, low cognition, paralysis). These secondary conditions and/or impairments require specific adaptations to standard health promotion programs to ensure successful integration and outcomes.

An additional barrier to health promotion involves the lack of training among health care providers regarding the needs of people with disabilities. Most health promotion specialists are not trained to modify or adapt existing programs for people with various types and severities of disabilities. For example, many professionals will recommend walking as the primary mode of physical activity because it can be conveniently done in various settings (i.e., mall, outdoors), and it does not require expensive equipment or a membership to a fitness center. However, individuals with lower extremity disabilities may not be able to walk or may have difficulty walking. An alternative to walking would be to recommend hand cycling, wheeling, or performing chair exercises.

KEYS AREAS OF HEALTH PROMOTION

Physical Activity and Disability

The health benefits of an active lifestyle that includes moderate amounts of medium to vigorous physical activity on a regular basis have been detailed in the Surgeon General's report, *Physical Activity and Health* (U.S. Department of Health and Human Services 1996):

> Regular physical activity greatly reduces the risk of dying from coronary heart disease, the leading cause of death in the United States. Physical activity also reduces the risk of developing diabetes, hypertension, and colon cancer; enhances mental health; fosters healthy muscles, bones, and joints; and helps maintain function and preserve independence in older adults. (Foreword of the Executive Summary)

Unfortunately, the vast majority of people with disabilities are not obtaining the recommended amount of physical activity needed to confer health benefits and prevent secondary conditions associated with a sedentary lifestyle (e.g., heart disease, type 2 diabetes, obesity, and osteoporosis). The *Healthy People 2010* report notes that significantly more people with disabilities reported having no leisure-time physical activity, 56 versus 36 percent, compared to people who did not have a disability.

As persons with disabilities age, they often experience increasing difficulty performing activities of daily living (ADLs) (e.g., dressing, showering) and instrumental activities of daily living (IADLs) (e.g., ambulation, doing laundry, grocery shopping). Persons with disabilities also must overcome various physical obstacles during the day as a result of environmental barriers that require greater energy expenditure to perform certain physical tasks (e.g., wheeling up and down ramps and curb cuts, performing transfers). And various secondary conditions that often accommodate a disability (e.g., increased weight gain, pain, spasticity, weakness, fatigue, loss of strength and function) make it more difficult to sustain these physical tasks. When combined with the natural aging process, the likelihood of requiring assistance to perform various ADLs and IADLs is likely to increase.

Based on evidence from studies conducted with various disabled populations, deconditioning in the form of reduced strength, flexibility, and aerobic capacity result in an earlier onset of reduced health and function. There is a substantial amount of health improvement that can be obtained by people with disabilities with minimal increases in physical activity. Finding ways to overcome environmental barriers to physical activity participation is an important priority in public health.

One example of a primary barrier to physical activity participation among several groups of individuals with disabilities is the lack of information on where or how to exercise at home or in the community. Much of the general literature and public health messages promoting physical activity encourage Americans to walk more often, with the goal of 30 minutes a day most days of the week. While this recommendation may be appropriate for the general population, it is often inappropriate for people who have difficulty walking (e.g., cerebral palsy, multiple sclerosis, stroke) or who are unable to walk (e.g., spinal cord injury, polio) or must be supervised while walking (e.g., severe mental retardation or mental illness, Alzheimer's disease). A more inclusive message would have a greater likelihood of reaching a more diverse population.

National Center on Physical Activity and Disability

Through a grant from Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Disability and Health Division, the National Center on Physical Activity and Disability (NCPAD) was established to collect, synthesize, and disseminate information on various programs and services related to physical activity and disability. This web-based research and information center has many unique features that can assist health professionals in developing appropriate physical activity programs for people with disabilities. The website (http://www.ncpad.org) contains a national directory of accessible recreation and fitness facilities along with a listing of equipment vendors that manufacture or sell adaptive equipment. There is also an extensive database on physical activity and disability that allows the user to search for information by disability or activity. The toll-free telephone number (800-900–8086) allows end users to consult with an information specialist if they do not have access to a computer.

Nutrition and Disability

While government agencies responsible for nutritional information emphasize optimum levels of nutrients for the general population, specific guidelines for people with physical and cognitive disabilities are lacking. Although having a disability does not necessarily require a significant alteration from national dietary guidelines (e.g., low fat, low cholesterol, high fiber), certain modifications to the nutritional component of a health promotion program may need to be tailored to people with various types of disabilities. For example, individuals with cerebral palsy, Down syndrome, and spinal cord injury are more susceptible to osteopenia (reduced bone mass) and osteoporosis (significant bone loss). While there are no specific guidelines for daily calcium intake in younger, disabled populations with osteopenia or osteoporosis, it is plausible that a higher calcium intake may be required at an earlier age to slow or reduce the progression of bone loss.

Individuals with stroke who are taking the blood thinner Coumadin to prevent blood clots and a recurrent stroke may need to avoid a high intake of vitamin K. Vitamin K has an essential role in blood clot formation and counteracts the effects of Coumadin. A comprehensive nutrition program for stroke survivors would include food choices that have a low concentration of vitamin K while still maintaining adequate levels of other important vitamins and minerals.

Fluid intake is another area of nutrition that may need to be tailored to individuals with certain types of disabilities. For example, individuals with spinal cord injury (SCI) may require higher amounts of fluids to avoid dehydration. However, many individuals with SCI are reluctant to drink large amounts of fluids because of the difficulty with catheterization and/or the greater frequency of having to perform this task. Yet, without adequate hydration, people with SCI are more susceptible to urinary tract infections, syncope, and impaired thermoregulation. Constipation is another secondary condition found in various subgroups with disabilities, and increased fluid intake would help improve motility and evacuation of bowel contents.

Many individuals with disabilities have large increases in weight often related to medication use, lack of physical activity, and poor nutrition. For example, one of the major side effects of psychotropic medications is excess weight gain. Health professionals must be aware of the impact that various medications can have on nutritional status and take appropriate action to avoid large increases in weight through reductions in caloric intake and increased physical activity.

Good nutrition that is tailored to the needs of individuals with disabilities can have a dramatic effect on improving health and reducing various secondary conditions. In general, nutrition recommendations for the general population should be followed by people with disabilities. However, in cases where the individual's impairment may alter certain metabolic processes, specific nutritional guidelines must be included for that individual.

Health Behavior and Disability

Health behavior can have a significant impact on empowering people with disabilities to manage their own health. The current state of practice in most health behavior programs is to educate participants about the benefits of the various components of health promotion, which can include anything from cancer prevention screening (e.g., breast and prostate exams), to spirituality, stress management, exercise, and proper nutrition.

The transtheoretical model is one of the most widely used behavioral models in health psychology. The model uses the phrase "stages of change" to integrate change processes through a variety of intervention strategies. There are five primary stages that range from people who are not even thinking about making a change (precontemplation) to people who have changed a behavior and are working to maintain the new behavior and prevent relapse (maintenance). In between, people can be thinking about making a change in the next six months (contemplation), getting ready to make a change in the next 30 days (preparation), or be in the first six months of a behavior change (action).

Implementation of the transtheoretical model in health promotion programs for people with disabilities is a viable approach to ensuring better outcomes. Intervention strategies should be tailored to the stage of change that the person is currently in and that will serve as a useful guide for moving the individual to the final stage of maintenance. It is becoming increasingly clear that there is a greater likelihood of successful adherence to health promotion programs when the program is tailored to the needs, interests, and comprehension level of the individual learner.

—James H. Rimmer

See also Activities of Daily Living (ADLs); Disease; Exercise and Physical Activity; Health; *Healthy People 2010*.

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HEALTH RESOURCE RATIONING

THE NEED FOR A SYSTEM OF RATIONING

Health care is uniquely important. Modern medicine has been extremely successful in discovering new kinds of health care and improving the old kinds. But medical innovations have come at increasingly high prices. The cost both of the best health care and even moderately good health care is rising much faster than our ability to pay for it. This creates a problem. If a society wishes to provide health care to its citizens, some form of rationing has become a necessity.

The very idea of health care rationing is objectionable to many people. Citizens of the United States are especially opposed. This is partly because the United States has no universal health care system. The two national U.S. health programs (Medicare and Medicaid) cover only 26 percent of the population, those who are elderly, poor, or significantly disabled. Health care for the remaining 74 percent is left to the marketplace. This is seen as desirable by many, who believe that a free market will ensure freedom of choice in health care. But the effect of this “free market rationing” by the year 2002 was that 15 percent of the population—more than 43 million people—had no health insurance at all, and that number is increasing. Some public system involving rationing is likely to be required in the future. It is already used in the U.S. national systems and in private health maintenance organizations, so U.S. citizens will have to accept the concept of rationing in some form. Most other developed countries have universal health care programs. Because rationing decisions are always made within these programs, the concept is seen as less objectionable.

Health care rationing is a genuine necessity within any publicly funded system. It is easy to argue that national health care systems are underfunded. Nevertheless, the funds that would be necessary to purchase unlimited health care for everyone are beyond any nation’s capacity. Increases in funding can produce better health care but not unlimited health care. If health care must be limited, then both fairness and efficiency demand that it must also be rationed in some way. We should spend health care funds *wisely,* so that expensive procedures are funded only when they are worth the expenditure in comparison to other procedures. This follows from the fact that an expenditure on any one patient reduces the funds available to other patients. But we should also spend funds *fairly,* so that everyone gets a just share of the benefits of the system. Crafting a health care rationing system that is both efficient and fair is a tremendously complex process. But it is also a necessity.

Both the efficiency and the fairness of a system of health care rationing are difficult to establish. The simplest programs are easy to apply, but they have serious moral flaws. These flaws have been recognized, and attempts have been made to circumvent them. One group of people is especially vulnerable to disadvantage from rationing systems: people with impairments and chronic illnesses. Even systems that are intended to fairly and efficiently distribute health care resources can discriminate quite seriously against disabled people, as we shall see. This discrimination results from questionable moral assumptions about the goals of health care, from questionable factual assumptions about quality of life, and even from disagreements about the nature of disability itself.

Conflicts between the medical community and the disability rights community are almost inevitable, for one simple reason. The medical community considers disability to be a medical problem, to be solved (if at all) by medical means. The disability rights community considers disability to be a social problem, to be remedied by social changes that make environments more accessible and integrate disabled people with the rest of society. These activists consider disabled people to be similar to an ethnic minority, harmed by discrimination from mainstream society. The so-called medical model of disability is a basic assumption of the medical community, but it is a misconception according to disability rights activists. This is one source of conflict over the relation between disability and health care policy.

SOME SYSTEMS AND THEIR PROBLEMS

One might think that statistical analyses of health care efficiency would result in simple statistical facts, not in moral problems. But statistical analyses often begin with hidden assumptions that infect their outcomes. One early analysis of health care efficiency was called cost-benefit analysis (CBA). The goal was to determine the costs of nationally funded health care in terms of its impact on economic productivity. The analysis indicated that health care expenditures on workers who were young, productive, and highly paid would repay the costs by increased productivity. But other expenditures did not produce the same payback. Health care for unemployed and elderly people was a bad investment. The use of these results to prioritize public health care was immediately recognized as unfair. The moral goal of health care is not only to maximize the nation's economic production but also to make its citizens healthier whatever their economic contribution.

It is not difficult to calculate the relative cost-effectiveness of different treatments when they are aimed at producing the same outcome. The calculation of the cost-effectiveness of certain screening tests for colon cancer, for example, is merely the cost of one test multiplied by the number of such tests it would take to detect a single tumor. This kind of analysis can lead to useful results. But this kind of analysis, alone, cannot compare different kinds of outcomes; it cannot compare treatments that extend life with those that control pain, or improve function. A way had to be found to compare the different health-related outcomes with each other. This would allow cost-effectiveness analysis to be applied to *health itself,* instead of being limited to individual kinds of outcomes. It would also remove the unfairness of CBA's focus on the economic consequences of health. The health of unemployed and elderly people would receive equal consideration as that of high-wage earners. This was surely a moral improvement. But how can one measure health itself? The concept has proven surprisingly problematic.

The first step in measuring health itself was the recognition that the goal of health care was not only to extend lives but also to make lives better. The relief of pain and discomfort and the improvement and maintenance of function are legitimate goals of health care even if lives are not lengthened. Life extension and life improvement were seen to be distinct dimensions of health care. To compare two distinct dimensions of health, a measure had to be constructed that incorporated them both. Some amount of life extension must be seen to be comparable to some amount of life improvement. This would be possible if health itself were seen to be the product of multiplying the *length* of life produced by a medical treatment (the longer the better) by the *quality* of the life produced (the better the quality, the better the outcome). But now we see another problem. One of those goals is easily measurable but the other is not. Length of life is simply a number of years. But how does one measure the "goodness" of life?

THE INVENTION OF "QUALITY OF LIFE"

In the 1970s, this problem led to the coinage of the expression "quality of life" (QOL). The expression rapidly became a buzzword. But it is important to remember its origin. Even though *quality of life* has entered ordinary language, it retains its specialized meaning among those who deal with health care rationing systems. In ordinary speech, quality of life refers to the subjective satisfaction and fulfillment that an individual experiences. But in its original technical sense, quality of life refers to *everything except life extension* that is a beneficial outcome of health care. Subjective satisfaction is irrelevant. The technical concept is quite problematic, as we will see. One of its ironies is that the technical term *quality* of life was invented only because of the need for *quantification.* Health care economists had to be able to quantify—to measure, count, add up, and compare—the valuable outcomes of health care. For the purposes of health care rationing, QOL is a quantity.

With QOL understood as a quantity, an amount of goodness, health care economists believed that they could calculate the total amount of *health itself* in an individual or in a population. Total health is a length of time multiplied by the QOL during that time. The quality adjusted life year (QALY) became the standard measure of total health. Numerical comparisons can now be made. One QALY is one year of life at its maximum quality (set at 1.0 by convention), or two years of life at the QOL of 0.5, or four years of life at the value of 0.25. The number of individuals involved does not matter: Four years of one person's life at a given QOL is equivalent to two years of two people's lives at the same QOL. Health care can now be rationed with the help of objective measures. A system called cost-utility analysis (CUA) was devised by applying cost-effectiveness analysis to the production of QALYs. (*Utility* is a term used by economists and philosophers to designate an amount of welfare or happiness. In the case of CUA, utility is measured in QALYs.)

To illustrate the use of CUA in health care policy, imagine a decision between two programs of life-extending treatment. Program A and Program B have the same costs and the same size patient groups (say, 1,000 patients), and each program extends the lives of its patients for one year. The patient group for Program A has the highest possible QOL of 1.0. The group for Program B has a lower QOL of 0.8. Which program should be funded? Clearly, Program A. It produces 1,000 QALYs (1,000 people with a one-year life extension at 1.0 QOL), while Program B produces only 800 QALYs. A greater amount of *health itself* is purchased for the same price. CUA shows that the QALYs produced by Program B cost 1.25 times as much as those produced by Program A. Given this choice, it would be a financial waste to fund Program B.

QOL AS A THREAT TO HEALTH CARE FOR SOME

We are very close to the point at which health care rationing discriminates against people with permanent impairments or chronic illnesses. One further step is needed, and it is almost always taken. It is this: People with impairments are determined to have a lower QOL than nondisabled people merely because of their impairments. The overall goal of maximizing QALYs implies that, under certain circumstances, people whose QOL is permanently low will receive a lower priority for certain kinds of health care than people whose QOL is high. This will not happen in every circumstance, of course. If two individuals with different QOLs contract a disease that lowers each of their life qualities an equal amount, then the treatment for the disease would result in the same QOL increase for each person, whatever their baseline QOL. Because each treatment results in the same increase, they have an equal priority for treatment even though they began at different QOLs. But consider life-saving treatments. Saving the life of a person with a high QOL produces a larger number of QALYs than an otherwise similar person who has a permanent impairment (and therefore a lower QOL). For treatments like these, disabled people will have a lower priority for health care than otherwise similar nondisabled people.

This version of CUA is beginning to sound like CBA, with its focus on economic outcomes. Instead of discriminating against non–wage earners, we discriminate against people who have a low QOL. One would think that the same objections would apply. Many non–wage earners have a lower QOL than wage earners, and so would be disadvantaged by a QOL-based CUA just as much as by the old income-based analysis. Presumably, many poor people, elderly people, lonely people, and people who have lost a loved one have a low QOL, and so would also be subject to discrimination. Shouldn't fairness dictate that health care not discriminate against these groups of people? Should all sad people be classified in the same category as disabled people, and have their access to health care reduced by their low quality of life? Is health care only for happy people?

Not according to the actual rationing systems that have been developed. Advocates of CUA are not interested in maximizing overall QOL, in the ordinary sense of the subjective enjoyment or fulfillment that individuals experience in their lives. Keep in mind the original purpose of the concept of QOL. It was meant to quantify non-life-extending health care so that it could be compared and traded off with life-extending health care. Unhappiness-causing characteristics such as poverty and loneliness are not treated by the health care system. So they are ignored by CUA advocates. The term *health-related quality of life* (HrQOL) is now used to call attention to this difference. CUA advocates insist that disability is health related and that loneliness and poverty are not. So a person whose life is made unhappy by disability receives a lower priority for health care. But a person whose life is made unhappy by widowhood or unemployment does not. All sadnesses are not equal.

But are these generalizations even true? Are the lives of people with impairments significantly lower in quality than nondisabled people? It depends on whom you ask. When people with impairments are asked about their lives, they report a QOL only slightly lower than that reported by nondisabled people about their own QOL. But when nondisabled people are asked about the QOL of disabled people, they report (or estimate, or guess) that it is extremely low. Even more paradoxically, health care workers have a lower estimate of the QOL of disabled people than does the general public. Gary Albrecht and Patrick Devlieger (1999) have reviewed the literature on this paradox.

WHO SHOULD WE BELIEVE ABOUT QOL?

So the question arises: Whose reports should be used in the rationing system? Should we incorporate the high-QOL reports of disabled people themselves, or the low reports that are given of disabled lives by nondisabled commentators? Biomedical ethicists have shown a strong tendency to trust only the nondisabled reports (or, more likely, their own intuitions). They dismiss the reports of disabled people as a mere lowering of personal standards. On the other hand, social psychologists have known of this discrepancy for much longer than the ethicists. Psychologists such as Daniel Kahneman and his colleagues (Kahneman, Diener, and Schwarz 1999) have taken the reports of disabled people seriously. The phenomenon fits into other psychological knowledge about how people find happiness in life. Ask yourself this: How happy would you be a year after you won a fortune in a lottery? You probably expect that you would be extremely happy. But the empirical facts do not fit your prediction. After an initial exultation, lottery winners almost always return to their original level of life satisfaction. The same happens with most people who experience major difficulties, whether from disability or the loss of a loved one. Nondisabled commentators *expect* that disability would cause them to have permanently low QOL, and lottery winning permanently high QOL. Both expectations are mistaken. This implies that people who are living with impairments (and those who are living with lottery fortunes) are the best judges of their own QOL. The contrary assessments of the nondisabled public, biomedical ethicists, and health care economists are clouded by a prejudice well known to psychological researchers.

So there is good empirical reason to doubt that the lives of most people with impairments have much less subjective satisfaction or fulfillment than the lives of nondisabled people. Insistence that they do would be seen as mere bigotry by disability rights advocates. But the CUA advocates have an additional argument to use in support of the lower QOL of people with impairments. They claim that it is logically incoherent to accept reports of high QOL from disabled people.

According to the principles of CUA, logical consistency requires us to link any expenditures dedicated to cures and prevention of a given condition with the QOL of a person who lives with that condition. If Condition A is regarded as extremely mild, then Condition A will have a low priority placed on it for purposes of prevention or cure, and people who live with Condition A will have a very high QOL. Conversely, if Condition B is one that is very important to cure and prevent, then a life with Condition B must involve a seriously reduced QOL. For example, if you consider it important to spend health care funds to prevent or cure blindness, then you are logically required to believe that people who are blind have a low QOL. If they did not, then why should we devote health care funds to prevent or cure blindness? The mere fact that we want to prevent disabilities logically implies that disabled people have a low QOL. What they report about their own QOL has no relevance to the matter.

This appearance of logical necessity is a consequence of the assumptions behind CUA accounts of rationing. CUA presupposes a utilitarian moral theory. Utilitarianism asserts that morality is a matter of the production of *consequences:* The rightness of an act is the amount of happiness it produces. A well-known shortcoming of utilitarianism is that it is unable to account for certain moral intuitions involving fairness, justice, and rights. Utilitarianism often seems to give the correct moral answers only when one assumes that no preexisting rights are involved in the question. CUA advocates make this assumption. The purpose of health care rationing is to maximize the amount of *health itself* that is created by the rationing system. No individual has any particular right to health or to health care. The only claim that any citizen has on health care comes from that citizen's ability to convert the expenditure of health care funds into high amounts of HrQOL.

Citizens who can "reimburse" health care expenditures with high HrQOL will receive health care. Those who cannot, will not. The status of an individual person within this system is merely to represent a potential health outcome, a contribution to the overall sum of *health itself.*

The utilitarianism behind CUA presupposes that the maximization of HrQOL is the categorical goal of health care, and therefore of health care rationing. But this assumption is challenged by many biomedical ethicists, and independently by the general public. Tom Beauchamp and James Childress (2001) have reviewed the ethicists' critiques. Peter Ubel (2000) and Erik Nord (1999) have conducted studies on how the general public perceives the importance of various kinds of health care. Ordinary citizens consider the strict application of pure CUA analysis to be unfair and would prefer systems that would actually produce a lower HrQOL than the maximum. For example, they would spend more funds on extremely ill patients than would be justified by CUA analysis. This "rule of rescue" requires that funds be spent on extremely ill patients even when the costs of their treatment are unlikely to be compensated by large improvements in their QOL. Ordinary citizens are also reluctant to give nondisabled people a higher priority than disabled people for life-saving treatments *even though they believe* that disabled people have a lower QOL. So the prejudice of the general public against the high QOL of disabled people seems to be compensated by their refusal to go along with CUA in its implication that disabled people should have a lower priority for health care than their nondisabled peers.

The utilitarianism of CUA is inconsistent with the concerns for fairness that are expressed by many biomedical ethicists and the general public. It is unclear which values will be reflected in future rationing schemes. With respect to life-saving measures at least, the general public seems to consider people with impairments to be similar to ethnic minorities—disadvantaged groups that should be protected from further discrimination. This matches nicely with the views of disability rights advocates. But the assumption that disability implies low QOL is shared by the general public and by CUA advocates.

The artificial notion of HrQOL is potentially hazardous to disability rights. HrQOL is a special form of quality of life that links disability and health care. But it artificially separates disability from other life experiences that can cause unhappiness—experiences such as sudden unemployment and the loss of a loved one. It reinforces the deep prejudice that the disadvantages of disability are a special curse from nature itself. A person's biology (not an inaccessible environment) is the cause of the person's unhappiness. This is merely a modernized reincarnation of the same old stigma that disability has always held. Unlike other causes of sadness that can be accommodated and learned from, disability is seen to be a permanent loss of life's goodness.

An important principle of the disability rights movement is the exact opposite. The disadvantages of disability arise not from biology but from social arrangements, such as inaccessible environments. Technical rationing concepts such as the HrQOL misrepresent the causes of disadvantage for disabled people. Even if disabled people are able to resist the loss of access to health care that would result from a CUA rationing system, they may be equally harmed by the assumption (shared by biomedical policy makers and the general public) that they "by definition" have a lower QOL than their nondisabled peers. If this were true, then improvements to environmental accessibility could benefit them only in small ways. Why bother trying to improve the life of a person who "by definition" has a low QOL anyway? If the technical concept of HrQOL reinforces the public's belief that disability is unavoidably associated with a low QOL, it may undercut the disability rights arguments for greater inclusion and more accessible environments.

—Ron Amundson

See also Ethics; Health Care and Disability; Health Care Systems; Health Management Systems; Outcome Measures; Quality of Life.

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HEALTHY PEOPLE 2010

Healthy People is the term used to identify the agenda for improving the health and safety of Americans. The publication of *Healthy People: The Surgeon General's Report on Health Promotion and Disease Prevention* in 1979 set the initial objectives addressing the reduction of mortality across four age groups—children, adolescents, young adults, and adults. A fifth objective aspired to increase independent functioning among senior adults.

The second decade of Healthy People commenced in 1990 with *Healthy People 2000.* This agenda included 316 health-related objectives in 21 chapters. During deliberations about areas to include, disability was discussed during the late 1980s. Little data were available, however, to monitor the health and well-being of people with disabilities. Therefore, no specific emphasis was given to disability and health as the specific objectives were created. Throughout the 21 chapters of *Healthy People 2000,* 16 objectives referenced disability-related themes. Seven focused on the primary prevention of conditions associated with disability, and nine addressed health issues of people with disabilities. These seven included "people with disabilities" as a subpopulation in the analyses. The areas included leisure activity, weight, stress, mental health treatment, and clinical preventive services. The major emphasis for subpopulations was to assess differences with the general population. In the final review of *Healthy People 2000,* results indicated that of the six objectives that could be measured, half showed the disparities between people with and without disabilities to have been reduced or eliminated, and the remaining three to have stayed the same or moved away from the overall target.

In the mid-1990s, the U.S. Department of Health and Human Services began a dialogue with the Centers for Disease Control and Prevention to include people with disabilities in the third edition, *Healthy People 2010.* Disability has become an emerging public health issue due to the increased survival of children and adults experiencing limitations due to aging, chronic illness, traumatic injuries, and developmental disabilities. Two opportunities for inclusion were provided. First, "people with disabilities" was proposed as a demographic variable, alongside age, ethnicity, sex, and education level, for example, as subpopulations to describe the health of Americans. Second, a chapter specifically focusing on issues that are more specifically related to people with disabilities. The overarching goals of *Healthy People 2010* were to increase quantity of quality of life for all Americans and to eliminate health disparities. These goals were then able to be monitored for people with disabilities. The development of objectives took six years and included 250 individuals representing 75 advocacy, professional, university, and governmental entities. From the 28 chapters in *Healthy People 2010,* more than 100 objectives included "people with disabilities" as a subpopulation for data gathering. This will provide badly needed information that will allow health disparities among people with disabilities to be identified and monitored.

Chapter 6, "Disability and Secondary Conditions," is the disability-directed chapter and includes 13 objectives. There are several core issues addressed by the chapter:

> Challenging two commonly held false equations: that disability equals illness and that health equals medical intervention
>
> Affirming the role of the environment as critical to improving health and well-being
>
> Acknowledging the need for a standard definition of *disability* for use in surveys
>
> Establishing a common conceptual and coding framework for science, program, and policy—the World Health Organization's International Classification of Functioning, Disability, and Health

The 13 objectives are as follows:

> 6–1 Include in the core of all relevant *Healthy People 2010* surveillance instruments a standardized set of questions that identify "people with disabilities."
>
> 6–2 Reduce the proportion of children and adolescents with disabilities who are reported to be sad, unhappy, or depressed.

6–3 Reduce the proportion of adults with disabilities who report feelings such as sadness, unhappiness, or depression that prevent them from being active.

6–4 Increase the proportion of adults with disabilities who participate in social activities.

6–5 Increase the proportion of adults with disabilities reporting sufficient emotional support.

6–6 Increase the proportion of adults with disabilities reporting satisfaction with life.

6–7 Reduce the number of people with disabilities in congregate care facilities, consistent with permanency planning principles.

6–8 Eliminate disparities in employment rates between working-aged adults with and without disabilities.

6–9 Increase the proportion of children and youth with disabilities who spend at least 80 percent of their time in regular education programs.

6–10 Increase the proportion of health and wellness and treatment programs and facilities that provide full access for people with disabilities.

6–11 Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed.

6–12 Reduce the proportion of people with disabilities reporting environmental barriers to participation in home, school, work, or community activities.

6–13 Increase the number of Tribes, States, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and caregivers.

Workshops were convened in 2000 and 2002 to develop strategies to initiate new activities or encourage already-existing strategies to achieve the objectives. Workgroups are currently convened in five areas—data, policy, program, training, and children—to implement the strategies that were developed. *Healthy People 2020* should provide opportunities for furthering the objectives for which work has begun.

—Donald J. Lollar

See also Health Promotion; Quality of Life.

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HEARING IMPAIRMENT

The central issue for people with hearing impairments is that they cannot hear. While that seems totally obvious, its importance cannot be overlooked. Whether people with hearing impairments can hear some sounds; which sounds they can hear; when they can hear; and whether they can talk, use a telephone, read lips, or sign are all variable, but the fact of not being able to hear is not. Thus, one can make few assumptions about people with hearing impairments other than that they cannot hear some or all of the sounds in the environment. Hearing impairments make communication difficult; thus, the most disabling result of hearing loss can be isolation.

The physical nature of hearing impairment is also extremely varied. Hearing impairments may be genetic or environmentally caused, usually by illness. They may be accompanied by other conditions or they may not: Some hearing impairments coexist with other conditions, but often a person with a hearing impairment is otherwise perfectly healthy. Thus, the assumption that a person with a hearing impairment is ill is unwarranted without further information.

People with hearing impairments who know sign language can communicate effectively and at as high a level as their education will permit—but only with other people who know how to sign. People who can read lips are able to interact with speaking people, but lipreading itself is problematic. In English, for example, lipreading is about 25 percent successful for the average user and 50 to 75 percent for really skilled lipreaders.

Various types of assistive technology can provide remedies for the communication impairment that results from hearing losses, but none remedy the hearing impairment itself. Hearing aids can attenuate the hearing loss, but they work better for some people and in some situations than in others—primarily in one-to-one situations in quiet rooms. Cochlear implants also appear to be variably successful; although the predictors of success or failure are not fully established at this writing, people with previous knowledge of sound seem to do better than people without. Assistive listening systems, captioning systems, and computer technologies can be useful in ameliorating the communication impairment, although they are expensive and depend on more advanced technology than is likely to be available in developing countries. Several types of telephone substitutes can be used successfully where adequate phone systems exist.

Sign language, cued speech, or oral interpreters are available in some situations, as are phone relay systems that use operators as intermediaries. All are expensive and are not sufficiently available, even in developed countries, and they are of no use to someone without the requisite skills.

The variability in causes, presentation, amelioration potential, and results means that people with hearing impairments are not homogeneous. Some feel they are members of a deaf community, although many do not.

Deaf communities have tended to form whenever a sufficient "critical mass" is achieved. In the United States, where schools for deaf children began in 1817, deaf people tended to stay in the area after they graduated, sometimes finding jobs at the same school. Other deaf communities formed in localities where a concentration of deaf people worked in a specific industry. For example, deaf workers were "drafted" for work in tire plants in Akron, Ohio, during World War I, so a large deaf community formed there. In the United States, the fact that many deaf men worked as printers facilitated the growth of newspapers for the deaf community and contributed to its solidarity. In many countries in Europe and Africa, deaf communities formed around residential schools. Sometimes the communities were so separated that, because transportation was difficult and interacting unlikely, each had its own sign language. For example, in Zimbabwe, four sign languages had grown up around the residential schools, but the National Association of the Deaf was only formed (officially) in the late 1980s.

With the founding of the World Federation of the Deaf in 1951, the deaf community became international. Its goals at this time are improving the status of national sign languages, attaining better education, improving access to information and services, and improving human rights for those in developing countries.

Members of a deaf community may refer to themselves as "Deaf, not deaf." The capital *D* indicates a political or ideological stance that includes a strong preference for the use of sign language, an acceptance of deafness as a normal condition and not a disability, an unwillingness to accept the idea of becoming hearing, a desire for deaf children, and a desire to see the deaf community continue (and thus may include objections to mainstreaming and the closing of residential schools for deaf children).

People who live in deaf families or deaf communities or spend time among other deaf people have very different experiences from those who spend most of their time with hearing people, since they are unlikely to experience the communication barriers and consequent isolation experienced by people who cannot communicate with those around them.

There are two major dimensions that have a large impact on the experience of hearing impairment: age of onset and severity of hearing loss. Combined, these two dimensions create four categories, which are shown in Figure 1 and discussed below.

Cell 1: People with severe, prelingual hearing losses. Early-onset deafness can cause major problems in learning to speak, read, and write. These problems can lead to subsequent problems in education and employment. Children in this situation are at high risk for educational impairments unless they can develop an early linguistic foundation. Some children do succeed in developing that linguistic base through lipreading, but many do not. The earlier linguistic interaction starts, the more likely a child is to develop the necessary linguistic base, whether the interaction is spoken or signed. People in this category are most likely to consider themselves to be culturally deaf.

	Severity of Hearing Loss	
Age of Onset	more severe	less severe
prelingual	Cell 1	Cell 3
postlingual	Cell 2	Cell 4

Figure 1 Conditions of Hearing Impairment

Cell 2: People with severe, postlingual hearing losses. For some people, postlingual hearing impairment emerges slowly, over months or years, while others may literally wake up deaf after an illness or injury. For some, this happens in their teens or young adulthood, and for others it happens in later life. People who develop postlingual hearing impairments have very different experiences from those with prelingual impairments, because they can talk and can interpret speech if it is mechanically amplified. Their deafness may be as isolating as it is for earlier deafened people, but some of their communication modalities, such as speaking and writing, may remain useful. But with postlingual deafness comes the necessity for resocialization. That is, formerly hearing people must "become" deaf. Not only may they need to learn a sign language or another form of communication, but they may also need to overcome a cultural stigma against deaf people, since now "they" are "me." They may need to reorganize family relationships, occupational situations, and social networks.

Cell 3: People with less severe, prelingual hearing losses. People in this category may be even more marginalized than those with more severe impairments. Children may be considered to be "hard of hearing" and taught to speak and lip-read (often to the detriment of academic subjects), or they may be considered just to have "a little hearing problem." Some may succeed in developing a linguistic base through lipreading, but many do not. They are more likely to be sent to mainstreamed educational programs, where they may get a better education than those in "deaf" schools, but they are likely to be more socially isolated. As adults they may find themselves not able to function well with hearing people and so may need or want to move toward the deaf world. But the deaf community may not accept them because they are "not deaf enough." Especially if they do not know how to sign, they may find themselves between two worlds.

Cell 4: People with less severe, postlingual hearing losses. People in this category are likely to have lost their hearing at a later age than people in the other three categories. In developed countries, such people make up by far the largest proportion of people with hearing impairments. However, they are the group that is least likely to identify with other deaf people and/or to have any desire to learn a sign language. They are the most likely to experience the isolating consequences of hearing loss, although newer technological remedies may provide some assistance.

Overall, the variability of the condition of hearing impairment as discussed above is reflected in the polarizations within the deaf population. Some of the divisive issues are oralism (speech and lipreading) versus signing, assimilation (to the hearing world) versus separation, segregated versus integrated education, and Deaf versus deaf. These issues have led to contentious political actions, including the "Deaf President Now!" protest at Gallaudet University in 1988 as well as many others in all parts of the world. These polarizations make the possibility of one unified deaf community unlikely.

—Sharon Barnartt

See also Deaf, History of the; Deaf Culture; Sign Language.

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HEATH, JEFF 1955–2004

Australian activist and author

Jeff Heath was a self-described social entrepreneur, who gained public recognition for pursuing innovative projects aimed at social change for people with impairments. Heath had a significant physical impairment and was a wheelchair user from childhood. He was a Paralympian and sailor, who loved family life and cooking. Throughout his 30 years as a disability and antiwar activist, he was a persistent lobbyist who became a force in access campaigns, opposing economic rationalist dogma and euthanasia.

Heath subscribed to the belief that knowledge is power. Professionally, he was a writer, journalist, and editor of Australia's leading disability magazine, *Link*. He was a founder of the Disability Information Resource Centre in Adelaide, a prolific contributor to mainstream media, and a popular motivational speaker.

Heath had allies in countless forums in many countries was a member of many advisory structures. From 1988 to 1993, he was executive director of Disabled Peoples' International (DPI) South Australia. However, all who worked with him knew his impatience with group processes. Heath was at his energetic best when focused on tasks, analyzing public policy and hassling for positive change for people with impairments and subsequently the wider Australian community.

—Lorna Hallahan

See also Activism; Paralympics.

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HIP FRACTURE

In the United States, approximately 300,000 people fracture their hip every year, and half of them are age 80 or older. The incidence of fracture has increased as people are living much longer, and elderly people's unsteadiness on their feet can be affected by medication, dementia, and general frailty. Often the reason for the hip fracture is a fall, either in the home or on the street, and it is the way that elderly people fall that makes them particularly vulnerable to this type of fracture. For the younger patient, hip fractures are often caused by accidents, often involving motor vehicles and to a lesser extent sporting activities. Studies have shown that it is essential that treatment be carried out quickly, within 24 hours. Treatment usually consists of surgery to insert a bone plate or, in some cases, a hip replacement. The average cost to the health services for a patient with a hip fracture estimated in 1990 was US$20,000, and the entire cost to both private and public providers is estimated to be about US$5 billion per year.

The prognosis for very elderly people surviving hip fracture is poor in the immediate to long term. Complications for elderly people include thrombosis, pneumonia, and infections after surgery. Even with ever improving medical and surgical techniques, the long-term prognosis for the older person is still poor. In a study in six New England states, 24 percent of hip fracture patients died in the first year following surgery. Class and gender affect rates; for example, women have better survival rates than men, and those from lower socioeconomic groups have the worst.

To aid recovery after surgery, ward off potential complications, and increase the likelihood of survival, patients are encouraged to move and begin to walk with aids as soon as possible. Generally, for the younger patient this presents few difficulties. However, many elderly people are not able to take advantage of the rehabilitation programs due to their frailty, so sometimes their ability to improve after surgery is limited. In some cases, rehabilitation programs are not available so many elderly people who have fallen endure a diminished quality of life due to the disabling effect of a hip fracture and the loss of confidence that it can cause. As to be expected, younger people have better rates of recovery, although total hip replacement may be required as the patient gets older.

Since the results following surgery remain mixed, it seems that prevention of hip fractures for elderly people may be the best way to ensure that they do not have to endure surgery, the threat of complications, the potential for long-term disability, and a reduction in their quality of life. Charities in Britain run fitness training courses particularly for elderly people in order that they retain some flexibility and strength. Engineers are developing aids that reduce the potential for a fractured hip if an elderly person does fall. These include hip guards that are inserted in pockets in a special undergarment and act as a type of body armor to protect the hip. As research into preventive strategies improves, it can be hoped that the incidence of hip fracture and its disabling effects, which can cause a significant reduction in the quality of life of individuals, can be limited.

—Julie Anderson

See also Aging; Frailty.

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HIPPOCRATES (428–347 BCE)

Greek physician

Hippocrates was a physician, teacher, and author on the island of Cos in Greece. Little is known of his life. A corpus of roughly 60 Greek works (written between 420 and 350 BCE) has been associated with his name, though no text is certainly attributed to his hand. The sweep of the Hippocratic corpus includes texts on disease, deontology, therapy, and physiology among others. A cardinal feature of the corpus is its emphasis on natural, rather than divine or religious, etiologies of disease, often an imbalance of one of the four humors. The clearest evocation of this feature is in the case of epilepsy, which in other ancient sources was considered a religious or magical phenomenon. In the Hippocratic text *The Sacred Disease,* epilepsy was categorically identified as having "specific characteristics and a definite cause," namely, a surfeit of the humor phlegm. Similarly, paralysis, the Hippocratic *Aphorisms* tell us, is a sign of melancholia, or too much black bile.

By and large, the Hippocratics were more interested in generating a *prognosis*, or description of the past, present, and future of a condition (particularly its likelihood of improving) rather than theoretical etiologies and even diagnoses, though both are manifest.

The Hippocratic corpus includes references to scoliosis, limb fractures and lameness, epilepsy, paralyses, congenital conditions, sexual dysfunction, general debility, autoamputation, pain, and sensory impairments. Deafness was often seen more as a diagnostic sign than as a disability. Etiologically, the bowels were linked to deafness, which connection was used by later authors as a therapeutic mandate. Therapy within the corpus includes fracture reduction, crutches, orthoses, and humoral management. Psychiatric and cognitive conditions are also well represented.

The power of the Hippocratic corpus exists in large measure because of the emphasis that later authors placed on it, particularly Galen (AD 129–ca. 199/216); the first university professors of the Middle Ages; and eighteenth-century Western clinicians. To this day, a form of the "Hippocratic Oath" is still taken by many graduating medical students, thus demonstrating the long influence of authors more than 2,400 years ago on the medical model.

—Walton O. Schalick III

See also Galen; Humors, Theory of.

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HISTORY OF DISABILITY: ANCIENT WEST

The "ancient West " is a difficult term, calling into question cultural and geographic perception (*whose* west?). For the purposes of this entry, the term will refer to the ancient Graeco-Roman world, which was itself a shifting amalgamation of cultures, often distinctly "non-Western" cultures. The ancient Graeco-Roman world spans several millennia, from the third millennium BC through the fall of Rome in the fourth or fifth century AD. In short, the generalizations presented here do not necessarily apply to all places and phases of Graeco-Roman society.

Ideas about disability in the ancient world are part of our common consciousness. Images of Homer, Oedipus, and the Emperor Claudius—along with the phenomenon of Spartan infanticide of deformed infants—are often the first images that come to mind.

Greek civilization, especially fifth- and fourth-century classical Greek civilization, is generally considered the cultural and philosophical ancestor of the West. Current scholarship, though, is quick to qualify the view of antiquarians such as Johann Winckelmann, the eighteenth-century foundational scholar of art history, who viewed classical Greece as the pinnacle of human achievement and who assumed that Greek people themselves were the embodiment of perfection. As Charles Freeman wrote in *The Greek Achievement* (1999), "This was certainly a sanitized version of the original Greece and one could be forgiven for believing that ordinary human beings did not exist in ancient Greece at all." Indeed, people with disabilities are simply omitted in the earliest accounts of daily life such as Jerome Carcopino's *Daily Life in Ancient Rome* (1940).

But people with a wide variety of somatic and psychiatric variations did inhabit both the Greek and Roman worlds, and disability is one of the most recent categories of ancient social history to be examined. Interpreting disability has been influenced both by the romanticized vision of a heritage of perfect Western antiquity and by modern assumptions about what disability means. If one assumes a medical model of disability, in which disability is an individual misfortune to be corrected as far as possible by medical technology, the picture is indeed bleak. Howard Haggard's *The Lame, the Halt, and the Blind* (1932) tells dramatic tales about societies that lack rational medicine.

There has been a growing scholarly interest during the past decade in variations of the human body in the ancient world. Veronique Dasen couched her 1995 iconographic study, *Dwarfs in Ancient Egypt and Greece,* as a study of physical minorities. Daniel Ogden published *The Crooked Kings of Ancient Greece* in 1997. In addition, interest in the study of the human body in the ancient world is represented by a special volume of *Arethusa*, titled "Vile Bodies: Roman Satire and Corporeal Discourse" (Braund and Gold 1998). In 1999, the University of Michigan Press published *Constructions of the Classical Body*, a collection edited by James Porter.

A few scholarly works explicitly employ the perspective of disability studies, which is based on the tenet that disability is at least in part a socially constructed phenomenon—that is, no matter how real a missing limb or a psychiatric disorder might be, the meaning that any given society applies to the condition shifts over time and between cultures.

Among scholars of disability studies, there is no static or intrinsic universal assumption about what the human body should look like. Robert Garland, in *The Eye of the Beholder* (1995), transcends the understanding of disability in the modern, developed world and considers deformity from the perspective of the ancient Graeco-Roman world. Garland considers not only familiar categories of disability such as blindness, but he goes on to discuss emaciation and obesity and points out that baldness was a "serious and inhibiting social handicap." Nicholas Vlahogiannis also transcends the medical model by exploring the formation of attitudes in the discourse of social constructions of disability. Vlahogiannis looked at the disempowerment of disabled people through such systems as punishment and social positioning. Vlahogiannis's essays can be found in *Changing Bodies, Changing Meanings* (1998), edited by Dominic Monserrat, and in the collection *Health in Antiquity* (2005), edited by Helen King. My own work, which examines the intersection between ancient Greek and modern, Western portrayals of disability, is summarized in *The Staff of Oedipus* (Rose 2003).

Disability studies includes all types of disability, including cognitive and psychiatric. While there is no shortage of writing on mental illness in the ancient world, such as Bennett Simon's *Mind and Madness in Ancient Greece* (1980), most works focus on the interaction between Greek mythology and Freudian psychology. Allen Thither's *Revels in Madness* (1999) is refreshing in that it treats "madness" as a shifting concept. Patricia Clark's dissertation, "The Balance of the Mind" (1993), is the only work that examines the effects of mental health and illness on ordinary human beings, in the context of ancient daily life. This work is, unfortunately, not yet published. Even less scholarly material exists for cognitive disability, but quality makes up for quantity in the work of Chris Goodey's essays such as "Politics, Nature, and Necessity" (1999); Tim Stainton, too, has examined the phenomenon in essays such as "Reason and Value" (2001).

Some disabilities are mentioned in the ancient medical texts, most notably epilepsy, the standard work on which is Oswei Temkin's *The Falling Sickness* (1971). Many other disabilities are not even mentioned in the ancient medical literature, as disabilities were not seen as the categorizable medical phenomena that they are today. The evidence for physical disability is scattered, scant, and often contradictory. No discussion of disability survives that is composed by a person who identifies himself or herself as disabled. Nevertheless, literary, papyrological, and archaeological primary sources contribute to our knowledge about disability. Following are sketches of three impairment categories: mobility impairment, deafness, and blindness. These are modern categories, not ancient; many other disabilities existed; and people would have had multiple disabilities, not necessarily one at a time. Still, this sketch provides a sample and an overview of a few issues of disability studies in the Graeco-Roman world.

The ancient landscape included a wide variety of human variation, far more varied than portrayed in images of Graeco-Roman perfection that is the Renaissance and neoclassical artistic legacy. Some people acquired disabilities in the womb or in infancy; an ancient physician writing in the Hippocratic tradition observed that lameness lies in heredity. Impairments such as spinal malformation and clubfoot can be acquired in the womb regardless of genetic configurations. A mother's inadequate nutrition was a significant factor in the ancient world in terms of producing offspring with physical anomalies, and even if a fetus were to grow unharmed in the womb, its birth might be premature. Prematurely born babies are at risk for disability such as cerebral palsy and motor incoordination.

Children born without a handicap could acquire one from a variety of circumstances later in life. Permanent physical disability could result from injured, diseased, and lost limbs; from diseases such as arthritis; and from several other conditions. Even the most minor injury could have permanent consequences. Accidents or events causing fractures were common. Whether as a result of improper healing or as the result of infection, fractured and dislocated bones were likely to result in a permanent physical handicap in the ancient world. In the developed world, we take for granted that, with medical attention, even the most severe fracture will be undetectably repaired. Without medical attention, fractures sometimes spontaneously and completely heal, but not always.

While it is assumed in the developed world that medical attention to a broken bone will result in its healing, a visit from a doctor in the ancient world could have a range of possible results. In the ancient world, a doctor's training was not standardized, licensed, or necessarily respected. There was no standard medical treatment for any given malady, but rather a variety of treatment methods. Some treatments seem sound; others seem of dubious value to the modern eye. For example, the second-century AD Roman physician Galen was in favor of letting blood as a remedy for injured limbs.

Even if a bone is tended to and set properly, it must remain immobilized to effect complete healing. While animals with broken bones do this by instinct, the need to tend a shop or a field would probably override any human instinct to remain idle. The paleopathologist Srboljub Živanović, in *Ancient Diseases* (1982:27), wrote that "the morphological deformities that arose are really beyond imagination at the present time."

Ancient material about deaf people in the ancient world is even more limited than that about people with mobility impairments, but the evidence that exists suggests a grim life for the deaf person who did not speak. There is no suggestion of any sort of formal sign language. Muteness went beyond a physical condition in ancient perception. An inability to speak went hand in hand with an inability to reason, hand in hand with stupidity, embodied even today in the obsolete expression "deaf and dumb." Deafness was indeed a curse, sometimes literally. The word *deaf* appears in the surviving Greek inscriptions almost exclusively as a curse, and a powerful one. Deprivation of hearing, because it meant a deprivation of verbal communication and perceived intelligence, meant separation from the political and intellectual arena. A curse of deafness was appropriate not only for one's political opponents, whose speech could harm, but also for anyone who had too much power—many curse tablets are aimed at litigants.

In trying to reconstruct the daily realities of deaf people from scraps of information, it is worth considering that issues of speech and intelligence were different for the literate elite than they were for the bulk of the population but that we rely on the literate elite for almost all our information about deafness. The elite valued the very skills—such as fluency in communication—that they thought deaf people lacked. The deaf child of a farmer or shepherd, even if considered utterly stupid and incapable of political activity, could certainly carry out any number of tasks. Life in the ancient Graeco-Roman world for anyone who did not speak must have been frustrating occasionally. But while the consequences of deafness are synonymous with exile or death in the literature, it is important to remember that more people in the ancient world were interested in farming than in rhetoric; that is, the majority of the population was composed of peasant farmers, not politicians. Limited conversational ability among peasants might have been a frustration, but not an insurmountable condition.

In contrast to the dearth of deaf people in ancient literature, several blind archetypes are household names. The blind bard Homer, the blind seer Tiresias, and Oedipus Rex, who was blinded by divine punishment, dominate most discussions of blindness in the ancient Greek world. By supplying an apparent historical precedent, generalizations made from the tales of these figures support modern attitudes toward blindness and blind people, such as the idea that blind people are special but horrifying. It is fallacious, though, to transfer attitudes seen in the grand sweep of legend and tragedy to everyday life and to generalize that Greeks and Romans viewed blindness as a fate worse than death. In fact, the ancient concept of vision had little to do with the modern one. There was no measured scale of vision, from perfect sight to legal blindness. One was able to see, even if only a little, or one did not see at all.

No one in the ancient world was immune to blindness. Most of us in the developed world live in the luxury of assuming that we will not—among other fates—become blind. In the ancient world, it was perhaps more reasonable to assume that one would lose at least some of one's sight. It follows that in the ancient world, sighted people knew blind and sight-impaired people well enough to understand the abilities and limitations of failing vision and that there was not the cultural gulf between the sighted and the blind that exists today.

Ancient myths and tales reflect truths and anxieties about sight and blindness in the ancient world. The tales of blind people come from the ancient, contextual understanding of what blindness meant. Blindness meant adapting one's life and activities to the individual's unique condition. In contrast, measurements and categories for degrees of vision determine one's legal status as a sighted or blind person in the modern, developed world. Blindness itself, regardless of individual circumstances, is seen as pitiful and tragic, and, like any evident disability, overrides any other physical characteristic.

In conclusion, and in general, disability in the ancient world was treated as a family and civic issue, rather than a medical one, in which what was conceived of as a "problem" was inherent in the individual. Disability status was defined and negotiated between individuals on a case-by-case basis within a community. On one hand, this does not suggest a utopia; indeed, the lack of a recognized disability status negates the possibility of systematized accommodation and service. On the other hand, people with what we call disabilities were not discriminated against as a group.

—M. Lynn Rose

See also Blind, History of the; Emperor Claudius; Deaf, History of the; Galen; Homer.

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HISTORY OF DISABILITY: EARLY MODERN WEST

In the early modern West (1500–1800), *disability* was commonly defined as the inability to work sufficiently to take care of life’s necessities. Physically disabling conditions that were recognized by contemporaries included chronic illness, maims, deafness, blindness, mental problems (illness and intellectual impairment), and infirmity brought on by age or service. Several disabling conditions were understood via reference to the Christian religion and the dominant humoral theory of medicine, especially early in the period. Charitable and state provision became increasingly important, with the origins of disability benefits emerging as military pensions. That disability is a social and political construct is clear in its origins, with medicine being brought in only later merely to serve certain functions in the administration of benefits. In the seventeenth and eighteenth centuries, there were efforts to educate those with certain disabling conditions. Special institutions were created for that purpose.

During the medieval period, there were institutions for lepers (a disease that receded from the fourteenth century in Europe, but not in other places such as Brazil), almshouses, and hospitals for the sick poor. Institutions became more significant from the late sixteenth century for many disabled people, and they grew in number and size (madhouses; workhouses; hospitals for the poor, orphaned, aged; as well as veterans’ and military hospitals). The emergence of these institutions was a result of a change in policy. Whereas in the medieval period the disabled poor were free to wander and beg, this was curtailed from the early sixteenth century on, with begging criminalized. Increasingly, efforts were made to force the able-bodied to work. Efforts were also made to create pensions and to house those disabled to work in institutions. The old English poor law largely emphasized relief outside institutions in the parishes, paid for from compulsory local taxes from 1598 on. This system was influential to a greater or lesser degree in colonial North America. In much of continental Europe, private institutions run by religious confraternities or municipalities were created and grew in size. By 1591, Rome, with a population of nearly 120,000, had nearly 4,000 hospital residents, for example.

In seventeenth-century France, the Catholic Church reformed its charitable institutions, with the Company of the Holy Sacrament creating the Hôpital Général in Paris, housing and detaining thousands of disabled people. By 1700, more than 100 hôpitaux généraux existed in France, with over 100,000 inhabitants, including the insane, the chronic sick, alongside petty thieves, prostitutes, and single mothers. Some scholars have termed this development "the great confinement" (Michel Foucault). Large city hospitals—the Hôtel Dieu—treated the sick and disabled poor and became more medicalized in the eighteenth century, hiring surgeons and appointing physicians. Nursing orders such as the Daughters of Charity (1633) provided practical nursing skills and hospital labor.

Institutional treatment became increasingly important for those afflicted with a disease that was new to the West in the early modern period: venereal disease. Classic secondary symptoms of this disabling disease include terrible pains in bones leading to limited mobility and skin disruptions resulting in disfiguring scars, and for some, collapse of the nose. Although it had previously been believed that sufferers afflicted with this disease could not gain access to a hospital place, recent scholarship has proven that, on the contrary, hospital provision was widespread and a significant factor in the lives of those most affected. For example, up to 30 percent of patients in St. Thomas's Hospital in late-eighteenth-century London were victims of venereal disease (known as "foul" patients).

The origins of disability as a social and political category emerged with military pension schemes. The first state disability benefits were created in England in 1593, when Parliament enacted Europe's first national system for those disabled in war. Initially, the system had a very strong basis of entitlement: Disability experienced in military service entitled men to lifelong pensions. Poverty and financial assets were not criteria. Soldiers and sailors wounded in the service of the realm were treated as members of the community of honor, with hospitality extended to them in a way reminiscent of traditional noble hospitality. Even though the veterans were economically and socially inferior, they were nevertheless to be treated as part of the social world of the host (to enquire too closely into their financial resources would have been dishonorable). Governed (veterans) and governors (council and Parliament) in Elizabethan England thus agreed that disabled ex-servicemen were entitled to statutory relief. This strong conception of entitlement was not, it should be noted, rooted in modern notions of equality or citizenship but in premodern ideals of hierarchical social obligation based on status. In time, this entitlement basis was challenged in practice and later in law by developing, contemporary, poor law notions of disability that were based on the belief that only those disabled to work should be accorded benefits.

From the late sixteenth century, pension evidence from the disabled themselves shows the influence of the humoral understanding of the body on the disabled and those who administered pension schemes, military, and later, poor law. The disabled would narrate their service or life history, their wounds, describing the ways in which their wounds disabled them physically. Some also cited colds and disease, violent fevers and fluxes, which they had contracted in service or domestic life. These continued to plague them for a long time afterward, so as to make labor difficult. Several of the citations of cold and disease correspond to contemporary understandings of the humoral theory of the body, a theory that was understood and accepted by laypeople of different social classes as well as medical practitioners. Thus, the diagnosis was offered by the disabled veterans or domestic poor themselves, and it was generally accepted by those administering the pension systems.

Within the medical theory of humoralism, the human body was believed to be a semipermeable, irrigated vessel in which moved the four humors (blood, phlegm, yellow bile, and black bile). Health was maintained by the preservation of internal stability—balance—through evacuation of bodily fluids and the avoidance, if possible, of environments and conditions of life that upset one's internal stability. The humors moved with differing degrees of fluidity. And they left with varying degrees of efficiency. Heat was believed to promote solubility, cold to hamper it. Several disabled petitioners demonstrated a keen awareness of the permanent effect of heat and, especially, cold in military service and life upon their physical state.

In their general descriptions of wounds, men sometimes mentioned their loss of blood and bruises (the extravasation of blood) suffered on the battlefield. This was often combined with citing old age. It is clear that people believed that a significant loss of blood, or its being forced from its proper vessel in the case of serious bruising, could have permanent effects on the human body. The blood was believed to carry the humors, and as such an inordinate loss of it could irreparably upset one's internal balance. As one got older, the loss of a great deal of blood on one or more occasions would have a greater effect on one's health and strength. This was because it was believed that the bodies of the aged contained less blood than the bodies of younger adults. Aging was understood as a process of people gradually drying out. Thus, although in 1628 William Harvey revealed that blood circulated and that more of it flowed through the heart than could be created as a result of digestion, people continued to believe for some time that the body's production of blood was related to consumption and other factors such as age.

The meaning of some illnesses, as with wounds, was thus cast in historical terms by petitioners. What we would deem medically insignificant events triggered long-term chronic disability. It is clear from the petitions that although age was important in contemporary notions of pensionable disability, one had to be old and disabled to be considered: People were expected to work as long as possible.

By the late eighteenth century, petitions from the war disabled exhibit a marked decline in explanations founded in humoral theory, with mention of the effect of bad humors, as well as cold and heat in service, disappearing. Instead the surgeon's opinion is cited much more than it was in the seventeenth century, and explanations tended to be based more on physical diagnosis rather than the patient narrative. It may be that the decline of humoral medical theory in midcentury among elite physicians—the body as a machine—was filtering through, entering popular culture. In addition, developments in military medicine were influential, with an increasing emphasis on identifying diseases as entities and the development of standardized diagnosis and treatment. These developments contributed to the gradual decline in practice and importance of the disabled patient's story within a humoral context. Within pension systems, medical practitioners gradually became influential as functionaries from approximately the mid-seventeenth century on, after which they were gradually brought in to assist with the assessment of disability.

Some illnesses and disabling conditions in individuals (e.g., madness, epilepsy) and society (e.g., the plague) were linked traditionally to supernatural causes—fate, the devil (i.e., witchcraft), or more commonly, God's will (divine providence). This declined from the late seventeenth century. Contemporary links between illness, disability, and divine providence did not arise within the context of veterans' and old age benefits. Maims experienced in military service were the work of other men, and not God (no matter which side He fought on), and it was accepted that the elderly were more susceptible to disabling conditions.

Over the course of the early modern period, developments in science, philosophy, and medicine had a significant impact on understandings of disabling illnesses. This was particularly the case with respect to mental illness. Cartesian mind/body dualism fundamentally challenged the previous view that mental illness was caused by disturbances in the immortal soul or the mind. Instead, it gradually became accepted that such illnesses were caused by material, corporeal, problems within the body and brain. Thomas Willis (1621–1675) studied the pathology of the brain and the nature of the nerves, developing ideas about the physical origins of problems that had previously been assigned supernatural causes (e.g., epilepsy, narcolepsy). This shift occurred at the same time as a move away from the belief in an interventionist God to one that was much more distant and respectful of universal scientific laws. In addition, scientists became more careful to distinguish between mental illness and intellectual disability. With these intellectual changes over time madness lost much of its stigma, and new ideas about humane and scientific care and treatment developed.

Technological changes also had an impact on the way disabled people were perceived. With the invention of printing, for example, society saw a very gradual movement away from a primarily oral culture in which there was a link between civilization and deafness. Printing brought increased literacy and interest in improving eyesight, with the common use of eyeglasses by the sixteenth century.

From the sixteenth century on, there was increasing interest in understanding the nature of a number of disabling conditions. First deaf people and later the blind were studied and educational methods were developed. Education for the deaf is believed to have begun in Spain in response to inheritance laws that prevented deaf males from inheriting if they could not speak (early legal codes of nearly every European country did not allow a disabled person to make a deed, contract, or will or to testify in court). Aristocratic sons were taught to read and speak by a Benedictine monk, Pedro Ponce de Leon (1520–1584).

This work was continued by Jean Pablo Bonet (1579–1629), who used a hand alphabet and lipreading in his educational methods, an account of which he published in 1620. Seventeenth-century developments in England were influenced by the Spanish experience, with Sir Kenelm Digby (1603–1665), John Wallis (1616–1703), and others in and outside the Royal Society studying practical ways to teach the deaf. Attention was also devoted to the blind. John Bulwer (*bap.* 1606–1656) suggested a special school for the mute in the mid-seventeenth century, and later, Henry Baker (1698–1774) made his living educating the deaf. The British commonly used finger alphabets, likely with some use of signs, whereas in Europe teachers such as Johann Conrad Amman (1669–1724, Swiss) focused on teaching the deaf to speak. In the eighteenth century, deaf schools were established throughout Europe, with a dozen up and running by 1789.

Eighteenth-century developments in the education of the deaf and blind were influenced by intellectual changes. John Locke's *Essay Concerning Human Understanding* (1690) was significant in this regard. Locke (1632–1704) argued that the mind developed as a result of sensory perception and reflection (rather than innately). Accordingly, new experiences could develop new faculties: The deaf and blind could be taught.

The National Institute for Blind Youth was opened in Paris in 1784, founded by Valentin Haüy (1745–1822), who was one of the first to employ embossed print. Similar institutions were later founded in Berlin, Liverpool, and elsewhere. During the seventeenth century, an Italian, Francesco Lana-Terzi (1631–1687), recommended a system of lines and dots representing letters of the alphabet. In 1825, Charles Barbier, a sighted military officer, invented a raised-dot system intended to allow officers to communicate with one another in the dark. This system was refined by Louis Braille (1809–1852).

The growth of institutions for particular disabilities included the development of specialized treatments and educational services. Although positive in many ways, this process also reinforced existing, and created new, boundaries between the normal and those perceived as abnormal in society.

—Geoffrey L. Hudson

See also Blind, History of the; Deaf, History of the; Humors, Theory of; Poor Laws (United Kingdom).

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HISTORY OF DISABILITY: KOREA

Disability is *jang-ae* in Korean, which means barrier or hindrance, and *jang-ae-in* is the widely used term to call disabled people. The term for disabled people has been changed over time from *byeongsin*, *bulguja, janghae-ja, simsinjang-ae-ja*, and *jang-ae-ja* to *jang-ae-in*.

Historical studies of disability in Korea, which mostly emerged in special education, rehabilitation, and social welfare policy, have focused on legislation and state policies for people with disabilities. Traditional attitudes toward disability have been explored through the examination of proverbs, ancient folklores, religious scriptures, royal chronicles, and literature. Some explorations of disability history in Korea find parallels with the Western histories such as the experience of stigma, the interpretation of disability as moral punishment, and widespread and institutionalized exclusion of disabled people. Through modernization and Western influence, disability policies have been thought to enhance disabled people's lives. Others sought to read Confucian, Taoist, and Buddhist principles regarding body and disability as the indicators of traditional attitudes toward disabled people before modernization and generalized them as "humane," "benevolent," and "holistic" in comparison to Western maltreatment of disabled people.

ANTIQUITY AND MIDDLE AGE

The alleged earliest reference to disability is in *Samguk Sagi* (*The History of Three Kingdoms*, 1145). This book documents King Yuri Isageum of Silla (a kingdom that existed from 57 BC to AD 935), who provided food to widows, widowers, orphans, people without families, the elderly, the diseased, and people who were unable to support themselves in the winter of AD 25. Similar records appear regarding Goguryeo (37 BC to AD 668) and Bakje's (18 BC to AD 660) relief policies around the fourth century. The stories of disabled people in the text of *Samguk Yusa* (*The History of Three Kingdoms*, complied approximately in the 1280s by Ilyeon) provide rich texts in which one can explore the meaning of disability within ancient Korea from the fourth century BC to the seventh century AD. It contains stories about a disabled person being exorcised and receiving eyesight and being healed from an illness by the power of Buddhism. These stories show that disability was appropriated to expand the power and influence of Buddhism. In parallel, there is a story where the state rewards a daughter who sold herself as a slave to support her blind mother, and this story is also used to emphasize Confucian value of filial piety (Ji'eun story in *Samguk Sagi* and a filial daughter in *Samguk Yusa*). Similar stories have appeared later including "Sim Cheong Jeon" ("The Story of Sim Cheong"), which deals with a blind father whose disability is eventually cured through the sacrifice of his daughter. Disabled figures in other Confucian tales often provide moral challenges to nondisabled characters by becoming obstacles to overcome. For example, Tomi's story from *Samguk Sagi* is about chastity of a wife after her husband was made blind as a punishment.

It is common to interpret ancient texts presenting disability as a punishment of moral wrongdoing, as well as reflecting karma from a previous life. Disability is often positioned as a sign of sin or as dishonor of the family in this context and is often blamed on the parents, mothers in particular. Interestingly, however, disability is also presented as a sign of being more likely to reach spiritual transcendence in some ancient texts, such as in the Chinese Taoist scripture *Chuang-Tzu* (or *Zang-Za*) and often considered as vantage point due to the possible exemption of labor conscription and military services.

Later, in the Goryeo Dynasty (936–1392), there is a record in *Goryeosa* of blind people, shamans, and blind monks as having superstitious power. In *Dongsagangmok* (1778), there is a reference to a guide dog for a blind orphan who managed to survive when the parents died in a disease epidemic. In this period, oriental medicine facilities were developed to provide relief care and shelters to people who suffered from poverty and diseases through Dongseo Daebiwon and Hyeminguk. King In-Jong gave people with disabilities and minors reduction of the punishment, and King Won-Jong required that a person be designated to support each sick person in the village. Disabled people and their caregivers began to be exempted from army service and labor draft (Im An-Su 1993). Seonghyun wrote in *Yongjechongwha* that blind people were hired and educated in Myeongtongsa as prognosticators for royal governance.

In the Chosun Dynasty (1392–1897), blind people continued to receive royal education in prognostication studies (Myeonggwahak), yin and yang studies

(Eumyanghak), and music education in Seowungwan until the fifteenth century. Gwanhyeon Maeong'in refers to royal blind musicians. Royal chronicle shows a record of the official position and promotion given to blind musicians (Chosun Wangjo Sillok, 1431). Specialization of blind people as musicians appeared in the *Analects of Confucius* (when Sagwang made himself blind to sharpen his hearing sensibility and Confucius taught how to accommodate blind musicians). There were legislations and vocational trainings to provide poverty assistance for people with disabilities (especially blind people) to assist their independence (An Byeong Zeup and Jeong Jae Gweon 1983). Some folklores tell that blind people in this period were farmers and teachers in addition to fortune tellers, and the origins of their blindness vary from the ancestor's sin, punishment of heaven, fung sui, violation of taboo, and aging. Rules of decorum, *Sasojeol*, written in the eighteenth century taught that it was unfair and dangerous to call disabled people pejorative names. Military exemption became systematized in the constitutional law *Kyeongguk Daejeon* (1485) for the eligible group of people including minors below age 16 and people with epilepsy; blind in two eyes; who had amputations of more than two limbs; who were mute, deaf, or dwarf; or who had paralysis in more than one limb.

PREMODERN LITERARY REPRESENTATIONS

"Nocheonyeoga" ("Song of an Old Spinster") appeared in *Samseolgi* and introduces a first-person poetic narrative that addresses how the narrator's "deformed" status causes her singleness in the traditional kasa form (Choi 2001). It consists of a narrator's prose preface and epilogue and the spinster's soliloquy and shows that the disabled spinster attempts to address her abilities and effort to get married. In addition, this story demonstrates the normalization of disabled people through marriage by showing that the spinster's disability disappears after the marriage; this transformation also appears in the folk tale "The Half Man." There is another nineteenth-century short reference in "Heungbu Jeon" ("The Tale of Heungbu"), in which a party of blind men came out of a gourd, picking their way with their longsticks, while their sightless orbs were raised toward the unseen heavens and offered them to tell the fortunes of the family. They were employed in order to chastise the brother of Heungbu for his stinginess and greediness and to extort money from him with other groups of people such as shamans, kisaeng, Buddhist priests, a jester, and officials.

In the premodern period, disabled people were called *byeongsin,* which means sick body as an overall term. There were individual terms referring to specific disabilities such as *jeolleumbari* (a lame person); *anzeunbang'i* (a quadriplegic); *jangnim*, *sogyeong*, *chambong,* or *bongsa* (a blind person); *beong'eori* (a mute person); *kwimeogeori* (a deaf person); *kopchu* or *kopsadeung-i* (a person with a humpback) and *kombaepari* (a person with a short arm); and *babo*, *cheonchi*, and *meojeori* (a person with cognitive disability). It seems that there were less terms for cognitive disability in this era, which is read to be due to the emphasis placed on physical ability by the primarily agricultural society. *Byeongsin* is still used today often as a curse word. Bak Hee Byeong traces the usage of this term in premodern literature and concludes that it was used in a descriptive way referring to a sick body but started to have pejorative meaning implying inferiority of the persons in the late eighteenth century. According to Bak, in the late nineteenth century during the Enlightenment period, this word started to be employed as a symbol of the old customs that must be eliminated in order to build a strong nation.

In the Patriotic Enlightenment period (1905–1910), disabled characters were culturally employed to represent Korean identity amid the conflicts between traditional values and customs and modernization. Kyeong-Hee Choi argues that the trope of disability surfaced largely within a sociopolitical perspective that emerged in response to a sense of national crisis. The newspaper *Daehan Mae'il Sinbo* presented the unique genre of a serialized story in 21 installments with two disabled characters, "Sokyeong'gwa Anzeumbang'i Mundap" ("Questions and Answers between a Blind Man and a Quadriplegic") from November 17 to December 13, 1905. The anonymous writer's dialogue style satire subjects able-bodied people and the social situation to the scrutiny of two disabled characters; however, two characters signify old value and custom.

MODERN SPECIAL EDUCATION

Modern special education and institutions for disabled people were first introduced in Korea by the imperial inspectors Sinsayuramdan, sent to Japan to learn modern civilization, and Yu Gil Jun, who traveled Japan and Western countries. Yu Gil Jun introduced asylums in the West and special education facilities in his book *Seoyugyeonmun* (1895). With the arrival of American missionaries, modern special education is believed to have begun in Pyeongyang in 1894 by Rosetta S. Hall when she first started teaching a blind girl. Western missionaries fed imperialism in the form of medical and educational practices without making evident the Christian mission in order to get permission to start their activities. Missionaries especially focused on disabled people and women. Jung Keun Sik (2002) argues that missionaries "rediscovered" lepers in Korea in the process of implanting modern medicine and Protestantism. Jung also argues that missionaries maintained competitive relationships with Japanese colonial management for disabled bodies.

It is possible to see the effects of the Christian origins of the special education system, particularly in its cultural positioning of such education as an act of mercy and because many private special education schools are affiliated with Christian organizations. Hall's first special education class was initially located in the Hospital for the Children and was directed toward teaching blind and deaf girls and also providing medical treatment to women. It developed into the special education school called the School for the Blind and Deaf in 1909. Other residential schools for the blind opened in different areas including the School for Blind Boys established by the Presbyterian missioner Alice Moffett in Pyeongyang (1903) and the Custodial Care Facility in Seoul established by the British missionary Jean Perry in 1914. In 1923, Pak Du Seong established the Korean Braille system, Hunmaengjeong'eum, when Hall's New York style Braille was found insufficient in the application to Korean letters.

Until the late 1960s, special education was mostly aimed at blind, deaf, and cognitively disabled children. Children with mobility impairments started to be educated in special schools in the late 1960s. In 1911, the Japanese colonial government opened Jaesaengwon to provide custodial care to orphans and deaf, blind, and other disabled children. Maeng'abu in Jaesaengwon was the first public school for the disabled and provided vocational training. After decolonization, Maeng'abu changed into the National School for Blind and Deaf. Paramedical vocational trainings such as acupuncture and massage therapy were set up as the curriculum for blind people. The first special education class was installed in a regular elementary school, Dondaemun gongnip gukminhakguo, in 1937 (Kim Byeong Ha 1983).

Special education was moved from the public health domain into the category of education after the Korean War. The war left many people disabled and led to the establishment of the rehabilitation institute and the growth of rehabilitation medicine. Postwar institutions for orphans and disabled children were usually connected in some way to church or charity organizations. The independent South Korean government set various laws and regulations with respect to mandatory education. However, Article 98 of the Education Act exempted certain children from elementary schooling. These children are "those with a disability, developmental delay, imperfection, illness or any other condition making school education impossible." The disability movement would later argue that this exclusion amounted to discrimination against disabled children. In the 1950s, legislation focused on supporting disabled veterans and their families, and in the 1960s, policies for compensating veterans were reinforced. Policies also started focusing on supporting industrial disability compensation insurance.

SURVEYS

In 1961, the first national-level survey of disabled children, *Hankuk Janghae Adong Josa* (Handicapped Children's Survey), was conducted and funded in part by the Pearl Buck Foundation and the U.S. Army. Categories of the survey include "paralytic or palsied, deaf and dumb, deaf only, blind in one eye, hunchback, stuttering, totally blind, hare lip or cleft palate, epileptic, partially blind, psychotic, clubfoot, and racially mixed." It is noteworthy that racially mixed children mostly born between Korean women and U.S. soldiers are included and labeled as "socially handicapped."

The 1966 census of people with disabilities, *Janghaeja josa,* by the Ministry of Health and Social Affairs was based on the 1961 survey and maintained the same categories. "Children of mixed racial parentage" disappears in later statistics and definitions of disability. Later categories appeared to have a more medically influenced definition system including mental retardation, mental disability, physical disability, visual disability, hearing disability, and language disability.

Saenghwalbohobeop (Social Security Law, 1961) allowed the establishment of rehabilitative institutions, and minimum social security was promulgated; 1961 marks an important beginning of governmental control over the disabled population by forwarding institutionalization under the banner of "protection." Mojabogeonbeop (Maternity and Child Health Law, 1973) started allowing abortion in case of "genetic or eugenic causes" or "contagious diseases." The government from this period drove an intensive economic development policy and the welfare of the citizens was left behind.

Statistical surveys on disability people continued in 1962 by the Institute for Economic Planning on injury rates, the 1966 census of disabled people, and the 1968 and 1975 national statistics on disabled people supplemented the population census. The effort to identify the realities and the magnitude of the disabled population was forwarded even more in the 1980s. National surveys of disabled people from 1980 and 1985 show this effort, and after 1990, it became required by law to conduct surveys every five years. The 1980 survey did not include disabled people who lived in the institutions. The term *jae-ga-jang-ae-in* referring to disabled people who reside in the domestic space started to be used in 1991 national statistics as a distinctive category as opposed to institutionalized disabled people, *si-seol-jang-ae-in*. In 1988, the government began to require that all disabled people register to be identified as having a disability to be eligible for benefits. It is common to see disabled people explain their gradients of disability given by this registration procedure and medical examination along with the types of disability. The gradient is entitled based on the degree of limitations, and the first degree of disability refers to the greatest limitations. These gradients reflect the categorization of disability according to functional limitations and its effect on disabled people's identities.

In 1973, there was an attempt to embark the Sterilization Law of Mentally Retarded People (Kim Mi-Ok et al. 2004). In addition, given that the competitive educational system allowed only six years of universal education and required entrance examinations for middle school and high school, which included physical fitness tests, people with post-polio syndrome—who were more frequently included in regular education in spite of its inaccessibility—were often subjected to this specific discrimination until the exemption of physical tests was enacted in 1972. Many people with post-polio syndrome born in the 1950s and 1960s attempted careers in medical or paramedical disciplines, pharmacies, and oriental medicine; this practice was in line with the public belief that those professions were appropriate for some disabled people—mostly those who could walk or had minimal physical disabilities—with less discrimination. However, in the 1970s universities often rejected them due to their disabilities. In 1967, Hanguk Ilbo forwarded a campaign reflecting the social attention to people with post-polio syndrome under the slogan "Let able-bodied people take care of children with polio" (Kim Mi-Ok et al. 2004).

Under the influence of the 1981 International Year of Disabled Persons, the Ministry of Health and Social Affairs developed the Welfare Law for Mentally and Physically Handicapped (Simsinjang'aeja Bokjibeop) under the military government's "Welfare State" propaganda. Paradoxically, the number of institutions grew in this period significantly and custodial care started to be supplemented by medical rehabilitation, therapies, and vocational trainings in the institutions. The Special Education Promotion Law was enacted in 1977. However, less than 20 percent of disabled people benefited from formal education until the early 1990s. The expansion of special education classes from the mid-1970s is also characterized by an effort to exclude students who are identified as below certain standards in school achievement or who are considered as interrupting the education of others. Economic support started to be provided to people with disabilities such as social security pensions and tax exemptions in the 1980s. The legal term for people with disabilities changed to *Jangae'in* from *Jangaeja* in this period.

The International Year of Disabled Persons in 1981 and the declaration of disabled people's human rights and the principles of antidiscrimination provided a background as the disability movement in Korea emerged during the mid-1980s. The discourse of social responsibility of disability rather than individual fault regarding the problems faced by disabled people emerged. The human rights of disabled people became the dominant rhetoric of the disability movement. In 1986, various disability groups such as National Union of Physically Disabled Students became very politically active, aiming at the presidential election the following year. In April 1988, the public protest of disabled people was held in front of the Myeongdong Catholic Church. The disability movement had opposed the hosting of the Paralympics in Seoul because it was believed to cloak the severe violations of the rights of disabled people in their everyday lives and extreme poverty. For instance, sterilization is still practiced on many women with cognitive disabilities as a form of contraception. Depo-Provera has been suggested by medical doctors to parents as a means of removing the menstruation of females with cognitive disabilities. Also, corrupt private institutions that exploit disabled people by using them to raise funds were also the targets of the disability movement. The shared goal of disability organizations was to amend the welfare law to enhance social status of people with disabilities, and to establish legislation for employment and affirmative action in higher education. Activists often viewed disability oppression mainly as a class and poverty issue under the capitalist system that considers disabled body as useless in terms of labor power.

The disability movement celebrated the passage of legislation of the Employment Promotion Act for People with Disabilities in 1990, which requires a 2 percent quota system for eligible workplace. The Accessibility Promotion Law for disabled people, pregnant women, and the elderly enacted in 2000. The amendment of the Welfare of People with Disabilities Act expanded the definition of disability. It includes physical disability, brain neurological impairment, visual impairment, hearing impairment, chronic illnesses, language disability, cognitive disability, mental disability, and developmental disability.

The emergence of the disabled women's movement illustrates the importance of gender in the experience of disability (Kim Eunjung 1999). Disabled women asserted their different needs and experiences from disabled men and nondisabled women during the late 1990s. For instance, sexual violence in institutions and communities especially against women with cognitive disabilities has been a neglected issue from both the women's movement and disability movement. Often staff and volunteer workers were responsible for this violence. Disabled female activists who encountered a male-centered atmosphere within disability movement started to organize feminist groups with an alliance of non-disability-identified women. The disabled women's movement came forward launching cultural celebration of different bodies and pride as women with disabilities and providing challenges and different perspectives on the body, sexuality, beauty, and femininity. There has also been increased awareness among disabled women of the needs of an alliance with marginalized groups such as lesbians and women laborers, and some links have been made with the organizations for women in the sex industry in which the exploitation of disabled women occurs as well. Enhanced penalties for sexual violence when the victim has a physical disability were expanded to include mental and cognitive disability in the Sexual Violence Act.

Access to public transportation has been an important issue in contemporary Korea. Prompted by the deaths of several disabled people while using unsafe devices such as a stair lift in the subway that had been employed as an expedient remedy for accessibility, the disability movement has undertaken militant actions such as hunger strikes, blocking public railroads, and delaying subway trains in 2001. Along with these protests, some organizations called for antidiscrimination legislation.

In spite of the efforts of disability organizations, many people in Korea continue to see assistance for disabled people as an act of kindness or a benefit, rather than an issue of human rights. The disability movement continues to raise important issues such as cultural invisibility, economic hardship, unemployment, insufficient medical services, lack or inaccessibility of education, inaccessible housing and transportation, institutionalization, and human right violations such as forced sterilization, infanticide, and double suicide of parent and disabled child.

With regard to the North Korean situation of disabled people, very little information is available and only through the testimony of people who escaped or through international human right reports. It has been reported that in the 1960s, there was a massive forced migration of little people in one village in Hamgyeognamdo by the command of Kim Il Seong. Pyeongyang, the capital of North Korea, has been kept from having disabled people in public by expelling disabled people to rural areas. It is allegedly known that due to city beautification and reproductive control, little people and people with hereditary diseases or physical disabilities are institutionalized. The 1998 North Korean Human Rights White Paper documented that there has been forced sterilization of disabled people practiced (Choi Eui Cheol et al. 1998).

—Eunjung Kim

See also Advocacy; Blind, History of the; Confucius.

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HISTORY OF DISABILITY: MEDICAL CARE IN RENAISSANCE EUROPE

The European Renaissance lasted roughly from 1400 to 1600, its period varying somewhat by region, but it had little effect on medical practice. The two events that influenced medical concepts significantly were the writings of Paracelsus (1493–1541) that opened the possibility of questioning Galenic dogma, and the two anatomical texts of Andreas Vesalius (1514–1564) that corrected some Galenic anatomical beliefs. Health care was practiced according to the 1,300-year-old traditions of Galen (AD 129–ca. 199/216) by a few university-educated physicians who largely served the clerical and secular nobility. There were a larger number of apprenticeship-trained barber surgeons, as well as itinerant quacks, while the peasantry in general cared for themselves. The little information there is regarding care for the chronically disabled pertains mainly to the institutional management of those diagnosed with leprosy. Some towns, Nuremberg, Bavaria, for example, made a considerable effort to provide financial aid to the unemployable.

This entry presents a sampling of sixteenth-century medical opinions regarding some of the causes and treatments of psychiatric, neurologic, orthopedic, and gastrointestinal conditions that would now be considered potentially disabling. It is based on four books published between 1543 and 1596, each of which had earlier editions. The authors were Giovanni de Vigo, an Italian, who was surgeon to Pope Julius II; Felix Wirtz, a Swiss surgeon; Christoph Wirsung, a German physician; and Hieronymus Brunschwig, a German surgeon. The first three were texts for other practitioners, the last a home medical guide.

The symptoms these writers have provided frequently are inadequate to make a modern diagnosis, being lumped or split into diseases consistent with pathologic concepts of the time but inconsistent with ours. On the other hand, the modern reader may be tempted to make a diagnosis by interpreting an astute observation quite differently from the observer's belief. Pathologic explanations were based almost entirely on the imbalance of or obstruction by humors. A principal pathogenetic diagnosis was "aposteme" or its synonym, "impostume." This may be "hot" or "cold." Specifically, it is an abscess, a localized accumulation of pus. Any superficial swelling might have been so designated, as well as any localized internal symptom. Palpation and color could determine whether a superficial aposteme was hot or cold. Internally, this differentiation appears to have been arbitrarily made by the writer. Surgeons wrote less about humoral pathology than physicians because they dealt more with trauma.

Overall, more space was devoted to "effective cures" than to the description of diseases. The "cures" were largely botanical, and the descriptions were only occasionally accompanied by instructions for their preparation and administration. Actually, few people ever were treated by a physician, and there is no information about how extensively a particular medicine really was employed. Furthermore, a remedy may have appeared in numerous publications because of its reputation rather than its availability. Some circumstances were deemed incurable and some signs of imminent death were specified. However, descriptions of the duration of an illness were consistently lacking.

While medical symptoms had humoral explanations, behavioral peculiarities still were widely attributed to magico-religious causes. Wirsung addressed this unequivocally. In regard to phenomena that we might interpret as preconvulsive auras or hysteria:

> They are not signs of a pinching devil or witches . . . but in truth none other but a natural sickness. [Describing either coma or hysterical rigidity:] the common people [believe that] Satan mingles his wiliness, . . . but this numbness agrees with infirmities of the brain. There are three kinds of "altered disposition": [1.] Delirium, which when associated with fever is called frenzy, is caused by the admixture of phlegm to hot humors. [2.] Mania is caused by hot humors, mainly yellow bile. [3.] Dementia, in which the patient is "wholly out of his right mind" only results from cold humors.
>
> The brains are the uppermost and chiefest of all the inward members of man's body, a place and abode of the understanding, memory and judgment. . . . Hence do also spring all the sinews and spread themselves through the back over all the body, strengthening and conjoining it, making it movable and sensible. (p. 117)

In Wirsung's psychiatric discussion, nerves are "sinews," while in the musculoskeletal section "sinews" clearly are tendons and ligaments. Contrary to "sinews," tendons and ligaments lack sensation. The brain is "insensible," but "this precious and tender part is subject to many accidents which bring very great inconveniences. . . . When sinews become inflamed the brain is affected so that there is mental deterioration."

"Palsy is indeed a swift, grievous and terrible disease which has its offspring in the brain" (p. 134). This comprehensive designation includes a gradually developing lethargy (perhaps encephalitis); tremor or small palsy (perhaps including Parkinson's disease); epilepsy in old men and young children which occurs with or without motion, and is most severe if there is incontinence; sudden loss of motion and sensation without loss of consciousness; and the most severe, apoplexy. This may initially resemble death. The main indicator of its severity is the characteristic of the respiration.

Residuals of a stroke are not described, but "albeit that it were cured, yet it does turn to some other sickness."

Palsy may result from trauma: "If so be that one falls so hard, or is beaten or struck that thereby forthwith he is taken with the Palsy, then it is not to be helped; but if it comes slowly afterwards upon one." There are various medications. Facial palsy is considered separately. "[It] is a convulsion of the mouth and lips to the right or left side, at other times shutting one eye." (This probably includes Bell's palsy.) Lameness has many causes such as apoplexy, the pocks (possibly syphilitic arthropathy), hectic consumption (possibly tuberculous arthropathy), and chronic dislocations. It is associated with withering of limbs and contractures and is mainly treated with poultices.

De Vigo succinctly attributed various functions and dysfunctions to specific parts of the brain. Each of its four parts is controlled by a different humor: blood in the front, phlegm in the rear, bile in the right, melancholy (black bile) in the left. He conceived there to be three ventricles: The largest, in front, receives sensations; the rear houses imagination; and the middle, common sense. An aposteme in the substance of the brain is fatal. A cold aposteme in the middle ventricle causes forgetfulness. Vapors in this region cause vertigo or loss of vision, while obstructive humors cause a palsy. If all ventricles are blocked, the result is apoplexy. "The cure of the palsy . . . I will leave to my masters, the Physicians, for most often it has a physical cause and therefore its cure pertains to them." Nevertheless, since palsy may result from head trauma, some medicines will be described.

Three writers differed in their discussion of joint diseases, while Brunschwig ignored them. According to Wirsung, arthritis is "the pain of the joints, or an inflammation of the joints, which proceeds from within the body, and the Tendons be annoyed, hurt and pained. It is none other than a dispersed Podagra over the whole body." Tophaceous (genuine) gout is incurable. Wirsung and de Vigo agree that hot gout is indicated by erythema and is associated with blood. It has dire and potentially fatal consequences. Cold gout is indicated by pallor and mild discomfort, but it is the most protracted. Its cause is predominantly phlegm. Wirsung defined an intermediate severity caused mainly by the bilious humor, with sharp pain but no erythema. In addition to appearance, cold gout is differentiated from the most severe variety by the quality of the pulse.

Wirtz, like de Vigo, a surgeon, did not concern himself at all with etiology, but discussed trauma that causes drainage of synovial fluid from an injured joint. Normal synovial fluid, he believed, is produced by ligaments and is required for joints to function. It must be differentiated from pus, but in an improperly treated wound may become purulent. Prolonged loss of this fluid from a joint can destroy it, or can fatally drain moisture from the entire body. Such an injury must be treated by drying medicines and proper bandaging. The treatment of fractures by setting, splinting, and binding is primarily the responsibility of surgeons. However, advice is offered in regard to auxiliary medical remedies.

Worm infestation was the one medical ailment for which the pathogen did not require invocation of humors. Its causes included (presumably communal) bathing and eating pork. This suggests that trichinosis was recognized, but since muscle pain is not cited, this is unlikely. The association of worm infestation with children who eat much fruit suggests a belief that maggots in fruit become intestinal worms. Wirsung recognized three varieties: long worms (possibly tapeworms) that reside in the upper intestine, ascarids that reside in the stomach, and small worms "like maggots" (possibly pinworms) that reside in the rectum and cause severe itching. The surest sign of infestation is that the patient excretes in the stool small things resembling gourd kernels. The main symptoms in children are irritability and restless sleep. Adults experience severe abdominal pains. Treatment is necessary because obstruction and, last, painful death may occur. High-lying worms are best treated orally and low-lying worms by enemas or suppositories. The choice of vermifuges is particularly large. Some treatments were biphasic: the first potion to kill the worms, the second to expel them.

Wirsung warned in regard to blood letting: "Good heed is to be taken of the strength and power of the patient, for . . . the veins in the lower parts weaken the body more when they be opened than those in the uppermost parts." Compared to medications and bleeding, bathing was infrequently recommended, probably because this was less effective than bleeding or purging in eliminating noxious matter. One may bathe in seawater or sulfur water. Simply bathing in lukewarm water after a stroke was permissible, but would be more effective if steeped cooling herbs were added. Baths that opened the pores and caused perspiration were more effective, but not necessarily by immersion in hot water. Alternatively, the patient might be exposed to a vapor created by spreading powdered herbs over hot irons over which scented water is poured. He is then washed with water after he leaves the steam. Since bathing opens the pores, it is potentially hazardous because it permits entry of "infection." In a communal bath "as well the pores of the [plague] infected as of the sound are opened, whereby the venomous vapor of the infected is let forth, and may easily be received of the healthy. . . . If one cannot sweat, heat bricks or other stones very hot and wrap them in a wet cloth. Place them under the feet, armpits, on his sides or between the legs. The vapor will cause the patient to sweat."

Little advice is given for convalescence, and none for the care of the disabled. According to Wirsung, when "sick folks begin to mend, and the disease wears away, the breath begins to be free, the pain to cease, the sleep to come, and have appetite for meat . . . the patient begins to recover" and a light diet is recommended. Above all else for the recovery from all diseases, the patient should relocate, "especially to draw near to mountains or hills where it is dry, far from the sea and stinking lakes." Brunschwig, writing for families rather than colleagues, did not describe signs of convalescence nor diets. He recommends baths "for them that have been long sick or whose bone marrow is corrupt, or whose blood is corrupt and deficient." Various ingredients should be put into as much water as is practical, and "bathe in the morning fasting so long as he can endure it," but do not add more water, presumably because this would dilute the effect of the additives.

Opinions about opium, one of the few botanicals having major pharmacologic effects (henbane, the source of atropine alkaloids, is another), varied. Wirtz was particularly positive. "It calms agitation, eases pain in the head, creates calm sleep, drives off visceral pain, strengthens the brain, stimulates the spirits, brings on happiness and a good appetite. . . . You must first evaluate the patient carefully because dosage depends on the circumstances." His only warning was not to prescribe opium in the presence of pulmonary symptoms. The authors leave the implication that apothecaries had ready access to opium.

Wirsung gave several receipts for oral or topical administration using seeds of the white poppy. Made into an oil, it "assuages all pain, cools, and by anointing the temples sedates and as the hot vapors draw to the head in any hot sickness it assuages throat pain, the heat of agues and nightmares." He stated that poppy seeds are used in almost all receipts for sleep, but if such receipts are not effective "then opium of necessity must be used" to obtain some rest, but not without the counsel of an experienced physician.

De Vigo believed that there are 15 kinds of pain, but three types of treatment: (1) external medicines that evaporate the cause by restoring normal heat; (2) altering the evil complexion (humoral imbalance); and (3) "suppressing the natural heat of the member and taking away its feeling, which is done by medicines of opium." De Vigo appears to have been the most reluctant to use opium. Opiate medicines palliate pain but should be used only "in great necessity." Although the pain will temporarily be suppressed, "it will return with greater vehemence." A purge should be given before administering opium, and opium should not be given to a weak patient. "The malicious nature of opium" is reduced by the addition of other herbs. Whether it may be used orally or only as a plaster is not clear. Among home remedies Brunschwig mentions neither opium or poppy seed concoctions, presumably because of their perceived danger.

A considerable amount of the clinical writings, both of physicians and surgeons, in the sixteenth century described proper behavior toward patients. The following example is unusual in that a surgeon (Wirtz) appears to hold physicians up as superior models:

> A surgeon for many reasons should guard against submitting to drunkenness. Would a complete physician rather be able to diagnose an injury or a wound if he is confused in his head and bereft of proper understanding? How can he examine a wound correctly, view the signs and decide on their significance while he is not sharp, or sharp enough, or sees everything double? And how can he grasp and palpate a fracture properly while his hands tremble and are in other ways clumsy and coarse? (p. 105)

The ideals of healers were the same as those of modern medicine, as Brunschwig indicated: “Let every Physician and Chirurgion follow this rule: to well and exactly know and search for the cause of the disease, so that he the more certainly know how to heal the patient.”

—*Thomas G. Benedek*

See also Galen; Humors, Theory of; Medicine.

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HISTORY OF DISABILITY: MEDIEVAL WEST

There is a medieval nursery rhyme,

> I saw three headless [people] play at a ball,
> A handless man served them all;
> While three mouthless men lay and laughed,
> Three legless [men] away them drew.

The fact that children might learn of disability in their crib and at play suggests how profoundly quotidian was medieval disability. However, disabilities in the Middle Ages are only now beginning to be investigated as a group. For the medieval child or adult, aggregating experiences and conditions, which we would consider disabling, would have been peculiar.

The period of the Middle Ages in the West, conventionally is held to run from roughly 500 to 1500 CE, although the nature of the medieval world shifts dramatically from the south of Europe, which experienced the Renaissance earlier, to the north of Europe from the extreme west to the extreme east. In general, the Middle Ages embraced social and intellectual changes from the fall of the Roman Empire to the rebirth of antique culture in the Renaissance and the origins of the nation-state.

Our view of disability during this period is still highly fractured. This entry presents an overview of several of the fragments. Ideas about and experiences of disability during the Middle Ages varied dramatically. The conceptualization and experience of disability by a serf with a lower-extremity paralysis in twelfth-century England was notably different from that of a fifteenth-century Italian duke with a speech impediment or an eleventh-century German nun with depression. In addition, the social expectations of medieval people were rather different from those today in the West. As a consequence, the following survey will be at best imagistic.

Medieval disability originated from many directions. Given that, some studies report, nearly 50 percent of children died before age 21, death was a fiercely regular occurrence in the home and community. Nearly a third of the inhabitants of a York cemetery were children during the Middle Ages. Parasites were frequent, suggested by archeological studies of cesspits. Accidents were a regular occurrence. Hunger and starvation were probably common in the full life of a medieval rural person; conditions of nutritional deficiency, such as rickets, were not uncommon. Still, infectious diseases were probably the most common cause of death. But death was only an extreme.

Owing to variable survival of sources, it is difficult to generate any kind of accurate epidemiologic statistics of disabling conditions from the Middle Ages. We know that tuberculosis, plague, and leprosy, among others, were infectious diseases, which could leave survivors with long-term disabilities as attested to by both archeological and textual evidence. Data derived from miracle records at the shrines of saints suggest a range of symptomatic/diagnostic conditions with disabling features, including blindness, deafness, mutism, a variety of paralyses, and leprosy. While we have only the barest sense of epidemiology for medieval disabling conditions, we can gather that disabilities were common enough both to provoke notice and yet often to deny total "otherness" by the degree of accommodation and integration invoked by society at large.

The experience of disabilities by medieval people is only now beginning to be elucidated. Biographically, we know any number of figures with disabling conditions. Henry the Minstrel, fifteenth-century chronicler of William Wallace of Scotland, was known as "Blind Henry," though not all scholars agree to the veracity of that epithet. Some famous figures with disabling conditions, like Hermann von Reichenau (also known as Hermann "the Lame" because of a congenital lower-extremity impairment), were born into the nobility and went on to positions of great intellectual productivity denied to the poorest medieval peasant. Hermann was educated at an abbey and became a well-known chronicler, poet, musician, and mathematical astronomer. Teresa de Cartagena, who became deaf as a child in the fifteenth century, 20 years later, as a nun, wrote *Arboleda de los enfermos* (*Grove of the Infirm*), possible only because her family was wealthy enough to have her tutored. King Baldwin IV of Jerusalem was a child when he contracted leprosy, and yet he continued to fight in crusades before his death at around age 24. Another leper, this one very poor, lived in Venice and spent much of his life begging on the fourteenth-century streets. The Old Norse *Landnámabók* refers to a certain Bjargey Valbrandsdóttir, wife of Hávarðr halti ("the lame"). A famous woman with a potentially disabling condition, the mystic Hildegard of Bingen had visions, which have been postulated to be severe migraine headaches with scotoma. Rather than impairing her vision while toiling in the fields, these images became a religious experience, which transformed both her individual relationship to God and also those influenced by her writings. On the other hand, King Sancho the Fat (r. 955–958 and 958–960) of León in the eleventh century was driven from his throne for severe obesity. It was not until after he was successfully treated by the Jewish physician Hasdai ibn Shaprut, perhaps with opiates, that he was able to return to the thrown. As well as class, religion, race, and gender certainly altered the experience of disability.

The world around the medieval person was potentially disabling at all times. In one example, a medieval fisherman netting a torpedo fish became paralyzed in his upper extremities. The often-analyzed Hippocratic *Aphorisms* explained how winds from the south make one deaf. In addition to the vagaries of nature, accident, happenstance, and bad fortune were clearly agents of disabling etiology. More frequently, etiology was attributed to witchcraft or evil magic, as when King Alfred the Great was enjoying his wedding night and was attacked by a severe pain, which some attributed to witchcraft. But religious explanations were widespread and promulgated by ecclesiastical doctrine. As a consequence, the role of relics and saints' shrines in miraculous cures of disabling conditions is undeniable (see below).

Increasingly, into the thirteenth and fourteenth centuries, a process of "medicalization" provided another explanatory system. This was hardly to the extent of the medicalization of the nineteenth and twentieth centuries, but still significant. For many disabling conditions, a common medieval medical explanation was framed in terms of humoral theory. Having been propagated by Hippocrates and Galen in antiquity, the four humors were initially understood incompletely in the early Middle Ages prior to being recovered in the wave of translations from Greek and Arabic into Latin in the eleventh through fourteenth centuries. Thus, elite theories about disabilities may be divided in a bimodal fashion—the early medieval and the late medieval conceptualization. Characteristic of the early medieval is a vague understanding of the four humors; characteristic of the late medieval is a highly complex understanding. Where medical experts in antiquity were greatly interested in prognosis, the role of the late medieval physician increasingly fell to diagnosing conditions, and indeed in officially certifying them. That certification could become a tool for market competition. One thirteenth-century university physician, Jean de Saint-Amand, described a drug he prescribed for its special property of attracting phlegm from the head if scrubbed on the palate. In this way, he treated a patient who according to common wisdom was essentially dead because of her inability to talk and listlessness. Using the drug, he restored her ability to talk long enough for her to give her final confession then died. In this example, Jean not only displayed his ability to alter humors, relieve a disability, and assist a patient in her crucial religious function, but he also distinguished his refined knowledge from that of the untutored. Jean also treated a patient with another drug to forestall leprosy; the therapy worked for three years, when the patient contracted the condition. In stories like these, elite physicians used the care, treatment, and prevention of disabilities to their marketplace advantage. As the physicians became more influential in social circles, surmounting surgeons, apothecaries, and barbers in their medical roles, the "lesser" disciplines tried to emulate the physicians and disabilities could play a role. Thus, Lanfranco of Milan, a thirteenth-century surgeon in Paris, treated a patient only after a lay healer admitted his ignorance of the condition.

For disabling conditions such as leprosy, medicalization was an important shift. As a consequence, the rise of institutions, previously devoted to charitable care like leprosaria, increasingly allowed for population-wide "social control" of some of those with disabilities. Disabilities could offer complications to the elite theoretician. At times, the presence of a disabling condition, such as epilepsy, could incite caution for doctors in the drugs they prescribed. Thus, Avicenna, an eleventh-century Arabic physician widely studied in Latin translations in Europe, noted that celery was contraindicated in epileptics as it could cause status epilepticus. On the other hand, one condition could induce another disabling one. According to Taddeo Alderotti, a thirteenth-century Bolognese physician, diarrhea could induce stuttering or stammering. Similarly, chronic, untreatable conditions of a disabling nature could be cause to withhold certain kinds of charity care. Thus, the Hospital of St. John the Baptist in Oxford did not accept people with those conditions, nor did it accept those with epilepsy or women pregnant out of wedlock. Simply taking mercury could cause paralysis in everyone. Occasionally, medical and technical interventions for disabilities have had long-standing consequences. The invention of eyeglasses in the fourteenth century, for example, has accommodated presbyopia ever since.

In addition to elite theories of disabling conditions, religious explanations helped people with disabilities and those caring for them to understand their conditions. Thus, the ill will of the devil could cause a crippling pain, the loss of faith in a patron saint could cause the reoccurrence of blindness, or unrepentant breakage of a Commandment could cause mania. Not surprisingly, the Catholic Church's role in ministering to the disabled was considerable; that role was even represented in religious symbology. Hence, the bishop's crosier was designed to indicate a support for the disabled and infirm. The Bible and its multiple exegeses are rife with metaphoric descriptions of intellectual and spiritual blindness and deafness, many of which were then cured through divine intervention.

The twelfth-century monk and pioneering biographer Guibert de Nogent tells how his mother became paralyzed after a devil's visitation. Even the divine could have disabilities. Angels, for example, were considered by some medieval theologians to have a kind of disability in lacking the bodies to experience sensory passions; they could only experience intellectual passions (cognition). Yet the divine was, in Bible and sermon, frequently the source of healing for disabilities. Appeals to saints for miracle-based cures were commonplace. In this role, religious healing was an economic competitor of lay medical "cures." Even those perceived as holy by laypeople, such as the flagellants during the Black Death, could generate healing imagery. So the blood of flagellants was sometimes collected by women on the street side and applied to the eyes for preventing or curing blindness.

At other times, the two certified systems of healing—religion and medicine—could team up to stave off the ministrations of the magical healer, of whom both the doctor and the priest disapproved. Such magical healing was based on "superstitious" notions of causation ranging from the evil eye to fear of a particular color to belief in malignant magical elves or dwarfs who shot arrows of disease into a person. Consequent cures ranged from application of folk remedies containing various plant, mineral, and animal products to the verbal chant of Old Norse poetry. These latter were considered magical by the Christian theologian, but for the pre-Christianized Icelander, they hearkened to his own polytheism, including Odin the All-father, who had one eye, and Völundr, the Norse god of smiths, who was lame. The Old Scandinavian *Vọlundarkviða* and *Þiðrikssaga* retell the story of the elf Vọlundr, who was hamstrung by his enemy, King Niðuðr, and forced to become the royal smith. Similarly functional in literature were dwarfs who played critical roles in plots from the *Niebelungelied* to *Tristan and Iseult*. Disability in religion and magic was all in the eye of the beholder.

Certainly, people with disabilities themselves could be identified as etiologic agents of disease, enhancing their nature as "others." Thus, with the advent of the Black Death in 1347–1348, some lay people targeted "cripples" or "the mutilated poor" as the source of the epidemic, along with Jews and the wealthy. The cause of such fear was clearly a sense of otherness. Disability was as ostracizing a feature of the life of a medieval commoner as non-Christian religion or elite status. In this latter translation, we can detect an inherent association between poverty and disability. Disabilities could also be part of curses—"may you go blind," "damn your eyes"—in the Middle Ages and beyond, furthering the negative imagery of disabilities. Similarly, as charity provoked almsgiving some beggars in thirteenth-century Paris disguised themselves as disabled people to generate more alms. When they were discovered, a more general backlash against all beggars ensued.

But the topos of disability, feigned or otherwise, had less sinister meanings and more nuanced as well. The residents of Norwich, for example, feigned madness when King John was to visit their town in order to avoid having to pay to feed his retainers; disability could have its uses. The topos of concealing body-type could be important for recognition of the ideal. In one version of the lay of *Tristan and Iseult*, Tristan feebly disguises himself, and Iseult says he is not her lover, Tristan, because he is not "tall and straight-backed." Disability in medieval literature could be used as comedic counterpoint, as moralistic trope or as social wedge to address liminal issues such as homosexuality, as in the thirteenth-century French play *The Boy and the Blind Man*.

Medieval disabilities, through the lens of concepts such as charity, transformed the medieval landscape, literally and figuratively. Thus, institutions, notably the Catholic Church but also municipal and early state governments, played a significant part in resource allocation for people with disabilities who were unable to achieve social independence. Charity was a critical religious guide for medieval disability. Given the depredations of war, disease, natural disasters and climatic shifts, economic cycles, crime, old age, large but young families, and accidents, many medieval people, more often among the poor but not infrequently among the wealthy, experienced periods of deprivation, which threatened their life and health. It is noteworthy that the relationship between the "haves" and the "have-nots" in the Middle Ages was complex. While the poor lacked terrestrial power, they, as recipients of alms, held the metaphorical power to obviate sins. Poverty was not seen as an alleviable condition, but a state of permanence, betokened in part by the plethora of the poor, especially in the urban setting. The Biblical parable of the rich man feasting while his dog licked the wounds of beggars at his door, the two then reversing benefits in heaven, suggested the dangers of wealth, which could be mitigated by the gratitude and prayers of recipient poor. The tension in the Church between its rhetoric of poverty and its evident wealth, notably among its "princes," sparked internal and external criticism, reform and backlash, especially in the thirteenth century with the Franciscan order's creation. But with the high-wage labor shortages of the later fifteenth century, hostility to the poor rose, even among Church leaders.

Medieval Christian charity took many forms—for example, almshouses, hospitals, clothes, food, money, and goods dispensed at church doors, even temporary employment. Some 20,000 leper hospitals were established by 1300 throughout Europe dotting the spaces circumscribed by town walls and notions of "us/them." Yet in any one locale, that charity was probably insufficient to meet the needs of a populace of poverty, including the disabled. Even in a time of decreased population, after the Black Death, relative plenty could not do away with the permanence of poverty and the need for charity.

Tensions also existed in the characterization of the poor—significantly in anticipation of the early modern differentiation of the deserving and undeserving poor. Disability played some role in these assignations, as at times, lepers were castigated with moral inequity, often of a hypersexual variety. On the other hand, lepers and those unable to work because of physical incapacity (e.g., old age or physical disability) were often the specific target of open charity. To that end, the poor were sometimes impugned with allegations of cutting off one of their children's extremities or blinding them in hopes of attracting more charity. In the end, the repulsive forces inherent in notions of difference were offset by the attractive needs of living in fairly small communities. For example, medieval laws, which governed cognitive disabilities, changed over time from the comparatively tolerant to the more invasive, yet they frequently allocated full rights of land ownership. The poor disabled could be pitied, reviled, reared, and acknowledged as part of the community. The heavenly world overlapped the terrestrial in a myriad of ways.

The Roman Catholic Church, both materially and doctrinally, had an enormous role in shaping the experience of disabilities in the Middle Ages. From pulpits, parishioners heard of the laudable need for charitable works. But they also heard stories of miraculous cures of the disabled by Jesus. Certain conditions, such as leprosy, increasingly were castigated by the Church as being the result of sin, thus accentuating social stigmatization. And the doctrinal relationship between medieval Christians and their body changed markedly from the early to the late Middle Ages. Notably, the rise of mimicry of Jesus' suffering ennobled pain as a venue toward redemption. Throughout the Middle Ages, the symbolic power of Jesus' body motivated creation and recreation of the import of the physical body. In the early Middle Ages the *body* was most closely associated with the peasant and manual labor. In the later Middle Ages it became an emblem of contest between the individual and the community and an object of redemption. Thus, painful conditions or pain in general, previously perhaps more socially disabling, became badges of Christian virtue to be sought out and embraced. Similarly, the rise of the Franciscan order in the early thirteenth century and new modes of charity altered the potential reaction of the disabled beggar and the almsgiver.

Documentation of a wide range of conditions, which we associate with "disabilities," exists from throughout the Middle Ages. Differentiation into "physical" and "mental" is anachronistic and does not convey the complex intermingling of the medieval mind, body, and soul. Hrabanus (Rabunus) Maurus, a ninth-century monk, for example, observed that "disabilities/infirmities of the flesh mirror disabilities of the mind, and earthly ointments represent the soothing agents of heavenly grace" (Maurus 1864). Examples of paralyses, amputations, scolioses, seizures, madness, blindness, deafness, developmental disabilities, birth defects, chronic infection, and many others abound from this time period. Collectively, it is difficult to identify words that one may clearly translate as the modern, nuanced *disability*, from medieval Latin, French, German, Italian, English, Spanish, Catalan, and the other tongues of the Middle Ages. Thus, modern scholars must be cautious in generalizing and adducing synthetic conclusions from medieval statements.

> Henry Hotspurs hath a halt,
> And he is falling lame.
> Francis Physician for that fault
> Swear[s] he was not to blame.

This medieval children's rhyme reminds us that the signification of disabilities in the Middle Ages was manifold. At once founded in the historically objective and in the culturally inflected, medieval disabilities are redolent for the modern reader and worthy of much more investigation.

—Walton O. Schalick III

See also Teresa de Cartagena; Galen; Hippocrates; Humors, Theory of.

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HISTORY OF DISABILITY: PLEISTOCENE PERIOD

THE ANTIQUITY OF HUMAN DISABILITY

Assessments of the presence, severity, and incidence of forms of disability among early human societies can provide us with indications of the degrees to which afflicted individuals were able to survive under conditions vastly less conducive to recovery and persistence than is normally found in modern, technologically aided human societies. In particular, it is helpful to evaluate the presence of significant disabilities among Pleistocene human populations since it is during this time period that the underlying biological pattern characterizing all of living humanity appeared. This period, from approximately 1.8 million years ago to about 10,000 years ago, began with the emergence of the genus *Homo,* saw its spread throughout the Old World and eventually into the Pacific and Americas, and concluded with the emergence of humans of modern form about 100,000 years ago and the beginnings of sedentary life by 10,000 years ago.

Any evaluation of human disabilities in the Pleistocene era must acknowledge the nature of the evidence and the series of steps necessary for the identification and interpretation of possible impairments of normal function. The evidence consists entirely of the incomplete skeletal and dental remains of extinct human groups. Until people began burying their dead about 100,000 years ago, it consists principally of cephalic portions of the calcified tissue. In addition, sample sizes remain small, geographically scattered, and spread out over thousands of years, making calculations of incidence levels largely meaningless.

The interpretive issues involve a series of logical steps. First, the observed skeletal/dental anatomy has to be identified as abnormal and not confused with expected normal ranges of variation, bearing in mind that there have been significant changes in human anatomy during the past 1.8 million years. Second, accurate diagnoses must be made of the observable lesions or abnormalities in overall skeletal morphology. Third, the lesions have to be integrated into a more general diagnosis of the individual’s abnormalities. In so doing, the scholar must consider that the observed alterations may be linked or independent and may have occurred synchronously or sequentially. Often, given the limitations of fossilized remains, it may only be possible to narrow the diagnosis to a set of possible etiologies, rather than specifying a specific cause for the lesions. Fourth, depending on the diagnosis, the presence of significant soft tissue abnormalities must be assessed, ones that can only be inferred from the skeletal biology. Fifth, a determination has to be made whether the diagnosis would imply any loss of function. Sixth, if some reduction of function is implied, the individual’s disability must be evaluated in terms of whether it would have affected the survivability of the individual in its social, technological, and environmental context. However, since survival of the condition is required for the formation of skeletal lesions or abnormalities, all known cases are by definition cases of some degree of survival. A methodological consequence is that we have little or no data on socio-biomedically lethal disabilities, only the chronic ones.

In addition to the compounding levels of inference from lesion identification to survivability, one must realize that all of these Pleistocene human populations were hunters and gatherers, living exclusively from foraged resources naturally occurring on the landscape. For most of the Pleistocene, until less than 30,000 years ago, population density was extremely low, and the associated social integration behaviors were strictly local. Fundamental aspects of technology, such as effective weaponry and fire, were established only about 400,000 years ago, and mobility on the landscape was essential. In fact, before 10,000 years ago, there are no known cases of lesions of the lower limbs that would have impaired walking, and there are several cases of individuals persisting in walking despite severe osteoarthritis and less disabling injuries to the legs and feet.

Despite these limitations of the human fossil record and the inferential process, there are numerous identified cases of lesions among Pleistocene humans. Most are relatively minor traumatic and degenerative lesions, and only a few would be classified as disabilities. The extent to which each one would have affected survivability without significant social assistance remains debated.

The oldest known case is from Salé, Morocco, from 400,000 years ago. It consists of a partial cranium of a young adult with reduced and altered development of the nuchal plane, which has been interpreted as the result of congenital torticollis. It is followed about 200,000 years ago by an isolated adult mandible from Aubesier, France, with pervasive periodontal inflammation, apical abscesses, and almost complete tooth loss, requiring complete processing of any ingested food outside of the mouth. Slightly younger, at 150,000 years ago, is the isolated mature cranium from Singa, Sudan, with unilateral labyrinthine ossification, which would have seriously impaired the individual's equilibrium.

One Neanderthal specimen, from Shanidar Cave, Iraq, dated to about 50,000 years ago, survived multiple, possibly related, lesions. The more serious of them include a lateral facial fracture disrupting the functioning of the left eye and multiple fractures, atrophy, infection, and possible amputation at the elbow of the right arm, leaving little more than a withered stump. The same individual had sufficient leg and foot injuries to induce an abnormal gait that resulted in bowing of the left leg. He also represents the oldest known case of DISH (diffuse idiopathic skeletal hyperostosis). To this individual could be added two other Neanderthals, one from Shanidar that survived a unilateral pneumothorax for at least several weeks and another from the original Neanderthal site in Germany that had a fractured elbow with sufficient deformity to reduce elbow flexion and produce atrophy of the arm bones.

Among early modern humans, there is a child from Qafzeh, Israel, who lived to about three years of age with pronounced hydrocephaly, resulting in both characteristic cranial changes and limb alterations. A more recent individual from Dolní Vestonice, Czech Republic, survived to young adulthood with an undetermined congenital dysplasia, which produced asymmetrical shortening of the legs, abnormal bowing of the right thigh and upper arm, and secondary changes of the left arm and facial skeleton. Yet, this latter individual exhibits a level of limb strength similar to those of other humans from the same time period, implying that he kept up with and assisted his highly mobile social group.

These few examples are those for which there is sufficient confidence in the identification and diagnosis of the individual lesions and deformities and are likely to have caused more than short-term reduction of some vital function (bearing in mind that what was "vital" in the Pleistocene need not be essential for survival in current sedentary and technologically aided societies). What remains uncertain is the degree to which any one of these sets of abnormalities would have directly affected the survivability of the individuals in their prehistoric social contexts, requiring the prolonged direct assistance of other members of the social group. However, it is probably not coincidental that these conditions first appear in the human fossil record about the time (400,000 years ago) that there are significant improvements in weaponry, fire control, and other aspects of human behavior, all of which would have facilitated survival in harsh environments.

—Erik Trinkaus

See also Archaeology.

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HIV/AIDS

As we enter the third decade of the AIDS pandemic, its global impact is highly evident. Since the first reported cases of AIDS in the United States in June 1981, the disease has crossed all geographic boundaries; numerous countries in Africa and Asia already confront serious decimation of their populations while other global regions and countries are on the edge of emergent crises. The statistics are staggering. The World Health Organization (WHO) estimates that, worldwide, approximately 40 million people are living with HIV/AIDS; 22 million men, women, and children have died; and 14,000 new infections are contracted every day. Around the world, in the year 2003, the AIDS epidemic claimed an estimated 3 million lives, and almost 5 million people acquired HIV, 700,000 of them children. Over the next decade, the only prognosis for those without effective treatment will be to endure its complications and die.

THE VIROLOGY OF HIV/AIDS

The human immunodeficiency virus (HIV) mediates its effect in the human body by interfering with cell-mediated immunity that eventually destroys the entire immune system and compromises all major organ systems. Without successful medical treatment, most people infected with HIV go on to develop the most advanced stage of the disease known as acquired immunodeficiency syndrome (AIDS). In addition to provoking immunodeficiency in the body, HIV also activates autoimmunity and nervous system dysfunction. AIDS manifests itself clinically as a spectrum of diseases that cause both physical and mental disability in those affected. People living with the virus can experience a wide variety of symptoms due to opportunistic infections, malignancies, and wasting.

Early HIV symptoms, which typically occur between 1 and 4 weeks following exposure, often mimic flu or mononucleosis-like symptoms. These symptoms include headache, loss of appetite, night sweating, a sore throat, and swelling of the lymph nodes. A skin rash may develop on the chest, abdomen, and/or back. HIV seroconversion, which refers to the development of detectable HIV antibodies in the blood, is most likely to take place at 3 to 6 weeks following exposure, although it can occur at any point in the following six months.

The incubation period for AIDS refers to the interval that begins with HIV infection and ends when the person exhibits the first signs of developing AIDS, as specified by a set of clinical criteria. In young to middle-age adults, the median incubation period is about 10 years, although the interval appears to be lengthening or even forestalled as new and more effective treatment options become available. While this incubation period tends to be shorter in children and individuals over age 50, it does not appear to vary significantly by gender or race. A host of cofactors are believed to play a role in disease progression, including genetic factors, age, gender, route of HIV infection, drug use, smoking, nutrition, and the co-occurrence of other infectious diseases. Without treatment, the period from AIDS diagnosis to death, known as AIDS survival time, ranges from 1 to 20 years with a median interval of 10 years.

DISEASE CLASSIFICATION AND STAGING

A variety of classification and staging systems have been proposed for understanding and mapping the full progression of the disease from HIV infection to the advanced stages of AIDS and possible death. Most use some combination of the CD4 lymphocyte count and symptoms. In 1993, the Centers for Disease Control and Prevention (CDC) made the CD4 lymphocyte count central to its classification system for HIV disease. Since then, CDC expanded its AIDS surveillance case definition to include all HIV-infected persons who have < 200 CD4+ T-lymphocytes/microL, or a CD4+ T-lymphocyte percentage of total lymphocytes of < 14, as well as the addition of pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer to the 23 clinical conditions in the AIDS surveillance case definition published in 1987.

The progression of HIV immunosuppression generally correlates with CD4 lymphocyte count or percentage; thus, CD4 lymphocyte count is currently the principal laboratory test used in clinical management of HIV infection, including antiviral therapy as well as prophylaxis of opportunistic infections. The combination of CD4 lymphocyte count, viral load (quantity of HIV detected in the peripheral blood), and clinical symptoms is likely to provide the basis for future attempts at staging HIV disease.

Counting subsets of lymphocytes is often impossible in developing countries because the needed technology is not available or is too expensive for routine use. As an alternative, the World Health Organization (WHO) Global Programme on AIDS proposes the following simplified staging system that does not rely on lymphocytes testing, and its diagnostic criteria are clinically based and sufficiently flexible for use in different parts of the world:

Early HIV disease (Stages 1 to 3). In these stages, individuals may develop opportunistic infections such as tuberculosis, malaria, pneumococcal pneumonia, shingles (herpes zoster), staphylococcal skin infections, and septicemia. These diseases can also occur in individuals with normal immune systems. With HIV, these diseases occur at much higher rates.

Advanced HIV disease (Stage 4, equivalent to AIDS). This stage is characterized by the development of opportunistic infections such as pneumocystis and toxoplasmosis. In addition, the diseases listed under Stages 1–3 are present in atypical ways, for example, tuberculosis disseminated from the lung or recurrence of non-typhi salmonella septicemia. Malignancies such as Kaposi's sarcoma and other cancers may also arise.

MODES OF TRANSMISSION AND RISK FACTORS

The principal modes of transmission for HIV are through sexual contact, introduction of the virus into the blood stream by blood or blood products, and through vertical transmission from mother to infant either before and during childbirth or via breastfeeding. Body fluids, which have been scientifically proven to transmit HIV, include blood, semen, vaginal fluid, and breast milk. Other suspected but unproven possibilities include cerebrospinal fluid, synovial fluid, and amniotic fluid. Extensive research documents that HIV is not transmitted through casual contact such as handshaking or insect bites. Globally, the leading cause of HIV infection is through sexual contact.

The first AIDS cases reported in June 1981 in the United States were among younger men who had sex with men. Later, it became known that people of both sexes and all age groups are susceptible to HIV and AIDS. Groups in the United States who are particularly vulnerable to infection are men who have sex with men, injection drug users and their sexual partners, members of racial/ethnic minorities, and an increasing number of women. The following are the most common modes of transmission in the United States:

> unprotected sexual contact, particularly with multiple partners;
>
> use of HIV-contaminated equipment among injection drug users, including needles, cotton, cookers, and water used in drug administration; and
>
> needle stick injuries among health care professionals.

Although once a serious problem, the risk of transmission though blood transfusion from infected blood and blood products has decreased significantly since the mid-1980s after legal enactment of national blood-screening requirements. The United States also has seen dramatic reductions, since the mid-1990s, in mother-to-child transmission due to widespread promotion of routine HIV counseling and voluntarily testing of pregnant women for HIV, and as the result of offering antiretroviral therapy to infected women during pregnancy and delivery and for infants after birth.

HIV PREVENTION STRATEGIES

Without a vaccine available to protect against HIV, the major focus of preventive efforts at the individual, dyadic, and social network levels are designed to minimize the transmission of HIV through unsafe sexual practices and the sharing of contaminated injection drug equipment. A number of methods have been developed and scientifically shown effective in reducing risky behavior when applied under specific conditions. These methods include indigenous leader and peer outreach strategies, prevention case management, needle hygiene and syringe distribution programs, social support groups organized around risk reduction, and Internet interventions. At the health services level, prevention efforts focus primarily on promoting HIV counseling and testing, offering therapy for HIV-positive pregnant women and their infants, continued stringent screening of all products used medically for blood transfusions, and appropriate protection of health care workers.

The process of "partner notification" is gaining increasing attention for preventing the spread of infection from patients with diagnosed HIV (index patients) to healthy persons. Through this process, sex and needle partners of index patients are informed of their possible exposure to infection and the need for medical evaluation. There are two basic mechanisms of partner notification: provider referral and patient referral. *Provider referral* is a confidential process in which public health personnel or other appropriate counselors request names and identifying information about sex partners from the index patient to notify those partners of their exposure. *Patient referral* is a process by which partners are notified by index patients on their own without assistance. The goal of partner notification is to help ensure that individuals who are HIV seronegative remain so and to identify and bring those individuals who have unknowingly contracted the virus into the health care system for early treatment and care.

HIV/AIDS DIAGNOSIS

Early detection of HIV infection is critical to instituting timely and effective therapeutic regimens. Since the first HIV antibody tests became commercially available in 1985, HIV diagnostic technology has progressed remarkably. The most common types of screening and confirmatory assays are the following:

Enzyme-linked immunosorbent assays (ELISAs). These are the most widely used type of assays; they have high sensitivity and specificity and are able to detect HIV-1/HIV-2 and HIV variants. ELISAs are especially useful for screening large numbers of specimens needed for surveillance and centralized blood transfusion services. The most recent "combination assays" combine p24 antigen ELISAs with traditional antibody ELISAs, allowing for the simultaneous detection of HIV antigen and antibodies using a single test.

Simple/rapid assays. These are the high-quality, easy-to-use HIV tests, which require little or no additional equipment. The tests are designed for use with individual or a limited number of samples. These tests are increasingly being used in voluntary counseling and testing centers and antenatal clinics where making same-day results available can result in timely treatment interventions.

Confirmatory assays. These assays are used to confirm whether specimens found reactive with a particular screening test contain antibodies specific to HIV. The most commonly used confirmatory test is the Western Blot (WB). However, it is a very expensive test and produces large numbers of indeterminate results. Similar confirmatory assays, generically called Line immuno-assays (LIAs), have been developed, which in general produce fewer indeterminate results as compared to WB, although they are equally expensive. There is evidence that combinations of ELISAs or simple/rapid assays can provide results as reliable as the WB at a much lower cost.

p24 antigen and nucleic acid technologies. A number of other assays have been introduced in recent years that in addition to establishing the diagnosis of HIV infection may also be used to monitor the progress of the infection and the response to therapy. These procedures are particularly valuable for early diagnosis of mother-to-child transmission and for monitoring the viral load of patients who are taking antiretroviral therapy. From a practical standpoint, this technique can have limited specificity; needs sophisticated equipment, rigorous laboratory conditions, and highly trained staff; and is very expensive.

Alternative specimens. HIV diagnostic technology has also evolved to the development of assays that can use alternative body fluids to serum/plasma such as saliva, whole blood, and urine. Potential advantages include safety, convenience, noninvasiveness, and cost-effectiveness. The quality of these assays as compared to conventional serological tests, however, is still undetermined.

HIV/AIDS TREATMENT

In the first 15 years of the AIDS epidemic, individuals with HIV infection had few treatment options. Since then, research has shown that certain antiretroviral drugs can inhibit HIV replication, delay immune deterioration, and improve survival and quality of life. Prior to the initiation of antiretroviral therapy, patients require a clinical assessment, which includes a thorough clinical history, physical examination, and ancillary tests. Other critical elements of the assessment include a past medical history, current and past HIV-related illnesses, coexisting medical conditions (such as tuberculosis, hepatitis B or C, or pregnancy), and concomitant medications in use that may influence choice of therapy. Minimum laboratory tests include an HIV antibody test and hemoglobin or hematocrit level. Where resources permit, it is preferable to get a complete blood count, CD4 count, serum alanine and aspartate aminotransferase levels, serum creatinine, blood urea nitrogen, serum glucose, bilirubin, and lipids levels, and pregnancy tests for women.

Treatment modalities for HIV are rapidly changing as the result of scientific research. No single medical regimen is universally accepted, although some are now preferred for initial therapy. At the time of this writing, the Food and Drug Administration (FDA) has approved the use of 20 different drugs to combat HIV infection—often in some form of combination. These drugs fall into four main types:

1. *Nucleoside and nucleotide analog reverse transcriptase inhibitors* inhibit HIV's ability to copy a healthy cell's DNA. HIV needs the cell's DNA, or genetic instructions, to replicate itself. Without complete DNA, HIV cannot make new virus copies. Drugs include zidovudine, lamivudine, stavudine, abacavir, didanosine, zalcitabine, emtricitabine, and tenofovir. Brand combination drugs include Combivir (lamivudine and zidovudine) and Trizivir (abacavir, lamivudine, and zidovudine).
2. *Nonnucleoside reverse transcriptase inhibitors* also prevent HIV from using a healthy cell's DNA to make copies of itself, but they have a different mechanism of action. Drugs include nevirapine, delavirdine, and efavirenz.
3. *Protease inhibitors* prevent infected cells from releasing HIV into the body. Drugs include saquinavir, indinavir, ritonavir, nelfinavir, amprenavir, lopinavir (combined with ritonavir as Kaletra), fos-amprenavir, and atazanavir.
4. *Fusion inhibitors* prevent the entry of the HIV virus into healthy cells. Presently, the only FDA-approved drug in this class is enfuvirtide.

Highly active antiretroviral therapy (HAART) refers to combination antiretroviral regimens of three or more drugs from one or more different classes of anti-HIV drugs to suppress HIV replication and prevent progression to AIDS and death. Two key classes of drugs include those that prevent the virus from copying itself (reverse transcriptase inhibitors) and those that prevent the virus from becoming infectious (protease inhibitors). The main goal of using combination therapy is to address the issue of constant mutations of the HIV virus, which leads to the ongoing emergence of new and drug resistant strains. Resistance to any single drug is thought to occur almost universally at the baseline even prior to initiation of drug therapy. It is not uncommon, however, for the effectiveness of different drug combinations to diminish over time. Hence, new combinations may need to be implemented over the course of a person's treatment. The actual drugs and their regimens are constantly under investigation and are revised as new information and medications become available.

A recent study from the National Institute of Allergy and Infectious Diseases, at the National Institutes of Health, indicates that the combinations and particular order of antiretroviral drugs must be considered when designing treatment strategies for patients new to antiretroviral therapy. When HIV-infected individuals begin treatment with a combination of the drugs zidovudine (better known as AZT), lamivudine, and efavirenz, the treatment retains its effectiveness for a longer period of time than when individuals begin treatment with one of several other three-drug regimens.

Meanwhile, administering a single dose of nevirapine to an HIV-infected woman at the onset of labor and to her child within 72 hours of birth have been found to markedly reduce the rate of HIV transmission in newborns. The WHO endorses this method as routine procedure for preventing mother-to-child transmission in HIV high-prevalence developing countries. However, this strategy is not without controversy; some recent evidence suggests that administering nevirapine treatment at infancy may result in greater vulnerability to infection following HIV exposure in later life.

GLOBAL DISPARITIES

The AIDS epidemic takes on different prevalence patterns and epidemiological profiles in different parts of the world. The continent of Africa, particularly the southern region, continues to have the highest HIV/AIDS incidence and prevalence rates globally. Many of the highly industrialized countries of the Western Hemisphere, including the United States, report declining epidemiological trends in AIDS overall, but their incidence rates in certain subpopulations are rising. In the Eastern Hemisphere, countries that once formed the Soviet Union face a young and rapidly growing epidemic. Latin America and the Caribbean exhibit evidence of a growing threat, while East and Southeast Asia, which include countries such as China and India that contain some of the world's largest populations, may someday outstrip Africa in terms of their absolute number of cases if their current escalating rates of HIV/AIDS go unchecked. Not all countries, however, are experiencing such acceleration. Brazil, Thailand, and Uganda serve as role models for others in successfully reducing previously rising transmission rates.

Throughout the world, the high cost of antiretroviral drugs places treatment beyond the range of many individuals living with the virus, particularly residents of the developing world. The exact cost of antiretroviral therapy in a particular geographic location varies and is determined by a complex set of factors including global politics, the existence of donor funds, public and private insurance and/or entitlement programs, and the policies and drug-testing activities of large pharmaceutical firms. At present, the cost of antiretroviral therapy in the least developed countries ranges from US$300 to US$1,200 per annum, a sum that places it out of reach for many. Currently, 6 million people infected with HIV in the developing world are estimated to need access to antiretroviral therapy to survive. Only 400,000 have this access. A number of global programs are either poised for or actively engaged in facilitating or providing treatment, but the demand throughout the world far exceeds the numbers to be served.

WHO policy, in recognizing that the multiple challenges involved worldwide in stopping the HIV/AIDS epidemic, calls for the adoption of a comprehensive public health approach to reach this goal. Not the least of these challenges lies in improving access to and reducing the cost of antiretroviral drugs. Other recommendations include establishing sustainable financing for AIDS treatment and drug procurement, regulatory mechanisms to ensure blood safety and appropriate delivery of HIV/AIDS services, improvement in health infrastructure, training of health care workers, education and involvement of communities, and the mobilization of diverse stakeholders. In addition to the development of a vaccine to end the AIDS epidemic, WHO recommendations also point to the need for developing and implementing scientifically proved strategies to encourage technology transfer and the successful adoption of evidence-based behavioral interventions and appropriate clinical treatment and care.

GLOBAL COST OF THE AIDS PANDEMIC

Besides taking an enormous toll in human life, the AIDS epidemic also erodes both personal and national capabilities including those of human sustenance and economic development. Private costs of living with HIV/AIDS can be categorized into direct and indirect costs. The direct costs of living with HIV/AIDS include service-related expenses for medication, general therapy and ongoing care in health care facilities or at home, and increasing dependence on transport for traveling to and from health providers and care facilities due to reduced mobility. Among the disease's many indirect costs are the possibilities of increased absenteeism from work, loss or reduction of income, lowered productivity both at home and in society's public/private sectors, and the incurring of personal stigma associated with the disease. Family members of those with HIV/AIDS and others in their social networks also may incur some level of costs directly and indirectly, as do the functionary agencies and institutions that serve human economic, social, and health services needs. In some parts of the world, the AIDS epidemic, in combination with its emergent fiscal and health care crises, is driving countries toward insolvency. In Zimbabwe, for example, one-third of the population between the ages of 15 to 49 is infected with HIV/AIDS.

Such grim statistics remind us that AIDS is more than a life-threatening illness; its occurrence is also a societal problem inherently linked to and fed by existing social disparities and invidious socioeconomic conditions. Lack of access to antiretroviral therapy and the social stigma attached to the disease mitigate against many HIV-infected individuals' chances of living a long and symptom-free life. Almost universally, a diagnosis of HIV infection engenders significant stigma that can result in the shunning of infected individuals by their communities and even family members. Many HIV-positive persons also face difficulties in finding or retaining employment or housing once their HIV status is known. Meanwhile, growing gender imbalances in HIV rates among women globally, and the tendency for the virus to be found disproportionately among marginalized and disadvantaged populations throughout the world, mirror deeply entrenched systems of societal inequality that help to fuel further spread of the epidemic.

Even in the face of such societal and personal disaster, it should be acknowledged that most people worldwide have not acquired the virus. An important public health challenge is to enable individuals at risk to protect themselves against HIV while providing appropriate treatment to those living with the virus. Although a number of drugs currently are available that halt or modify AIDS disease progression, no vaccine currently exists to prevent infection, and once acquired, there is no cure for HIV infection. Until these become available, societal and behavioral prevention remain the world's main defense in halting the epidemic and its consequences.

HIV/AIDS AND DISABILITY

The creation and reinforcement of physical, mental, and social disabilities constitute some of the epidemic's most serious and far-reaching consequences in the world's fight against AIDS. Physical disability related to HIV/AIDS is mainly due to the manifestations of the disease process and/or the adverse effects of therapy that result in some form of physiological impairment. HIV-infected persons also may experience disabling mental health conditions including memory loss, depression, and psychosis. These conditions require clinical or other forms of effective treatment such as HIV counseling and testing and follow-up referral services to ensure needed psychosocial support. Social disabilities occur when people with HIV/AIDS, due to their illness, lose or encounter reduced opportunities to take part in society on an equal level with others. These three categories of disability are not mutually exclusive, and some individuals experience all three forms.

Because AIDS affects almost all the organs of the body as well as all systems, only patients who have a positive response from therapy are likely to lead a life that does not require some form of adaptation to physical disability or somatic compromise. Among those receiving HIV/AIDS treatment, the difficulties associated with ongoing multiple-drug intake and their adverse effects are substantial. Adverse effects include gastrointestinal symptoms, such as bloating, nausea, and diarrhea, which occur commonly and may be transient or persist throughout therapy. Generalized fatigue, malaise, headache, anemia, peripheral neuropathy, and hypersensitivity reactions are other adverse effects associated with various individual and combination drugs. More serious but less common adverse effects include lactic acidosis, hepatic steatosis, hyperlactatemia (elevation of venous lactic acid), hepatotoxicity, hyperglycemia (leading to diabetes mellitus), fat maldistribution (lipodystrophy), hyperlipidemia, bleeding disorders, bone loss, and skin rashes. Fatigue is common among patients with HIV/AIDS and may contribute to limitations in physical functions and disability. Fatigue may occur in conjunction with multiple AIDS-related opportunistic infections, wasting, myopathy, adrenal insufficiency, and hypogonadism.

The physical conditions of HIV/AIDS and its treatment can negatively influence the mental well-being of people living with the virus and also engender considerable social stigma and other disadvantages. Consider the example of the physical, mental, and social effects of developing *lipodystrophy.* This medical term denotes the changes in body shape that were first reported in 1998 among people taking anti-HIV therapy. Originally thought to result from treatment using protease inhibitors, the condition later was found among people who had never been treated for HIV or whose therapy did not include such drugs. The literal meaning of lipodystrophy is accumulation of fat. The pathogenesis of lipodystrophy is complex and likely due to combined endocrine and metabolic abnormalities including dyslipidemias (low levels of high-density lipoprotein and high levels of low-density lipoprotein and triglyceride in the blood), high blood sugar, insulin resistance and raised liver enzymes, and accelerated bone loss. Associated conditions include heart disease, stroke, and pancreatitis. Risk for lipodystophy is greater for people with other co-occurring disorders such as high blood pressure, diabetes, obesity, smoking, or a family history of heart disease. It also occurs in 15 to 50 percent of those taking antiretroviral therapy.

The body fat changes often seen in people with HIV include both fat gain and fat loss. Fat deposition mainly occurs around abdomen, breasts, jaw, and dorsocervical spine (upper back and neck)—causing the “buffalo hump.” The abdominal fat gain is due to visceral fat accumulation around internal organs, causing the belly to feel taut and pushed out. This symptom (absence of squeezable fat) is distinguishable from the fat deposition due to overeating or lack of exercise. Fat loss is usually evidenced by facial wasting, especially of the cheeks, wasting of the buttocks, and prominent veins in the arms and legs. Such visible evidence of HIV and its alteration of the body may call attention to the person’s illness and become the basis for or exacerbate negative reactions from others. The resulting stigma and the challenges of coping with an altered body image are potential sources of stress and worry among people who experience the condition.

As is true for many AIDS-related illnesses, the best course of treatment for lipodystrophy is unknown. Treatments under study to stem the disorder span a gamut of drug and behavioral options including the use of human growth hormone, anabolic steroids, appetite stimulants, weight training, regular exercise, smoking cessation, switching from the contraceptive pill to another form of birth control, dietary changes, and/or changing anti-HIV therapy.

Lipodystrophy is just one of numerous conditions that people living with HIV may need to physically, mentally, and socially manage. For those individuals who receive life-prolonging treatment or otherwise achieve effective symptom management, HIV/AIDS constitutes a chronic condition that must be managed similarly to other serious long-term or permanent debilitating illnesses. This includes coping with the treatment itself. Therapy with antiretroviral drugs is not free from adverse effects, and most drugs have potential interactions with other drugs. Up to 25 percent of patients discontinue their initial HAART therapy due to treatment failure, toxic effects, or noncompliance. Drug toxicity needs to be monitored clinically based on patient reports and physical examination, supplemented by laboratory tests. After initiating therapy, viral RNA tests need to be performed every 4 to 6 weeks until reaching the therapeutic goal of undetectable viral RNA. Subsequently viral RNA tests are needed every 3 to 4 months. In case of treatment failure, a second-line regimen is recommended. In sum, living with HIV and AIDS is an ongoing physical, mental, and social challenge for those afflicted.

CO-OCCURRING DISABILITIES

While a substantial body of literature addresses the array of disabilities associated with HIV and AIDS in previously healthy individuals, there is a paucity of research concerning individuals who were living with a disability prior to contracting HIV/AIDS. Globally, *approximately 600 million people are estimated to be living with a physical, sensory, intellectual, and/or mental health disability. Some unknown proportion of these individuals either has, or is, at some risk for HIV/AIDS.*

In this regard, from the standpoint of normal human behavior, it is highly probable that the major risk factors associated with HIV infection also are present among people who experience disability through other conditions. Unfortunately, in terms of HIV/AIDS vulnerability, individuals living with a disability also are more likely than their unimpaired peers to live in poverty, to be less educated, and to be unemployed. In addition, due to experiencing more than one disabling condition, they may encounter multiple stigmatizations that decrease their likelihood of participating fully in the social, legal, religious, and political decision making and affairs of their communities that would give them a voice in managing their own health care. From the standpoint of prevention programming, all too often, people living with a disability are assumed to be sexually inactive, nonusers of illicit drugs, and unlikely to be victims of violence including rape. In reality, they can be at risk for HIV/AIDS for all of the same reasons as people without disabilities.

Misconceptions about the risk for HIV infection in persons with disability translate into insufficient preventive and therapeutic efforts targeting this population, and few research studies are conducted that would help inform this effort. One notable exception is a global survey on HIV/AIDS and disability, sponsored by the World Bank, currently under way by researchers at the Yale University School of Public Health in the United States. The study includes a survey that was distributed to more than 3,000 organizations, advocates, and activities in July 2003, and thus far has yielded responses from 57 countries. Although collection and analysis of the survey are still under way, some preliminary results indicate the following:

> HIV/AIDS is a significant and almost completely unrecognized problem among populations of people with disabilities worldwide;
>
> while all individuals with a disability are at risk for HIV infection, certain population subgroups are a higher risk—most notably women, members of ethnic and minority communities, adolescents, and institutionalized individuals; and
>
> HIV/AIDS educational, testing, and clinical programs are largely inaccessible to individuals with disabilities.

Further results from the study are expected to provide additional information regarding risk factors and interventions to mitigate risk to persons with disabilities.

PROTECTION OF HUMAN RIGHTS

Even with the challenges that living with HIV/AIDS presents, people who receive appropriate treatment are typically capable of successfully carrying out their daily lives. Also, with more effective drug therapies becoming available, HIV-positive individuals are living longer and remaining in or returning to the workforce as productive workers in increasing numbers. In many, but not all, countries, those who experience disabling conditions due to the disease have the right to the same legal protection, care, and consideration given to people confronting other physical and/or mental disabilities.

The American with Disabilities Act (ADA) enacted in 1990 in the United States aims to provide broad protection against disability discrimination, including discrimination against people infected with HIV. The act is based on a U.S. Supreme Court ruling that declares that HIV infection must be regarded as a physiological disorder with an immediate, constant, and detrimental effect and, therefore, the properties of the illness satisfy the definition of a disability during every stage of the disease. The ADA, which covers employers of 15 or more people, applies to employment decisions at all stages. Despite enactment of this legislation, however, individuals infected with HIV face discrimination in finding employment, and lawsuits filed by HIV-infected workers continue under the ADA. Similar problems of job discrimination and social stigma are reported worldwide, although efforts are under way on a number of fronts to reduce this condition.

The increasing involvement of people living with HIV/AIDS in community-based organizations and at national and international forums for the development of policies and the delivery of services on their behalf is an encouraging trend toward meeting their needs. Of note is the “Montreal Manifesto,” released at the V International AIDS Conference in 1989, in Montreal, Canada. It advocates for an international code of rights to promote the active involvement of effected communities of people with HIV disease in decision making that may affect them. This document, while more than a decade old, is a continued call to action by everyone to ensure that all people affected by HIV/AIDS have proper food, housing, education, employment, and health care and that they are able to exercise their rights in this regard without any hindrance whatsoever.

—Memoona Hasnain and
Judith A. Levy

See also Americans with Disabilities Act of 1990 (United States); Child Care; Disability in Contemporary Africa; Emerging Disabilities; Immunologic Diseases.

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HOFFMAN, C. COLDEN

(1819–1865)

American missionary

Reverend Cadwallader Colden Hoffman, an American Episcopalian minister, was a missionary in Liberia from 1849 until his death (Fox 1868). He included some deaf boys in his schools (Brittan 1860) and started teaching blind people to read using Moon's embossed script. While itinerating up-country, Hoffman came in contact with many disabled people leading what he considered pitiful existences. He opened a small center on the coast, where blind and other disabled people could live while learning handicrafts and reading: "I have received into it a native man, armless and with a crooked spine, who is only 3 ft. 5 3/4 ins. in height, but of good mind. He begins to read, and can thread a needle, turn a hem, and sew, with his toes" (Moon 1877). Hoffman also planned a center for deaf people, but died before this could be achieved. In sub-Saharan Africa, Hoffman's efforts are among the earliest recorded formal educational and vocational work with blind and deaf people.

—Kumur B. Selim

See also Blind, History of the; Deaf, History of the.

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HOME MODIFICATION

Home modification represents the area of assistive technology in which accessibility and universal design concepts are incorporated into private residences. Through this application, an individual with a disability is able to maximize his or her independence in areas that include entry to and exit from the home, personal care, transfers, meal preparation, cooking, and housekeeping.

In the United States, the Americans with Disabilities Accessibility Guidelines (ADAAG) provide information on the required architectural elements for accessibility in public spaces. Regarding private residences, a municipality may refer to ADAAG, state guidelines, or local codes that address accessibility. Where guidelines differ from one another, the stricter code takes precedence.

Where sufficient space exists, entry to and exit from the home is addressed through the use of ramp systems. The maximum slope allowed for ramp systems is 1:12 (one inch/unit of rise for every 12 inches/units of run). Level platforms are required at the top landing, so that individuals with disabilities can maneuver through the doorway without being on a ramped surface, and at any turns or rest areas. Where space is limited, an electrically powered vertical platform lift may be appropriate.

Accessible bathroom designs include elements to maximize access and safety. This may include the use of a cantilevered sink, lever-profile water faucet handles, and insulated water supply and drain lines. A taller toilet profile makes use easier for those who have difficulty in sitting or standing, or for those who transfer from a wheelchair. Grab bars provide surfaces for stability as an individual transfers or uses the toilet. For bathing, roll-in or walk-in showers with limited-threshold profiles enable individuals to enter and exit the space. Single-lever water controls not requiring fine motor control can make setting of a comfortable temperature possible. Pressure-balancing valves within the wall help keep the water at the set temperature, compensating for water pressure fluctuations due to water use elsewhere in the home. Grab bars assist in this area as well.

Transfers between bed and mobility bases can be assisted through the use of powered transfer lifts. Supported from the ceiling, these electrically powered devices provide vertical travel of a sling or frame support, enabling the user to be lifted safely. For individuals transferring independently, the device can be powered in the lateral direction as well, traveling along a ceiling track to a position above the second surface. For others, the device travels along this track via a ball bearing system, making it easy for the person providing assistance to move the user laterally.

Modifications made in the kitchen to promote independence include lowered countertops, cabinets with D-shaped door handles and carousels or pull-out shelves, countertop or table space with knee clearance beneath, stoves with controls along the front edge, side-by-side refrigerators, and sinks with knee clearance beneath.

In general, wide doorways and pathways within the home, lever-profile doorknobs, and accessible-height light switches and outlets can make efficient use of the space feasible. Retrofitting of these elements into existing homes is usually possible. Home modification elements can easily be incorporated into new home design.

—Glenn Hedman

See also Accessibility Codes and Standards; Aids for Activities of Daily Living; Fair Housing Act Amendments of 1988 (United States); Independent Living.

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HOME SUPPORT

Home support—otherwise known as home care, personal supports, or attendant care—is the provision of human assistance to a person with a disability that enables his or her greater participation in society. Dumont-Lemasson, Donovan, and Wylie (1999) defined home care as "an array of services which enables clients, incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives." The service can assist people with disabilities to perform activities of daily living such as eating, bathing, meal preparation, and errands when it is difficult or impossible for them to do these things on their own. Importantly, in some regions of the world this service facilitates the achievement of life goals in areas associated, for example, with employment, education, health, recreation, and spirituality.

Home support is a concept that is most frequently found in the developed world and in particular countries where social and health care programs exist. People with disabilities consider this a critically important service because it can enable an individual who lives with physical, emotional, or cognitive impairment to engage in society as a participating citizen, particularly when the home support activities are directed and controlled by the disabled user of the service. The development of the notions of user flexibility, choice, and control of personal assistant service is closely tied to the independent living movement. It is also a service that has become increasingly necessary in a context of people leaving institutions to live in the community and as people are discharged earlier from hospital care.

ISSUES

Direct Funding

When people who receive the home support service play a direct role in determining how to implement it, this is often referred to as direct funding or self-directed care. This approach to the provision of home support exists for people who live in countries such as the United States, the United Kingdom, and Canada and is guided by the independent living principles of flexibility, choice, and control. Users are provided with resources to pay for the service, and they are responsible for administrative duties, including interviewing, hiring, training, and firing their attendants. Consumers of the service are not paid for doing administrative work, which reduces overall costs. However, it is important for such programs to involve a local disability organization, which can provide support to individual consumers.

This approach is distinct from other systems of support provision affiliated with government departments or private health care agencies that are guided by principles of efficiency rather than consumer control. High staff turnover results in workers not becoming aware of the preferences, personality, and life goals of the individual they are expected to support.

Unionization of Workforce

This is an important issue, currently being debated in Canada. People who provide assistance are primarily women who are paid a relatively low wage. While those who receive home support services recognize that workers deserve protections and a decent wage, they may be concerned that unionization will further transform their homes into institution-like workplaces and reduce their choice in directing their own care and lives.

Pressures on Informal Care Providers

As populations age, governments are projecting an increase in the need for home support, and as private agencies become increasingly involved in the provision of this service, there is a greater concern for economic returns. Over the past decade, efforts have been made to make it increasingly difficult to be eligible for services and, when services are provided, to narrow the range of services. These factors put greater pressure on families, friends, and neighbors to provide needed care, which in turn has had a negative impact on the health, both of those receiving assistance and the informal unpaid caregivers. Children are expected to care for a disabled parent, a spouse is expected to provide care while also working to meet the family's financial needs, and older women with impairments themselves are having to care for their spouses as their health deteriorates.

DEVELOPMENT: THE EXAMPLE OF CANADA

In countries such as Canada, home support has undergone significant changes during the past decade. In some regions of Canada, the eligibility requirements have become more restrictive, resulting in fewer people accessing the service. The range of services in some regions has now been reduced to basic personal care—bathing and toileting—and no longer includes meal preparation, household cleaning, or any other activity relating to the person's social, economic, political, or spiritual participation in society. In fact, many users can only receive this support inside their own homes. People who have received supports for years are being reassessed using the newer, more restrictive, criteria. There are few arms-length appeal mechanisms for people with impairments to use when they have their services reduced or denied. Disability organizations have found that it can be particularly problematic for people, more often women, who have impairments that are invisible and fluctuating.

Although the Canada Health Act is in place to protect universal access to health-related services in Canada, home support has never been included under this act. At the time the act was developed, deinstitutionalization, community-based models of health care, and the independent living movement had not yet increased awareness of the need for home support service. Because the service is not protected under the act, it is particularly vulnerable to social and economic pressures. The same is true in the United States and other countries with partial health coverage such as Medicare and Medicaid.

Policy making in this area has been influenced by medical models of disability and economic reductionism. Policies reflect and emphasize the notion of disability as a biological limitation rather than one that recognizes the role of society in creating barriers for people who accomplish their goals differently. Services in some regions aim to keep people merely alive and are unconcerned with providing supports that would allow them to leave their homes or bedrooms. This has led some disability activists to see this move as another form of institutionalization.

Policies also tend to be guided by notions of economic restraint, further fueled by rhetoric about the rising cost of health care and the growing number of older Canadians requiring care. Some regions of the country have developed policies that emphasize the goal of spending less on home support service, viewed in isolation. The policy ignores the holistic analysis in which the objective of home support not only is self-direction of one's life but also maintaining its role in health prevention and promotion (e.g., by addressing the social determinants of health and increasing basic nutrition). When people with physical impairments, for example, no longer receive basic care to maintain their lifestyle and health in the community, they can experience a worsening of their health, which in time will require more costly acute care treatment. Home support is clearly less expensive than institution- or hospital-based care, but more important, the disability community views this economic emphasis as a step backward in terms of their human rights.

THE NEED FOR NATIONAL STANDARDS

In Canada and other countries, the administration of home support programs tends to be decentralized to provinces, regions, or smaller administrative units. Studies have indicated that without a national standard there will be significant differences in eligibility criteria, user fees, and range of services across the country. Variation in approaches to service delivery will also exist. In some areas, services are directly provided by public employees, in others competitive tendering results in private agencies delivering services, and in yet others a partnership is created between government and nonprofit providers.

Differences in eligibility criteria are a particular problem, as they appear to be designed to create ineligibility simply in order to reduce costs, rather than to facilitate the exercising of rights. Competition between provinces or municipalities to "reduce costs" threatens the eligibility for services of people who live with long-term impairments. Reassessment can be introduced across the board in regions or it can be initiated by factors such as an individual's move to a region. People with disabilities are not free to move from one location to another because there is no assurance that their services would continue under new local eligibility criteria. A set of national standards for home support established by the central government could help to solve this problem, especially if, as in Canada, the standard-setting, federal government makes adherence to the standards a condition for qualifying for federal funding or cost-sharing.

INTERNATIONAL CONTEXT

Home support should also be seen in light of internationally developed conventions and treaties developed to protect or ensure rights of children and adults who live with disability. Article 23 of the Convention on the Rights of the Child states that "parties recognize that a mentally or physically disabled child should enjoy a full and decent life in conditions that ensure dignity, promote self-reliance, and facilitate the child's active participation in the community." The UN Standard Rules of Equalization of Opportunity was developed in collaboration with member states and disability representatives with the intent of developing a guiding framework for developing policy and services while supporting community participation for people with disabilities. Rule 4 of the UN Standard Rules stipulates that "states should support the development and supply of services including assistive devices, personal assistance and interpretation programs to people with disabilities."

What the future holds for home support depends to a degree on pressure from the international community to live up to the standards set by the UN Standard Rules and possibly in the near future, to the UN Disability Convention. Much will also depend on the willingness of the United Nations and national and local governments to directly involve those who are affected by these home support policies—people with disabilities, parents of children with disabilities, family members—to contribute and be listened to.

At the same time, the growth and ever-increasing power of multinational health care corporations, guided entirely by economic concerns, will redirect attention away from consumer control and citizen-based outcome criteria for services. Government may increasingly feel the pressure to transfer health care services to the multinationals. An increasingly aware, and active, disability movement, joining forces with the rest of the population whose life and health will be affected by these developments, will be required to ensure that home support can involve, and be under the control of, those who are directly affected by these services.

—Kari Krogh

See also Disability Law: Canada; Independent Living; Personal Care Attendants; United Nations Standard Rules.

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▣ HOMER (EIGHTH CENTURY BC)

Greek epic poet

The earliest surviving Greek epic poems, the *Iliad* and the *Odyssey* (dated around the eighth century BC) have traditionally been attributed to Homer, even though his existence has been questioned by many since antiquity. He was believed to have been born blind or to have lost his sight from an eye disease early in life, before completing the *Iliad* or beginning the *Odyssey.* His blindness was accepted by such ancient authors as Herodotus, Theopompus, Plutarch, Cicero, Pausanias, Silius Italicus, Hesychius, and Suidas. It is also represented in several ancient portraits of the poet, whereas others depict him with a piercing gaze. His account, in the eighth book of the *Odyssey*, of Demodocus the blind bard of the Phaeacians (with its implicit notion of the gift of song as a compensation for loss of sight) has been taken as a self-portrait of the poet. The Greek historian Thucydides (fifth century BC) regarded as a genuine work of Homer the "Hymn to the Delian Apollo" in which the author describes himself as a "blind man living in harsh Chios."

Several ancient biographers of Homer mention his blindness, but all of them are late. In the *Phaedrus* (Section 243a), Plato draws a strange parallel between Homer and the poet Stesichorus, who was said to have been punished with blindness for his attack on Helen.

Many modern scholars contend that Homer's blindness is apocryphal, being the result of a misattribution projected from one of the characters of the *Odyssey*. Rejection of Homer's blindness is implied by authors who stress the importance of visual memory for description, such as Velleius Paterculus (AD first century) among the ancients and Minchin (2001) in modern times. Similarly, although Homeric references to eyes and vision are formulaic, Homeric facial gestures may reflect aspects of character and reveal psychological situations, thus standing in for acts and, especially, words (Soteroula 1994). The idea, suggested by Schumann in 1955, that the peculiar structure of Homeric dreams is a proof of their author's blindness has been rejected by scholars such as Mirko Grmek in 1989.

The picture of the blind Homer has left its profound impact on the notion of the blind singer, although the notion itself is not confined to classical Greece. Some recent scholars have endeavored to understand the role of the blind characters in the Homeric poems (such as Tiresias, Demodocus, and Polyphemus) in connection with the legendary blindness of the poet himself.

—D. P. M. Weerakkody

See also Blind, History of the; Marcus Tullius Cicero.

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HOUSING: LAW AND POLICY

Throughout North America and in most European countries, organized housing for people with disabilities was historically derived from charity-based models relying on institutionalization in one form or another. For example, much of the Western approaches to housing law and policy have roots in the Elizabethan poor laws of 1601. These laws were an attempt in early industrial England to dichotomize the poor as either deserving or nondeserving. Those orphaned, blind, or otherwise disabled were viewed as deserving by their conditions and thus were more entitled to charity than the nondeserving poor. Housing for the deserving poor took the form of almshouses and other charity-based facilities. Individuals who were blind, deaf, or had cognitive or other types of disabilities would move into a facility for shelter and education and live out their entire lives within walls.

Contemporary Western approaches to housing policy have seen a shift from charity and welfare models to a focus on community-based models of housing. This has given rise to the adoption of a number of antidiscrimination housing laws and policies in the United States and internationally. Nevertheless, institutions housing individuals with disabilities still exist today, although their numbers are decreasing.

U.S. HOUSING LAW AND POLICY

Fair Housing Act of 1937

Federal housing policy in the United States emerged from the Great Depression of the 1930s and the economic conditions that produced widespread unemployment. In the housing sector, both the finance and construction markets were severely challenged by the Depression. In response, policy makers created the Federal Housing Administration (FHA). The FHA insured private mortgages in order to increase housing construction and stabilize the housing economy.

To assist the poor, a group that included people with disabilities, policy makers also created a public housing program. Under the Fair Housing Act of 1937, the federal government created a program to fund almost the entire cost of public housing. The housing itself was built and managed by local housing authorities, who were required to manage the public housing following federal guidelines.

By the 1960s, new solutions to housing problems emerged including housing for senior citizens, rent supplements, and housing allowances, followed by the Section 8 program in 1974. The Section 8 housing allowance program provided funding through local housing authorities to subsidize housing rehabilitation, implement new construction, and subsidize rents in private housing.

The Section 8 program exists today. In the program, housing vouchers are issued to low-income families and families with members who have disabilities. These vouchers allow the individual or family to do a housing search and find private housing that fits their needs. Under the Section 8 program, the family pays 30 percent of its total income for rent and the housing authority pays the remainder. The local housing authority maintains a listing of public housing and allocates the housing to individuals who meet its eligibility requirements. Housing authorities may choose to give preference to certain groups including individuals living in unsatisfactory conditions, terminally ill people, and people with disabilities. Individuals who fit within these criteria are allowed to move into housing sooner than others on the registry.

Government subsidization is not a program unique to the United States. A number of countries, including the United Kingdom, Austria, and Australia, have created housing programs for people with disabilities subsidized with government funds.

Housing Law

Until the early 1970s, housing laws generally did not include individuals with disabilities as a protected class. Rather, laws such as the Fair Housing Act (Title VIII of the Civil Rights Act of 1968) addressed discrimination on the basis of race. It was not until the passage of the Rehabilitation Act of 1973 in the United Sates that housing law specifically dealt with discrimination faced by individuals with disabilities in housing.

Section 504 of the Rehabilitation Act

Under Section 504 of the Rehabilitation Act of 1973, qualified individuals with disabilities are protected from discrimination in housing programs that receive federal funding. Qualified individuals with disabilities are defined as persons who have a physical or mental impairment that substantially limits them in one or more major life activities. Impairments may include, but are not limited to, visual or hearing impairments, mobility impairments, psychiatric impairments, HIV infection, cognitive impairments, and drug addiction (not current illegal use).

Major life activities include caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working. Substantial limitation in these activities is determined by whether or not the average person can perform them with little or no difficulty.

Newly constructed federally funded housing is required to be physically accessible to tenants with disabilities under Section 504. At least 5 percent of units (or a minimum of at least one unit) must be accessible to tenants in wheelchairs and other mobility devices. Two percent (or at least one unit) must have the accessibility features needed by individuals with hearing or vision impairments. Accessible units are to be distributed throughout housing sites to ensure that tenants with disabilities have a variety of options in location and amenities. There are also requirements for physical accessibility when federally funded housing is altered as well.

Reasonable accommodation for tenants with disabilities is another major feature of Section 504. Accommodations may include changes to a policy, program, service, or dwelling unit that allow tenants with disabilities to fully participate in the housing experience. For example, the federally funded housing program may install a ramp for a tenant in a wheelchair or allow a service animal despite a “no pets” policy. These modifications are to be carried out at the expense of the federal funding recipient, unless it would result in an undue financial or administrative burden. Undue burden is defined as substantial administrative difficulty or expense. When deciding whether or not an action would be an undue burden, the housing entity must consider all resources available to them.

Fair Housing Act Amendments of 1988

The Fair Housing Act of 1968 prohibits discrimination in housing practices on the basis of race in almost all forms of housing sold or rented in the United States. It was amended in 1988 to include protections for people with disabilities. This amendment extended protection for people with disabilities beyond those in Section 504 to include private housing. Disability is defined under the Fair Housing Act using the same criteria as under Section 504 and the Americans with Disabilities Act.

Actions prohibited under the act include the refusal to sell or rent to an individual with a disability or to a family that includes a member with a disability. The Fair Housing Act also prohibits the refusal to negotiate; making housing unavailable; denying a dwelling; setting different terms, conditions, or privileges for sale or rental; providing different housing services; falsely denying that housing is available for sale or rental; persuading owners to sell or rent; or denying anyone access to or membership in a facility or service to people with disabilities.

Mortgage lenders are not allowed to refuse to make a loan, refuse to provide information regarding loans, impose different terms or conditions on a loan, discriminate in appraising property, refuse to purchase a loan, or set different terms or conditions for purchasing a loan when working with individuals with disabilities protected under the Fair Housing Act.

Similar to Section 504, housing entities must make reasonable modifications to policy and procedure to allow individuals with disabilities to use their housing. For instance, an apartment complex that provides unassigned parking to its tenants would have to allow a tenant with a mobility impairment a reserved accessible parking space near his or her unit.

Tenants with disabilities are also allowed to make reasonable modifications to their dwellings as well as to the common areas of the complex if this will allow them the use of their unit or the public areas. For instance, if a tenant with a disability needed to widen the doorways in an apartment, under the act, the landlord would have to allow the tenant to make the needed changes. The tenant would be responsible for restoring the unit to its original state when he or she moves. The costs of the reasonable accommodations provided by federally funded housing programs under Section 504 of the Rehabilitation Act are the responsibility of the housing provider, but reasonable modifications under the Fair Housing Act are at the expense of the individual with a disability.

Housing complexes that first had occupancy after March 13, 1991, and have an elevator or four our more units are required to be physically accessible to tenants with disabilities. In addition to the accessibility of the public and common areas, ground-floor dwelling units must also be accessible. Accessible features include doors and hallways that are wide enough for wheelchairs, accessible light switches and other environmental controls, reinforced bathroom walls for the possible installation of grab bars, and kitchens and bathrooms that are usable by tenants with mobility impairments.

Americans with Disabilities Act of 1990

The Americans with Disabilities Act of 1990 (ADA) prohibits discrimination in employment, state and local government programs, the provision of goods and service in business, transportation, and in certain circumstances, housing. Individuals with disabilities are protected under the ADA in housing in several situations. If housing is part of a public accommodation or business that is open to the public such as a hotel, it is covered under the ADA. Specifically, hotel rooms need to be physically accessible under the ADA. Hotels are also required to provide auxiliary aids and services such as visible alarms and text telephones (TTY) for guests who are deaf. Places of lodging might also have to modify policies and procedures if those policies discriminate against guests with disabilities such as eliminating a no-pets policy for guests with disabilities who have service animals.

Hotels that include residential areas would be covered both under the ADA and the Fair Housing Act. The area occupied by individuals living in the hotel would be subject to the requirements outlined in the Fair Housing Act, while the transient lodging section of the facility would be held to the regulations in the ADA. Public areas in housing complexes such as rental offices and community rooms may also be covered under the ADA. For instance, if the community room of a housing complex is rented to community members for events, it would then fall under the ADA and need to be accessible to individuals with disabilities.

INTERNATIONAL CIVIL ANTIDISCRIMINATION LAWS

Many countries across the world have enacted civil antidiscrimination laws protecting people with disabilities from discrimination. Some of the most extensive antidiscrimination laws including protection for individuals in housing have been enacted in Australia, Canada, the United Kingdom, and the United States. These laws in general protect people with disabilities from discrimination in employment through the provision of accommodations and public accommodations or business in regard to the provision of physical access and policy modification.

Internationally, Hong Kong, the Philippines, Costa Rica, Hungary, India, Israel, Japan, Nepal, New Zealand, Peru, and Thailand all have antidiscrimination laws that include protection for people with disabilities in employment, services, and public accommodations but not housing.

Disability Discrimination Act of 1992 (Australia)

The Australian Disability Discrimination Act of 1992 (DDA) prohibits discrimination against people with disabilities in employment, education, land possession, the provision of goods and services, and access to premises, clubs, sports, other facilities, and housing.

Under the act, it is illegal for housing agents to discriminate against an individual with a disability or anyone associated with an individual with a disability by refusing the person's application for housing, discriminating in the way the housing is offered, deferring the application of a person with a disability, limiting or denying access to any service or privilege related to housing, evicting due to disability, and refusing to allow the individual with a disability to make alterations to housing related to disability at the individual with disabilities' expense.

Human Rights Act of 1985 (Canada)

The Canadian Human Rights Act of 1985 prohibits discrimination against individuals with disabilities in the provision of goods and services and facilities that are open to the general public, employment, commercial premises, and housing. Under the act, discriminatory practices in the provision of housing or residential accommodation include denying occupancy to an individual with a disability or giving preferential treatment to a person without a disability over an individual with a disability in any housing negotiation.

Disability Discrimination Act of 1995 (United Kingdom)

The Disability Discrimination Act of 1995 (DDA) provides protection for individuals with disabilities in employment, access to goods and services, and housing. In the area of housing, the DDA makes it illegal to sell or rent property in ways that would discriminate against people with disabilities.

FUTURE OF HOUSING LAW AND POLICY

The future of housing law and policy as it relates to people with disabilities is predominantly a positive one. Throughout the world, many laws have been enacted and policies created that give greater and greater protection to people with disabilities in almost every aspect of housing rental, sale, and purchase. Housing law and policy has moved from a welfare and charity focus to one of empowerment and independence. If the past is any indication, this trend should continue to grow in the future.

—Charles Davis

See also Americans with Disabilities Act of 1990 (United States); Charity; Disability Discrimination Act of 1995 (United Kingdom); Fair Housing Act Amendments of 1988 (United States); Rehabilitation Act of 1973 (United States).

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HUMAN RIGHTS ACT OF 1998 (UNITED KINGDOM)

"Disability was, until very recently, the forgotten dimension of human rights and unacknowledged as a subject for a right to equality" (Daw 2000:8). It is fair to say, however, that the implementation in October 2000 of the UK Human Rights Act 1998 has led to an increase in the (successful) use of human rights arguments in the context of disability specifically in the United Kingdom.

Prior to the implementation of the act, anyone who wished to complain of a violation of the EU European Convention on Human Rights (referred to below as the convention) had to exhaust domestic remedies for complaint and then take their case before the European Court of Human Rights—there was no means by which a claim of breach of the convention could be brought in the UK courts.

The act—as well as making virtually all of the convention rights directly enforceable in the UK courts—brought fundamental change to the way in which courts and tribunals interpret legislation. Section 6 of the act provides that it is unlawful for a public authority to act in a way that is incompatible with a convention right (i.e., it cannot act in a way that would breach any of the rights in the convention—this is a positive duty placed on public authorities to uphold the convention rights); Section 3 of the act obliges courts to "read and give effect" to legislation in a way that is compatible with the convention rights (this means that when considering any piece of legislation, the court must interpret it in line with the convention rights; e.g., any family law provisions will have to be considered in light of Article 8, the right to respect for private and family life). And courts can make a "declaration of incompatibility" where a legal provision cannot be read and given effect in a way that complies with the convention (i.e., state that it is not possible to interpret the provision in such a way as to be compatible with the convention). Although the government would not be obliged to act following such a declaration, it is likely that it would do so, as otherwise a successful claim against the government could be brought in the European Court of Human Rights.

The convention rights, listed in Schedule 1 to the act, are as follows:

Right to life

Right to freedom from torture and inhuman and degrading treatment

Right to freedom from slavery or servitude

Right to liberty and security

Right to a fair trial

Right to no punishment without law

Right to respect for private and family life

Right to freedom of thought conscience and religion

Right to freedom of expression

Right to freedom of assembly and association

Right to marry

Right to enjoyment of the rights and freedoms without discrimination on any ground

Some of the rights—such as the right to life—are absolute, while others are qualified.

In purely numerical terms, mental health has been one of the areas in which the Human Rights Act has been frequently raised—there have been 10 declarations of incompatibility, three of which have related to the Mental Health Act 1983 and one of which has led to remedial legislation being introduced. Many of these challenges have related to Articles 5 and 6, the right to liberty and the right to a fair trial, respectively.

The key articles that have otherwise been invoked in relation to disability have been Article 2, the right to life (particularly in relation to the withdrawal/refusal of treatment of disabled people); and Article 8, the right to respect for private and family life (and dignity—successfully invoked in a case involving the provision by the local authority of care in the home, and the provision of local authority housing). While it is too early to fully judge the impact of the act in relation to disability, it can nevertheless be said that it is being increasingly invoked by disabled people and there have been some significant successes in cases brought under it.

—Catherine Casserley

See also Disability Discrimination Act of 1995 (United Kingdom).

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HUMANITIES

Disability studies in the humanities has arrived somewhat belatedly, the field having been dominated by medical professionals, rehabilitation specialists, or social scientists who tended to focus on institutional or pathological contexts. Certain studies within the social sciences such as Erving Goffman's *Stigma* (1968), Georges Canguilhem's *Le normal et le pathologique* (1966), and Michel Foucault's *The Birth of the Clinic* (1963) provided humanist scholars with significant tools for complicating the medical model that had dominated the field until the mid-1980s. The emergence of cultural studies in the 1990s helped link disability with identity categories based around gender, race, and sexuality and provided a set of methodological tools for doing cross-cultural analysis. Publications such as David Mitchell and Sharon Snyder's collection, *The Body and Physical Difference,* Rosemarie Garland Thomson's *Extraordinary Bodies,* and Lennard Davis's *Enforcing Normalcy* explored the cultural meanings of disability and linked the disabled body to other identity categories. Special issues of journals devoted to disability issues, the formation of the Modern Language Association's Committee on Disability Issues, the emergence of the Disability in the Humanities chatlist (DS-HUM), and the evolution of interdisciplinary disability studies programs at various universities created a context for studying disability within the humanities.

Disability studies has proceeded through several stages, analogous to those undergone within feminism, queer, or minority activism. Unlike these other identity movements, these stages within disability studies are relatively coterminous, each modifying and adumbrating the other rather than succeeding each other in a linear sequence. The first stage has involved identifying stereotypes of the disabled figure in cultural texts and exploring ways that a physical impairment has been used figuratively as a sign of lack, instability, or moral phobia. First-wave disability studies has created an archive of texts—novels, films, poems, autobiographies, paintings—in which disability is featured and assesses the possibilities for resistance to and rearticulation of those stereotypes.

The second stage—the cultural nationalist moment—coincides with the rise of an activist disability movement and involves establishing a disability community. On the one hand, this implies wresting the category "disability" from definitions established within the medical and psychoanalytic professions. On the other hand, it means establishing consensus among constituencies who may be isolated within medical and therapeutic regimes. Vital to this stage of disability studies is the proliferation of first-person accounts by disabled artists and intellectuals such as those by Nancy Mairs, Audre Lorde, Paul Monette, Robert Murphy, John Hockenberry, and Susan Sontag. Such life-stories are essential for a population that often lacks access to official publishing and media venues and whose narratives are often told by doctors and health care professionals. At the same time, a renewed interest in disabled artists creates a new consciousness of the role that disability has played in the arts (Toulouse Lautrec, Chuck Close, Goya), literature (John Keats, Samuel Johnson), and music (Beethoven). Thus, a main component of second-wave disability work involves giving voice to the disability rights slogan "Nothing about us without us."

A third stage of disability studies emerges in the 1990s, influenced by work in cultural studies and post-structuralism, that attempts to understand processes by which a physical or cognitive impairment becomes stigmatized. Key works by Rosemarie Garland Thomson, Simi Linton, Michael Bérubé, and Lennard Davis focused on the ways that bodily normalcy is reinforced within able-bodied (or what Thomson calls "normate") society. These works remove the emphasis on the impairment and shift the focus to the ways that society enforces certain cognitive, physical, and sensory ideals.

The stress on a social rather than medical model has led to significant research on the cultural meaning of disability in literature, art, film, and history. Historical work on late nineteenth-century medicine, for example, has revealed the extent to which the concept of disability was invented through projects of national consolidation and racialization. Rosemarie Garland Thomson and Robert Bogdan showed how the phenomenon of freak shows, in which nontraditional bodies were displayed as "human curiosities," becomes an extension of a larger impulse toward standardization of the body. Such scholarship suggests that disability, like homosexuality or race, is largely a product of a specific historical period for which technologies (photography, film), methodologies (statistics, comparative anatomy, psychoanalysis), and social theories (eugenics) contribute to an ideal of normalcy in the Victorian period.

Third-stage disability studies by Lennard Davis, David Mitchell, Sharon Snyder, and Tobin Siebers, while drawing on key formulations by Judith Butler and Michel Foucault, have nevertheless questioned the limitations of social constructionist definitions when faced with actual, historical bodies. Many social constructionists, Siebers (2001:742) argued, "assume that it is extremely difficult to see through the repressive apparatus of modern society to any given body, but when they do manage to spot one, it is rarely disabled. It is usually a body that feels good and looks good." Davis similarly observed that identity is perhaps not the "sharpest instrument" around which to base an intellectual project if the end of all rights-based claims is the ideal of achieving the status of white, middle-class males. It is possible that beneath the liberatory rhetoric of identity politics lurks an idealized norm, for which the disabled body provides an antidote. In *Bending over Backwards* (2002), Davis has created a portmanteau term, "dismodernism," to describe how disability undermines identity positions that emerged with early modernism and that were based around medical and eugenics models.

Third-stage disability studies builds on a cross-cultural analysis, finding parallels between disability and queer or colonial or racialized identities. Many disability theorists have seen their critical projects as analogous to queer theory, "cripping" (on the analogy of "queering") normative discourse to reveal implications of able-bodiedness. Instead of seeing the person with a disability as a metaphor for some other condition (castration, moral phobias), scholars and disability activists have studied the constitutive function of such figures in various cultural objects and documents. David Mitchell and Sharon Snyder, for example, noted that the disabled figure in novels and films perform a "prosthetic" function for narrative. Not only do novels rely on a disabled character to create pathos (Tiny Tim, the Elephant Man) or pathology (Ahab, Lear); such figures are foundational for narrative form itself. What, for example, would be the meaning of Oedipus's tragic loss if he were not blind? Like the prosthetic limb, the disabled person provides an illusion of presence and wholeness that must be eliminated by the end of the novel or film so that the able body can be restored.

These developments in scholarship have important implications for humanities pedagogy. If the humanities is underwritten by an idealized body, what happens when that body does not match Michelangelo's heroic David or Leonardo's Vitruvian Man? More specifically, what happens when the humanities classroom includes a disabled student or instructor? At one level, both have greater access to the physical classroom itself, due to legislation such as the Americans with Disabilities Act and the growth of new technologies (computers, voice translators, distance learning) that make learning more accessible. On another level, the introduction of disability as a subject challenges the student to ask new questions about the self-evident categories of aesthetic and epistemological endeavor. What might the study of poetry be like for a Deaf student for whom "heard melodies" may not be so sweet as those produced by sign language? What is this student to make of terms such as "oral tradition," "limping meters," "eye rhymes," "accentual verse," and other basic terms of prosody that presume a hearing readership and print representation of a spoken text? In like manner, what might humanities study be like if we were to treat *Paradise Lost* as the product of a blind person, the dissonant harmonies of Beethoven's late quartets as the product of a deaf person? Disability asks such questions in order to rethink the "human" in "humanities" and imagine that it includes a woman with a cane, a child using sign language, a man with a compromised immune system.

—Michael Davidson

See also Anthropology; Disability Studies.

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HUMORS, THEORY OF

Humors are bodily fluids that according to some ancient physicians presided over illness and health. The excess of any one of the humors would lead to specific diseases, as a good balance was the condition of health. The theory of humors, which was central in medical theory for centuries, is now completely banished from the field of medicine, even if it is still part of the heritage of some alternative medicines.

The first medical references to humors are found in the Hippocratic corpus:

> The body of man has in itself blood, phlegm, yellow bile and black bile; these make up the nature of his body, and through these he feels pain or enjoys health. Now he enjoys the most perfect health when these elements are duly proportioned to one another in respect of compounding, power and bulk, and when they are perfectly mingled. ([Hippocrates], *Nature of Man* 4, translation by W. H. S. Jones)

These were to become the canonical four humors, but even the Hippocratic corpus contains variations. For instance, the treatise *Diseases* IV lists phlegm, blood, bile, and water ([Hippocrates], *Diseases* IV, 32).

The text *Nature of Man* not only names the humors but also links them with the four seasons and with the mixtures of the qualities warm, cold, dry, and humid. Although the humors are always present in the body and are necessary to life, they are found in greater quantities according to the times of the year: phlegm in the winter, blood in the spring, yellow bile in the summer, and black bile in the autumn. The predominance of one humor is connected with a similarity between the humor and the season. For instance, the increase of phlegm in the winter is related to the fact that phlegm is the coldest humor. Daily occupations, the way you live, and food influence the quantity of the humors in the body: Dark wines, lentils, snails, and the meat of bulls and goats are all prone to produce black bile. Humors are natural and necessary to life, but their mixture needs to be in a state of balance toward one another. An increase in the amount of one humor or in the concentration of one humor in one place can cause diseases, such as hemorrhoids, anthrax, and cancer in the case of black bile. The cures to such imbalances are found in purgation and bloodletting.

The names of the four humors and the theory of humors were to become prevalent because they were attached to the name of Hippocrates and because they were adopted and developed by Galen, the second-century AD physician, who was to become central both in occidental and Arabic medicine. Yet there were competing theories. Praxagoras of Cos, for instance, was able to distinguish 11 humors. On the other hand, Erasistratus of Iulis did not reject the theory of humors, but showed caution, and was bitterly reproached by Galen for this reason. Asclepiades of Bithynia and the Methodists, a medical school that became popular in Rome, rejected the explanation of humors as a cause of diseases.

Galen adopted a system relating the humors to the four elements—earth, air, fire, water —and to a mixture of qualities—warm, cold, dry, humid—and to a certain extent to seasons and ages. Some of the developments of the theory were specifically medieval: the complete theory of the four ages of life; the four temperaments, namely, phlegmatic, sanguine, choleric and melancholic; and the perfect integration of the microcosm into the macrocosm. Critiques of the humoral theory appeared as early as the Renaissance, but the system was influential until the nineteenth century.

—Anne-France Morand

See also Galen; History of Disability: Early Modern West; Hippocrates; Melancholy.

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HUNT, PAUL (1937–1979)

British activist

Paul Hunt is regarded by many disability activists as the founder of the modern disabled people's movement. He has been influential not only in the United Kingdom but internationally. It was at Le Court Leonard Cheshire residential home that he and other disabled people first developed the ideas and philosophy that were to inform the Union of the Physically Impaired against Segregation (UPIAS). UPIAS was established in 1972 and can be seen as a key starting point for the development of the British disabled people's movement. Its Fundamental Principles of 1976 gave birth to the social or social oppression model of disability.

Paul Hunt's edited collection (1966) of disabled people's accounts is now identified as one of the key texts in the development of the British disabled people's movement and disabled people's thinking more generally. He was influential both through his writings and as a key participant in UPIAS. Hunt also played a pioneering role in the development of disabled people's (emancipatory) research. He and other disabled people invited academic researchers into Le Court to hear their views and felt betrayed when these researchers conceived of them instead as "parasites." Paul Hunt in turn described such researchers as "parasites, questioned the balance and neutrality of traditional disability research, and raised the question of "whose side are you on?" which continues to concern disability research.

—Peter Beresford and
Fran Branfield

See also Disabled Peoples' International; Union of the Physically Impaired against Segregation (UPIAS).

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HUSSEIN, TAHA (1889–1973)

Egyptian intellectual and modernizer

Taha Hussein (also spelled Husayn) was born in an obscure village of Upper Egypt and lost his sight in early childhood. He learned locally to memorize and recite the Qur'an and continued in 1902 to Al-Azhar University where for centuries there has been a school for blind students of Islam (Dodge 1974). He studied further at the new secular university at Cairo, writing a dissertation on the freethinking blind poet Abu 'l-`Ala al-Ma`arri, with whom he identified. Taha Hussein's abilities and persistence earned him a ticket to study in France from 1915 to 1919. He acquired a doctorate and some Braille, but he relied also on a French reader, Suzanne, who became his wife. Returning to Egypt, Hussein taught literature at the University of Cairo. His first book, using source criticism on pre-Islamic poetry, seemed to impugn parts of the Qur'an, which led to a great uproar. The first volume of his autobiography *Al-Ayyam* (*The Days*) had a better reception, and it is this cumulative work for which he became internationally celebrated (Husayn 1926–1927, 1940, 1955; Malti-Douglas 1988). A prolific writer, critic, and energetic campaigner for modernization, he was briefly Egypt's Minister of Education (1950–1952), and in the longer term a cultural ambassador between the Arab and Western worlds (Goldschmidt 2000).

—Kumur B. Selim

See also Abu 'l`Ala al-Ma`arri; Blind, History of the.

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HYDROTHERAPY

Common usage of the term *hydrotherapy* refers to use of relatively large quantities of water on the external surface of the body, including wounds, for water's properties of buoyancy, cleansing, and high thermal capacity, that is, its ability to heat or cool. Related terms include *aquatic physical therapy*, *hot tub therapy*, and *whirlpool bath*. As with other forms of therapeutic heat and cold, hydrotherapy is a treatment, or adjunct to treatment, and not a cure in itself.

The property of buoyancy comes from the pressure exerted on the body by the surrounding water, in proportion to the volume of water displaced by the body. Buoyancy, depending on the depth of the water, allows walking with reduced weight bearing on the joints of the lower limbs. It also reduces the load on the back. This affords the patient with rheumatoid arthritis and other forms of arthritis the chance of near pain-free ambulation. This, in turn, results in improved range of joint motion and even increased fitness, if the patient is very deconditioned to begin with, and the exercise is done with progressively increasing vigor.

The cleansing action of water is greatly helped by agitation and the use of a detergent. This is similar to the action of a clothes washing machine, except that far less detergent is used or needed in hydrotherapy, and the detergent may have antibacterial and emollient (skin softening) properties in addition to breaking up the surface tension of the water, allowing it to "wet" better. Hydrotherapy of this type may be applied with the large Hubbard Tank, which is shaped like the "angels" children make when they lie on their backs in the snow and spread their arms and legs. This shape permits the nurse or therapist to come close to the buoyant patient and remove adherent dressings as they begin to float away from the burns or other wounds. Jets around the sides of the Hubbard Tank agitate the water.

Various sizes and shapes of whirlpool baths enable the patient to sit in a tub or place an arm and hand or leg and foot in the water. Jets can provide more concentrated agitation than is possible with the Hubbard Tank. The most focused form of hydrotherapy for cleansing is applied with pulsatile lavage. With this, no part of the body is submerged, but a device similar to the one used in many homes for teeth and gum hygiene applies sterile saline (salt water in a concentration similar to that of human blood) directly to the wound, to improve the local environment for healing. With pulsed lavage, care must be taken to be sure that there is no *Acinetobacter* in the wound or this can result in pneumonia of the patient treated or other patients in the hospital.

Finally, hydrotherapy allows application of therapeutic heat or cold. The larger the amount of the body submerged, the more care must be taken not to greatly disturb the core (center) temperature of the body. This high thermal capacity of water can be used to the advantage of multiple sclerosis patients, whose symptoms are greatly worsened by heat. They can swim in cool (about 72 degrees F) and obtain aerobic exercise benefit without the adverse effects of increased body temperature.

Water can also be used to "couple" ultrasound to the body part being treated, but no agitation should be used, since the bubbles will reflect ultrasound and make it ineffective.

—Barbara deLateur

See also Arthritis and Cartilage Diseases and Injuries; Burns.

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HYPERTENSION

Hypertension is one of the most frequently diagnosed disorders in the developed world. In the United States, the cost of antihypertensive drugs accounts for about 10 percent of the country's total spending on medications. Increasingly, hypertension is viewed as a problem also in the developing world. In 2001, the African Union placed it second only to AIDS in the health challenges facing African countries.

Hypertension today is predominantly treated as a risk factor for stroke and heart disease, and treatment is preventive. This has not always been the case. Well into the 1950s, hypertension itself, in its malignant phase, was feared as a disabling and often deadly disease. Most noticeably disabling were effects on patients' eyesight, breathing difficulties, and headaches. Before effective treatments became widely available, people with hypertension were expected to die within one year of diagnosis. Malignant hypertension has become rare in the developed world since the 1940s and 1950s, when more and more patients were treated first by surgery and later with the new antihypertensive drugs. However, poorer sections of the population and members of ethnic minorities still face a higher risk of complications from undiagnosed and untreated hypertension than the more affluent.

The modern, noninvasive method of measuring blood pressure was devised in 1905 by a Russian army surgeon, Nicolai Korotkoff. Physicians examining applicants for industrial life insurance policies in the United States were the first to systematically apply this method. Compilations of actuarial data gathered by the insurance companies, as well as several long-term epidemiological studies undertaken in different countries since World War II, produced evidence of a statistical association between blood pressure and life expectancy, indicating that the higher a person's blood pressure, the higher was the probability that this person might die prematurely. However, the causes of the high blood pressure itself have remained unclear for the majority of patients.

As moderately high blood pressure is statistically associated with a higher probability of early death but does not produce any immediate symptoms, questions of treatment and the determination of a clear boundary between normal and pathological blood pressures have been the subject of intense debates among medical experts. The early drug therapies caused serious side effects, often worse than the symptoms of the disease. These drugs demonstrated that long-term treatment increased the life expectancy of patients with malignant hypertension, but only the development of drugs with less severe side effects, such as thiazide diuretics or beta-blockers, allowed the preventive treatment of patients with mild and moderate hypertension.

Most physicians today follow a pragmatic approach to therapy. They prescribe antihypertensive drugs if the benefits of long-term treatment are likely to be greater than the risks associated with the medication. However, some have continued to argue that in many cases both the neurosis caused by being labeled "hypertensive" and the side effects of the antihypertensive drugs might have worse consequences than the high blood pressure itself.

—Carsten Timmermann

See also Cardiac Conditions; Stroke.

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HYPOCHONDRIA

Hypochondria, a word of Greek origin, meaning literally "below the cartilage" (referring to ailments in the abdominal region), gradually acquired the designation of a psychological malady: the morbid preoccupation with serious illness without demonstrable organic disease. This preoccupation is based on a misinterpretation of bodily sensations, functions, or symptoms and persists despite appropriate medical evaluation and reassurance. Affected patients are significantly distressed, and there is impairment in personal, social, and occupational functioning. The beliefs about illness are not delusional in that the individual can acknowledge the possibility of exaggerating symptoms and admit that a dreaded disease state may not exist. Nevertheless, there tends to be a high use of medical care, repeated doctor visits, and costly laboratory and diagnostic testing. The persistence of this pattern for at least six months is necessary to classify it as a psychiatric disorder.

Prevalence estimates for hypochondria in the medical setting, both in the United States and internationally, range from 3 to 5 percent of this population, and it is equally common in males and in females. There does not appear to be any correlation with socioeconomic status, educational level, race, or marital status. Onset can occur at any age but tends to be most common in young adults. There tends to be a high comorbidity with other psychiatric conditions, such as depression, anxiety disorders, and personality disorders. Hypochondria is distinguished from other psychosomatic illnesses by its core feature of fear of having or contracting a disease, as opposed to concern about symptoms (as in somatization disorder), concern about physical appearance (as in body dysmorphic disorder), or disturbances in motor or sensory functions (as in conversion disorder). In addition, hypochondria should be distinguished from malingering or manipulation in that the hypochondriacal patient actually experiences symptoms and is quite anguished about them.

There are various theoretical explanations regarding the psychological origins of hypochondria. These include the transformation of unacceptable hostile or aggressive feelings into physical complaints, that is, to reproach one's caregivers with unremitting suffering; the physical expression of wishes for care and nurturance; a defense against low self-esteem; a defense against guilt, with physical suffering serving as atonement; an attempt to gain sympathy or to control and manipulate, that is, what can be thought of as the secondary gain of the sick role; and as a form of selective attention and cognitive distortion regarding physical sensations.

Although hypochondria tends to be chronic and episodic, some patients do recover, and many respond to a sensitive, individualized treatment approach. Cognitive-behavioral therapy, group therapy, and psychodynamic therapy have all demonstrated some effectiveness. In addition, pharmacotherapy, such as the use of antidepressants, can be used as an adjunct to psychotherapy and educational treatments, especially if there are comorbid symptoms such as depression. In general, a guiding principle of treatment is care rather than cure. The goal of treatment should be aimed at helping the individual cope with and tolerate symptoms rather than trying to eliminate them. An attempt should be made to disconnect the experience of bodily symptoms from receiving care and to encourage the direct, verbal expression of feelings. In the words of the nineteenth-century British anatomist Henry Maudsley: "The sorrow that has no vent in tears makes other organs weep" (quoted in Cantor 1996:60).

—John L. Perri

See also Depression; Psychiatric Disorders; Psychiatry.

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HYSTERIA

No longer part of psychiatry's official diagnostic nomenclature, *hysteria* is a term that continues to capture the public imagination, despite the fact that its significance is largely historical. The term, whose origins and definition have been the subject of centuries of scholarly debate, is generally used to describe a wide range of behaviors and symptoms—from paralysis to blindness to cough—that do not appear to result from physical illness. From the ancient Egyptians to Hippocrates to Freud and Charcot to contemporary psychiatry, hysteria has played an important role in our efforts to understand the duality of mind and body.

ANCIENT ORIGINS

Taking its name from the Greek *hystera,* meaning uterus, hysteria originated as a disorder of women. Although the standard historical account dates its inception to Hippocrates, called the father of medicine, references to the disorder can be found as early as 1900 BC in the *Kahun Papyrus,* an Egyptian medical manuscript. The ancient Egyptians believed that the uterus was an independent organism whose movement within the body led to behavioral disturbances. This idea was further elaborated by classical healers and philosophers (including Plato), who believed that as the womb wandered throughout the body, it created symptoms particular to its location. For example, cough and loss of voice, as well as a choking sensation known as *globus hystericus,* were believed to be the result of the uterus migrating to the throat.

Hippocratic texts linked uterine migration to abnormal sexual activity, including abstinence, and consequently recommended marriage and pregnancy as primary treatments. Additional measures—derived from the ancient Egyptians—focused on returning the womb to its proper location, either by cleansing the woman's vagina with fragrant substances to attract the uterus or by ingesting foul-tasting potions to drive the womb away from the upper body. Galen of Pergamon (AD 129–ca. 199/216), who believed that hysteria was due not to movement of the uterus but to uterine retention of a fluid analogous to male semen, proposed a cure that involved release of the congested sperm through increased sexual activity or digital manipulation by the physician—essentially, cure by orgasm.

Beginning in the seventeenth century, the uterine theory of hysteria gave way to a neural etiology, as physicians such as Thomas Sydenham (1624–1689) began to describe hysteria as an affliction of the mind that found expression in the body. It was now theoretically possible for men, in whom similar symptoms had previously been diagnosed as hypochondriasis, to suffer from hysteria. In practice, however, most of the patients remained women.

JEAN MARTIN CHARCOT (1825–1893)

Jean Martin Charcot, a French physician who was the director of the Paris women's hospital, the Salpêtrière, in the 1880s, is widely considered to be the father of modern hysteria. A neurologist who had made a name for himself using the "anatomical-clinical method" to study multiple sclerosis, poliomyelitis, neurosyphilis, and amyotrophic lateral sclerosis, Charcot turned his considerable nosologic skills to hysteria. He described a four-stage epileptiform attack, three categories of hysterical stigmata (sensory disturbances, such as anesthesias; disturbances of the senses, such as deafness or blindness; and motor disturbances, such as paralysis), and 20 hysterogenic zones on the female body. Charcot demonstrated the attacks at two weekly public performances at the Salpêtrière, in which hysterical patients would be hypnotized and display their symptoms to audiences of as many as 500. Toward the end of his life, Charcot's ideas were challenged by his rivals, including both some of his own students and Hippolyte Bernheim of the University of Nancy (known as the Nancy school), who suggested that

Charcot's patients had been coached and were not acting under natural hypnosis.

After his death, Charcot's study of hysteria was continued by his protégé, Pierre Janet, a French physician who delivered a famous series of 15 lectures titled "The Major Symptoms of Hysteria" at the inauguration of the new buildings at Harvard Medical School in 1906. Janet described hysteria as characterized by *idée fixé* (fixed ideas) that lingered below the surface of consciousness, and he may have predated Freud in his belief that treatment of hysteria involved making these unconscious ideas manifest.

SIGMUND FREUD (1856–1939)

Sigmund Freud, the father of psychoanalysis, studied with Charcot at the Salpêtrière in 1885 and 1886 and developed his own account of hysteria's neurotic origins. Based on 10 years of work with hysterical patients, he and Joseph Breuer wrote *Studies on Hysteria* (1895), a volume of case studies in which they argued that hysterical symptoms were the expression of psychic trauma and that the cure involved retrieving memories of the originating event, often through hypnosis. Breuer's first case was of Anna O. (a pseudonym for Bertha Pappenheim, who later became an active feminist), a young woman who developed multiple physical symptoms—cough, headaches, contractures of her right arm and leg, sleepwalking, and loss of voice—in the context of nursing her ill father. During the course of her treatment with Breuer—a method she called "the talking cure"—she translated her symptoms into a narrative, bringing to light her internal conflict between her guilt over her father's death and her desire to escape a repressive, patriarchal family. "Hysterics suffers mainly from reminiscences," Breuer and Freud wrote, theorizing that hysterical symptoms are due to selective blockage of memory. Out of hysteria, psychoanalysis was born.

By 1896, Freud had developed the "seduction theory," a model of hysteria based on the notion that the condition originated from repressed memories of childhood (and sometimes infantile) sexual abuse, often perpetrated by the father. By the following year, however, he had abandoned this theory, hypothesizing instead that hysterical patients were expressing fantasies based on their own unconscious Oedipal desires. In 1905, he published "Fragment of an Analysis of a Case of Hysteria," in which he described the case of Dora (a pseudonym for Ida Bauer), a young woman with relatively mild hysteric symptoms—chronic cough, headaches, and depressions—who had been brought to see Freud by her father after threatening suicide. Dora accused her father of having an affair with a family friend, Frau K., and felt that because of his desire to protect the secret of his own adultery, her father had turned a blind eye to the fact that Frau K.'s husband, Herr K., was making sexual advances toward Dora. Freud interpreted the situation in light of his own Oedipal theories, concluding that Dora was unconsciously attracted to Herr K. as a stand-in for her father. After 11 weeks, Dora broke off the treatment; but despite its short duration, this case remains one the most important in the history of hysteria, providing the first example of Freud's theory that hysteria represented a conversion of forbidden (and unconscious) libidinous impulses into physical symbolization.

Women treated for hysteria in the nineteenth century were often significantly disabled. Unable to engage in the work of relationships and daily life, they frequently required 24-hour care at home, or—if their families could not afford in-home care—were institutionalized for life.

IN THE TWENTIETH- AND TWENTY-FIRST CENTURIES

In the years after Freud, hysteria splintered into multiple psychiatric diagnoses, including hysterical conversion (or conversion hysteria), hysterical personality, and multiple personality disorder. The change reflected the conflict between a symptom-based approach (hysteria as something that one *has*) and a character-based approach (hysteria as something that one *is*). *Conversion hysteria* described the disorder in which psychological phenomena are expressed through physical symptoms, while *hysterical personality* described a character structure distinguished by emotional instability, dependency, self-dramatization, vanity, attention seeking, seductiveness, self-centeredness, and immaturity (traits listed in the second edition of the *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association). In 1952, hysteria was removed from psychiatry's lexicon, partially in response to criticisms that the term was too nebulous and that it perpetuated misogyny. Around the same period, in an attempt to clarify and destigmatize the disorder, hysteria was renamed *Briquet's syndrome*, after the French physician Pierre Briquet, who treated hysterics in the mid-nineteenth century.

With the publication of *DSM-III* (*Diagnostic and Statistical Manual of Mental Disorders*, third edition), hysteria was subsumed by three major categories: somatoform disorders, dissociative disorders, and personality disorders. In *DSM-IV* (American Psychiatric Association, 2000) conversion hysteria is now known either as *conversion disorder*, a disorder in which pseudo-neurological symptoms (including blindness, numbness, paralysis, and pseudo-seizures) appear without organic etiology and context of stressful life events, or *somatization disorder*, in which unexplained physical symptoms occur in three domains (sexual, pseudo-neurological, and gastrointestinal). Hysterical personality is now known as *histrionic personality disorder*, a disorder diagnosed mostly in women and characterized by excessive emotionality and attention seeking.

The notion of dissociated traumatic memories, once so important to understanding hysteria, has been relegated to the category of dissociative disorders, including a range of phenomena, from *dissociative fugue*, characterized by a brief period of amnesia, to *dissociative identity disorder*, in which a person's consciousness has been splintered into multiple distinct identities (often as a result of childhood sexual abuse).

—Sonya Rasminsky

See also Depression; Dissociative Disorders; Sigmund Freud; Hippocrates; Psychiatric Disorders; Psychiatry.

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I

IBN AL-ATHIR (1149–1210)

Arab scholar

Majd Ad-Din ibn Al-Athir was a learned man of Mosul who wrote works on hadiths and philology and held high office in the administration. Eventually the opportunity of associating with powerful men lost its charm. While working as secretary of state to the lord of Mosul, Ibn Al-Athir suffered paralysis of his arms and legs, which obliged him to retire from public service. A healer from the Maghreb came to treat him, and Ibn Al-Athir began to regain the use of his limbs. He then asked his brother to pay the healer a suitable fee and send him away. He explained that, in his present condition, he was under no obligation to visit the great and court their favor with the usual tedious ceremonies. He was enjoying rest and solitude. If anything serious occurred that needed his attention, people would come and ask his advice. To remove this liberty by continuing in therapy would be pointless. He preferred to spend his remaining days in peace. Ibn Al-Athir's family admitted the strength of his argument and discontinued the treatment.

—Kumur B. Selim

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IBN SIRIN (654–728)

Arab law lecturer

Muhammad ibn Sirin of Basra was an esteemed law lecturer, also valued as an accurate transmitter of sayings of the prophet Muhammad, though these skills seem hardly to have been lucrative. His father had been a coppersmith, a trade hazardous to the hearing of anyone near the noise. Ibn Sirin worked as a draper but was imprisoned for debt and is said to have died in debt. He was well known to have impaired hearing. To students of law, "As-Shabi used to say 'Stick to that deaf man!' meaning thereby Ibn Sirin; because he was dull of hearing" (*Ibn Khallikan's Biographical Dictionary* 1842–1871), but evidently he was worth hearing on law and on the sayings of Muhammad. He also became famous for interpreting dreams and was a man of great piety and notable eccentricity.

—Kumur B. Selim

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IBN UMM MAKTUM (SIXTH CENTURY)

Companion of the prophet Muhammad

Abdullah ibn Umm Maktum, a companion of the prophet Muhammad and relative of Muhammad's wife Khadijah, was born blind. He was among the earliest believers in Islam and was reportedly keen to learn the Qur'an from the mouth of Muhammad. Once when Muhammad was debating with leaders of the Quraysh tribe, Ibn Umm Maktum interrupted the prophet, who frowned and turned away. Afterward, Muhammad announced a revelation from Allah, which appears in the Qur'an, Sura 80. This seems to censure Muhammad for turning away from Ibn Umm Maktum (other interpretations also exist). Several incidents are recorded in which Ibn Umm Maktum's blindness figured. For example, once he failed to give the dawn call to prayer until a sighted person told him it was morning; another blind man was allowed to pray at home because he lacked anyone to guide him to the mosque, but Ibn Umm Maktum was not granted this dispensation, possibly because he was a potential prayer leader. Sometimes when Muhammad needed to be away from Madinah, he is said to have made Ibn Umm Maktum governor of the city during his absence, indicating high confidence in his character and ability.

—Kumur B. Selim

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ICF/ICIDH

See International Classification of Functioning, Disability, and Health (ICF/ICIDH)

IDENTITY

Identity can be defined as the way people view themselves and how others understand them and their roles and relationships in society. Identity is important because it allows individuals to answer the questions Who am I? and Who are you? Identities have personal and social dimensions—they have both commonalities (what people share with each other) as well as unique elements (which characterize an individual alone). The development of identity is therefore a continual, reflexive process.

Like other forms of identity, disability identity is an incredibly complex phenomenon. The experience of disability is only one element of a person's identity—among the many other factors that may also influence identity are age, gender, race, religion, class, sexuality, and nationality. Some people with disabilities argue that disability is one of the least important elements of their identities, whereas others suggest that it is central to their lives and personalities. Negative stereotypes about disability mean that some people are reluctant to identify as disabled for fear that they might face discrimination and prejudice. On the other hand, others have been encouraged to identify publicly as disabled by the growth of disability culture and the disability pride movement.

Identity formation is often influenced by wider cultural processes of representation and stereotyping, which can give individuals a sense of their expected roles in society. These social processes can allocate some groups to the social margins and give others a sense of entitlement and power. A number of common stereotypes regarding disability have influenced the identity formation processes of many disabled people. The work of Wolf Wolfensberger has helped to identify many of the stereotypes that have historically been associated with disabled people, including representations of disabled people as animals or as subhumans, as a burden, as eternal children, as a menace to society, as sick or diseased, as objects of ridicule, and as holy innocents. Each of these stereotypes, in its own way, contributes to the social devaluation and exclusion of disabled people. Such stereotypes not only lead some disabled individuals to feel less valuable than other persons, they can also contribute to wider social processes of rejection, segregation, abuse, loss of opportunities, and poverty. Two quite different responses have developed in regard to these processes of devaluation: a conservative response, known as *normalization,* and a more radical response, known as *disability pride.*

Normalization involves attempts to organize the lives of disabled people and to structure service delivery in ways that will ensure that disabled people occupy "socially valued" roles. Wolfensberger and

Thomas (1983) argue that human services should support disabled people in participating "in valued activities, in valued settings with valued citizens" (p. 1). This means that service-providing agencies should blend in with their community settings. They should also be located away from devalued groups and should engage in activities that enhance the social image of their clients. Within the disability rights movement, normalization is often regarded as a conservative philosophy and practice, because it is an approach that tries to change disabled people rather than the practices of a disabling society. Also, it assumes that the norms of the dominant group in society are unproblematic—that disabled people need to adopt "socially valued" identities rather than build their own positive social identity as disabled people. In this regard, normalization seems quite hostile to diversity and difference.

A more radical approach to difference can be found in the cultural politics known as disability pride, which is based on the idea that developing a positive sense of disability identity involves challenging narrow conceptions of normality. It therefore involves finding merit in the atypical, beauty in the uncommon, and value in the unusual. Disability activists who support this philosophy have often argued that *normality* and *abnormality* are value-laden terms that have enormous power to harm. For instance, Linton (1998) suggests that these concepts affect individuals' most private thoughts about their worth, social position, and acceptability. The association of disability with abnormality denies legitimacy to the experiences of disabled people. Likewise, Davis (1995) understands disability not as an object of the body but as part of a hegemonic way of thinking about the body and its role in the body politic. Davis believes that the goal of disability activists has often been "to help 'normal' people to see the quotation marks around their assumed state."

Carol Gill (2001) argues that the identities of disabled people are often devalued by messages of partial acceptance. She highlights the contradictory nature of many responses to disability, such as admiration and nurturance combined with charity and paternalism. Many disabled people are socialized into believing that parts of them are unacceptable, and they feel compelled to hide some parts of themselves in order to project a more acceptable image. Gill stresses that such processes can reduce a person's self-esteem and self-determination. In an article first published in 1995, Gill identifies four distinct elements of the development of disability identity and disability culture: fortification, unification, communication, and recruitment. She argues that collective gatherings of disabled people and expressions of disability culture fortify the identities of disabled people; unite disparate sections of the disability movement around common issues; promote a shared appreciation of certain art, language, symbols, and rituals; and form the basis for recruiting new members into a vibrant community. It nevertheless needs to be recognized that membership in the disability community is different from belonging to many other cultures. In particular, unlike people who are members of ethnic minority groups, many disabled people grow up in families where they are the only members with that identity. This can make it difficult for a disabled person to develop a positive sense of identity, as family members are sometimes ashamed of the disabled person or feel guilty about his or her disability. Like many people with nonheterosexual identities, many disabled people experience familial estrangement and look elsewhere for peer support.

A SENSE OF "US" AND "THEM"

When people organize in groups, they mark their identities by distinguishing themselves from others. In times of crisis, people tend to desire a sense of certainty and may gain security from the feelings of belonging that their identities bestow on them. Group identities are therefore based on a sense of difference, and there is often a temptation within groups to develop a binary approach to identity—that is, a strong sense of "us" as very distinct from "them." In practice, members of groups often strengthen their own sense of identity by exaggerating group members' differences from nonmembers and ignoring the diversity that may exist within their own group. For instance, within a group of disabled people there may be individuals from different socioeconomic groups, ethnicities, and locations, but the group members may develop a sense of collective identity by highlighting what they have in common rather than focusing on their differences.

The boundaries of identities are always open to dispute. Groups always exclude some people who challenge that exclusion by contesting the boundaries of the groups' identities. Likewise, some people assert their right to their own unique identities and object to assumptions that they are represented by any group. A good example of this issue within a disability context is the case of Deaf people. Some people who are Deaf assert that they belong to a unique cultural and linguistic group, and they believe that they are not "disabled." Others emphasize the experiences of discrimination based on physical difference that they have in common with disabled people in general and strongly identify as disabled. This example reflects one of the biggest problems with identity politics—the fact that boundaries are not as secure as some political rhetoric might suggest.

Identities are often represented symbolically. For instance, in many Western countries, a common symbol used to represent disability identity is that of a wheelchair. Depictions of wheelchairs are used on signs in malls, parking garages, and other public spaces in order to indicate that a space can accommodate the needs of disabled people. However, there is often an element of exclusion embedded in such symbols (for instance, a wheelchair symbol may not seem appropriate for people who do not use wheelchairs and whose impairments are located in other parts of their bodies). Identities require a personal emotional investment, and when people feel alienated by symbols that they feel do not include them, they may resist identifying with the groups represented by those symbols.

Mental health system survivors constitute another group of people who have voiced significant problems with the disability identity. Barnes and Shardlow (1996) point out that there are particular exclusions from citizenship rights (such as involuntary commitment, forced medical treatment, and supervision following discharge from hospital) that mental health system survivors alone experience, and the disability movement in general has avoided discussion of these issues. Also, people who have experienced severe mental distress may be very reluctant to identify as disabled when they are well (i.e., when they are not experiencing any symptoms of their illness).

The long-term process of living with a disability identity is very different from the "sick role" that Talcott Parsons envisioned in 1951. Parsons suggested that "being sick" was a temporary, socially sanctioned interruption to good health. His arguments were innovative because he realized that illness is as much a social role (excusing people from work for a short period of time) as it is a medical condition. Although this concept was useful in the 1950s because it challenged the biological reductionism of that era, it relied on a health/illness binary that did not exist in practice, and it did not recognize that many disabled people are not ill (although some are). The process of developing and maintaining a positive disability identity involves a far more complex dynamic than simply managing one's health.

For people with developmental disabilities, the advocacy group People First has provided an important impetus for a positive disability identity. Based on principles of self-advocacy, this organization's work is based on the principle that developmentally disabled people need to engage in self-advocacy, emphasizing, "We are people first; our disabilities come second." This emphasis on a language of "people first" is different in some respects from the approach of those British disability activists who have chosen to identify as "disabled people." The rationale for this language is that disability is a form of oppression similar to racism and sexism, and in the same way as one would not use the language "person with racism" or "person with sexism," one would not refer to a "person with a disability." This argument is very popular in Britain, but it is a minority position in other countries.

The concept of stigma, as developed in the work of Erving Goffman (1961, 1963), has been very important in terms of an understanding of disability identity. According to Goffman, stigma is a deeply discrediting experience that separates certain groups of individuals (such as disabled people) from what he calls "normals." Goffman highlights many of the social processes that can undermine a disabled person's self-esteem, such as public staring, unwanted help, and invasions of privacy. He also addresses the differences in experiences between people whose stigma is visible and those whose stigma is invisible. For the latter group, Goffman notes, negotiating identities involves making decisions about "passing" and disclosure. Michael Oliver (1990) has criticized Goffman's concept of stigma because it suggests that disability is an individual trait rather than a social dynamic rooted in structural oppression. Watson (2003) argues that Oliver's reading of Goffman is unfair and incomplete, however, and asserts that the connections between stigma and broader social structures are present in Goffman's work.

NARRATIVES AND IDENTITY

Tom Shakespeare (1996) stresses the importance of narratives in terms of disability identity, stating, "Disability identity is about stories, having the space to tell them, and an audience that will listen" (p. 111). He suggests that the stories we tell about the lives of disabled people are very important in terms of their individual and collective effects. Positive narratives of disability help disabled individuals to develop a sense of pride and overcome internalized oppression, but such narratives also are a condition for collective organization. Likewise, Shakespeare argues that involvement in the collective disability movement can assist individuals in the development of a positive disability identity.

Major cultural stereotypes have significant effects on the types of narratives told about disabled people, with attendant effects on disability identities. One of the major cultural constructions around disability that has had a significant impact on the identities of many disabled people is the image of the poster child. In his history of the American disability rights movement, Joseph Shapiro (1993) comments that "no other symbol of disability is more beloved by Americans than the cute and courageous poster child—or more loathed by people with disabilities themselves" (p. 12). The concept of the poster child is controversial because it assumes the presentation of the disabled child as a symbol of pity, and pity is associated with identities that are inferior, tragic, helpless, and dependent. The images of disability associated with the poster child are also controversial because of their connections to another important disability stereotype: the "supercrip"—that is, a disabled person who has successfully "overcome" his or her disability, triumphing over presumed tragedy. This image also has important effects on disability identities. Shapiro argues that fear underlies both pity for the poster child and the celebration of the supercrip. Neither the supercrip nor the poster child is accepted as equal to the nondisabled—both, in different ways, are positioned as "Other." Another historically important barrier to positive disability identities was the freak show. In the freak show, disabled people were often positioned as "monstrous," "deformed," and "bizarre." Hierarchies of embodiment were cultivated by the freak show, leading many disabled people to loathe themselves and their bodies. Cultural spectacles such as the freak show helped to establish a disability identity as a mark of otherness.

The development of a disability culture and the rise of disability pride have been major influences on the identities of many disabled people in recent years. Eli Clare (1999) has highlighted the importance of disability pride in providing an impetus for collective action, such as the campaigns of disability rights activists around the inappropriate placement of disabled people in nursing homes. Clare believes that the significance of disability pride lies in its capacity to overturn shame, isolation, and silence around human rights abuses. Whereas pride involves strength, joy, and anger, internalized oppression involves shame, denial, fear, and self-loathing. It is therefore an act of resistance, Clare argues, to turn internalized oppression into pride.

Clare promotes a transgressive disability identity that involves *flaunting,* which includes the reclaiming of words of hatred to turn them into words of pride. In recent years, some disability activists have reclaimed words such as *crip* and *gimp* as a form of cultural defiance. However, Clare notes that flaunting may be a double-edged sword, because words of hate still retain their original meanings at some level. Those who argue for transgression and flaunting often also explicitly reject another political position—assimilation. The argument for assimilation rests on the common humanity of disabled and nondisabled; it emphasizes that disabled people are "just like you" and therefore deserve exactly the same rights as nondisabled people. The proponents of transgression suggest that this is a minimalist agenda that leaves unchanged some of the major elements of disability oppression, such as restrictive notions of body shape, beauty, normality, and intellect.

Ian Parsons makes an argument similar to Clare's in his book *Cripples, Coons, Fags and Fems: A Look at How Four Human Rights Movements Have Fought Prejudice* (1999). Parsons argues that social movements encourage their participants to move beyond a simple pride in their humanity into a celebration of their difference. In this context, Parsons encourages disabled people to develop transgressive identities that accentuate, rather than minimize, their sense of difference. According to Parsons, in order to challenge and change traditional structures, people must sometimes adopt confrontational and controversial tactics, such as organizing along separatist lines (as do organizations that accept only disabled people as members).

VARIABLES AFFECTING DISABILITY IDENTITY

Disability is only one of many identities that disabled individuals have. Diversity is the hallmark of the disability movement, and no one person or group can speak on behalf of all disabled people. Disability scholars from ethnic minority backgrounds, such as Ayesha Vernon (1998), have argued that there is a temptation to separate discussions of disability from other dimensions of social life, such as experiences of racism and sexism. Vernon asserts that such an approach is based on a problematic additive model of identity that fails to examine the ways in which social forces often operate together. Vernon stresses that sexism, racism, and disableism can operate in isolation or in combination, and that when these forces operate simultaneously, they are often more powerful than the sum of the parts. In this context, Vernon argues that disabled people who are also members of ethnic minority groups can often be positioned as "multiple Others." Likewise, Ahmad, Darr, and Jones (2000) suggest that cultural diversity within the Deaf community is often ignored, and experiences of racist marginalization among Deaf people are rarely acknowledged. These authors note that self-organization by ethnic minority Deaf people involves negotiating an identity that includes Deafness as well as ethnicity and religion. What this means in practice is that professionals have a responsibility to assist Deaf children in becoming aware of their ethnic and religious backgrounds as well as their Deafness.

Historically, disability has been central to debates about social inequality, immigration, and citizenship. People with other stigmatized identities have often made significant efforts to distance themselves from disability, which has often been assumed to be a marker of real, biological inferiority. Douglas Baynton's (2001) excellent historical research on immigration policy in the United States—an area not usually associated with disability—suggests that the central discourse used by various immigrant groups in order to define their worthiness as U.S. citizens was that *they were not disabled.* The absence or presence of disability was a key factor in debates over who deserved to be included and excluded as citizens. Likewise, Rosemarie Garland Thomson (1997) observes that discursive links have often been drawn between women and disabled people in attempts to denigrate and sometimes to defend women. In making this connection, however, Thomson notes an important difference between feminization and disability when she argues that people stare at disabled people, whereas they gaze at women.

Over the past 30 years, disabled women and feminist scholars have consistently emphasized the fundamental importance of gender in the experience of disability and in the development of disability identities. However, Morris (1991) argues that the political agenda of the disability movement has tended to ignore the specific concerns of disabled women with regard to gendered family and domestic roles. Meekosha and Dowse (1997) assert that disabled women are often placed in an ambiguous position relative to the public and private spheres—somewhere between the public and the private, and yet framed as a "burden" in both. These authors stress that disabled women's identities are structured by the intersection of gender, disability, and the denial of citizenship rights in many areas, including sexuality, reproductive rights, and marriage rights.

Rolland (1988) argues that the type of identity developed by a disabled person is strongly dependent on the type of impairment the individual has and whether the impairment is new, chronic, or terminal. For instance, for people with progressive impairments such as Lou Gehrig's disease or diabetes, the increasing severity of their impairment over time has a huge impact on their individual identities. Rolland suggests that although it may be possible for a person in the early stages of such impairment to deny a disability identity, as the impairment becomes more severe, the individual needs to incorporate this experience into his or her identity. In contrast, people with sudden and traumatic impairments often experience crises of identity as they struggle to come to terms with their new life experiences. Rolland asserts that such a sudden identity crisis is less likely in an individual whose impairment has existed since birth. Rolland suggests that people who have relapsing or episodic impairments face a different set of identity issues, particularly relating to disclosure, denial, and anxiety over relapses.

Priestley's (1999) examination of the experiences of disabled children in mainstream schools suggests that the identities of disabled children are structured by the discourses that circulate throughout the education system, such as those of "charity," "treatment," and "provision." Middleton (1999) notes that disabled children are often assumed to be genderless, raceless, asexual, and classless, and so they need to be supported in developing positive self-images in all these areas. In their study of children and disability, Baker and Donelly (2001) found that four important social dynamics have significant effects on the identities of disabled children: Disabled children (a) generally have few disabled friends, (b) socialize with peers who are not disabled, (c) are less popular and more often abused than nondisabled children, and (d) have more unstable, conflictual, and uncooperative relationships than do nondisabled children. Baker and Donelly therefore argue that increased attention needs to be placed on the environments in which disabled children grow up; family and school responses to disability need to be changed in order to cultivate safer environments and more positive identities among disabled children.

Marks (1999) identifies four major psychological processes that discourage acceptance of a disability identity: splitting, projection, reaction formation, and rationalization. These defenses against disability can, respectively, lead people to attribute negative characteristics to all disabled people, to project negative attributes onto disabled people, to hide or obscure their real feelings around disabled people, and to rationalize discriminatory treatment.

Robert Scott's classic study *The Making of Blind Men* (1969) emphasizes another important factor in the development of a disability identity: contact with the disability service system. Scott argues that blindness is a learned social role, rather than a biological fact: "Blind men are not born, they are made" (p. 121). He stresses the social nature of this role by pointing out that the vast majority of people who are classified as blind can actually see at some level. Rather than being completely sightless, Scott presents these people as "sighted people who experience difficulty seeing" (p. 43). The importance of socialization is evident because of the key role that "blindness workers" play in the development of the attitudes, behaviors, and emotions associated with being blind. In effect, Scott argues, these workers teach their clients how to behave like "blind people."

ERIKSON'S THEORY OF IDENTITY DEVELOPMENT

One of the most influential psychoanalytic theories dealing with identity development is that presented by Erik Erikson (1963). This theory suggests that human beings pass through eight stages of identity development over the life cycle. In the first stage, from birth to 18 months of age, babies develop their sense of trust, or mistrust. From 18 months to 3 years, toddlers develop some sense of autonomy—or a sense of shame and doubt. In the preschool age, from 3 to 6 years, children develop a sense of initiative, or they develop a fear of failure as a result of guilt or punishment. From 6 to 11 years, children develop a sense of industry (confidence and skills for work as they learn to enjoy their achievements), or they develop a sense of inferiority. In adolescence, from 12 to 18 years, young people develop a sense of identity (or role confusion) in terms of sex roles, occupation, religion, and politics. Erikson invented the term *identity crisis* to explain the troubled sense of self that some people experience. In young adulthood, from 19 to 40 years, people develop a sense of intimacy or isolation in terms of personal relationships. From ages 40 to 65, adults face a basic conflict regarding generativity or stagnation—finding a meaningful way to support the next generation. After 65, individuals reflect on their lives and experience either ego integrity or despair. Erikson believed that each of these developmental crises occurs at a certain stage in a person's life but is never resolved permanently. For instance, people return to the struggle over trust and mistrust at various stages of their lives. There is a danger that people's achievements in one of these areas may be undermined by later developments—but, conversely, failure to negotiate one of the stages of identity development successfully can be rectified by later growth.

A number of disability scholars have taken issue with Erikson's theory. By mechanistically applying the stages described by Erikson, psychologists have positioned many disabled people as having automatically missed key stages of human development. In their critique of Erikson's theory, Mackelprang and Salsgiver (1999) argue that nondisabled people are the template for the theory, which ignores the healthy development of disabled people—or assumes that such development is impossible.

ESSENTIALIST AND SOCIAL CONSTRUCTIONIST APPROACHES TO IDENTITY

Political rhetoric often draws on notions of a well-defined community with a shared past and tradition in order to bind people to a common identity. This rhetoric, which relies on a sense of clear-cut boundaries around an unchanging, fixed identity, has been called a tendency toward essentialism within identity politics. An essentialist approach to disability identity would suggest there are certain characteristics that all disabled people share. An essentialist approach to identity can be contrasted with a social constructionist approach, which emphasizes the socially constructed, contingent, and fluid nature of identity. A social constructionist approach to disability identity would suggest that there are significant differences as well as similarities among disabled people and would recognize that the meaning of disability changes over time and across cultures. It would therefore problematize any claim that one set of experiences is the only "true" disability identity.

Some sociologists, such as Anthony Giddens (1991), argue that the modern world could be characterized as a "risk society"—that is, a society in which social change is progressing at such a rapid rate that people experience a heightened sense of uncertainty that profoundly affects their identities. Giddens asserts that traditional patterns and habits are less influential in a risk society, where people are pressured to express their identities through their lifestyles. As a sociologist, Giddens is interested in the social and economic pressures that operate in modern consumer societies. He highlights the social and economic changes that have resulted in a veritable explosion of ways in which to express individual lifestyles, preferences, and identities. These social and economic pressures make essentialist notions of identity even less credible.

In his book *Bending over Backwards: Disability, Dismodernism and Other Difficult Positions* (2002), Lennard Davis argues that disability identity is inherently unstable, but that this malleability can be part of a new way of thinking about identity. Davis asserts that essentialist notions of identity are discredited and outdated, but that the instability inherent in self-definitions of disability allows disability identity to transcend the problems of identity politics. Davis therefore believes that disability may be "the postmodern subject position." His argument is very similar to that of Corker and Shakespeare (2002), who also acknowledge that postmodern ideas present significant challenges to the ways in which disability has traditionally been conceptualized. Postmodernism problematizes issues of identity, embodiment, discourse, power, and agency far more than do traditional notions of disability. Corker and Shakespeare suggest that the rich tapestry that makes up the disability movement, involving people of all ages, with different impairments, challenging dominant notions of embodiment, exerting their own agency while they experience disabling barriers and simultaneously face a range of other inequalities, means that disability is "the ultimate postmodern concept."

CONCLUSION

Identity is of fundamental importance to the modern world, allowing people to connect with others as well as to experience feelings of uniqueness. Many disabled people lack disabled role models in their families, do not necessarily feel connected to the wider disability movement, and struggle to develop a positive disability identity. For others, developing a positive self-image often involves challenging internalized oppression and refusing to be defined by rigid definitions of normality. Disability identity is also influenced by such factors as the nature of the impairment and the ethnicity and gender of the person. Identity presents different challenges at various stages of the life course. Therefore, disability identity is a complex topic. For some people, becoming involved in the disability movement, connecting with disability culture, and developing disability pride are very helpful actions in terms of building self-esteem and a sense of belonging. Others see their experience of disability as shameful and seek to avoid the stigma of disability by hiding their identity. Many people try to find individual solutions for themselves, for instance, by being critical of rigid notions of normality and by finding beauty in difference.

—Mark Sherry

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IEP

See Individualized Education Program

IMMIGRATION: LAW AND POLICY

One of the driving forces behind early U.S. federal immigration law, beginning with the first major legislation, the Immigration Act of 1882, was the exclusion of "defective" people (as well as those considered criminal or immoral, problems seen at the time as resulting from "mental defect"). Federal legislation throughout this period repeatedly, and with ever-increasing urgency, identified defective immigrants as a threat to the nation. In 1907, the *Annual Report of the Commissioner of Immigration* declared that "the exclusion from this country of the morally, mentally, and physically deficient is the principal object to be accomplished by the immigration laws" (U.S. Bureau of Immigration 1907:62). When immigration quotas based on nationality were enacted in 1924, a rhetoric of "inferior races," based on claims that people of certain nationalities are prone to be physically and mentally defective, was instrumental in creating the image of the "undesirable immigrant."

The desire to keep disabled immigrants out of the United States was not an isolated development; rather, it was one aspect of an era that saw the segregation of disabled people into institutions, the sterilization of the "unfit" under state eugenics laws, intensified stigmatization of disability, and increasing willingness to exclude disabled people from social and cultural life. The Immigration Act of 1882 prohibited entry to any "lunatic, idiot, or any person unable to take care of himself or herself without becoming a public charge." Those placed in the categories of "lunatic" and "idiot" were supposed to be automatically excluded. The "public charge" provision was intended to encompass people with disabilities more generally, and decisions were left to the examining officer's discretion (*United States Statutes at Large* 1883:214). The criteria for excluding disabled people were steadily tightened as the eugenics movement and popular fears about the decline of the "national stock" gathered strength. The Immigration Act of 1891 replaced "*unable* to take care of himself or herself without becoming a public charge" with "*likely* to become a public charge" (*United States Statutes* 1891:1084; emphases added). In 1907, the law was modified to deny entry to anyone judged "mentally or physically defective, such mental or physical defect being of a nature which *may affect* the ability of such alien to earn a living" (*United States Statutes* 1907:899; emphasis added). Although nondisabled immigrants were still admitted unless found to be "likely to become a public charge," disabled people were subject to this more rigorous standard.

Exclusions for mental defect were steadily expanded. In 1903, people with epilepsy were added, as well as "persons who have been insane within five years previous [or] who have had two or more attacks of insanity at any time previously" (*United States Statutes* 1903:1213). In 1907, "imbeciles" and "feeble-minded persons" were barred, in addition to "idiots" (*United States Statutes* 1907:898). In 1917, the classification of "constitutional psychopathic inferiority" was added, which inspection regulations described as including "various unstable individuals on the border line between sanity and insanity, such as persons with abnormal sex instincts." Officials were instructed to exclude persons with "any mental abnormality whatever . . . which justifies the statement that the alien is mentally defective." This provision, the regulations explained, was intended "as a means of excluding aliens of a mentally inferior type, not comprehended in the other provisions of the law, without being under the necessity, as formerly, of showing that they have a defect which may affect their ability to earn a living" (U.S. Public Health Service 1917:25–26, 28–29, 30–31).

The rules governing exclusion for physical disabilities were equally vague and expansive. Regulations specified that "each individual should be seen first at rest and then in motion" so that officials could detect "irregularities in movement" and "abnormalities of any description." Among the many defects listed as causes for exclusion were arthritis, asthma, bunions, deafness, deformities, flat feet, heart disease, hernia, hysteria, poor eyesight, poor physical development, spinal curvature, vascular disease of the heart, and varicose veins (U.S. Public Health Service 1917:16–19). An Ellis Island medical inspector later wrote that his task was "to detect poorly built, defective or broken down human beings" (Safford 1925:244).

These laws were usually presented as an economic issue. Many immigrants who were excluded, however, had been self-supporting before they left their home countries. Others had been offered jobs while awaiting their immigration hearings but still were deported as likely to become public charges. More important, the laws located the problem in individual bodies rather than in social structures, despite the fact that immigration restriction was just one aspect of a pervasive system of discrimination that made it difficult for disabled people to live and move about independently. For example, the diagnosis of "poor physique" was often used to exclude immigrants as "likely to become a public charge." The immigration service defined it as covering those "who have a frail frame, flat chest, and are generally deficient in muscular development" or who are "undersized—markedly of short stature—dwarf" (Stoner 1912). As one official explained, the "immigrant of poor physique is not able to perform rough labor, and *even if he were able,* employers of labor would not hire him" (McLaughlin 1905:532; emphasis added). That is, the belief that an immigrant was unfit to work justified exclusion, and so did the belief that an immigrant was *likely to encounter discrimination* because of a disability. The diagnosis was also in part a eugenic judgment, as this 1905 memo from the commissioner general of the Bureau of Immigration illustrates:

> A certificate of this nature implies that the alien is undersized, poorly developed and physically degenerate, and not only unlikely to become a desirable citizen, but also very likely to transmit his undesirable qualities to his offspring, should he unfortunately for the country in which he is domiciled, have any. (Sargent 1905)

On January 30, 1906, immigrant Israel Bosak was certified for "poor physique." He was not destitute, having $65 in his possession, usually more than enough for admittance. Bosak had owned a tailor shop in Russia before it was destroyed by a mob during an anti-Jewish pogrom. He intended to send for his wife and children as soon as he got established, explaining that he had "plenty of countrymen here who are just as good as relatives, to help me." Two members of the board voted for admission, but the third held firm for deportation, which meant that the secretary of the U.S. Department of Labor would decide. In his letter to the secretary, the third board member emphasized the danger to the nation's eugenic health of admitting such people, "whose offspring will reproduce, often in an exaggerated degree, the physical degeneracy of their parents." The secretary concurred, and Israel Bosak was returned to Russia (National Archives, file no. 49,968/4).

Because the screening of immigrants was mostly a matter of detecting visual abnormality, the appearance of an individual played a central role. Inspectors prided themselves on making "snapshot diagnoses" as immigrants streamed past them, single file. For most immigrants, a normal appearance meant a quick passage through the immigration station. An abnormal appearance, however, meant a chalked letter on the back—"L for lameness, K for suspected hernia, G for goiter, X for suspected mental illness," and so on (Kraut 1994:55). Once an individual was chalked, a closer inspection was required.

Donabet Mousekian had an abnormal appearance. On April 23, 1905, this Armenian Turk stood before the Board of Special Inquiry with an inspection certificate that read "feminism." In other instances, the term used for his condition was "lack of sexual development." In this case, "feminism" meant an absence of male sexual organs; in others, it referred to insufficient development. Mousekian's hearing was extraordinarily brief. No one mentioned the diagnosis. After asking the most basic questions concerning Mousekian's identity and background, and noting that he brought $48 with him, the board quickly voted to exclude him as likely to become a public charge. In his appeal, Mousekian explained that he had fled the violent oppression of Armenians in Turkey and had officially renounced his citizenship. As he would never be permitted to return to Turkey and remain free, rather than be sent back, he wrote, "it would be much better that you kill me." His relatives were all in America, including his two brothers who were citizens and well employed. A photographer by trade, as well as a skilled weaver and dyer of rugs and a cook, Mousekian could have worked at any of these trades. He wrote:

> I am not ill, have no contagious disease; my eyes, feet, hands and ears are sound; only I am deprived of male organs; this is not a fault because it has come from God and my mother: what can I do? It won't do any harm to my working; or what harm can I do to the U.S. by my being deprived of male organs?

His brothers wrote in much the same vein, asking plaintively,

> How is it his fault? Our father and mother are dead; he is our only brother; we guarantee that he will not be a public charge; we are able to give the required guarantee; he can not return to Turkey; we are US citizens, hence we beg US government not to separate our brother from us.

The commissioner at Ellis Island supported the board's decision on the basis of Mousekian's appearance: "Appellant is devoid of every external evidence of desirability. He is weak, repulsive in appearance, the doctor's certificate furnishing sufficient indication of his physical defects." Mousekian was returned to Turkey, where, if he lived that long, he would witness the "Armenian holocaust" 10 years later (National Archives, file no. 48,599/4).

The U.S. surgeon general explained in a memo the reasoning behind this exclusion:

> These persons present bad economic risks. . . . [T]heir chief failure to adjust is due to the fact that their abnormality soon becomes known to their associates who make them the butt of coarse jokes to their own despair, and to the impairment of the work in hand. Since this is recognized among employers, it is difficult for these unfortunates to get or retain jobs, their facial and bodily appearance, at least in adult life, furnishing a patent advertisement of their condition. (Cumming 1922)

The disabilities that justified exclusion in the cases described above were matters of abnormal appearance that might invite discrimination and therefore poverty. Thus, these exclusions were based on economic arguments, but at two steps removed.

The justifications given for exclusion were not always economic, however, whether directly or indirectly. Nicolaos Xilomenos was refused entry in 1912 for "lack of sexual development." The commissioner noted that while "the individual may appear strong and robust" and brought with him sufficient cash, his condition indicates the probability of "perversions or mental instability" (National Archives, file no. 53,452-952). In a similar case in 1908, Helena Bartnikowska was refused entry. The physician explained that "this supposed woman" was a hermaphrodite, and that hermaphrodites are "usually of perverted sexual instincts, and with lack of moral responsibility." He added significantly that Bartnikowska's voice was masculine and that she had facial hair. Although her family was willing and able to guarantee her support, she was deported (National Archives, file no. 51,806-16).

In March 1905, Domenico Rocco Vozzo, a 35-year-old Italian immigrant, was puzzled to find himself barred from entering the United States at the port of Boston. Vozzo was a migrant worker on his second trip to the United States, and he had encountered no difficulty on his first trip three years earlier. He was certified for "debility" and excluded as likely to become a public charge. Vozzo's attorney argued in his appeal that Vozzo was robust and healthy. He noted that Vozzo "looks perfectly healthy below the head" but has a "curiously shaped head, and his skin looks rather white, almost bleached, and his ears are quite thin." During his previous two-year sojourn in the United States he had fully supported himself while saving money. He brought with him $20 in cash and had friends who filed affidavits on his behalf. The commissioner at the Boston station, however, recommended against admission: "I enclose his picture which I think will convince you that he is not a desirable acquisition." Vozzo was deported (National Archives, file no. 48,462).

The principle that persons of abnormal appearance were not "desirable acquisitions" was neither universally held nor consistently applied. For example, when Abram Hoffmann, a 25-year-old tailor with a prosperous brother in New York, was deemed likely to become a public charge in 1906 because of a curved spine, his attorney labeled "ridiculous and absurd" the assumption "that one who is unfortunate enough to suffer from a certain infirmity, is likely for that reason alone, to become a public charge." Warming to the subject, the attorney asked, "Are we living in this enlightened Twentieth Century where everyone is supposed to be given a fair opportunity, or are we going back to the times of the Salem witch-craft, when, because a woman was old and afflicted with a high back [spinal curvature], she was considered and treated as a witch? . . . The immigrants affliction can in no wise affect his earning capacity as a tailor." The commissioner at Ellis was torn. On the one hand, he noted, visually "the spinal curvature for which [Hoffmann] is certified is quite obvious." On the other, "I may state in appellant's behalf, that he is a man of considerable intelligence, is very well dressed, and came as a second cabin passenger." In the end, the positive aspects of Hoffmann's appearance and class status trumped the negative appearance of his disability, and he was admitted (National Archives, file no. 49951-1).

The precise number of immigrants turned away from the United States for disability each year is difficult to pin down. Until 1908, exclusions based on physical defects were mixed with nondefectives in the category of "likely to become a public charge." After 1908, rejected immigrants were counted in the category of "mental or physical defective" if they were deemed defective but not likely to become public charges, and counted in the "public charge" category if they were determined to be both defective and potential paupers. In any case, taken together, exclusions in both categories grew considerably, if erratically, over the years. In 1895, 1,720 were excluded, or .6 percent of all immigrants. By 1905, the number excluded had increased to just over 8,000, or .7 percent of all immigrants. And in 1910, 16,000, or 1.6 percent, were excluded. Due to wartime disruptions, the numbers during and just after World War I fluctuated widely, making useful comparisons difficult (U.S. Immigration Commission 1911).

These numbers are all likely to be only the tip of the iceberg, however. Those inspected at American ports had already been through several screens. First, many were deterred by the general inaccessibility of transportation. Second, given that American immigration laws were widely advertised, many must have decided not to risk the journey, knowing they might be turned back. Third, ship captains were required to examine passengers and certify that they were not physically or mentally defective (*United States Statutes* 1893:569, 1907:901–902). Fourth, the shipping companies that brought rejected immigrants to the United States were required to return them and pay a fine for each, and immigrants later discovered to have disabilities that initially passed unnoticed could be deported for up to three years at the expense of the companies (*United States Statutes* 1903:1218, 1907:901, 905). Shipping companies therefore had strong incentives to refuse passage to disabled people, and ship captains became an unofficial arm of the immigration service. Finally, ticket agents stationed throughout inland Europe were fined by the shipping companies if they sold tickets to anyone turned away at boarding time. In 1894, the superintendent of immigration noted approvingly that steamship lines instructed their agents to refuse tickets to "the blind, deaf and dumb, and crippled persons" (U.S. Immigration Service 1894:12–13). There is reason, then, to suppose that those rejected at the borders were a small minority of those who were deterred. In 1911, the U.S. Immigration Commission estimated that about 10 times as many were refused transportation for medical reasons as were barred at U.S. ports (U.S. Immigration Commission 1911:26).

In 1924, a new quota system was instituted, based on national origin, that severely limited immigration from southern and eastern Europe. In the debate leading up to this legislation, disability figured prominently. Quota advocates, as well as superintendents of institutions, philanthropists, immigration reformers, and politicians, warned that certain nationalities were disproportionately prone to be mentally defective (Trent 1994:166–169). Rhetoric about "slow-witted Slavs," the poor physiques of Jews, the "neurotic condition of our Jewish immigrants," and the "degenerate and psychopathic types, which are so conspicuous and numerous among the immigrants," was pervasive (Grayson 1913:103, 107–109). Quota advocates emphasized the inferior appearance of recent immigrants. One wrote that "the physiognomy of certain groups unmistakably proclaims inferiority of type." In "every face there is something wrong, . . . sugar-loaf heads, moon-faces, slit mouths, lantern-jaws, and goose-bill noses." Most were physically inadequate:

> South Europeans run to low stature. A gang of Italian navvies present, by their dwarfishness, a curious contrast to other people. The Portuguese, the Greeks, and the Syrians are, from our point of view, undersized. The Hebrew immigrants are very poor in physique . . . the polar opposite of our pioneer breed. (Ross 1914:285–290)

The issues of race, ethnicity, and disability were inextricably intertwined. The characterization of people as physically and mentally defective, and therefore inherently inferior, was used to stigmatize people and to rationalize their exclusion. Similar rhetoric worked to incarcerate, institutionalize, and sterilize untold numbers of disabled and minority citizens during the same period. The label "defective person" was used to justify the denial of basic human rights. Although it is certain that immigration restriction rested in good part on a fear of "strangers in the land," in John Higham's phrase, it was fueled at least as much by a fear of defectives in the land.

National quotas were removed in 1965, and most of the restrictions that applied specifically to disability were removed from U.S. law in 1990. Today, disabled immigrants can still be denied an entry visa on the basis of the "likely to become a public charge" clause, but because records are not kept of such exclusions, it is not known how often this occurs (Stanton 1996:451).

—Douglas C. Baynton

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IMMUNOLOGIC DISEASES

Immunology is the field of science encompassing the study of the specialized molecules and cells involved in defending an organism against infection. Human immunology has its beginnings in the empirical observations of Edward Jenner on the prevention of smallpox in English milkmaids previously infected with cowpox. These important studies provided our initial understanding of the ability of the immune system to acquire memory of an infecting organism and formed the basis for our current practice of immunization against myriad potential infectious diseases. Immunodeficiency diseases arise from defects in the immune system and are classified as primary, usually inherited genetic causes, or secondary, arising from infection or drugs that impair immune system function. In all cases, immunodeficiency diseases may result in considerable physical disability with long-term requirements for medical and rehabilitative care.

The widespread introduction of antibiotic use into the practice of medicine in the middle of the twentieth century permitted recognition of children with multiple recurrent episodes of bacteremia (bacteria in the bloodstream), pneumonias, or skin abscesses. These primary immunodeficiencies are the results of inherited defects in specific genes required for normal immune responses. The study of children with these rare diseases has revealed a great deal about how the normal immune system functions and has resulted in the development of specific therapies aimed at replacing or restoring normal immune system function. In some cases affected children survive with a lifetime of infusions of immune sera, whereas in other cases bone marrow transplantation is required. In all circumstances, affected children as well as their parents and siblings require considerable support for these lifelong chronic diseases.

Secondary immunodeficiencies may arise from infection of the immune system and destruction of cells critical for the normal immune response. The most serious of such infections is caused by the human immunodeficiency virus (HIV), which infects lymphocytes, a specialized white blood cell required for immune function, resulting in acquired immunodeficiency syndrome (AIDS). There is currently no effective vaccine against HIV, and infection is fatal in the absence of long-term treatment with complex, expensive, and relatively toxic drug regimens. The current worldwide pandemic of HIV infection has resulted in devastating human and economic disability for entire nations in Africa and Southeast Asia. In developed countries such as the United States, the disabling effects of HIV infection have imposed enormous cost restraints on the health care system.

Secondary immunodeficiency also occurs following treatment with drugs that suppress immune system function, such as glucocorticoids. These medications are required in patients with diseases such as rheumatoid arthritis and multiple sclerosis and following organ transplantation. In all circumstances these drugs create the potential for serious life-threatening infections. Given the prevalence of these diseases in the population and the increasing frequency of solid organ transplantation in developed nations, such secondary immunodeficiency is becoming a common cause of disability and chronic care in the population. When combined with HIV infection, these immunodeficiency diseases are among the most prevalent and costly sources of human disability worldwide.

—*Jonathan D. Gitlin*

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IMPAIRMENT

Impairment is one of the most contested and complicated terms in disability studies, second only to *disability* itself in terms of multiple definitions and theoretical arguments made around its meaning and significance in the experience and scholarship of the body. It can be traced both chronologically and ideologically, and it continues to be the subject of considerable debate.

The origins of *impairment* as a term in disability studies may be positioned in the development of documents by such organizations as the Union of the Physically Impaired Against Segregation (UPIAS) in Great Britain and the World Health Organization (WHO). In 1976, UPIAS offered its own definitions, omitting *handicap* as a term of art and drawing a distinction between impairment and disability: *Impairment* refers to "lacking part or all of a limb, or having a defective limb, organ or mechanism of the body"; *disability* refers to the social oppression (whether due to stigma or to restrictions) imposed on people with impairments. The important distinction for UPIAS lies in location: Impairment is located in the body; disability is located in society or culture.

In 1980, the WHO's International Classification of Impairments, Disabilities, and Handicaps (ICIDH, revised in 1993 and again in 2001, when it became the International Classification of Functioning, Disability, and Health, or ICF) distinguished among *impairment, disability,* and *handicap* as terms to describe what might be categorized as "nonnormate" bodies. The ICIDH defined impairment as "any loss or abnormality of psychological, physiological or anatomical structure or function." It defined disability as the lack of ability to perform particular acts or functions in a way that is "normal," and handicap as the disadvantage(s) resulting from impairment and disability. Like most such classification systems, all versions of the WHO's definitions were criticized from various corners of the scholarly and professional world, often because such critics thought the distinctions either too rigid and unrealistic in representing the overlaps among the categories or because they saw the definitions as lacking in social consciousness or analysis.

From these competing sets of definitions arose a body of scholarship—originating primarily in Great Britain with such writers as Michael Oliver and Tom Shakespeare—that distinguished between a "social model of disability" and a "medical model of disability." *Impairment* as a term was assigned to the medical model, which was also seen as positing the location of the body's "problems" within the individual and which looked to such tropes as cure, charity, personal tragedy, and pain and suffering as dominant modes of thought. In some circles, much, if not all, of rehabilitative science and practice came to be understood to be located within the medical model. Thus, *impairment,* which in its earlier usage might have been viewed as a neutral term (if such a thing can be said to exist), became a negative, oppressive term in this binary of social/medical pairing, if only by association.

Some theorists argued that discussions of impairment (by which they meant the physical, psychological, and cognitive experiences of individuals) should either be eliminated from disability studies discourse or, at the very least, shared only within the disability community "behind closed doors." Reasons for this argument varied, but they included concerns that any frank discussion of what might be construed as "limitations" might be used to oppress disabled persons even more (i.e., such discussions might be considered evidence that disabled persons really are, in important ways, "inferior" because of their bodies) and might, for example, be used in arguments supporting such things as discriminatory employment practices and physician-assisted suicide. Others feared that too much emphasis on narratives of impairment might depict disabled people as participants in victimology—that such narratives might represent disabled persons as passive, or whiny, or irrational. Later, as the 1990s drew to a close, many of the original theorists of the social/medical dichotomy began to rethink its efficacy, and the term *impairment* began to be reintroduced in a more wide-ranging set of discursive formations. One of the criticisms of the dichotomy between social model and medical model was that it created an unreal or inaccurate division between impairment and disability; another was that it in some respects was guilty of setting up two "models" where only one group had actually articulated a model—in other words, it is unlikely that physicians and therapists would ever have agreed that they subscribed to all of the things attributed to the "medical model" per se.

One of the most significant critiques of the impairment/disability binary and its respective medical/social model rhetoric came from feminist disability scholars. Most vocal among these were such figures as Susan Wendell, Sharon Stone, Jenny Morris, and Liz Crow. These theorists were particularly articulate in deconstructing the often masculinist assumptions present in the binary, including a devaluing of the significance of pain and suffering in the lived bodies of people with impairments/disabilities and the ways in which bodies affected by invisible or less-visible impairments were often neglected in such discourse. It is probably no accident that many of these lesser-discussed impairments are conditions that disproportionately affect women: chronic fatigue syndrome, depression, and others. Such theorists called for a return of lived experience to the discourse of disability studies and, along with it, a fuller and more detailed theorizing and representation of impairment. Whereas social model scholarship tended to draw its theoretical underpinnings from Marxism and materialist cultural studies, feminist disability studies often came out of phenomenological and ethnomethodological bases. It is important to remind ourselves that to draw a simple gender binary is to be as guilty of reductionism as was the social/medical model; nonetheless, the contribution of feminist disability scholars, particularly women, cannot be underestimated in the reintroduction of impairment as a legitimate area for discussion, scholarship, and theorizing.

A "third wave" of *impairment* as a terminological basis for disability studies theory and scholarship may be seen as emerging in the past several years. In important respects, this wave is actually a cluster of approaches and perspectives, all of which respond to various previous uses of the term and the theories surrounding it. One area is what is being called "sociology of impairment" by theorists such as Bill Hughes and others. This approach argues that the division between social and medical models is incomplete not simply because it runs the risk of demonizing impairment as a concept, but because it misses or underestimates the degree to which impairment itself may be viewed as a social product. For example, Alex Lubet, a disability scholar and trained professional musician, has argued that the field of classical music training in the West has been both disabling and impairing. As instruments and pedagogy have assumed right-handedness as normate, people who are left-handed dominant are required to learn to play music not only in a way that is not natural to their bodies, but in ways that may produce impairments through strain and stress on parts of the body. One can imagine many more examples of instances where either workplace or public facilities that do not accommodate various kinds of bodies may result in different and additional impairments, which, in turn, lead to any number of kinds of disabling conditions, such as limitations on work opportunities or access to various venues of participation in public and private activities.

In addition to the "sociology of disability," there has also been a growing interest (or revival of interest) in what might be termed the phenomenology of impairment, either with or without explicit sociopolitical implications. Disciplinary approaches to such phenomenological methods range from philosophy (e.g., those who build explicitly from the work of such Continental writers as Merleau-Ponty and Husserl) to occupational therapy (e.g., Gary Kielhofner's work on a "model of human occupation" and his various accounts of the phenomenology of hand impairment) to sociologists (e.g., Rod Michalko, who combines phenomenological accounts of his blindness with consideration of socially oppressive implications of this impairment for himself and others) to humanists and artists who either represent or write critically about representations of impairment in the arts and in culture at large. One might include here writers of personal narratives and other literary accounts of impairment ranging from Lucy Grealy's *Autobiography of a Face* (1994) to Kenny Fries's *Body,* *Remember* (1997) as well as fictional accounts of impairment by writers such as Mark Salzman and dramatic texts by John Belluso, Susan Nussbaum, Tony Kushner, and others. Visual artists such as Riva Lehrer and performance artists such as Greg Walloch, Terry Galloway, and Petra Kuppers create a discourse of impairment representation in their work as well. There is a sociopolitical dimension to the work of almost all these artists, bringing the once seemingly disparate concepts of impairment and disability closer together through their embodiment in artistic texts.

Impairment will continue to be a "word in process" in disability studies, mapping out different concerns, emphases, and rhetorical positions in various contexts, times, and sites. It is unlikely that, like *handicap,* it will disappear anytime soon, as there is a genuinely productive value in drawing certain distinctions between impairment and disability as phenomena to be analyzed; what is useful is the continuing opening up and inclusion of it in the growing body of disability studies scholarship.

—Bruce Henderson

See also Language of Disability.

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INBORN ERRORS OF METABOLISM

The identification and categorization of inborn errors of metabolism are among the most important conceptual advances in medical genetics during the twentieth century. Credit for this intellectual revolution belongs primarily to the English physician and scientist Sir Archibald Garrod, whose curiosity was evoked by alcaptonuria, an arthritic disorder in which the urine turns to a reddish brown color when exposed to air. Garrod, who was familiar with the principles of Mendelian genetics, noted the appearance of this syndrome in siblings and its occasional passage through successive generations. He proposed that the discoloration of alcaptonuric urine reflects the inherited deficiency of a "ferment" (enzyme) that in healthy subjects favors the breakdown of homogentisic acid (alkapton), a metabolite of the amino acid tyrosine. Accumulation of this acid, he theorized, gives rise to the arthropathy and discoloration (onchronosis) of cartilage and urine that characterize the disorder. Furthermore, the disease appears only if both (unaffected) parents transmit a "latent factor" to the child.

The estimated incidence of the inborn errors of metabolism is approximately 1 in 5,000 live births, making these disorders a significant source of human disability. They may involve any aspect of human metabolism, including the handling of amino acids, lipids, carbohydrates, and nucleic acids. In most instances the underlying cause is the inheritance of a mutant enzyme or transport system that mediates either the metabolic transformation of one metabolite to another or the movement of a compound across a cell membrane. Inheritance of these diseases usually conforms to an autosomal recessive pattern, although dominant and sex-linked mechanisms are well documented.

Detection of inherited metabolic disease has been facilitated by the advent in recent decades of two complementary technological developments. The first of these has been the development of chromatographic, electrophoretic, and enzymatic techniques for the isolation and quantitation of relevant metabolites in blood and urine. As a result, it is possible to define those departures from the biochemical norm that ratify Garrod's (1923) insight that "behind a superficial uniformity there exists a diversity which is no less real than that of structure, although far less obvious" (p. 1).

Diagnosis is enabled by a second technological development: the revolution in molecular biology that permits the characterization of mutations in either nuclear or mitochondrial DNA. This methodology can unambiguously characterize those fundamental alterations of the genetic code that give rise to metabolic aberrations. Genetic analysis has proved invaluable for the diagnosis of affected individuals, the detection of heterozygotes, and the assessment of the fetus at risk.

Inborn errors of metabolism can result in injury to virtually any tissue, but the most dramatic and characteristic consequence is damage to the developing brain. In most instances the encephalopathy reflects the accumulation of an otherwise normal metabolite that becomes toxic when present in excess concentration. An example is the extreme elevation of the amino acid phenylalanine that accompanies a congenital defect of phenylalanine hydroxylase, the mutant enzyme in classical phenylketonuria. The biochemical sequence that leads from phenylalanine accumulation to frank mental retardation remains obscure, although it is likely that the underlying pathophysiology evokes alterations of brain energy metabolism, neurotransmitter synthesis, and myelin formation.

The outlook for the affected child has improved dramatically in recent years. Diet therapy, or the purposeful interdiction of a potentially injurious nutrient, often attenuates or even prevents brain injury and permits normal neurological development, even when the underlying metabolic defect is near complete. For many disorders, transplantation of bone marrow or of liver or kidney has palliated the underlying lesion and afforded near-normal metabolism. A particularly exciting therapeutic prospect is gene therapy, or the administration of a vector that safely and efficiently carries the deficient gene to cells of the affected patient, thereby reconstituting normal or near-normal enzymatic competence.

—Marc Yudkoff

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▣ INCLUSION AND EXCLUSION

The question of the inclusion and exclusion of disabled people cannot be separated from the way in which a society constructs social cohesion or produces social dissociation. Each society has its own way of integrating and rejecting certain categories or certain subjects, that is, of creating social links or not. The two terms *inclusion* and *exclusion* go in tandem and can be understood only in relationship to each other; for any definition of inclusion there is a corresponding definition of exclusion.

MECHANICAL INCLUSION, ORGANIC INCLUSION

Durkheim (1930) accurately saw that in modern societies, with their growing complexity, an evolutionary process is initiated, namely, that the fundamental forms of solidarity in traditional societies, "mechanical" or through resemblance, increasingly give way to solidarities that are "organic" or effected through complementarity. But the latter bring with them a growing individualism, which comes into conflict with the priority traditionally given to the social whole.

The dynamic character of our present-day societies is emphasized, but so is the permanent challenge that confronts them. Thus, there are greater risks of social dissociation than in traditional societies but also increased possibilities, because of their organicity, of integrating the new and alien.

Societies characterized by mechanical solidarity are strongly integrated but cannot admit "foreign bodies." When they exclude, they do so in radical fashion and are often incapable of assimilating the new. Modern societies have a very broad capacity for inclusion but, on the other hand, are in danger of putting apart by creating enclaves within themselves.

In societies with mechanical inclusion, the individual is a constituent of an indestructible whole. He or she has a fixed place, given at birth, and in this sense is fully integrated, a cog in the overall works. There is no question of changing place, which would disrupt the global mechanics, leading the society to defend itself against the defective part that no longer performs its task and punish it. Thus, integration can be defined as a place—a single, fixed place—in a whole that has no plans to change. The person who does not have a place of this type is literally not part of the society. This person is the stranger, excluded by negation and not through a positive act. Barbarians could not become Romans; foreigners could not (except through a special procedure) become citizens of Athens, and so on. A positive act of exclusion, on the other hand, can occur in cases where an individual questions his "integration."

In societies featuring organic solidarity, the individual tends to be isolated. He or she cannot count on a place assigned by tradition and culture. Integration is a long road and a constantly reimposed obligation to take further steps, because the division of labor and social division entail the continuous refinement of legislative, institutional, and financial procedures, so that individuals are not exposed to the rigors of competition and isolation. When these procedures are relaxed, individuals risk being set adrift. There are no longer sufficient common measures to maintain the social link. In addition, there need to be enough shared representations on the global level that these procedures are maintained.

Everything has contributed to the formation of societies that, relying only on themselves and on the strength of their members, have become entirely responsible and accountable for people "living together." We must recall the "autonomization" of society with regard to any reference to the transcendent (a characteristic of modernity) and the autonomization of the individual (Weber 1920). This also explains such societies' vulnerability; the risks of marginalization, even of social abandonment or exclusion, are substantial.

THE PROCESS OF NORMALIZATION

One of the principal procedures in the attempt to effect integration is normalization. Here it is a matter of defining averages, comparing discrepancies with these averages, and then trying to close the distance to come as close to the average as possible.

For children with mental impairments to be admitted to schools, for example, they must be able to follow along in class and thus reach the required level of competence, failing which they are placed in separate institutions that are supposed to bring them (back) to the norm. In the event that this proves impossible, they risk being segregated for almost their entire lives. For disabled adults to gain employment in the business environment, they must acquire personal autonomy and vocational competencies equivalent to, once again, the average. It is on this idea of deviation from the conventional norm that the notions of the first International Classification of Impairments, Disabilities and Handicaps, proposed by the World Health Organization in 1980, are based. Here we can recall Goffman (1963), who quite humorously described the average American by showing how anyone who deviated in any respect from the standard was considered defective and more or less to blame.

The will toward normalization is tied to another force active throughout contemporary societies: the attraction of the universal. Modern Western societies, which are driven by the necessity of establishing on their own the conditions of inclusion to further cohesion and reduce inequalities, consider their forms of sociability to be the most advanced.

From this follows the preference for the *assimilation* model.

The point of departure is the undeniable universality of humanity. The human species is a unity. The other can only be another I. There are, in principle, no limits to the rights of human beings as such. This is the great achievement of democratic revolutions. But we move very quickly from a recognition of equality to a desire for identicalness. It is this discourse that more or less is generated by the assimilation model: There are common values, common objectives, canons of conduct—averages that we must strive to approach. One must agree to live according to these norms, and this kind of public space can become "blind to differences." The critical point is this: If we fall into what might be called "assimilationism," we end up denying others their irreducible differentness, their right to be themselves, just the way they are.

In contrast to the assimilation model, a *differentiation* model has been formulated. The first form of the differentiation model is the "hierarchical" one. It is a way of integrating differences by holding them together in a coherence, which is at the same time a system of submission. For example, man and woman represent two ways of being human but, because of the traditional relationship of dominance, the social roles associated with these two ways of being have resulted in one having precedence, greater dignity, and greater worth than the other (political vs. domestic role, productive vs. nurturing role, authoritative vs. affective role). The hierarchical model makes it possible to control differences. Still in the universe of differentiation, we meet a second model: that of "juxtaposition." The recognition of a difference is pushed far enough that each individual remains on his or her own, a stranger in the midst of strangers. With the juxtaposition model in its extreme form, which can be called differentialism, it is said: You are another but you have nothing to do with me unless it is to submit to a scale of value on which I am more perfect than you. Juxtaposition, like hierarchy, is a way of putting some people at the top and giving the impression that they alone represent the universal.

THE DIFFERENT FORMS OF EXCLUSION AND INCLUSION

The doubtless most dynamic notion of inclusion leaves room for the work of adjustment, acceptability, and social participation, while the idea of integration presupposes conformity, an alignment that is always experienced as domination, even oppression, by the group that defines the norms or of the majority over the minority. Being included can signify a situation of which one is organically a part, without being necessarily obliged to behave according to a rigid norm. On the other hand, inclusion, like insertion, can prove to be weak and may merely be synonymous with simple presence, simple admission, simple tolerance. You can be tolerated without being recognized. You can be admitted without being incorporated.

On the other hand, exclusion may reference several phenomena: radical exclusion from society, segregation within society, discrimination, also within, concerning access to goods and social spaces, disaffiliation, and an exit from the social exchange system.

Varying according to cultural practices (Ingstadt and Reynolds 1995) and historical periods (Stiker 1999), inclusion and exclusion may assume different meanings; they are not univocal and are not historically fixed. There is diversity in exclusion and diversity in inclusion.

We can observe that each of these kinds of exclusion, even if it has been generally characteristic of a given ancient society, nonetheless displays survival in contemporary Western societies. Establishing a typology of the different forms of inclusion and exclusion that can be observed in the social treatment of disability is comparable to a construction in terms of ideal-type according to Max Weber. An ideal-type is always a mixture of abstract relations and contingent data. By raising practices, albeit empirically different and historically separated, to the point where they can be subsumed in an abstract characterization, we try to associate possible configurations with some conjectural behavioral outcomes.

The Elimination Model

The most extreme form of social exclusion is death. One of the first identifiable types of exclusion, then, is exclusion through elimination. The elimination of disabled people can be effected directly by putting them to death or indirectly by radical abandonment or the withholding of care. Elimination, less of persons than of disability itself, may also be considered to occur before birth; this raises questions related to the termination of pregnancy when an impairment is discovered in the fetus, and even before pregnancy with new developments in genetic testing. Eugenicist theories show the possible link in continuity between the social practices of elimination of ancient societies and the practices associated with the most recent advances in technology of contemporary societies. Making this observation is not in contradiction with a legal right to abortion.

The Abandonment Model

The practices of abandonment can be distinguished from those of elimination by the fact that they do not entail death, or at least not in such direct fashion. Practiced in ancient cultures, exclusion through abandonment is also reflected in the contemporary forms of "social death" and social abandonment. Examples of abandonment practices are not lacking: the abandonment of children born deformed, the severely wounded, and very dependent elderly people.

Abandonment may amount to conferring of parental authority on another, leaving the fate of a newborn in God's hands, or in more modern fashion anonymously giving up a child for adoption (Dumaret et al. 1998). Abandonment can also be ceasing to look after people, depriving them of care. Relevant here is the question of passive *euthanasia.* The "surplus population thesis" has been advanced as one of the chief explanations of exclusion through abandonment (Oliver and Barnes 1998).

The Segregation Model

Sequestration and the whole set of practices of putting apart constitute one of the most widespread forms of exclusion. It is also the form of social treatment that, by clearly distinguishing an inside and an outside, offers the best fit with the basic meanings of inclusion and exclusion. The point here is that this putting apart does not necessarily take place outside the community but frequently at its very heart. Lastly, we may note that this segregation may be more or less constraining, with a greater or lesser deprivation of freedoms.

One of the paradoxes is that what is often called a segregating detour, for example, through temporary schooling in a separate institution, is often touted as having integration as its ultimate goal. And indeed today this form of segregation is most often conceived of as a side trip that will facilitate a sound return to the ordinary environment (even if the detour never proves to be a way back). Thus, the will is not to exclude, but to include at a later stage. Segregation is as well an attempt of *deferred inclusion.*

The Assistance Model

The relationship with work invites consideration of another form of exclusion: exclusion through assistance, an "economic" form of exclusion that been a social issue since the end of the Middle Ages.

Assistance is a form of close protection and concerns those who, through their inaptitude for work, cannot meet their own needs. Assistance admittedly creates a weak form of participation in society. It confers social substatus. But to assist is not to exclude in the strongest sense of the term, since those helped are part of society simply by virtue of society's concern for them. Those so assisted are part of society on the condition that they stay in their place. Georg Simmel (1908) has convincingly shown that poverty lies not in being without means but rather in being assisted, such assistance itself being a means to ensure social cohesion. The ideal-type that assistance represents can be expressed by the idea of *conditional inclusion.* On one hand, it is still a form of exclusion, because the disabled person is not allowed to acquire a status equivalent to that of the able-bodied and other social groups, but on the other hand, it is a form, albeit weak, of inclusion.

The Marginalization Model

In the precise meaning of the term, *marginalization* is the process of moving to the side through the refusal of, or the impossibility of accepting, current recognized rules of social functioning. The marginalized are defined by transgression of, or protest against, commonly held values and habits, whether this is a decision to become an outsider or rejection by the dominant group. What has been at stake in rehabilitation has thus been to reduce this deviation from the norm. The action on the individual who is to be reintroduced into the mainstream is therefore informed by the goal of effacing differences. The individual should "act like" others even if this necessitates technical aids, devices, or prostheses.

But it is this same concern for a reduction of the deviance that lies at the ground for the normalization developed by Wolfensberger (1972) with regard to people with mental retardation. Here we can see, more clearly than previously, that even a position on the margin can be qualified as *inclusion through normalization.*

The Discrimination Model

To discriminate is to distinguish or to separate out a social group and restrict its rights. These distinctions made in social life at the expense of disabled people may be judged unacceptable because they violate social norms and the principle of equality before the law, even though in other societies and at other times they may be current practice.

To define discrimination as the action of treating equal individuals inequitably shows to what extent the concept is tied to modern society, which puts equality at the center of its value system.

With the development of civil rights, most modern democracies instituted judicial protections against intentional negative discrimination based on criteria relative to the impairments of an individual. Nonetheless, forms of statistical discrimination are no less evident (Ravaud, Madiot, and Ville 1992), and these are much more difficult to contend with.

Discrimination can also be positive and have the restoration of equality as its goal. Positive discrimination can be effected by social assistance measures in cases with an extrinsic character (e.g., income). It can be effected through authoritarian measures (which raises the question of personal freedoms) or finally by preferential measures (e.g., employment quota policies that favor disabled workers). It can be conceived of as a compensatory measure and defended on the basis of distributive justice.

CONCLUSION

The principal question posed today in Western countries is the nature of the citizenship that can be exercised by disabled people. Modern policy excludes the possibility of distinguishing among different categories of people in the public sphere. Behind these questions of discrimination and exclusion we discern the principle of equality rights of citizens as a moral ideal of a democratic nation.

Exclusion needs to be seen from a global perspective that comprises both the views of the excluded people and those of the entity that rejects them. For, contrary to contemporary representations now in circulation, exclusion is not an abstract phenomenon, implacable, agentless, in its extreme form a fatality resulting from the entry into a new global economy. Exclusion is clearly also inscribed in the social relationships of power (Elias 1965).

It seems impossible to ignore the fact that the two poles are always in evidence: civic universalism, on the one hand, and differentiated groups and individuals, on the other.

—Jean-François Ravaud and
Henri-Jacques Stiker

See also Democracy; Normalization.

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INCLUSIVE EDUCATION

The concept of inclusive education is grounded in the principle of "normalization," which asserts that individuals with disabilities have a right to access the same opportunities, including the same daily experiences and routines, as persons without disabilities. Inclusive education has been strongly endorsed by the international community. Article 23 of the United Nations Convention on the Rights of the Child states:

> A mentally or physically disabled child has the right to a full and decent life in conditions which ensure dignity, promote self-reliance and facilitate active participation in the community. The state shall provide special care, free of charge, whenever possible, to ensure that the disabled child receives education, training and services leading to the fullest possible social integration and individual development.

This stance by the United Nations represented a major leap forward in establishing education as a "right" of children with disabilities. The UN convention did not, however, provide a definitive statement regarding inclusion. The international community has adopted a vision of "education for all" (EFA), which means that every child, regardless of status, is entitled to an education. The World Declaration on EFA was first adopted in Jomtien, Thailand, in 1990 by more than 1,500 persons representing the international community, including government officials, members of nongovernmental organizations, policy makers, researchers, and key international donors such the World Bank. (UNESCO, the lead UN organization for special needs education, was one of five organizations that convened the Jomtien conference and continues to work with other international agencies and nongovernmental agencies to achieve the goal of providing equal access to education to children with disabilities.) Subsequent conferences, such as the Salamanca World Conference on Special Needs Education in 1994 and the Dakar World Education Forum in 2000), reaffirmed the goal of EFA, and the international community has increased its commitment to promoting policies that support educational opportunities for all.

According to the Salamanca Statement, every child has a fundamental right to an education, and schools should develop a child-centered philosophy to accommodate the needs of all children. The design of education systems and programs needs to account for the wide diversity of child characteristics, including those of a range of children with disabilities, gifted children, street children, working children, children from remote and nomadic populations, children from minority groups (whether linguistic, ethnic, or cultural minorities), and children from other disadvantaged areas or groups.

According to the Salamanca Framework for Action:

> The fundamental principle of the inclusive school is that all children should learn together, wherever possible, regardless of any difficulties or differences they may have. Inclusive schools must recognize and respond to the diverse needs of their students, accommodating both different styles and rates of learning and ensuring quality education to all through appropriate curricula, organizational arrangements, teaching strategies, resource use and partnerships with their communities. (UNESCO 1994:11, para. 7)

The Salamanca Statement advocates educating children with disabilities within regular schools and eliminating, as much as possible, the use of segregated special schools for these children.

DEFINITIONAL ISSUES

Within the international community, the notion that every child is entitled to an education is not debated. Inclusive educational policies are those that address the specific needs of every child of school age regardless of gender, race, ethnicity, language, culture, economic status, or disability. However, where the education is provided continues to be confounded by disability classifications. The International Classification of

Functioning, Disability, and Health (ICF), developed by the World Health Organization (WHO 2001) is the dominant tool used for defining disability in policy and research. This classification system focuses on the types and levels of interventions appropriate for individuals with disabilities within specific contexts, such as in education. Its purpose is to assist in the development of inclusive policies and research through refinement of classification. Yet the idea that children with disabilities need to be categorized has been challenged by some in the international community because of concerns about the stigmatizing effect of labeling children. For example, in many countries, a child's ICF classification can determine whether or not the child will be allowed to stay in a regular public school. Thus, the preferred approach is not to focus on the disability and instead create schools that can meet the needs of any child.

However, this is not a universal goal. To illustrate: Consider students who have physical and sensory disabilities and no cognitive or intellectual impairments. Children with these types of disabilities will likely require some adaptations to their physical environment in order to be able to access education. These can include accessible facilities as well as transportation. Students with sensory impairments may also require specially designed interventions and curricular materials (e.g., interpreters, large-print or Braille materials). While all such interventions may be provided within regular schools and classrooms, advocates for some of the sensory disabled populations question the capacity of regular schools and/or classrooms to provide interventions for individual children who may be hearing or visually impaired. Advocates for the deaf and hearing impaired also maintain that it is important for children with these impairments to be educated with others like themselves so that they are included in Deaf culture. They assert that equality of educational opportunity is best achieved in specialized settings, such as special schools.

Children with intellectual and learning disabilities have special educational needs, although the latter are not universally recognized as having a disability. For children experiencing difficulties learning to read as well as those children with marked levels of cognitive and developmental disabilities, inclusive education means individually designed and child-centered pedagogy. However, where that education is provided may be subject to debate. For example, in the United States and Canada, where learning disability is recognized as a classification, advocates question whether the regular classroom can provide the intensive instruction these students need to access and progress in the curriculum (McLaughlin & Jordan forthcoming). For students with moderate to severe intellectual disabilities, inclusive education is often interpreted as both individualized and provided in regular classrooms. Education for these students places great emphasis on developing communication strategies and social competencies that will permit these students to interact with and be integrated into the community at large.

EMERGING ISSUES

Several issues have emerged in recent years concerning inclusive education in countries with and without well-developed special educational systems. First and foremost, *every* child with a disability must have access to public education. Within developing countries, there is growing acknowledgment that a paucity of data are available pertaining to childhood disability. The WHO and the United Nations generally agree that approximately 10 percent of the world's population is affected by some kind of physical, mental, or sensory impairment (Metts 2000). However, reported estimates on the proportion of disabled persons in the population have ranged from 5.2 percent to as high as 20 percent. The WHO has stated that it is not possible to determine the percentages of individuals with disabilities more accurately because of differences among the classification systems used to determine who is disabled. For example, children with severe disabilities are sometimes not included in estimates because they are hidden from society and excluded completely from the educational system. These children may also reside in institutions or, as is the case in many developing countries, may be receiving care or education in one of a number of small community organizations supported by various charitable organizations (Peters 2003).

Another emerging issue concerns increased demand for educational accountability in the form of higher levels of student academic achievement. Greater attention to educational productivity is challenging schools to improve the performance of students with disabilities in specific academic content areas (McLaughlin & Jordan forthcoming). Whether accountability demands will lead to improvement or restriction of the education of students with disabilities in regular schools and classrooms remains to be seen. Some believe that increased scrutiny of the academic achievement of students with disabilities, and other subpopulations of at-risk students, will motivate schools to implement curricula and pedagogy that will address diverse learners. Others are concerned that such scrutiny will lead regular schools and classrooms to become less tolerant of students who require extensive support or adaptations and to see these students as better served in more specialized settings.

Inclusive education, in all of its meanings, is not a specific program that can be implemented. Rather, inclusion is a philosophy and a process that must be implemented at many different levels of the educational system (Hegarty 1995). Inclusion requires the restructuring of the physical environment, the broadening of instructional strategies and curricula, and changes in the social and psychological attitudes of teachers, administrators, and students.

—Margaret J. McLaughlin

See also Education, International; Education, Primary and Secondary; Education and Disability.

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INDEPENDENT LIVING

ESSENTIAL DEFINITIONS

The term *independent living* refers to the emancipatory philosophy and practice that empowers disabled people and enables them to exert influence, choice, and control in every aspect of their lives. Independent living is an ideology as well as a social and political movement. Originally inspired by the example of the American civil rights movement and also by the growth of the women's movement, participants in the independent living movement see it as a civil rights movement of disabled people.

The Washington Declaration, which came out of a global summit on independent living held in Washington, D.C., in 1999, defines the principles of independent living as follows:

> That all human life has value and that every human being should have meaningful options to make choices about issues that affect our lives;
>
> That the basic principles of Independent Living Philosophy are human rights, self-determination, self-help, peer support, empowerment, community inclusion, cross-disability inclusion, risk-taking and integration.

Within this broad understanding, the concept of independent living has developed a different character in different regions of the world.

HISTORY

Some of the ideas inherent in independent living predate the naming of the first center for independent living (CIL). Within the United Kingdom, for example, disabled people with sensory impairments were uniting to press for rights to education and to paid work as early as the nineteenth century. Most people, however, accept that the birth of the modern independent living movement took place in Berkeley, California, in the 1970s. There a group of physically impaired students rebelled against the notion that they should accept living in a nursing home and united to demand the right to an accessible living environment and to paid aides to give them the personal assistance necessary for them to lead normal daily lives.

This group, originally called the Rolling Quads, worked to support other disabled students at Berkeley. The group swiftly extended its services to the community, and the Berkeley Center for Independent Living was born. The concepts that underpinned the Berkeley initiative—of accessible environments, affordable technology (e.g., a wheelchair repair service), personalized daily living support (personal assistance), and peer advice (disabled people supporting and helping each other)—have remained central in the independent living movement. The CIL came into being at an institution with a reputation for social radicalism, in an era of social radicalism. So the other characteristic it embodied was a political dimension, an identification with struggles for social justice.

SPREADING THE IDEA

The CIL concept was exported to Europe in the late 1970s through the work of a few well-traveled disabled activists. The concept was taken up enthusiastically in northern Europe, including the United Kingdom. Activists from these countries and from the United States took the idea to other parts of the world. There is now a global independent living movement.

The movement has developed in various ways from region to region. In most of the developing world, independent living has been associated with economic independence, so the movement has focused on employment opportunities, often linked to providing services to other disabled people. In Zimbabwe, for example, a wheelchair manufacture business provides both work and a service for disabled people as well as generating income for the CIL.

AGAINST INSTITUTIONS

In Western Europe the independent living movement has focused on ensuring that disabled people have alternatives to residential care institutions. Most European CILs, as well as the European Network on Independent Living (ENIL), focus on personal assistance as a key component of independent living. This is because lack of personal assistance is closely linked to individuals' being forced to live in institutional care. ENIL was set up in 1989 at a conference held in Strasbourg. The conference resolution (known as the Strasbourg Resolution) states:

> This conference has focused on Personal Assistant Services as an essential factor of Independent Living, which itself encompasses the whole area of human activities, e.g. housing, transport, access, education, employment, economic security and political influence. . . .
>
> We condemn segregation and institutionalisation, which are direct violations of our human rights, and consider that governments must pass legislation that protects the human rights of disabled people, including equalisation of opportunities.
>
> We firmly uphold our basic human right to full and equal participation in society as enshrined in the UN Universal Declaration of Human Rights . . . and consider that a key prerequisite to this civil right is through Independent Living.

This resolution locates independent living firmly within the framework of human rights. This is not about doing good to disabled people, or providing them with welfare. It is about ensuring that disabled people can exercise their human and civil rights equally with nondisabled people. The Strasbourg Resolution expresses independent living philosophy in a form that governments can understand.

DIRECT PAYMENTS

One of the tools that disabled people have developed as a way of achieving the control and choice that characterize independent living is direct payments. This is a method of giving disabled people cash to pay for personal assistance instead of having assistance arranged on their behalf by local authorities. Direct payments have been popular in Europe, including the United Kingdom, because they provide an alternative to home care or residential care. The fact that direct payments give disabled individuals control over the budget and over hiring (and, if necessary, firing) the people who assist them has been a major challenge to the prevailing welfare philosophy.

In the traditional mode of service provision, disabled people are seen as dependent precisely because they need help with daily tasks such as getting dressed. With direct payments, disabled persons can take control over these daily tasks. More important, when they can accomplish such basic tasks as getting dressed or washed efficiently, disabled people can use their time doing more productive and enjoyable things, such as working, bringing up children, and going to art galleries.

Some welfare professionals have opposed direct payments, stating concerns that users may spend the money on the "wrong" things or hire the "wrong" workers. Such concerns are born of a belief that disabled people are vulnerable, that they need professionals to hire the "right" workers for them. These concerns also reflect a belief that public money should be spent only on activities sanctioned by professionals. Both these ideas are based on a view of disabled people as less than wholly adult, not able to make their own decisions and take their own risks. Direct payments challenge this view. However, supporters of direct payments do not pretend that disabled people do not need help in making choices or implementing decisions. They argue that CILs, run by and for disabled people, can provide this help. A number of CILs in operation today started as peer support groups for people using direct payments.

A COMPREHENSIVE PHILOSOPHY

Independent living is more than an individual aim. It encompasses a change in social relations. It is both a philosophy and a practical approach. It brings disabled people together to work for civil and human rights. They espouse equal opportunities for everyone as well as self-determination for themselves. The basic meaning of independent living can be expressed very simply: "Independent Living means that disabled people want the same life opportunities and the same choices in everyday life that their non-disabled brothers and sisters, neighbours and friends take for granted" (Ratzka 1996). This simple definition encompasses all of social and economic life. Many disabled people are still denied the opportunity to grow up alongside nondisabled siblings, to go to the neighborhood school, to use the same buses and get the same kinds of jobs as their nondisabled friends. The independent living movement says that they can attain these simple aims through collective action.

CHANGING SOCIAL RELATIONS

The independent living movement wants to change the social relations of disabled people, particularly to remove enforced reliance on family members as primary caregivers. Simon Brisenden wrote one of the most memorable criticisms of being forced to rely on a family member for assistance: "It exploits both the carer and the person receiving care. It ruins relationships between people and results in thwarted life opportunities on both sides of the caring equation" (quoted in Morris 1993:27).

This view is not universally accepted—some people see giving assistance to a family member as an expression of love or of wider familial duty—but it is one that underpins much of the work of the independent living movement. Nasa Begum has described the "burden of gratitude" placed on people who are always beholden to others for simple things such as taking a bath; the independent living movement attempts to remove that burden by making assistance into a straightforward working relationship, rewarded with appropriate wages, delivered in ways chosen and directed by the disabled person. This approach does not reject the family—rather, it values family members in their own right, as wives, fathers, sisters, sons, rather than forcing them into the role of unpaid attendant.

INDEPENDENCE IS NOT ISOLATION

Some critics of independent living have argued that it is an individualistic philosophy, that the focus on supporting individual people ignores the wider social and economic pressures facing disabled people. This claim ignores the whole culture of independent living.

At the 1999 global summit on independent living mentioned above, delegates noted:

> The Independent Living Philosophy recognizes the importance of accepting responsibility for our own lives and actions, and at the same time, the importance of community to foster Independent Living.

Achieving the social aims of independent living requires collective action. Independent living is developed through the self-organization of disabled people. The movement is based on collectively developed solutions to individually experienced barriers. The movement recognizes that many disabled people will not manage to achieve independence on their own, that the system we live in puts too many obstacles in the way. "The cornerstone of Independent Living Philosophy is . . . control and choice. . . . Systems advocacy is of ultimate importance because some choices for disabled people still need to be created" (Holdsworth 2000).

This recognition, that society needs to create choices for disabled people, is one of the reasons disabled people have come together to set up their own organizations, including centers for independent living. CILs are always controlled by disabled people; often all of the voting members on the governing boards of CILs are disabled people. This is not because of hostility toward nondisabled people. Rather, it is an expression of a necessary step toward independent living. As Adolf Ratzka (1992) notes: "Disabled people need to be in charge of their own lives, need to think and speak for themselves without interference from others." This is as true in organizations as it is in the lives of individuals.

INDEPENDENT LIVING AND THE SOCIAL MODEL

In the United Kingdom, the philosophy of independent living is closely linked to the ideas embodied in the social model of disability. Some of the theorists of the social model were pioneers of the U.K. independent living movement. This model shows us that (a) historically, society's reaction to impairment (and failure to meet needs relating to impairment) has undermined disabled people's human and civil rights; and (b) this is not inevitable—in other words, impairment does not have to determine life chances. Biology is not destiny.

The social model recognizes that disabled people are different from nondisabled people in that they have *additional requirements,* such as mobility needs and needs for communication assistance or personal assistance. These additional requirements stem both from experiences of impairment and from the disabling barriers of negative attitudes and unequal access.

The pioneers of independent living in the United Kingdom identified 7 "basic needs" of disabled people—that is, essential additional requirements that must be met if disabled people are to achieve independent living and thus equality of opportunity with nondisabled people. That initial list was later extended to the following 12 basic needs:

- Full access to the environment
- A fully accessible transport system
- Technical aids (equipment)
- Accessible adapted housing
- Personal assistance
- Inclusive education and training
- Adequate income
- Equal opportunities for employment
- Appropriate and accessible information
- Advocacy (toward self-advocacy)
- Counseling
- Appropriate and accessible health care provision

This list echoes similar priorities identified a few years previously at the CIL in Berkeley.

INDEPENDENT LIVING AND INCLUSION

Historically, CILs have struggled to provide services for all sections of the disabled community. In most cases their founders have been people with physical impairments, but they have always taken an inclusive approach to disability, aiming to serve all disabled people, regardless of the nature of their impairments. Some CILs have had problems in fulfilling their inclusive aims, often because of limited material and human resources. CILs' success in achieving such aims can also be affected by entrenched opposition from vested interests within agencies that provide traditional disability services. For example, some traditional service providers have castigated CILs in the United Kingdom for being insufficiently knowledgeable about the communication needs of people with learning difficulties (intellectual impairments) while at the same time jealously guarding their own knowledge. In such cases, the concept of sharing knowledge in order to make the service better is not put into practice.

Some disability activists, particularly in the United Kingdom, where social model thinking is especially influential, have adopted the terms *integrated living* and *inclusive living* in place of the original *independent living* to characterize the philosophy on which their activities are based. By doing so, they demonstrate their recognition that humans are by definition "social" beings, and that *all* humans, regardless of the degree and nature of impairment, are interdependent and, therefore, a truly "independent" lifestyle is inconceivable. This recognition is especially important to the independent living movement in regions where interdependence is a strong part of the culture, such as in Southeast Asia.

GLOBAL SUMMIT

As noted previously, in 1999 a global summit on independent living was held in Washington, D.C. The summit brought together activists from more than 70 countries. Despite regional variations in how independent living was being developed around the world, the delegates agreed on a set of basic principles. These principles, which are laid out in the Washington Declaration, include a restating of the basic needs identified by CILs in the United States and United Kingdom: "that we recognize the importance of equal and inclusive education, employment opportunities and entrepreneurship, assistive technology, personal assistance, accessible transportation and a barrier free environment to promote Independent Living." The principles also restate the movement's aspiration to universality:

> that the Independent Living Principles and Philosophy have applications on a global scale and are to be implemented on the local, national and international levels without regard to disability, sex, religion, race, language, ethnic background, political affiliation, age or sexual orientation.

INDEPENDENT LIVING IN THE TWENTY-FIRST CENTURY

Current concerns in the independent living movement center on sustaining the movement, on creating real independent living opportunities in the developing world, and on promoting the link between independent living and human and civil rights. These concerns are interlinked. Activists who meet at global and regional gatherings devoted to the topic of independent living have noted that many of the pioneers of the movement are aging and that no large cohort of younger activists is replacing them. One result of the success of independent living in the United States and Europe has been that more disabled people can now take it for granted that they can get education, get assistance, get a job. They thus have less direct motivation to devote time to managing and supporting independent living organizations. The movement is looking for ways to sustain its collective base in an era when individual consumerist culture is the dominant mode.

One method by which advocates of independent living are sustaining a wider perspective is found in Scandinavia, where national disabled people's organizations support independent living projects in several developing countries. By emphasizing the global links among disabled people, they are helping to create a sense of community.

Finally, the movement is revisiting the philosophical roots that informed the first CIL in Berkeley, stressing that disabled people have the same civil and human rights as everybody else. Independent living is a tool for achieving these rights. Activists are now challenging residential institutions, not just because they stifle individual autonomy but because they rob those who live there of essential human rights. In the United States, the Free Our People campaign uses the direct action tactics developed by Adapt. In the United Kingdom, the government-sponsored Disability Rights Commission is backing a campaign for a right to independent living on the grounds that it is essential to enable disabled people to enjoy civil rights. This reaching out from disability organizations to the wider world of civil and human rights has been the hallmark of the independent living movement and distinguishes it from other, welfare-based approaches to meeting disabled people's needs.

Independent living can be summed up in two words: freedom and participation. Independent living gives disabled people the freedom to make choices and the means to participate in their communities, taking both opportunity and responsibility.

—*Frances Hasler*

See also Activism; Advocacy, International.

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INDIA

See Disability in Contemporary India; Disability Policy: India; Experience of Disability: India; India, Impact of Gender in; India, Marriage and Disabled Women in

INDIA, IMPACT OF GENDER IN

Historically, disability has been defined as a medical condition and perceived as the personal tragedy of the "affected" person. However, slowly but surely disabled people have come to question this understanding. As the disability movement has gained impetus, the experiences of marginalization and multiple exclusions associated with disability have come to be comprehended as the results of social oppression. It has become clearly evident that factors such as widespread inaccessibility in the built environment, segregation in education, rampant unemployment, unavailability of alternative formats of communication, and a general lack of acceptance in society have been responsible for the subjugation of the disabled. Disability therefore is in reality a social construction and not a natural category.

Gender, on the other hand, has historically been synonymous with sex. In the 1970s, however, the concept of gender as different from sex made its appearance in feminist discourse. Since then, the term *sex* has been understood to refer to the biological characteristics that make men and women different, and *gender* has been conceived as referring to the social and psychological characteristics related to femininity and masculinity. To the feminist world, this distinction is extremely significant in that it underlies the different forms of domination experienced by women universally. According to feminist theorists, every societal configuration has a sex-gender system—a set of arrangements by which the biological raw material of human sex and procreation is shaped by desired social interventions. Sex is related to what was bestowed by nature, and gender is related to what results from nurture. Within the emerging feminist understanding of the 1970s, this distinction was significant as it avoided the underpinning of *women* as a natural category. It thus became evident that femininity and masculinity are to be understood as acquired characteristics with social significance.

Despite a clear enunciation of the gendered character of societal parameters, mainstream feminism went on to replicate the inequities of the patriarchal society by leaving out of its ambit many categories of women who are marked by given systems as "different" and are oppressed due to factors such as class, ethnicity, caste, and physical or mental diversity. Implicit in mainstream feminism was the idea of universal sisterhood, which signified that all women experience similar oppressions; however, this idea was contested by those who felt that their unique life conditions were not reflected in the collective experience. Disability was one of the categories excluded from deliberations within the evolving awareness of feminism.

The inevitable fallout of this reasoning was that the disability movement mirrored the gendered nature of larger society, making the female members uncomfortable habitants of the resistance that the disability movement has been putting up against the hegemony of the normality. Even sensitive students of disability have focused on disability as a singular concept and have taken it to be not merely the primary status, but apparently the exclusive status of disabled people. Disability is not the only social marker of distinctiveness, as gender coalesces and makes the experience increasingly doubly oppressive. Thus, both disability and gender are social constructions, endorsing the cultural inscriptions on the bodily impairment and the biological sex, respectively. The realization that both identities are similar in that they are biological entities that are assumed to become problems when placed in a hostile social context has become crystal clear. It is precisely this understanding that has rendered the lives of disabled women across the globe invisible and devoid of any control.

The process of discrimination against disabled people starts at birth. It is not uncommon in some parts of the world for disabled infants and very young children to be killed or left to die. In India, technological advances that allow the determination of the sex of the fetus have created a eugenics movement that might be unheard of in the West. The widespread desire for male offspring has translated into the abortion of many female fetuses. While activists in the West have been vehemently protesting against the killing of disabled infants in India, the preference for sons has resulted in the lowest ratio of female to male births ever. Although feminists have engaged in plenty of debates about the ethical contradictions involved in the selective killing of female fetuses, as well as the right to abort, the use of new technologies for prebirth genetic screening to predict disability has not been addressed. Coupled with the predominant negative presumptions held about impairment and disability, it is not in the least surprising that the abortion of impaired fetuses is not even mentioned in these debates.

The survival to birth of a disabled girl child, however, does not guarantee her a struggle-free existence. The road she will have to traverse is not easy. In any nation, a disabled girl child is likely to experience inequities in terms of basic entitlements (such as food, health care, education, and employment opportunities) and often has little hope of being included in the cohesive net of the family. Although most if not all disabled girls around the world are subject to such difficulties, a majority of disabled girls who live in developing countries are currently living lives in which every one of their human rights is being violated.

In the early 1980s, feminists in the West drew attention to the danger inherent in applying the feminist critique of patriarchy to disabled women's experiences. They realized that this critique would not offer an adequate account of the oppression of disabled women, as disabled women have not been "ensnared" by many of the social expectations feminists have challenged. In reality, this "freedom" from expectations signified the loss of traditional roles that provided living space to women marked as disabled. The constant privileging of "normal" women worsened the situation of disabled women. The intimidation of hegemony that worships physical and mental perfection has a definite impact on the resistance that disabled women can put up against their recurrent marginalization.

In such a context, it is not easy to think of viable strategies. Despite swift social, cultural, and economic changes and the current drive toward a global society, women are still defined in terms of their connectedness with traditional social roles. For instance, in India, throughout her life, a woman is largely defined by her roles as daughter, wife, and mother. Any position she holds outside the home is not considered to be her primary role. However, disabled women are not considered "marriageable" because their impairments are seen as "imperfections" that could be passed on to their children. Their ability to fully look after a home and family is also questioned.

The incidence of marriage for disabled women is lower than that for disabled men throughout the world, but it is lowest in cultures where traditional roles are highly valued. In a similar vein, whereas specific cultural taboos may vary, the universal reality is that disability and motherhood are not perceived as complementary. Even in cultures where single motherhood is acceptable, disabled women often find it difficult to express their desire for this role. The denial of traditional roles thus adds to disabled women's vulnerability and desolation.

Much of the uncertainty about disabled women's suitability for the role of motherhood stems from assumptions concerning their physical capacity to carry pregnancies. If disabled women do manage to be reproductive, grave doubts still exist in most societies about their competence as mothers. The emotional strength that they can provide their children is viewed as inconsequential, as the stereotypical image of disabled women is that of dependency. That disabled women can be caretakers too is often missed in the dialogue of care. This appears in contrast with more emancipated "normal" women, because of the limitations imposed on disabled women, who cannot become partners in this celebration because they do not have opportunities to participate in the more productive activities of a given culture.

The economic strain and isolation created by the relatively few opportunities disabled women have for productive work or gainful employment lead to a lack of participation in the labor market, producing and reinforcing the dependency that is assumed to be characteristic of disabled women. In this sense, feminist positions are guilty of amplifying the importance of women's employment until it has become a standard of womanhood against which disabled women shrink into invisibility. Striving for equality not only with men but also with "normal" women induces in disabled women a desire to be recognized as persons first and then as being female.

In many societies, women who are considered intellectually disabled frequently encounter the severest form of oppression in the form of forced sterilization. Without their consent or even their knowledge, they are provided with an "effortless" and "realistic" solution to their "predicament." Sterilization is said to "relax" the disabled woman, as she no longer has to manage menstrual hygiene or deal with pregnancy or the "risk" of bearing a disabled child. It is often argued that sterilization protects a woman from sexual abuse. Although sterilization is imposed predominantly on women who are intellectually different, many women with physical and sensory disabilities are also subjected to this inhumane treatment.

This is quite paradoxical, as it is popularly assumed that disabled women are asexual. This contradiction places them in an extremely perilous situation. In a society that imposes ruthless standards for attractiveness and desirability, disabled women require a sort of physical legitimacy in order to obtain love and acceptance, with a certain sexual model as the entrée to both. This creates confusion, as disabled women obviously cannot adhere to rigorously defined standards of acceptable body dimension, weight, and physical competence with the ability to be sexual. This becomes a discouraging and inexorable process for those who don't measure up to the normative standards. The consequences for these women are feelings of guilt, shame, and fear when they are confronted with the possibility of sexual intimacy. Slowly but surely, this conveys messages of unattractiveness as well as leads to a state where it seems that the body has lost the potential to respond to sexual cues. Thus, all these measures are designed to control disabled women rather than to address the societal arrangements that do not provide security and support for these women.

The oppression and invisibility that disabled women experience have negative impacts on their self-esteem. Stigmatized from birth, through neglect they grow up with the tyranny of a society that demands perfection. In addition, disabled women—especially those who are severely disabled and fully dependent on the assistance of others to accomplish their day-to-day life activities—have to contend with caregivers who objectify disabled women, often completely disregarding their feelings and their right to decide on matters concerning them.

The difficulties that disabled women experience are rooted in the meanings that impairment has for nondisabled people. If the nondisabled view the difference of disabled women as deviance, this has a negative impact on disabled women's internal strength and resistance. It is not easy to acknowledge and retrieve one's agency to resist dominant patterns when the signals communicated to one by others are those of dismay, fear, and pity. The right to self-definition and an evolving worldview is a fundamental political right that is denied to many disabled women. As disabled women confronting their recurrent exclusion, they are deprived of the right to have expertise regarding their own lives. Thus, disabled women must struggle not only to assert their own identities but also to assert their difference and to account for the injustices done to women that have not found expression in the language of feminism.

The stigma attached to disabled girls and women does not leave their mothers unblemished. A form of torture accrues to them for having given birth to disabled daughters. Once again, the feminist discourse in India has paid scant attention to the issues faced by women who are the mothers of disabled children, especially girls. Women who cannot validate their social status as mothers who have borne healthy children for their husbands' families, such as those who have given birth to disabled children, are condemned to live in shame. There have been instances in India of women being divorced or even tortured because they gave birth to disabled children. Given the preference for sons, "mother blaming" is even more severe when the disabled child is a girl.

In addition to such direct onslaughts—which are always met with protests—disabled women have to contend with the use of their life situations as a metaphor to illuminate the issues and concerns of nondisabled women. The genesis of this probably lies in the fact that the sociocultural meanings ascribed to female bodies and those assigned to disabled bodies are similar. Excluded from full participation in public and economic spheres, both are conceived in opposition to a norm that is assumed to possess natural superiority. Such comparisons can be both emancipatory and oppressive. If the objective of invoking such comparisons is to understand the lived experiences of people and grasp their legitimacy, the potential is immense. However, when the underlying realities of the categories serve only at a metaphorical level, this can lead to a total erasure of the category that is being invoked. The consequent effect is that whereas one category gets "valorized" the other is very often "suppressed" in the process. Consequently, when nondisabled women are portrayed as experiencing social disability, the strategic advantage of the metaphor gets lost.

A shift from the theoretical/metaphorical to the material, which is essential to render visible the "cultural constructions" that have supported the currently flawed conceptualizations of disability and womanhood, is critical. A careful analysis of metaphors that use disability as explanatory categories is required to unearth their meanings and functions, if their power is to be subverted. Until the popular refrain that "being a woman is the biggest form of disability" operates, the road to empowerment is going to be a difficult one. Another significant issue to remember is that disabled women are also divided by many factors, such as class, caste, ethnicity, rural/urban divide, sexual orientation, and type of disability. In the context of the relationship between disability and gender, we must understand how these marginalizing aspects play a significant role.

For disabled women to resist the hegemony of normality, both advocacy and research are essential. Within India what is perhaps needed is an interrogation of the normative standards that construct disabled women as passive and dependent. However, given the cultural context, this cannot be accomplished through an emphasis on "independence and autonomy," as family structures are interdependent in Indian society. Whereas women in the West have attained a reasonable amount of success in challenging the "perfection-driven norm," this has been a result of a significant attitudinal change that has led to a more accessible built environment and changes in other structural inequalities. Research in developing countries needs to focus on actual living conditions so that it can accurately assess the impact of disabling conditions associated with gender. Researchers need to resist the tendency to borrow from the Western understanding, as the local reality is extremely important.

The cause of disabled women in India would be greatly supported by cross-cultural research that listens to diverse voices and recognizes that there is no single grand narrative of "the disabled woman." Thus, the idea of universal sisterhood, while sound in principle, will remain a myth if researchers overlook the nuances of specific realities in order to arrive at broad generalizations. Although rhetorically the women's movement may be represented as inclusive, the reality belies the claims. Encapsulating diversity within every universal category can be a daunting task, but the initiation has to come from the grass roots. It is only then that the necessary agency can be located and the hegemonies of both the disability movement and the women's movement can be challenged.

—Anita Ghai

See also Disability Policy: India; Experience of Disability: India; India, Marriage and Disabled Women in.

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INDIA, MARRIAGE AND DISABLED WOMEN IN

A study of the literature on disabled women reveals that the issue of marriage has been addressed very little from an empirical perspective. Most of the claims about the marital status of disabled women are based on estimates rather than actual research conducted with large samples. In countries such as the United States, Canada, and the United Kingdom, where disability studies is evolving as an independent discipline, a significant body of literature discusses gender, feminism, personal experiences, and the sexuality of women with disabilities. This literature briefly alludes to the issue of marriage, but it does not move beyond giving a selected group of women with disabilities the choice between remaining single or getting married. In developing countries such as India, hardly any research has been conducted on this issue, and therefore very little archival material, if any, is available. The subject of marriage and disabled women in India needs to be critically and thoroughly researched and documented. This entry is offered with the hope that it will provide scholars with some leads into the issue.

Before this discussion can begin to approach the significance or insignificance, and the availability or nonavailability, of the institution of marriage for disabled women, it must briefly address the basic question of the importance of marriage for women, the changing perception of the institution in the wake of awareness generated by the feminist movement, and how a single woman is looked at in a volatile yet strongly traditional Indian society. Also, marriage is addressed here as it exists between men and women; the topic of same-sex marriage is not considered, as this practice is not a norm and therefore uncommon in India. Of late, however, some deaf lesbian women have come out, but it is beyond the scope of this entry to delve into multiple issues; the focus here is primarily on the traditional institution of marriage and its availability to women with disabilities in India.

It is pertinent to note that, owing to the diversity of India's population and the country's colonial history, which has been questioned as not allowing subalterns sufficient voice, this entry does not seek to offer a monolithic picture of the issue. While some aspects of the topic may fall into a linear singular pattern, others may be contextualized and located in diverse cultural, educational, regional, religious, caste, and socioeconomic realities. Although the experience of discrimination, deprivation, and exclusion is common to most disabled women in India and cuts across different contexts, the primary focus here is on Hindu women. This entry attempts to trace a recurring pattern of experiences of disabled women in the majority Hindu community because constraints of time, space, and scope as well as the availability of literature on the experiences of Hindu women make it most feasible to concentrate on this group.

IMPORTANCE OF MARRIAGE FOR WOMEN IN INDIA

In Hindu society, even today, one of the key roles a woman is expected to subscribe to is that of a wife. In fact, from the time of birth itself, the girl child is groomed, trained, and prepared to take this role after marriage. By and large, the feminist literature in India has regarded marriage as an oppressive institution, as it operates to strengthen patriarchy and perpetuate women's exploitation. Women are expected to conform to the laws or rules laid down in the Laws of Manu—the ancient lawgiver—and the ideals of womanhood described in several other ancient Hindu religious scriptures, epics, mythological tales, rituals, and practices. According to Desai and Krishnaraj (1987), these prescribe an ideal of womanhood that confines the woman to the roles of devout wife and doting mother. In these roles she does not function as an entity independent of her husband or children. Together, these roles put women in a lower, dependent position. Many writers, including Rao and Rao (1982), Dhruvarajan (1989), Bumiller (1990), Bagchi (1995), Nair and John (1998), Gandhi (1942), and Sharma (2002), have endorsed similar views, stating that a woman's career path is oriented toward marriage, which is arranged by parents in more than 90 percent of cases. It is the religious and social responsibility of parents to "settle" their daughters in marriage. Fruzzetti and Östör (1992) have observed that marriage is central to the lives of Bengali women. They note: "Daughters are not meant to remain permanently in their father's house. It is expected that all women will marry and leave for their husband's place. Marriage completes the cycle of cultural expectation for women" (pp. 39–40). In conjunction with such expectations, it is difficult to find aspirations or models for single women in this society. This practice of placing a premium on the virtues of wifely duty and maternity is followed in other cultures and religions in India as well, including Sikhism, Jainism, and Christianity.

In a 1953 study, Margaret Cormack found that single women were considered unholy and inauspicious in Hindu culture. This may not be an absolute truth today, because with changing times the numbers of women choosing to remain single have increased, but they still constitute a minuscule minority. In fact, a recent study conducted by economists of the London School of Economics found that among Indian cities Mumbai has the largest number of single women; based on their findings, the researchers projected that with growing economic and social independence, many Indian women may prefer not to marry (cited in Mukhopadhyaya 2004). In discussing the reasons some women remain single, Cormack observes that a majority of single women do not have the option of getting married for one or more of the following four reasons: They may be considered unattractive, they may be too qualified and hence cannot find husbands with higher qualifications than themselves, their parents may be unable to provide sufficient dowry, or they may not be able to find the "right man." In urban areas of India, a small proportion of women are found to be wedded to their careers and professions, which brings some amount of respect. A career provides some buffer because unmarried women without good careers are treated as objects of pity or lead lives of social exclusion and stigma.

Despite the feminists' reprobation against the age-old institution of marriage, it is imperative to understand why such a premium is still placed on it, especially for women in Indian culture. Marriage, for women, is seen as an institution that confers certain entitlements, privileges, status, respect, and access to other life accomplishments, such as motherhood, family life, and experience of sexuality. It is a means of gaining social acceptance in society; hence, it ensures participation and inclusion. These avenues become shut off to women who never marry. In most cases, marriage is also a route to economic and financial security. Although the Hindu Succession Act of 1956 gives equal rights to women to inherit parental property, as Kishwar (2004) points out, in practice women have little access to property.

EXPERIENCES OF DISABLED WOMEN IN INDIA

If marriage is perceived as the ultimate destiny of nondisabled women, then why is the destiny of disabled women different from that of their able-bodied counterparts in India? This is not to suggest that marriage should be the destiny of disabled women, but rather that disabled women might have the alternative of choosing—that is, of deciding their destiny vis-à-vis marriage. A considerable literature indicates that disabled women are less likely to be married than are disabled men or able-bodied women. The 1996 report on the National Conference of Disabled Women put the proportion of unmarried disabled women in India at that time at 80 percent. Another report on the status of blind women in India, published by the Women's Committee of the Asian Blind Union in 2000, put the proportion of unmarried blind women at 73 percent. However, the latest findings of the National Sample Survey Organisation of India, brought out in December 2003, project a completely different picture. They show a higher number of disabled women being married than disabled men, but the percentage of widowed, divorced, or separated disabled women is about 30 to 31 percent, in contrast with 7 to 8 percent of disabled males. This pattern is observed in both urban and rural areas.

Researchers need to probe further into the reasons behind these higher rates of widowhood, divorce, and separation among disabled women in comparison with disabled men. This difference suggests problematic partnerships and devaluation of status for women after marriage. It could be possible that young disabled women are married off to men much older than themselves, or another possibility could be that they are tied to ailing men and therefore suffer a higher rate of widowhood. The higher rate of divorce and separation postmarriage for disabled women is again indicative of the fact—as Jeeja Ghosh and Shampa Sengupta (2003) projected based on the findings of a study in West Bengal, India—that they are often abandoned or physically and mentally abused, treatment associated with their disability. It is a situation of double bind: Whether disabled women are unmarried or married, they are in a disadvantageous position because the stigma of disability is permanently marked on their bodies. They either cannot get married because of their disability or, if they do marry, disability makes the survival of a happy marriage difficult.

At times, having disabilities opens several avenues for women in India that may otherwise be denied to them, such as education, employment, and subsequent financial independence. But such benefits come at the cost to disabled women of having it instilled in their minds that the avenue of marriage is closed to them and that it is futile even to think of it. According to Anita Ghai, this nonavailability of the traditional roles puts disabled women in a state of rolelessness. In her book *(Dis)Embodied Form: Issues of Disabled Women* (2003), she presents case studies in which she examines in detail the experiences of disabled women within and outside marriage. Ghai asserts that while feminists analyze the oppression of able-bodied women within the traditional role of wife and mother, they have chosen to ignore the oppression that disabled women feel due to the unavailability of traditional roles. She notes that in India marriage and motherhood have a cultural value, and that when disabled women are denied these markers of womanhood, the result is "a social obscurity and annulment of femininity" (p. 68).

Many educated and professionally accomplished disabled women refuse to marry disabled men or men who are not their equals in professional terms. The same holds true for disabled men as well. From my personal experience I can corroborate that professionally qualified disabled men prefer less than equal, able-bodied woman as partners to qualified and accomplished disabled partners. Marriage entails many compromises for disabled women that are humiliating. To begin with, due to the lack of choice they have owing to disability, they are left with no option but to accept spouses who are socially, economically, and intellectually not their equal. Sometimes they are physically and mentally abused and tortured, disability again being a major cause of their victimization. As indicated by the proceedings of the National Conference on Empowerment and Mainstreaming of Women with Disabilities, held in Jaipur, India, in August 2002, given such realities, many educated disabled women are choosing not to marry.

Where disabled women have little or no education or any skills that allow them to be productive and contributing members of society and thus improve their chances of marrying, they are treated by their families as a burden, and at times like damaged property that can be bargained in the matrimonial market. In a bizarre incident reported recently in the *Times of India* (Farooqui 2003), a father who had failed to find a groom for his disabled elder daughter, Preeti, who is a wheelchair user, laid the condition that he would give the hand of his younger, nondisabled daughter, Ragini, to any man who would marry his disabled daughter as well. The marriage of both the daughters to one man was solemnized with Amarnath Verma—who has been lauded by many people for setting a precedent in rehabilitating a helpless disabled woman—on November 25, 2003; and, to the shock of everyone, the feminists remained silent toward this open practice of bigamy, something that is prohibited by Hindu Personal Law. This incident raises many questions about the options and choices available to disabled women, especially in India. Disabled women have no role models and little access to any community in India. The issues of their education and employment, their sexuality, and the violence, abuse, exploitation, and denial of rights and deprivation to which they are subject are rarely talked about or raised by disability activists or scholars. The disability movement has kept these issues under wraps, and disabled women activists as well as scholars hesitate to address them. India's disability movement is dominated by men with disabilities who set the agenda. And the agenda is based on the issues that concern them. Disabled women activists just follow that agenda. One disability activist recently had the following to say on this subject:

> Though we come across as strong activists shouting slogans, fighting for our rights . . . who takes care of our right to be loved (emotionally and physically), to be a life partner, to be mother and so on? Yes one can never force someone to love. It is the most natural process of life. But sadly it is dependent on the outward looks of a human. . . . I have kind of become numb and immune to these feelings though I am very emotional, sentimental and romantic at heart but I don't have the strength and guts to go through any pain. . . . And besides there is no future (marriage) even if I got involved with someone cause I can't manage things the way other women do. And our culture and traditions don't allow live-in relationships or have affairs w/o marriage . . . so there's no point. Of course, I feel lonely and crave for a companion but I can't do anything about it. (personal communication, November 5, 2003)

The yardstick used to measure a disabled woman's eligibility for matrimony is set by the traditional precedence of an able-bodied woman's roles of wife and mother. In an anthropological study conducted in rural South India, Erb and Harris-White (2002) found that disabled men are not interested in marrying disabled women because they feel such women will not be able to perform household or work tasks and undertake child-rearing activities. These researchers also found that disabled women decide against marriage due to fear of childbirth and fear of being abandoned. This may be seen as their internalization of disability oppression. In fact, the myths that disabled women are not sexually active, do not marry, and therefore do not even become mothers keep them out of the purview of government family and child welfare programs as well as reproductive and child health care programs. Although feminists criticize these programs for relegating women to the role of mother, the programs' exclusion of disabled women deprives them of access to marriage by perpetuating the myth that disabled women are incapable of becoming mothers and thus succeeding in family life. This also puts them in a cycle of economic deprivation, for, in India, marriage is also sometimes a route to financial empowerment (although the high percentage of widowed, divorced, and separated disabled women indicates otherwise).

Although some disabled women in India have made successful marriages, disabled women have no role models or ideals in this area to emulate. Those disabled women who have been successful in marriage tend to negate their disability identity; as Ghai (2003) has observed in her examination of Meekosha's work, they are "reluctant to share their personal stories, in fear that they might be seen as spectacles" (p. 100).

For the status quo to change, so-called privileged disabled women must come out of their closets and prove by example that disability is not a barrier to experiencing sexuality, motherhood, love, and family life. The news and entertainment media need to be enlightened on this issue and motivated to play a more active role in challenging the stereotypes of disabled women by bringing to light positive instances and precedents. And above all, disabled women activists and scholars should discuss the issue of marriage more openly, lobby for the inclusion of disabled women in reproductive and child health programs, and seek to revise the feminist agenda so as to shatter the myths that disabled women are incapable of motherhood and of taking part in child-rearing activities. In India, marriage is as much a route to social rehabilitation for women with disabilities as it is an issue of their right to have family lives and to be mothers. Marriage is a rights issue for disabled women in developing countries as much as it is in developed countries. The only difference is that in developed countries, disabled women themselves have taken up the issue more forthrightly.

—Meenu Bhambhani

See also Disability Policy: India; Experience of Disability: India; India, Impact of Gender in.

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INDIVIDUALIZED EDUCATION PROGRAM (IEP)

According to Section 300.15 of the U.S. Department of Education federal legislation, the acronym IEP stands for *individualized education program.* Since the passage of the Education for All Handicapped Children Act (P.L. 94-142) in 1975, the IEP has been a mechanism for ensuring that students with disabilities up to the age of 21 receive a free appropriate public education (FAPE) in the least restrictive environment (LRE) that is individualized to meet their needs. The IEP process is also intended to hold educational systems accountable for student progress. An IEP initiates a process that is completed and guided through the creation of a document that communicates legal intent. In the United States, the Individuals with Disabilities Education Act (IDEA) of 1997 requires that an IEP be developed for every student with a disability who receives special education and/or related services.

Before any student is identified as having a disability, a comprehensive evaluation must be completed. This evaluation includes an assessment of the student's potential and achievement, home and social environment, biological development, and (if related areas of difficulty are observed) speech and language ability and fine and gross motor skills. An IEP is developed only if the identified disability has a negative impact on the student's learning and/or academic progress. In cases where the disability does not have such an impact, a section plan may be developed for the provision of accommodations and modifications in accord with Section 504 of the U.S. Rehabilitation Act.

A student's IEP is developed with information gathered by an interdisciplinary team through a comprehensive evaluation of the student. The IEP is designed to ensure that a student with any type of disability that affects his or her progress in learning receives specialized and individualized instruction. These outcomes are reached primarily through the development of annual goals and quarterly benchmarks. Goals and objectives are linked to individual student progress and are not based primarily on available professionals' services. Goals and objectives are developed with parental and student involvement and consider individual student strengths and needs. The parents are required members of the IEP team, and the student is also encouraged to attend and participate in planning sessions. Special education experts recommend that a student's IEP goals and objectives, not his or her disability diagnosis, be used to determine the service delivery setting. Furthermore, the model calls for services to be provided in the LRE, ensuring that students with disabilities are not segregated from nondisabled peers as a direct result of their disabilities.

The IEP process provides an opportunity for the individualization of educational services for students with disabilities. The IEP details individualized services and teaching that focus on the attainment of goals and objectives. Attention to individual student progress on set goals and objectives is intended to ensure that educators and service providers address the student's learning needs. Well-developed IEPs have the power to have a positive impact on students' learning if the services are implemented and interventions and progress are reviewed and revised on at least an annual basis. Although individualized education plans are not mandated for students in general education, many educational systems recognize the benefits that IEPs afford and are beginning to adopt such strategies for general education settings.

The IEP model is used in early childhood, elementary, and secondary school education. Thus, adults with disabilities do not benefit from IEPs in workplaces or in institutions of higher education. However, careful attention to including secondary school students with disabilities and their families in the IEP process can help to prepare these students to access services later, as adults with disabilities. Furthermore, adults with disabilities can use the IEPs developed during their school years to provide proof of disability when they desire to access services and resources from adult service agencies. The information contained in an IEP can potentially guide the creation of supports within higher education and/or employment settings.

The implementation of the IEP model has not been without challenges. Primary among these has been the ability of schools to include parents and students in the IEP process and obtain students' perspectives on transition issues. This issue of meaningful involvement arises in part because IEP team meetings often are held on weekdays, while the parents of affected students are at work. Parents may lack familiarity with the law and/or the school system and thus may be unaware of their rights. As students with disabilities approach adulthood, it is also increasingly critical to prepare them for their adult lives. While the IEP can establish a mechanism to promote this goal, affording students with disabilities an equal voice in the process demands a change in the culture of the school, which can be more deliberate than speedy.

Other significant concerns include creating individualized plans that are adjusted annually and changing schools so that students with disabilities learn in the least restrictive environment. School professionals who head IEP development are often responsible for many students, and it is frequently extraordinarily difficult for them to allocate sufficient time to the creation of goals that are adequately individualized to each student and updated regularly. A national teacher shortage in special education only adds to the difficulty of addressing this problem. Finally, school systems have been slow to develop environments that do not segregate students with disabilities from other students solely because of disability. It is important to note that the IEP process can be powerful in overcoming this challenge, at least at an individual level.

—Teresa Garate and Jose Mendez

See also Individuals with Disabilities Education Act of 1990 (United States); Special Education.

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INDIVIDUALS WITH DISABILITIES EDUCATION ACT OF 1990 (UNITED STATES)

The Individuals with Disabilities Education Act (IDEA) is the title of legislation passed by the U.S. Congress in 1990 guaranteeing the right to free and appropriate education for children and youth with disabilities. The IDEA was the reauthorization of the Education for All Handicapped Children Act (EHA), which was passed in 1975 as the first separate federal legislation authorizing special education for children and youth. Previous legislation had included the legal basis for special education as early as 1965, but it was included in acts pertaining to elementary and secondary education. The EHA was reauthorized in 1986 and later as the IDEA in 1990 and 1997. As federal legislation, it requires states to provide specific services to eligible individuals with disabilities who are ages 3 to 21 and to have procedural safeguards in place to ensure that those services are in fact provided in an equitable and nondiscriminatory manner. Under the IDEA, children with disabilities are entitled to evaluations of their needs as the basis for individualized education plans (IEPs) and placement in the least restrictive environment (LRE) for their education. They are also entitled to the provision of related services, such as transportation, therapies, medical support, and assistive technology, to ensure that they receive maximum benefit from the educational experience.

Procedural safeguards are built into the legislation in the form of requirements for parental involvement in evaluation, planning, and placement activities; parental consent to school decisions; and parents' right to appeal decisions made about their children's placement. For children under three years of age, the 1986 reauthorization encouraged states to extend services under the IDEA to children from birth to age three, encompassing early intervention and support for families in their caregiving roles.

HISTORY OF THE IDEA

Prior to 1975, children and youth with disabilities in the United States were either denied education altogether or did not receive education appropriate to their needs. Children did not have a right to education, and schools could selectively refuse to admit any children they judged to be ineducable. The consequence was that only a fraction of children with disabilities were provided an appropriate education. In the 1960s and early 1970s, parents and advocates challenged the exclusion of children with disabilities from public education under the provisions of the equal protection and due process clauses of the Fourteenth Amendment of the U.S. Constitution. Two key cases were brought before the courts to argue for the rights of children with disabilities to equal access to education—*Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania* (1971) and *Mills v. Board of Education of the District of Columbia* (1972). The success of these cases was incorporated into the passage of the EHA in 1975, defining a free and appropriate public education for children with disabilities from the ages of 5 to 21.

The first reauthorization of the EHA occurred in 1986, with two important modifications. The first was the downward extension of the age range from five to three years of age for eligibility for special education. The second was the formalization of early intervention services for infants and toddlers from birth through age two years. In 1990, the EHA was reauthorized as the Individuals with Disabilities Education Act. The most recent reauthorization was in 1997, and it is likely that the reauthorization process will be repeated at regular intervals. Although the IDEA does not compel states to provide free and appropriate education for children with disabilities, it does require states to adhere to the specific elements of the act if they wish to receive federal funds.

ELEMENTS OF THE IDEA: SPECIAL EDUCATION

In the 1997 reauthorization of the IDEA, provisions are divided into four parts: Part A defines the various terms used in the law, Part B spells out the special education services required for children and youth ages 3 through 21, Part C describes requirements for the provision of early intervention services for children birth through 2 years of age, and Part D constitutes the capacity-building component of the law, in terms of how education and related agencies in states need to ensure the provision of special education and early intervention to all children needing such services. Part D also specifies the ongoing role of the federal government in ensuring the preparation of personnel by institutions of higher learning, the development of new instructional approaches and technology, and the conduct of research on effective practices.

The rights of children with disabilities as defined in the IDEA can be summarized as falling within the following major themes: eligibility, assessment, parent involvement, the IEP, LRE, and related services. In order to receive special education services under the IDEA, a child must meet the criteria for assignment to 1 of 13 categories defined in the act. Eligibility determination is based on individualized assessment carried out by qualified specialists and approved by a school-based team.

Eligibility Determination and Categories

Under the IDEA (1997), eligibility for special education encompasses children who are defined as

> (i) . . . children with mental retardation, hearing impairments, deafness, visual impairments including blindness, deaf-blindness, multiple disabilities, speech and language impairments, serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments or specific learning disabilities and (ii) who by reason thereof, need special education and related services.

Following referral by a parent or by health care or school professionals, a child is given an evaluation appropriate to the referral to determine whether he or she meets the criteria for 1 of the 13 categories. Eligibility was expanded beyond these 13 categories in the 1997 reauthorization to include children ages three to nine years

> (i) experiencing developmental delays as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, cognitive development, communication development, social or emotional development or adaptive development and (ii) who by reason thereof, need special education and related services.

In contrast to the 13 categories, the use of developmental delay as the basis for special education eligibility is at the discretion of individual states and is variably implemented.

Assessment

Comprehensive assessment is carried out to identify the nature and extent of a child's need for special education. Such assessment involves a school-based team, the members of which include a school psychologist; physical, occupational, and speech therapists; and teachers in both regular and special education. The assessment may involve the use of standardized tests, observation, parent interview, and professional judgment. Every child who is found to be in need of special education is reevaluated at three-year intervals to determine whether he or she continues to be eligible for one of the categories and thus eligible to receive special education services.

Individualized Education Plan

The IEP provides a yearly specification of goals for the child and a road map for the services the child needs in order for appropriate learning to occur. The IEP is produced by the school-based team in conjunction with the child's parents and the child whenever possible. It is a living document that is used for periodic review of the child's progress. In addition, the IEP should be seriously reviewed each year in which the child is in need of special services, as it is important that the next year's plan reflect evaluation of the child's progress each year. If the child has not made progress, it is important that the IEP reflect changed expectations, alternative educational interventions, or a combination of the two.

Parent Involvement

Parents are deemed to be partners with school staff in crafting the child's IEP. They are supposed to be involved at each step of the process, and the IDEA provides them with recourse to school- or system-based mediation if they have differences with the school over the child's plan. If resolution is not achieved through these means, differences between parents and the school can be dealt with through due process.

Least Restrictive Placement

The IDEA's underlying principle for student placement is full inclusion—that is, a child is to be placed in the setting that will allow him or her the greatest participation with peers of the same age without disabilities. The nature and extent of inclusion of the child's placement is spelled out in the IEP.

Related Services

In addition to direct instructional accommodations to meet the child's educational needs, other services that are needed to improve the child's performance in school are also provided under IDEA. These services may include physical, occupational, and speech therapy as well as the provision of assistive technology. Environmental accommodations may also be provided under Section 504 of the act.

IMPLEMENTATION ISSUES

Accountability

Under the IDEA, documentation that special education is beneficial for children and youth with disabilities has taken two forms. The first is the monitoring of each child's progress on an annual basis with a review of the goals spelled out under the IEP. This typically leads to revision of the goals defined for the child in the IEP. The second form of accountability is the expansion of the participation of children and youth with disabilities in the large-scale assessments carried out for general education students. In this context, special accommodations may be made for students with disabilities; for example, they may be provided with additional time and/or modified materials to allow them to complete the annual tests taken by all students. As noted earlier, due process is another form of accountability for the child.

Transition

In addition to education services, students with disabilities are also eligible under the IDEA for individualized transition plans to assist them in making the move from school to the community. This is a crucial process and may begin during early adolescence although children may continue in special education through the age of 21 years.

—Rune J. Simeonsson and
Donald J. Lollar

See also Education, Primary and Secondary; Education and Disability; Individualized Education Program (IEP); Special Education.

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INDUSTRIALIZATION

Industrialization is the process by which manufacturing displaces agriculture and commerce to become the dominant economic activity in a society. Driven by inanimate sources of power, industrialization allows the concentration of machines in factory settings and their regular, reliable deployment. In Britain—the first industrialized nation—this transformation was initially understood as a cataclysmic event. Subsequent interpretations have stressed the long-term origins in the breakdown of the feudal system and the emergence of capitalist modes of production and exchange, particularly associated with the growth of towns since the late seventeenth century. Revolutions in commerce, transport, and agriculture consolidated these developments. During the 40 years after 1660, Britain's foreign trade increased by more than a third, generating unprecedented prosperity. By 1760, long before the mid-Victorian railway boom, an impressive network of canals and turnpike roads was springing up, and simultaneous improvements in agricultural productivity not only freed up labor for industrial purposes but also prevented inflationary food prices, thus releasing surplus income for the purchase of manufactured consumer goods.

Entrepreneurs, who thrived in Britain thanks to the stimulus of religious nonconformity and the potential for social mobility, faced few constraints in exploiting these economic conditions. The lax enforcement of apprenticeship regulations, for instance, aided the recruitment of new workers, and landowners and merchants had little difficulty in financing ambitious projects despite legislation intended to discourage irresponsible speculation. Consequently, for almost a century prior to 1780—the traditional starting point of the Industrial Revolution—real national income in Britain was expanding at an average rate of 0.70 percent each year. This indicator peaked at a mere 1.97 percent during the decades of fastest growth between 1801 and 1831. None the less, the accumulated effects of this gradualism were dramatic. In 1760, agriculture and related economic activities accounted for 37 percent of British national income; by 1871, the proportion had slumped to 14 percent. Conversely, manufacturing, mining, and building had escalated in importance, explaining just 20 percent of national income in 1760 compared with 38 percent in 1871. The factors shaping this particular experience were not exactly replicated elsewhere. In the second half of the nineteenth century, however, the Industrial Revolution spread to other areas of Europe, the United States, and Japan, ending Britain's tenure as the "workshop of the world."

Industrialization has been pivotal to the social model of disability and its location of disability—as opposed to impairment—in the material and ideological organization of modern societies. In 1980, Vic Finkelstein blamed new productive technologies for the rise of the segregated institution; the production lines of big industry were designed to fit able-bodied norms and thus shut out disabled people, who had previously been integrated and socially active members of their classes and communities. Michael Oliver (1990) later put forward a more detailed case, arguing that whereas full-fledged capitalism was exclusive, agriculture and small-scale industry did not prevent most disabled people from being economically active. Most recently, Brendan Gleeson (1999) has suggested that bodily impairment, an accepted and constituent element of medieval peasant life, became problematic only when industrial workplaces severed the connection between home and employment and began to discriminate against uncompetitive workers.

Like the heroic reading of the Industrial Revolution, however, the assumption that premodern societies were friendly to disabled people neglects the significance of incremental change. Long in advance of industrialization, the religions and cultures of ancient Greece and Rome, and the art and literature of Renaissance Europe, were constructing impairment in a pejorative light. Work was also a preoccupation before the Industrial Revolution. In early modern Britain, for example, the Tudor Poor Law struggled to distinguish "deserving" from "undeserving" or work-shy applicants. Similarly, letters recommending patients for admission to eighteenth-century hospitals such as the General Infirmary at Bath stressed the contributions of these individuals to their households' economies. For men, the emphasis was on paid employment: For instance, Newton Highhorn, a painter of 20, had been "greatly afflicted" by lead poisoning and had "so far lost the use of his hands as to be disabled from working at his trade or earning his bread." For women, the emphasis was on family responsibility: Mary Coombs, a married woman of 32, had experienced severe rheumatic pains for six months and was "now in great measure disabled and incapable of performing the usual labour for the support of her family" (Bath City Record Office 1750–1758). Regardless of gender, impairment was represented as a deficiency with damaging economic consequences.

Although disabled people were economically marginalized before the Industrial Revolution, the raft of changes that followed in the wake of industrialization transformed their predicament. Economic changes were themselves a cause of impairment because industrial enterprises polluted the human environment and led to workplace injuries and diseases. Furthermore, the inequalities that motivated the capitalist economy bred impairments that were correlated with social deprivation, such as rickets, tuberculosis, and infantile paralysis. Governments wedded to the virtues of private enterprise were slow to regulate the harmful effects of industrialization, and disabled people disadvantaged in the labor market had no option but to exist on meager incomes or parsimonious poor relief. The Great Depression of the 1930s compounded their financial difficulties. Conversely, World War II temporarily opened up job opportunities as able-bodied workers joined the armed services. After 1945, however, the employment policies implemented in industrial societies were largely ineffective in achieving economic inclusion. Even the British welfare state—celebrated for its health provision—offered little more than a minimally enforced quota of disabled employees.

The industrial societies that were inhospitable to impairment underwent profound social and political changes, although the changes were sometimes slow in coming. One example is found in the social implications of the factory system, often regarded as the emblem of the Industrial Revolution. As late as 1851, only 6 percent of the total labor force was working in textile factories, the sole employment sector where this mode of production had made significant inroads, and principal cotton workers continued to recruit their relatives to factory teams, preserving a reduced economic role for the formerly self-sufficient preindustrial family. Nevertheless, the adoption of heavy machinery did ultimately entrench a geographic separation of home and work that became a defining feature of industrial societies.

Andrew Scull (1993) has linked such change in family life to the rise of the segregated institution. Examining madness in nineteenth-century Britain, he concluded that the relatives of the mentally ill were compelled to incarcerate them because industrialization had eroded families' capacity to provide care. In sprawling industrial cities social networks were fragile, but smaller industrial towns developed complementary support mechanisms through workplace clubs, friendly societies, and cultural groups. Therefore, factors aside from industrialization explained the asylum, not least the appearance of a psychiatric profession with a scientific discourse on insanity and, later, mental deficiency. Other medical specialists endorsed the confinement of physically disabled people, reinforcing the influence of the eugenics movement. The voluntary sector was a pioneering supplier. As industrial states became more interventionist, however, the health and welfare professions increasingly collaborated with the public sector to deliver institutional solutions.

Although industrialization did not invent the work ethic, its protection through low taxation was perceived as essential to a thriving economy. In the "developing" world, where the modern plants that permitted extensive industrial production were not widely dispersed, the resources had never been available to build expensive institutional infrastructures. In the industrialized world, however, from the second half of the twentieth century concerns about costs encouraged community care as a cheaper, and more humane, alternative to institutional provision. At the same time, industrialization was entering a new phase. Manufacturing was being overtaken by the service industries, the benefits of limitless economic growth were being challenged, and innovative technologies were transforming the acquisition, processing, and distribution of information. Sociologists debate whether these postindustrial societies are now postmodern. Work has indeed been reconfigured by the information revolution, the welfare state has been fragmented into a mixed economy with charitable and commercial as well as statutory inputs, and professional power has been weakened by a loss of faith in scientific rationalism. But for disabled people there is no escape from the discrimination that is a characteristic of industrialization.

—Anne Borsay

See also Employability; Employment.

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INFANT STIMULATION PROGRAMS

Infant stimulation is a form of sensory enrichment that is used with clinical populations (i.e., at-risk and disabled) of infants as well as nondisabled (i.e., healthy) infants. For at-risk infants, infant stimulation is a process of providing supplemental sensory stimulation in any or all of the sensory modalities (visual, auditory, tactile, vestibular, olfactory, gustatory) to an infant as a therapeutic intervention. The intervention uses supplemental stimulation to compensate for the lack of normal/typical environmental sensory stimulation or the presence of abnormal/atypical environmental sensory stimulation. For example, sick infants born prematurely and hospitalized in a neonatal intensive care unit (NICU) are exposed to high levels of intense and aversive sensory stimulation related to necessary medical care (e.g., venous and arterial punctures, heal sticks, injections) and the general NICU environment (e.g., intense lights and alarms). Further, these sick infants do not receive the same caregiver stimulation and interaction that healthy full-term infants generally receive from their parents in the home environment.

Infant stimulation programs are instituted to compensate for the atypical sensory stimulation of NICU hospitalization. Such programs include the administration of sensory stimuli—including tactile (e.g., touching, rubbing, massage), vestibular (e.g., rocking, positioning, picking up), auditory (e.g., soft music, human voice), and/or visual (e.g., high-contrast pictures, mobiles) modalities—by nurses or therapists. The stimulation may be unimodal or multimodal and is usually presented on a regular schedule for specific amounts of time (e.g., 30 minutes per day for 20 days). The most frequently used stimulations are tactile, vestibular, and/or auditory, administered to approximate the stimulation the infant would have received in the womb. As the sick infant gets older and healthier, visual stimulation is added, and the program is modified to approximate the typical sensory environment of the home and caregiver.

Much of the research that has evaluated the efficacy of these types of infant stimulation procedures (e.g., regularly scheduled presentation of sensory stimuli) with sick preterm infants has generally been of poor scientific quality (e.g., use of heterogeneous groups, lack of control groups), and even the most scientifically sound studies have found little evidence of effectiveness. Thus, infant stimulation programs are currently evolving to be more "infant centered" and to have an important "social-psychological component" (SPC). Infant-centered programs focus on the infant's communication to the caregiver about the types and amounts of sensory stimulation the infant can tolerate (e.g., an infant's eye-to-eye contact with a caregiver indicates tolerance of the stimulation, whereas the infant's looking away from the caregiver indicates lack of tolerance). This allows the caregiver to cease stimulation of the infant prior to the infant's becoming "overloaded" (homeostatically challenged and dysregulated); additionally, the caregiver can recognize the signals of the infant's readiness for stimulation. The SPC of infant stimulation programs includes the use of the infant's own primary caregiver (e.g., mother, in contrast to nurse or therapist) as the provider of the sensory stimulation. The caregiver administers stimulation interactively with the infant, modulating the stimulation by reading the infant's communication of tolerance levels and preferences for the sensory stimuli. This component adds a more natural interaction between the caregiver and infant and facilitates the caregiver's understanding of the infant's behavioral capacity and potential. The infant-centered focus and SPC of NICU infant stimulation programs are also applicable to impoverished infants and their families, as well as other at-risk subgroups.

For healthy infants, infant stimulation enrichment programs generally include early experiences with classical music, being read to, educational play, home schooling, and participation in organizations such as Parents-as-Teachers. One of the major rationales for infant stimulation programs for both atypical and typical infants is based on the plasticity of the nervous system. Neuroplasticity is the ability of the nervous system to change throughout the lifespan. Research with a variety of species, including humans, indicates that the brain can change (e.g., growth of nerve cells, generation of new nerve cells, increases in neural connections and circuits) as a function of use and experience (e.g., using fingers to learn computer keyboarding, being challenged by enriched and complex environments). The ability of sensory experience to modify the nervous system has been shown to be greater for infants than for adults, because of the high nervous system growth rates already present during early development. There is also evidence that certain sensory experiences are required during important periods for normal development of the nervous system. The visual system, for example, requires "early visual experience" for normal structural and functional development of the visual cortex that enables form and depth perception. Research also indicates that sensory stimulation is important for brain and behavioral development of brain-injured populations. Thus, the importance of infant stimulation is becoming well established; current research questions are focusing on evaluating different types of stimulation, when and how stimulation should be administered, how much stimulation infants should receive and how often, and who is best suited to provide the stimulation, for different infant populations.

Infants, as well as adults, are constantly being bombarded with sensory stimulation during both waking and sleeping hours. Nevertheless, infant stimulation programs seem particularly beneficial for at-risk and disabled infant populations, and these programs continue to be an important focus of clinical and research attention as well as public interest. Although infant stimulation programs often supplement sensory stimulation to counter sensory deprivation, they may also focus on reducing sensory stimulation based on sensory appropriateness.

Modern interest in infant stimulation programs was energized in the 1940s when Rene Spitz showed that long-term hospitalization of infants with little or no stimulation was associated with abnormal behavioral development. Similarly, in the 1950s Harry Harlow showed that monkeys raised in isolation (i.e., without maternal stimulation) displayed abnormal development. These findings, coupled with the relatively long-term hospitalization of sick infants in NICUs, indicated a potential need for infant stimulation programs to promote normal development. However, hospitals and agencies throughout the world differ considerably with regard to their use of infant stimulation programs.

As therapeutic interventions in NICUs, infant stimulation programs became relatively popular in the 1970s. However, these programs began to evolve dramatically during the 1980s, and that evolution continues today. In the 1970s, medical practice was expanding to allow increasing use of infant stimulation programs, especially for infants born prematurely who were isolated within NICUs. This was based in part on two realizations: that the long-term hospitalization of infants born prematurely was generally associated with a high frequency of invasive medical procedures that were disruptive and painful to these infants (e.g., aversive conditioning or learning) and that the general hospital environment was associated with forms of environmental stimulation that were considerably different from those found in the home and family environment. Thus, early stimulation programs with preterm infants were designed to overcome the abnormal sensory environment of the NICU. The earliest programs focused either on mimicking the environment of the womb (e.g., use of water beds to provide for tactile and vestibular stimulation) or on correcting the sensory deprivation or abnormality of the NICU environment. An important finding of early research was that some types of stimulation procedures (including typical medical procedures) could actually be harmful to infants (e.g., producing hypoxemia). Such findings led to major changes in the form of infant stimulation programs. Since the 1980s, and continuing through the present time, programs have been moving away from the simple presentation of unimodal or multimodal sensory stimulation to infants on some arbitrary timing and intensity schedule. In recent years, many infant stimulation programs have moved toward infant-centered and SPC approaches. Another important change, brought about by the movement toward infant- and family-centered care in the NICU, has been the reorganization of the timing of medical procedures and nursing care. Rather than having medical procedures administered to infants at any time throughout the day, these procedures are now grouped together within short periods so that infants can experience longer periods without aversive stimulation and increased time in interaction with caregivers.

Thus, the evolution of infant stimulation programs toward infant- and family-centered approaches is providing infants with meaningful sensory stimulation with a social-psychological component within the NICU environment. Such programs maximize the opportunity for attenuation of aversive sensory stimulation to facilitate optimal growth and development. Future research on infant stimulation programs will include a focus on determining the effects of infant- and family-centered approaches on the short- and long-term development of at-risk infants.

—C. Robert Almli

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INFANTICIDE

The ancient Greeks and Romans practiced exposure, the discarding of unwanted infants. Because it is often assumed that disabled babies were unwanted babies, the issue of exposure is intimately connected to the question of physical disability in the ancient Graeco-Roman world. That the Greeks, especially the Spartans, regularly disposed of newborns with visible physical anomalies was commonly accepted in nineteenth- and twentieth-century scholarship and popular culture. For example, in *Should the Baby Live? The Problem of Handicapped Infants* (1985), Helga Kuhse and Peter Singer write that infanticide was common among the Greeks and Romans, and that the recommendations of the philosophers to destroy defective infants "would not have seemed anything out of the ordinary to their contemporaries" (p. 111). A deeper inquiry, however, reveals that the source material is far too thin to support the drawing of such certain conclusions. More important, it is misleading to superimpose modern social, economic, religious, and military assumptions about the value of disabled people on the ancient world.

The Greek material that discusses or alludes to the exposure of deformed infants is limited, comprising five short passages ranging from the fourth century BCE through the second century CE. Two of these passages are from the works of Plato, and there is one each from Aristotle, Plutarch, and the second-century physician of the Roman imperial period, Soranus. The sources that discuss deformed offspring in the ancient Greek world are too sparse to support the conclusion that the exposure of such infants was standard practice; in fact, there is evidence that children born with disabilities survived. For example, the fifth-century BCE tragedian Sophocles has the chorus in *Oedipus at Colonus* ask

Oedipus if he had been born blind (lines 148–149). Roman primary sources are also scant. Robert Garland (1995) finds instances of "defective" babies' survival, and adds that "there are . . . indications of a somewhat sympathetic attitude towards deformed infants in the Roman Imperial period" (p. 18).

For discussion of the exposure of children with physical disabilities in the ancient Greek world, see my book *The Staff of Oedipus* (Rose 2003), and regarding the Roman world, see Robert Garland's *The Eye of the Beholder* (1995). Good literature on ancient infanticide in general includes articles by Marc Huys (1996) and Cynthia Patterson (1985). Ruth Oldenziel (1987) traces and discusses the secondary literature on infanticide in Greece in her chapter in a collection titled *Sexual Asymmetry,* and John Boswell summarizes the literature for Rome in his book *The Kindness of Strangers* (1988:40–41, n. 96).

Modern assumptions about the economic worth and aesthetic appeal of deformed people, cloaked in the standards of medical health, do not provide an appropriate framework of interpretation for the evidence about the lot of anomalous infants in the ancient Graeco-Roman world.

—M. Lynn Rose

See also History of Disability: Ancient West.

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INFECTIOUS DISEASES

Infectious diseases and disability are intricately linked in terms of both causal relationships and complicating factors. In considering these issues, it is helpful to distinguish between those infectious diseases that cause disability and those that complicate preexisting disability.

Ample evidence links certain infectious diseases to the onset of disability in previously able-bodied individuals. Well-known examples include the profound central motor and cognitive neurological disabilities resulting from viral brain infections (e.g., St. Louis encephalitis and West Nile virus infection) and from overwhelming bacterial infections of the brain and/or its coverings (e.g., syphilis, meningococcal infection, and Rocky Mountain spotted fever). Certain other infections when suffered in pregnancy are implicated as important causes of long-term disability in the neonate, such as the so-called TORCHES group of infections (toxoplasma, rubella, cytomegalovirus, herpes simplex virus, syphilis). A progressive inflammation of the nerves (e.g., an ascending polyneuropathy such as Guillain-Barré syndrome) is often seen as a postinfectious complication following a viral or bacterial infection (classically seen after campylobacter diarrhea). Additionally, some investigators have proposed an infectious etiology for such disabling illnesses as multiple sclerosis, diabetes mellitus, and chronic fatigue syndrome, although these linkages are controversial. Finally, it is important to note the disabling nature of chronic, long-term infectious syndromes such as AIDS, hepatitis C, tuberculosis, and certain parasitic diseases such as filariasis or malaria, which clearly have negative impacts on quality of life and impair sufferers' ability to perform daily activities.

Perhaps more immediate and of greater day-to-day consequence for both patient and clinician is the extent to which disability predisposes individuals to acute and chronic infections. In general, disability serves to impair the normal host's natural defense mechanisms against invasion by microorganisms, thereby increasing the likelihood of colonization and subsequent pathogenic transformation. Integrity of the body is dependent on satisfactory functioning of host defense strategies. When these are impaired, infectious complications commonly develop. Bacterial colonization of normally sterile sites leads to acute and chronic infection. Repeated treatment with antibiotic medications preferentially selects for the persistence of resistant organisms, making future treatment more difficult. Conditions that impair the host immune response (e.g., diabetes, cancer, AIDS) place the individual at increased risk for infection with unusual or difficult-to-treat organisms.

Respiratory, genitourinary, and integumentary systems are most crucially at risk for infection in the disabled, with those structures at particular risk being dictated by the nature of the host disability. For example, clearance of bacterial pathogens from the upper respiratory tract is facilitated by adequately functioning cilia, and individuals with impaired ciliary function (as in chronic obstructive pulmonary disease) are at greater risk for bacterial colonization and development of recurrent lung infections. Genitourinary tract integrity is preserved through the maintenance of urine production and flow through the kidneys, ureters, and bladder. Impairment of flow leading to urinary stasis (as in persons with neurogenic bladder due to spinal cord injury) predisposes the individual to bacterial colonization and urinary tract infection. Catheterization of the bladder is another complicating factor, inasmuch as bacteria adhere to and are introduced into the urinary tract with the catheter. In general, the use of an indwelling catheter presents a greater long-term infectious risk than chronic intermittent catheterization for those patients requiring repetitive bladder drainage. Finally, disability may predispose skin and soft tissue structures to breakdown due to chronic pressure on particular dependent or insensate areas of the body. Ulcerations that develop at these pressure sites are at risk for colonization and invasive infection and may lead to deep-seated infection of underlying structures (e.g., osteomyelitis).

Treatment of infections among the disabled should be tailored to the particular circumstances of the host and should take into consideration the nature of the host disability, the body system involved, the specific pathogen being targeted, and the acute versus chronic nature of the infection. Certain infections, once established, may become very difficult to cure, requiring instead suppressive therapy to control and limit progression. Other infections may require combined medical and surgical approaches to achieve cure. With this in mind, caregivers need to anticipate potential infectious complications and seek to implement preventive measures to avoid serious outcomes.

—Bradley P. Stoner

See also Disease.

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INFERTILITY

Infertility is typically defined as the inability to become pregnant after a year of having intercourse without contraception. The American Society for Reproductive Medicine (ASRM) and RESOLVE, the principal advocacy organization for the infertile, describe infertility as a "disease" that hinders "the body's ability to perform the basic function of reproduction." Ordinarily, however, infertility is considered a *condition* that might be caused by one or more diseases. In women, some examples of such diseases are endometriosis (in which the tissue that lines the uterus grows outside the uterus), polycystic ovary syndrome (in which the follicles in which the woman's egg is enclosed mass together to form a cyst, and no mature egg is released), and premature ovarian failure (in which a woman under age 40 no longer produces ova). Among men, infertility can result from mumps experienced after puberty, certain infections (e.g., prostatitis, orchitis), and diseases of the pituitary or hypothalamus, all of which can reduce or destroy the capacity to produce sperm. Various testicular injuries as well as chromosomal abnormalities and those of the testes, such as cryptochrodism (failure of the testes to descend into the scrotum), cancer, and direct trauma, are also among a range of conditions that can cause male infertility. Infertility is distinct from surgical sterilization, which was once used as a form of state-sponsored social control, but today—at least in the United States—is more often a voluntary procedure.

The term *infertility* is of relatively recent origin. American colonists in the seventeenth and eighteenth centuries used the word *barrenness* to describe the inability to bear children. Only a woman could be barren; any man capable of sexual intercourse was automatically deemed fertile. In the nineteenth century, especially as gynecologists became more prevalent in treating the condition, the term *sterility* came into common use. The terminology was important; *sterility* conveyed the growing medical conviction that men as well as women were affected. As early as the 1860s, a few physicians advocated the microscopic analysis of semen, and by end of the nineteenth century several prominent gynecologists began to urge husbands to be tested, although many men refused to subject themselves to what they considered an outrage against their masculinity. *Infertility* gradually replaced the older term in the 1940s and 1950s, as optimism about treatment soared. Most experts currently believe that about a third of infertility cases are caused by conditions that affect men and another third are caused by those that affect women, with the rest attributable to both halves of the couple. About 20 percent of cases, overall, remain unexplained.

Authorities nowadays generally agree that infertility affects about 10 percent of the population. In spite of a widespread perception that infertility rates rose dramatically in the late twentieth century, the 10 percent figure is consonant with estimates made in the late nineteenth and early twentieth centuries. The national fertility studies begun in the United States in 1965 put the infertility rate at 11.5 in the 1960s and 8.5 in the 1980s, albeit with a rise in primary infertility and a decline in secondary infertility. (*Primary infertility* is the term used to describe those couples who have never been able to conceive or carry a pregnancy to term. *Secondary infertility,* once called *one-child sterility,* describes couples who have borne children but are no longer able to do so.)

Most cases of infertility are treatable by conventional medical techniques, including surgery, artificial insemination (practiced since the nineteenth century), and the use of ovulation-inducing therapies. However, an estimated 15–17 percent of the infertile make use of assisted reproductive technologies, 99 percent of whom undergo in vitro fertilization using their own or donor eggs. In vitro fertilization may be accompanied by ICSI (intracytoplasmic sperm injection), a technique that seeks to compensate for male subfertility through the injection of a single sperm directly into the woman's egg. Whether the treatment is low-tech or high-tech, about two-thirds of the infertile are able to achieve biological reproduction. The other third may circumvent their condition through adoption or surrogacy or learn to live with it.

Infertility can have profound social, cultural, and psychological effects on those who have the condition. Societies everywhere assume that women want to become mothers, and women who choose not to have children, or who fail to express maternal feelings, frequently face social opprobrium. In turn, those who long for children and are unable to bear them often feel that they have been denied a fundamental right, the "right" to reproduce. Although infertility affects men just as often as it does women, social scientists have discovered that women in infertile unions often find their situation intolerable, a threat to their fundamental identity as women. Men, in contrast, tend to be disappointed but not devastated. Many who fruitlessly yearn for children often internalize a profound feeling that their bodies have betrayed them. In this sense, then, infertility might be viewed as a psychological disability as well as a social and medical condition.

—Margaret Marsh

See also Gender; India, Impact of Gender in.

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INFORMATION TECHNOLOGY

Information technology (IT) may be seen as both enabling and disabling. From the earliest days of computers, people with disabilities have been integrally involved with this technology, yet it has continued to be shaped by nondisabled norms. As computers and other IT developed and became ubiquitous features of work, education, home, and everyday life, they developed a profound role in the shaping of ability and disability. People with disabilities began to make their mark as users of IT with the advent of the personal computer (PC), although the accessibility of the technology was limited. Although accessibility has increased, barriers remain, and new forms of IT have been disabling as well as enabling. Disableism is ever present in the ideologies, structures, and power relations that are part of, and inform, IT. Nondisabled designers often incorporate disability in the technology through taken-for-granted norms.

THE RISE OF THE PERSONAL COMPUTER

The early computers that featured in the advent of commercial computing after World War II operated with punch cards, which required of users the manual dexterity associated with card readers and other input devices. Herman Hollerith, who devised the punch cards used for processing and tabulating data in the 1890 U.S. Census, is said to have had great problems learning spelling, something that might be regarded today as a learning disability. In 1896, Hollerith founded the Tabulating Machine Company, which later became International Business Machines (IBM).

In the early 1970s, the invention of the microprocessor displaced both mainframe and minicomputers and led to the rise of the personal computer in 1974–1975. The PC's development paralleled the increasing role of IT in everyday lives. The basic PC unit was built around particular norms of design, code, and input and output, requiring people to conform to those norms. The PC needs of people with disabilities led to a set of contests regarding three key technologies: hardware, operating systems, and applications.

Specialized assistive technology, both hardware and software, emerged for people with disabilities. This showed the potential range of input and output devices that could be used in conjunction with computers, such as Braille embossers to create documents readable by blind people and hardware and software for speech synthesis (e.g., the 1976 Kurzweil Reading Machine). Yet such developments also raised the political and practical question of whether disability demands special or mainstream solutions. The consumer and disability movements took an early lead, for example, when they formed the Committee on Personal Computers and the Handicapped in Illinois in 1981.

Breakthroughs in the accessibility of mainstream computing proved elusive. Apple introduced the Macintosh computer in 1984, and although many acclaimed its graphical user interface as user-friendly, and it greatly influenced the development of its now ubiquitous Windows counterpart, for some users with disabilities, such as blind users, it was not ideal. However, Macintosh took an early lead in incorporating accessibility into its operating system.

In contrast to the graphical interface, the MS-DOS operating system was a text-based platform that worked in conjunction with text-based programs such as early versions of Word and WordPerfect. Computer users who were blind or vision impaired could use screen readers that would speak the text of DOS files.

Many hailed Microsoft's relatively late introduction of a graphical user interface with Windows (especially its successful 1990 Windows version 3) as a breakthrough, but blind and vision-impaired users viewed it as a great threat. The move from text-oriented DOS-based to graphical Windows-based computer operating systems resulted in serious losses in access and jobs for persons using speech or Braille for communication.

Corporate initiative alone was not sufficient to stimulate the development of products to increase IT accessibility for people with disabilities, so activists used other strategies, such as lobbying for legislative protections. One result was the inclusion of IT requirements in the Americans with Disabilities Act (ADA) of 1990. Also critical was Section 508 of the 1973 Rehabilitation Act, which requires that information technology procured, developed, maintained, and used by federal agencies must be accessible to people with disabilities unless such requirement imposes an undue burden. Effectively, U.S. federal and state governments could use their purchasing power to encourage companies to make IT accessible. Activists in Massachusetts took the lead, lobbying the state government to use Section 508 to require the purchase of accessible computers.

The IT industry took several years to develop adequate accessibility strategies for Windows software, with little interest among mainstream software developers. In the early 1990s, Microsoft had only one person working on accessibility issues. Even as late as 1998, the company shipped Internet Explorer 4.0 with fewer accessibility features than had been in the previous version. The disability movement had to fight pitched battles with Microsoft before the company began to incorporate accessibility features in its operating systems and programs.

Despite positive corporate moves in this area, accessibility remains a threshold issue. Accessibility is vital for the incorporation of people with disabilities into computing technology, and thus the information society.

COMPUTER NETWORKING

The networking of computers through telecommunications to share resources, exchange data, and facilitate communications developed from the 1960s. In the 1980s, with the growth of bulletin boards, private networks such as America Online (AOL) and Compuserve, and the spread of the Internet, people with disabilities started to communicate and to share computer files online. Blind people as well as other people with disabilities were among the early Internet pioneers.

Disability accessibility has been a key issue for networked IT. In one important test case, a group of blind people invoked the ADA to force AOL to adopt accessibility measures. After requesting that AOL provide accessible Internet services for a number of years, the National Federation of the Blind filed suit against AOL in November 1999. Negotiations commenced, and the suit was suspended in July 2000 when AOL agreed to make its software accessible by April 2001.

Accessibility has been an integral feature of the design and deployment of the World Wide Web since the launch of the World Wide Web Accessibility Initiative (WAI) in April 1997. The WAI has raised the level of awareness of disability accessibility issues within the Internet community, especially among those who design and implement web pages. In principle, information on how to make web pages accessible is easily available—online. W3C is a consortium of organizations that work together consensually and issue recommendations regarding online accessibility. However, it is left to others to implement those recommendations, and many organizations do not. Hence the accessibility of the Internet for people with disabilities remains quite precarious (as is illustrated by the 2000 case of *Maguire v. Sydney Organising Committee for the Olympic Games*).

IT EVERYWHERE

IT has become pervasive in everyday business and private life in developed countries, and it is arguably a more subtle form of colonization in developing countries. Computer processors feature not only in PCs and modems, but also in media and communications devices (from televisions and radios to personal digital assistants, cameras, and mobiles), household appliances (refrigerators, ovens, alarms, lights, heaters), cars, and clothes (wearable computers). The average home in the twenty-first century is soon likely to contain hundreds of computer processors, with many of these devices likely to be connected to computer networks.

Information technology now actually has impacts on every major form of technological system utilized in Western society, incorporating norms that are rarely critically examined. The vision of the “smart home” and the “information society” is slowly being realized, and the convergence of the different sorts of IT involved presents important disability-related issues. To date, some IT companies, designers, and policy makers have reluctantly gained an understanding of the diverse expectations and needs of various people with disabilities. As IT is increasingly woven into the fabric of everyday life, accessible technology becomes all the more imperative because other alternatives may disappear. A further difficulty lies in the proliferation of different IT devices and applications, only some of which incorporate accessibility.

DESIGNING IT FOR DISABILITY

People with disabilities are often mentioned as being among the primary beneficiaries of IT, yet more often than not they are actually neglected in IT development. Sophisticated use of IT is providing smart homes and enabling lifestyles for people with severe disabilities, but such technology remains costly for individuals and society. In general, the potential uses of IT by people with disabilities are not systematically incorporated into the design, implementation, and marketing of IT products. Accessible IT still tends to be achieved through costly and tardy specially built solutions and retrofitting rather than through development that envisages disabled users and builds accessibility into mainstream design. Some innovative work has occurred around disability and design, including under the banner of universal design, but the issues of designing IT for all people with disabilities are complex, requiring an integrated approach, from invention and standards setting to manufacturing, procurement, promotion, marketing, product delivery, and training.

—Gerard Goggin and
Christopher Newell

See also Accessibility; Accessible Internet; Assistive Technology; Augmentative Communication.

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INSPIRATION

Inspiration is a popular-culture ritual that signifies the partial, ambivalent identification of normals with disabled people based on the willful “overcoming” of the putatively devastating effects of disability. In ubiquitous, stylized media stories presented by and for a normal perspective, disabled people are held up as (pseudo-) role models for refusing to quit against the overwhelming odds assumed to be posed by their own disabilities; rather, inspirers courageously mobilize their wills to superhuman heights, persevere, and overcome their disabilities, thereby pointing to and proving the existence of the “power of the human spirit.” Neither the specific activities themselves nor the skill with which they are performed is important to the inspirational relation, which can be invoked any time normals encounter disabled difference. Disabled people may thus be marked as inspirational for any participation whatsoever, from mountain climbing while blind to playing the piano with a mental illness diagnosis to shopping while using a wheelchair. All such activities represent the contradiction of patterned social expectations, namely, that the “normal” response to disability would be bitter, angry surrender.

To *inspire* literally means to “breathe into” another person, to have an animating or exalting influence on, and the concept of inspiration surely exists in some form in all societies. Traditionally, inspirational forces were traced either directly or indirectly back to the divine, but the secularizing trends of modernity have centered the unified, self-directing will of the individual. Stories about inspirational role models (e.g., Martin Luther King Jr., Mother Teresa) stand in for the divine in their selfless transcendence for the common good. Identification with such inspirers supposedly allows admirers to achieve by overcoming resistance, both external and internal.

Disability inspiration became prominent in the twentieth century and appears (its history has not been written) to draw on facets of nineteenth-century Victorian sentimentalism and the ideology of the freak show. From the latter, inspiration preserves conformist normality's horror before otherness—indeed, it collapses without it—along with an identificatory fascination regarding "How do they do it?"; from the former, it continues the narcissistic self-congratulation of beneficence before social inferiors while subtly shifting its point of identification from empathic understanding to willful overcoming.

In its valorization of a similar, if extraordinary, human will thought to reside within its objects of admiration, disability inspiration reflects a generalized advance in social status for people with disabilities. Although cross-cultural comparisons await, it would seem unlikely that disability inspiration can exist in societies in which disability presents as uniformly and overwhelmingly negative.

Nevertheless, as scholars such as Paul Longmore (2003) and Beth Haller (1999) have noted, disability inspiration places a drag on the quest for equality: It functions to deny *social* oppression by individualizing disability and maintains deviance by presuming an inability that must be "overcome" through "supercrip" achievement. Disabled people tokenized as inspirational also become ideological hammers against the rest of the group, for if one can succeed, why can't the rest? Inspiration is thus fundamentally reactionary and works against political solutions. In the end, inspiration reveals itself as a relationship of bad faith, wherein what disabled people supposedly overcome is precisely what has been done to them in the first place.

—John B. Kelly

See also Normality; Normalization; Representations of Disability, Social.

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INSTITUTIONALIZATION AND SEGREGATION

The writer Jack London once noted that "the chief horror of leprosy obtains in the minds of those who do not know anything about the disease." The same can be said about many conditions that affect the ordinary physical appearance of a person and confer visible physical distortions in the body together with obvious physical disabilities. In this entry, leprosy, particularly in colonial South India, is used as a context within which the characteristics of institutionalization and disability are examined.

LEPROSY AND DISABILITY

Knowledge about leprosy and the reasons for the physical damage it can cause has increased significantly since the late nineteenth century, although much about the illness remains a mystery. *Mycobacterium leprae,* the bacillus that causes leprosy, was discovered in 1873 by Gerhard Henrik Armauer Hansen, from whom the common name for leprosy, Hansen's disease, comes. Even so, the action of the bacteria was not understood until medical science advanced further in understanding the role of bacteria in causing illness and even disability. The advent of sulfa drugs in the 1940s offered the first effective medical cure for leprosy. However, the emergence of drug-resistant strains of the disease by the 1960s swiftly returned leprosy to the status of an intractable illness. Only with the development of a consistently effective form of multidrug therapy in the 1980s did a cure for leprosy again become viable.

Owing to the persistent difficulties with the diagnosis and treatment of leprosy through to the 1980s, together with the physical disfigurement and accidental damage to limbs anesthetized as a consequence of the body's immune response to the disease, those with leprosy have tended also to suffer disabilities.

In the context of modern rehabilitative medicine and occupational therapies, leprosy has been studied as a cause of physical disabilities that can to some extent be minimized and managed even if not entirely remedied by treatment and physical therapy. Typically, a person with leprosy experiences a range of physical disabilities according to the type, severity, and duration of the illness. The hands often become clawed as fingers are foreshortened and lose sensation, resulting in loss of fingers through ulceration and accidental damage. Similarly, feet lose nerve sensation, and bones and joints deteriorate. Toes and even whole feet can be lost through accidental damage and ulcerating infection. It is not unusual for a person with leprosy, particularly when left without treatment or care, to have only stumps where hands and feet once were. Damage to eyes, nose, and palate also occurs in some forms of the disease, inhibiting and even destroying the capacity for sight, smell, and speech.

Stigma

In many, although not all, societies and times, those suffering from leprosy, like those with many disabilities, have been stigmatized because of their physical appearance. The external manifestation of leprosy in facial deformity, loss of limbs, and blindness has made the leprosy sufferer vulnerable to social ostracism and segregation from the economic, religious, and domestic life of their communities. During the nineteenth century, horror at the appearance of leprosy sufferers contributed to the establishment of systems for the isolation and segregation of those with the disease as much as did concerns about the contagiousness of the illness.

Segregation

Segregation and institutionalization of leprosy sufferers has occurred in a variety of countries throughout the history of the disease. The Hawaiian island of Molokai, where Father Damien lived and died among the leprosy sufferers, and the later island settlements of Makogai in Fiji, Peel Island off the Queensland coast of Australia, and Quail Island in New Zealand's South Island port harbor of Lyttleton are all famous examples of state efforts throughout the late nineteenth and twentieth centuries to segregate leprosy sufferers completely from the world. In each of these instances, the response to leprosy of the indigenous population was not necessarily the same as that of the white colonial or settler government. However, principally because of settler fear of contagion and the horrific appearance of those suffering the disease, complete physical separation and confinement of leprosy sufferers within the physical space of an island was believed necessary.

Institutionalization

Dedicated residential care for leprosy sufferers in institutions, often termed *asylums* in the nineteenth century, was also a typical response of colonial authorities to the disease. It was not, however, unique to British and other colonies. In the United States, a national leprosarium was completed in 1922 at Carville, Louisiana, on the Mississippi River to provide the best available medical treatment, rehabilitation, and assistance in living for those disabled by the physical effects of the illness. Built on 4,000 acres of land, it also provided accommodation as effective as the island settlements in segregating those with leprosy from the larger community.

Attempts to institutionalize leprosy sufferers occurred in a broader social as well as medical context. Systematic confinement of the sick, including leprosy sufferers, and the creation of *cordons sanitaires* to contain disease were the results of plague experience in fifteenth-century Europe. In nineteenth-century Europe and America, prisons, mental hospitals, workhouses, and almshouses emerged concurrently, providing, in an age of reform and social change, apparent solutions to both the social problems of crime and disorder and the demands of charity. Although in the late eighteenth century the doctor Philippe Pinel in Paris and the Quakers in Northern England instigated supportive care as an alternative to incarceration of the "insane," institutional confinement prevailed as the preferred medical and social means of managing those perceived as "deviants and dependents"—that is, people who did not conform to social and economic "norms."

The French intellectual Michel Foucault (1975, 1988) has written on marginalization and the confinement of ostracized groups, including leprosy sufferers and the insane. The value of Foucault's work lies in his invitation to consider the symbolic significance of those who are excluded and marginalized and to understand confinement as a logical progression from other forms of complete isolation, such as island segregation. Through Foucault's eyes we are drawn to see institutional confinement and isolation more as a consequence of the symbolic status of the poor, the leprosy sufferer, the mentally ill, and the criminal than as any direct result of a societal concept of the best way to provide economic or medical care or administer justice.

The rise of institutions in the nineteenth century reflected not only changes in psychiatric and social thinking but also greater reliance on government and law, rather than private philanthropy and religious organizations, to resolve social problems. A strong relationship developed between the provision of residential facilities for health care and administration of justice and the emergence of legislation compelling both quarantining of the unfit and institutional confinement.

INSTITUTIONAL CONFINEMENT OF THE DISABLED

Leprosy Sufferers in Nineteenth-Century South India

In the light of contemporary medical understanding, the physical disability of leprosy sufferers is seen as the effect of leprosy but not essential to the disease. This has not always been the case. In nineteenth-century India, for example, leprosy was conceptualized in traditional Hindu and colonial British culture as both disease and infirmity. Both Hindu and British concepts of infirmity included those suffering physical disabilities such as blindness and lameness as well as those with physical signs of leprosy. It is the historical position of the leprosy sufferer as infirm/disabled in both the Indian and British traditions that makes a focus on the experience of the leprosy sufferer in colonial India suitable for this exploration of the confinement and institutionalization of those with disabilities.

Not all physical infirmities attracted confinement and institutionalization in colonial India. Although the Lepers' Act, a form of vagrancy legislation, was passed in 1898 to enforce the confinement in asylums of leprosy sufferers who were poor and vagrant and thus visible on the streets, others who were vagrant and lame, deaf, or blind (the principal forms of disability recognized in both colonial and Hindu Indian culture) were not similarly targeted. The legislation, developed after years of debate, was virtually impossible to enforce, but it did confirm the tenor of nineteenth-century social, medical, and governmental thinking on the social status of the leprosy sufferer in India.

Vulnerability to confinement was not a consequence of the disability itself, nor even of the contagiousness of the leprosy causing the disability, but of societal perception of the disabled. In the case of leprosy in India, the fact that the condition was incurable raised for colonial government and medical authorities the issue of contagion as a factor in their decision making concerning whether or not leprosy sufferers should be confined. Ultimately, however, socioeconomic issues were the deciding factor. The vulnerability of leprosy sufferers to institutionalization increased as their socioeconomic status declined. Despite being known to run the highest risk of spreading infection, those who lived and were supported within their families or were still able to earn their own living were not the subject of legislation. Rather, the poor and vagrant, those who posed the least risk of communicating infection through close personal contact, were targeted. Those who were so disabled that they were not able to support themselves became the subject of police and, later, legal attention.

Further, part of the justification for removing leprosy sufferers from the streets had less to do with health than with aesthetics. Leprosy sufferers, ravaged in appearance by the disease, were considered offensive to the eye and disturbing by both Indian and British in the colony. The value of the disabled leprosy sufferer was thus measured in both socioeconomic terms—according to his or her place in the family and capacity to earn a living—and aesthetic terms. While often arousing compassion, the horrific physical appearance of the leprosy sufferer resonated strongly with British concepts of morality and stigmatizing illness and with Hindu ideas of the karmic responsibility of the individual for his or her condition. For both leprosy sufferer and the community, the physical degradation of the body was felt to reflect a deeper spiritual and moral decay.

The Nature of the Institution

The government institutions developed for leprosy care in nineteenth-century colonial India could not be termed *total institutions* in the sense defined by the sociologist Erving Goffman (1987). Rather than the complete separation of patients/inmates from family and community ties—an essential element of Goffman's concept of the total institution—these institutions featured constant interaction between patients and their families and the outside world. Although visiting hours were restricted at the Madras Leper Hospital, patients were permitted to leave the hospital, and there was little restraint on their continued social and personal interaction. As the hospital's surgeon in charge noted in 1889, some aspects of family life remained. Husbands and wives could visit each other, and many babies were born to inpatients.

Even so, tension and confusion existed concerning the true nature of these institutions, whether they were hospitals for patient care or prisons to ensure the confinement of a diseased and disfigured population. Linked with these issues was ambivalence over the status of leprosy sufferers, whether institutionalized individuals were patients or prisoners.

The issue of compulsion was never far away from attempts to institutionalize leprosy sufferers, and it aroused complex intercultural and class-related questions concerning the nature of medical care and the purpose of segregation. India was not acculturated to any form of institutional care for the sick or disabled. Rather, the family and community, supported by religious beliefs and indigenous medicine, were the context for care. Thus, any form of institution, even where compulsion to remain was not a factor, could be perceived as a prison. The building of the Madras Leper Hospital in 1816, with its high surrounding wall, made fear of imprisonment in the hospital inevitable.

Experience of Institutions

Despite considerable confusion as to whether the leprosy asylum was a prison or a hospital, until the passage of the 1898 Lepers' Act, there was no law in India under which leprosy sufferers could be forcibly confined in institutions. The difficulties in implementing the act meant, however, that enforced institutionalization was the experience of only a few with leprosy, notably those who were also imprisoned for criminal offenses and occupied the Leprosy Hospital at Port Blair in the Andaman Islands penal colony and, later, the Criminal Leper Ward of the Madras Leper Hospital. For most leprosy sufferers, institutionalization was a temporary experience that they resorted to by choice to obtain food and shelter when family and friends were unable to support them and destitution overcame them. The hospital was rarely seen as a place for cure, although at times rumors of leprosy cures did bring people into the hospital.

The ambiguous status of leprosy sufferers living in institutions had implications for their experience of institutional life. Some climbed the wall to escape the Madras Leper Hospital, not realizing that voluntary departure was an option. Medical staff were well aware of the voluntary nature of institutionalization, however, and in the interests of attracting and retaining patients for long enough to at least improve their physical condition, they tried to make hospital life acceptable and even appealing.

Hospital staff recognized that incentives were necessary, not just to lift patient morale and encourage compliance with the treatments available, some of which were painful and unpleasant, but to prevent leprosy sufferers from leaving the institution for the more stimulating, if hazardous, life of begging, pilgrimage, and relative freedom. Patients who had families to support and crops to tend found it impossible to enjoy the benefits of hospitalization for long. The need to find money and food, even by begging, and the seasonal demands of cultivation and harvest made flight from hospitals a necessity for the survival of the whole family.

Institutions made considerable efforts to meet the spiritual and cultural needs of leprosy patients in order to encourage them to stay. South Indian institutions made provisions to enable patients to practice their religion and for patients of different castes to live according to their cultural requirements. Generally, the staff of leprosy institutions recognized the tedium and routine irritations of hospital life, and to counteract this, in some hospitals they encouraged patients to cultivate plots of land and to sell for their own profit any garden produce they could raise.

Living conditions for those with leprosy in institutional care were generous in comparison with what was available to other hospital populations. Basic clothing, fuel for fires, and lamp oil enabled patients to follow ritual practices and to cook for themselves according to caste rules if necessary. A diet rich in protein and fats was provided, with the additional luxuries of betel nut to chew and tobacco allowances. The generosity of the diet was matched, however, by its monotony. In 1878, in an incident that indicates the negotiating power of the patients within the institution, Indian patients at the Madras Leper Hospital convinced the surgeon in charge that the benefits to patient happiness, improved discipline, and greater treatment compliance would far outweigh the additional cost of providing greater variation in the evening meal.

As noted above, patients were free to leave the Madras Leper Hospital; however, certain areas of discipline were enforced with the threat of discharge. Patients were permitted only hospital food and were forbidden to give food away or to take food out of the hospital. Similarly, except in cases where patients were bedridden, smoking was not permitted in the wards. Generally, discipline was in place to maintain the routine working and safety of the institution and to ensure that patients received the benefits of good food, treatment, and healthy activity rather than to coerce or demean them. Even so, staff sometimes applied pressure to patients to enforce cooperation, using the threat of reduced privileges or diet.

The agency of the patients within the Madras Leper Hospital in the face of such pressure is evident in the action taken by a group of inpatients in 1873 in protest against a request from the surgeon in charge that they take on some work, including light labor, tailoring, and running messages. The surgeon considered such work to be both a beneficial diversion for the patients and a means of reducing the need for salaried help in the hospital. The rebel group disagreed, however, and, given the ultimatum of compliance or reduction to a "spoon diet"—broth for the European patients and rice porridge for the Indian—left the hospital to take their protest directly to the local magistrate at the Madras Town Police Office. The magistrate heard their complaint but upheld the surgeon's request. The patients returned to hospital and took up the work, having asserted both their freedom to leave without restraint and their right to negotiate, even if unsuccessfully, the types of conditions under which they wished to receive treatment in the institution.

FUTURE DIRECTIONS

In the last decades of the twentieth century, institutionalization again became less attractive in the "developed" world as a means of managing issues of health and justice. The decline in the growth of institutional "solutions" has as much to do with the often high capital value of institutional land and the costs of institutional care as with shifts in ideological and cultural understandings of the benefit of institutions to either the individual or society. Disability care has followed the trend of deinstitutionalization, although leprosy care in India has been slower to follow suit.

In "developed" countries today, individuals with moderate to severe disabilities are more likely to receive government or insurance funding for independent living within the community than to be offered institutional care. The movement away from institutional care toward independent living has been further supported by public advocacy through disabled support groups, increased government awareness, and the development of antidiscrimination legislation. Individuals with disabilities have also benefited from technological advances in computers and other devices designed to assist in daily life and work as well as from developments in physical and occupational therapeutics. Today, public perception of disability is moving toward recognition of those who face its challenges as worthy of respect and admiration rather than as requiring separation from society and community in institutions.

—*Jane Buckingham*

See also Deinstitutionalization; Experience of Disability: India; Inclusion and Exclusion; Stigma.

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INSURANCE

See Risk and Risk Selection Related to Insurance

INTERDISCIPLINARY TEAM

Within the medical model of disability, clinical activities have been broken down into professionalized disciplines, such as nursing, occupational therapy (OT) and physical therapy (PT), and social work. The interdisciplinary team is a managerial concept that has as its goal the efficient execution of care by team members through cooperation, communication, and identity as a unit within a larger structure.

Currently, four models of "team" dynamics exist: (a) the strict medical model, in which the physician maintains all authority for both communication and referral to "team" members in a strictly vertical hierarchy; (b) the multidisciplinary model, in which the physician coordinates all communication, usually vertically, but occasionally horizontally, among consulting services (e.g., PT, OT); (c) the interdisciplinary model, in which communication takes place laterally between consulting services as well as vertically through the physician; and (d) the transdisciplinary model, in which individuals are trained in several disciplines, encompassing their own interdisciplinary team. Each model has disadvantages and advantages, and consequently each is valuable in some situations but not in others. Too little research has been conducted to allow an "objective" delineation of the differences.

The "team" has traditionally followed the hierarchical medical model, with the physician "leading" it, but recently broader social shifts have made the pyramid of authority less vertical, encompassing interdisciplinary and transdisciplinary models. The concept of the team is based on a Western model, and so it is examined here in that milieu.

The idea of an interdisciplinary team necessitates the existence of disciplines. In the West, medicine—the area of expertise of the putative leader of the medical team, the physician—appeared as a discipline during the high Middle Ages. With the birth of the medical universities came an increasingly verticalized pyramid of authoritative health care. Physicians, in concert with civil and religious authorities, often sought out means to regulate broader medical care. From its inception, physician-coordinated regulation also implied that the physician would be working with other kinds of health care providers. Nursing, too, had its start in late antiquity and the Middle Ages, although the modern incarnation of nurses as professionals dates at the latest from the 1860s, when Florence Nightingale, the "Lady-in-Chief," applied statistical and managerial techniques to create a nursing hierarchy. This movement established nursing "teams" inside broader medical teams. Within nursing, the "team" concept has remained an especially potent paradigm from Australia to the United States. Social workers, occupational therapists, physical therapists, dieticians, psychologiss, and others joined the ranks from the last quarter of the nineteenth century into the late twentieth. With such a panoply of disciplines, it is not surprising that the concept of the interdisciplinary team did not become formally voiced until the mid-twentieth century.

Similarly, a location for these workers to come together and function as a team in actuality was not necessitated until the rise of the modern hospital. An early form of the hospital started in antiquity and got on its feet during the Middle Ages; the hospital reached its apotheosis at the end of the nineteenth century and the beginning of the twentieth. The hospital as the home of the operating theater, expensive equipment, and the locus for controlling patients and staff has been particularly nurturing to this form of organization.

In the English medical literature, at least, during the nineteenth century it was uncommon to find the word *team* unless in reference to accidents occurring with runaway horse teams. By the first two decades of the twentieth century, even before World War I, the term appeared most frequently in reference to surgical teams, although Cooter (2004) suggests that it entered medicine from social work through Harvard physician Richard Cabot's 1909 book *Social Service and the Art of Healing.* The war certainly accelerated diffusion of the team concept into the medical profession through the experience with military organization. Thereafter, it appeared in literature from psychiatry to general practice to dentistry to public health to hospital ward care, finding particularly fertile ground in anesthesia and the surgical suite. World War II enhanced that association. By the 1960s, medical literature was rife with descriptions of psychological and sociological characterizations of medical team dynamics from the operating room to the schoolroom. Increasingly, too, business-oriented management techniques and educational concepts have infiltrated the military connotations.

In rehabilitation care, particularly in institutions, the team model also became popular. The metaphorical power of the body's systems working together as a "team" often entered the language of early advocates of team care, such as the pioneering British orthopedist Robert Jones (1857–1933). As it was used in the 1920s and 1930s, the word *team* was applied equally to groups of people with disabilities working together and to health care professionals providing multidisciplinary care. In the late 1940s and early 1950s, however, physiatrists increasingly employed this concept to describe their role in rehabilitation. They envisioned directing the many multidisciplinary ("integrated") activities of the health care providers surrounding those with disabilities. It became one more tool in their professionalizing armamentarium.

To take a specific example, in pediatric care, the rudiments of the team model undoubtedly started in the mid-nineteenth century in institutions such as the Hôpital des Enfants Malades in Paris and the Great Ormond Street Children's Hospital in London, among others. The laicization and professionalization of nursing and the creation of training programs specifically in pediatric nursing reinforced this process. In the first third of the twentieth century, medical care providers for children with cerebral palsy included physicians, social workers, nurses, teachers, psychologists, and therapists. The full model, if not the term, was pioneered in New York through the Society for the Ruptured and Crippled and in Boston at the Children's Hospital. The stated goal of these pioneers was usually the reintegration of the child into an educational setting; this necessitated work with teachers as well as with early social workers to apply new techniques in social engineering. Developmental psychology, which was becoming increasingly influential in the clinics, in research halls, and in the popular press, also demanded that pediatricians work alongside psychologists. In the eyes of some interdisciplinary pioneers, the inherent dependence of the developing child, with or without disabilities, necessitated careful coordination among professionals.

By the middle of the twentieth century, interdisciplinarity became the founding mantra of professional organizations such as the American Academy of Cerebral Palsy, was the subject of testimony before the U.S. Congress, and inspired celebratory articles in the lay press about patients who had been saved by the team process. Governmental agencies sponsoring both clinical research and health services redesign also began sponsoring team models in the last half of the century.

In the United States this occurred through the Veterans Administration and eventually Medicaid/Medicare; in the United Kingdom it took place through the National Health Service. U.S. national accreditation standards now require that rehabilitation facilities maintain interdisciplinary teams. Multidisciplinary clinics, however, in which multiple specialists saw children with disabilities simultaneously, offering families efficiencies of time, were rejected by U.S. governmental reimbursement models in the late 1980s.

In some measure, the impulse of the clinical team model paralleled the growth of ever-specializing "team science" in the biomedical sciences. Since the mid-nineteenth century, the reductionist style of laboratory science provoked knowledge production models in which workers (technicians and students) are supervised by the manager (the scientist). The parallel processing inherent in the system increased productivity, but it also sparked many of the false steps of capitalist production models in general. In physiology, for example, conflicts at times arose around the team or "factory" model, in which there are many laborers but one person gets the credit. Thus, Ivan Pavlov's candidacy for the Nobel Prize in physiology was hampered by the Nobel committee's concerns about who really generates knowledge in a large laboratory model.

In the clinical realm, at times, physicians have directly altered the constituency of teams, even at the level of redirecting already established disciplines. Thus, in a highly resource-rich rehabilitation network in Brazil the directors have favored developing their own in-house universal therapist, replacing the traditional occupational, physical, and speech-language therapists while creating new managerial flexibility outside the bounds of traditional disciplinary teams.

As a management paradigm, the team has proliferated, from the transplant procurement team to the hospital restructuring team to the palliative care team, all joining the surgical and rehabilitation teams. However, the application of the term *team* in multiple situations has also given it a protean expression, sometimes valuably. For example, in many settings, the "patient" has finally joined the model formally as a nearly full participant in his or her care and in the literature about team dynamics. In addition, the pressure of, for example, interdisciplinary team structures has led to a change in language—from "prescriptions" written for PT and OT, implying a hierarchical status, to "referrals," implying a coequal relationship. Although the *Oxford English Dictionary* still includes a definition of "team" as yoked beasts of burden, health care systems and organizational centers widely advocate the use of "teams" for their part in reducing the burden borne.

—Walton O. Schalick III

See also Models; Occupational Therapy; Physical Therapy.

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INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH (ICF/ICIDH)

Since its creation in 1947, the World Health Organization (WHO), based in Geneva, Switzerland, has had the mandate of collecting information about the health of populations around the world to provide input into public health policy. Although the collection of information on causes of death that the WHO undertook initially was useful for calculating life expectancies, the organization recognized early on that information about the lived experience of health would be valuable, and in particular data about levels of functioning in all areas of life. Given the WHO's very broad definition of health ("a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"), the collection of complete functional status information was considered to be fully within its mandate. Because functional status is continuous rather than dichotomous, unlike mortality, collecting this information required sophisticated assessment and measurement instruments. But first, a classification of kinds of human functioning was needed, as well as a conceptual map of the complex domain of functioning. These needs led, by 1976, to the initial draft of the WHO's International Classification of Impairments, Disabilities, and Handicaps (ICIDH), a groundbreaking and controversial classification system tentatively released for trial purposes in 1980.

ICIDH (1980)

In the ICIDH, "disablement" (the overall phenomenon of decrements in human functioning) was modeled as a sequence of levels of health experience flowing from disease, trauma, mental illness, and chronic or age-related health conditions. An initial pathological change may lead to awareness of an impairment, defined as "any loss or abnormality of psychological, physiological, or anatomical structure or function." Impairments involve parts of bodies or body systems; they are temporary or permanent differences of structure or function. If an impairment adversely affects a person's range of activities, then the person is said to have a disability, defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." Finally, impairments and disabilities may disadvantage the individual by limiting or preventing the fulfillment of six "survival" roles: orientation, physical independence, mobility, occupation, social integration, and economic self-sufficiency. When that happens, the negative social consequences—that is, the social disadvantages of being a person with impairments and disabilities—constitute a handicap, defined as "a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual."

The drafters of the ICIDH wished to incorporate the insights of what is often called the social model of disablement without losing sight of the fact that the concept of disability is grounded in the biomedical reality of impairments and, ultimately, background health condition. They were fully committed to the view that both the existence and the experience of disabilities and handicaps are created in part by the social and physical environment in which the individual lives. The social disadvantage of a handicap is as much a product of demands imposed by the environment as it is of the functional decrement of the impairment itself: "Handicap is thus a social phenomenon, representing the social and environmental consequences for the individual stemming from the presence of impairments and disabilities." Unfortunately, this insight—that the experience of disability is an outcome of an interaction between features of the person and features of the person's environment—was obscured by careless expression. Throughout, the ICIDH refers to the disadvantage of handicap resulting from the individual's "being unable to conform to the norms" of his or her social universe, as if the "problem" lies exclusively with the individual rather than with the norms.

The ICIDH had a negligible impact on disability statistics or data collection, because the classifications were viewed as incomplete, idiosyncratic, or difficult to use. The research community, however, argued that the ICIDH was a vast improvement over the purely medical classifications and assessment instruments that had dominated clinical practice up to that time. Therapists in particular appreciated the fact that the ICIDH acknowledged the role of the person's social and physical environment in both the creation and severity of his or her handicaps. Disability scholars tended to ignore the ICIDH or to dismiss it as little more than a modified medical classification, which is ironic given that, as Mike Bury (2000) has noted, the aim of the ICIDH was precisely to challenge the medical model.

ICF (2001)

By the 1990s it was clear that, at best, the ICIDH was a first attempt, and if it was ever to be of use in data collection or management, it needed to be substantially revised. Disability scholars criticized the ICIDH for defaulting to a medical model in which impairments created disabilities, which in turn created handicaps. They objected that the ICIDH only paid lip service to the crucial role of the social environment in the creation of disability, and that it was a classification of "inferior" people that would facilitate eugenics and other practices of eliminating people with disabilities. They also asserted that the ICIDH promoted Western imperialism in that it ignored cultural and linguistic differences.

These were substantial and damning criticisms, yet the urgent need for an international classification of human functioning remained. By 1993, an international collaborative process to revise the ICIDH had begun. In the end, the revision clarified the underlying model of disability, reconceptualized the dimensions, added a complete classification of environmental factors, and expanded, reorganized, and updated the three classifications. Each item was operationally defined within a strict hierarchical structure, and the coding system was revamped. Drafts of the new classification system were subjected to extensive field trials to determine cross-cultural and linguistic applicability of the model and the classificatory structure and language. In May 2001 the renamed International Classification of Functioning, Disability, and Health (known as the ICF) was unanimously endorsed by the World Health Assembly and released for use in international research, surveillance, and reporting.

Time will tell whether the ICF's classifications transform the world's health and disability data collection systems or become the basis for "state-of-the-art" clinical assessment tools. The "biopsychosocial" model of the ICF may well be more influential than the classification system itself in the long run.

Briefly, the ICF identifies three dimensions of human functioning: body function or structure, activity, and participation. Observable or measurable decrements in these are dimensions of "disability" (understood in the ICF as an umbrella term referring to one or more of the three dimensions): impairments, activity limitations, and participation restrictions. Depending on how the ICF is used, the classification provides a coding structure that identifies specific categories of functioning in these three dimensions, with qualifiers to roughly assess severity and to identify whether the category is being understood as a "capacity" (inherent functioning of the person, usually measured in a standardized environment) or "performance" (a description of what the person actually does in his or her actual current environment). The definitions of these elements of the ICF model are presented in Table 1.

Table 1 Definitions of Elements of the ICF Model

Body functions are physiological functions of body systems (including psychological functions).

Body structures are anatomical parts of the body, such as organs, limbs, and their components.

Impairments are problems in body function or structure, such as significant deviations or losses.

Activity is the execution of a task or action by an individual.

Participation is involvement in a life situation.

Activity limitations are difficulties an individual may have in executing activities.

Participation restrictions are problems an individual may experience in involvement in life situations.

Finally, the environmental factors classification sets out in general categories all features of the physical, human-built, social, and attitudinal world that may either create disability (and, in particular, participation restrictions) by acting as barriers or lessen (or eliminate) disability by acting as facilitators. (Another contextual dimension, personal factors, is not explicitly classified in the ICF.) In general structure, as Figure 1 illustrates, disability phenomena (that is, impairments of body function or structure, activity limitations, and participation restrictions) are outcomes of interactions between features of the person, including background health condition, and environmental factors.

This model can be understood as a synthesis of what is useful in both the medical and social models of disability, without making their mistake of reducing the whole, multidimensional notion of disability to one of its aspects. This integration of the biomedical and the social means that "disability" can be disaggregated into its interacting components. The biomedical phenomena inherent within the physiological function of the person can be clearly identified and distinguished from features of the inherent capacity of the person to execute discrete simple and complex actions and from the extent of the person's participation in his or her actual environment, in the full range of socially constructed areas of human life.

Significantly, the ICF model offers no account of how or *why* disability comes about, beyond the statement

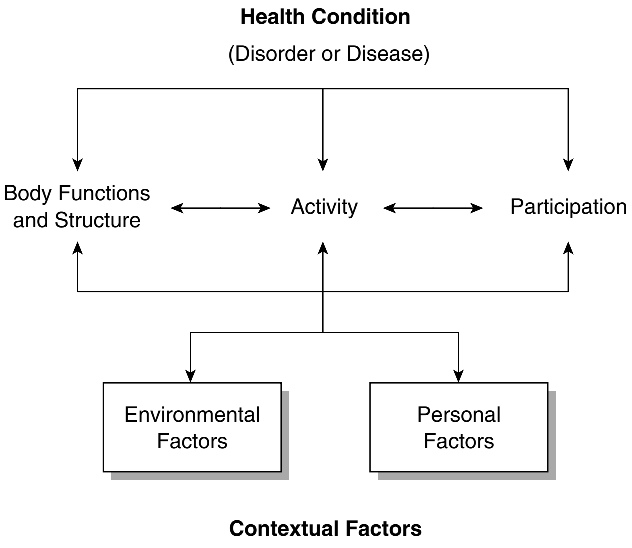

Figure 1 The Structure of Disability Phenomena

that disability arises out of an interaction between person and environment. If a researcher wishes to show, for example, that employment restrictions for people with mobility problems are the product of social prejudice, unaccommodating workplace environments, the underlying impairment, or some combination of these, the researcher can rely on the ICF to collect relevant evidence. The model of the ICF is itself (relatively) theory neutral, in the sense that it is compatible with whatever explanation of how disability arises, at the individual and population levels, that evidence may confirm.

The ICF is thus based on a *multidimensional* and *interactive* model of human functioning and disability. It is nonreductive (in the sense of not assuming that, e.g., the medical dimension is fundamental or "what disability really is") and, as just described, relatively theory neutral. In this sense, the ICF's model is closer to Saad Nagi's influential model, inasmuch as it offers a general structure for functioning and disability phenomena for data collection and management, policy development, and administrative and scientific research rather than an explanatory account of what causes or is responsible for disability, as in the medical model or the model developed by the Union of the Physically Impaired against Segregation (UPIAS).

Another important conceptual feature of the ICF model is universality. This can best be explained in terms of three other principles that guided the development of ICF. The first might be called etiological neutrality—that is, no assumption should be made about the nonenvironmental causal background of any particular functional decrement. For example, "reading" is a complex activity found in the ICF's "Activities and Participation" classification. The operational description of this item makes no reference to any disease, injury, or other health condition, or to specific impairment such as vision or cognitive problems. Problems in a person's capacity to read or in his or her actual reading performance are associated with many potential background health conditions or impairments. There undoubtedly are causal connections, but a classification must not assume these connections. The second principle is that classification is based on parity between the mental and the physical. Indeed, the ICF does not distinguish between "physical" and "mental" disability at all—it is all a matter of human functioning. Finally, in the ICF functioning and disability lie on a continuum, a spectrum from "complete functioning" to "no functioning" with an infinite number of gradations between the two extremes. Depending on user purposes, explicit "threshold" points can be determined (e.g., "mild," "moderate," "severe"), but this is a matter of usage and is not dictated by the ICF itself.

These three principles (etiological neutrality, parity, and continuity) taken together ensure that the ICF is not a classification for or about a particular group of people ("the disabled"); rather, it is about all of humanity. This is truly a paradigm shift in our way of thinking about disability, which is usually construed as an all-or-nothing phenomenon, a medical or social label that applies or not, or a social minority group to which an individual either belongs or does not. The ICF, in contrast, presents disability as a continuum that is relevant to the lives of all people in different degrees and at different times in their lives. Disability is not something that happens only to a minority of humanity, it is a common (indeed natural) feature of the human condition. The ICF is for all people, not just people traditionally referred to as "disabled" and isolated as a separate group.

The ICF thus "mainstreams" the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to the full range of lived experiences, it places all health conditions on an equal footing, allowing us to compare them using a common metric—the ruler of health and disability. From emphasizing people's disabilities and labeling people as "disabled," we now focus on the level of health and functional capacity of each individual. This may be the most important, and politically significant, aspect of the ICF's model of functioning and disability.

—Jerome E. Bickenbach

See also Models; Quebec Model of Disability Creation Process; Rehabilitation Medicine, International.

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INTERNATIONAL DISABILITY ORGANIZATIONS

Supports and services for people with disabilities are recorded as far back as the Old Testament. However, the emergence of organizations of and for persons with disabilities is a much more recent phenomenon, and the emergence of an international disability movement is newer still.

The Stockholm Deaf Club, established in 1868, is the first recorded organization of people with a disability. Since 1922, when Rehabilitation International was established, organizations of and for people with disabilities have been linking together internationally. Interest in sharing information related to disability increased following World War II. The World Federation of the Deaf and Inclusion International were founded in 1951 and 1962, respectively, and the International Association for the Scientific Study of Intellectual Disability (originally the International Association for the Scientific Study of Mental Deficiency) was founded in 1964.

Until the early 1980s, the Council of World Organizations Interested in the Handicapped represented the community of nongovernmental disability organizations in dealings with the United Nations. The council comprised the following organizations, all of which had consultative status with the United Nations: Rehabilitation International, the World Federation of the Deaf, the International League of Societies for the Mentally Handicapped (now Inclusion International), and the World Blind Union. However, in 1981 the creation of Disabled Peoples' International (DPI), with its strong focus on empowering "a voice of our own" for people with disabilities, changed the balance of power in disability organizations' dealings with the United

Nations. DPI played an important role in coordinating the work done during the International Year of Disabled People (1981) and in the subsequent development, together with other international disability organizations, of the World Programme of Action Concerning Disabled Persons and of the International Decade for Disabled Persons (1983–1992).

In 1987, a group of experts evaluated the outcome of the first five years of the International Decade. They determined that too little progress had been made toward the overall goal of "full participation and equality" for persons with disabilities. The international disability organizations therefore requested that the United Nations establish more concrete guidelines. The result was the UN General Assembly's adoption, in December 1993, of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. An important element of the Standard Rules was the creation of an independent and active monitoring mechanism, which included three elements: the UN Commission for Social Development, a special rapporteur whose duties were to conduct the monitoring and report to the commission, and a panel of experts named by the nongovernmental disability organizations. Bengt Lindqvist, a former Swedish cabinet minister, founding member of DPI and leader of the World Blind Union, was named special rapporteur. The panel of experts was composed of five women and five men representing Disabled Peoples' International, Inclusion International, Rehabilitation International, the World Blind Union, the World Federation of the Deaf, and the World Federation of Psychiatric Users (now the World Network of Users and Survivors of Psychiatry).

THE INTERNATIONAL DISABILITY ALLIANCE

During his tenure of three terms as special rapporteur, which ended in 2002, Lindqvist consistently worked with the panel of experts. This not only enabled the disability groups to play a significant role in monitoring the implementation of the Standard Rules, but it also served as an education for the disability organizations about international issues and created a spirit of collegiality among the groups. Individuals who did not have leadership positions within their organizations represented several of the groups, and so the presidents of the various organizations began to hold regular meetings, at first in conjunction with the panel meetings (see Lindqvist 2003-2004). These informal gatherings led to the establishment of the International Disability Alliance (IDA) in Cape Town, South Africa, in 1999.

There was a lapse between the end of Lindqvist's term as special rapporteur and the appointment of his successor, Sheika Hessa K. A. Al-Thani, but the IDA continued to meet. The network became a mechanism for collaboration among the world's major international disability organizations on matters of common concern, especially on matters related to the United Nations and its agencies. Currently, the IDA's member organizations are Disabled Peoples' International, Inclusion International, Rehabilitation International, the World Blind Union, the World Federation of the Deaf, the World Federation of the Deafblind, and the World Network of Users and Survivors of Psychiatry. In order to encourage cross-disability collaboration, and also to support the participation of international disability organizations in the elaboration of a proposed UN convention on disability, the IDA received financial support from the Swedish International Development Cooperation Agency.

Although each IDA member organization has its own mission and objectives, there is a strong commonality of approach among members. Enns (n.d.) summarizes the roles of organizations of disabled people as follows: self-representation, identification of grassroots needs, representation to government service providers and UN bodies, evaluation and monitoring of services, self-development, mutual support and solidarity, provision of a vehicle for self-help projects, provision of networking mechanisms, and promotion of public awareness. The current IDA member organizations are described below (some of these also have their own separate entries in this encyclopedia).

Disabled Peoples' International (DPI)

Disabled Peoples' International, a network of national organizations and assemblies of disabled people, was established to promote the human rights of disabled people through full participation, equalization of opportunity, and development. DPI has consultative status with the UN Economic and Social Council, the World Health Organization, and the special list of the International Labor Organization.

DPI's mission is to ensure equal representation of its members through a decentralized "regional" structure that also facilitates leadership and strategy development at the local level. DPI currently has approximately 120 national members, more than half of which are in developing nations. Any organization controlled by disabled people can be a member of the national assembly in that organization's country.

A major goal of DPI is the full participation of all disabled people in the mainstream of life, particularly those in developing countries.

Inclusion International (II)

Inclusion International is a federation of more than 200 associations, in more than 115 countries, whose individual members are people with intellectual disabilities, their families, and other supporters. II's vision is a world where people with intellectual disabilities can participate equally and be valued in all aspects of community life. II has consultative status with the United Nations and its agencies.

With its member societies, II is an agent for change based on four main principles affecting the lives of people with intellectual disabilities and their families: inclusion of all persons in all aspects of everyday society, full citizenship for all that respects individual human rights, self-determination and individuals' control over decisions affecting their lives, and family support through adequate services and support networks.

II's Millennium Development Goals use the UN Millennium Development Goals as a framework for expressing the organization's objectives on behalf of people with intellectual disabilities. These goals, which provide a clear agenda and targeted objectives, focus on the following major issues: inclusive education, poverty reduction, children and families, maternal and child health, values and ethics, and human rights.

Rehabilitation International (RI)

Rehabilitation International is a federation of approximately 200 national and international organizations and agencies in 80 nations covering all of the world's regions. RI maintains official relations with the UN Economic and Social Council, the World Health Organization, the International Labor Office, UNESCO, UNICEF, the Organization of American States, the European Union and the Council of Europe, the UN Economic and Social Council for Asia and the Pacific (UNESCAP), and others.

RI develops and promotes initiatives to protect the rights of people with disabilities, to improve rehabilitation and other crucial services for disabled people and their families, and to increase international collaboration toward these objectives. Adopted in March 2000 at the World NGO Summit on Disability, RI's agenda emphasizes working toward the following in regard to people with disabilities: improvement of overall quality of life; reduction of deprivation, hardship, and poverty; improvement of education, training, remunerative work, and participation in decision making; elimination of discriminatory attitudes and practices; elimination of information, legal, and infrastructure barriers; and increased allocation of resources to ensure equal participation.

World Network of Users and Survivors of Psychiatry (WNUSP)

The stated purpose of the World Network of Users and Survivors of Psychiatry is to serve as a global forum and voice through which the users and survivors of psychiatry can promote their rights and interests. The WNUSP began as the World Federation of Psychiatric Users in 1991; it adopted its current name in 1997.

The WNUSP's aims are as follows: to advocate for the advancement of human rights, to provide international representation and consultation to the users and survivors of psychiatry, to encourage the development of national user/survivor organizations, to facilitate effective information exchange among user/survivor organizations, to develop networking opportunities for individual users and survivors of psychiatry, and to carry out any other activities that are consistent with WNUSP's purpose. The organization is also concerned with the advancement of human rights and expresses this concern by preparing, developing, lobbying for, and supporting human rights work. At the same time, the WNUSP promotes the facilitation of national and international user/survivor networks.

World Blind Union (WBU)

The World Blind Union represents 180 million blind and visually impaired persons from 600 different organizations in 158 countries. The WBU, which has consultative status within UN agencies and the UN Economic and Social Council, is a nonpolitical, nonreligious, nongovernmental, and nonprofit organization divided into six regions, each with its own constitution.

The WBU is based on a commitment to the concept that all persons, including the blind and partially sighted, are born equal and entitled to personal dignity and fundamental human rights. The WBU is working to achieve inclusion of blind and partially sighted people in all UN conventions and covenants in all countries of the world, to increase in number and strength the organizations of the blind and partially sighted, and to take on the role of information provider to society in general. The WBU seeks to promote the interests and societal involvement of all blind and partially sighted people of the world. The organization works to strengthen its close contacts with the United Nations, governments, and national politicians in order to ensure that all blind and partially sighted persons enjoy the same rights and opportunities as others. The WBU uses all available ways and means, including existing laws and regulations, to fight for equal rights and full participation for all blind and partially sighted people through the United Nations, national governments, and nongovernmental organizations, and to provide information to the general public at the international, regional, and national levels.

World Federation of the Deafblind (WFDB)

The World Federation of the Deafblind is an international organization created by and for Deafblind persons in 1988 during the Helen Keller World Conference in Paipa, Colombia. The WFDB is a nonprofit, benevolent society that includes as members national organizations of Deafblind persons, Deafblind individuals, and other concerned individuals. It was organized for the purpose of advancing the economic, educational, and social welfare of Deafblind persons.

World Federation of the Deaf (WFD)

The World Federation of the Deaf is an international nongovernmental organization comprising national associations of Deaf people worldwide. A nonprofit organization, the WFD works for human rights and equal opportunities for Deaf people everywhere. The organization's goals are to improve the status of national sign languages, to improve the education of Deaf people, to improve Deaf people's access to information and services, and to improve human rights for Deaf people in developing countries.

The WFD was established in 1951 during the first World Deaf Congress in Rome, Italy, which makes it one of the oldest organizations in the world for people with disabilities. The WFD's 123 Ordinary Members represent all five continents, and the organization's regional secretariats are as follows: Asia and the Pacific, Central America and the Caribbean, Central Europe, Eastern Europe and Middle Asia, Eastern and Southern Africa, South America, and the Arab Region (Interim). It also has a regional cooperating partner in Europe. The WFD has consultative status with the United Nations.

—Diane Richler

See also Advocacy; Disabled Peoples' International; Rehabilitation Medicine, International.

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World Federation of the Deafblind, http://www.wfdb.org
World Network of Users and Survivors of Psychiatry, http://www.wnusp.org

INTERNET

See Accessible Internet

INTERSEX

Intersex is a term used to describe someone who has an anatomy that is not clearly either male or female. Various medical terms have been used to refer to such anatomy, including *androgen insensitivity syndrome, Kilefelter's syndrome, progestin virilization, mixed gonadal dysgenesis,* and *true hermaphroditism.* As these terms suggest, the experience of being an intersexed person is often pathologized through the medical model as a birth defect that should be corrected. Like many disabled people, intersex people often report significant pressures to change their bodies through surgery in order to make them more "socially acceptable" and "normal."

Many intersexed people are forced into surgery to adjust their bodies at very young ages. Common operations of this type include clitoral reduction and vaginoplasty. These surgeries often leave intersexed people feeling ashamed about their bodies as well as confused about their sexuality or their gender. In recent years, intersexed people have responded by starting a political movement to prevent infant surgeries and change medical practices toward children with ambiguous sexual anatomies. The intersex movement challenges dominant social interpretations of bodily differences, such as medical practices that define some penises as "too small," some clitorises as "too large," and the absence of a vagina as meaning a person is "not a real woman." The intersex movement generally objects to anatomy-changing surgery unless it is absolutely medically necessary, such as a lifesaving operation in which a urethra is rerouted so that a child can urinate.

In the past, many intersexed people were labeled "hermaphrodites." However, the category of intersex includes many people who do not conform to the standard medical definitions of "hermaphroditism"—namely, having both ovarian and testicular tissue. It is actually more common among intersexed people for their genitals to be ambiguous, regardless of whether they have ovaries or testes. When there is gender ambiguity, the child is usually allocated a female gender. In this context, it is important to note the social factors that often influence medical decisions—such as the common desire of doctors and family members to assign a gender to the child as soon as possible. The social importance placed on announcing a child's gender at the time of birth, regardless of whether the infant's gender is clear, often places the child and the child's family in uncertain territory in terms of personal identity. Many doctors assert the need to assign gender decisively and irreversibly at birth, but such a pronouncement often belies the complexities presented by intersexed infants. In major medical centers, the medical teams that are involved in assigning gender may include the original referring doctor, an obstetrician, a pediatric surgeon, a geneticist, and a pediatric endocrinologist. Team members may conduct tests and rely on procedures that take months to provide results.

In addition to emotional ordeals, many intersexed people experience physical complications and side effects as a result of the surgeries they have undergone. Although reports of complications from genital surgery are rare in the medical literature, some of the complications that can arise include stenosis (a narrowing of the vaginal canal), scarring, and urinary tract infections.

—Mark Sherry

See also Inclusion and Exclusion; Normality; Sexuality.

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INVALID WOMEN

Although the term *invalid* has fallen out of use as a medical category and now colloquially refers to someone who is incapacitated, there was a time when it meant simply weakness and a tendency toward illness. During the nineteenth century, women were presupposed to be weak, and femininity itself was considered akin to illness, so in one sense, all women—no matter their actual state of health—were seen as invalids. This representation of women as ill pervades the literature, art, and medical tracts of the period. Modern feminist critics have understood this phenomenon in four ways: as the result of misogynist cultural conditioning and the patriarchal power to define and control women's bodies, as resistance to such conditioning, as a kind of power in itself, and as a specific manifestation of cultural privilege and power in which illness functions as both power and powerlessness.

The double meaning of *invalid*—that is, both ill and not valid—serves to challenge women's standing as full citizens and was in fact used in arguments against suffrage and equal opportunity for women; middle- and upper-class women were assumed to be too frail to stand up to the rigors of officeholding, voting, or employment, despite the evidence of working-class women's stamina throughout the world. In this way, invalidism paralleled disability: Unfounded assumptions about a group's physical inferiority led to discrimination. Although there are and have been some important differences between invalid women and women with disabilities, quite often the two are indistinguishable, and the cultural associations attached to them are very alike. At the same time, women have sometimes further stigmatized disability in their attempts to deny invalidism. More recently, however, many articulate writers about disability have been women with chronic diseases who have drawn important links between illness and disability and have called attention to the role of gender in thinking about disability.

In the mid-nineteenth century, Edgar Allan Poe (1846) claimed that "unquestionably, the most poetical topic in the world" is the "death . . . of a beautiful woman" (p. 165). Representations of ill and dying women throughout the nineteenth century bear out his claim. Whether in paintings of mad, dead, or dying women (such as Albine and Ophelia), in operatic and dramatic renderings of tragic illness (as in *La Dame aux Camelias, La Traviata,* and *La Bohème*), or in literary depictions like Poe's, the numerous tubercular heroines of sentimental novels, or the delicate ladies fainting on couches that populate many novels and stories, representations of women in this period are often representations of illness and weakness. Nor did such depictions of women end in the nineteenth century. Many contemporary films and other fictional works continue to focus on dramatic episodes of women's illnesses; to mention just a few, one could point to such films as *Girl, Interrupted* and *One True Thing* or to novels such as Ana Castillo's *So Far from God* and Jane Smiley's *A Thousand Acres.*

Explanations of how women came to be understood as invalid usually focus on the cultural conditioning that is part of a patriarchal system. These arguments usually take one of two forms, maintaining either that oppression actually caused the illness or that oppressive norms caused women to be defined as ill no matter what their actual physical condition. Proponents of the former view argue that many expectations of women—that they wear corsets, that they bear numerous children, and that middle- and upper-class women refrain from much exercise—would in fact have led to illness; they point out further that powerlessness over life choices (whether to have a career, whom to marry, how to manage finances, or even whether to play a role in government) would have led to mental and emotional strains that likewise could have caused illness. Proponents of the latter view point out that in the mid-nineteenth century, normal experiences of feminine physicality (menses, pregnancy, menopause) were coming to be circumscribed by medical intervention.

Critics have addressed female illness not only as an issue of powerlessness, however. Elaine Showalter (1997), for example, argues that female illness in the nineteenth century can be read as resistance to power. She asserts that hysteria, especially, might be read as a mode of protest. Thus, many women who were diagnosed as ill might in fact have been rebellious or politically resistant. Other critics have examined the way that scenes of illness may provide audiences with moral exempla of virtue and stoicism. Finally, it is important to note, too, that not all uses of illness for power are positive; there are numerous examples of female characters who dominate whole communities through feigned illness and demands for attention, probably nowhere more famously than in Harriet Beecher Stowe's *Uncle Tom's Cabin.*

Rosemarie Garland Thomson (1997) points to some important similarities between cultural assumptions about women's bodies and the bodies of people with disabilities. She argues that in many ways, especially if one traces writings about disabilities back to Aristotle, femininity itself can be seen as a disability—Aristotle classified the absence of a penis as a deformity—and that both femininity and disability have been understood as bodily differences that are not simply alternative forms but deficient ones. Thomson points out that by reading disability through a historical lens of discrimination against women, we can see that such oppression is a matter of social "norms" rather than concrete bodily differences.

We cannot, however, make an easy or historically continuous connection between feminist politics and disability politics. In the course of their historical struggle to gain access to political and social rights, women have sometimes argued against their "invalidity" by expressly contrasting themselves to the disabled. Suffragists argued their fitness to vote and hold office by defining their abilities against those of physically, emotionally, and intellectually disabled men. As historian Douglas Baynton (2001) argues, this sets out able-bodiedness as an unquestioned positive value. In many ways, then, the suffragists did not urge a rethinking of the paradigm of invalidism—that it equaled invalidity—they simply argued that they did not fit that paradigm.

In recent years, writers about female illness and disability have thought through the relation between the two in a much more nuanced way. Perhaps the most important of these writers has been Nancy Mairs, whose nonfiction prose collections explore the relationship between femininity—especially as it is connected with sexuality and beauty—and disability, when it takes the form of visible difference, but Lucy Grealy and Anne Finger have likewise grappled in their work with the overlaps between illness and disability. In *The Rejected Body* (1996), Susan Wendell tackles philosophical questions that link feminism, disability, and illness. Most contemporary representations no longer depict women's illness as a result of their own weakness or invalidity, and often do not feature women who are ill as "poetical" or beautiful subjects, either. Contemporary writers and artists are tackling the question of women's illnesses today without casting the ill woman as the invalid. In addition to those mentioned above, one might see the work of Lucille Clifton, Marilyn Hacker, and Margaret Atwood. Many of these representations challenge contemporary culture as the cause of "dis-ease" for women and, as Ann Folwell Stanford (2003) argues, urge a more cultural idea of healing.

—Diane Price Herndl

See also Normality; Sexuality.

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IQ

IQ stands for *intelligence quotient,* a numerical score derived by combining a person's chronological age with his or her "mental age" as determined by the person's performance on a standardized intelligence test. Intelligence testing has become a standard tool in the diagnosis of two specific forms of disability: learning disabilities and intellectual disabilities (also known as developmental disabilities or mental retardation). Intelligence tests are also used in the assessment of giftedness and in the assignment of students to ability tracks within public schools.

Individual intelligence tests such as the Stanford-Binet Intelligence Scale, the Wechsler Intelligence Scale for Children, and the Wechsler Adult Intelligence Scale are used to provide a single measure of overall intellectual functioning. Intelligence tests are statistically normed so that all scores are distributed according to the pattern of a normal or bell curve. A high number of scores cluster at or near the center around an average value of 100. Fewer scores occur along the two tails of the curve. About 2.3 percent of all scores occur at or below 70, and 2.3 percent occur at or above 130.

Intelligence tests generally consist of two subscales, verbal and performance, each of which comprises five separate tests of specific skills within that domain. Verbal scale tests use language-based items, whereas performance scale tests use visual-motor items, which are less dependent on language skills. The two subscales contribute equally to the individual's total or full-scale score.

Learning disability diagnosis typically involves a formula that sets a specific criterion (often 1.5 or 2 standard deviations) for discrepancy between a total IQ score and a score on a standardized test of academic achievement. The purpose of comparing scores on an intelligence measure and an academic skills test is to uncover any unexplained deficit in a basic area of academic skill (such as reading, mathematics, writing). IQ is viewed as the measure of global intellectual capacity, a gauge of how well a student or other individual is expected to fare on academic tasks. The achievement test provides an actual measure of academic ability in a specific skill area. It is expected that a person scoring in the average range on an intelligence test will score in the average range on an achievement test. When a person scores significantly lower on an achievement test than on an intelligence test, that discrepancy is viewed as a possible indication of a learning disability.

The diagnosis of intellectual disabilities typically involves the use of an intelligence test and other measures of social functioning, such as adaptive behavior scales. An IQ score below 70 is generally interpreted as an indication of a significant intellectual deficit that may (depending on agreement of other measures) be described as an intellectual disability.

Educators and psychologists have often used intelligence tests as part of systems of intellectual stratification that interpret individuals' ability to learn and function in school and society based primarily on IQ. Educators have often categorized individuals across three cognitive levels: educable, trainable, and untrainable. Students classified as *educable* (IQ approximately 50–75) were viewed as being able to learn simple academic skills but not able to progress above a fourth-grade skill level. Children believed to be *trainable* (IQ approximately 25–50) were expected to be able to learn to care for their daily needs but to learn very few academic skills. Children who appeared to be *untrainable* (IQ approximately 0–25) were viewed as totally dependent and in need of long-term care in residential settings.

Psychologists have often used a similar stratification system consisting of either three or five general levels of intellectual disability. The more recent five-level system consists of the following categories: *borderline* (IQ 67–83), *mild* (IQ 50–66), *moderate* (IQ 33–49), *severe* (IQ 16–32), and *profound* (IQ < 16).

Often educators and psychologists have translated intelligence test scores into a concept of a *mental age.* If a score of 100 means that a person is functioning intellectually at the developmental level expected of his or her age peers, then a score of 50 indicates cognitive functioning equivalent to half that person's age. In this way, adults with intellectual disabilities have often been viewed as operating much like children.

For many years, the diagnosis of intellectual disabilities relied solely on the use of a single intelligence test. Also, the usual cutoff score for intellectual disability diagnosis was 80 or 85. In the 1960s, concern arose in the United States about the overidentification of intellectual disability in African Americans and members of other minority groups. Many educators, psychologists, and social critics maintained that intelligence tests were biased against minority and lower-class populations. In 1973, the American Association on Mental Retardation responded by reducing the diagnostic criterion level for intellectual disability (or mental retardation) to 70 to account for problems of bias and measurement error.

In the public schools, a series of court cases struggled with the same issues. In *Larry P. v. Riles* (1979), a California class-action case, it was argued that African American students had been inappropriately placed in educable mentally retarded (EMR) classrooms solely on the basis of IQ scores. The case also claimed that the IQ tests used were culturally discriminatory against African American children. The court found that the IQ tests were culturally biased against African American students. This case and others brought about a shift in public school utilization of intelligence tests, leading to a requirement that no special education diagnosis be made based solely on a single intelligence test.

In 1904, the French minister of public education commissioned Alfred Binet to develop a technique to identify students who could benefit from special education assistance. Binet put together a hodgepodge of tasks and games designed to enable the assessment of a wide variety of cognitive skills. His original insistence that no intelligence test could capture the many human abilities in a single score was generally ignored by the American psychologists who translated and popularized his test.

H. H. Goddard, Lewis M. Terman, and Robert Yerkes were prominent American psychologists who adapted Binet's test for various applications in the early twentieth century. The work of these three men reflected and perpetuated common prejudices of the times. Goddard believed that social problems such as violence, drug abuse, and poverty are rooted in individual mental deficit that is both innate and inherited. His answer was to develop intelligence tests to identify the high-level feebleminded in order to isolate them, thereby segregating social evil in institutions and reducing the chances of defective offspring. Yerkes developed intelligence tests for the U.S. Army during World War I that were given to thousands of soldiers for the purpose of matching individual intelligence with military rank and responsibility. The intelligence data gathered through these tests documented disproportionate levels of mental defect among immigrants and African Americans, providing scientific support for anti-immigrant and racist sentiments among many citizens and leaders. Yerkes's research was instrumental in the passage of the Immigration Restriction Act of 1924, which set strict limits on the numbers of immigrants accepted from Southern and Eastern Europe and Asia. Terman reached similar conclusions in his application of a version of the Binet test (early Stanford-Binet) to schoolchildren in northern California. He found that children of immigrants from Latin American as well as Southern and Eastern European countries fared very poorly in comparison with students of Northern and Western European backgrounds. His work simultaneously introduced intelligence testing to the public schools as a means of sorting students into ability-level groups and supported racist and jingoistic attitudes.

Racial issues returned to the forefront of the discussion regarding intelligence in 1969 when Arthur Jensen claimed in an article in the *Harvard Educational Review* that African Americans typically score lower than white persons on intelligence tests because African Americans are intellectually inferior. This racial argument returned again more recently in Herrnstein and Murray's book *The Bell Curve* (1994). Both of these publications continue a version of a philosophy of intelligence called *hereditarianism,* which was put forth in various ways by Goddard, Terman, and Yerkes. According to this philosophy, intelligence is an innate, unitary mental capacity that is primarily inherited through genetic transmission. Thus, variations in intelligence scores across different social groups are indications of real differences in intellectual ability between the groups.

The opposing position, which has often been called *environmentalism,* asserts that variations in intelligence scores across social groups occur primarily because of differences in the social and physical environments in which various groups live and in the experiences and kinds of education that individuals within those groups tend to have.

More recently, proponents of a third position, called *multiculturalism,* have maintained that intelligence tests primarily test the extent to which an individual has experienced and learned the language and cultural features of middle-class Anglo-America. According to this stance, low scores achieved by various minority groups and lower-class whites demonstrate a cultural mismatch between the content of the tests and the cultural experience of the individuals.

Despite social critique, intelligence testing has become a mainstay of diagnostic practice among educators and psychologists. A wide variety of institutional authorities—including special education systems, vocational rehabilitation programs, adult disability service providers, and even courts deciding on issues of mental capacity in criminal cases and sentencing hearings—rely on intelligence testing as an authoritative guide to intellectual capacity.

—Scot Danforth

See also Learning Disability; Mental Illness; Mental Retardation, History of; Normality; Special Education.

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IRELAND

See Experience of Disability: Ireland

ISOLATION

In the summer of 1995, more than 700 people died in Chicago during a prolonged heat wave. More than 10,000 individuals died in France under similar circumstances during a three-week period in the summer of 2003. Many of these individuals were elderly and suffering from one or more chronic diseases or disabilities. Of even greater interest to public health officials was the recognition that most of the deceased died alone, isolated from social networks that might have identified their high-risk situations and intervened before the consequences were so severe.

The term *isolation* is used to refer to both voluntary and involuntary lack of contact with others in the community. An individual may be involuntarily separated from others for several reasons. Physical limitations may keep the person from leaving home easily or from accessing facilities where he or she can engage in either business or social activities. Psychological or behavioral conditions may also prevent an individual from establishing satisfactory relationships with others in the community with whom he or she should interact. Some individuals desire solitude and so choose to isolate themselves from the community as much as possible. The majority of isolated individuals, however, do not wish be isolated and often experience physical and emotional impairments because of their isolated status.

In the 1970s, individuals with disabilities were "mainstreamed" from institutions into the larger body of society. This change signified a change in attitudes toward the disabled, but even so, a large segment of this population became segmented from the mainstream. Despite the existence of community training centers and rehabilitation programs, some individuals with disabilities became separated from their communities and isolated in their homes. Reasons for this included limitations caused by disability itself, the limited ability of some individuals to adapt emotionally to the challenges of their disabilities, and the limited ability of some individuals to communicate with other members of society. Using a broad definition of disability that includes chronic illnesses, researchers who conducted an analysis in 1999 using data from the Survey of Income and Program Participation estimated that one in five American adults suffers from some disability. The major causes of disability were reported to be arthritis, rheumatism, back or spine problems, and cardiovascular disease. Less than 4 percent of those with disabilities reported a mental or emotional problem to be their primary cause of disability, and 20 percent of disabled individuals reported difficulty getting around outside of the home. Individuals over the age of 65 were only slightly more likely to report this difficulty than were those in the 18–64 age group.

Social isolation can result from a number of factors, including physical limitations. The issue of interest resulting from social isolation is the relationship between isolation and social loneliness, or the inability to derive satisfaction from interaction with other individuals or groups. The perception of loneliness results from a discrepancy between the level of those relationships that the individual desires and what he or she can achieve given the level of isolation dictated by the disability.

Several scales have been developed to measure loneliness. Studies using the UCLA Loneliness Scale have found that men are more likely than women to be lonely. In other studies using other scales, females have been found to have higher levels of loneliness. Although there is no consistent agreement on the variables that predict loneliness, an emerging body of literature has begun to link loneliness with poor physical and mental health.

Individuals with disabilities interact with primary health care providers with greater frequency than they interact with providers of rehabilitative or assistive services. This is especially true for individuals living in the community rather than in institutions, where rehabilitative services may be more accessible. There are differences in provision of services by gender as well. For females, most health care provided is related to the disability, and often women's preventive or wellness-based care is ignored. Females are also more likely to present with depressive symptoms.

Some research has attempted to differentiate between isolation and loneliness. Lonely young men and women have both been found to have poorer cardiac function than young people who are not lonely. Loneliness has not been found to be related to poorer health behaviors per se, but it has been found to be predictive of stress and poorer social interactions. In elderly persons with disabilities, attitudes toward social engagement have been found to be more important to overall rehabilitation than actual health condition or type of disability. Attitudes toward social participation related to the use of rehabilitative devices and services are often more predictive of the use of such services than the actual level of disability.

Coexisting psychosocial issues that occur in individuals with physical disabilities may not only increase the effects of their disabilities but also lead to further inability to self-manage as well as increase the incidence of new and preventable physical and emotional problems. Depression in older patients with coronary conditions has also been found to be correlated with poor quality of life, self-report of disability, and decreased physical endurance. Using volunteers who were willing to engage in community-based exercise programs, one study found that exercise improved physical function. Individuals with disabilities have been found to have higher rates of obesity than their counterparts who do not report such conditions. Obesity can aggravate the effects of some disabilities and lead to even less mobility.

Most studies of isolation in the disabled have focused on people with disabilities who live in urban areas. The problem may be even more acute in rural areas. One study found that individuals with HIV/AIDS living in rural areas, where such clients have even greater limitations on access to care than do those in urban areas, were more likely to be isolated and living in poverty. More than one-third of the affected individuals in the rural group reported that they had thought about suicide, and 6 percent seriously considered it to be an option.

Differences in age and the length of time individuals have had to deal with their disabilities may affect their ability to interact socially. As individuals with disabilities get older, they may have a tendency to move away from social interaction and develop self-imposed isolation because of changes in the social pressures on them to interact with others and because of general societal attitudes toward the elderly.

A major limitation of all of the published research findings to date on isolation among people with disabilities is that estimating the true number of individuals who are isolated is difficult, whether the isolation is caused by limitations associated with disability itself or by individuals' inability to function in social networks. The problem of isolation is receiving worldwide attention, however, and programs have been developed on every continent to address the problem. Approaches to the management of isolation have centered on case management and the use of telehealth and technology to assist the disabled in maintaining contact with society.

Most efforts to date have centered on community-based programs that provide home-based services, monitoring, and/or arrangements for specialized transportation. Although such approaches have assisted a great number of isolated disabled individuals, many more have been missed for a number of reasons. For example, health care providers may fail to recognize the special needs of their disabled clients, insurance may not cover the provision of specialized services, or disabled individuals may have ceased contact with the health care system because of their inability to leave home and make initial contact with health care providers. Disabled individuals residing in rural areas are especially vulnerable to isolation and inability to receive services.

In recent years, approaches to reaching the population of isolated individuals with disabilities have incorporated the use of various communication technologies. Social service organizations and health care facilities have used the telephone to establish contact with homebound individuals; such contact may be made by employees of these organizations or facilities, but this work is often done by volunteers. Senior citizens residing in assisted-living facilities have participated in phone contact programs with other senior citizens living alone in their communities. This approach not only creates peer support but also helps to identify individuals who need further intervention. The Internet is emerging as a useful tool for assisting isolated individuals, as it enables them to communicate with peers, other persons of interest, and health care providers. Ease of use, continuous availability, and ability to span geographic boundaries have made the Internet a powerful contributor to efforts to address isolation, as it enables individuals to develop and maintain the levels of social interaction they desire. Some studies have found a decrease in loneliness among isolated individuals after introduction of Internet communication access, but long-term research is needed to determine the economic and health status benefits that may be derived from Internet use. Most of the Internet-related interventions examined to date have involved the use of chat rooms, but continued development and increased availability of audio and video communication over the Internet may further enhance the benefits of this approach. As with the limitations of case management, recognition of individuals who may benefit from this type of intervention is key.

Finding and assisting isolated persons with disabilities is a societal obligation; working against isolation is not solely the responsibility of the isolated individual. Since the deadly heat wave of 1995, the city of Chicago has instituted programs to ensure that elderly and disabled citizens are contacted during times of extreme weather conditions by community volunteers who go door-to-door to check on them. This expensive, time-consuming process is limited to crisis management, but it has been effective in reducing deaths. Communities need to develop similar approaches to case finding and support that are cost-efficient and meet the needs of individuals in a variety of geographic areas and cultures.

—Mary K. Pabst

See also Caregiving; Community Living and Group Homes; Family; Social Support.

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ITARD, JEAN MARC GASPARD

(1774–1838)

French physician

Jean Marc Gaspard Itard was born in Oraison near Digne in southern France in 1774. He was charged by Lucien Bonaparte, interior minister during the Consulate, and by Abbé Sicard, director of the Institute for Deaf-Mutes on the Rue Saint-Jacques in Paris, with the care of a boy who had just arrived, in July 1800, and who was already being called "the wild boy of Aveyron." Itard undertook to teach him to speak and to civilize him, rejecting the diagnosis of idiocy made by Philippe Pinel, the famous specialist in mental disorders at the Salpêtrière asylum.

Contrary to Pinel, Itard judged that the wild boy had not acquired the benefits of civilization because he had been isolated in the forest without human contact. Dealing with a natural being, he thought that through education—the fundamental empirical concept—he could "return him to society," as the celebrated Sicard was doing with deaf-mutes. To achieve this, Itard employed methods intended for the deaf. These methods failed, however, since the wild child was very different from them. More different, in fact, than he would have thought, since we now know that early alterations in the brain are not, or are hardly ever, open to modification.

After some years of fruitless efforts, Chaptal, Napoleon's interior minister, suspended the financial support that had until then been given for the education of "Victor," so named because he had learned at least to sound the letter *O.* Itard then turned back to the deaf, for whom he invented a method of physiological education to teach them to speak. Before his death in 1838, he supported Eduoard Séguin's efforts in treating and training the mentally impaired.

In 1970, French filmmaker François Truffaut wrote and directed *The Wild Child,* a film based on Itard's work.

—Jean-René Presneau

See also Feral Children; Philippe Pinel; Eduoard Onesimus Séguin; Victor of Aveyron.

CHRONOLOGY

1500 BCE Egypt: The Ebers Papyrus, a medical textbook, devotes an entire chapter to eye diseases. It also shows that deafness is well understood and that clinical knowledge has developed.

400 BCE Graeco-Anatolian Hippocratic writings coin the word e*pilepsy* for a convulsive condition they view as a disease rather than a possession or punishment. Today, it is estimated that more than 80 percent of the 40 million people who currently have epilepsy throughout the world have little access or no access to contemporary treatments.

300 BCE China: *The Yellow Emperor's Internal Classic* is the first text to outline acupuncture. Ordinances on emergency relief for the disabled date to the Han Dynasty, 206 BCE–AD 220. Fiscal and administrative disability classification date at least to the Tang Dynasty, 618–907.

1250–1350 High point of medieval medicalization during which theoretical explanations for conditions gain currency in Western Europe. Prior to this time, in the most general of terms, lay explanations held more sway, ranging from the superstitious to the spiritual to the vindictive. With the founding of the universities, medical theory, typified by the four humors, became more influential in governmental, legal, and elite social circles. Disabling conditions like epilepsy, strokes, and paralyses, as well as psychiatric conditions, increasingly fell under the social control of doctors.

1400 Turkey: Deaf people work in the Ottoman Court from the 15th to the 20th centuries. Sign language becomes a recognized means of communication among both hearing and deaf courtiers.

1593 England: The origins of disability as a social and political category emerge with the first state disability benefits being enacted by Parliament for those disabled in war.

1593 Europe and the United States: English Parliament initiates Europe's first national system of benefits for rank-and-file disabled veterans. The first veterans' homes—France's Hôtel des Invalides, Britain's Chelsea Hospital, and Frederick the Great's Invalidenhaus in Berlin—are established in 1633, 1685, and 1748, respectively. Following the American Civil War, the U.S. government responds with a system of homes, preferences in government hiring, land grants, free prosthetics, and pensions for disabled veterans (however, southern veterans were limited to usually scanty state pensions).

1601 England: The Poor Law is passed to provide family and community support for those unable to make a living for themselves.

1604 Laws on witchcraft in the colonies all evolve from a 1604 English Statute that makes "being a witch" punishable by death. During outbreaks of witch-hunting, the "different" body itself is targeted as a sign and symptom of one's confederation with demonic forces.

1697 England: The first English workhouse for people with mental and physical disabilities is established in Bristol in 1697.

1704 Bethlem Hospital in the United States has 130 residents housing the "furiously mad."

1714 ◆ Canada: The Bishop of Quebec opens the first building in Canada exclusively for the confinement of mentally disturbed individuals. It is adjacent to Quebec General Hospital.

1749 ◆ France and England: Denis Diderot pens one of the most influential treatises on the blind and education in his *Letter on the Blind* in which he argues that the blind can be educated. In 1784, Valentin Haüy opens the first school for the blind in Paris. He perfects a system of raised *letters* to enable the blind to read. In 1828, Louis Braille modifies a raised *dot* system invented by Charles Barbier, which is used today by blind persons to read and communicate. In 1847, William Moon, an Englishman, develops an embossed script based on Roman capitals that blind adults can learn to read in a few days. It is the first reading system for the blind to be widely adopted across the world, but because it is costly to print, the Braille system, which can be produced by blind individuals for themselves, overtakes Moon's system.

1755 ◆ France, the United States, and Germany: The Abbé Charles-Michel de l'Épée establishes the first state-supported school for the training of young deaf children, where he teaches sign language. The school serves as an inspiration for the establishment of other European schools and has a dramatic impact on social attitudes toward the deaf. In 1817, Thomas Gallaudet and Laurent Clerc establish the Asylum for the Deaf (now American School for the Deaf) in Hartford, Connecticut. Clerc imports the French sign system, which influences the makeup of contemporary American Sign Language (ASL). In 1778, Samuel Heinicke establishes a school in Leipzig, Germany, where the "oral method" is used.

1800 ◆ France: Victor of Aveyron, a "feral child" found in southern France, is brought to Paris. Jean Marc Gaspard Itard, a French physician, develops a systematic training program for the boy and works intensively with him for five years. Itard considered his attempt at educating Victor to be a failure because the boy did not learn to use a language. Nevertheless, Itard's disciples, including Edouard Séguin, Maria Montessori, and Alfred Binet, continue his work by establishing classes for children considered to be "mentally retarded."

1802 ◆ France: The world's first pediatric hospital, L'Hôpital des Enfants Malades, is founded.

1817 ◆ The American School for the Deaf is founded in Hartford, Connecticut. It is the first school for disabled children in the Western Hemisphere.

1817 ◆ James Parkinson, a London physician, describes what is to become known as Parkinson's disease.

1817 ◆ Thomas Gallaudet and Laurent Clerc open the American Asylum for the Education of the Deaf and Dumb in Hartford, Connecticut.

1828 ◆ Frenchman Louis Braille, blind from childhood, modifies a raised-dot system of code, one of the most important advances in blind education. It not only allows the blind to read at a much faster rate but also makes it possible for the blind to be teachers of the blind. UNESCO creates the World Braille Council in 1952.

1829 ◆ France: Louis Braille publishes an explanation of his embossed dot code.

1832 ◆ Samuel Gridley Howe is chosen to direct what is later to be called the Perkins School for the Blind in Boston. It becomes the model for schools around the nation. Laura Bridgman and Helen Keller attend Perkins. In 1837, Ohio establishes the first state-sponsored school for the blind.

1834 ◆ England: The English Poor Law Amendment stipulates five categories of those unable to work: children, the sick, the insane, defectives, and the aged and infirm. This sets the stage for the development of specialty institutions that isolate the disabled from the community.

1841 ◆ P. T. Barnum purchases Scudder's American Museum in New York City. This moment is considered to be the beginning of the "Golden Age" of freaks, which persists until the 1940s. The tension

between freaks and disability rights comes to a head in 1984, when disability rights activist Barbara Baskin successfully lobbies the New York State Fair to remove Sutton's Incredible Wonders of the World Sideshow, featuring a limbless man who performs as the "Frog Boy," from the midway.

1843 ◆ Due to the influence of Dorothea Dix, an American social reformer, the Massachusetts legislature allocates funds to greatly expand the State Mental Hospital at Worcester. Dix also plays an instrumental role in the creation of 32 mental hospitals and becomes nationally known for her reform efforts. By the late 1840s, Dix focuses on developing a national plan that addresses the treatment of people with mental illness.

1846 ◆ William Thomas Green Morton discovers anesthesia and in 1867 Joseph Lister provides a model for antisepsis. These new technologies play a central role in the future of aesthetic surgery as well as surgical intervention for every type of disability that calls for it. Penicillin is discovered in 1929, cutting mortality rates in hospitals dramatically.

1848 ◆ The North Carolina School for the Deaf begins the first publication for Deaf persons with its school newspaper, *The Deaf Mute.* First published in 1907, the *Matilda Ziegler Magazine for the Blind* is an ongoing Braille publication.

1848 ◆ Samuel Gridley Howe founds the first residential institution for people with mental retardation at the Perkins Institution in Boston.

1851 ◆ In the United States there are 77 residential institutions for children, 1,151 by 1910, and 1,613 by 1933. By the 1950s and 1960s, family members and politicians throughout Western Europe, Canada, and the United States push for the deinstitutionalization of people with disabilities.

1851 ◆ The first International Sanitary Conference is held in Paris, France, with 12 countries participating. It leads to the World Health Organization, the WHO, which formally comes into existence in 1948.

1857 ◆ Edward Miner Gallaudet, youngest son of Thomas Hopkins Gallaudet, establishes the Columbian Institution for the Instruction of the Deaf, Dumb, and Blind, located in Washington D.C. Its college division, eventually known as the National Deaf-Mute College, is the world's first institution of higher education for deaf people. Abraham Lincoln signs its charter on April 8, 1864; today it is known as Gallaudet University.

1857 ◆ English philosopher Herbert Spencer is first to use the expression "survival of the fittest." The application of his idea in combination with Charles Darwin's theories in his 1859 book, *The Origin of the Species,* is called Social Darwinism. It is widely accepted and promoted in Germany in the 1920s and leads Adolf Hitler to express prejudice against the weak, sick, and disabled.

1863 ◆ Louis Agassiz, a significant American naturalist, advocates the permanence of different races and worries about the "tenacious influences of physical disability" if races were mixed.

1864 ◆ Germany: Karl Ferdinand Klein, teacher for deaf-mutes, and Heinrich Ernst Stotzner are considered the founding fathers of the *training school,* which calls for schools to be created for less-capable children with the goal of improving their lot. Training schools remain in effect today, but critics maintain that there is an over-representation of socially and economically underprivileged students in this type of setting experiencing little academic success.

1868 ◆ Sweden: The Stockholm Deaf Club is the first recorded organization of people with disabilities.

1870 ◆ England and Wales: Education for children with disabilities begins when universal elementary education is first introduced around this time. From 1895 onward, schools for "defective" children spring up. In 1899, Alfred Eichholz, an inspector of special education, draws up key recommendations, which leave their mark on the historic 1994 Education Act legislation. In 1978, the Warnock report

introduces the term *special needs education,* which soon gains acceptance worldwide. With the 1994 UNESCO Salamanca Statement and Framework for Action on Special Needs Education, a major shift in organizing educational services for children with disabilities is confirmed internationally.

1876 ◆ Isaac Newton Kerlin, Edouard Séguin, and others establish the Association of Medical Officers of American Institutions for the Idiotic and Feeble-Minded Persons. Today, it is known as the American Association on Mental Retardation. Séguin, who staunchly believes in the educability of those with significant cognitive disabilities, is styled as "apostle to the idiots," by Pope Pius X, reflecting the attitude of the time.

1880 ◆ The United States National Association of the Deaf (NAD), the first organization of deaf or disabled people in the Western Hemisphere, is established. In 1964, the Registry of Interpreters for the Deaf (RID) is formed to establish a national body of professionals who are trained and certified to enable communication between deaf, signing persons and nondeaf, speaking persons.

1880 ◆ Helen Keller is born in Tuscumbia, Alabama. An illness at the age of 19 months leaves her totally deaf and blind. In 1887, Anne Sullivan, recently graduated from Perkins Institution for the Blind, joins the Keller household as Helen's teacher and remains Keller's companion for nearly 50 years. For many, Keller's story is the quintessential overcoming narrative.

1881 ◆ The Chicago City Council enacts the first American "ugly law" forbidding "any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself to public view."

1882 ◆ The first major federal immigration law in the United States, the Immigration Act of 1882, prohibits entry to "lunatics," "idiots," and persons likely to become unable to take care of themselves. Most of the restrictions that apply specifically to disability are removed from U.S. law in 1990. Today, disabled immigrants are still denied an entry visa if they are deemed "likely to become a public charge."

1887 ◆ Walter Fernald serves as superintendent of the Massachusetts School for the Feeble-Minded (now known as the Fernald Center) from 1887 to 1924. Unlike most of his colleagues, Fernald moderates some of his earlier extreme views and eventually develops one of the country's largest "parole" systems for moving institutional residents back into smaller, community-based residences.

1887 ◆ The American Orthopaedic Association is founded. German and British counterparts are founded in 1901 and 1918, respectively.

1895 ◆ The chiropractic profession is founded. This type of care is used to relieve musculoskeletal pain, one of the most common causes of disability.

1899 ◆ Maria Montessori and a colleague open the Scuola Magistrale Ortofrenica in Rome, an educational institute for disabled children and a training institute for instructors. Her method relies on the concept of sensory-based instruction as a means for developing intellectual competence. Her methods allow the child the greatest possible independence in order to foster his or her own development (the child's own inner "building plan").

1904 ◆ Sir Francis Galton, half first cousin of Charles Darwin, defines the term e*ugenics* (which he coined in 1883) in a paper he presents to the Sociological Society on May 16. He argues for planned breeding among the "best stock" of the human population, along with various methods to discourage or prevent breeding among the "worst stock." Galton also develops the idea for intelligence tests. The term *feeblemindedness* is defined as broadly as possible and is widely used by eugenic social reformers to conflate myriad social problems. Further naming, classification, and labeling provides eugenicists with a troubling rationale for treating people with coercion, disrespect, and profound inhumanity. Persons within the various categories of sub-normality become particularly vulnerable

to state-sanctioned segregation, institutional confinement, and enforced sterilization. Eugenics is widely practiced in Europe, the United States, and Canada, culminating in the systemic murder of more than 260,000 disabled people by the Nazis between 1939 and 1945. Today, the so-called new eugenics, known as "human genetics," appeals to the needs of the individual. Critics (some of the first in Germany), however, criticize individualistic eugenic approaches and disclose the connections between human genetics, national socialist racial hygiene, and eugenics.

1905 ◆ Alfred Binet and Theodore Simon publish the first intelligence scale, known as the Binet-Simon Test.

1908 ◆ The publication of Clifford Beers's *A Mind That Found Itself* initiates the mental health hygiene movement in the United States. Speaking out against mistreatment and neglect within the system, Beers establishes the Connecticut Committee of Mental Hygiene, which expands in 1909, becoming the National Committee for Mental Hygiene and is now known as the National Mental Health Association. In 1940 there are 419,000 patients in 181 state hospitals. In 1943, the patient-doctor ratio is 277:1, and by the mid-1950s in New York state alone, there are 93,000 inpatients. The Bazelon Center for Mental Health Law, founded in 1972 by a group of committed lawyers and professionals in mental health and mental retardation, attempt to improve mental health service provision through individual and class action suits. In 1980, a group of these lawyers form the National Association of Rights Protection and Advocacy (NARPA). One-third of its board of directors must identify themselves as current or former recipients of mental health care. The association is committed to the abolishment of all forced treatment.

1908 ◆ Pastor Ernst Jakob Christoffel establishes a home in Turkey for blind and otherwise disabled and orphaned children. This grows into Christoffel-Blindenmission (CBM), an independent aid organization of Christians of various denominations united to help disabled people in third world countries. Today, it supports more than 1,000 development projects in 108 countries. In 1999, CBM, other agencies, and the World Health Organization initiate VISION 2020: The Right to Sight, a global initiative for the elimination of avoidable blindness by the year 2020.

1909 ◆ Germany: The German Organization for the Care of Cripples is created as an umbrella organization for the care of the physically disabled. The Prussian Cripples' Care Law of 1920 for the first time provides a right to medical care and scholarly and occupational education for this group.

1912 ◆ Henry H. Goddard publishes *The Kadikak Family,* supports the beliefs of the eugenics movements, and helps create a climate of hysteria in which human rights abuse of the disabled, including institutionalization and forced sterilization, increases. In 1927, the U.S. Supreme Court, in *Buck v. Bell,* rules in favor of forced sterilization of people with disabilities, further fueling eugenics movements—the number of sterilizations increases.

1914 ◆ By this date, Sigmund Freud develops his most enduring influence on the study of disability, namely, the theory of psychosomatic illness in which a psychopathological flaw is given corporeal form as a symptom, thereby establishing the notion that people succumb to disease or disability because they feel guilty about past or present repressed desires.

1918 ◆ The Smith-Sears Veterans Rehabilitation Act passes, authorizing VR services for World War I veterans. In 1916, the National Defense Act marks the beginning of the U.S. government's supportive attitude toward rehabilitation. In 1920, the Smith-Fess Act marks the beginnings of the civilian VR program. The Social Security Act of 1935 establishes state-federal VR as a permanent program that can be discontinued only by an act of Congress.

1919 ◆ Edgar "Daddy" Allen establishes what becomes known as the National Society for Crippled Children. In the spring of 1934, the organizational launches its first Easter "seals" money-making campaign. Donors place seals on envelopes containing their contributions. The seal is so well-known that it

becomes part of the organization's official name. Today, Easter Seals assists more than one million children and adults with disabilities and their families annually through a nationwide network of more than 500 service sites. During the 1920s, Franklin D. Roosevelt inspires the March of Dimes.

1920 At about this time, the Shriners open hospitals for the care of crippled children. President Herbert Hoover establishes a "Children's Charter" in 1928 highlighting the need to attend to the needs of crippled children.

1921 Franklin D. Roosevelt contracts poliomyelitis. Despite damage to his legs (which makes him a wheelchair user) and deep depression, through enormous rehabilitative effort, he eventually re-enters politics and becomes president of the United States. His triumph over personal disability becomes legendary. Critics, however, fault him for choosing to minimize his disability in what is called his "splendid deception." He establishes a center for the treatment of polio patients in Warm Springs, Georgia, called the Georgia Warm Springs Foundation (1927), which hires medical specialists from Atlanta to direct orthopedics. In 1937, President Roosevelt becomes the prime mover behind the National Foundation for Infantile Paralysis Research.

1921 Mary L. McMillan (Molly) establishes the American Women's Physical Therapeutic Association, which is known today as the American Physical Therapy Association (APTA).

1921 The American Foundation for the Blind is established.

1921 Canada: Researchers isolate the hormone insulin. In 1922, Frederick Banting, Charles Best, J. B. Collip, and J.R.R. Macleod produce and test the pancreatic extract on people with diabetes, for which they are awarded a Nobel Prize. Insulin becomes a wonderful treatment for diabetes, but not a cure.

1921 France: Three historical waves of advocacy movements can be identified beginning with the National Federation of Injured Workers (FNAT) in 1921 and other organizations that focus essentially on the protection of rights. Another factor that stimulates advocacy groups in the first wave is the wounded veterans of World Wars I and II. A second wave dates from the period after World War II. Many advocacy groups form between 1950 and 1970, such as the Union of Associations of Parents of Maladjusted Children (UNAPEI) in 1960. A third wave finds a gradual emergence of three types of associations: those that run specialized facilities (for example, Living Upright, which, in 1970, leads to the creation of the first group living facility); those interested in trade unions; and those represented by user-advocate associations. Financing comes in large part from public funds, thereby creating a government-association partnership.

1922 The founding of Rehabilitation International sets the stage for the establishment of other international organizations of and for people with disabilities that link together throughout the world. Later international organizations include, among numerous others, the World Federation of the Deaf (1951), Inclusion International (1962), the International Association for the Scientific Study of Intellectual Disability (1964), Disabled Peoples' International (1981), and the International Disability Alliance (1999).

1925 The American Speech-Language-Hearing Association, today the American Academy of Speech Correction, is established to provide high-quality services for professionals in speech-language pathology, audiology, and speech and hearing science, and to advocate for people with communication disabilities.

1928 Charles Nicolle is the first deaf person to be awarded a Nobel Prize.

1929 Seeing Eye establishes the first dog guide school in the United States.

1930 The Veterans Administration is created to administer benefits, promote vocational rehabilitation, and return disabled veterans to civil employment. There is a record of provision for disabled veterans in the United States since the Revolutionary War and the Civil War. After World War I, three agencies administer veteran's benefits.

1932 Herbert A. Everest, a mining engineer with a disability, and Harry C. Jennings collaborate to design and patent the cross-frame wheelchair, which becomes the standard for the wheelchair industry that exists today. Developed during World War I, the first powered wheelchair appears, but doesn't gain popularity for another 30 years.

1935 President Franklin D. Roosevelt signs the Social Security Act of 1935 on August 14. Beginning in 1956, SSA amendments provide disability benefits.

1935 By 1935, in the United States more than 30 states pass laws allowing for the compulsory sterilization of those deemed genetically unfit in state and federal institutions. By 1970, more than 60,000 people are sterilized under these laws.

1935 As a result of being denied participation in the Works Progress Administration (WPA), six young people with disabilities hold a sit-in at the offices of New York City's Emergency Relief Bureau, demanding jobs in non-segregated environments and explicitly rejecting charity. The League of the Physically Handicapped is born out of this activism and operates in New York from 1935 to 1938. The League identifies social problems that remain issues today.

1935 Peer support in the United States is traced to the establishment of Alcoholics Anonymous in this year. Interest in peer support increases in the 1960s and is adopted by the disabled community. Movements, such as the Center for Independent Living, and groups, such as the National Spinal Cord Injury Association, make peer support one of their major activities.

1936 The American Academy of Physical Medicine & Rehabilitation is founded, leading to the approval of the American Board of Physical Medicine & Rehabilitation by the American Medical Association in 1947.

1937 The Fair Housing Act of 1937 passes with a mandate to assist the poor, a group that includes people with disabilities, by creating public housing. However, it is not until the Rehabilitation Act of 1973 that housing law specifically deals with discrimination faced by individuals with disabilities in housing programs that receive federal funding. The 1988 amendment to the Fair Housing Act of 1968 extends protection for people with disabilities beyond those of Section 504 of the Rehabilitation Act to include private housing.

1939 The Nazi regime institutes the Aktion T4 program in Germany. Children and, later, adults with disabilities are selectively killed both in hospitals and in special centers. The program was officially terminated by Adolf Hitler in August 1941, but practitioners "informally" continued it through a phase historians have called "wild euthanasia."

1940 State activists for the blind, including Jacobus Broek, come together in Wilkes-Barre, Pennsylvania, to charter the National Federation of the Blind (NFB). In 1957, the NFB publishes the first edition of the *Braille Monitor,* which is still in print today. In 1960, dissatisfied NFB members form the American Council of the Blind (ACB).

1940 Paul Strachan establishes the American Federation of the Physically Handicapped, the nation's first cross-disability, national political organization.

1942 The American Psychiatric Association develops a position statement in favor of the euthanasia of children classified as *idiots* and *imbeciles.*

1943 The LaFollette-Barden Act, also known as the Vocational Rehabilitation Amendments, adds physical rehabilitation to federally funded vocational rehabilitation programs.

1943 The United Nations is established on October 24 by 51 countries. The global Programme on the Disability is the lead program concerning disability. Many other types of programs, activities, and instruments include the 1975 Declaration on the Rights of Disabled Persons, the 1981 International Year of

Disabled Persons, the 1982 World Programme of Action Concerning Disabled Persons, the 1983–1992 UN Decade of Disabled Persons, and the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In 1988, the first UN Disability Database (DISTAT) publishes statistics from 63 national studies covering 55 countries and the 2001 publication presents 111 national studies from 78 countries, indicating a growing interest worldwide for the collection of usable data. In 2005, a UN Ad Hoc Committee continues to consider a Convention on the Rights of Disabled Persons that is a legally binding human rights instrument. Today the UN membership totals 191 countries.

1943 Sweden: In possibly the first reference to the concept of normalization, the most significant driving force in the ongoing closure of state-run or state-funded institutions for people with a disability is made by the Committee for the Partially Able-Bodied, established by the Swedish Government. Through the advocacy of people such as Niels Erik Bank-Mikkelsen, normalization, with its profound positive effect on the lives of people who were once removed and segregated from society, remains relevant today.

1944 Richard Hoover invents long white canes known as Hoover canes that are used by many blind people.

1944 The word *genocide* first appears in a book by a Polish lawyer Raphael Lemkin titled *Axis Rule in Occupied Europe* in which he describes Nazi Germany's practices but also seeks the adoption of legal restrictions so that genocide will not occur. In 1948, the United Nations adopts a declaration and then a convention on genocide that describe both against whom genocide might be directed and acts constituting genocide. Article 6 of the Rome Statute of the International Criminal Court (ICC), established in 2002, uses language identical to that in the UN convention to define genocide. More than 90 countries are parties to the ICC, but not the United States.

1945 President Harry Truman signs into law an annual National Employ the Handicapped Week. In 1952, it becomes the Presidents' Committee on Employment of the Physically Handicapped, a permanent organization, which reports to the President and Congress.

1945 Canada: Lyndhurst Lodge, the first specialized rehabilitation center for spinal cord injury (SCI) in the world, and the Canadian Paraplegic Association, the first association in the world administered by individuals with SCI, are established.

1946 The first chapter of what will become the United Cerebral Palsy Association, Inc. is established in New York City. It is chartered in 1949, and along with the Association for Retarded Children, it becomes a major force in the parents' movement of the 1950s.

1946 The National Mental Health Foundation is founded by attendants at state mental institutions who aim to expose abusive conditions. Their work is an early step toward deinstitutionalization.

1946 The National Institutes of Mental Health (NIMH) are founded in the United States.

1946 Europe: The European Union is founded on September 17 in Paris. It consistently shows its commitment to eliminating discrimination on many fronts through joint declarations, resolutions, directives, and action programs. With regard to disability, the European Union supports actions in favor of people with disabilities, principally in the form of European Social Fund interventions. Action programs aim at facilitating the exchange of information between member states and nongovernmental organizations with a view to identifying good practices, integrating people with disabilities into society, and raising awareness of related issues. The EU Council of Ministers Recommendation on the Employment of Disabled People (1986) calls on member states to "eliminate negative discrimination by reviewing laws, regulations and administrative provisions to ensure that they are not contrary to the principle of fair opportunity for disabled people." Further

steps are taken in 1996 when a communication on equality of opportunities for disabled people sets out a new European disability strategy that promotes a rights-based approach, rather than a welfare-type approach. This is strengthened in 1997 when the heads of state act to strengthen Article 13 of the European Community Charter of Fundamental Social Rights of Workers (1989), giving the European Community specific powers to take action to combat a broad spectrum of discrimination that includes disability.

1948 The National Paraplegia Foundation is established as the civilian branch of the Paralyzed Veterans of America.

1948 The World Health Organization is established. The WHO actively promotes human rights and the principle of equity in health among all people of the world, including persons with disabilities. Today it consists of 191 member states, but strives for universal membership. In 1980, the WHO publishes the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and issues a revised version in 2001, the International Classification of Functioning, Disability, and Health (ICF).

1948 The United Nations General Assembly adopts the "Universal Declaration of Human Rights," which promotes and affirms the fundamental rights to life, liberty, and security; to medical care and social services; and to the benefit from scientific progress and its uses.

1948 Sir Ludwig Guttmann organizes the first Stoke Mandeville (England) Games for the Paralysed, thus launching the Paralympic movement. The Games become international in 1952. In 1960, the first Paralympic Summer games are held in Rome and the first Paralympic Winter Games follow in 1976. The Paralympic Games are multi-disability, multi-sport competitions and have become the second-largest sporting event in the world, only after the Olympic Games.

1948 World War II bomber pilot and war hero Leonard Cheshire establishes what is to become the largest charitable supplier of services for disabled people in the United Kingdom. In the 1960s, the resistance of disabled people who live in one Leonard Cheshire home, Le Court, plays a major role in establishing the British disabled people's movement. In the late 1990s, the Leonard Cheshire organization establishes the Disabled People's Forum, which is run by disabled people and supports disabled people's involvement and empowerment.

1949 Timothy Nugent founds the National Wheelchair Basketball Association, and the first Annual Wheelchair Basketball Tournament takes place.

1949 Europe: The Council of Europe, an intergovernmental organization, is founded. Its activities cover all major issues facing European society other than defense. Human dignity, equal opportunities, independent living, and active participation in the life of the community form the heart of the Council of Europe's activities in relation to people with disabilities. The European Social Charter of 1961 and its revision in 1996 include specific wording and expand the rights of individuals with disabilities.

1950 The Social Security Amendments of 1950 provide federal-state aid to the permanently and totally disabled (APTD), which serves as a limited prototype for future Social Security assistance programs for disabled people.

1950 The National Mental Health Association is formed with the mission to continue 1908-advocate Clifford W. Beers's goals of "spreading tolerance and awareness, improving mental health services, preventing mental illness, and promoting mental health."

1950 The National Association for Retarded Children (NARC) is established by families in Minneapolis. It is the first and most powerful parent-driven human-services lobby in the nation to emerge in the 1950s.

1950 Amniocentesis is developed by a Uruguayan obstetrician. Later, advanced prenatal testing provides a battery of powerful medical tools to predict risk of disability and provide information to parents about their pregnancies.

1951 With the founding of the World Federation of the Deaf, the deaf community becomes international.

1953 Francis Crick and James Watson propose a three-dimensional structure for the DNA molecule. The paper they publish also gives clues to genetic mechanisms. Today, more than 6,000 monogenic disorders have been identified, and these affect approximately 1 in 200 live births.

1955 The polio vaccine, developed by Dr. Jonas Salk, becomes available, thus ending polio epidemics in the Western world. A new oral vaccine, developed by Dr. Albert B. Sabin, is approved for use in 1961.

1956 Social Security Disability Insurance (SSDI) becomes available through amendments to the Social Security Act of 1935 (SSA) for those aged 50–64. Other important amendments to SSA include the following: 1958: provides for dependents of disabled workers; 1960: removes age limit; 1965: Medicare and Medicaid provide benefits within the framework of the SSA (until 1977); 1967: provides benefits to widows and widowers over the age of 50; 1972: Supplemental Security Income (SSI) establishes a needs-based program for the aged, blind, and disabled; 1984: the Social Security Disability Reform Act responds to the complaints of hundreds of thousands of people whose disability benefits have been terminated; 1996: President Clinton signs the Personal Responsibility and Work Opportunity Reconciliation Act, making it more difficult for children to qualify as disabled for SSI purposes.

1959 The UN Declaration of the Rights of the Child is adopted; the UN Convention on the Rights of the Child is adopted in 1989. A central principle of both documents is access to education for all children including those with disabilities. In 1993, a related UN document, the Standard Rules for the Equalization of Opportunity, extends this to preschool children, and in 1994, UNESCO's Salamanca Statement and Framework for Action specifies the provision of special education for children with disabilities or learning difficulties. These documents constitute a universal bill of rights that can serve as a framework in the development of national policies worldwide.

1961 The American Council of the Blind is established.

1961 Europe: The European Social Charter (ESC) protects "the right of physically and mentally disabled persons to vocational training, rehabilitation and social resettlement." In 1996, it is revised, updated, and expanded to take account of social changes.

1961 Michel Foucault's work *The History of Madness in the Classical Age* becomes obligatory reading for those concerned with the archaeology of madness and its treatments. It continues to be an academic *rite de passage.*

1962 Battered child syndrome is defined. Researchers estimate that the incidence of maltreatment of children with disabilities is between 1.7 and 3.4 times greater than of children without disabilities.

1962 Russia: The Moscow Theater of Mime and Gesture is the first professional deaf theater in the world. It has been in continuous operation for more than 40 years and has staged more than 100 classic and modern plays.

1963 Congress enacts new legislation to ensure funding for a comprehensive program of research on mental retardation through the National Institute on Child Health & Human Development. In 1965, the Office of Economic Opportunity launches the Elementary and Secondary Education Act (ESEA), commonly known as Project Head Start. The goal is to prevent developmental disability by providing increased opportunities for disadvantaged children in the preschool years.

1963 The Developmentally Disabled Assistance and Bill of Rights Act (DD ACT) is authorized, with its last reauthorization in 1996. It focuses on individuals with developmental disabilities such as intellectual disability, autism, cerebral palsy, epilepsy, and hearing and visual impairments, among others.

1964 The Civil Rights Act is passed. It becomes the model for future disability rights legislation.

1964 France: L'Arche is established. By the beginning of the twentieth-first century, it includes more than 113 communities in 30 countries. "The Ark" is a distinctive style of community living, based on "core members" and "assistants," who view their commitment as sharing life *with* people with disabilities, rather than as caregivers.

1965 Newly enacted Medicare and Medicaid provide national health insurance for both elderly (over 65) and disabled persons.

1965 The Vocational Rehabilitation Amendments of 1965 are passed. They provide federal funds for the construction of rehabilitation centers and create the National Commission on Architectural Barriers to Rehabilitation of the Handicapped.

1965 The Autism Society of America is founded.

1967 Deaf actors establish the National Theatre of the Deaf (NTD). It is the world's first professional deaf theater company and the oldest continually producing touring theater company in the United States. Today, after almost 40 years, the NTD chronicles over 6,000 performances. The National Theatre Workshop for the Handicapped begins in 1977 and the Other Voices Project in 1982. These groups are among the earliest groups formally to place the disability experience at the heart of their creative endeavors.

1967 Heart transplantation is introduced. This technology is preceded by open-heart surgery developed in the 1950s and coronary bypass and internal pacemakers in the1960s. The Framingham Heart Study begins in 1948. It collects data over the next decades that help identify major risk factors contributors to heart disease.

1967 Paul Lemoine in France in 1967 and Kenneth Jones and David Smith in the United States in 1973 independently describe the condition fetal alcohol syndrome (FAS), which comprises a recognizable pattern of birth defects attributable to the adverse effects of maternal alcohol abuse during pregnancy.

1967 England: St. Christopher's Hospice in South London opens. It is the first attempt to develop a modern approach to hospice and palliative care.

1968 Congress enacts the Architectural Barriers Act. The ABA requires access to facilities designed, built, altered, or leased with federal funds.

1968 The Fair Housing Amendments to the Civil Rights Act of 1968 guarantees civil rights of people with disabilities in the residential setting. The amendments extend coverage of the fair housing laws to people with disabilities and establish accessible design and construction standards for all new multifamily housing built for first occupancy on or after March 13, 1991.

1968 Sweden: The origins of People First® go back to a meeting of parents of children with intellectual disabilities whose motto is "we speak for them." However, the people with disabilities in attendance wish to speak for themselves and start their own self-advocacy group. Similar groups quickly spread to England and Canada. The name People First is chosen at a conference held in Salem, Oregon, in 1974. People First is an international self-advocacy organization run by and for people with intellectual disabilities to work on civil and human rights issues.

1970 ◆ Landmark legal cases such as *Diana v. State Board of Education* (1970; Latino students) and *Larry P. v. Riles* (1971–1979; minority students) challenge biases inherent in standardized testing procedures used to identify students as eligible for special education. Both cases call into question the widespread use of "scientifically" objective measures to gauge intellectual ability. Today, despite reforms, a disproportionate number of students from racial, ethnic, and linguistic minorities continue to be placed in special education classes.

1970 ◆ Japan: The Disabled Persons' Fundamental Law (DPFL) becomes one of the 27 fundamental laws that stipulate basic principles in each policy area. Major revision takes place in 1993 reflecting a progress of guiding principles in disability policy that are deeply influenced by international movements such as the International Year of Disabled Persons (1981) and the UN Decade of Disabled Persons (1983–1992). Disability Studies as well as modern disability movements are born this same year, when members of Aoi Shiba, a group of people with cerebral palsy, protest publicly for the first time against sympathetic views toward the killing of disabled children by their parents. Aoi Shiba and other disability movements join in the establishment of Disabled Peoples' International in 1981. In 1986, the Rehabilitation Engineering Society of Japan (RESJA) is established. In 1992, disability movements in Japan initiate the Asian and Pacific Decade of Disabled Persons 1993 to 2002. The Japan Society for Disability Studies is established in 2003 and a unified national organization, Japan Disability Forum (JDF), is established in 2004.

1970 ◆ United Kingdom: The Chronically Sick and Disabled Persons Act (CSDPA) strengthens the provisions in the 1948 National Assistance Act (NAA). Later, the Disability Discrimination Acts of 1995 and 2005, together with the Disability Rights Commission Act of 1999, constitute the primary source of antidiscrimination legislation for disabled people.

1971 ◆ A U.S. District Court decision in *Wyatt v. Stickney* is the first important victory in the fight for deinstitutionalization.

1971 ◆ WGBH Public Television establishes the Caption Center, which provides captioned programming for deaf viewers.

1971 ◆ Gerontologist M. Powell Lawton defines *functional assessment* as any systematic attempt to objectively measure the level at which a person is functioning in a variety of domains. Over 30 years later, functional assessment, in combination with *outcomes analysis,* is considered one of the "basic sciences" of rehabilitation. In 1980, the World Health Organization proposes a series of definitions, which have a profound impact on the assessment of functional status and outcomes in rehabilitation. It is modified and revised in 1993 and 2001.

1971 ◆ The Declaration on the Rights of Mentally Retarded Persons (UN 1971), the Declaration on the Rights of Disabled Persons (UN 1975), and the World Programme of Action Concerning Disabled Persons (UN 1982) indicate the emergence of a global discourse of rights for disability.

1972 ◆ A group of people with disabilities (including Ed Roberts, John Hessler, and Hale Zukas), known as the Rolling Quads, living together in Berkeley, California, formally incorporate as the Center for Independent Living (CIL). This first CIL in the country becomes the model for Title VII of the Rehabilitation Act of 1973. In the late 1980s and early 1990s the group's advocacy efforts help pass the Americans with Disabilities Act (ADA). CILs are always controlled by disabled people. Accepted by most people as the birth of the modern independent living movement, the Berkeley concept migrates to other countries. In 1999, a global summit on independent living is held in Washington D.C. The summit brings together more than 70 countries. The Washington Declaration that comes out of the conference establishes a set of basic principles. In 1996, the Ed Roberts Campus, an international center and a service facility, is created in Berkeley, California, in memory of Edward V. Roberts, founder of the independent living concept.

1972 ◆ A young television reporter for the ABC network, Geraldo Rivera, is given a key to one of the wards at Willowbrook State School on Staten Island, New York. Established in the late 1930s as a state-of-the-art facility for the "mentally deficient," by 1972, Willowbrook becomes a warehouse for the "socially undesirable" of New York City, with a substantial minority having no disability at all. The inhumane conditions deteriorate to the extent that a visitor remarks, "In Denmark we don't let our cattle live this way." Rivera's exposé leads to a lawsuit that results in the Willowbrook Consent Decree of 1975, which creates a detailed system of monitoring and oversight of all residents living there at that time, to be met until the last of the "class clients," as they are sometimes referred to, pass on. The property has since been sold to a college.

1972 ◆ Paul Hunt's call for a consumer group to promote the views of actual and potential residents of institutional homes for the disabled in the United Kingdom results in the establishment of the Union of the Physically Impaired against Segregation (UPIAS). The group's aim is to formulate and publicize plans for alternative forms of support in the community. Hunt is regarded by many disability activists as the founder of the modern disabled people's movement.

1972 ◆ New Zealand: Three key pieces of legislation pass have long-term effects on the disabled community: the 1972 no-fault Accident Compensation Act that provides monetary compensation to victims based on level of impairment suffered; the 1975 Disabled Persons Community Welfare Act, giving assistance to disabled people, parents, and guardians, as well as voluntary associations; and the Human Rights Act of 1977, which does not include disability as a recognized grounds for discrimination. Today, disabled populations in New Zealand continue to fight to establish an identity as disabled people rather than a group needing "welfare." One task is to promote legislation that includes disability as a group against whom discrimination is outlawed.

1973 ◆ The Rehabilitation Act of 1973 lays the foundation for the disability rights movement. Its Section 504 asserts that people with disabilities have equal rights that prevent discrimination based on their disability in programs or activities that receive federal funding. This is the first major nationwide antidiscriminatory legislation designed to protect disabled Americans. These rights are further protected with the landmark Americans with Disabilities Act (ADA) of 1990.

Section 501 of the Act requires affirmative action and nondiscrimination in employment by federal agencies of the executive branch. Section 502 creates the Access Board, which grows out of the 1965 National Commission on Architectural Barriers to Rehabilitation of the Handicapped. As a result of the commission's June 1968 report, Congress enacts the Architectural Barriers Act (ABA). Section 503 requires that to receive certain government contracts, entities must demonstrate that they are taking affirmative action to employ people with disabilities. The enduring hallmark of the act, Section 504, provides that no otherwise qualified individual with a disability shall, solely by reason of his or her disability, be excluded from the participation in, denied the benefits of, or subjected to discrimination under any program or activity receiving federal funds. However, it would take five years of lobbying and protesting before the American Coalition of Citizens with Disabilities (ACCD) wins the release of regulations that allow Section 504 to be implemented.

The Act is in many ways the direct predecessor to the ADA. However, the primary focus is vocational training and rehabilitation, and over the next half-century, disability law and advocacy move from the medical (medical issues) and vocational (often a justification for welfare and benefits) models to a civil rights model, which seeks to remove the barriers that impede the full integration of people with disabilities into society.

1973 ◆ The term *mainstreaming* emerges within the educational jargon associated with the Education for All Handicapped Children Act (EHA), the early U.S. legislation subsequently reauthorized as the Individuals with Disabilities Act (IDEA) in 1990.

1973 ◆ Ronald Mace is the driving force behind the creation of the first accessible state building code in the United States (North Carolina, 1974) and in the drafting of national accessibility codes and

standards. He coins the term *universal design* to capture and promote his expanded philosophy of "design for all ages and abilities"—curb cuts being his favorite example.

1973 Washington D.C. introduces the first handicap parking stickers. The Federal-Aid Highway Act funds curb cuts.

1974 First Lady Betty Ford and investigative reporter Rose Kushner are diagnosed with breast cancer. They help break the public silence on this topic. In 1954, Terese Lasser begins Reach to Recovery, a program of volunteers who have previously undergone radical mastectomies who provide emotional support to hospitalized women who have just had the operation. Today, one in eight women is diagnosed with breast cancer during her lifetime.

1975 The Education for All Handicapped Children Act, the first separate federal legislation authorizing special education for children and youth, passes, due, in part, to the advocacy efforts of a group of parents. In 1990, it becomes known as the Individuals with Disabilities Education Act, or IDEA.

1975 The Developmentally Disabled Assistance and Bill of Rights Act, providing federal funds for programs that provide services for people with developmental disabilities, passes.

1975 The Association of Persons with Severe Handicaps (TASH) is founded. It calls for the end of aversive behavior modification and deinstitutionalization of people with disabilities.

1975 The UN General Assembly adopts the Declaration on the Rights of Disabled Persons, which states that all persons with disabilities have the same rights as other people. This document is not legally binding and can be attributed in part to a UN Ad Hoc Committee set up in 2001 to consider a Convention on the Rights of Disabled Persons that is legally binding.

1975 United Kindom: The Union of the Physically Impaired against Segregation (UPIAS) publishes a paper that redefines the term *disability,* which becomes known as the social model of disability as it radically transforms the way disabled people see themselves and their place in society.

1976 The Higher Education Act of 1965, which establishes grants for student support services aimed at fostering an institutional climate supportive of low-income and first-generation college students, is amended to include individuals with disabilities. In March 1978, the Association on Handicapped Student Service Programs in Post-Secondary Education is founded. It later becomes the Association on Higher Education and Disability (AHEAD).

1976 Sponsored by Ralph Nader's Center for the Study of Responsive Law, the Disability Rights Center is founded in Washington D.C.

1977 Protesting the federal government's delayed enactment of the rules and regulations for the implementation of the Rehabilitation Act of 1973, disabled activists on April 1 organize protests at the federal offices of the Department of Health and Human Services in various cities across the United States. In San Francisco, protesters hold the regional offices hostage for 28 days, gaining national attention and resulting in an agreement with federal officials for the rapid establishment of the rules and regulations to implement Section 504 of the Act.

1977 Max Cleland is appointed to head the U.S. Veterans Administration. He is the first severely disabled person to hold this post.

1977 S. Z. Nagi defines *disability* as an individual's performance of tasks and activities related to achievement of social roles—a distinct concept, different from *impairment*. It is further formalized with the introduction of the World Health Organization's International Classification of Impairments, Disabilities, and Handicaps in 1980 and further refined in 2001 in its International

Classification of Functioning, Disability, and Health. Nagi's model is used as the basis for the Americans with Disabilities Act, for almost all disability social policy in the United States, and for statistics at the United Nations and in Europe.

1978 ◆ The Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 and the Adoption Assistance and Child Welfare Act of 1980 promote the adoption of children with special needs, including disabilities.

1978 ◆ The Atlantis Community, the second independent living center in the country after Berkeley, is established in Denver, Colorado, in 1975. On July 5–6, 1978, twenty disabled activists from the Atlantis Community block buses with their wheelchairs and bodies and bring traffic to a standstill at a busy downtown intersection. This act of civil disobedience results in the American Disabled for Accessible Public Transit, the original name for the American Disabled for Attendant Programs Today, or ADAPT.

1978 ◆ Legislation creates the National Institute on Handicapped Research. In 1986, it is renamed the U.S. National Institute on Disability and Rehabilitation Research (NIDRR). Its mission is to contribute to the independence of persons of all ages who have disabilities. It is located in the Department of Education under the Office of Special Education and Rehabilitation Services.

1978 ◆ The World Health Organization starts to promote the concept of community-based rehabilitation (CBR) as a means of helping people with disabilities in the developing world. It emerges, in part, from the WHO primary health care campaign Health for All by the Year 2000. Around the same time, in Western countries, home-visiting programs in which a trained worker regularly visits the family to advise on ways of promoting child development become one of the success stories of modern disability services. Among the best-known programs are those based on a model originating in Portage, Wisconsin, and now used in many countries.

1978 ◆ England: The Warnock report introduces the term *special needs education.* It marks a major shift in organizing educational services for children with disabilities and results in the new conceptualization of special needs education. This change is confirmed internationally by the Salamanca Statement and Framework for Action on Special Needs Education at the UNESCO's Conference held in Salamanca in 1994. This theoretical shift is marked with the change of the term *integration* to *inclusion* or *inclusive education.*

1978 ◆ USSR: The Action Group to Defend the Rights of the Disabled is established to advocate for legal rights for Soviets with disabilities.

1979 ◆ The Disability Rights Education and Defense Fund (DREDF) establishes itself as a leading cross-disability civil rights law and policy center. It is founded by people with disabilities and parents of children with disabilities. Because its philosophy is closely aligned with other civil rights struggles, in 1981, DREDF is invited to join the executive committee of the national's largest coalition of civil rights groups, the Leadership Conference on Civil Rights. In 1987, DREDF establishes the Disability Rights Clinical Legal Education Program and begins teaching disability rights law at the University of California's Boalt Hall School of Law.

1979 ◆ The National Alliance for the Mentally Ill (NAMI) is founded. NAMI is an advocacy and education organization.

1979 ◆ Germany: The first Cripples' Group is founded as a cross-disability group with emancipatory aims. In an attempt to reinterpret disability in positive terms, the cofounders choose the term *Krüppel* over handicapped or disabled.

1979 ◆ Nicaragua: The Organization of the Revolutionary Disabled is set up in the wake of the Sandinista victory.

1980 ◆ The California Governor's Committee on Employment of People with Disabilities and entertainment and media industry professionals establish the Media Access Office (MAO).

1980 ◆ About the time Congress is considering passage of the ADA (1990), marketers begin to acknowledge the economic potential of the disabled community; consequently, the appearance of disabled characters in consumer goods advertising mushroom and ability-integrated advertising becomes much more commonplace. Organizations such as MAO and NOD (National Organization on Disability) provide advertising strategies and guidance.

1980 ◆ The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), an interdisciplinary association composed of individuals interested in technology and disability, is founded.

1980 ◆ The World Health Organization's International Classification of Impairments, Disabilities, and Handicaps (ICIDH), a groundbreaking, but controversial, classification system is tentatively released for trial purposes with the goal of uniform information collection worldwide. It has a negligible impact on disability statistics or data collection; however, researchers argue that it is a vast improvement over available tools. It is renamed and vastly revised in 2001.

1980 ◆ England: Graeae Theatre Group, composed of disabled actors, directors, and other theater professionals, is founded in London by Nabil Shaban and Richard Tomlinson. It takes its name from the the Graeae of Greek mythology, three gray-haired sisters who shared one eye and one tooth. Graeae's first production is *Sideshow*.

1980 ◆ Netherlands: The Liliane Foundation starts by assisting 14 children. In 2002, it helps 31,982 children spread over 80 countries. The Foundation's efforts are directed primarily toward children with disabilities living at home. Its aim is to have direct contact with the child within the home situation and to assist the personal growth and happiness of the child, thus providing "tailor-made" assistance.

1980 ◆ Taiwan: The Physically and Mentally Disabled Citizens Protection Law is promulgated. It guarantees legal rights for the disabled and creates a significant improvement in their welfare. Although most of the disabled people in Taiwan still struggle to earn their due respect, today, public awareness of this group is emerging gradually and significantly.

1980 ◆ United Kingdom and Europe: The Black Report (*Report of the Working Group on Inequalities in Health)* is published. Among other groups it targets disabled people for better conditions that lead to better health. The report does not find favor with the Conservative government, but begins to be implemented under the Labour government in 1997. With its central theme of equity, the report plays a central role in the shaping of the World Health Organization's Common Health Strategy of the European Region.

1981 ◆ The Reagan Administration begins to amend and revoke disability benefits, a policy that continues throughout his administration and leads several disabled people who are in despair over the loss of their benefits to commit suicide.

1981 ◆ Justin Dart, recognized as the founder of the Americans with Disabilities Act (ADA, 1990), is appointed to be vice-chair of the National Council on Disability. The council drafts a national policy on equal rights for disabled people; the document becomes the foundation of the ADA.

1981 ◆ The Committee on Personal Computers and the Handicapped is established in Illinois, an indicator of the disabled community's interest in information technology (IT) accessibility, but in order to stimulate the development of suitable products, activists lobby for legislative protections, which are included in the Americans with Disabilities Act of 1990. In 2000, a suit brought by the National Federation of the Blind against AOL is suspended when AOL agrees to make its software accessible by April 2001. The World Wide Web Accessibility Initiative (WAI) launches in 1997. It raises the level of awareness of disability accessibility issues within the Internet community, especially among those who design and implement web pages.

1981 ◆ The first reported cases of AIDS in the United States appear in June. Today, the World Health Organization estimates that worldwide, approximately 40 million people are living with HIV/AIDS; 22 million men, women, and children have died; and 14,000 new infections are contracted every day. Around the world, in the year 2003, the AIDS epidemic claims an estimated 3 million lives, and almost 5 million people acquire HIV, 700,000 of them children. Currently, 6 million people infected with HIV in the developing world are estimated to need access to antiretroviral therapy to survive, but only 400,000 have this access.

1981 ◆ Disabled Peoples' International (DPI) is officially founded at a meeting in Singapore. The establishment of such international organizations around this time represents the disability movement becoming a global social movement instead of a national one. DPI is directed by persons with disabilities working in human rights advocacy. It sponsors World Assemblies, which are held every four years to develop a multiyear action plan. The most recent one is held in 2002 in Sapporo, Japan, where delegates from more than 100 countries come together. A leading slogan for DPI and other disability groups, coined in the early 1990s, is "nothing about us without us."

1981 ◆ The International Year of Disabled Persons encourages governments to sponsor programs that assimilate people with disabilities into mainstream society. Despite the positive worldwide effects it has, the UN program also creates some angry activists with disabilities who protest against the charity approach officially adopted for the event. Consequently, the activists build their own infrastructure consisting of counseling and advocacy facilities as well as job creation programs.

1981 ◆ Australia: Australia's modern disability policy takes shape after the 1981 International Year of Disabled Persons. Examples: The 1980s see a shift away from institutional care; the Commonwealth Disability Service Act provides a framework for the provision of disability services; and in 1991, the federal Disability Reform Package maximizes the employment of disabled. In 1995, a legal decision represents a watershed in telecommunications policy for people with disabilities when a commission's inquiry finds the national carrier, Telstra, guilty of discrimination against people with severe hearing or speech impairments. The success of the action results in the Telecommunications Act of 1997, which includes new provisions for the deaf community.

1981 ◆ Mexico: The Program of Rehabilitation Organized by Disabled Youth of Western Mexico begins as a rural community-based rehabilitation program.

1981 ◆ Soweto: The Self Help Association of Paraplegics begins as an economic development project.

1981 ◆ United Kingdom: Disabled people set up the British Council of Disabled Persons (BCOPD), the United Kingdom's national organization of disabled people, to promote their full equality and participation in UK society.

1981 ◆ Zimbabwe: The National Council of Disabled Persons, initially registered as a welfare organization, becomes a national disability rights group.

1982 ◆ Disability Studies originates with the formation of the Society for the Study of Chronic Illness, Impairment, and Disability. In 1986, it officially changes its name to the Society for Disability Studies (SDS). Disability Studies is a critical field of study based in human and social science.

1982 ◆ *In re Infant Doe* (commonly known as the Baby Doe case) launches the debate as to whether parents or medical authorities should choose to let a disabled infant die rather than provide the necessary medical treatment and nourishment essential to sustain life. In response to this and other cases, the U.S. Department of Health and Human Services creates a rule maintaining it unlawful for any federally funded hospital to withhold medical treatment from disabled infants. In 1984, the U.S. Congress enacts the Child Abuse Amendments, which calls for the medical treatment of newborns with disabilities unless the child would die even with medical intervention. The issue makes it to the U.S. Supreme Court in 1986 with the *Bowen v. American Hospital Association* case. The Court holds that denying treatment to disabled infants does not constitute legally protected discrimination under Section 504 of the Rehabilitation Act and that hospitals and physicians are to implement the decision of the parents. The decision results in the passage of the Child Abuse Prevention and Treatment Act Amendments of 1984. In the year 2000, a scholar argues that the Amendments, presidential commission writings, and disability advocates "have all combined to ensure that most babies who can benefit from medical interventions do receive them."

1982 ◆ Disability Awareness in Action (DAA) and other groups such as the Disabled Peoples' International (DPI) and International Disability Alliance (IDA) are the driving force behind the globalization of disability issues through the World Program of Action (1982), the United Nations Standard Rules of Equalization of Opportunities for People with Disabilities (1993), the World Summit for Social Development (1995), and the Education for All Framework for Action (2000), as well as the current campaign to secure a UN convention on the rights of disabled people.

1982 ◆ The National Council on Independent Living (NCIL) is formed in the United States. It provides an excellent example of leadership for people with disabilities by people with disabilities.

1982 ◆ Canada: The Charter of Rights and Freedoms section of the Constitution provides protection to persons with disabilities.

1982 ◆ France: Handicap International is founded in Lyon. It is active in various areas associated with all the causes of handicaps, both traumatological (land mines, road accidents) and infectious (polio, leprosy). In the 1990s it begins working on mental disability issues as a result of experience with Romanian orphanages and the war in the Balkans. In 1992, Handicap International creates its first two mine clearance programs and in 1997 it is the joint winner of the Nobel Peace Prize for its leading role in the fight against landmines.

1983 ◆ Rights-based approaches to disability rapidly gain currency in many developing countries since the UN Decade of Disabled Persons, 1983–1992. UNESCAP's Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-Based Society for People with Disabilities in Asia and the Pacific sets the priorities for the extended Decade of Disabled Persons, 2003–2012.

1983 ◆ Access and accessibility are concepts discussed throughout the World Programme of Action Concerning Disabled Persons passed by the UN General Assembly. The General Assembly in 1993 passes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

1983 ◆ England: The first Covent Garden Day of Disabled Artists is held in London.

1983 ◆ Thailand: DPI-Thailand is established.

1984 ◆ The Access Board issues the "Minimum Guidelines and Requirements for Accessible Design," which today serves as the basis for enforceable design standards. The 1990 Americans with

Disabilities Act (ADA) expands the board's mandate to include developing the accessibility guidelines for facilities and transit vehicles. The Rehabilitation Act Amendments of 1998 give the Access Board additional responsibility for developing accessibility standards for electronic and information technology. In 2001, Section 508 of federal law establishes design standards for federal websites, making them accessible to individuals with disabilities.

1985 ◆ The U.S. Department of Health and Human Services issues the first comprehensive national minority health study, which shows racial disparity in health and concludes that the difference in mortality is not acceptable. In 1998, studies indicate that racial disparity has not improved as much as hoped; consequently, President Bill Clinton launches an initiative that sets a national goal of eliminating disparities in six key areas by the year 2010. Some of these areas include diseases and conditions considered to be disabling as well as life threatening.

1986 ◆ The Air Carrier Access Act (ACAA) passes. It requires the U.S. Department of Transportation to develop new regulations that ensure that disabled people are treated without discrimination in a way consistent with the safe carriage of all passengers. The relevant regulations, Air Carrier Access rules, are published in March 1990.

1986 ◆ The National Council on the Handicapped publishes its report *Toward Independence.* It recommends that "Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities" and suggests that the law be called "the Americans with Disabilities Act." In its 1988 follow-up report, *On the Threshold of Independence,* the council takes the somewhat unusual step of publishing its own draft of the ADA bill.

1986 ◆ The Equal Opportunities for Disabled Americans Act allows recipients of federal disability benefits to retain them even after they obtain work, thus removing a disincentive that keeps disabled people unemployed.

1986 ◆ Australia: The Disability Services Act provides that a person with disability has the right to achieve his or her individual capacity for physical, social, emotional, and intellectual development. In 1992, the Disability Discrimination Act supports nondiscrimination in education and training. It also makes it unlawful to discriminate in relation to access to premises, including public transportation.

1986 ◆ Canada: The Employment Equity Act mandates the institution of positive policies and practices to ensure that persons in designated groups, including persons with disabilities, achieve at least proportionate employment opportunities.

1986 ◆ England: The first issue of the magazine *Disability Arts in London* (DAIL) is produced in London.

1986 ◆ Southern Africa: The Southern Africa Federation of the Disabled is formed as a federation of nongovernmental organizations of disabled persons.

1988 ◆ The Technology Act (Technology-Related Assistance for Individuals with Disabilities Act of 1988 and its 1994 amendments), and, in 1998, the Assistive Technology Act (AT) provide financial assistance to states to support programs of technology-related assistance for individuals with disabilities of all ages. The1988 act defines *assistive technology* (AT). The Americans with Disabilities Act of 1990 prohibits discrimination against people with disabilities in employment, public institutions, commercial facilities, transportation, and telecommunications, which includes accessibility to all entrances, bathrooms, program areas, and parking spaces as well as interpreters for the deaf and Braille and large-print materials for the blind. The Telecommunications Act of 1996 requires the telecommunication industry to make equipment that will support transmission of information in forms accessible to people with disabilities including broadband and television program captioning. By 2000, approximately 10 percent of the U.S. population uses AT devices and/or modifications to their home, work, or school that allow them to participate in major life activities.

1988 Congress introduces a series of amendments to the Civil Rights Act of 1968, including a prohibition of housing discrimination against people with disabilities. These amendments are known as the Fair Housing Act Amendments of 1988.

1988 China: Deng Pufang, a wheelchair user and son of the late Chinese leader Deng Xiaoping, is the driving force behind a series of laws and programs initiated to improve life for the disabled. In 1984, he sets up the China Welfare Fund for Disabled Persons and, in 1988, the China Disabled Persons' Federation, which endeavors to improve public images of disabled people. Today, there are 60 million disabled people in China.

1989 The European Network on Independent Living (ENIL) is set up. It focuses on personal assistance as a key component of independent living.

1990 ADAPT, the American Disabled for Attendant Programs Today, originally called the American Disabled for Accessible Public Transit, continues to gain public awareness through tactics of civil disobedience until regulations are finally issued with the passage of the Americans with Disabilities Act (ADA).

The ADA passes, after ADAPT uses tactics of civil disobedience, in the tradition of other civil rights movements, in one of the largest disability rights protests to date (600 demonstrators), the "Wheels of Justice March," during which dozens of protesters throw themselves out of their wheelchairs and begin crawling up the 83 marble steps to the Capitol to deliver a scroll of the Declaration of Independence. The following day 150 ADAPT protesters lock wheelchairs together in the Capitol rotunda and engage in a sit-in until police carry them away one by one.

George H.W. Bush signs the ADA on July 26. It provides employment protections for qualifying persons with disability. It is the most prominent and comprehensive law prohibiting discrimination on the basis of disability in the United States, expanding the mandate of Section 504 of the Rehabilitation Act of 1973 to eliminate discrimination by prohibiting discrimination in employment, housing, public accommodations, education, and public services.

In June 2000, the National Council on Disability issues a report, *Promises to Keep: A decade of Federal Enforcement of the Americans with Disabilities Act,* which includes 104 specific recommendations for improvements to the ADA enforcement effort. On December 1, 2004, the council issues a final summary report, *Righting the ADA,* in order to address "a series of negative court decisions [that] is returning [Americans with disabilities] to 'second-class citizen' status that the Americans with Disabilities Act was supposed to remedy forever."

1990 The ADA requires public entities and businesses to provide effective communication to individuals with disabilities. Title IV of the ADA mandates that nationwide telecommunication systems be accessible to persons with speech or hearing disabilities. The Federal Communications Commission (FCC) requires relay services to be in place by July 26, 1993. The Telecommunications Act of 1996 adds provisions to the Communications Act of 1934 that requires manufactures and providers of telecommunications equipment and services to ensure accessibility to persons with disabilities. In 2000, President Bill Clinton establishes regulations governing the accessibility to people with disabilities of the electronic and information technology used within the federal government.

1990 The Individuals with Disabilities Education Act (IDEA) is enacted. It guarantees the right to free and appropriate education for children and youth with disabilities and focuses on higher expectations, mainstreaming students where possible, and an increased federal rule in ensuring equal educational opportunity for all students. IDEA requires schools to provide a free and appropriate public education to eligible children with disabilities. It also requires schools to develop an individualized education plan (IEP) for each child and placement in the least restrictive environment (LRE) for their education. IDEA is amended in 1997 and reauthorized again in 2004 as the Individuals with Disabilities Education Improvement Act.

1990 ◆ Legislation establishes the National Center for Medical Rehabilitation Research (NCMRR), whose mission is to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of persons with disabilities. It has primary responsibility for the U.S. Government's medical rehabilitation research that is supported by the National Institutes of Health (NIH).

1990 ◆ The World Declaration on Education for All (EFA) is adopted in Jomtien, Thailand, by more than 1,500 persons representing the international community. Article 23 of the UN Convention on the Rights of the Child states that disabled children have the right to a "full and decent life" and that member nations provide free education and training to disabled children whenever possible in order to provide the "fullest possible social integration and individual development." UNESCO is the lead UN organization for special needs education.

1990 ◆ Korea: The disability movement celebrates the passage of the Employment Promotion Act for People with Disabilities. The government imposes control over the disabled population in the 1960s and 1970s by forwarding institutionalization under the banner of "protection," promoting sterilization, and violating the rights of disabled people in general. The 1981 International Year of Disabled Persons influences the government, and new laws, such as the Welfare Law for Mentally and Physically Handicapped, are enacted, and the human rights of disabled people becomes the dominant rhetoric of the disability movement.

1990 ◆ United Kingdom: The National Disability Arts Forum is launched at the UK-OK Conference at Beaumont College in Lancashire, UK.

1991 ◆ The Resolution on Personal Assistance Services is passed at the International Personal Assistance Symposium. Personal assistance services are the most critical services for individuals. Critical aspects of these services are that they must be available up to 24 hours a day, 7 days a week, to people of all ages, and with access to governmental payments. In the United States alone, personal assistance services affect the lives of more than 9.6 million citizens with disabilities.

1991 ◆ Australia: The federal Disability Reform Package is introduced; the Disability Discrimination Act, which covers issues of discrimination in education, is enacted in 1992; and the Commonwealth Disability Strategy, designed to provide equal access to government services for people with disabilities, is first introduced in 1994 and then revised in 2000. During the 1990s similar discrimination legislation emerges in other countries, such as New Zealand's Human Rights Act, the U.K.'s Disability Discrimination Act, Israel's Disabled Persons Act, Canada's Human Rights Act, and India's Disabled Person's Act.

1991 ◆ China: The most important laws and initiatives reside in the 1991 Law on Protection of Disabled Persons and a series of National Work Programs for Disabled Persons (1988, 1991, 1996, 2001), which integrate disability into the government's Five-Year Plans. China participates heavily in the United Nations Decade of Disabled Persons, 1983–1992, and initiates the Asia Pacific Decade of the Disabled Persons, 1993–2002. China continues to collaborate with UN projects involving the disabled and will host the 2007 International Special Olympics in Shanghai.

1991 ◆ Serbia and Montenegro: From the 1960s to the 1980s, post–World War II Yugoslavia is lauded for being a socially advanced nonaligned nation, but the contemporary wars that decimate Yugoslavia begin in 1991, and today there are more than one million disabled citizens, refugees, and casualties due to the wars. Disabled people in Serbia and Montenegro (formally named the Federal Republic of Yugoslavia—FRY) are left with shattered pieces of the spent past with little hope for the near future. Although the FRY constitution prescribes special protection of disabled persons in accordance with legal provisions and Serbia is party to numerous UN documents and acts, a disabled expert in 2004 admits that discrimination against persons with disability in Serbia and Montenegro is a

long-term problem that people without disability tend to ignore. Two of the most effective advocacy groups making in-roads today are the Association of Students with Disabilities and the Center for Independent Living in Belgrade.

1992 ◆ The UN Economic and Social Commission of Asia and the Pacific (ESCAP) proclaims a 10-year program known as the Asian and Pacific Decade of Disabled Persons 1993–2002 with goals of full participation and equality for persons with disabilities.

1993 ◆ The United Nations publishes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which becomes the international legal standards for disability programs, laws, and policies. Although not legally enforceable this instrument sets an inclusive and antidiscriminatory standard that is used when national policies are developed. It marks a clear shift from the rehabilitation and prevention paradigm to the human rights perspective on disability.

1993 ◆ Slovak Republic: The Czech and Slovak Republics separate into two independent countries. They both join the European Union in 2004. In Slovakia, a large number of highly innovative and resourceful grassroots nongovernmental organizations emerge to address the human rights, quality-of-life, and independent living priorities of citizens with disabilities. They pursue this mission, however, with extremely limited resources and with varying degrees of support from a multiparty parliament.

1993 ◆ Sweden: The Independent Living Institute (ILI) is founded.

1994 ◆ Two networks, one for elderly persons and the other for persons with disabilities, join together to form the U.S. National Coalition on Aging and Disability. In following years, policy makers and advocates begin to see the benefits of merging some services.

1994 ◆ Germany: The disability rights movement is successful in using for its own aims the reform of the German constitution, which is made necessary by the reunification process. An amendment to the constitution forbids discrimination on the grounds of disability. Other such laws as the Rehabilitation of Participation Law (2001) and the Federal Equal Rights Law (2002) are formulated with the active contribution of disability rights activists, and in 2003, the official German program of the European Year of People with Disabilities is organized by a prominent activist.

1994 ◆ Sweden: The Swedish Disability Act (LSS) comes into force. It expands the 1985 Special Services Act. The LSS is also more ambitious than its predecessor, calling for "good living conditions" rather than just an "acceptable standard of living."

1995 ◆ The National Council on Disability, a federal agency, makes recommendations to the president and Congress on disability issues. Among other issues, it calls for the end to the use of aversives (techniques of behavior control such as restraints, isolation, and electric shocks) because they are abusive, dehumanizing, and psychologically and physically dangerous. Other organizations follow, such as the Autism National Committee in 1999, TASH in 2004, and the International Association for the Right to Effective Treatment in 2003.

1995 ◆ The Commission for Case Management Certification (CCMC) incorporates. Case management is a process of care planning and coordination of the services and resources used by people with disabilities and their families.

1995 ◆ Europe: The Association for the Advancement of Assistive Technology in Europe (AAATE) is founded as an interdisciplinary association devoted to increasing awareness, promoting research and development, and facilitating the exchange of information. AAATE is composed of more than 250 members from 19 countries. It interacts with sister organizations in North America, Japan, and Australia to advance assistive technology worldwide. The Tokushima Agreement, signed in 2000 by AAATE, the Rehabilitation Engineering and Assistive Technology Society of North America

(RESNA), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation and Assistive Technology Association (ARATA), promotes exchange of information and collaboration.

1995 ◆ United Kingdom: The campaign for antidiscrimination legislation begins in earnest with the emergence of the disability movement in the late 1970s. The Disability Discrimination Act of 1995 (DDA) together with the Disability Rights Commission Act of 1999 constitute the primary source of antidiscrimination legislation for disabled people in the United Kingdom. The Disability Discrimination Act 2005 extends the protection.

1996 ◆ There are 1.4 million fewer disabled older persons in the United States than would have been expected if the health status of older people had not improved since the early 1980s.

1996 ◆ Advocates for mental health parity such as the National Alliance for the Mentally Ill (NAMI; 1979) believe that mental illnesses are real illnesses and that health insurance and health plan coverage for treatment should be equal with coverage of treatment for all other illnesses. Due in part to advocacy, the Mental Health Parity Act becomes law in 1996. In 1999, mental illness ranks first in causing disabilities among many industrialized nations, including the United States, which experiences a loss of productivity in this year of $63 billion. In the United States, 5 to 7 percent of adults suffer from serious mental disorders and 5 to 9 percent of children suffer from serious emotional disturbances that severely disrupt their social, academic, and emotional functioning.

1996 ◆ Costa Rica: Approval of a law called Equal Opportunities for People with Disabilities is a turning point for the population with disabilities, which is among the most excluded sectors of society. The law is inspired in part by the United Nations Standard Rules on the Equalization of Opportunities for Disabled People (1993). Disability experience in Costa Rica is definitely transformed as a result of the mandates of this generic law, as people with disabilities and their families start to use this legal instrument as a strategy to empower themselves.

1996 ◆ Europe: Created in 1996, the European Disability Forum (EDF) is today the largest independent, trans-European organization that exists to represent disabled people in dialogue with the European Union (EU) and other European authorities. Its mission is to promote equal opportunities for disabled people and to ensure disabled citizens full access to fundamental and human rights through its active involvement in policy development and implementation in the EU. The EDF has national councils in 17 European countries and has 127 member organizations. The European Year of People with Disabilities 2003 is one of the EDF's most important campaigns.

1996 ◆ India: The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, becomes law. It is the first legislation for equal opportunities for disabled people. Prior to this, disabled persons receive services but not legal protection. Improvements in conditions begin in 1981 with the International Year of Disabled Persons. India is a signatory to the UN resolution of 1976 establishing it and is thereby committed to improving the lot of the disabled. The Lunacy Act of 1912 is repealed and the National Mental Health Act is passed in 1987. Nonetheless, with approximately 70 million disabled people residing in India (in a population of over a billion), the government does not include the domain of disability in the 2001 census, which reflects the attitudinal barriers in acknowledging the disabled identity.

1997 ◆ Government expenditures on behalf of persons with disabilities may total as much as $217.3 billion (taking into account the costs that would be expected among persons with disabilities in the absence of the disability), the equivalent of 2.6 percent of the gross domestic product in the United States for 1997.

1997 ◆ The landmark 1997 UNESCO Universal Declaration on the Human Genome and Human Rights frames the actual application of the new scientific developments raised by genetics. As a policy

statement, it provides the first signs that genetics will be applied in ways that maintain human rights. In 2003, the Council of Europe and the council's Steering Committee in Bioethics issue policy statements in a working document titled Application of Genetics for Health Purposes. In the case of gene therapy, in 1994, the Group of Advisors on the Ethical Implications of Biotechnology of the European Commission voices concern regarding equity, maintaining that all genetic services that are available for the entire population should be equally available for persons of disability. Today, UNESCO's Human Genome Organization's Ethics Committee, the World Health Organization, the Council of Europe, and consumer organizations such as Inclusion International, Rehabilitation International, and Disabled Peoples' International play major roles in translating genetic innovations into health service and public health fields, helping develop policies that focus on the general recognition, respect, and protection of the rights to which all people, whether disabled or nondisabled, are entitled. Concerns related to the possible undermining of human rights are expressed in 2003 when Disabled People's International demands a prohibition on compulsory genetic testing.

1997 Colombia: The General Act for People with Disabilities, also known as the Disability Act: Law for Opportunity, passes. The 2003–2006 National Plan of Attention to Persons with Disabilities estimates that 18 percent of the general population has some type of disability. Despite the existence of at least 37 disability-related legal policies (2001), the government provides limited spending on programs that protect the rights of people with disabilities, and the lack of enforcement of rights remains a major concern. Today's awareness efforts include marathons with the participation of the general population to raise money for educational programs for children with special needs, Special Olympics, new organizations such as the Colombian Association for the Development of People with Disabilities, and media awareness campaigns.

1998 President Bill Clinton issues an executive order ensuring that the federal government assumes the role of a model employer of adults with disabilities.

1998 President Clinton signs into law the Rehabilitation Act of 1973 Amendments. Section 508 requires that electronic and information technology (EIT), such as federal websites, telecommunications, software, and information kiosks, must be usable by persons with disabilities.

1998 Ireland: The Irish Employment Equality Act entitles all individuals, including disabled persons, equal treatment in training and employment opportunities. The Education Act of 1998 requires schools to provide education to students that is appropriate to their abilities and needs. The Education for Persons with Disabilities Bill passes in 2003. A Disability Bill published in 2001 fails to underpin a rights-based approach and is withdrawn amid a storm of protest in 2002; a redrafting of a new Disability Bill is suffering from continuing delays. Traditionally, Irish voluntary organizations play a reactionary role in the development of services for people with disabilities and a key role as pressure groups trying to keep disability issues on the political agenda.

1999 The National Center on Physical Activity and Disability (NCPAD) is established as an information and resource center that offers people with disabilities, caregivers, and professionals the latest information on fitness, recreation, and sports programs for people with disabilities.

1999 Established by a panel of experts brought together to evaluate the UN Standard Rules on the Equalization of Opportunities for Persons with Disability, the International Disability Alliance (IDA) encourages cross-disability collaboration and supports the participation of international disability organizations in the elaboration of a proposed UN convention on disability.

1999 England: The first disability film festival, Lifting the Lid, is held at the Lux Cinema in London.

2000 ◆ The National Telability Media Center collects documentation of 3,000+ newsletters, 200 magazines, 50 newspapers, 40 radio programs, and 40 television programs dedicated to disability in the United States alone. *The Ragged Edge, Mainstream* (Internet-based), and *Mouth* are examples of disability rights-focused publications.

2000 ◆ *Healthy People 2000,* the second edition of the Surgeon General's report on health promotion and disease prevention (the first edition published in 1979), includes some reference to the health and well-being of people with disabilities, but few data are available. In the mid-1990s, the U.S. Department of Health and Human Services begins a dialogue with the Centers for Disease Control and Prevention to include people with disabilities in the third edition, *Healthy People 2010.* The resulting report includes more than 100 objectives that include "people with disabilities" as a subpopulation for data gathering.

2000 ◆ The World Bank, increasingly concerned with how to include disabled persons in the economies and societies of developing nations, establishes an online clearinghouse to make documents concerning the disabled readily available to member nations and the general public and holds its first course on disability issues in 2004 in Guatemala.

2000 ◆ Africa: The African Decade of Persons with Disabilities, 2000–2009, is adopted by the Declaration of the Organization of African Unity. The African Network of Women with Disabilities (2001) and the community-based rehabilitation organization CBR Africa Network (CAN) are examples of the many activities that result from the African Decade.

2000 ◆ Brazil is one of the few countries to include an entire section on disability in its 2000 census. Results show that 14.5 percent of the population, roughly 24 million people, report having some form of disability, the poorest region, the northeast, reporting the highest percentage and the richest, in the south, the lowest. People with disabilities in the first half of the twentieth century have no voice or representation. In 1932, the first Pestalozzi Society, a community-based school for children with intellectual disabilities, is founded. By the end of the twentieth century, there are 146 Pestalozzi Societies and more than 1,700 chapters of the Association of Parents and Friends of the Exceptional. The first center for independent living is established in 1988 (CVI-RIO). In 1992 and 1995, CVI-RIO organizes two international conferences on disability issues called DefRio, out of which comes "Goals of the ILM," a document that delineates the basis for the independent living movement in Brazil; however, financial support is not provided by the government, creating a struggle for sustainability. Brazil has progressive policies toward disability. The constitution includes sections on the rights of people with disabilities, and laws have been passed with regard to accessibility, education, and employment.

2000 ◆ Europe: A European Community directive requires all member states to have introduced antidiscrimination laws in the fields of employment and training by the end of 2006. It seeks to establish a general framework for equal treatment in employment and occupation and to render unlawful discrimination based on, among other categories, disability. The European Union Charter of Fundamental Rights sets out in a single text, for the first time in the EU's history, the whole range of civil, political, economic, and social rights of European citizens. Disability is included in the general nondiscrimination clause (Article 21), but Article 26 specifically states that the Union recognizes and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community.

2000 ◆ The Human Genome Project (HGP), an international effort to specify the 3 billion pairs of genes that make up the DNA sequence of the entire human genome, produces its first draft in June 2000. Formally begun in October 1990, it is completed in 2003.

2001 President Clinton declares in Executive Order No. 13217 the commitment of the United States to community-based alternatives for individuals with disabilities. This ensures that the *Olmstead v. L.C.* decision (1999), which mandates the right for persons with disability to live in the least-restrictive setting with reasonable accommodations, is implemented in a timely manner. The executive order directs federal agencies to work together to tear down the barriers to community living.

2001 In the United States, census data indicate that only 48 percent of citizens 25 to 64 years old with severe disabilities have health insurance compared with 80 percent of individuals with nonservere disabilities and 82 percent of nondisabled Americans. Women with disabilities in general are more likely to live in poverty than men. Minorities with disabilities are more likely to live in poverty than nonminorities with disabilities. In 2003, in the United States, about 28 percent of children with disabilities live in poor families compared with 16 percent of all children.

2001 A UN Ad Hoc Committee begins discussions for a legally binding convention under the draft title Comprehensive and Integral Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Its fifth session is held in early 2005.

2001 A new World Health Organization classification of people with disabilities, the International Classification of Functioning, Disability, and Health (ICF), replaces the old International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The ICF definition shifts the focus from disability as an innate deficit (“medical model”) to disability as constructed through the interaction between the individual and the environment (“social model”). This shift encourages a focus on the kinds and levels of interventions appropriate to the needs of individuals.

2001 UNESCO launches pilot education projects for disabled children in Cameroon, the Dominican Republic, Egypt, Ghana, India, Madagascar, Mauritius, Nicaragua, Paraguay, South Africa, Vietnam, and Yemen. The global initiative Education for All 2000 has as its primary millennium development goal universal education by the year 2015.

2002 The U.S. Supreme Court rules that executing persons with mental retardation is unconstitutional.

2002 Disabled Peoples’ International’s 2002 Sapporo Platform, developed by 3,000 delegates from more than 90 countries, urges members to take every opportunity to seek publicity and awareness in order to change negative images of disabled people.

2002 Canada: The Canadian International Development Bank announces the approval of the Canada-Russia Disability Program, a four-year $4 million project, focusing on education, disability studies, social work practice, social policy, and information dissemination.

2003 A national survey that updates the Disability Supplement to the 10-year-old National Health Interview Survey highlights barriers to care among the uninsured. The uninsured are four times as likely to postpone care and three times as likely to go without needed supplies.

2003 The National Association of Social Workers (NASW) issues a policy statement that discusses their core values with respect to working with people with disabilities, including self-determination, social justice, and dignity and worth of the person. The statement emphasizes that social workers are responsible to take action with people who have disabilities in advocating for their rights to fully participate in society.

2003 The Disability Awareness in Action (DAA) database contains a total of 1,910 reports of known abuse affecting nearly 2.5 million disabled people. In the area of education alone, it documents

118 cases affecting 768,205 people in 67 countries. Responding to this documentation and other reports, the United Nations Commission on Human Rights creates the Global Rights campaign to address human rights abuses. Disability rights organizations use this information to insist on a UN convention on the rights of disabled people that would be legally binding on nation-states.

2003 The International Association for the Study of Pain has more than 6,700 members, representing more than 100 countries and 60 disciplinary fields. Chronic pain is one of the leading causes of recurrent and permanent disability in the developed world today, yet less than 1 percent of the U.S. National Institutes of Health's budget supports research into mechanisms and management of pain. The U.S. Congress declares 2000–2010 the Decade of Pain Control and Research.

2004 The *Journal of Gene Medicine* (January) reports that 636 gene therapy clinical trials are completed or ongoing, involving 3,496 patients. The first gene therapy clinical trials begin in the early 1990s.

Today Seventy to eighty percent—approximately 400 million—of the world's disabled people (600 million, or 10 percent of the world's population) live in the developing world, and of the world's poorest of the poor, 20 to 25 percent are disabled. In most countries, 1 out of 10 persons has a disability. Many international efforts are under way to address poverty and disability, such as those of the Action on Disability Development and the Chronic Poverty Research Centre.

Today E-health is the use of emerging interactive telecommunications technologies such as the Internet, interactive TV, kiosks, personal digital assistants, CD-ROMs, and DVD-ROMs to facilitate health improvement and health care services, including those with disabilities. E-health relies on environments that use a variety of technologies that can compensate for the lack of sensory ability. Telerehabilitation is an example of services delivered information technology and telecommunication networks.

Today Celebrating difference is the mantra and visible manifestation of disability culture in all regions of the world.

SEARCHING FOR AND EVALUATING WEBSITES

Anne Armstrong

The Internet, or Web, provides a vast number of channels through which researchers can find information on virtually any subject. The expansiveness of the Web can be daunting to new researchers. On the other hand, researchers often assume that they have mastered the Web in its entirety when indeed they have merely scratched the surface in terms of the numbers of resources they have consulted and searches they have performed.

Because the field of disability studies is continually evolving and inherently multidisciplinary, Web searchers can draw on previously conducted research from disciplines within the humanities, social sciences, and health sciences. This guide aims to expose beginning researchers to a mixture of general and subject-specialized Web-based search tools, as well as strategies for performing sophisticated Web searches and criteria for evaluating websites. In addition to its broad subject coverage, the field of disability studies differs from most fields in that many researchers may themselves have disabilities affecting their ability to perform research on the Web. For this reason, this description concludes with an overview of accessibility issues on the Web and suggestions for further reading.

OVERVIEW OF WEB-BASED RESEARCH TOOLS

When approaching Web searching, researchers should be aware of the multitude of search tools available to them, in addition to the varying purposes of these tools. Many users approach Web searching with the assumption that "everything is in Google," but this is a limiting misconception. No single search engine contains everything on the Web. Furthermore, all search engines function differently and rank results differently. Therefore, sampling various search tools increases the comprehensiveness of results on any topic. This discussion outlines multiple types of search tools available on the Web and offers potential starting points for Internet research on issues related to disability studies, whether from a health sciences, social sciences, or humanities perspective.

The Web-based search tools outlined in this chapter include general search engines, subject-specialized search engines, directories, indexes, catalogs, and Listservs. It is important to note that different types of search tools cover different parts of the Web. The Web is composed of layers. The top layer is detectible by general search engines, while a deeper layer termed "the invisible Web" can be penetrated only by specialized search engines, indexes, and catalogs. Readers should be aware that because the Web is in a constant state of flux, currently available resources may become obsolete over time, and newer, more sophisticated search tools will undoubtedly evolve.

General Search Engines

Most people who have searched the Web are familiar with sites such as Google, HotBot, or Lycos, which allow them to enter a string of keywords into a search box to retrieve a list of relevant websites (see Table 1). These sites, referred to as search engines, search the Web by means of a program called a *spider* (also

Table 1 Selected General Search Engines

Name	*URL*
AltaVista	www.altavista.com
Excite	www.excite.com
GO	www.go.com
Google	www.google.com
HotBot	www.hotbot.com
Lycos	www.lycos.com
Yahoo!	www.yahoo.com

called a *robot* or *crawler*). Since search engines tend to index millions of websites, they are most useful for entering specific search terms rather than broad concepts such as disability studies.

While Web searchers tend to pick a favorite search engine and return to it repeatedly, it is important to note that different search engines produce varying results, and that a truly comprehensive Web searcher should compare the results of multiple search engines. The variation between search engines can be attributed to differences between the spiders fueling the search engines as well as differences in the level of indexing and the order in which results are ranked. While some search engines index the full text of documents, others may index only the first page, or merely the *meta-tags*, which are lines of code containing keywords. Web searchers should be aware that developers of websites may intentionally increase their usage of certain words or meta-tags to increase the prominence of their website among search results. This practice has been referred to as *spamdexing* and is most prevalent among the developers of commercial websites advertising products and services. Due to the constant fluctuation of the Web, no search engine is entirely up-to-date; results produced by identical searches can vary greatly from one day to the next, even when one is using the same search engine.

Subject-Specialized Search Engines

Subject-specialized search engines (also referred to as subject portals) developed by educational institutions, associations, government agencies, and corporate entities narrow the broad scope of the Web, providing a focused channel by which researchers can search for information when they have determined the discipline from which their topic stems. Examples of such search engines are listed in Table 2. While subject-specialized search engines index considerably fewer websites and documents than general search engines, the information contained within them has been preselected, ideally by experts within a given field. Many subject-specialized search engines expose searchers to parts of the "invisible Web" not indexed by general search engines. Subject-specialized search engines can ease the research process by whittling down the Web to a more manageable size. However, researchers who use them should take the time to view the criteria for selection of

Table 2 Examples of Subject-Specialized Search Engines

Name	*URL*	*Subject Coverage*
Center for International Rehabilitation Research Information and Exchange (CIRRIE)	http://cirrie.buffalo.edu	Rehabilitation research
FamilyDoctor.org	http://familydoctor.org	Health sciences
FirstGov	www.firstgov.gov	Government
Google's Uncle Sam	www.google.com/unclesam	Government
Health*Web*	www.healthweb.org	Health sciences
Mayo Clinic	www.mayoclinic.com	Health sciences
MedlinePlus	http://medlineplus.gov	Health sciences
National Center for the Dissemination of Disability Research (NCDDR)	www.ncddr.org	Disability studies
Social Science Information Gateway (SOSIG)	www.sosig.ac.uk	Social sciences
Thomas	http://thomas.loc.gov/	Legislative information
Voice of the Shuttle	http://vos.ucsb.edu	Humanities
*Web*MD	www.webmd.com	Health Sciences

information contained within them. This information is usually posted within online "help" or "about" pages on the home page.

Table 3 contains search tools that have been developed distinctly for the purpose of locating specialized search engines by subject.

Table 3 Resources for Finding Subject-Specialized Search Engines

Name	*URL*
CompletePlanet	www.completeplanet.com
Direct Search	www.freepint.com/gary/direct.htm
InfoMine	www.infomine.com
Invisible Web Directory	www.invisible-web.net
Librarians' Index to the Internet	www.lii.org
Search Engine Colossus	www.searchenginecolossus.com

Directories

Directories are hierarchically arranged subject guides composed of websites chosen by or recommended to editors of the directory (Table 4). Usually, directories follow a template in which major subject categories such as health, sciences, social sciences, or humanities are posted on the top-level page. Each of these links leads to lists of narrower subcategories. The links on the second level lead to narrower subcategories, and so on. A sample hierarchy from the directory created by Google (available at http://directory.google.com) lists the following subject breakdown: Society → Disabled → Disability studies.

Directories provide Web searchers with the ability to browse recommended resources in various subject areas without having to enter specific search terms. Other useful attributes of directories are that they often contain summaries and evaluations of websites.

Table 4 Selected Directories

Name	*URL*
eBlast	www.eblast.com
Google Directory[a]	http://directory.google.com
Internet Public Library	www.ipl.org
LookSmart	www.looksmart.com
Yahoo! Directory[a]	www.yahoo.com

a. These sites contain both directories and general search engines.

Article Indexes

Article indexes allow researchers to search by topic for published articles in magazines and scholarly journals. Researchers could certainly locate journal and magazine articles using a freely available search engine such as Google, but they would merely be skimming the surface of what has been published. While the Web provides access to *more* content, it does not provide comprehensive access to research published in journal articles. Article indexes are for the expressed purpose of finding journal articles. With a few exceptions (such as PubMed, an article index of health sciences journals developed and maintained by the National Library of Medicine), article indexes are not freely available on the Web. Libraries purchase subscriptions to multiple article indexes covering a wide spectrum of disciplines. The indexes available through a given library are often dictated by the curriculum of the college or university that the library serves. Thus, large research institutions offer a greater number of specialized article indexes than smaller institutions and public libraries. Due to licensing agreements between article index providers and libraries, off-site access to indexes is usually limited to faculty and students of a college or university. However, there are many libraries that allow members of the public to use their article indexes from within the library. A local public library would be a good starting place for those not connected with academic or commercial organizations.

Since article indexes are proprietary products developed by companies for sale to libraries, they tend to offer specialized search features that are not always available on freely available search engines. These features include subject headings, thesauri, abstracts (summaries of articles), and frequently the full text of articles. Researchers should familiarize themselves with online tutorials, "help" screens, and "about" pages to increase the effectiveness of their searching.

Freely available article indexes relevant to disability studies include the following:

- PubMed: A product of the National Library of Medicine, which includes more than 14 million citations for biomedical articles dating back to the 1950s. URL: http://www.ncbi.nlm.nih.gov/entrez

- CIRRIE: Center for International Rehabilitation Research Information and Exchange, a database containing more than 24,000 citations of international research published from 1990 to the present. URL: http://cirrie.buffalo.edu

Catalogs

While researchers can search indexes to find articles on specific topics, they can search online catalogs to find books. Some catalogs list the books available at individual libraries, while others contain the holdings of multiple libraries and institutions. The individual catalogs of public libraries and universities are usually freely available on the Web. The most comprehensive catalog is called WorldCat, developed by an organization called OCLC (Online Computer Library Center). WorldCat lists books available at public and academic libraries throughout the world. Like most article indexes, WorldCat is not freely available on the Web and must be accessed through a library.

Listservs

Listservs are mailing lists on the Internet that facilitate online discussions on various subjects. They allow researchers within a given field to communicate about scholarly issues via email. People customarily sign up for Listservs by sending an e-mail to the Listserv address stating that they wish to subscribe. Several Listservs related to disability studies are listed in Table 5. In addition, Web searchers can perform a search on a database called tile.net to search for Listservs by topic.

Table 5 Disability Studies Listservs

Name	*URL*
ADA-LAW	http://listserv.nodak.edu/archives/ada-law.html
Disability-Research Discussion List	http://www.leeds.ac.uk/disability-studies/discuss.htm
Disability Studies at Yahoo.com	http://www.groups.yahoo.com/group/disabilitystudies
Disabled Student Services in Higher Education (DSSHE-L)	http://listserv.acsu.buffalo.edu/archives/dsshe-l.html
Women's International Linkage on Disability (D-WILD)	http://groups.yahoo.com/group/d-wild

SEARCH STRATEGIES

Since search capabilities vary from site to site, Web searchers should use online "help" screens and tutorials to learn search tips and strategies for improving their search results. Some search techniques common to several Web-based search tools are summarized below.

Quotation Marks

When entering a search, users should enter phrases in quotation marks to stipulate that they would like the results to contain a specific word combination and order. For instance, multiword concepts such as "disability studies," "adaptive technology," and "section 508" should be entered within quotation marks. Proper names can also be entered within quotation marks.

Truncation

Truncation symbols allow Web searchers to simultaneously search for multiple endings of a given word. For instance, assuming that the asterisk is the designated truncation symbol in a search engine, entering the word "impair*" would produce results including all forms of the word after the root, including "impair," "impaired," "impairment" and "impairments." In addition to adding truncation symbols to the end of words, users may also insert internal truncation symbols if there are potential variations for the spelling of the middle of a word. For instance, entering the word "colo*r" would simultaneously search for the words "color" and "colour." "Help" screens or "search tips" usually list the designated truncation symbol for a given database.

Boolean Logic

Developed by the English mathematician George Boole, Boolean logic is a mathematical framework that Web searchers can apply to broaden or refine their searches. There are three words, or *operators*, that Web searchers can use to combine their keywords to perform more complex searches: AND, OR, and NOT. The three Boolean operators are summarized below, along with potential applications. It is important to read the online "help" section of a database before performing a Boolean search, as Boolean searching does not work in all databases.

Using the Boolean Operator "AND"

Combining words with "AND" narrows a search, as the database retrieves only items that contain *all* the words entered. The second search example below will produce fewer results than the first, since there are three keywords that must appear within the content of each result.

"disability studies" AND theory
"disability studies" AND theory AND history

Using the Boolean Operator "OR"

Entering the term "OR" between keywords stipulates that any, but not all, of the words entered must appear within the search results. Using "OR" is a way of searching for synonyms or related terms when there are multiple words for the same concept. The example below shows how you could broaden your search if you wanted to search for multiple adaptive technology applications in a search engine. The second search example will potentially produce more results than the first, since there is an additional keyword that the results could include.

JAWS OR "Ruby OpenBook"
JAWS OR "Ruby OpenBook" or "window eyes"

Using the Boolean Operator "NOT"

Entering the Boolean operator "NOT" after a word stipulates that the word should not appear within the results. Using "NOT" in a search can be particularly useful if a word is frequently used in multiple contexts and you wish to eliminate results dealing with a particular topic. In the example below, the second search will ideally eliminate items relating to the state of New Mexico, given that the researcher is looking for information on legislation related to disabilities in the country of Mexico. The use of NOT can be too limiting. The second search would eliminate results that discussed both Mexico and New Mexico.

Disabilities AND legislation AND Mexico
Disabilities AND legislation AND Mexico NOT "new mexico"

Nesting

Nesting allows Web searchers to simultaneously search for multiple search terms relating to the same topic. The grouping of synonymous terms within parenthesis is referred to as nesting, as multiple terms relating to the same idea are clustered together as a single concept. When using nesting, the words within the parenthesis are connected by the Boolean operator "OR."

To find information about software for people who are visually impaired, search results are increased by using nesting to group multiple words for each facet of the topic:

(software or "adaptive technology") AND ("visually impaired" or blind)

Plus and Minus Signs

Most general search engines allow users to enter plus or minus signs before a particular word. Entering a plus sign before a word (e.g., +ADA) stipulates that the word must appear within the search results. A minus sign before a word (e.g.,–mobility) stipulates that the word should not appear within the results. Since some search engines also use plus and minus signs as substitutes for Boolean operators, it is important to view online "help" or "search tips."

Search Limits

Most search engines allow users to limit their results by date, language, or document type. Limiting capabilities vary from site to site and are customarily outlined in online "help" screens. In general, article indexes have more sophisticated limiting capabilities than search engines that are freely available on the Web.

EVALUATING WEBSITES

A researcher weighing the quality of a journal article faces a lesser challenge than a researcher considering a website as a potential resource. The publishing industry applies labels to periodicals of varying type: Scholarly journals, popular magazines, trade publications, and newspapers comprise the major categories. Articles submitted to scholarly journals undergo a peer review process by experts in a given field. If in doubt as to the suitability of journal for scholarly purposes, a researcher can consult a directory of periodicals such as *Ulrich's Periodicals Directory,* which indicates whether or not a journal is peer reviewed.

The fact that the Web has no comparable methods of control complicates the task of determining whether a website is appropriate for research purposes. While websites produced by certain types of agencies and organizations certainly undergo a form of *internal*

review, the Web is a free forum; people can post anything they want, and no one has the right to force to take it down if it fails to meet certain standards of quality or accuracy. To complicate the matter, inaccurate or inexpert information can hide like a wolf in the sheep's clothing of sophisticated graphics, layout, and design. The Web has no peer review process to ensure quality. While none of the evaluation criteria outlined below can provide the final word as to the suitability of a website for scholarly use, a researcher who searches the Web with multiple evaluation criteria in mind expedites the process of finding quality information.

Authorship

When determining the credibility of a website, researchers should use multiple techniques to determine the credentials of the author as well as the character of the organization hosting, or sponsoring, the site. If individuals are listed as authors, researchers should take steps to determine their credentials and reputation in the field by performing a search in a general search engine to find biographical information or other documents written about the author. This will also produce references to the author on the sites of other authors within a field. Researchers can also consult a number of biographical sources available at libraries, such as *Who's Who in the America* or sources tailored to particular fields of study, such as *Who's Who in Science and Engineering.*

Website addresses, or URLs (Uniform Resource Locators) can also provide hints as to author affiliations and potential bias. Personal websites are often hosted on commercial ISP (Internet Service Provider) Web servers such as aol.com, or geocites.com. URLs of personal websites often contain first or last names, as well as percent (%) or tilde (~) signs. While personal websites may contain authoritative information, researchers should question why the same content does not appear on a site sponsored by an educational or research organization.. Was the site created as a pastime or to serve as a forum for airing personal views? Or does the site reflect serious scholarship backed up by other credentials and research published in scholarly publications?

Every website URL ends with a *domain name*, usually a series of three letters preceded by a period. The domain name denotes the type of institution that hosts the website and can often provide clues as to the purpose or potential bias of a site. Common domain names include the following:

Educational sites: .edu
Government sites: .gov, .mil, or country codes (e.g., .uk = United Kingdom, .au = Australia, .do = Dominican Republic)
Nonprofit organization sites: .org
Commercial sites: .com

Most URLs contain multiple levels separated by slashes (e.g., http://www.nod.org/stats/). To learn more about the sponsor or publisher of a particular site, you can remove levels of the URL one by one to see where the site is hosted and determine the character of the sponsoring entity. For instance, if a site is hosted on the site of an association, viewing the mission statement on the home page of the association can provide clues as to the bias or purpose of the content. When judging the credentials of the publishing entity, researchers should look for contact information and institutional logos. In general, sites devoid of identifying information or contact numbers and addresses should raise suspicion.

Audience

When evaluating a site, researchers should determine whether the content succeeds in addressing the stated audience through tone and presentation. Sites for adults should not have a childlike appearance or tone. Likewise, sites may be deliberately overrun by technical language or jargon to confuse or mislead a particular audience. High-quality sites clearly define their intended purpose.

Currency

Medical research findings or population statistics may become obsolete at a faster rate than research in the humanities. Web researchers should check sites for copyright dates and the date of the last update. Broken links are a sign of neglect, as they may indicate that URLs have changed or become obsolete since the last update of the site. To verify the currency of information on a site, researchers should check for several sites covering the same subject matter.

Accuracy

Determining accuracy involves further research to ensure that the claims or findings on a site are substantiated by other sources. If a site presents original research, the methods of the research and instruments used should be clearly explained, as well as potential limitations of the research. If authors make claims or conclusions, they should cite their

sources, and these sources should be tracked down to ensure their existence and authenticity. Websites should contain a list of works cited or footnotes on par with any print book or article. Since websites sometimes include fabricated resources, and erroneous or incomplete citations, sources should be verified using library tools such as indexes and catalogs. Lists of works cited with multiple errors reflect irresponsible research. If a website contains links, the links should be checked. Researchers should be wary of websites populated by broken links or links to defunct websites.

Quality

In general, sites that are poorly organized or sloppy should be approached with caution. Shoddy design may point to further weaknesses. Poor grammar and spelling errors are also red flags.

Bias

While bias is not always a negative attribute, Web searchers should be cognizant of bias as the search for information. The bias of a website can be partially discerned by the domain name (as discussed above under "Authorship"). Commercial websites may be motivated by the goal to market a product or service. Nonprofit organizations may promote a political agenda. While bias may be clearly stated in mission statements and "about" pages, many websites deliberately shroud their bias. Thorough research involves consulting additional sources to determine the history and activities of a particular organization. If a site contains links to other sites, those links should be checked to discern the character and activities of the other organizations listed. If a site is sponsored by other organizations, researchers should consider the relationship between the sponsors and the creators of the site.

Special Considerations for Evaluating Health Information on the Web

The American Medical Association (AMA) has published "Guidelines for Medical and Health Information Sites on the Internet" outlining evaluation criteria for websites publishing health information, whether for consumers or health professionals. While these guidelines are technically enforced only on sites sponsored by the AMA or affiliated organizations, they could be applied to all sites containing health information. Many of these guidelines mirror the previously outlined criteria for evaluating all websites, but there are certain factors that are heavily emphasized in the AMA guidelines, including the importance of peer review by experts in the field, the importance of clearly identifying sources of funding, an explanation of the relationship between individual researchers and the institutions sponsoring the research, the importance of clearly stating the purpose and intended audience of a site, and the need to address the stated audience in a consistent and effective tone. Seven criteria for assessing the quality of health information on the Internet have been developed by the Health Summit Working Group (Health Information Technology Institute 1999).

Information on health-related websites should be verified by checking sources such as journal articles, books, and other websites. These measures are needed as health information on the Web frequently includes unsubstantiated claims.

OVERVIEW OF ACCESSIBILITY ISSUES ON THE WEB

Disability studies research is unique in that many scholars in the field have disabilities that may impact their ability to effectively search the Web. While in many ways the Web "evens the playing field" by making a vast number of resources available electronically, inaccessible design frequently places barriers on Web searchers with disabilities.

Principles of Web accessibility have been developed by the World Wide Web Consortium's (W3C) Web Accessibility Initiative (WAI). The WAI establishes guidelines for creating accessible websites, browsers, and authoring tools to increase the ease of use of the Web for users with disabilities. Multiple scenarios outlining potential challenges to Web searchers with disabilities are summarized in a W3C working draft titled "How People with Disabilities Use the Web" (2001). Among other scenarios, the document emphasizes that many Web searchers with cognitive or visual disabilities use OCR (optical character recognition) software, which reads Web page text and transmits the information to a speech synthesizer and/or refreshable Braille display. Many users with visual disabilities use text-based Internet browsers instead of standard graphical browsers. The successful use of these tools requires that images on websites be accompanied by descriptive text and *ALT tags*. ALT tags are textual labels that appear on the computer screen when a mouse moves over an image. Since visually impaired

Web searchers often enlarge Web-based text using screen magnification programs, Web designers must create pages with nonfixed font sizes that can be altered as necessary. These are only a few of the issues facing Web searchers with disabilities. Other population groups with disabilities discussed in the guidelines include individuals with cognitive disabilities, hearing impairment, and mobility-related disabilities. Readers should consult the WAI website for the complete guidelines (http://www.w3.org/WAI/).

To support the goals of WAI, an online tool called Bobby™ helps website developers test the accessibility of their sites and adhere to accessibility guidelines. By entering a URL into the Bobby website, a Web developer can generate a report outlining which features of the site need to be adjusted to make it "Bobby compliant" and adhere to both W3C accessibility guidelines and guidelines established by the U.S. government's Section 508, a 1998 amendment to the Rehabilitation Act requiring that all federal agencies make their electronic and information technology accessible to people with disabilities. Complete information about these guidelines can be found on the Section 508 website (www.section508.gov).

CONCLUSION

While "one-stop shopping" in Google may be tempting, there is no single search engine leading to everything on the Web. Comprehensive and effective research in disability studies involves consulting multiple search tools, including but not limited to general search engines, subject-specialized search engines, directories, and indexes. In addition to using multiple search tools, Web searchers should experiment with multiple search strategies to maximize the effectiveness of their searching. As there are no standards of quality on the Web, researchers should apply multiple evaluation criteria to every website, verifying that research findings posted on sites are supported by other sources. Web accessibility is a crucial component to disability studies, as the Web has the potential to deliver equal content to all users but frequently presents barriers to people with disabilities by failing to adhere to standards of accessible design. Researchers can develop an awareness of accessibility issues on the Web by familiarizing themselves with the standards outlined by W3C's Web Accessibility Initiative and Section 508.

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(1946-present)

J

▣ JACKSON, WILLIAM HENRY (1889–1931)

English educator and priest

Father William Henry Jackson lost his sight in early childhood, became an Anglican priest, and worked in Myanmar (formerly Burma) for 14 years.

Formal education for blind children had been started at Moulmein by a newly blind teacher, Maung Pe Gyu, in 1900. A school opened at Rangoon in 1901, and some Burmese Braille books were produced. The Mission to the Blind of Burma was begun in 1914 by Will and Mary Purser, bringing people to Rangoon for eye surgery and providing education and job training to some blind children. Mary Purser's brother, "Willie" Jackson, who was ordained in 1912, had studied at London, Oxford, and Leeds. He traveled to Burma in 1917 with Will Purser and immersed himself in Burmese language and lifestyle: He "adopted Burmese dress and food; he sleeps on the floor without a mosquito curtain, and he eats his food with his hands and goes about without any covering on his feet or head" (Purser 1922).

Jackson engaged vigorously in education and skill training of blind Burmese children and young people, and he was a powerful role model. He accepted no limits to what blind people could do. In 1930, the government of Burma awarded him the highest civilian honor, the Kaiser-i-Hind gold medal. He died young but had inspired many Burmese blind people with the confidence to live fuller lives.

—Kumur B. Selim

See also Blind, History of the.

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▣ JAHIZ, AL- (ABU OTHMAN AMR BIN BAHR) (776–777)

Arab intellectual and essayist

Al-Jahiz, nicknamed for his "goggle eyes" (*jahiz*), was an erudite, prolific, and notably ugly writer at Basra and Baghdad. His essays on many topics are still much quoted in the Middle East. Reacting against public disdain for his own facial appearance, he became one of the earliest advocates for greater acceptance of disabled people. Al-Jahiz (1954) asserted that impairments or odd appearance "do not hinder an individual from being a fully active member of the Muslim community or bar him from important offices"; on the contrary, these "may be called signs of divine blessing or favor." He distinguished various levels of hearing impairment and noted that when a deaf person could not speak it was because "having never heard sounds, articulated or otherwise, he does not know how to produce them" (Al-Jahiz 1969). Elsewhere, Al-Jahiz (1983) commented on the silent language of signs and gestures used at meal-times by courtiers under the Sassanid rulers (224–636 CE).

—Kumur B. Selim

See also Abu 'l-`Ala al-Ma`arri; Abu 'l Aswad ad-Duwali; `Ata ibn Abi Rabah; Khalil, Al-; Middle East and the Rise of Islam.

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JAPAN

See Disabled Persons' Fundamental Law of 1993 (Japan); Experience of Disability: Japan; Rehabilitation Engineering Society of Japan (RESJA)

JERNIGAN, KENNETH

(1926–1999)

American activist

Kenneth Jernigan, born blind, was one of the pre-eminent leaders of the struggle for equality waged by blind people during the twentieth century. He served as president of the National Federation of the Blind (NFB) from 1968 to 1986, with one brief interruption in 1978–1979. As president emeritus, he remained actively involved in the NFB and its operations until his death in 1999. Jernigan was mentored by Jacobus tenBroek, the NFB's first president, and one of the most influential voices addressing discrimination against the blind in the United States.

Born in Detroit, Jernigan grew up in Tennessee on a family farm. He held many jobs as a young man, including furniture maker, insurance salesman, and, briefly, professional wrestler. He received a degree in literature from Peabody University, and soon after went to teach at the Tennessee School for the Blind. In 1953, he was encouraged by tenBroek to move to California to work at the Orientation Center for the Blind in Oakland. In 1958, he became the first blind director of the Iowa Commission for the Blind, a position he held until 1978. During his time in Iowa, the commission was transformed from the worst to the best agency serving blind adults in the United States, and Des Moines became the epicenter of the blind movement.

Jernigan joined the NFB in 1949, and he was its vice president by 1958. Jernigan's rise to power occurred in the context of a bitter struggle for the leadership and direction of the NFB, resulting in the expulsion of several state affiliates and the creation of a splinter group in 1961, the American Council of the Blind (ACB).

Jernigan's philosophy of blindness was that the average blind person could do the work of an average sighted person when the former was given proper blindness adjustment training. With such training, Jernigan asserted, blindness could be reduced to a mere physical nuisance.

—Brian R. Miller

See also Activism; Blind, History of the.

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JIRI, JAIROS (1921–1982)

African philanthropist

As African philanthropist and founder of the Jairos Jiri Association in 1950, Jairos Jiri and his accomplishments in Zimbabwe stand out in the history of

African rehabilitation services. The son of a local chief, Jiri obtained virtually no education. At the age of 18, he set out to Bulawayo, where he was struck by the fate of disabled people as beggars. Encouraged by the knowledge that something could be done, he took them into his home and generated help from others in teaching them basket making and shoe repair. The efforts institutionalized very quickly, first with the assistance of the colonial administration, and later with international aid.

This led to one of the largest associations of its kind, the Jairos Jiri Association, serving more than 13,000 disabled children and adults annually. Among its many establishments are schools, clinics, homes, hostels, vocational training centers, community-based rehabilitation programs, scholarship funds, orthopedic workshops, and outreach and follow-up integration programs. The association looks to (1) assist, treat, and rehabilitate persons with physical, visual, and hearing impairments; (2) establish clinics, schools, centers, and other institutions for the education and welfare of the handicapped; and (3) liaise with the government of Zimbabwe and local and international agencies.

—Patrick Devlieger

See also Developing World; Experience of Disability: Sub-Saharan Africa; Job Training; Vocational Rehabilitation.

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JOB ANALYSIS AND PLACEMENT

JOB ANALYSIS

The goal of a job analysis is to describe the tasks associated with the job and then articulate the human attributes necessary for successfully performing those tasks. Job analysis is an important part of what an industrial/organizational (I/O) psychologist does. Information from a job analysis is used for many purposes, and there are many methods for conducting a job analysis. This entry briefly describes these purposes and methods.

Purposes of Job Analysis

Information from job analysis can be used for many different purposes, such as job description, recruitment and selection, placement, performance assessment, training, compensation, criterion development, career development, legal issues, job design and redesign, and workforce reduction and restructuring. Professionals in human resources departments of business organizations and government agencies make extensive use of the information from a job analysis for these and other purposes. A disability-related application of job analysis occurs when rehabilitation counselors develop vocational plans to assist persons with disabilities obtain employment.

Methods of Job Analysis

Many of the methods used in performing a job analysis can be categorized into either a work-oriented approach or a worker-oriented approach. In a work-oriented approach, the emphasis is on the tasks performed by an incumbent or what a person does on the job. These tasks can be further subdivided into activities, and each activity may consist of several actions or elements. Two of the most well-known methods of job analysis in the work-oriented approach are the functional job analysis (FJA) and task inventories.

FJA was used in developing the *Dictionary of Occupational Titles* (*DOT*), which was designed to match people to jobs in the U.S. economy. The fifth edition of the *DOT*, published in 1991, provides information on more than 13,000 occupations in the U.S. economy. Task inventories are very popular in business organizations. Based on interviews with a small, representative sample of subject matter experts (SMEs) such as incumbents and supervisors, task inventories are developed and administered to incumbents and supervisors for gathering information on which tasks are performed on the job, how frequently tasks are performed, and their importance. In general, more tasks are included in a task inventory than in an FJA. Finally, another example of a work-oriented approach to job analysis is the critical incident technique (CIT). With CIT, SMEs are asked to recall specific instances of worker behavior, which represent either exceptional or unacceptable performance on the job.

In a worker-oriented (or person-oriented) approach, the emphasis is on obtaining information about the attributes and characteristics required for a successful performance on the job. These attributes and characteristics are commonly referred to as KSAOs (knowledge, skills, abilities, and other personal characteristics such as personality variables, interests, training, and experience). One of the most popular methods of job analysis in the worker-oriented approach is the Position Analysis Questionnaire (PAQ). It is a commercially available questionnaire, with computer scoring and multiple report-generation options. The PAQ consists of 194 items. Other examples of methods in the worker-oriented approach are the job element method, Job Element Inventory, Job Components Inventory, Occupational Analysis Inventory, and Common Metric Questionnaire.

A new method of job analysis, which reflects both the work-oriented and worker-oriented approaches, is the Occupational Information Network or O*NET. It was developed by the U.S. federal government and was designed to replace the *DOT*. The O*NET is a collection of databases with an expert computer system for facilitating person-job matches. The foundation of the content model underlying the O*NET centers on worker requirements, experience requirements, worker characteristics, occupational requirements, occupation-specific requirements, and occupation characteristics. The O*NET system is relatively new and web based, but it does not include all jobs/occupations.

Sources of Information

Typically, job analysts, incumbents, supervisors, and trained observers are the sources of job analysis information. This information can be obtained in interviews, via questionnaires, by observation, and by actually performing the job in question. Multiple sources and collection methods are often used in practice.

Each job analysis method has its own strengths and weaknesses, and no one method is adequate for all purposes. So the choice of a method must be based on the purpose for a job analysis. Careful consideration should also be given to the costs associated with implementing a given job analysis method.

JOB PLACEMENT

In filling vacancies in a given job, the emphasis is on finding the most qualified people for the job (or individuals most likely to succeed on the job). This is a case of straightforward selection. When there are vacancies for several jobs, one is concerned about how best to fill all vacancies simultaneously with the same applicant pool. This is a case of placement. That is, one is called on to *place* an applicant rather than to *select* an applicant. One may think of selection as choosing one applicant from among many applicants to fill a job opening. In contrast, placement involves matching multiple applicants with multiple jobs. In general, placement is more involved and complex than selection. In either case, reliable and valid job analysis information is a prerequisite.

Selection has received much more attention than placement by I/O professionals. Failure to attend to issues of placement can be long-lasting. All individuals who want to work should have the opportunity to do so. If an individual does not meet the minimal requirements for one job, she or he should be considered for other available jobs. That is, job placement should be given a top priority.

—Nambury S. Raju

See also Employment; Job Retention; Job Training; Vocational Rehabilitation.

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JOB RETENTION

Involuntary job loss either by plant closings, layoffs due to slack demand, or firings for cause will have negative short-run effects on discharged workers' earnings and can have significant long-term effects on the economic well-being of their families. Because the U.S. labor market is considerably less regulated by government than other Organization for Economic Cooperation and Development (OECD) countries and because only about 10 percent of U.S. private sector workers belong to unions, American workers have much less formal protection against involuntary job loss than workers in other OECD countries.

On the other hand, the greater flexibility of American labor markets also means that American workers are better able to enter the labor market and voluntarily move from one job to another. In addition, American firms are better able to adjust their mix of machines and labor in their production process, introduce new technologies, and compete in the international marketplace.

The end result is that the American labor market is more flexible, allows greater voluntary job mobility, and is better able to reward skilled and highly educated workers but also has greater wage inequality, more lower-paying jobs, and greater risks of involuntary job loss than the more regulated labor markets in other OECD countries.

Working-age people with disabilities in the United States likewise have much less formal job protection either via government regulation or union protection and must compete in much more dynamic labor markets than their counterparts in other OECD countries. Germany, for instance, has a formal quota system (that penalizes firms that do not employ a minimum percentage of workers with disabilities) and prohibits employers from dismissing workers based on their disability. In contrast, the United States forbids the use of job quotas and allows employers much greater freedom in hiring and firing workers. The Americans with Disabilities Act of 1990 (ADA) is the most significant piece of protective legislation for U.S. workers with disabilities and has strict limits on whom and how much firms must accommodate.

The United States experienced two major business cycles over the past two decades of the twentieth century—1979 through 1989 and 1989 through 2000. Over the first, the employment rates of working-age people with and without disabilities were pro-cyclical, falling over the recession years of the early 1980s and rising over the long period of growth from 1982 to 1989. However, the rise in the employment of those with disabilities was not as great as those without disabilities, so over the decade their employment rate fell relative to those without disabilities.

The relative employment rate of people with disabilities fell even more over the 1990s business cycle. While the employment of both those with and without disabilities fell from 1990, the business cycle peak year, to 1993, during the growth years 1993 to 2000 the employment of those without disabilities rose while the employment of those with disabilities fell. The employment rates of both those with and without disabilities fell between 2000 and 2003, but the employment rate of those with disabilities fell faster than that of those without disabilities.

Between 1979 and 2000, the household income of working-age people with disabilities remained about the same. Their wage-earning declines were offset by increases in their disability transfers (Social Security Disability Insurance [SSDI] and Supplemental Security Income) and by the greater earnings of other household members. But their overall household income fell relative to those without disabilities, whose income rose significantly over this period of substantial economic growth.

Most working-age people with disabilities experience the onset of their disability after they enter the labor market. Research shows that the social environment, rather than the impairment itself, is the critical factor in determining how long workers with disabilities remain in the work force. The average length of time before they apply for SSDI benefits following onset is 15 years, and only 72 percent of workers with disabilities will ever apply for SSDI benefits. The rest continue in the labor force until they exit onto the

Social Security retirement program. The timing of SSDI application is affected (holding the seriousness of the worker's impairment constant) by a worker's characteristics and the economic incentives he or she faces.

The variables that most affect how long a worker will delay application for SSDI following the onset of a work-limiting health condition are the worker's age at the onset of the condition, the worker's education, whether the worker was accommodated, and the relative rewards of working versus going onto SSDI.

Other things equal, younger and better-educated workers will delay application longer than older or less-educated workers. But accommodation matters. Employees who are accommodated by their employer stay in the labor force longer than those who are not. This is true across a wide range of accommodations. The most frequent firm accommodations are not costly from an accounting perspective, although they may be from a work organization perspective. They are changes in job hours and changes in job responsibilities.

But economic incentives also matter. Those workers whose future earnings are higher or who are less likely to be accepted onto SSDI will delay applying for benefits and continue in the labor force longer than workers with lower future earnings and higher likelihoods of SSDI acceptance.

These findings are based on the accommodation behavior of firms and their workers prior to the implementation of the ADA in 1992. About 23 percent of workers who experienced a disability were accommodated prior to 1992. Simulations that project the experience of these accommodated workers on all workers suggest that their average duration before applying for SSDI benefits would rise by about 2.5 years, if accommodation were provided to all workers following the onset of a disability. But this positive employment policy initiative could be offset by further easing of SSDI acceptance rules or increases in SSDI benefits relative to future earnings.

The recent employment experience of working-age people with disabilities is discouraging. Despite the increased duration in employment that accommodation brings and the likely rise in the percentage of workers with disabilities who were accommodated in the 1990s following the implementation of the ADA, their employment rates fell over the entire 1990s business cycle and has done so, relative to those without disabilities, since the mid-1980s. The causes of this decline in relative employment are controversial, but the preponderance of the evidence suggests that it was not caused by an increase in the severity of their impairments. Rather, the causes are related to the changing social environment faced by workers with disabilities.

The most likely cause is the substantial reduction in the eligibility standards for entry onto the SSDI rolls that occurred in the mid-1980s. Research has shown that U.S. workers who experience the onset of a disability in states with higher SSDI acceptance rates are quicker to apply for benefits and that in such states the employment rates of workers with disabilities are lower relative to those without disabilities.

It has also been argued that the increased costs firms must bear to accommodate workers with disabilities have made them less likely to hire such workers and that this unintended consequence of the ADA offsets its positive impact via increased duration on the job for those who are accommodated. The evidence of a negative ADA effect on employment is more controversial and has been shown to be sensitive to alternative definition of the population with disabilities.

Market forces influence the employment of working-age people with and without disabilities. The skills that people with disabilities bring to the job will affect their chances of employment, their duration on the job, and the age they leave the labor market. The wage premium that those with more than a high school education command has dramatically increased over the past two decades. This is true both for those with and without a disability. The best predictor of job market success is one's level of education, and in the constantly changing American job market, the long-term rewards to well-educated workers demonstrate its value. Hence those workers with good job skills and high education levels are the most likely to be retained by their employers during bad times and to command higher salaries during both good and bad times.

Government policy can also influence the employment of working-age people with disabilities. Pro-work policies that foster rehabilitation, job-enhancing skills, and accommodation will increase job retention and more generally integrate working-age people with disabilities into the labor market. Reduction of eligibility standards for SSDI and other disability transfer programs that require beneficiaries to demonstrate that they are not able to work before they can receive benefits will have the unintended consequence of further reducing the employment of working-age people with disabilities who could work.

—Richard V. Burkhauser

See also Americans with Disabilities Act of 1990 (United States); Disability Law: United States; Employability; Employment; Employment, International.

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JOB TRAINING

Job training, both for those employees new to the work setting and those needing to acquire additional work skills, is often viewed as a way of assisting the employee in mastering the essential function of a job. The outcome of such training is the development of skills that will allow the employee to meet the standards set by the employer. Job training can be viewed as generalized preservice and mentorship/apprentice training or training that occurs in response to a specific job. For persons with disabilities, when considering job training one has to consider the broader perspective of identification, accessing, and maintaining employment since these are intertwined in the process of securing and advancing in employment.

This entry briefly reviews the principles driving job training, approaches for persons with disabilities, and the challenges and opportunities to job training in the future. This overview will provide the reader with a broad view of job training for persons with disabilities from a philosophical as well as a practical level. While this entry addresses job training for individuals who have a disability, it is important to note that the approaches used are more similar than different for all job seekers, those with as well as without disabilities.

PRINCIPLES DRIVING JOB TRAINING

The changing perceptions about the capacity of persons with disabilities, advances in job training strategies, and new technologies have all contributed to a new way of looking at job training for persons with disabilities. The realization that persons with disabilities can and in many instances want to work has been supported in many countries by changes in legislation, policies, and practices that have encouraged persons with disabilities to consider employment and employers to view persons with disabilities as part of the workforce.

Legislation banning discrimination, providing incentives to hire, and establishing hiring quotas have all contributed to an increased awareness about the employment of persons with disabilities. In a complimentary fashion, the recent movement toward self-advocacy has also served to increase the awareness by persons with disabilities about the opportunities that may exist in the labor market. The combination of increased self-advocacy, changing ways to support and match individual skills to industry needs, and administrative incentives has served to support increased employment of persons with disabilities in many countries.

APPROACHES TO JOB TRAINING

The evolution of employment for persons with disabilities is reflective of overall societal perceptions of disability in general. This evolution has gone from no expectation to a recognition that persons with disabilities can and want to work. Job training approaches for job seekers who have a disability have moved from a pretraining or readiness design to one that places greater emphasis on on-the-job training. Early training efforts focused on the identification of individual deficits, the remediation of those deficits, and then the development of work-hardening or work tolerance skills. A myriad of work samples, paper-and-pencil, and trial work strategies were the cornerstone of job training strategies in many countries. These assessment approaches were based on deficit identification followed by remediation and skill development. This focus on deficit identification and work conditioning placed the entire responsibility for job success on adaptations by the individual with little recognition of any modifications in the actual work setting.

In the past two decades, the emphasis on job training has shifted to one of building on skills and interests and maximizing the abilities of the individual. Informal and formal assessments addressing preferences and interests were providing greater information than the more traditional work assessment tools. There was also a growing recognition that situational assessment, conducting an assessment in an actual work setting, provided greater information on both skills and interests. There continued to be, however, a focus on the person fitting the job. Moving from the utilization of situational assessments, job training in many countries has embraced the strategy of matching individual skills and interests to demands in the work setting. This focus has led to a "goodness of fit" perspective where job training is a combination of skill building and job modifications. Here both the individual and the job setting are adapting.

Paralleling this evolution of focus was a shift in the nature of the training setting. Total reliance on specialized training and work settings is giving way to direct placement and on-site supports based on the results of considerable research in supported employment. Job training is happening in the workplace with the assistance of an outside support, an employment training specialist, or job coach. This support addresses not only skill acquisition but also identification of available social supports that are naturally present in the work setting. The employment training specialist facilitates initial training, fading support and shifting the training and support to the employer and coworkers as the individual with disabilities approaches employer expectations and assimilates into the culture of the workplace. The linking of external supports to those naturally existing in the work setting and the training of coworkers as support resources, the hallmark of supported employment, are now common practice in many countries.

As a reflection of this shift, trainers have evolved from more formal skill trainers who may offer classroom instruction in an external setting to on-site employment training specialists. Training on the essential tasks of the job is not the only function of the employment training specialist. Job accommodations and job modification may be introduced to both support productivity and assist the individual with a disability in being successful on the job. Modifications may include the restructuring of tasks, the simplification of task sequences, the use of assistive devices and aids (e.g., pictures, cue cards), and the identification of coworker supports for the individual. Job training has moved away from specific skill acquisition to whole-job training including skill acquisition, social supports, and job modification.

FUTURE CHALLENGES

As the nature of an economy changes so do the demands of businesses. These demands require that the workforce adapt, continually acquiring new skills. During the farming and manufacturing periods, it was not uncommon for workers to remain at one job for their entire work history. With the advent of the technology and information era, job movement and job change became the rule rather than the exception and changes in tasks were at times a daily event in some industries.

More recently, with globalization, technology changes, and virtual work settings, the demands for increased flexibility and greater proficiency in the use of technology continue to change the job training arena. The idea of initial training has given way to continuous training where changes in the consumer marketplace have given rise to the creation of new products and new jobs. New approaches and technologies such as multitasking, voice-activated information systems, smart technologies, and virtual work settings, along with globalization and workforce diversity, are all requiring those involved in job training to think and behave differently.

These challenges are requiring job training professionals to think differently about both the nature of training strategies and the setting for the delivery of training. The rate of job change, the changes in job duties, and the increased use of distance education resources are an opportunity for job training to use technology for delivery of information as well as a way of reinforcing skill acquisition. Web-based training, Listservs, and chat rooms are all ways that job training can be delivered now and in the future. Common instructional materials delivered through electronic media and reinforced by local trainers or support staff assist persons with disabilities in learning new skills not only at time of job access but also as a way of maintaining employment. The use of multistimulus input systems (seeing, hearing, touching), vehicles for immediate feedback, and strategies for rapidly refreshing learned skills are all ways that job training can support both initial learning and job growth for persons with disabilities.

Effective strategies for job training have relevance for all employees. With older workers remaining on the job for longer periods of time, workforce mobility reflecting not just local but global tendencies, and increased recognition of the employment potential for job seekers with disabilities, effective job training strategies can be applied not only to job seekers who have a disability but also to older workers and the nonnative workforce in many countries. Job training has the potential for broadly supporting access and career development for both the emerging workforce and the typical workforce in the coming decades.

—William E. Kiernan and Robert L. Schalock

See also Affirmative Businesses; Consumer-Run Businesses; Employability; Employment; Jiri, Jairos; Job Analysis and Placement; Job Retention; Vocational Rehabilitation.

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JOHNSON, SAMUEL (1709–1784)

English author and lexicographer

Both a "great Cham" (tartar monarch) and "Caliban" (Shakespeare's deformed slave in *The Tempest*) of letters, Samuel Johnson gave his name to an age as the most prominent literary author of his day. Best known for his Herculean (and Sisyphean) achievement of the first modern dictionary of the English language (1755), Johnson also was an editor of Shakespeare, a moralist in a variety of genres—periodical essay, Juvenalian satire, heroic tragedy, apologue, travel narrative—and in his *Lives of the Poets* (1779, 1781) a legislator of the English literary canon. Yet he was often remembered by subsequent generations more as a character than an author.

Blind in one eye, deaf in one ear, scarred by childhood tuberculosis of the lymphatic system (known as "scrofula") and by smallpox, Johnson suffered throughout his life from what his biographer James Boswell termed "a horrible hypochondria," what the psychology of the period would have termed religious melancholy (his greatest fear was damnation) and what would now be considered severe depression. This inner torment was accompanied by rituals, compulsions, and convulsive "tics and gesticulations" that have recently been diagnosed as evidence of Tourette's syndrome but that during Johnson's own time evinced eccentricity (the stuff of eighteenth-century English notions of individuality) rather than pathology. At his life's close, Johnson survived a stroke, while suffering congestive heart failure, kidney disease, emphysema, severe arthritis, and "dropsy" manifested most dramatically as a hydrocele of the testis. He fought death to the last, deploring his doctors' caution in treating his dropsy and hastening his demise by self-scarification. Johnson's embodied afterlife arises partly from Boswell's devoted preservation of his conversation in the *Life of Johnson* (1792), but also from his epitomization of literary authority as a paradox that united monumental style with a singular body in ambiguous motion.

—Helen Deutsch

See also Blind, History of the; Deaf, History of the; Depression; Representations of Disability, History of.

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JOURNALISM

Although the political issues of people with disabilities rarely made the mainstream news until the 1990s, the people themselves have been in the news since American journalism began the practice of identifying sources by physical characteristics. The norms of journalism that developed by the early twentieth century meant that anyone who was not white or able-bodied would, in many cases, be identified by their ethnicity or disability. For example, an *Atlantic Monthly* article about the blind African American pianist and composer Thomas Bethune in 1862 was headlined "Blind Tom," which was his well-known moniker. Most disabled people did not garner the nineteenth-century media attention of Blind Tom, but any journalist writing about a person with a disability in the nineteenth century or the present would rarely fail to mention a disability, especially blindness or deafness. When Erik Weihenmayer climbed Mount Everest in 2001, every journalist mentioned his blindness.

However, these reports of individual people with disabilities in the news did not mean the issues that affected them made the news. In fact, journalism's focus on specific individuals with disabilities became the standard of coverage for decades. When the disability rights movement arose in the 1970s, activists and media researchers began questioning why journalists continued to write primarily about individuals with disabilities, rather than the major civil rights initiatives afoot.

RESEARCH ON REPRESENTATIONS IN JOURNALISM

The concept of handicapism is germane to journalistic coverage of people with disabilities. In developing the concept in 1977, Robert Bogdan and Douglas Biklen defined *handicapism* as "a set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences." Their data and impressions suggested that mass media, by portraying prejudicial or stereotypical images of disabled persons, contributed to handicapism in society.

Therefore, many researchers began to take seriously the influence of journalism on the understanding of disability. Researchers from the areas of rehabilitation began to look at news representations. For example, rehabilitation researcher E. Keith Byrd and Timothy Elliot of Auburn University studied various aspects of media images of disability over the course of the 1980s. Psychologists also looked at news images of disability. James M. Gardner and Michael S. Radel studied both newspapers and prime-time television coverage of disabled people in 1978 to identify the major themes in coverage: dependence, independence, abuse, and deviance.

Disability studies scholars paid attention to journalistic images of disability in the 1980s as well, especially when major media issues arose. Douglas Biklen looked at the print media coverage of the 1984 Baby Jane Doe case, in which parents and doctors fought over the severely disabled baby's right to live or die, and the Elizabeth Bouvia case, in which a severely disabled woman wanted the right to starve to death. Biklen found that journalists uniformly "cast in terms of tragedy, of charity and its attendant emotion, pity, or of struggle and accomplishment."

The language used in journalism to characterize people with disabilities also has significance. Disability studies scholar and historian Paul Longmore studied the social meaning of language that referred to disabled people in 1985 and found three forms. One form represents people solely in terms of a disability and are therefore medicalized and dependent. This form creates abstract nouns from adjectives (the disabled, the deaf) or borrows medical labels such as "suffers from." Another form used euphemistic labels such as "special" or "exceptional." And the third form refers to politicized language that allows disabled people to create their own identity.

More mass communication scholars turned their attention to journalism and disability topics in the 1990s. The preeminent scholar in this area was John Clogston, a former radio journalist who was a wheelchair user. He wrote his dissertation at Michigan State University, "Reporters' Attitudes toward and Newspaper Coverage of Persons with Disabilities." In 1990, Advocado Press, the publisher of *The Disability Rag,* published Clogston's content analysis of the coverage of disability topics in more than a dozen major U.S. newspapers. Through his research, he developed five models of news media representation of disability, which fit into either a traditional or progressive category.

Clogston's traditional categories include the medical model, the social pathology model, and the supercrip model. In the medical model, disability is presented as an illness or malfunction. Persons who are disabled are shown as dependent on health professionals for cures or maintenance. In the social pathology model, people with disabilities are presented as disadvantaged and must look to the state or to society for economic support, which is considered a gift, not a right. In the supercrip model, the person with a disability is portrayed as deviant because of "superhuman" feats (e.g., ocean-sailing blind man) or as "special" because they live regular lives "in spite of" disability (e.g., deaf high school student who plays softball).

Clogston's progressive categories include the minority/civil rights model and the cultural pluralism model. In the minority/civil rights model, people with disabilities are portrayed as members of the disability community, which has legitimate political grievances. They have civil rights that they may fight for, just like other groups. Accessibility to society is a civil right. In the cultural pluralism model, people with disabilities are presented as a multifaceted people and their disabilities do not receive undue attention. They are portrayed as nondisabled people would be.

News media researcher Beth Haller used Clogston's models in her 1995 dissertation, "Disability Rights on the Public Agenda: News Coverage of the Americans with Disabilities Act." However, she added three models to reflect the changes in society that came with the 1990 Americans with Disabilities Act (ADA). In addition, Haller expanded the use of the models by recognizing that more than one model may be present in a story. This was especially appropriate in news stories about the ADA, in which government, business, and disability rights sources came together.

Haller's added traditional category model was the business model, in which people with disabilities and their issues are presented as costly to society and businesses especially. Making society accessible for disabled people is not really worth the cost and overburdens businesses; in other words, accessibility is not profitable. The two added progressive models were the legal model and consumer model. In the legal model, the media explain that it is illegal to treat disabled people in certain ways. The ADA and other laws are presented as legal tools to halt discrimination. In the consumer model, people with disabilities are shown to represent an untapped consumer group. Making society accessible could be profitable to businesses and society in general, because if disabled people have access to jobs, they will have more disposable income and less need for government assistance.

These models created a systematic way to study and categorize representations of people with disabilities in journalism. Clogston was also instrumental in developing the Media and Disability Interest Group as part of the Association for Education in Journalism and Mass Communication (AEJMC), which is the major academic organization for journalism scholars. Another founding member of the interest group and important journalism and disability scholar is Jack Nelson. He gathered together media scholars and edited a 1994 book looking at many aspects of the topic in *The Disabled, the Media, and the Information Age.* This was the first solely news media/disability-research focused book in the United States, although in 1987 Alan Gartner and Tom Joe edited a scholarly collection called *Images of the Disabled, Disabling Images,* which included some chapters on news and disability. A British study of disability images on TV, both fiction and nonfiction, resulted in a book in 1992. Guy Cumberbatch and Ralph Negrine's (1992) *Images of Disability on Television* found themes in news programs such as fitting into normal life, the physical progress of a person with a disability, the lack of understanding by society/individuals, and fighting for civil rights.

JOURNALISM FROM THE DISABILITY COMMUNITY

All this research over the years confirmed that news media do a mediocre job of covering people with disabilities and their issues. Because mainstream media presented stereotypes or no information at all, many disability groups created their own journalism. Many disability publications have a long history in the United States; for example, one that has been ongoing since 1907 is *The Matilda Ziegler Magazine for the Blind* Braille publication.

Like ethnic publications or the alternative press, the disability publications react to the same kind of exclusion and stigmatization that other outsider groups have experienced. Disability publications allow people to pull themselves together as a community with similar goals and aspirations. As Erving Goffman (1963) suggested in *Stigma,* people with a stigmatized status in society develop their own publications because they allow them to debate the societal issues related to them that rarely make the mainstream press.

Charlie Winston, who tracks the disability press annually in *America's Telability Media* guide, estimated that in the late 1990s at least 1,200 mass media resources for the disability community in the form of magazines, newspapers, newsletters, radio/TV programs, and recurring newspaper columns existed. Winston said the disability media range from an individual creating a two- to four-page newsletter at a very low cost to a glossy, four-color magazine such as *New Mobility* (telephone interview by author with C. Winston, March 26, 1999).

Lillie Ransom, in her 1996 dissertation on disability publications, identified three main patterns among the publications: activist/political, mainstreaming/assimilationist, and special interest. She said that a publication such as *The Ragged Edge* is embedded within the disability rights social movement, making it an activist/political model publication; *The Arc and the Dove,* a publication for the ARC of Maryland, fits within the mainstreaming/assimilationist model because they want people with mental retardation to be accepted in the mainstream community; and a publication such *as The National Amputee Golfer* is described as a special interest model. However, whatever their pattern, each publication has the commonality of serving people who are "outsiders" and who face societal barriers due to physical or mental difference. Disability journalist Douglas Lathrop explained that these disability publications reflect that people with disabilities think of themselves as a community.

In addition to giving a voice to the entire community of Americans with disabilities, disability journalism gives apt examples that people with disabilities are a multifaceted community. Because different disabilities make for different societal barriers, publications based on specific disabilities arose. For example, the U.S. deaf community has a long tradition of its own journalism. The North Carolina School for the Deaf began the first publication for deaf persons in 1848 with its school newspaper, *The Deaf Mute.* Other disability-related publications continued a tradition of fostering solidarity within the different subcultures of the disability community. After World War II, soldiers who had been disabled in war came home, which led to the Paralyzed Veterans of America's development of the magazine *Paraplegia News,* in 1946.

In terms of disability rights–focused journalism, disability publications such as *The Ragged Edge, Mainstream,* and *Mouth* helped fuel the disability community's civil rights agenda. *Mainstream* magazine began in 1975. (Its print publication ceased in 1999.) The precursor to *The Ragged Edge, The Disability Rag,* started in 1980. *Mouth* began in 1990. Lucy Gwin, the editor of *Mouth,* explained: "Nobody [in the mainstream media] is going to cover the disability-rights movement, so we're just going to have to cover it our own damn selves."

EFFORTS TOWARD BETTER JOURNALISM

A few people still believed that mainstream journalism could change its coverage patterns and do a better job of reporting on disability issues. They also realized that most Americans get their information from mainstream news media and that they could have significant influence on the general public's perception of disability rights. In 1988, the U.S. government tried to foment this change. The National Institute on Disability and Rehabilitation Research (NIDRR) funded a national workshop on news media and disability issues. A workshop organizer said the reason behind the project was that "recent news articles and features have tended to divide disabled individuals into two categories: the poor pathetic creature of charity or the heroic, undefeatable 'super crip.'"

Another government-funded project to improve journalism on disability topics was produced in 1989 by the Advocado Press. Edited by Mary Johnson, *The Disability Rag* editor, and Susan Elkins, the publications coordinator for the Research and Training Center on Independent Living at the University of Kansas, the manual, *Reporting on Disability: Approaches & Issues,* drew together contributions from activists, ethicists, writers, and broadcasters, all of whom had experience covering disability issues. Intended for use with journalism students, the manual gave guidance on reporting issues specific to disability topics, how to find new and less stereotypical angles in covering disability, information about disability rights history and laws, ethical considerations, and examples of good reporting on disability topics.

Several journalists who contributed to the manual went on to write important books about disability rights, which included information about news media coverage. In 1993, Joseph Shapiro of *U.S. News & World Report* wrote *No Pity: People with Disabilities Forging a New Civil Rights Movement,* considered one of the best journalistic books on the disability rights movement. Tari Susan Hartman and Mary Johnson wrote a book called *Making News* in 1993 that provided a guide to activists on how to get news coverage of disability rights issues. Johnson then deconstructed backlash against the ADA in her 2003 book, *Make Them Go Away: Clint Eastwood, Christopher Reeve and the Case against Disability Rights.*

Associations of journalists gained awareness of their flaws when reporting on disability issues by 1990. The American Society of Newspaper Editors formed its Disabilities Committee and in 1990 published a booklet, *Reporting on People with Disabilities.* Bill Beisky, the editor of the *Cape Cod Times* and the father of a daughter with a disability, instigated the development of the booklet. The booklet makes some suggestions on reporting issues but was primarily a language guide on the preferred terminology when referring to disability topics. In a similar effort, the Research and Training Center on Independent Living at the University of Kansas also released a terminology guide in 1990, *Guidelines for Reporting and Writing about People with Disabilities.* The guide is now in its sixth edition. To pursue similar efforts at journalism education, freelance photographer Suzanne Levine developed the National Center on Disability and Journalism (NCDJ) in 1998. NCDJ created an online style guide about disability terms, as well as posting tip sheets on topics such as interviewing people with disabilities and developing curriculum for teaching about disability in the college journalism classroom.

In 1993, the Freedom Forum Media Studies Center at Columbia University also addressed the news media's problematic reporting on disability in *A Parallel and Imperfect Universe: The Media and People with Disabilities* (Gazsi 1993). The Society of Professional Journalists (SPJ) began acknowledging the need for better coverage of disability issues as well. Its society magazine, *The Quill,* had been publishing occasional articles about the topic since the 1980s when Laura Rensom Mitchell wrote “Beyond the Supercrip Syndrome.” By 2002, SPJ developed an online searchable Rainbow Sourcebook, which included sources on disability issues.

In the late 1990s, NIDRR again identified the need to better educate the public about disability issues through the mainstream media. It funded the San Diego–based Center for an Accessible Society, run by the former publisher and editor of *Mainstream* magazine, Cyndi Jones and William Stothers, and Mary Johnson of *The Ragged Edge.* Its charge is to get information about disability topics and independent living out to the general public. It does this by creating an online resource guide for journalists on a myriad of disability topics and by providing sources on disability issues for journalists. It also funds research to track major news media coverage of disability topics.

—Beth A. Haller

See also *Cripple*; Disability Culture; *Handicap*; Language of Disability; National Institute on Disability and Rehabilitation Research (NIDRR) (United States).

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National Center on Disability and Journalism, www.ncdj.org

The Ragged Edge, online magazine, http://www.ragged-edge-mag.com/

Research and Training Center on Independent Living, http://www.rtcil.org/

JUDAISM

Central to Jewish disability issues is Scripture Tanach (Old Testament) and its interpretation, Talmud (oral law). Collectively, these (and later commentaries) are known/studied as Torah. References to numerous impairments abound, often conflated with other conditions including, most notably, childhood. With Scripture, especially Talmud (the first diasporic literature), virtually the only record of ancient everyday Jewish life, the nature of these references must be considered. Much of Talmud is utopian/idealistic. Largely composed of religious case law, its admonitions may more reflect common transgressions than common practice. In addition, disabilities are often used hypothetically to illustrate extremes in test cases.

Judaism prior to the destruction of the Second Temple and the first state of Israel (70 CE) was rooted in the priestly Temple cult and sacrificial rite. The "perfect priest" required physical "blemishlessness" to withstand the ardors of animal sacrifice in God's presence within the temple. The priest represented an archetypal ideal rather than a norm, a far higher standard than mere able-bodiedness. Although restoration of the temple and priesthood remains an idée fixe in Judaism, the diaspora's practical archetype became the sage (the professional rabbinate emerged only later). The precarious nature of diaspora—metaphorically, a disabled Israel—idealized intellectual attainment through Torah study, rather than physical perfection. Throughout and beyond the era of Bavli (the definitive Babylonian Talmud, fifth–seventh century CE) impairments become progressively better understood and accepted, if only incrementally until recent times.

A culture that idealizes intellectual discourse would naturally regard cognitive/communication impairments as most disabling. The Talmud subsumes these in the category *cheresh, shoteh v'katan*: deaf/mute persons, mentally ill/mentally disabled persons, and children. More than earlier Scriptures, Bavli recognizes nonverbal communication by the deaf/mute, the intermittency of some mental illness, and practical attainments of the developmentally disabled and maturing children. Thus, correspondingly, it advocates, within limits, greater rights and responsibilities for these groups. Judaism has never sanctioned infanticide.

With cognition and communication so privileged, mobility impairments are of little concern in Jewish law. Blindness is regarded as a disability only in a few contingencies. Several Talmudic sages were blind, including Rabbi Yosef, whose advocacy of rights and responsibilities for the blind is considered definitive. Still, disability is sometimes regarded as God's punishment, though also, as in Buddhism, an opportunity for atonement and even a conduit for prophecy.

Contemporary Judaism has virtually abolished the category *cheresh;* deaf/mute persons are no longer consider insensate. There are deaf synagogues, a deaf seminary, and deaf Jewish community centers. Israeli Sign Language is very similar to Palestinian Sign Language. Since 1992, Vertigo, an Israeli mixed-ability dance company, has toured worldwide.

Anti-Semitism is often expressed in a discourse of pathology and defect. In the context of nineteenth- and twentieth-century Western racism and eugenics, the Nazis implemented genocidal programs against Jews, people with disabilities, and others including Sinti/Roma ("Gypsies") and gays and lesbians.

—Alex J. Lubet

See also Deaf, History of the; Religion.

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JUKES, THE

The first of many editions of Richard L. Dugdale's *The Jukes, a Study in Crime, Pauperism, Disease, and Heredity* appeared in 1877. The book told the story of five generations of poverty, crime, and disability in the Jukes family, the fictitious name of a real family. Departing from the dominant antebellum claim that heredity represented capricious degeneration, Dugdale held that hereditary disabilities followed intergenerational patterns. Thus, alcoholism would not necessarily produce so-called insanity or feeblemindedness in later "skipped" generations, but it might well produce more alcoholism in the next generation, and with alcoholism came poverty.

Dugdale also stressed a relationship between heredity and the environment. Juke family members who lived in healthy surroundings were less likely to be paupers than were family members who lived in unhealthy environments. Drawing the attention of the emerging "scientific charities" movement, the book reached its largest audience after Dugdale's death in 1883. Departing from his insistence on the interrelationship between the environment and heredity, this audience appropriated the story of the Juke family to argue for the immutability of heredity. From 1883 to the 1920s, North American social welfare officials portrayed many poor, and often rural and white, families like the Jukes as hopelessly degenerate, victims of their ancestral vices and ignorance. For this reason, the story of the Jukes became a precursor of the eugenics movement in the United States and Western Europe.

—James W. Trent

See also Degeneration; Eugenics; Normality.

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JUSTICE

Theories of justice are, in part, about what people are entitled to—as members of a political community, or more controversially, merely as human beings. These theories differ in what they regard people as entitled to: fair play, respect, a minimum or an equal share of material resources, access to the various goods of life, psychological satisfaction, and recompense or redress for past wrongs by others or punishment for one's own wrongs. These entitlements are not mutually exclusive, of course, but theories of justice differ in the importance or emphasis they place on them. For example, concerns about appropriate and proportionate punishment are often seen as matters of corrective justice; appropriate resources, access, or satisfaction as matters of distributive, patterned, or end-state justice; and fair play and respect as matters of procedural or relational justice. The lines between and relationships among these different types of justice are vague and disputed. But more important, there is strong disagreement about what people are entitled to under all three rubrics.

These distinctions among types of justice are well illustrated by the claims of people with disabilities, claims that figure significantly in contemporary disputes about justice. For example, many disability advocates have questioned the claim of recent theories of distributive justice that people with disabilities have strong entitlement to the resources needed to correct their impairments. Without rejecting such entitlements altogether, advocates regard them as unduly influenced by a medical model, which sees disability exclusively in terms of biological impairment or dysfunction. Drawing on an interactive model of disability, they stress the need for resources to accommodate disabilities, to make the built environment accessible to people with disabilities. And because most societies have failed to make such accommodations, disability advocates often insist that people with disabilities are entitled to restitution or compensation for past exclusion. Finally, some disability advocates have seen the focus on distribution as misplaced: What disadvantages people with impairments is largely their stigmatization not their impairments. On this view, the primary goal of justice should be to eliminate that stigma and the social exclusion accompanying it; the redress of material disadvantages will follow.

For all these critiques, one of the challenges facing contemporary theories of justice in relation to disability is to avoid the strictures of the medical model; to see disabilities in interactive terms and to find justice and injustice in the terms of that interaction. Unfortunately, the recent debate among competing theories of justice has tended to reinforce the medical model, by assuming that the justice claims of people with disabilities are not only medical and rehabilitative but virtually inexhaustible, and by assuming that significant impairments preclude a high quality of life. In reviewing these theories, this entry points out their reliance on such dubious assumptions and then suggests ways in which those theories have been, or could be, modified and strengthened in response to the disability critique.

RELEVANCE OF IMPAIRMENT TO JUSTICE

Most societies make provisions for persons with disabilities. Medical, rehabilitative, educative, and other resources are provided to cure or treat health conditions or improve functional capacities. Social assistance, pensions, workers' compensation, and other forms of income supplements attempt to compensate people with disabilities for their inability to work. Antidiscrimination laws seek to redress intended or unintended denials of equal opportunity associated with misperceptions, stereotypes, and the stigma of disability. These and other laws require public accommodations, employment and education settings, and communications and transportation services to be accessible. Yet other laws and programs directly provide assistive technology and educational and employment opportunities to raise the level of economic and political participation by people with disabilities.

Some laws view impairments as functional deficits that get in the way of the person's social participation; others emphasize the social stigma of impairments and the obstacles that that creates for people with disabilities. As functional deficits, impairments create needs for services, resources, and accommodations. When laws and policies address these needs, the underlying rationale is distributive justice: Impairments negatively affect social participation, so justice requires that these disadvantages be ameliorated as much as possible. Laws that focus on the social stigma of impairments view lack of participation in basic areas of social life as harms inflicted on people with disabilities either through prejudice, misunderstanding, or neglect. On the face of it, the underlying rationale is compensatory, namely, to undo the damage to people with disabilities caused by individuals or, systematically, through existing social institutions.

Since impairments are relevant to social justice in two different ways—as functional deficits and as social markers—there is potential for confusion about the appropriate objectives of laws and regulations. A law requiring public schools to allocate resources to accommodate the specific requirements of children with disabilities should be viewed as responding to a demand of distributive justice (e.g., that all children should benefit from the educational experience). If we treat it as a compensatory law, then it is vulnerable to the plausible objection that most needs of most disabled children are not harms that any individual or institution has caused. On the other hand, an antidiscrimination law such as the Americans with Disabilities Act of 1990 (ADA) cannot be easily justified as a tool for securing distributive justice, since it exempts individuals and institutions from making reasonably accommodations for people with disabilities if doing so would impose an "undue burden" or "hardship" and it does not require the state to assume that burden, however reasonable the accommodation. But it is also difficult to see the ADA strictly as demanding procedural justice, because it *does* require that individuals and institutions sometimes incur substantial (although not undue) costs for reasonable accommodations, a material burden that has no obvious counterpart in most other antidiscrimination laws.

A more plausible stance to take here is that impairments are relevant to justice in several ways: For the sake of justice, we need to acknowledge that people differ with respect to their repertoire of functional capacities, and so differ in what material and social provisions they require to fully participate in society. We also need to recognize that impairments are fraught with social meaning, most of which is disadvantageous to people with disabilities, and that the harms that are caused—either intentionally or not—need to be addressed for the sake of justice. In some instances, it must be said, disability raises justice concerns that appear to move among compensation, distribution, and respect: If public buildings are not accessible to a person with a mobility problem, one might argue that the failure to retrofit the building is discriminatory, in failing to treat people with mobility impairments as potential users or residents of that building. And such a slight may require compensation. But one could also argue that the benefits of access to public buildings must be distributed, as fairly across the public as possible, and so excluding this individual is distributively unjust.

One might contend that if justice demands a response to unfair disadvantages associated with impairments, it does not matter whether that response is understood in terms of procedural, distributive, or compensatory justice. It is difficult to distinguish the disadvantages "naturally" associated with impairments from those created by the attitudes and behaviors of others, or social arrangements generally. It should therefore not matter much if we view accommodation and retrofitting as conferring on people with disabilities the resources they are entitled to as a matter of distributive justice, treating them with the respect due to them as equal members of the community, or compensating them for having failed to do what distributive or procedural justice requires.

Of course, neither accommodation nor compensation will be thought to be owed if one denies that the state has any obligation to achieve a particular distribution of resources or opportunities, if one regards disadvantages associated with impairments as "natural," and if one insists that the only procedural or relational obligations we owe, in the absence of special relationships, are honesty, trustworthiness, and conformity to jointly accepted rules. But most people reject such a minimalist view of distributive and procedural obligations, and a generation of disability scholarship has made it clear that many of the disadvantages associated with impairments cannot be regarded as natural. But the rejection of minimalist views leaves room for disagreement about the character and extent of the entitlements that people with disabilities can claim.

Much of the philosophical activity in this area has been in the domain of "patterned" distributive justice, in particular, in the explication of the kinds of equality, or constraints on inequality, that distributive justice should seek. Because distributive theories have been the most fully developed, and the most frequently criticized by disability scholars and others, especially feminists, this entry focuses next on those theories and their treatment of disability. The entry then assesses the challenges they face and the adequacy of alternative and hybrid approaches in meeting those challenges.

THEORIES OF DISTRIBUTIVE JUSTICE

Despite the obvious relevance of impairment to justice, recent theories of justice have by and large alternated between a benign neglect, tabling provisions for the impaired until a just "basic structure" for society has been established, and an oppressive solicitude, treating people with impairments as having a greater claim to restoration of normal functioning than the claims of "normal" members of society have to material resources. As Martha Nussbaum has pointed out in an important critique, the neglect or postponement of justice for people with impairments by the leading political philosopher of the past century—John Rawls—arises from three factors of continuing relevance for justice and disability. One is the basic "contractarian" character of Rawls's theory of justice, in which justice is derived from the agreement reached by self-interested bargainers ignorant of their position in society or conception of the good life. Although the stipulated ignorance secures a kind of moral objectivity to the contract, the objective remains individual benefit, and people with impairments, assumed to be less productive or costly to accommodate, tend to be excluded as unattractive bargaining partners. The second factor is the theory's need for a simple metric of comparative advantage—deficits in physical or mental function do not fit easily beside wealth and income in a single, summary metric of well-being. Third, and particularly relevant to cognitive impairment, the bargainers are assumed to be rational. People who cannot engage in practical reasoning, let alone elaborate calculations of expected utility, do not have a place at the bargaining table.

Other philosophers have attempted to accommodate people with disabilities within a Rawlsian, or more broadly contractarian, framework. The most well-known, and controversial, effort has been made by Norman Daniels. Rather than ignoring people with impairments or tabling their claims, Daniels makes the correction of impairments a matter of utmost urgency by insisting that claims to the restoration of normal functioning are stronger than even those of the economically worst-off members of society. Arguing that normal human functions are essential to equality of opportunity, Daniels gives priority to health care and other impairment-correcting resources. A person with disabilities on his view has a special claim on society if his or her level of functioning falls short of the normal range (as determined biostatistically). Impairments directly reduce the range of opportunities open to a person. So too do deficits in talent and skill, but justice only requires fair equality of opportunity, namely, the equalization of opportunity for persons with similar skills and talents.

Many critics, including disability scholars, have contended that Daniels's augmentation of Rawls requires excessive and inappropriate redistribution of resources to people with lower functioning at the expense of people with limited talents and skills, who may well experience greater social disadvantage. They dispute the centrality that Daniels accords to normal functioning for fair equality of opportunity, and the priority he assigns to its achievement or restoration. They suggest that his exaggerated premium on normal functioning reflects his uncritical acceptance of a medical model of disability, and his resulting neglect of the social contribution to disability.

Another influential philosopher offering a quasi-contractarian theory of justice, Ronald Dworkin, does recognize that social preferences and practices play some role in the creation of disability, but his response may be even less appropriate than Daniels's. Unlike Rawls, Dworkin simply stipulates that the members of society are entitled at the outset to an equal share of the world's resources, but he does not believe that this entitlement can extend to individuals' highly variable "internal" resources—functionings and talents. Dworkin attempts to deal with the "brute bad luck" of poor internal resources—impairments as well as limited, obsolete, or undesirable talents—by relying on a hypothetical insurance scheme. We are to imagine what people, ignorant of what opportunities they might want to pursue in life, would be willing to pay by way of insurance against the prospect of acquiring a disability. If we could reach a social consensus on what would provide fair compensation for blindness, immobility, or cognitive deficit, then that would be an objective measure of the cost of relevant resources that the state should, in justice, provide people with disabilities. The hypothetical insurance buyer is willing to insure against deafness or blindness, not because he believes that these conditions directly lower his quality of life but because they would be impediments to life plans he would have likely had, given the social environment in which it is reasonable to expect he will find himself.

Central to Dworkin's approach is the recognition that the social impact of disabilities is not identical to the functional impact of impairments: The extent to which an impairment limits one's equality of opportunity depends on the physical, social, and attitudinal environmental in which the individual with that impairment lives. Although this is an important insight from a disability perspective, Dworkin blunts its impact by assuming that we can generalize about the overall impact of impairments in any social environment. More important, he implicitly ignores the effects of systemic accommodation and environmental modification. The price the hypothetical insurer thinks is prudent is based on the need for individual material resources to deal with an utterly hostile and unaccommodating social environment. In short, while Dworkin recognizes the environmental cause of the disadvantages of disabilities, his scheme for a "just" solution involves no more than paying people with disabilities to live in a disability-unfriendly world.

It might be suggested that the underlying difficulties with Dworkin's account can be traced to the fact that it relies on material resources as a metric of advantage, measuring outcomes and compensating shortfalls by money. Dworkin favors resources over welfare, preferring a more objective metric over a subjective one, such as feelings of pleasure or satisfaction. A resource metric would not punish those with low expectations and modest tastes nor reward those with high expectations and extravagant tastes. Several philosophers have argued, however, that it is possible to have a metric of advantage based on capabilities, which are as objective as material resources but more sensitive to the multivalued character of well-being. The economist Amartya Sen and the philosopher Martha Nussbaum have proposed accounts of the goal of distributive justice in terms of equality of capability.

Sen (1980:217) defines *functionings* as the things and activities that people have a realistic choice among in their lives. A functioning is more than a physical or mental capability (and so more than the mere absence of an impairment). It also includes all of the social, physical, and attitudinal features of the person's environment that are preconditions to the realization of a choice. A *capability*, then, is a set of functionings over which a person has a choice. In general, the complete set of a person's capabilities describes his or her "positive" freedom over alternative ways of living.

Sen's approach is well suited to account for what disability scholars argue are the true disadvantages associated with disability. A limitation of functioning in Sen's sense is either the incapacity caused by impairments or, more often, the barriers imposed by features of the person's world that aggravate the incapacity or otherwise restrict the person's freedom to achieve his or her life plans. When both the impairment and the social environment contribute to the disadvantage, justice requires both impairment-relevant resources and public policy and social action to remove the environmental obstacles. Justice requires, in short, equalization of capabilities.

Achieving justice in this sense would not be without practical difficulties. Even if we agreed on what capabilities were critical and what level of each capability had to be reached—matters on which Sen is deliberately silent—it would not be an easy matter to identify all the barriers to achieving them or ascertaining what would effectively remove or circumvent them. Yet we are now in the territory of public policy, where these practical issues are at least well-known. There are, moreover, several potential policy tools that can be brought to bear: cash by way of compensation or income maintenance; tax adjustments; in-kind services; provision of employment and educational opportunities; provision of assistive technology and other impairment-relevant resources; antidiscrimination law to address specific abuses; mandated, publicly funded accommodations for work, school, and home; and public education to remove stigma and stereotyping. There are legal models for each of these strategies in most developed countries.

But once one moves to this practical level, some troubling features of Sen's approach come into view. Does justice require equality of capability across the board, and for everyone? Does every measurable decrement of capability entitle one to resources in the name of justice, or is there a minimal core of capabilities relevant to justice? If so, what is this core, and must it be the same for everyone? These are huge questions. Even if we could agree on the core, it is extremely unlikely that anyone, across a lifespan, would possess complete capability in all its domains. Impairments are ubiquitous across the population; almost everyone develops joint aches, muscle fatigue, and diminished vision, hearing, and memory as they age. Each of these impaired functionings, in unaccommodating settings, may limit some core capability. If we think it absurd that everyone should qualify for disability benefits, how do we set the thresholds? How much inequality in capability can we tolerate?

Some of these questions have been addressed in a forthright—if not always satisfactory—way, by Martha Nussbaum, who is specific and concrete, where Sen is vague and schematic, about the capabilities required for humanity and human flourishing. She has come up with a list of 10 capabilities that a just society must ensure its members achieve, at least to a minimal degree. Over the years, her description of these capabilities has become more general, in part because the more narrowly framed they are, the more categorically they are precluded by specific impairments. Thus, Nussbaum has gone from making “the exercise of the five senses” a requirement of humanity—which would deny the blind and deaf the status of human beings—to making it a condition of human flourishing—which would deny that the blind or deaf can flourish—to broadening the capability to encompass rich sensory experience from any combination of sensory modalities—which makes human flourishing available to the blind and deaf and imposes the obligation on a just society to ensure that they achieve it.

Yet every society will contain individuals whose impairments make the achievement of one or more core capabilities, however broadly framed, a practical impossibility. As Nussbaum recognizes, many severely retarded individuals, or individuals in permanent comas or persistent vegetative states, simply cannot fashion their own conception of the good life, no matter how intensive the support they receive from society. Nussbaum does not regard a society as unjust for failing such individuals; rather, she regards their incapacity as “tragic.”

This survey of how disability figures in some prominent theories of distributive justice indicates the beginnings of a more serious attempt to come to terms with disability, without identifying it with impairments or treating it exclusively as a matter of health. Increasingly, philosophers are becoming aware of the more robust models of disability and their effect on traditional arguments about the demands of justice. Yet there remain difficult and practically significant issues arising out of the interaction between justice and disability with which future theories will need to deal.

CHALLENGES TO DISTRIBUTIVE JUSTICE THEORIES

Accounts of distributive justice are a target of disability critics who see them as inherently demeaning. This change is apt for contractarian theories that exclude people with disabilities from the bargaining table altogether because of their presumed low productively or lack of capacity to form a conception of the good life. We need not consider this critique further. But disability scholars have also criticized theories that are not contractarian and aim directly at equality, variously conceived. Equality theories are also seen as demeaning insofar as they treat disabilities as individual deficits that require special resources to achieve equality, rather than disadvantages resulting from unjust social arrangements. This critique raises more serious doubts about distributive approaches, even those that pay lip service to the interactive character of disability. Can distributive justice theory adequately accommodate the radical changes in attitudes, practices, and environment that justice truly requires?

The disability critique tends to favor more procedural or relational approaches, which identify stigmatization, exclusion, and oppression as the primary sources of injustice and insist on policies aimed directly at those evils. This critique has also inspired some mainstream political philosophers to develop hybrid approaches, which acknowledge the diagnosis offered by the critique but propose a constrained distributive treatment for the underlying injustice. The specific challenges of the disability critique require separate treatment.

Social Basis for the Disadvantages of Disability

The first challenge has been mentioned several times already: Philosophers writing on justice from a roughly egalitarian basis often assume that impairments intrinsically, and dramatically, reduce subjective or objective well-being by limiting basic activities such as walking, seeing, communicating, activities essential to most life plans. The problem posed by disability, as a result, has been to find "special measures" to compensate for functional deficit, whether by Dworkin's hypothetical insurance, Daniels's unlimited resource transfer to restore normal functioning, or Sen's equalization of capability. Philosophers writing from the disability perspective, such as Anita Silvers, argue that this obsessive concern with the comparative well-being of people with disabilities is not only demeaning—since it tends to view people with impairments as defective rather than neglected—but that it also ignores the sources of inequality faced by people with disabilities, namely, the disadvantages caused by unaccommodating, stigmatizing, and discriminatory social arrangements.

Although this critique has considerable merit, it is unlikely that it goes to the heart of the overall project of "patterned" distributive justice—to identify some arrangement of welfare, resources, opportunities, or whatever that can serve as the goal of redistributive policies. On the face of it, one need only identify the full range, and sources, of social disadvantage and adjust interventions appropriately to address the range of disadvantage the theory mandates must be reduced or eliminated. As we have seen in examining the capabilities approach, a clearer appreciation of the complexity of disability will also assist in theorizing about what is often called the "currency of equality," namely, what it is that egalitarian theories of justice seek to equalize.

Distributive Justice and the Goals of Accommodation and Accessibility

As noted above, there is no theoretical barrier to a theory of distributive justice based on an interactive model of disability, one that treats the individual's social environment as responsible for the disadvantages associated with impairments. Such a theory would challenge the assumption that impairments invariably, or in isolation, lower well-being, create inexhaustible needs, or severely restrict the range of available life plans. Yet the question remains whether the current crop of distributive theories can fully incorporate the social goals of accommodation and environmental modification for accessibility. The problem is that most theories share an assumption that has historically held an iron grip on disability policy, namely, that it is always cheaper, more efficient, and publicly acceptable to provide resources to individuals than to modify the physical or social environment in which they live.

The assumption ignores the fact that privileging the "standard environment" in this way means that disability policy will always be piecemeal and ad hoc, a "special needs" policy that confirms the prejudice that people with disabilities are inferior and cannot make it in the "real world." On the other hand, however, opening up the range of interventions for distributive justice to include changes to the environment is not without theoretical and practical difficulty. First, the standard physical, social, and attitudinal environment is disadvantageous to many people in society other than those with impairments. People who are poor cannot take advantage of financial opportunities or savings that are readily available to the rich; people who do not speak the official languages of a country share with sign language users the need for translation for public communication; and children of marginalized minorities, in common with children with cognitive impairments, may require substantial accommodations to benefit from education. Second, accommodations and environmental modifications must be individualized to be useful, but changes that accommodate people with one type of impairment may be useless or worse for those with other impairments or for the unimpaired population. Finally, for these and more general reasons of cost, convenience, and efficiency, there will inevitably be trade-offs, between individuals and groups, and between areas of social participation—employment versus education, access to shopping centers versus access to public buildings or houses of worship. These trade-offs need to be resolved, but it is unclear how to do so.

Although there are large issues, it is encouraging that they are paradigmatic problems of distributive justice rather than fundamental challenges to the project itself. And indeed, some headway has been made. The theoretical underpinnings of universal design, for example, directly address all three problems. Universal design in architecture and product design insists that buildings, public spaces, and products should be designed to be usable by people with the widest possible range of functional capacities as possible. Maximally inclusive design reduces the need for difficult trade-offs among groups and individuals; by eliminating the need for retrofitting and modifying a standard building or product, such design both responds to concerns about social cost and avoids the appearance that people with impairments are being given special privileges or unfair priority over other disadvantaged groups. Much more work needs to be done, but the notion of distributive justice may not be robust enough to encompass all issues of accommodation. Yet it needs to succeed, because an approach to justice focusing exclusively on disrespect, discrimination, and disparities in power will be unavoidably incomplete.

Antidiscrimination Protection Is Enough to Secure Justice

A more comprehensive challenge, reinforced by skepticism about the adequacy of distributive approaches, is posed by so-called relational theories of justice, such as Iris Young's, which focus not on distributional outcomes but on the unjust social relationships of oppression, domination, and hierarchy. The initial appeal of relational theories for disability is that they tend to highlight precisely the same kinds of oppressive attitudes, practices, and social arrangements that lie behind what the disability rights movement has identified as the basis for social injustice, discrimination. Thus, the much admired ADA, while applying only to those with actual or perceived physical and mental impairments, clearly locates injustice in stigma and the related attitudes of devaluation that suffuse social practice. For many disability advocates, the dynamics of discrimination are all that one needs to know to understand justice in the context of disability. Pattern-based distributional theories are, therefore, of little interest.

Although the debate is far from over, a growing consensus suggests that while antidiscrimination laws and policies, fully and competently enforced, do address the core evil in the treatment of people with disabilities, as a social policy for disability, these tools—and the background relational theory of justice—are radically incomplete. In structure, relational theories of justice adopt the core assumption of the procedural approach mentioned above, namely, that as long as the laws, social practices, and institutions are fair, whatever distributional outcomes that result, even if profoundly unequal, are just. In the case of disability, this means that if we could imagine a society in which all forms of prejudice, stigma, misunderstanding, and stereotyping of impairment were absent, where oppression, domination, and exploitation were no longer in evidence, social arrangements would be completely just with respect to people with disabilities, even if the current enormous gaps between able-bodied and disabled citizens in educational achievement, income, and employment remained, or even worsened.

But, it might be asked, if oppression and domination disappear, how could inequality remain? This could happen because an enforceable injunction against discrimination does not tell us what resources are required to meet impairment needs, or how we can alter the physical and social environment to accommodate the functional limitations of impairments, or what measures are required to make the social world more accessible.

To answer those central issues of disability policy, not only do we need to identify and measure the direct effects of impairments themselves (which will remain even if socially created disadvantage is eliminated), but, more vitally, since we do not have infinite resources, we need a standard for assessing the priority of the goals of access and accommodation. This implies our ability to decide what kind of equality we are aiming toward, or what kinds of inequality we are seeking to reduce. But these are not easy issues. Should we provide resources and make social changes to the point where everyone has "equal opportunity" in one of its myriad senses; or to the point where all burdens and benefits are equalized; or to the point where all citizens are equally satisfied with their lives? These are radically different standards. Having eliminated oppression and discrimination, we will of course be committed to, for example, redesigning our educational systems and structuring jobs so as to accommodate people with limited cognitive functioning. But how do we do that? Unfortunately, the purely antidiscrimination approach gives us no guidance.

Only a theory of distributive justice can provide a sense of the practical objectives our commitment to justice demands of us.

Disability Justice, Prioritarism, and Democratic Equality

Although the antidiscrimination approach has limitations as a theory of justice, it has played an important role in refining distributive accounts. Criticism of those accounts by disability scholars has converged with, and increasingly reinforced, challenges from mainstream philosophers about two features of egalitarian accounts: (1) their acceptance of equality as the objective, although it is not attainable on almost any metric and its single-minded pursuit may compel perverse results, such as "leveling down" the better-off to reduce inequality; and (2) their adoption of comprehensive notions of well-being, which concern all or most aspects of a person's life.

Rawls's own theory was neither strictly egalitarian nor concerned with equality in any comprehensive sense. While it required equal liberty for citizens, it accepted inequalities in "social primary goods" as long as they benefited the worst-off members of society. And his list of primary goods, ranging from income and wealth to the social bases of self-respect, was intended to include assets valuable on any reasonable conception of the good, not to serve as proxies for a particular comprehensive conception. But many influential political philosophers following Rawls, such as G. A. Cohen and Dworkin, have offered accounts that are both more egalitarian and more comprehensive than that of Rawls.

In recent years, other philosophers have voiced discomfort with one or both of these features. Some, such as Derek Parfit, have pointed out that a single-minded policy of equalizing well-being—which might well involve a dramatic leveling-down to an unacceptable, but equal, minimum—ignores the moral concern for people's absolute levels of well-being. Parfit argues for giving priority to the worst off in society, rather than trying to achieve an across-the-board reduction in inequality. "Prioritarian" accounts have problems of their own (how to characterize "the worst off'"), but they represent a more general concern about theories of "comprehensive equality" that ask too much of society and seek outcomes that are either impossible or contrary to other important values.

Thus, Richard Norman has rejected comprehensive egalitarian distribution on the commonsense ground that people are unequal in countless ways, not all of which should, or even could, be remedied. Antiegalitarians may have a point when they argue that seeking equality in the face of human diversity is at best Sisyphean, at worse unimaginably oppressive. Some people are incurably shy, others form relationships easily but destroy them just as fast; others strike a balance between these extremes. Even if we could somehow redistribute emotional sensitivity (or compensate the shy or emotionally volatile), would that be a proper role for a just society? Norman thinks for these inequalities we should just say, "That's life," although they lead to inequalities in well-being. Of course, the same may be, and has been, said of impairments.

But if egalitarianism cannot sensibly require the elimination of all inequalities and disparities, what does it require? One proposal is that justice requires the achievement of "democratic equality," that is, that society should eliminate all and only those disparities in well-being that threaten to undermine basic social or political roles in status and participation. Amy Gutmann (1987), for example, has argued in the context of education that principles of democracy implicitly create a democratic distribution threshold: "sufficient resources to education to provide all children with an ability adequate to participate in the democratic process" (p. 136). This threshold is measured in part by the objective of preventing unjust relationships created when some are excluded from political processes that affect all, and in part by an appraisal of what skills and abilities are required for political participation. The threshold, significantly, does not require equality of skill and ability, only the minimum necessary for political participation. The goal is not to "level down" to the threshold, but to guarantee it for all, including children with impairments, while at the same time providing some additional resources for children with the natural abilities to exceed the threshold.

Recently, Elizabeth Anderson has proposed a similar but more general threshold of democratic equality.

Drawing from both the "patterned" and procedural approaches to distributive justice, Anderson argues that the inequality that is truly unjust is that of a hierarchy of social rankings purporting to reflect intrinsic worth (which, in turn, invariably generates inequalities in the distribution of freedom, resources, and welfare). Following Sen, Anderson argues that eliminating the social hierarchy requires redistribution of those capabilities that people require to avoid, or escape, entanglement in oppressive social relationship. Alternatively, justice requires that everyone possess the capabilities necessary for functioning as equal citizens in a democratic society. These are the capabilities required to participate in the activities of civil society, and at bare minimum, those needed to function as a human being: "effective access to the means of sustaining one's biological existence—food, clothing, medical care—and access to the basic conditions of human agency—knowledge of one's circumstances and options, the ability to deliberate about means and ends" (Anderson 1999:317–318).

With respect to disability, Anderson argues that democratic equality demands that people with disability have "good enough access to public accommodations that they can function as equals in civil society." She makes it clear that "good enough" does not require strict equality of resources (or equality of satisfaction or subjective utility), nor does democratic equality require the elimination of disparities in happiness, pleasure, or resources that are not explicitly required for equal citizenship. On the other hand, achieving (more than perfunctory, but truly) effective access to medical care (one of the preconditions for functioning as a human being) is unachievable in even the most resource-rich society. And if equal citizenship requires freedom from pain or debility, then Anderson's goal is utterly unreachable. Similar points can be made about the "basic conditions of human agency": We could spend an indefinite amount on education, training, and support for people with cognitive disabilities without achieving deliberative competence.

The problem appears to be that, motivated by the perversity of leveling down to achieve welfare, resource, or even capability equality, Anderson sets the bar at "sufficient for equal citizenship," which, in practical terms, is either too vague to be useful or utterly unachievable. Ironically, Anderson is equally open to the objection that "equal citizenship" sets the threshold too low, since it is compatible with a joyless and barren life, and too high, because the capability preconditions make a huge demand on social resources. Nonetheless, as Richard Arneson has argued, democratic equality is useful as a rough proxy for well-being, which remains a contentious notion. As is usual in philosophical theorizing, some compromise has to be found between an account of well-being that is complete enough to be intuitively plausible and one that is concrete enough to guide the evaluation, and reform, of actual societies.

CONCLUSION

There is an intriguing symmetry in the challenges facing distributive and relational accounts of justice as they apply to disability. Distributive accounts must recognize the centrality to justice of equal social and political participation, and develop metrics of individual well-being in which the capacity and opportunity for such participation figure prominently. Relational accounts, in turn, must make the notions of nondiscrimination and nonoppression sufficiently determinate to guide the reconstruction of the physical and social environment. Hybrid approaches such as Anderson's—which require that all citizens be brought up to a minimum standard for democratic participation, not to any comprehensive equality—raise hopes for a convergence between extended conceptions of distributive justice and structural accounts of discrimination and oppression.

Those hopes, however, may be illusory. Justice, as Michael Walzer, David Miller, and others argue, may be irreducibly plural. Although both distributive and relational accounts of justice appear to be guided by a principle of equal concern and respect, the former emphasize concern, the latter, respect. The two kinds of accounts focus on inequalities that, however closely correlated, may be morally distinct. The failure to take adequate account of atypical functioning in the design of the physical and social environment may be a fundamentally different kind of wrong than the treatment of people with atypical functions as inferior beings. These wrongs may require different remedies:

the former, redistribution; the latter, recognition. Perhaps, then, a single theory of justice cannot do justice to both aspects of impairments, as sources of functional limitation and as stigmatized differences. We may require both distributive and relational accounts to guide disability policy. But even if the attempt to integrate the two in a democratic threshold account cannot succeed, it provides valuable insight into the kinds of revisions we need to make in both.

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See also Citizenship and Civil Rights; Civil Rights Backlash; Democracy; Ethics.

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K

▣ KALLIKAK, DEBORAH (1889–1978)

American subject of eugenics research

In his widely read eugenic study of 1912, *The Kallikak Family,* Henry H. Goddard introduced Deborah Kallikak as a quintessential example of "defective" heredity. At the age of eight, Deborah entered the Vineland (New Jersey) Training School after troublesome behavior marked her as potentially "feeble-minded." As Goddard and his fieldworkers gathered information on her familial background to assess the possibility of "hereditary taint," she became scientifically valuable for her relationship to a large and extended family "notorious for the number of defectives and delinquents it had produced" (Goddard 1912:16). Goddard invented the surname Kallikak from the Greek words for beauty (*kallos*) and bad (*kakos*) to indicate that the distant progenitor had produced both a *good* line and a *bad* line of descendants. In effect, Goddard's study scientifically designated Deborah, her living relatives, and her ancestors on the "bad" line as human *evidence* of the hereditary nature of feeblemindedness.

At the time of Goddard's writing, Deborah was 22 years old, but Binet tests charted her mental age at 9. Her accomplishments, however, make this diagnosis troubling. Deborah loved music, writing stories, gardening, and caring for children, but her inability to understand numbers and money, lack of abstract thought, and stubbornness convinced Goddard she was feebleminded. The most biased aspect of his diagnosis was the presumption she would lead a "vicious, immoral, and criminal" life outside an institution (Goddard 1912:12). Goddard used Deborah to exemplify the dangerous "borderline" types he designated as "morons," highly functioning but "defective" individuals who, if not properly identified and confined, threatened society with the inevitable result of producing more of their kind. Deborah died in 1978; she lived 81 of her 89 years in an institution.

—Michelle Jarman

See also Developmental Disabilities; Eugenics; Henry Herbert Goddard; Mental Retardation, History of.

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▣ KANNER, LEO (1894–1981)

Austrian-American psychiatrist

Leo Kanner was one of the most influential American clinical psychiatrists of the twentieth century. He has been referred to as the "father of child psychiatry" in the United States, and his textbook *Child Psychiatry,* first published in 1935, remained a standard reference work for 50 years. Kanner is perhaps best known for his description of "early infantile autism" in 1943 as a distinct clinical syndrome. Based on his observation of 39 children with similar behavior, Kanner described a common profile whereby the children did not relate "in the ordinary way" to people or situations. Instead, Kanner (1943) described a child whose "behavior is governed by an anxiously obsessive desire for the maintenance of sameness that nobody but the child himself may disrupt on rare occasions" (p. 243). Although he was to repudiate the term (and the theory behind it) by the 1970s, Kanner also coined the term "refrigerator mother" to describe the supposed emotional frigidity of parents that he thought caused, or at least contributed to, their children's autistic behavior.

Kanner was born in Klekotow, Austria, in 1894, and received his medical degree from the University of Berlin in 1921. He moved to the United States in 1924, and from 1930 until his retirement in 1959 was on the faculty of the Johns Hopkins Medical School. Even after his retirement, Kanner remained professionally active as a visiting professor at numerous universities and maintained a clinical practice until shortly before his death in 1981 at the age of 86.

—Philip M. Ferguson

See also Autism; Psychiatry.

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KATADA IBN DI`AMA AS-SADUSI (CA. 679/680–735/736)

Arab scholar

Katada ibn Di`ama as-Sadusi was blind from birth and had Bedouin origins. He became a learned man of the highest reputation at Basra, Iraq. Katada's renowned memory and recall led to his being often consulted on matters of history, genealogy, poetry, and Qur'anic interpretation by both rulers and scholars of his time. Evidently he prized his independence and developed a strong awareness of space and direction; it was recorded that he "used to go from one end of Basra to the other without a guide" (*Ibn Khallikan's Biographical Dictionary* 1842–1871).

—Kumur B. Selim

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KATAKORI

Katakori or *katakori kô* is a condition peculiar to Japan; the name of this condition is somewhat difficult to translate into English, but it comes closes to "pain in the neck." It corresponds generally to a combination of stiffness, tension, or pain in the neck and shoulders. Its etiology is often associated with reduced blood flow to muscle tissue. Some have suggested that it is a physical symptom that allows for medical care in the setting of Japanese stigma against psychological pain. Treatment ranges from anti-inflammatory medications to transcutaneous electrical nerve stimulation (TENS) to acupuncture.

While its history is suggestive of many comparative elements, modern medical researchers have used the status of *katakori* as a cultural-bounded syndrome to identify it and other somatic complaints as markers of depression in Japanese in cross-cultural studies. In popular culture, perhaps not unlike conditions such as anorexia, one can find reflexive affinity for *katakori,* suggested by T-shirts saying, "I ♥ *katakori.*"

—Walton O. Schalick III

See also Cultural Context of Disability; Disability Culture.

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KELLER, HELEN (1880–1968)

American author and lecturer

Helen Keller was born in Tuscumbia, Alabama, on June 27, 1880. At the age of 19 months, she contracted an illness, either scarlet fever or meningitis, that left her totally deaf and blind. In 1887, Anne Sullivan, a recent graduate of the Perkins Institution for the Blind in Boston, joined the Keller household as Helen's teacher. Keller learned to communicate using the manual alphabet for the Deaf. She graduated cum laude from Radcliffe College in 1904. She published nearly a dozen books as well as numerous articles, essays, tracts, and poems. Her work was primarily autobiographical, but she also wrote on such subjects as women's suffrage, women's health issues, the labor movement, and religion. She traveled widely, in the United States and throughout the world, as a lecturer and spokesperson for the American Foundation for the Blind, which she helped to found in the 1920s. She also toured on the vaudeville circuit for two seasons and appeared in several film documentaries on her life. She died at her home in Westport, Connecticut, on June 1, 1968.

For many, Helen Keller's story is the quintessential overcoming narrative. Through the sheer force of will and the self-sacrifice of her devoted teacher, she overcame her disability and serves as an inspiring symbol of the resilience of the human spirit. For this reason, her image appears on the state quarter of Alabama. By contrast, many in the disabled community, both during Keller's lifetime and today, have criticized her for the way she remained aloof from other disability organizations and causes. She angered many in the Deaf community by following the lead of her mentor, Alexander Graham Bell, and supporting auralism rather than Sign. More recently, disability studies scholars have begun to reexamine her life and work in an attempt to separate the myth from reality and gain a better understanding of her legacy.

—Georgina Kleege

See also Deafblindedness.

KENNY, SISTER ELIZABETH (1880–1952)

Australian nurse

Sister Elizabeth Kenny, a feisty, opinionated, largely self-educated bush nurse, enraged the Australian medical establishment with her pioneering treatments that significantly alleviated the effects of polio. Her methods, which she developed over several years of treating children with polio and cerebral palsy in Queensland, consisted of hot baths, foments, and mobilization of paralyzed limbs with passive movements to reeducate affected muscles. She passionately asserted that the traditional procedures of splinting and bracing immobilized limbs in metal and plaster casts caused major deformities and were tantamount to torture.

Damned by no less than a royal commission of the Queensland medical fraternity, in 1940 Kenny took her treatments first to the Mayo Clinic in Minnesota and later established the Elizabeth Kenny Training Institute in Minneapolis. Gradually her work gained acceptance and she gained fame and honor throughout the United States, where she resided for 11 years.

Kenny's legacy to the disability community extended far beyond her lifetime and is evident in medical rehabilitation therapies practiced today throughout the world. People with a range of neurological conditions involving some form of paralysis, including spinal cord and head injury, multiple sclerosis, stroke, and cerebral palsy, are indebted to Kenny's vision, common sense, and conviction. Sadly, she is a largely forgotten figure in Australia, but she is still widely revered in the United States.

—Joan Hume

See also Polio.

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KERLIN, ISAAC NEWTON

(1834–1893)

American institution administrator

From 1863 until the time of his death in 1893, Isaac Newton Kerlin was the superintendent of the Pennsylvania Training School for Feebleminded Children (better known as the Elwyn Institute), located outside of Philadelphia. Kerlin himself became one of the leaders of the first generation of superintendents for the so-called idiot asylums that were emerging in post–Civil War America. In 1876, in an effort to gain professional status equal to that of the more established leaders of the older insane asylums, Kerlin invited five other fellow superintendents and the prominent educator Edouard Séguin to join him in Philadelphia to found the Association of Medical Officers of American Institutions for Idiotic and Feeble-Minded Persons (now known as the American Association on Mental Retardation). Kerlin would serve as the secretary-treasurer of this organization for the next 16 years, actively publishing and disseminating the proceedings of the group's annual meetings. With the deaths of Samuel Howe in 1876 and Edouard Séguin in 1880, Kerlin arguably became the most prominent national expert in the treatment and institutionalization of the feebleminded population and remained so until his death in 1893.

Throughout his career, Kerlin was an aggressive proponent of institutionalization of individuals with intellectual disabilities. He was earlier than many of his colleagues in abandoning the educational optimism that with skilled treatment most feebleminded children could be cured or significantly improved. Even his descriptions of "moral idiocy" (or, in later terms, "moral imbecility" or "juvenile insanity") endorsed the notion of hereditary incurability and the need for custodial institutionalization for those with normal intelligence but a defective "moral sense."

—Philip M. Ferguson

See also Mental Retardation, History of; Edouard Onesimus Séguin.

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KESSLER, HENRY HOWARD

(1896–1978)

American physician

Henry Howard Kessler, a pioneer in the development of comprehensive rehabilitative services for people with physical disabilities, was born in Newark, New Jersey, on April 10, 1896. A 1919 graduate of Cornell University Medical School, Kessler earned a doctorate in social legislation from Columbia University in 1934. Inspired by Dr. Fred H. Albee, an orthopedic surgeon who practiced during World War I, Kessler became a well-recognized orthopedic surgeon, medical administrator, and international advocate for people with disabilities. He is recognized as the developer of the surgical technique of cineplasty for control of artificial arms, as for the pneumatic-operated prosthetic arm.

During his 12-year career in the U.S. Navy, Kessler served as a captain from 1941 to 1945. He was director of the New Jersey Rehabilitation Commission from 1921 to 1941. He founded the nonprofit, nonsectarian Kessler Institute for Rehabilitation in West Orange, New Jersey, in 1949 and served as its director until his death on January 18, 1978, at age 81. He considered the institute, which has long served as a model for centers for physical rehabilitation, his greatest achievement.

Kessler provided consultative services to Newark Beth Israel and Newark City Hospitals and the Federal Office of Vocational Rehabilitation of the Veterans Administration. He also directed the Rehabilitation Unit at Christ Hospital in Jersey City, New Jersey, and was clinical professor at New York Medical College.

He became internationally known for his work as a delegate to the International Congresses of Industrial Accidents and Diseases and as a consultant to the United Nations. Among his many citations and honorary degrees, most noteworthy are the Albert Lasker Award (1954) and the first President's (Truman) Award of the Committee on Employment of the Physically Handicapped (1952). His many publications include *Accidental Injuries* (1931), *Cineplasty* (1947), *Rehabilitation of the Physically Handicapped* (1947), *The Principles and Practices of Physical Rehabilitation* (1950), *Low Back Pain in Industry* (1955), *Peter Stuyvesant and His New York* (1959), and *The Knife Is Not Enough* (1968).

—Joel A. DeLisa

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Henry H. Kessler Foundation, http://www.hhkfdn.org

▣ KHALIL, AL- (CA. 710–787)

Arab scholar and teacher

Al-Khalil ibn Ahmad was a famous grammarian, prosodist, and teacher at Basra, Iraq. His son was impaired in intellect, and Al-Khalil was one of the earliest parents to record some thoughts about this issue. Once, hearing his father scanning a verse by the rules of prosody that he had invented, this lad ran out and told people his father had gone mad. Al-Khalil treated him in a kindly way and exercised patience toward other students who learned slowly or not at all. The learned scholar asked one such student to scan the verse, "If you cannot accomplish a thing, leave it and pass to another which you can accomplish." To his surprise, the student understood the politely coded message and gave up his fruitless studies. Al-Khalil reportedly lived as an impoverished scholar, with mind focused on higher things. He died after crashing into a pillar at the mosque, which he had not noticed as he was thinking about a problem.

—Kumur B. Selim

See also Abu 'l-`Ala al-Ma`arri; Abu 'l Aswad ad-Duwali; `Ata ibn Abi Rabah; Jahiz, Al- (Abu Othman Amr bin Bahr); Middle East and the Rise of Islam.

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▣ KHUJJUTTARA

Khujjuttara was the hunchbacked maid of Queen Samavati in ancient India. Converted under the Buddha's teaching, she immediately gave up her practice of stealing the queen's money. As Khujjuttara admitted her earlier thefts to the queen and explained why she had changed her behavior, she was asked to preach to 500 lady courtiers and soon attained a preeminent position as a religious teacher. This unprecedented rise from deformed female servant to teacher of the Law was endorsed by the Buddha. Khujjuttara's life is recorded to illustrate karmic retribution in the morally educational sense. In an earlier birth she had mocked a deformed holy man at Benares, and so earned a "corrective" rebirth as a hunchback herself, so that the progress of her soul should not be impeded by wrong thinking and behavior. Elsewhere, Khujjuttara played a substantial comedy role in one of the Buddha's lives, Kusa Jataka. There she took advantage of her position as royal nanny, locking up her mistress, Pabhavati, and generally throwing her weight around. She was named as Khujjuttara at the close of that story, where the Buddha identified various well-known characters.

—Kumur B. Selim

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KIRKBRIDE, THOMAS S. (1809–1883)

American psychiatrist

Thomas Story Kirkbride was perhaps the most prominent American psychiatrist (or "alienist," as psychiatrists were also called) of the mid-nineteenth century. He is best known as the creator of the "Kirkbride Plan" elaborated in his influential work on asylum design and construction, *On the Construction and Organization of Hospitals for the Insane,* published in 1854. Kirkbride was the first superintendent of the Pennsylvania Hospital for the Insane in Philadelphia, a position he held from its opening in 1841 until his death more than 40 years later in 1883. It was at Kirkbride's invitation that he and 12 of his fellow insane asylum superintendents gathered in Philadelphia in 1844 to found the organization that is now known as the American Psychiatric Association. Kirkbride's famous plan for asylum design and operation called for a linear blueprint with wings added on to a main central building. The plan also called for strict size limitations of no more than 250 residents (a principle honored mainly in the breach), with an ample, open campus surrounded by a large wall. As was the case among his early colleagues (e.g., Isaac Ray, Pliny Earle, Amariah Brigham), Kirkbride's encouragement of congregate care for the insane grew from a strong belief in the curability of the insane if they were given timely, appropriate, and therapeutic treatment.

—Philip M. Ferguson

See also Amariah Brigham; Isaac Ray.

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KNOTT, MARGARET (1918–1978)

American physical therapist

Margaret Knott was born in Oxford, North Carolina, in 1918 and graduated from what is now Appalachian State University in Boone, North Carolina, with a major in physical education. In 1942, she entered Walter Reed Army Hospital to study physical therapy and, on completion of her studies in 1943, was commissioned a second lieutenant in the U.S. Army Medical Corps. After leaving the army, she became affiliated with the Kabat Kaiser Institutes (later the Kaiser Foundation Rehabilitation Center), where she gained her reputation as a physical therapist treating injured mine workers. Knott had a long collaboration with Dr. Herman Kabat as they developed the concepts and approach to patient care called proprioceptive neuromuscular facilitation (PNF), which emphasizes the exercise of muscles in specific movement patterns. The first edition of her book *Proprioceptive Neuromuscular Facilitation: Patterns and Techniques,* was published in 1956. "Maggie" spent most of her professional life in Vallejo, California, where she was a magnet for physical therapists from many nations who came to study with her. She also traveled and lectured the world over.

—Helen J. Hislop and
Suzann K. Campbell

See also Physical Therapy.

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American Physical Therapy Association, http://www.apta.org

KOREA

See History of Disability: Korea

KŌTŌ, KUZUHARA (1813–1882)

Japanese musician and designer

Kuzuhara Kōtō lost his sight in early childhood. He studied under Kengyō Matsuno at Kyoto and became a renowned regional performer on the *koto* (Japanese zither). He had unusual spatial sense and dexterity, being credited with original designs in origami (the art of folding paper to produce decorative shapes) and living in a house that he himself designed in the city of Kannabe. In later life he made wooden printing blocks of a tactile nature for his own use, and with them he kept a personal diary for more than 30 years. The printing tools and diary are noted in Kannabe as important cultural property that is preserved for posterity.

—Kumur B. Selim

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KRAEPELIN, EMIL (1856–1926)

German professor of psychiatry

Emil Kraepelin, considered to be the founder of modern clinical psychiatry, was born in Neustrelitz, Germany, in 1856 and died in Munich in 1926. He taught in Dorpat from 1886 to 1891, in Heidelberg from 1891 to 1903, and in Munich from 1903 to 1922. His widely distributed textbook on nosology, *Compendium of Psychiatry,* published between 1883 and 1927 in a total of nine revised editions, made the symptomatic diagnosis of clearly delineated illnesses possible.

Even today's classification system, the World Health Organization's International Classification of Diseases, emerged out of the Kraepelin system. Psychiatric illness has, according to Kraepelin, a clear somatic cause; with this thesis, he relied on a psychophysiological parallelism. He did not consider psychosocial reasons, and this made him a proponent of natural scientifically oriented psychiatric doctrine. Consequently, he also subscribed to the popular theory of "degeneration." This was evident in his forensic publications.

Throughout his life, Kraepelin had a pronounced interest in clinical research. As a disciple of Wilhelm Wundt (1832–1920) in Leipzig, and with a focus on experimental psychology, he founded in 1917 the German Research Institute for Psychiatry in Munich. As a cofounder of psychopharmacology, he was influential through the end of the twentieth century.

—Vera Moser

See also Psychiatry.

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KYŌGEN COMEDY

Kyōgen plays emerged in fourteenth-century Japan as brief comedies played between performances of the more serious Noh drama. The repertoire of Kyōgen (literal meaning, "crazy words") grew to about 250 plays recognized in later compilations. They were not standardized texts in the earlier ages. Players worked up outlines in different ways, then continued refining their acts. Disabled characters appeared in some Kyōgen plots, the audience being crudely entertained by their defects, stupidities, and abuse by the world. In Akutagawa, two travelers, each trying to hide his own impairment, gleefully expose each other's defects to mockery. In Kagami Otoko, the bumpkin's naïveté is comically revealed when a peddler sells him a mirror but is exceeded by his wife's imbecility when he presents the mirror to her. She fails to recognize the woman she sees in it, but realizes that her husband must have been dallying with this hussy. He flees before her wrath.

Better known are the Zatō Kyōgen, which are based on blind characters. More than a dozen plays fall into this group—Dachin, Dobu-katchiri, Hakuyō, Inu-hiki, Kawakami, Kikazu zatō, Kiyomizu zatō, Mari-ke zatō, Muma-kari, Nuno-kai, Saru zatō, Tarashi, Tsuki-mi zatō—but some are now obsolete. Among the best known is Tsuki-mi zatō, in which a blind man engages in the refined Japanese custom of viewing the full moon in a field. He is most appreciative of the delightful choir of insects, which he describes aloud. He is joined by a sighted moon viewer from an upper-class area. They engage in polite conversation and share some wine. Then they take their leave, thanking each other for the company. Each feels content, the blind man because he had a pleasant encounter, the sighted man because of his exercise in polite condescension. The audience then hears another thought striking the sighted man: He could exercise his talents further by sneaking back and picking a fight with the blind man, using a disguised voice. He promptly does so, bumping into the blind man, cursing the man's clumsiness, knocking him down, then running away. The irony is heightened as the blind man wails about the contrast between the nice man he met first and the hooligan who knocked him down.

This is the essential Kyōgen as now understood, crazy stuff carrying a sharp message within the slapstick, pinpointing the ambivalence of attitudes, contrasting polite hypocrisy with underlying cruelty. Yet it seems that the early Japanese Zatō Kyōgen portrayed frank ridicule of blind men who suffered farcical tricks to amuse the watchers without any irony. The plays have become more politically correct in recent centuries, with interpreters introducing moralizing elements. Parallels have been drawn with medieval European drama in which serious reenactments of religious and moral themes were relieved by comedy with satire and slapstick. A crude French farce such as the thirteenth-century *Le Garçon et l'aveugle,* about a blind man whose servant plays tricks on him, could readily be adapted to the original Zatō Kyōgen style.

—Kumur B. Selim

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L

LABELING

See Stigma

LAGOVSKY, NIKOLAY MIKHAILOVICH (1862–1933)

Russian educator

Nikolay Mikhailovich Lagovsky was a deaf educator and director of the Mariinskoe school for the deaf in Murzinka village near St. Petersburg, Russia. He organized two boarding schools for the Deaf near Moscow (Aleksandrov, Pererva) and held a position as professor in deaf education of the Moscow State Pedagogical University. He wrote a number of books on deaf education and the history of deaf education, including *Methods of Instruction of the Deaf-Mute* and *St. Petersburg School for the Deaf-Mute.*

—Anna Komarova and
Victor Palenny

LAME, THE

In the twenty-first century, the word *lame* is used primarily as slang for a poor attempt. It is rarely used anymore to refer to human gait. Perhaps this shift in vocabulary reflects the physical landscape of the twenty-first century, in which people with variant gait are increasingly rare as a result of medical technology and aesthetic norm. In contrast, "the lame" were an ordinary part of the ancient human landscape.

The image in the mind's eye of the ancient world is influenced by the legacy of the Renaissance and onward, when scholars and artists depicted perfect Graeco-Roman buildings draped with perfect Graeco-Roman bodies. In fact, any given public gathering place in the ancient world would have included people with a much greater variety of physical conditions than we see in the developed world today. Permanent "lameness" could be acquired at many different stages in one's life. Inadequate nutrition during pregnancy was a significant factor in the ancient world in terms of producing offspring with physical anomalies. Clubfoot is just one example of "lameness" that can be acquired in the womb. Because of the easy corrective procedure available today for this condition, we do not see many people with clubfoot in developed countries, but it was quite common in the ancient world; the Greek god Hephaestus (the Roman Vulcan) himself was portrayed with a condition that matches the description of clubfoot.

Children born without irregular gait could acquire it from a variety of circumstances later in life. The bones of children who are underfed do not have a chance to develop properly. Vitamin deficiencies, especially in combination with swaddling, likely led to such malformations as rickets. A simple accident, such as a fall, could have irreversible consequences for both children and adults in the ancient world. In the developed world, we take for granted that, with medical attention, even the most severe fracture will be undetectably repaired, and we assume that medical attention to a broken bone will result in perfect healing. In the ancient world, a visit from a doctor could have a range of possible results, as doctors' training was not standardized, licensed, or necessarily respected.

However an ancient doctor treated a bone injury, it was not the injured bone but rather the infection that might ensue that was responsible for extreme damage. The bone-injured person would be lucky if the bone simply healed crookedly, because every bone injury was also susceptible to infection. Untreated by antibiotics, an infection can spread throughout surrounding tissues and then the bone itself, attacking even the bone marrow. In addition to injury and infection, disease was responsible for permanent physical impairment, and epidemic diseases could leave whole groups of people with permanent physical handicaps.

Far from the embodiment of the golden mean, the ancient population included a wide variety of somatic configurations. There is no evidence that wheelchairs existed in any form, nor is there evidence that people may have propelled themselves in small carts. People with missing limbs or with other significant mobility impairments probably got around however they could, using crutches as necessary.

—M. Lynn Rose

See also History of Disability: Ancient West.

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LANGE, DOROTHEA

(1895–1965)

American photographer

Dorothea Lange was born in Hoboken, New Jersey, in 1895. She contracted polio at age seven, which resulted in a weakened right lower leg and a visible limp. The changes in her body as a result of polio proved profound and shaped her personality and her later practice as a journalistic photographer. Her most recognized works involve pictures she took of impoverished migrant farmers during the Great Depression era in the United States. She claimed that her noticeable limp allowed her access to her subjects because it made her less threatening as a documenter of exploitation, poverty, and suffering. According to Lange: "I was physically disabled, and no one who hasn't lived the life of a semi-cripple knows how much that means. I think it perhaps was the most important thing that happened to me, and formed me, guided me, instructed me, helped me, and humiliated me" (quoted in Holland 1999). Lange paid a great deal of attention to feet in her work. During 1957, she produced more than a dozen photographs of her own disabled foot and leg.

—David T. Mitchell

See also Polio.

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LANGUAGE OF DISABILITY

In the new global disability universe, perhaps no more contentious debate exists than that surrounding language. Much abuse and harassment of disabled persons occurs as a matter of hate speech even as abusive acts can be covered over with euphemistic expressions and the benevolent rationalizations of professional discourse. Language study thus bears the onus of making visible the contours of disability experiences without erasing the realities behind rhetoric. Particularly since the Enlightenment (1700–1900), many philosophical efforts to explain "reason" as exemplary of what separates humans from animals derive from individuals' assessed competence with linguistic expression. In some frameworks, then, nonspeaking persons or those with communication-based disabilities may be negated as rational human beings out of an apparent lack of verbal fluency that is presumed to equate with an absence of value.

Disability historians sometimes remark that disability today constitutes a densely ramifying totality (see, e.g., Gerber 2000)—the phrase attempts to reckon with the fact that the term *disability* literally consists of conflicting investments among disciplines, sciences, and public cultures. In referencing disability in this manner, we can better understand the varied vocabulary and beliefs that inform our contemporary understanding of disability. This insight is worth picking up, given that so many professional and community interests intersect across the single figure of a disabled individual. Charity interests interpret pathos, pluckiness, tragedy, and deserving vulnerability in disabled persons. Educational interests see the difficult, special, unreachable, or uncontrollable "learner." Medicine approaches disability as a flaw to be conquered and as deviance to be overcome. Rehabilitation recognizes disability as a deficit in need of supplementation and concealment. Everywhere one finds terminology that selects the "cute ones" and conceals or gasps at the "gross ones." Thus, language becomes a barometer of the degree to which a culture openly grapples with the effort to accommodate all capacities or cater to a narrow range of abilities.

Insights from disability studies enter into this discussion in a reflexive manner, prompting us to pay closer attention to the language that filters our perspectives about human differences, particularly as a matter of grappling with the slippery metaphors and allegories that make body predicaments into emblems for cosmic, or simply social, dilemmas. Disability is rarely used to identify the realities of a life of difference—physical, cognitive, or cultural. A common, quite justifiable observation among disability scholars concerns well-placed discontent at having one's body image continually usurped into the expression of a universal motif. Economies are crippled, excuses are lame, a city council is blind to the consequences of some decision. Disability metaphors add combustion and intensity to commentary in any context; they take an expression of concern up a notch in the registers of rhetorical hyperbole. They up the ante on an atmospheric threat so that the strategic placement of a disability-based referent like *crippled* can lend a sentence the quality of an ominous threat. Horror, extremity, and tragedy are the emotions that these metaphoric equations seek—relying for their power on the premise that disability can parlay body differences into an equation with impending doom.

Because of this added punch supplied by the use of disability terminology, one crosscurrent in the field of disability poetics has been a determination to embrace the rhetorically charged references to crippled lives, akimbo limbs, lame figures of speech, cross-eyed stratagems, and limping gaits in poetic traditions. A privilege of being a practitioner of poetics, after all, is that one has permission to investigate language in all its permutations.

Disability poetics, then, assists in demonstrating that the historical language used to define, segregate, and confine people with disabilities is a rich but fraught area for research and interpretation. An encounter with this vast array of historical synonyms for physical, sensory, and cognitive "deviance" demonstrates that while we often seek a less dehumanizing vocabulary to reference disability, such a project proves difficult to achieve. In fact, the multiplicity of ways for referencing disabled lives suggests the degree to which comprehending disability constitutes a central social task in our own historical period. Even the widely accepted term *disability* denotes a form of euphemistic window dressing that cannot successfully exorcise the "barbarism" of previous terminology from which disabled people seek social redress.

Consequently, the battle over self-naming hits at the heart of language struggles themselves. Yet as one disability scholar argues in a discussion of the relationship of linguistic signs to the goals of political reform: "Rather than claiming or disclaiming any set of stigmata (or stigmatizing terminology), a successful poetics of disability would operate from a relentless skepticism of the motives and the truth-value of any sign (marks, names, labels, jargon). . . . Signs have no more an essential, autonomous existence than the categories they represent, and no sign can indelibly mark or irretrievably erase a meaning" (Jeffreys 1997:244). This "relentless skepticism" toward language fixes provides disability poetics with a more dynamic understanding of the politicized notion of language and helps to develop a less naive historical recognition that all terms become contaminated with the very ideas they seek to obliterate or refuse.

The need to develop a more protean sense of language surfaces as disability studies methodologies become increasingly prominent in academic circles. One witnesses numerous examples of critics and educators who refuse to include disability under current work on identity and minority experience. These arguments for exclusion seize on the "biological evidence" of disability as pathology in order to shore up disabled people's "real" difference from other *socially* disenfranchised groups. Within these arguments disabled people are refused a place at the table of social constructionism—they are deviant bodies, whereas other minorities have been unfairly cast as inferior. In such discussions disability poses as less of a linguistic product and more of a literal "flaw" in the mechanisms of living. In the midst of this refusal, medical labels are still assumed to offer up pure diagnostic definitions as opposed to social meanings. Within this rationale other marginal identities—such as gender, race, and sexuality—can be resignified as linguistically defined differences, but no amount of linguistic triage can put the disabled body back together again. Disability becomes a rent in the fabric of being itself rather than an adjudicator of social beliefs about biological differences.

There is a good deal of historical contingency to arguments about the celebratory nature of chosen identities such as blackness, femininity, and other culturally marginalized groupings. The capacity to embrace a historically devalued position takes generations of effort to effect, and one never absolutely arrives at the desired objective: a language free from stigma. Derogatory epithets such as *nigger, hysteric,* and *queer* still surface and, because of language's slippery properties, metamorphose into differently dehumanizing reference systems. They are the residue from historical associations of particular biologies with welfare, criminality, unproductivity, and inferior intelligence. While it proves difficult at some points in history to imagine that a group can effectively take up a despised identity as positive, such efforts are only mitigated by a repetitious history of linguistic dehumanization.

The embrace of formally derogatory language among disability groups is no different—efforts to make disability a matter of social identification rather than "flawed biology" afford an opportunity of semantic *choice* where received definition does not necessarily mean inevitability. While one cannot always choose to extricate oneself from a medicalized notion of abnormalcy projected from the outside, the "disability" rubric provides an opportunity to upend social expectations. The *choice* provided by self-designation flirts with the scandalous political potential of embracing the very identity that others believe to be inherently undesirable.

Counterdiscourse in disability studies sweeps up *crip,* for instance, into an embrace, just as gay, lesbian, and transgender studies came to flaunt *queer.* If one cannot drive away the insults of the playground, then one can take them up and repeat them as a matter of demonstrable fortitude. Such subcultural reclamations emphasize belongingness and chummy verbal communities. The counterdiscursive strategy performs one's place in language and thus exerts a modicum of control over the placement.

Depending on one's cultural location, the usage of *gimp* now results in poetic profit. For instance, the disability comedian Robert deFelice takes up the debasing terminology and turns it into a knowing affectation: "Gimp girls you have consulted with that man [the doctor] many times and look at you!" (in Snyder 1995). Such commentary suggests that strict obeisance to medical regimens of care may not prove helpful to those playfully identified as "gimpy." Likewise, the disabled performance artist Cheryl Marie Wade deploys *gnarly* and *crip* as terms of endearment for her various arts endeavors in Berkeley, California: Gnarly Bones and Wry Crip Productions. These efforts of ironic turnabout by disability performers set audiences into titillating hysteria as they adeptly expose the limits of professional definitions and linguistic assignments. Terms that seem to arrive as unalterably undesirable suddenly become points of community, camaraderie, and knowing mystery exchanged among the like-minded and like-embodied. These ruses of language reveal that labels function not as empirical descriptions of undesirable body types but rather as parameters that restrict meaning where it should be mobile. In the tongues of savvy disability commentators insulting terminology is speedily refashioned for impromptu moments of satirical reclaiming.

In the process of standing language on its head, these efforts not only set language on the run but, perhaps more important, begin to efface a lifetime of hurt for those who have borne the brunt of such abuse in school, in the doctor's office, and in the workplace. Recently a man successfully sued his employer on the basis of the fact that the metal plate in the man's head served as the opportunity for his fellow employees to call him "plate-head." The act of disarming harmful language in this manner ensures the retrieval of the individual's humanity in the face of daily language wars that would argue otherwise. It assists in exposing the violence that so often passes for "good fun" among those who take disability as a "self-evident" sign of an individual's dehumanization. Political correctness wars thus often reference disability in discussion of the ludicrous extremes to which our society will go to deny the obvious; yet, in doing so, these arguments seek to deny the degree to which the language we use shapes perceptions of those who are referenced by such terminology.

Many of today's language pundits spend time ruing the arrival of the "gerrymandering tendencies of linguistic reform movements" by using disability as the absurd example par excellence (Dutton 1996:551). As one prominent commentator argues: "Sooner or later the schoolyard finds out, and *retard* becomes the coinage of value. Everyone ought to deplore the abuse, but it is a delusion to suppose that we alter medical facts by dispensing new names, for *it is the medical condition that is the problem, not the words that describe it"* (Dutton 1996:559). Rather than deny that some persons embody a socially despised biology, the objective of disability studies, disability poetics, and the disability rights movements is to demonstrate that language debases some biologies in order to produce an environment of privilege in the cases of gender, race, sexuality, and ability. Analyses of language usage, consequently, set our sights on the contexts within which some biologies benefit at the expense of others. The object of such efforts is not to deny human difficulties, but rather to critique the idea that the complexity of any lived experience can somehow be confined to the determinism of a pathologizing medical label.

Hence the arrival of one of the more controversial issues in the history of disability language formation: person-first vocabulary. During the 1970s and 1980s, a movement of disability activists forged a social agenda in part around insistence on the phrase *persons with disability* rather than *the handicapped, cripples,* or *disabled person*—labels that were all treated as if they further consigned someone to a nonstandard, unjust future. Within such a linguistic formulation, *disability* would be backloaded as a mere adjective to the personhood of the individual described. In doing so, those who participated in such linguistic adjudications argued that disability would be an aspect of our lives but not an all-encompassing defining feature. In response, others in the same movement argued that placing *disability* last in the chain would amount to a form of denial tantamount to other euphemistic usages such as *physically challenged, special,* and *handicapper.* According to this perspective, *disabled person* is at least as acceptable as *person with disability* in that it overtly claims disability as a point of meaningful difference. Stigma is best combated, argued this language contingent, through an overt embrace of the characteristics directly affecting our lives. In formulating such discussions over appropriate terminology, disabled persons recognized language as one front in the battle for civil rights—it is not merely an adjunct or tangential issue of politically correct language policing.

In this debate, expertise once established by jargon-ridden labels developed by medical, social work, and rehabilitation professionals was challenged and, in some cases, completely overturned. Disability groups made direct claims for the necessity of developing vocabularies that meaningfully grapple with the etiologies and implications of bodily and emotional experiences that differ (or are perceived to differ) from the majority. Whereas "severe" medical vocabularies aspire to neutral description that drives out the last vestiges of freak-show provocations, disabled people deplored the objectification of their bodies that whittled them down to "conditions." Just as late-nineteenth- and early-twentieth-century freak-show performers became exotic spectacles—a man with atrophied legs metamorphosed into "the thinnest man in the world" or "the human skeleton," a woman of Mexican descent with facial hair became "the bearded lady," an African American man with scoliosis transformed into "the missing link"—the complex humanity of persons with disabilities would be usurped by a deterministic feature such as “mental retardation,” “muscular dystrophy,” or “deafness.” The goal here was expediency as opposed to clarity, and the politicized parsing of language was one vehicle of choice.

Yet in many ways some of those attentive to disability language charge that we have not sufficiently attended to the wild card of biology that operates as the point of most disabled people’s ostracization in the current political debates. According to this argument, one of the weaknesses of our current language politics is that people with disabilities cannot afford to overlook the vulnerability and “real” limitations of bodies. Often the problem with medical definitions is not that they pay too much attention to disability, but rather that they prove inaccurate as to the experience of the condition itself. Those with multiple sclerosis, for instance, would argue that a book by Nancy Mairs comes much closer to the nuances of the disorder than any deterministic medical textbook entry. In addition, others have argued that a discussion of disability that fails to take into account the social context of experience references little more than a body shorn of its environment—a corpse posing as a living condition.

Is it necessary to refuse a recognition of biological incapacity in order to establish an effective political movement? Can one not recognize the often very real limitations of the bodies that we inherit or acquire without having to give up on revising the language used to diminish the lives of persons with disabilities? In part, there exists a pressing practicality in this matter; for instance, in research one cannot locate disabled persons in history without searching the keywords by which they would appear in the dehumanizing, medicalizing, segregating, or infantilizing languages of their day. Thus, disability scholars ironically found themselves in a conundrum during the 1990s when the Modern Language Association (the largest humanities-based organization in the world) took it upon itself to excise all instances of debasing disability language from its database search engine. While the gesture proved moving as a safeguard against the use of derogatory speech, it also rendered an enormous amount of historical material invisible. The effect was to erase all written historical materials that relied on terms such as *crippled, demoniac, retarded,* and *gimp*—a sizable cache of materials, as it turned out. In a parallel example, educators might discuss research plans for studies into the future on whether or not sign language should be considered a natural language. For instance, deaf studies scholars have found themselves consternated over the discovery that American Sign Language has been classified under the rubric of “invented languages” alongside the Klingon language created by writers for the television series *Star Trek.*

Like many areas of disability, ideas about language reveal a geography of uneven development. For example, sign language poetry is currently enjoying a creative surge of interest, with international performances, an online journal, and literary prizes. Whereas a history of education for deaf individuals has made sign language usage off limits for deaf students, the effort repressed the idea that signed languages were the first communicative mode of interaction among human communities. In banning signing, then, such educational efforts privileged “voicing” as a preferred communication method in a hearing world. Work to explicitly forbid sign language forced alternative communication modes underground, so to speak, and the revival of sign language poetry attempts to reclaim the power of sign language as a rejection of such prejudicial premises. New ways of integrating the body into linguistic analyses have emerged based largely on the degree to which sign language poetry depends on the body itself as a vehicle of meaning making. The Flying Words Project performer Peter Cook and others have turned their bodies into instruments of communication that outdistance even the most articulate oral talker or writer.

Sign language analysis has also helped to unseat common beliefs that associate articulation with intelligence. Not only deaf people but many with communication-based disabilities have found themselves identified as idiotic, feebleminded, retarded, or delayed, depending on the historical period of their diagnoses. Today, difficulty in oral communication immediately earns an individual placement in special education classes, no matter how fluent he or she may be on paper or computer. Our cognitive sciences have labored long under the erroneous conception that a lack of spoken language acquisition is directly related to insufficient intellectual development where peak performance seems inevitably tied to assessments of oral fluency. To combat this prejudicial assumption, many technologies that facilitate communication have been developed to provide vehicles for communication. Such technologies serve to assist individuals who cannot speak, those whose speech is highly limited, and those who cannot point reliably. These prosthetic enhancements to communications have been widely debated with respect to the degree that they "simulate" the appearance of intelligence rather than reveal the presence of thinking individuals wielding a language of their own. However, such politicized debates only tend to demonstrate the degree to which those who oppose facilitated communication deny humanity to those with speech disorders.

Many prevalent disability clusters form around kinds of language acquisition technologies and assistance that can be readily marketed with payment assurances under different kinds of insurance reimbursement plans. Examples of this phenomenon include hearing-impaired individuals and listening devices (i.e., hearing aids, cochlear implants), people with visual impairments and reading technologies (i.e., Braille, magnification technologies, and so on), those diagnosed with developmental disabilities and various software technologies, and autistic individuals and communication hardware (i.e., portable speech boards, synthesized voicing technologies, and so on). To some extent, one may grow increasingly suspicious at the beginning of the twenty-first century that the technologies are now driving the diagnostic determinations. One will rarely find a disabled individual lacking a closet cache of useless technologies prescribed by one overzealous medical or rehabilitation professional or another. As history has demonstrated, once a technology becomes available human communities find it difficult to resist the ever-present temptation of application.

Finally, this entry will conclude with a discussion of art and advertising, which serve as key contexts for public reception of people with disabilities. The term *enfreakment* has been coined to designate the dire atmosphere of media representation that artificially generates atmospheric strangeness around disabled bodies. The most widely known examples of such phenomena can be found in the sadistic body art of Joel Peter Witkin and the deforming photography of Diane Arbus. In the work of both of these visual portraitists, disabled bodies are transformed into surreal landscapes that tend to emphasize the "grotesquery" of human differences. As one disability scholar argues, their depictions suggest that some impending calamity is about to befall their artistic subjects. Yet, as in the freak-show performances of old, these artistic endeavors consciously seek out the staging of their subjects in ways that artificially exaggerate disabilities as "oddities." Witkin's work slices, dissects, and violates the bodies of his subjects, and Arbus's photography uses alienating props such as Halloween masks, hand grenades, claustrophobic environments, and campy clothing to mock the figures depicted. Such artificial designs trade on the situation of disabled people in bizarre environments where their differences appear out of place and glaring. In all cases, debasing artwork cultivates a visual grammar that encourages viewers to participate actively in the dehumanization of disabled people. Such artwork conjures private language codes that leave art's consumers with little other than extreme emotional responses of distaste, danger, and/or discomfort.

Parallel efforts can be found in the language of charity forums such as telethons and walkathons. In these performance venues disabled people—usually depicted in a perpetually infantilized state as helpless children—are identified as fates-worse-than-death and public contributions promise to eliminate future individuals who might find themselves in the "affected" category. Almost every major disability now has its own charity "organ," and, in the case of the most renowned disabilities—such as muscular dystrophy, cerebral palsy, and "mental retardation"—a plethora of charity organizations have evolved and splintered off from each other. In order to become successful in an industry that has become increasingly competitive, charity organizations participate in the fashioning of severe and pathos-ridden language games in order to top the previous year's contributions. For instance, American telethon barker Jerry Lewis has been recorded as telling disabled people to "stay in their homes" if they do not want to be pitied by others. As this entry's opening discussion of hate speech notes, such aggravated commentary deploys language as a weapon that diminishes disabled people's lives in the midst of encouraging benevolent acts of monetary giving from viewers. Like their scientific partner, genetics, these media displays pursue discourses of prevention as the only appropriate response to unwanted human variations. In doing so, they often manage to avoid efforts at social provisions that would better allow existing disabled people to participate more fully in obstacle-ridden social contexts. Further, in "giving" of their hard-earned dollars, donors are encouraged to feel good about themselves as they contrast their more "fortunate" status with those who are described in terms that mark them as definitively "less fortunate."

By far, linguistic contexts for disability are overdetermined by detrimental ascriptions. Perhaps, as some more pessimistic analysts contend, disability is a difference that cannot be adequately accommodated within the strictures of contemporary vocabularies. At the very least, an examination of disability terminology suggests the degree to which cultures rely on perceptions of extreme human variation to test the outer limits of acceptable humanity. Language is the medium within which all bodies exist; as a result, words create the contexts, the expectations, and the imaginative possibilities for the future cohabitation of disabled and nondisabled bodies. The flexibility of our environments is greatly determined by the language we use to access and construct livable spaces. Let us hope that our language of disability can become as flexible as the bodily variations it references.

—Sharon L. Snyder and
David T. Mitchell

See also Facilitated Communication; Sign Language.

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L'ARCHE

L'Arche is an international federation of communities dedicated to the service of people with intellectual disabilities. It was founded in 1964 in Trosly, a French village north of Paris, by Jean Vanier (son of General Georges Vanier, former governor general of Canada), who was born in 1928. L'Arche emerged as one individual's reaction to and attempt to address the dismal living conditions in institutions for the developmentally disabled at the time.

L'Arche began when Vanier welcomed two persons with disabilities to live with him in a small home. His desire to share his life as a brother with these individuals, Raphael and Philippe, attracted others, and soon a community of several homes and workshops grew in the same village. Later, some of those living in Trosly left to begin similar communities in other parts of the world, at the same time maintaining strong links of friendship and support with one another. In 1972, L'Arche was constituted, and by the beginning of the twenty-first century it included more than 113 communities in 30 countries around the world. The organization's name, French for "The Ark," is taken from the Old Testament story of Noah. It signifies a place of refuge, of salvation from the flood. The name was at first applied to the original home begun by Vanier; it was later given to that first community he founded.

L'Arche is distinctive in that its style of community living is based on relationships, wherein the people with disabilities, called "core members," and people without disabilities, "assistants," live in an atmosphere of trust, security, and mutual affection. The core members are valued and accepted for who they are and the gifts they bring. The people with disabilities are not viewed as "residents" cared for by "staff." Assistants do not view their role as only that of caregiver, but rather as one of sharing life *with* people with disabilities. Assistants usually commit to live in a L'Arche community for one year. Many stay longer, and some assistants have chosen to live in L'Arche communities as a life vocation.

L'Arche communities are faith based, Christian in origin, and welcome people of all faiths and religions. The communities vary in size within and among the countries around the world, having from one to eight homes per community, and they are located in both urban and rural areas. L'Arche communities celebrate each person as being of unique and sacred value and strive to create homes where faithful relationships are nurtured, based on forgiveness and celebration. The same sense of communion unites the various L'Arche communities throughout the world. Bound together by solidarity and mutual commitment, they form a worldwide family.

Although L'Arche has experienced tremendous growth over the past 40 years, this growth has been primarily organic. L'Arche does not seek to expand greatly; rather, it seeks to serve as a sign of hope to society in a divided world.

—Clarissa Schoenberg

See also Community Living and Group Homes.

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LARYNGECTOMY

Theodore Billroth of Vienna performed the first successful laryngectomy in 1873. Laryngectomy is a surgical procedure to remove the larynx (voice box), which is situated above the trachea (windpipe) and in front of the esophagus (gullet or food pipe). This procedure is often done to treat larynx cancer if chemotherapy is unsuccessful. Laryngectomies may also be performed on people with gunshot wounds, severe fractures, or other trauma.

A laryngectomy may be partial or total. In a *partial laryngectomy,* only a portion of larynx or the surrounding muscles is removed. Although the voice is not lost and the individual may retain his or her usual patterns of speech and swallowing, the voice may sound weak or hoarse. The larynx is completely removed in *total laryngectomy,* which alters breathing and communication. A permanent opening (stoma) in the front of the neck allows the individual to breathe, but speech is altered. People who have had laryngectomies are known as laryngectomees; some refer to themselves as "larries."

Laryngectomees are taught one of three alternative ways of talking to restore communication: esophageal speech, tracheoesophageal speech, and electronic speech. The goal is to learn a new speaking technique that is most comfortable for the individual.

Esophageal speech is the oldest method of voice restoration, having been used for more than 100 years. In this technique, the individual draws in air through the mouth and forces the air into the esophagus by locking the tongue. The process is similar to a controlled burp. Esophageal speech is less costly than other methods because it requires no equipment or surgery; however, the vocal phrasing and low volume of the speech that results may make it difficult for others to understand the individual.

Tracheoesophageal speech is similar to esophageal speech, but the individual uses a device to redirect air from the trachea into the esophagus. The device is inserted at the stoma site with a *tracheoesophageal puncture* (TEP): A small shunt is placed through an opening between the trachea and esophagus. A small one-way valve placed into this opening allows the laryngectomee to force air from the lungs into the mouth. This method results in a more natural voice than does esophageal speech, and voice restoration occurs within two weeks of surgery.

Electronic speech involves the use of an electronic or artificial larynx, a device first developed by Johann

Czermak in 1859 to create a clearer voice and increase vocal volume. There are two types of artificial larynxes. The *extraoral type* looks like a flashlight; it has batteries in the handle and a vibrating disk on the end that the laryngectomee presses against the outside of the upper neck. The *intraoral type* consists of a shirt-pocket-sized battery pack connected to a sound emitter by a small wire that is held in the palm of the hand.

Following laryngectomy, some people experience depression and social withdrawal due to the changes in their voices and reactions of others. A number of support groups have been established for laryngectomees (e.g., WebWhispers Nu-Voice Club, the International Association of Laryngectomees), and many find that joining such groups is beneficial. Most laryngectomees successfully return to their jobs and resume most of their usual activities.

—*Kelly Hsieh*

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LATINO HEALTH

LATINO ETHNICITY AND IMMIGRATION

The terms *Latino* and *Hispanic* refer to people who are of Latin American or Spanish descent. There is a great degree of heterogeneity among Latinos, as this group is made up of people from many different races, cultures, and countries of origin. Within the U.S. population, the number of Latinos is currently growing. The majority of U.S. Latinos are of Mexican descent, and most live in the southwestern region of the country. In addition, many people of Central American and Puerto Rican descent live on the U.S. East Coast and many of Cuban descent live in Florida. Growing numbers of Latinos are also immigrating to many midwestern and southern states. The majority of Latinos who migrate to the United States do so in search of jobs that will allow them to support their families, both in the United States and in their countries of origin.

INTERNATIONAL LATINO HEALTH AND DISABILITY

A major cause of underdevelopment in many countries is repeated episodes of illness and long-term disability. Poor health and disability among Latino groups in developing countries are often the consequences of infectious diseases and noncommunicable conditions such as malnutrition, perinatal conditions, mental illness, diabetes, cancer, and cardiovascular diseases. Malnutrition and the spread of infectious diseases are the results of inadequate sanitation, lack of immunization, and poverty. Poor nutrition, lack of prenatal care, and environmental toxins cause perinatal conditions. Chronic diseases such as cardiovascular diseases and diabetes are increasingly becoming major contributors to disability and mortality, both within the United States and internationally. Latinos in Latin American countries and in the United States are at increased risk for these diseases due to a sedentary lifestyle, high-fat/calorie diet, hypertension, high cholesterol, and obesity.

U.S. LATINO HEALTH AND DISABILITY

According to the U.S. Census, 15.9 percent, more than 11 million, Latinos age five years and older have some kind of disability. Data from the mid-1980s indicate that the highest rates of anencephaly, spina bifida without anencephaly, and Down syndrome in the United States occurred among Latinos. Chronic conditions are major causes of disability among Latinos living in the United States. Most often, disabled

Latinos are of school or working age. Furthermore, the U.S. population of Latinos includes 1.6 million people age 65 and older. The Hispanic elderly population is the second-fastest-growing aging population. As the population ages, the number of Latino with disabilities will grow as well. The leading causes of disability among older adults include Alzheimer's disease, arthritis, cancer, cardiovascular disease, and diabetes. More Latinos have arthritis, the leading cause of disability in the United States, and activity limitations from arthritis than do non-Hispanic Whites. The prevalence of type 2 diabetes is 10.2 percent among Latinos in the United States, a rate that is two to five times greater than that among non-Hispanic Whites, and many disabling secondary diabetes-related conditions affect Hispanics as well. Another cause of disability among Latinos is occupational injuries. It is estimated that there are more than 3 million migrant and seasonal farmworkers in the United States, the majority of whom are Latino, and large numbers of Latinos work in high-risk industrial settings as well, such as animal processing plants. Occupational injuries are not uncommon, and many Latinos do not seek treatment for fear of facing questions about their immigrant status and perhaps losing their jobs.

Prevention and Treatment

Compared with non-Hispanic Whites, Latinos in the United States are less likely to engage in preventive practices and to obtain screenings to detect chronic disease risk factors and signs of disease. That is, they are less likely to regularly obtain routine checkups, to undergo blood pressure and blood cholesterol screening, or to be screened for colon, prostate, cervical, and breast cancer. There is also evidence that rehabilitation outcomes are less successful among Latinos than among any other ethnic groups. Many social, economic, and cultural factors influence the preventive and screening health practices of Latinos.

Factors Affecting Health and Disability among Latinos

It is well established that low income, low level of education, and lack of access to health care are associated with chronic disease risk factors and mortality. Latinos in general are poorer, less educated, and less likely to have health care coverage than are members of other ethnic groups in the United States. In 1999, the per capita income for all people 16 years of age and older in the United States was $21,587, whereas among Latinos it was almost half that ($12,111). About 45 percent of Mexican Americans working full-time reported earning less than $15,000 a year. Just over half of Latinos have at least a high school diploma, whereas just over 85 percent of non-Hispanic Whites have at least a high school diploma. Latinos also have less access to health care: More than 33 percent of Latinos in the United States do not have health care coverage. Research has also shown that Latinos are less likely than members of other ethnic groups to use public aid, even if they are eligible, for reasons of pride, fear of questions about their immigrant status, and lack of awareness of the system. The negative effects of lack of resources and access are compounded for Latinos with disabilities, who experience even more difficulty with access to health care and obtaining employment. They also experience difficulty in accessing public facilities and transportation. Language barriers and cultural differences among Latinos with disabilities may also impede their access to health care, their ability to obtain assistance from service agencies, and their ability to obtain employment. In addition, it is estimated that 10,000 Mexicans cross the border into the United States every day, and little is known about the prevalence of disability among recent immigrants or about the potential barriers that those with disabilities face.

CULTURAL BELIEFS AND VALUES

Cultural values about health and disability have been shown to affect the lifestyle choices that people make, decisions to access health care, and the services that people with disabilities seek out. It is important to note that among Latinos in the United States there is a great deal of heterogeneity in cultural beliefs and values. Differences in ethnicity, national origin, gender, income, and education, as well as in religion and level of acculturation (defined as the process of adopting the beliefs, behaviors, and values of the dominant culture), all influence cultural beliefs and values.

Religion plays an important role in Latino cultures, as it does in most cultures. Religious beliefs may influence individuals' views of and attitudes toward illness and disability. Latinos may see disability or illness as a test from God, as God's will, or as a punishment. Religious beliefs can also provide a positive framework through which to view disability and illness. Many Latinos believe that prayer, pilgrimages to holy sites, and vows can aid in curing or ameliorating symptoms, and many who are ill or disabled find sources of support in faith and in organized religion. Religious leaders and fellow parishioners provide everything from emotional support to instrumental support. Research has shown that faith in God provides a higher level of support than does religion as an institution. It is common for an individual to experience an increase in faith with the onset of an illness or disability, but disability or illness may also contribute to a loss of faith.

Latino cultures in general are collectivist. They are guided by duties to the group rather than to the individual, and collectivist norms influence how Latinos perceive health and disability. The value of placing the needs of the family above those of the individual influences Latinos' view of the world. Close extended families are more commonplace among Hispanics than they are among non-Hispanic White Americans. Latinos often turn to family members for social support and advice about health. A family's beliefs and knowledge about preventing and controlling disease shape the individual members' health beliefs and behaviors.

Familial roles also influence conceptualization of disability. For example, if a person with a disability is able to fulfill his or her traditional family roles, other family members may not think of that person as having a disability. The idea of being "normal" can be related more to being able to fulfill roles and expectations than to having an illness or being impaired. A person with an impairment may be considered a unique individual rather than described as disabled. Expectations related to gender roles also influence attitudes and behaviors related to disability and illness. For example, women may deny the impact of illness or disability because of a cultural expectation of *aguantar* (a verb meaning "to endure"). *Machismo* among men may contribute to denial of disability or illness and may cause them to avoid seeking services.

Beliefs about Causes of Disability and Illness

The beliefs of Latinos vary in respect to the causes and treatment of disability, the perception of the severity of disability, and the impact of disability on life. Latinos living in the United States hold varying degrees of both medical and folk beliefs about the causes and treatment of illnesses and disability. Medical beliefs about causality are related to genetics and accidents at birth or in childhood. Folk beliefs about the causes of disability and illness include such elements as imbalance between hot and cold, flies in a home, the evil eye (*mal de ojo*), and dreams during pregnancy. Bad air, germs, and poverty are blamed for symptoms and illnesses. Psychological states such as worry, fear (*susto*), anger, and envy may be labeled as causes of symptoms and disease, as well as turmoil in the family, amorality, and ethical violations. Faith in God, fatalism (a belief that disease onset is a result of fate, and thus individuals have little or no hope of preventing or controlling disease), and *personalismo* (personal relationships) both influence health conceptualization and lead Latinos to avoid or put off seeking treatment. Some Latinos use home remedies involving herbs, purification rituals involving holy water or candles, and the services of spiritual healers to treat illness or disability before or in place of seeking medical help. One study on the cultural norms related to Latinos' delayed use of medical care when chronic disease–related symptoms are present found that the factor with the most pronounced effect on care seeking was the perceived seriousness of the symptoms.

Cultural Competence

Health professionals in the United States are increasingly recognizing that they need to be aware of the social and cultural factors that influence how Latinos perceive health and disability. To improve the health and well-being of Latinos with disabilities, research is needed to examine the diverse health-related beliefs among various Latino groups. Although it is important to be sensitive to cultural beliefs, health professionals should avoid assuming that every Latino has traditional beliefs. Culturally competent and bilingual service providers are also needed to serve this population effectively.

—Janine M. Jurkowski

See also Cultural Context of Disability.

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LAVATER, JOHANN KASPAR

(1741–1801)

Swiss scientist and poet

Johann Kaspar Lavater was a Swiss scientist and poet who wrote in German. Lavater developed an influential science of physiognomy that linked facial countenance and bodily appearance with moral disposition. While physiognomy itself was not new—some scholars place aspects of this belief as far back as the writings of the ancient Greeks—Lavater's system sought to formalize a common practice as empirical method. His most famous book, *Art to Know the Men by the Aspect: The Physiognomy* (1775–1778), was a two-volume work that included silhouettes and illustrations of faces in profile exemplary of character traits such as greed, criminality, melancholy, miserliness, and virtue. He also included his own profile as well as those of celebrated individuals of his time whom he admired. The basis of his system of physiognomy was Lavater's belief that the body communicates the nature of the soul. Along these lines, he once argued, "Action, looks, words, steps, form the alphabet by which you may spell character." Significantly, several prominent disabled people of the eighteenth and nineteenth centuries opposed Lavater's theory on the basis of its prejudicial relation to disabled bodies. Disabled critics of this theory included the "hunchbacked" German mathematician Georg Christoff Lichtenberg (1742–1799), who mocked Lavater and other physiognomists of his time by explaining that they took their own bodies as the barometer of morality. According to Lichtenberg, "God created man in His own image, says the Bible; philosophers reverse the process: they create God in theirs."

—David T. Mitchell

See also Georg Christoff Lichtenberg.

LEADERSHIP

The term *leadership* is used to represent an office or position of leader or the ability to guide, direct, or influence people. By definition, leadership involves the holding of an elevated office or position—that is, leaders have a higher status than do those whom they are leading. Further, definitions of leadership stress that leadership is a group process that involves interaction between at least two persons as they work toward a common goal. In this way most directly, leadership has done much for the field of disability. This entry discusses types of disability leadership and their effects, which include advances for both leaders themselves and the general disability community.

TYPES OF DISABILITY LEADERSHIP

Specific to the field of disability, leadership has taken three major forms: leadership by persons with disabilities; leadership by parents, family members, and caretakers of persons with disabilities; and leadership of policy makers surrounding disability-related issues.

First, many people with disabilities have taken leadership roles themselves in a number of capacities, including in large organizations such as the American Association of People with Disabilities as well as in smaller grassroots community groups. As one example, the centers for independent living (CIL) movement began in the 1960s and 1970s due in large part to the leadership of Ed Roberts, an individual with an extensive physical disability as the result of contracting polio as a child. Roberts's leadership experience began with his advocating for his own equal access to an education and moved on to include his advocating for the rights of people with disabilities all over the United States. Another example is Deng Pufang, himself a wheelchair user, who founded the China Disabled Persons' Federation (CDPF) in 1988. The CDPF works to protect the human rights of persons with disabilities as well as promote their equal participation in society. In 2003, Deng Pufang was acknowledged with the UN Prize in the Field of Human Rights for the extensive work he has done for people with disabilities in China through legislation, programs, and activities.

Along these lines, much has been done to encourage the leadership of people with disabilities, including a number of national and local conferences that have chosen as a major theme the leadership of people with disabilities. In addition, a variety of disability leadership forums and training programs exist across the United States and the larger international community, including in places such as Illinois, Massachusetts, Michigan, Oregon, and Thailand. The majority of these projects have been designed to help youth or adults with disabilities uncover or further develop their leadership skills, sometimes in relation to a specific area, such as independent living.

Second, parents, other family members, and caretakers of persons with disabilities have also participated as leaders in the disability community. Parents of children and adults with disabilities have been responsible for beginning many support organizations, including United Cerebral Palsy, as well as networks such as the Parents Exchange, an informational, referral, and advocacy organization. Another example is the Kennedy Foundation, which grew in part out of Eunice Kennedy Shriver's experiences with her sister Rosemary's intellectual disability and continues to provide supports to serve those with mental retardation. These groups are essential to supporting people with disabilities as well as educating the able-bodied community regarding the strengths and needs of individuals with disabilities. Similar trends have been evidenced internationally. For example, in the United Kingdom a group of parents of children with disabilities formed the National Autistic Society in order to provide information and support to other family members of individuals with autism.

The third form of leadership in the area of disability has been that provided by policy makers and government agencies. For example, the National Institute on Disability and Rehabilitation Research (NIDRR) has been a strong leader in advocating for the rights of and equal services for individuals with disabilities. NIDRR has developed funding priorities that, among others, promote leadership training for people with disabilities. These priorities continue to ensure that disability remains an integral part of the research agenda in the United States. Another example of leadership by government agencies occurred in Australia during the early 1970s, when a larger community health movement took place. Under the Whitlam administration, local community health projects were made directly accountable to the communities they served. There was community involvement at every level of service development and delivery, which allowed channels of communication to open up among service providers, government officials, and consumers in areas such as disability and mental illness (among others). These types of policy initiatives provide a framework for both national and local organizations to strive to meet the needs of individuals with disabilities more effectively.

EFFECTS OF DISABILITY LEADERSHIP

Positive effects of disability leadership can be seen both in leaders themselves and in the broader disability community. First, serving as leaders can benefit leaders themselves. Much general research conducted across a variety of populations has found that helping others can have a positive impact on the person providing the help. Specific to disability, serving as a leader may benefit the leader in terms of self-determination, power, and control. For example, leadership training has been used to promote recovery in persons with psychiatric disabilities. Such training may lead to decreases in psychiatric symptoms as well as increases in self-efficacy, community living skills, and empowerment. Similarly, serving as a peer leader has been found to facilitate adjustment to a new disability among individuals with spinal cord injury. Leadership training can also open the door to further career opportunities. For example, in one leadership training program, graduating leaders had the opportunity to join local advocacy organizations on a formal basis as speakers who would advocate for effective supports for people with disabilities.

Second, leadership can also benefit the broader disability community in terms of advancements in the area of equal access and equal rights, as a catalyst toward person-directed services, and as a way to build a solid sense of disability community and identity. Perhaps the most significant impact that leadership in the disability community has had is seen in the passage of the Americans with Disabilities Act (ADA) in 1990. The development of leadership in the disability community in the United States led to the passage of the ADA, and in turn the ADA has raised the quality of life for many people with disabilities. Changes such as better access to employment, transportation, housing, education, communications systems, and public facilities for people with disabilities have all resulted from leadership in the disability community. Moreover, the passage of the ADA in the United States foreshadowed growing interest in disability rights legislation in other countries, such as Australia and Colombia.

Another example of the broader community impact of leadership is the CIL movement, which is dedicated to helping people with disabilities live independently and become productive, fully participating members of society. The National Council on Independent Living (NCIL), which was formed in 1982 in the United States, provides an excellent example of leadership for people with disabilities, by people with disabilities. The NCIL has been a leader in the disability community in terms of building local community bases as well as advocating nationally for disability rights.

Community impacts can also be seen on a smaller scale. For example, leadership training programs often foster the development of networks of individuals who have strong leadership skills. Such networks can then be effective tools for outreach and education of other people with and without disabilities about disability rights in the community.

In all of the examples presented above, leadership has facilitated the building of empowerment in the general community, which can also help new people develop as leaders in their communities, creating a solid feedback loop. Leadership serves as an effective and essential tool to effect change and advocate for a variety of rights for people with disabilities.

—Erin Hayes and
Jose Mendez

See also Advocacy; Advocacy, International; Advocacy Movements: France; Advocacy Movements: Germany; Empowerment and Emancipation; International Disability Organizations; Peer Support; Roberts, Ed.

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LEAGUE OF THE PHYSICALLY HANDICAPPED

The League of the Physically Handicapped was a grassroots organization of disabled activists that operated in New York from 1935 to 1938. In 1935, in the depths of the Great Depression, President Roosevelt established the Works Progress Administration (WPA) to provide jobs for the unemployed. However, among the groups considered "unemployable"—and thus ineligible for WPA jobs—were people with disabilities. In response to this policy, six young people with disabilities held a sit-in at the offices of New York City's Emergency Relief Bureau. At first merely aiming to speak with the bureau's director, they escalated their demands as the sit-in continued. An ongoing picket line of supporters at times swelled to hundreds, with thousands of onlookers. Six days later, when those sitting in finally met with the bureau director, the nascent group was demanding jobs in unsegregated environments and explicitly rejecting charity.

The League grew from this core of activists. Focused on employment rights, the organization engaged in picketing, public education, and meetings—often confrontational—with public officials. The group also wrote a 10-page "Thesis on Conditions of Physically Handicapped." Prefiguring later thinking, this work asserted that discrimination is the cause of disabled people's unemployment and critiqued the charity model, especially sheltered workshops.

—*Anne Finger*

See also Activism.

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LEARNING DISABILITY

Coming to agreement on the definition of learning disability (LD) has been a challenge since the 1960s. Various groups, such as the Learning Disability Association (LDA), provide their own definitions. However, the most widely used definition in the United States is that provided by the U.S. Department of Education under the regulations of the Individuals with Disabilities Education Act (IDEA) of 1997. According to the IDEA, the term *learning disabilities* refers to a group of neurological disorders that impact one or more of the brain's basic functions used to understand and interpret language, symbols, and gestures; such disorders are typically identified during the elementary school years. The manifestation of these neurologically based conditions can be observed in an individual's difficulty with reading, writing, listening, speaking, completing mathematical functions, fine motor skills, and even interpreting social cues and gestures. The term *specific learning disability* (SLD), which is sometimes used instead of the more general term *learning disability,* refers to a severe difficulty with one area of life and learning without any accompanying difficulty with others. For example, someone with an SLD in reading may experience great difficulty with written print but be able to complete complex mathematical computations and manipulate objects that require great dexterity.

Historically, three conditions have been considered in identifying a learning disability: (a) the presence of a discrepancy between potential and achievement, (b) the presence of intraindividual differences, and (c) the presence of average to above-average intelligence. These conditions pose a problem for professionals working in the area of LD. Most notably, procedures for determining whether a discrepancy exists are a source of great debate that centers on issues related to IQ testing and performance measures. As a result, the IDEA, the federal legislation in the U.S. that is designed to ensure that individuals up to the age 21 receive free appropriate public education that meets their needs, calls for a comprehensive, interdisciplinary assessment of strengths and needs for any student thought to have an LD. One critical factor to rule out in making a diagnosis of LD is that the problems themselves are a result of LD and not due to other disabilities or societal factors. However, LDs can coexist with nonintellectual disabilities, and in many schools it is common to find students with both LDs and emotional behavioral disorders.

More than 50 percent of individuals in U.S. schools who receive special education services have some type of LD. Adults who have learning disabilities may also go undiagnosed and thus experience great difficulties. Their undetected LDs may have negative impacts on their ability to work, engage in social relationships, and experience success. Because LDs are invisible, they pose some interesting challenges for individuals with LDs as well as their families, professionals working with them, and their peers and coworkers. An LD can affect every domain of an individual's life, and, as such, interventions designed to support success may vary greatly for different individuals.

Specific LD disorders include dyslexia, dyscalculia, dysgraphia, dysnomia, and dyspraxia, and in recent years the growing category of attention deficit disorder (ADD) has been included on this list. Individuals with the best-known type of LD, *dyslexia,* experience great difficulty understanding language and using various language-related skills, most commonly reading, writing, spelling, and speaking. This condition at times affects an individual's ability to interpret mathematical symbols to determine operations and may also influence the ability to interpret social cues (e.g., facial expressions). The next most common form of LD is *dyscalculia,* which has the same effect on an individual's learning and understanding of mathematical concepts and operations. Although the impact of this LD on a person who is in school is significant, it does not end once the individual exits the school setting. It can be observed in disorganization with balancing a checkbook, poor money management (e.g., late payments), and scheduling errors. *Dysgraphia* affects an individual's ability to develop written language and use it as a mode of communication. *Dysnomia* refers to difficulty experienced with the recollection of names, places, or specific object words. This form of LD can have a negative impact on children and youth, but it has a greater influence on adults as they attempt to communicate with coworkers, supervisors, clients, and related groups. *Dyspraxia,* the least common of the learning disabilities, is related to the manipulation of fine motor skills; it limits the individual's ability to engage in handwriting, drawing, typing, sequencing, and even daily self-care.

According to the Learning Disability Association, ADD and brain injury also fall under the category of learning disability. ADD affects an individual's ability to focus attention for any prolonged period of time; if hyperactivity is also observed, attention deficit/hyperactivity disorder (ADHD) may be diagnosed. In recent years, ADD and ADHD have become increasingly recognized. Until about 20 or 30 years ago, young people with similar behaviors were identified as hyperactive, impulsive, or disobedient. Now there is greater understanding of how this condition becomes or creates a learning disability. Given that brain injury affects an individual's neurological development, it is also considered a learning disability.

Since the 1990s, a new group of individuals has been considered as having a learning disability: individuals who are simultaneously gifted. Gifted LD individuals do not typically fit the criteria of experiencing failure, but they do meet the criteria for the presence of a discrepancy. In other words, individuals who are gifted LD may easily use their intellectual potential to compensate for their learning disabilities.

While the above description of LD conditions provides an outline of the various learning characteristics of individuals identified as having LDs, intervention options also need to be considered. Once a learning disability exists, it will not go away or be "cured" as an individual matures. The goal of intervention is to teach skills to address the challenges that are presented by the LD. Teaching the use of multiple learning modalities—visual, tactile, auditory, and kinesthetic—helps to "educate the brain," the source of this neurologically based disability. The use of assistive technology devices is becoming increasingly common among educators and employers for supporting individuals with LD. The technology that allows assistive devices to convert speech to written print, predict words, and/or read text is advancing daily. Such devices can open doors for individuals who may not be able to read or write but have excellent comprehension. They can make the difference in whether an individual with LD can access postsecondary education, participate in competitive high-level employment, and in other ways demonstrate his or her full potential.

Brain research demonstrates the neurological basis for learning disabilities and their impact on information processing, memory, and performance. However, symptoms associated with a learning disability can also be observed as a result of gaps in learning and of biased evaluations rather than the presence of a neurological condition. Consequently, there has historically been an overrepresentation of ethnic minority individuals identified as having LDs, as a result of both cultural bias and language bias. For example, professionals can easily misinterpret the characteristics of a potentially English-proficient student during the emergence of a second language as a language learning disability. However, if individuals go undiagnosed, they may experience great difficulties as adults living with undetected LDs that have the potential to limit their success in many ways.

The term *learning disability,* and the concept to which it refers, is relatively new. Learning disability was identified as a specific condition in the 1960s by a group of parents and advocates who observed unique learning styles in their children. The children in question had at least average intelligence and did not have physical or sensory disabilities. Professionals were at a loss to provide effective educational interventions for these individuals. Since that time, the recognition of this condition as a disability has extended beyond the United States and is now recognized internationally through brain research.

As with other disabilities, the presence of a learning disability has a significant impact on an individual for life. Unlike other disabilities, LDs are misunderstood as a result of their invisible nature and broad scope. Changes in the wording of legislation and subtle differences in definitions, whether theoretical or operational, can affect the diagnosis of LD. Students with LD are protected under the IDEA in the United States, but adults must use the protections of the 1990 Americans with Disabilities Act. Because of the ADA definition of disability, individuals with LD may not actually be protected unless they can prove that their disability has a negative impact on at least one major life function. In school, at workplaces, and in their communities, individuals with any type of LD are constantly pressured to perform actions that are in direct contradiction to their disability. Therefore, greater understanding of both the neurological basis for a learning disability and its vulnerability to the impacts of curriculum, poor education, and cultural bias is crucial.

—Teresa Garate

See also Dyslexia.

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LEONARD CHESHIRE

Leonard Cheshire is the largest charitable supplier of services for disabled people in the United Kingdom. It also operates globally. Founded by the World War II bomber pilot and war hero Leonard Cheshire, VC, in 1948, it greatly influenced the pattern of social care provision made for disabled people in the second half of the twentieth century internationally. This was particularly based on group living in residential institutions, which greatly restricted disabled people's opportunities to shape their own lives.

In the 1960s, the resistance of disabled people who lived in one Leonard Cheshire home, Le Court, played a major role in establishing the British disabled people's movement and the development of disability emancipatory research. The introduction of "community care" legislation in the early 1990s in Britain was intended to support disabled people to live in their own homes and neighborhoods.

In the late 1990s, the Leonard Cheshire organization established the Disabled People's Forum, which is run by disabled people and works within the organization to support disabled people's involvement and empowerment. The process of democratizing the organization, increasing the control of disabled people, improving the quality of services, and enabling disabled people to live independently, is still proving problematic, however. Leonard Cheshire's experience highlights some of the difficulties of making change from within traditional charitable organizations for disabled people.

—Peter Beresford and
Fran Branfield

See also Community Living and Group Homes; Empowerment and Emancipation; Independent Living.

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LEPROSY

Leprosy is increasingly known by the less offensive name of Hansen's disease (HD). It was the first chronic disease to be attributed to a bacterial cause, when the Norwegian physician Gerhard Armauer Hansen identified the bacillus *Mycobacterium leprae* in 1873. There still is no clear understanding of the transmission of the causative agent, which appears to require long-term exposure and has a long incubation period. Efforts to grow the organism in a cell culture, which is prerequisite to the development of a vaccine, remain unsuccessful. Divided into localized (tuberculoid) and generalized (lepromatous) forms, the disease manifests first in skin discoloration and then in nodules, lesions, and topical anesthesia. If unchecked, it gradually spreads over the entire body, attacks the soft tissue of the nose and throat, impairs vision, and damages the nervous system. Ultimately, extremities become deformed and paralyzed, and may fall off after repeated but unperceived injuries.

The intrinsic seriousness and disfiguring effects of leprosy and, in the West, an accumulation of misnomers and misconceptions related to the disease have triggered irrational reactions that have proven difficult to overcome. Fateful changes in nomenclature began in late antiquity. The Greek category of "scaliness" (*λέπρα*), which covered a wide range of skin conditions, and the analogous Hebrew *zarã'at,* which biblical law termed unclean and cause for ritual isolation, merged into the Latin term *lepra.* The most ominous confusion ensued when the term became interchangeable with *elephantia* centuries after the Romans noted this disease as new, foreign, and presenting symptoms matching those of HD; they reported that it caused horror and that they feared the transmission of this evil.

Horror and revulsion interacted with the belief that physical deformity implied moral perversity. Deep fear persisted as long as infectiousness was misconstrued as contagiousness. The highly visible effects of the disease, together with its endemic and frequently clustered incidence, led observers—and historians—to overestimate the epidemic dimensions beyond the maximum documented ratio of patients to population. The tendency of the disease to occur in families and to strike children was confused with heredity. The steady advance of symptoms, obscuring the secondary infections that actually were the lethal threats to the weakened body, led to the assumption that death was the natural and inevitable outcome of leprosy and that, therefore, patients were beyond medical help.

The abandonment of patients found its most dramatic expression in a funeral rite that accompanied their ejection in some areas of medieval Europe, but it did not preclude continued efforts at palliative care. Similarly, in most societies, public stigmatization and exclusion coexisted with the protectiveness of families. Even official banishment failed to eliminate the victims from communal life and consciousness. HD patients have been the objects of effusive charity and the subjects of stories of miraculous healing and of heroic missionaries from the twelfth-century foundation of numerous leprosaria to the current activities of global aid movements. Nevertheless, they must still contend with discrimination and assaults on their self-esteem in addition to the physical disabilities they incurred before receiving medical treatment. After ages of unproven remedies, in which snake meat figured prominently, and high but vain expectations for chaulmoogra oil in the early twentieth century, the introduction of dapsone in 1941 brought the first effective therapy. The drug takes a toll on the kidneys, which may cause some patients to forgo their medication and others to die when dialysis is not available. In addition, emerging drug-resistant strains of *M. leprae* have necessitated multidrug therapies. These carry more side effects, and their expense impedes application in the areas of the world with both the lowest prosperity and the highest incidence. Endemic leprosy declined markedly in early modern Europe, and currently no industrialized country has more than a hundred HD patients. In the developing world, however, hundreds of thousands of new cases are diagnosed each year.

—Luke E. Demaitre

See also Institutionalization and Segregation; Stigma.

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LEUPOLT, JANE (1812–1894)

British missionary and educator

Jane Leupolt, née Jane Chambers Jones, went to India in 1835 with the Society for the Promotion of Female Education in the East as a trained infants teacher. She married the Reverend Charles Leupolt in 1839 and for many years concerned herself with the education of blind children in the Orphan Institution at Sigra, Benares (Varanasi), and with local blind adults. After living in England, where she saw Moon's embossed reading materials, she returned to India in 1860 and organized formal literacy teaching of blind children with Mrs. Amalie Fuchs, a fellow missionary. By 1864 their efforts convinced the government to fund teachers for blind children. Using adapted Moon characters, Jane Leupolt succeeded in printing readers in Hindi. Light industrial work was also begun at Benares with blind youths at Raja Kali Shankar Ghosal's Asylum in this period, and Jane Leupolt's embossed books were used there from 1868 by Indian teachers whom she trained in their use. Although some earlier literacy work had begun in India with Lucas's script, Jane Leupolt was the first to organize the teaching of blind people on a larger scale and to gain government recognition. Before leaving India in 1872, the Leupolts passed the materials to the Reverend John Erhardt at Secundra Orphanage to add to the facilities of its famous printing house.

—Kumur B. Selim

See also William Moon.

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LEWIN, KURT (1890–1947)

German-American psychologist

Kurt Lewin was a German-American psychologist who profoundly influenced many fields. Lewin's environmental/contextual approaches to studying behavior and his integration of science and social change serve as cornerstones for contemporary conceptions of disability, disability research, and policy. Born in Prussia, Lewin studied and taught at the University of Berlin. In 1933, he emigrated to the United States to work at Cornell University, moving to the University of Iowa in 1935 and then to the Massachusetts Institute of Technology with the 1944 launching of the Center for Group Dynamics.

Lewin conceptualized behavior (B) as a function of the person (P) and the environment (E), expressed mathematically as $B = f(P, E)$. Person-environment interaction is key to the social definition of disability.

Lewin melded research and social intervention. His oft-quoted statement "There is nothing so practical as a good theory" characterizes his view that science and social change should be achieved simultaneously. Lewin called this combination "action research," and this approach is often used today in disability studies.

Much of Lewin's work dealt with reducing prejudice. Lewin demonstrated that nondiscriminatory policy led to decreased prejudice in mixed-race housing projects. Blacks and whites living as equals came to view each other as friends, a concept on which the inclusion efforts of disability advocates are based.

—Willi Horner-Johnson

See also Translating Theory and Research into Practice.

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LICHTENBERG, GEORG CHRISTOPH (1742–1799)

German physicist and philosopher

Georg Christoph Lichtenberg was born on July 1, 1742, in Ober-Ramstadt in Darmstadt, Germany, and died on February 24, 1799, in Göttingen. His father, who was a minister, wrote in the church register after Lichtenberg's birth: "birth'd son who despite weakness I baptized." From the age of eight, Lichtenberg suffered from a spinal deformation combined with a hunchback that was probably caused by rachitis. With the help of a governmental scholarship, he was able to attend university. In 1769, Lichtenberg was appointed professor of physics in Göttingen. It is said that Lichtenberg could write his lectures on the board without turning his back—that is, his hump—to the audience.

For a time, Lichtenberg lived with a flower girl, Maria Dorothea Stechardt. She was his housekeeper and lover, but she died at an early age. Soon thereafter he took in a new young housekeeper, Margarete Elisabeth Kellner, who also became his lover. She bore Lichtenberg six children, and late in his life he married her.

Lichtenberg, although fond of the monarchy, was not only an outstanding physicist but also a representative of Enlightenment philosophy. He became the father of the German aphorism. Many of his witty ideas, familiar quotations, and flashes of thought—or "penny truths," as he liked to call them—were connected with his life. These can be found in his so-called *Sudelbücher* (mess books), which remained unpublished during his lifetime and became available widely only at the beginning of the twentieth century. In some of his most famous aphorisms he addressed the philosophy of disability and physical impairment. Lichtenberg's fear of people was paired with the gift for observation concerning human behavior. This also generated his polemic "Über Physiognomik; wider die Physiognomen" ("On Physiognomics; against Physiognomy"), which was published in 1778.

In 1983, an exhumation of Lichtenberg's skeleton proved that in fact no smallness in stature or "misshapenness" could be ascertained. His impairment, although descriptions of it have been handed down by his contemporaries, seems to have vanished into the air. One could take this finding as an ironic commentary on the controversies among Lichtenberg's biographers. Even today, discussions arise as to whether the philosopher endured his suffering with patience or with humor, or whether he simply went about his daily life, feeling indifferent about his disability.

—Christian Mürner

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LILIANE FOUNDATION

The Liliane Foundation, located in the Netherlands, is committed to doing justice to children with disabilities in developing countries by giving them access to rehabilitation. In 1980, the Liliane Foundation started by assisting 14 children. In 2002, the foundation helped 31,982 children spread over 80 countries. As of that year, the total number of applications allocated and justified since the organization started its activities amounted to exactly 249,792.

Characteristic of the Liliane Foundation's assistance are direct contact with the child within the home situation and attention to the personal growth and happiness of the child. The key feature is "tailor-made" assistance—that is, assistance that varies according to the personality and the situation of each individual child. The guideline in the rehabilitation process is the child's individual rehabilitation plan, which sets out specific goals and describes the desired results. The final objective of the rehabilitation is the child's integration and participation in society.

The Liliane Foundation directs its efforts primarily toward children with disabilities living at home. From the start, the parents are closely involved in the rehabilitation process; this involvement (also in a material sense) is extremely important for the success of the rehabilitation.

The small-scale, direct, and person-centered assistance that is typical of the Liliane Foundation is made possible in practice through the foundation's collaboration with a worldwide network of "mediators" (local contact persons). Only representatives of nongovernmental or religious organizations can become mediators. The Liliane Foundation pursues its policy of strengthening the mediator network structurally by entering into partnership agreements with these organizations. The partnership agreements place the responsibility for the functioning and financial control of the mediators, as well as for the continuity of the work done, with the organizations.

Many mediators are social workers, physiotherapists, or nurses who work in the slums of big cities or in rural areas, where people often hardly know that rehabilitation is possible. Mediators or their coworkers arrange for the rehabilitation of the children with disabilities they come across in their work, requesting that the Liliane Foundation provide partial funding of the rehabilitation interventions needed. Because mediators and their coworkers have direct contact with these children and their families, they know the children's needs and the particulars of the local situation. They are aware of what kinds of assistance the children need most to cope better in their specific surroundings and circumstances.

The Liliane Foundation uses as many local facilities for rehabilitation as possible. Children who need surgery undergo it in the hospitals nearest to where they live and receive aftercare in the vicinity as well. Physiotherapy is provided in the children's homes or in nearby facilities, and any needed appliances are obtained locally. Children also receive education and vocational training in locations as close to their families' homes as possible.

—Patrick Devlieger

Websites

Liliane Foundation, http://www.lilianefonds.nl

LITERATURE, FOLLY

Folly literature is mainly a phenomenon of sixteenth-century Europe. Although the term *Narr* (fool) was used by earlier authors, it achieved its broad circulation only when Sebastian Brant (1457–1521) published the moral fiction *Narrenschiff* (*Ship of Fools*) in 1494. Shortly after the appearance of its first German edition, this book was translated into Latin, English, French, and Dutch. The passengers on the "Ship of Fools"—including the narrator himself—were fools because they were not able to conform to moral, religious, and ethical norms. The author not only criticized human sins and vices, such as drunkenness, adultery, and lavishness, but also condemned minor deviations such as the dislike of planning one's future. Brant's book became a best-seller and was a hallmark in Renaissance literature. It influenced many other pieces such as Erasmus von Rotterdam's *Encomium moriae* (*Praise of Folly*).

Besides their evident importance to moral fiction, fools played important roles in carnival plays and jest books. However, natural fools, being the main objects of interest from the disability studies perspective, were hardly ever mentioned in the *Ship of Fools* and similar fiction. In his sermons about the *Ship of Fools* in 1498 and 1499, the famous Strasburg preacher Geiler von Kaysersberg (1445–1510) explained that natural fools were fools without sins. They did not deliberately behave in deviant ways and therefore were not suitable to illustrate violations of moral, religious, and ethical norms. Instead, during the Middle Ages and Renaissance natural folly simply described a condition of essential mental difference. Natural fools were understood as differing not only from the normal but also from the mentally ill, since their condition was not a temporary, but a permanent one.

Although natural fools can be found in Renaissance literature even before the *Ship of Fools* was published, printed pieces about natural fools made up only a small segment of literature. For instance, in Wolfram von Eschenbach's thirteenth-century epic poem "Parzival," the protagonist's mother dressed his son as a fool to prevent him from becoming a knight. In doing so, the mother hoped that Parzival would return home quickly as soon as he was badly treated at court. However, as natural folly depended not only on a special costume, Parzival's princely origin could not be disregarded. In contrast, in Gottfried von Straßburg's epic thirteenth-century poem "Tristan," the hero voluntarily dressed as a natural fool when he met Queen Isolde. In this disguise, it was even possible for him to sleep at the door of his secret love. However, as natural folly was linked with asexuality, he could stick to his folly role only as long as he was not seen in bed with Isolde. Having betrayed his secret, Tristan had to escape. This plot serves as an example of high medieval German literature in which natural folly often offered a chance and disguise and dissembling.

In sixteenth-century Europe, jest books were another genre that collected anecdotes about all kind of fools. A good example of a jest book is *Schimpf und Ernst* (*Jests and Lessons*) by Johannes Pauli (c. 1450–c. 1520). Three main approaches to natural fools can be differentiated in folly literature. First, actions of natural fools were said to evoke laughter. Second, natural fools were shown as divine beings bearing messages from God. Third, natural fools were used as positive didactic examples. They were laughed at for their deviant behavior. For example, a popular anecdote told of a natural fool discovering a foal standing next to the fool's stud. The fool started to beat his horse for being a whore, and comforted the foal.

These anecdotes often had a closing statement that aimed at making the general audience laugh. The authors also understood the natural fools' deviance as divine intervention, and consequently interpreted their behavior as foretelling signs. It was Martin Luther (1483–1546) who related the anecdote about natural fool Claus Narr, who asked for water that would help him to extinguish a fire while at the same time in the distance a castle was burning. Other authors interpreted not only single episodes of a fool's life but the whole foolish behavior as a sign of prophecy or wise telling. These authors used natural folly as a didactic example for moral, religious, and ethic norms.

The German collection of 627 anecdotes of Claus Narr by Wolfgang Büttner is a prominent piece of this type of didacticism. The book was printed under the title *Sechs hundert/sieben und zwantzig Historien/Von Claus Narren. Feine schimpffliche wort und Reden/die Erbare Ehrenleut Clausen abgemerckt/und nachgesagt haben/Zur Bürgerlichen und Christlichen Lere [. . .] (Six hundred and twenty-seven anecdotes of Claus Narr. Fine and funny words and talks which honorable men noticed and retold. For civilian and Christian lessons [. . .]).* One anecdote in this book went like this: When Claus Narr saw a painted bird, he tried in vain to chase it away. Büttner interpreted this episode in a moral sense as a lesson that guests should not stay too long. Not only in everyday life, but also in the theological debates of sixteenth-century Europe, Claus Narr was presented as a model for true faith in God. For example, at one occasion he was asked about Martin Luther's future. Claus Narr answered that he was sure that the Reformation would prevail but added that his shoes and clothes became worse and worse. In his moralizing conclusion, Büttner called the fool a wise man as he foretold the continuation of the Reformation.

Until the end of the eighteenth century, Wolfgang Büttner's book was often reprinted. Other collections of jests and folly anecdotes quoted this source and continued to use the fool as a didactic example. Besides Claus Narr, who was a main source of reference in the sixteenth- and seventeenth-century folly literature, other natural fools became subjects of literature. In 1619, the Protestant preacher Philipp Cradelius printed a sermon for a natural fool's funeral. The life of the fool Hans Miesko was interpreted by him less as a sign of God but more as an object of pity. In that respect, Cradelius's sermon showed a slightly different approach to natural folly.

The various perceptions of natural folly remained in existence until the end of the eighteenth century. Until the Enlightenment, natural folly remained an object of laughter, of admiration, and of pity. At the beginning of the nineteenth century, however, the view of natural fools changed completely. They came to be classified as mentally ill. Consequently, books about natural fools such as *Claus Narr* were no longer read or understood. It is significant that in contrast to other examples of folly literature such as the *Ship of Fools* or the *Dyl Ulenspiegel,* Büttner's *Claus Narr* was not reprinted again. In the nineteenth century, the mental difference of natural fools became an object of medical and pedagogical institutions.

Literature about natural fools draws our attention to the fact that the concept of mental difference varies in history. It is therefore a fruitful source for disability studies as it serves to show the diverse constructions and functions once applied to mentally impaired people.

—Ruth von Bernuth

See also Fools.

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LOBBYING

Lobbying is relatively easy to define but less easy to explain, carrying as it does many negative connotations as well as a fairly high capacity for being misunderstood. This entry provides a definition of lobbying, a discussion of lobbying restrictions imposed by U.S. federal legislation as well as IRS regulations, and an illustration of lobbying taken from the 1998 reauthorization of a major disability law.

DEFINITION OF LOBBYING

The term *lobbying* refers to engaging in activities directed toward public officials for the purpose of influencing legislation and/or policy. Three factors are involved in a lobbying activity:

- *The government activity being targeted:* "Legislation and/or policy" in the above definition refers to an array of federal, state, and local governmental activities, such as preparation and passage of laws; adoption and implementation of rules, regulations, and policies; awarding and administration of grants and contracts; and confirmation of individuals nominated for official positions (Lobbying Disclosure Act, sec. 1602, defs. [8]).
- *The public officials being lobbied:* The title of "public official" covers a range of government-affiliated positions in the executive and legislative branches, including legislators and staff, and department and agency administrators and employees (U.S. Department of Education n.d.).
- *The method being used to lobby:* Lobbying activities include not only in-person exchanges but also written communication and background work, such as the planning of lobbying strategies, analysis of bills, and preparation of position papers (U.S. Senate n.d., sec. 3).

In essence, all attempts to influence government action, to persuade public officials of the rightness of one's position, are defined as lobbying.

LOBBYING REGULATIONS AND RESTRICTIONS

Lobbying has had a prominent presence in American government since the nation's earliest days. (In the late 1700s, veterans of the Revolutionary War petitioned Congress for reimbursement of personal funds expended on the war effort. See Byrd 1989.) As citizens of a representative government, Americans have the right to let their legislators know how they feel about laws, bills, policies, and nominees for positions in government.

That said, lobbying carries what one historian has called a "somewhat sinister and pejorative connotation" (Maskell 2001, sec. 2). Of course, this connotation has to do with improper behavior between lobbyists and public officials. Regrettably, lobbying holds a great potential to result in preferential treatment. Impropriety in lobbying has been described in the most severe of terms, including unsavory, corrupt and contaminated, and reprehensible.[1] Certainly, records provide ample documentation of lobbying abuses, describing the frequently tawdry, occasionally startling, and too-often-successful attempts of lobbyists to win favor with legislators and other public officials (Byrd 1989).

The Lobbying Disclosure Act

The U.S. Congress's answer to lobbying corruption has consistently been regulation, with the first attempt instituted in 1876 (Byrd 1989). The most recent overhaul of lobbying regulations occurred in 1995 with passage of the Lobbying Disclosure Act. This law requires lobbyists to register, disclosing such information as the organization(s) they represent and the issues they are addressing. In addition, twice a year lobbyists must file reports updating this information and adding estimates of how much money they will spend. An organization that engages in lobbying—whether using members of its staff or board of directors as its lobbyists or employing lobbying consultants—may be exempted from registration if it meets minimum thresholds related to money expended, time invested, and number of lobbying contacts made with public officials. Lobbying, it should be noted, requires serious record keeping, whether registration is necessary or not.

IRS Restrictions on Nonprofits

> This topic [lobbying by nonprofit organizations] often results in two extreme actions—some people warn that if your organization does any lobbying you risk losing your tax-exempt status with the IRS. Other people don't exercise enough caution and do put their organization at risk with the IRS because they don't understand the restrictions on lobbying that pertain to their non-profit. So what is the answer? Can we or can't we lobby? The answer lies somewhere in the middle. (Community Health Assistance Resource Team n.d.)

As the above quotation shows, lobbying by nonprofit organizations is an area in which there is much confusion and misinformation, especially for small nonprofits without the funds to hire professional lobbyists. For example, the staff at the Independent Living Research Utilization Program in Houston, Texas, have been providing technical assistance in the field of independent living for nearly 30 years, and one question they have been asked innumerable times is, "Can a center for independent living do lobbying?" One can easily replace "center for independent living" in this question with descriptions of other kinds of organizations, such as a counselor association, parent group, university, physical therapist organization, or hospital. The answer is always the same: "Yes, of course, but . . . ." And this is followed by the advice, "Be sure to run your plan of action by an attorney who specializes in lobbying."

A careful reading of the IRS rules pertaining to lobbying activities by nonprofits may reduce the confusion and misinformation to some degree. The rules make it clear that lobbying is entirely appropriate, given certain caveats such as the following:

- Federal funds may not be used for lobbying (Office of Management and Budget n.d.).
- A 501(c)(3) organization may not be involved in political campaigns (such an organization is "absolutely prohibited" from either direct or indirect participation) (Internal Revenue Service 2004).
- The lobbying activities of a nonprofit must not constitute a "substantial" portion of its total activities (Internal Revenue Service 2004).

The penalties for violating these restrictions are severe: An organization may lose its tax-exempt status, its income may be subject to tax, and penalties may be imposed against the organization's officers having complicity (Internal Revenue Service 2004).

Are there conditions under which the IRS considers it acceptable for a nonprofit to advocate strongly for its beliefs? Yes, as specified in this IRS (2004) statement:

> Organizations may, however, involve themselves in issues of public policy without the activity being considered as lobbying. For example, organizations may conduct educational meetings, prepare and distribute educational materials, or otherwise consider public policy issues in an educational manner without jeopardizing their tax-exempt status.

A POSITIVE LOOK AT LOBBYING

Much of this entry has covered the negative aspects of lobbying—as action that is morally corrupt or as action that jeopardizes the existence of an organization. There is another side to lobbying, however; lobbying is often a laudable activity undertaken by people committed to improving our way of life. The following illustration, taken from the arena of disability rights during the 1998 reauthorization of the Rehabilitation Act,[2] is provided to show how lobbying has been used to improve law, to expand opportunities for consumers with disabilities to live more independently, and to protect the civil rights of these consumers.

Background. In 1986, Section 508 was added to the Rehabilitation Act. It requires governmental departments and agencies to use accessible equipment when creating, duplicating, and sending information. This includes computers, copiers, faxes, telephones, and just about everything used in a modern office. The problem, as seen by disability rights advocates, was that Section 508 had no enforcement provisions, making it nonbinding, and compliance was not overwhelming (Association of Tech Acts Projects n.d.).

Desired changes. Members of a number of organizations active in the disability rights movement wanted to take advantage of the Rehabilitation Act's 1998 reauthorization to have Section 508 strengthened in three respects: by requiring development of standards of accessibility that all equipment must meet, by permitting individuals to file complaints and lawsuits against noncompliant departments and agencies, and by applying these two conditions to state governments.

Government activity addressed. Disability rights advocates wanted very badly to influence the writing of the law so that Section 508 would be enforceable. And just as ardently, they wanted to influence the procedure by which the compliance standards would be prepared so that the access needs of people with visual impairments, mobility impairments, and cognitive impairments would be met. And, because members of the entity given responsibility for preparing the standards (the U.S. Architectural and Transportation Barriers Compliance Board) were presidential appointees, they wanted to influence who was nominated for membership so that people who truly understood accessibility barriers would be selected.

Outcome. Under the principle of "win some, lose some," Section 508 was strengthened through the inclusion of enforcement provisions and establishment of sound access standards; however, its enforcement coverage was extended only as far as the federal government and not to state governments as disability advocates had wanted.

At the same time lobbying activity was being undertaken to address Section 508, other organizations of people affected by and/or working in the disability and rehabilitation fields were taking action to address *other* sections and titles of the Rehabilitation Act. For instance, it is likely that associations of rehabilitation counselors wanted to increase training programs under Title III, that advocates of supported employment wanted to strengthen and ensure continuation of that program under Title VI, and that researchers wanted to increase funding under Title II. (The National Council on Independent Living, for example, had its excellent reauthorization position paper written and circulated among legislators more than a year in advance.) This is the American system of lobbying at its best.

IN CLOSING: LOBBYING AND ONE'S DUTY

When considering lobbying, Americans need to remember that lobbyists are exercising rights that are guaranteed to all persons living in the United States, particularly those rights assured under the First

Amendment regarding speech and petition (Maskell 2001). Nearly a hundred years ago, the 11th edition of the *Encyclopedia Britannica* included a discussion of citizens' involvement in lobbying, observing that "people who are most intimately concerned naturally have a right to appear before the legislature or its representatives, the committee in charge of the bill, and present their side of the case." Indeed, who better to advise Congress on legislation, policies, and programs that increase opportunities for people with disabilities than those who have spent a lifetime in support of disability rights? It is the right, privilege, and, some would say, the duty of citizens to take part in the development of public policy.

—Laurel Richards and
Lex Frieden

See also Advocacy.

Notes

The authors are indebted to Bob Michaels (1998) for his study of lobbying regulations and their application to centers for independent living.

1. Sources for these descriptions are, respectively, the *Columbia Encyclopedia* (6th edition), Maskell (2001), and the 1911 edition of the *Encyclopedia Britannica*.

2. When the Rehabilitation Act was amended in 1998, it was incorporated into the Workforce Investment Act as Title IV. Until that time, it had been a stand-alone law.

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LOHSE-WÄCHTLER, ELFRIEDE (1899–1940)

German painter

Struggles, crises, and catastrophes characterize the biography of painter Elfriede Lohse-Wächtler, whose work the Nazis condemned as degenerate in 1937 and was first rediscovered at the end of the 1990s. Born on December 4, 1899, in Dresden, Elfriede Wächtler grew up in a lower-middle-class family. During her studies at the renowned Dresdner Königliche Kunstgewerbeschule (Dresden Royal Art Academy) in the department of fashion and applied graphic arts, she moved into a studio in 1915 that became one of the main meeting spots for modern artists in Dresden. There she began to paint and draw using a variety of techniques—the beginning of work that spanned expressionism, verism, and New Functionalism. She could not survive off the income from her artwork alone, as it earned her only little money. In 1921, she married the painter and singer Kurt Lohse, and in 1925 she moved to Hamburg to be with him. The marriage was marked by frequent moves, economic difficulties, and Lohse's infidelity. The definitive break came in 1929, with the divorce occurring at Lohse's instigation in 1935 "due to incurable mental illness."

The years 1925–1931 were Lohse-Wächtler's most intense creative period and included a few public exhibitions. At the same time, her health grew increasingly worse. In 1929, she was admitted to the psychiatric state institution in Hamburg-Friedrichsberg for two months because of paranoia. After her release, she showed her portraits of fellow inmates in a successful exhibition titled Friedrichsberger Köpfe (Heads of Friedrichsberg). Isolated and impoverished to the point of homelessness, she created primarily (self-)portraits, nude studies, and milieu studies in 1930 and 1931. Without means and exhausted, she returned to her parents' house in 1931, and her father subsequently had her admitted to the regional psychiatric institution in Arnsdorf. There she was diagnosed with schizophrenia, a diagnosis that is disputed today. Although her confinement left her in a state of despair, Lohse-Wächtler continued her artistic work until she was forcefully sterilized on December 20, 1935, despite her own and her family's enraged resistance. On July 31, 1940, Elfriede Lohse-Wächtler was "transferred" out of Arnsdorf to the NS-"Euthanasia" Institution in Pirna-Sonnenstein, where she was murdered.

—Petra Lutz

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LÜ K'UN (1536–1618)

Chinese scholar and administrator

Lü K'un was a forward-thinking senior administrator in Northern China who worked to establish institutions that would relieve poverty and encourage self-help among aged or disabled people: "For those among the last who were not too young nor too old he prescribed training in skills like basketry or the braiding of mats" (Goodrich and Fang 1976). Lü also invested time and effort in didactic writing and publication to guide the masses toward better health and improved agriculture. He encouraged careful record keeping by physicians and government officials, so as to improve their practice. His particular concern for blind people arose from his mother's many years of blindness. "Lü ordered the officials of each city to train the blind in a profession such as music, singing, storytelling, and fortune telling" (Goodrich and Fang 1976). He had no personal faith in fortune-telling, yet he "compiled a simple textbook from which the younger people among the blind might be orally taught" (Goodrich and Fang 1976). These were innovative attitudes and practices in his time, with some parallels to contemporaneous social thinking in Western Europe.

—Kumur B. Selim

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LUTHER, MARTIN (1483–1546)

German church reformer and scholar

Martin Luther, the German church reformer, polemicist, scholar, and pastor, is linked in some disability literature with an oral suggestion about killing a severely disabled boy who was considered not human but a changeling—that is, a devil exchanged for a child (LW 54:397). The report comes from a source notorious for editing and altering some of Luther's conversations (LW 54:ix–xxiii), yet Luther's writings do underline his belief in satanic powers of deception (LW 3:244; 24:74–75; 26:190). The "changeling" idea may derive from academic constructions, mistakenly attributed to folklore. Luther's much-loved personal assistant through most of his working life was a man with mild disabilities, Wolf Sieberger. Luther strongly advocated the inclusion of deaf or disabled people in church life. He believed that their spiritual qualities are in no way impeded by their physical condition (LW 30; 54:460; 35:110–111; 45). An overview of evidence suggests that Luther's attitudes and practices toward disabled persons were largely positive, although some of his views may seem strange in the twenty-first century.

—Kumur B. Selim

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LUXEMBURG, ROSA (1871–1919)

German revolutionary and journalist

The German socialist, revolutionary, and journalist Rosa Luxemburg was born on March 5, 1871, in the province of Zamosc in Russian-occupied Poland. She came from a Jewish family. After acquiring an illness at age five, she walked with a limp. In addition, she was noticeably small. Even as a young student, Luxemburg was active in politics. After fleeing Poland, she studied economics in Zurich and received a doctorate in political science. In Zurich she also became acquainted with Leo Jogiches, who became her lifelong companion. She obtained German citizenship through a sham marriage with another man.

From 1898 on, Luxemburg lived in Berlin, where she quickly became one of the most important politicians of the Social Democratic Party of Germany (SPD) and the left-wing party's leading representative. In spite of her disability, she undertook exhaustive election campaigning, gave rousing speeches, lectured at the party school, and positioned herself as an outstanding journalist, uncompromising—although her work was eventually futile—in her stances against war and for international solidarity. During this time she was the subject of numerous personal attacks. Her opponents—as well as members of her own party—attacked her heritage and her appearance, reviling her as a "small, ugly Jew." Luxemburg spent the majority of the World War I period in prison, with her feelings fluctuating between resignation and hope. Deeply disappointed with the SPD, in 1918 she became one of the founders of the German Communist Party (KPD). Right-wing Freikorps officers murdered Luxemburg (together with her fellow KPD member Karl Liebknecht) on January 15, 1919, in Berlin during the height of revolutionary unrest. Her corpse was first discovered months later in a Berlin canal and was buried in June 1919 at the behest of a highly sympathetic populace. Perhaps the most-often quoted statement from Luxemburg's work is this: "Freedom is always and exclusively freedom for the one who thinks differently."

—Hedwig Kaster-Bieker

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▣ MACE, RONALD L. (1942–1998)

American architect

Ronald L. Mace was a design visionary whose life as a disabled person influenced the focus of his life's work and shaped the genius of his architecture and product designs. He was a driving force behind the creation of the first accessible state building code in the United States (in North Carolina) in 1973 and in the drafting of national accessibility codes and standards. He later coined the term *universal design* to capture and promote his expanded philosophy of "design for all ages and abilities," which applies to all aspects of design—architecture, landscape, graphic, and product design.

Mace contracted polio at the age of nine and subsequently used a wheelchair for mobility; he personally experienced how inaccessible environments limit a person's ability to participate in the world. After graduating from North Carolina State University School of Design in 1966, he was the first to put a human face on access guidelines by using well-rendered, human-centered illustrations. Mace and his consulting firm, Barrier Free Environments, did pioneering work in accessible, or barrier-free, design focused on improving accessibility in the built environment so that disabled people could participate in the life of their communities. In 1988, Mace was named a Fellow of the American Institute of Architects for that groundbreaking work. He was also influential in drafting the 1988 Fair Housing Amendments Act and the 1990 Architectural Guidelines of the Americans with Disabilities Act, which require basic accessibility in the built environment for future generations. In 1992, he was honored with the Distinguished Service Award of the President of the United States for promoting the dignity, equality, independence, and employment of disabled people.

In his training of architects and designers around the United States, Mace emphasized that accessible designs make life easier for everyone—curb cuts being his favorite example. As his vision expanded, the North Carolina State University Center for Accessible Housing, founded in 1989, became the Center for Universal Design to reflect its expanded work in promoting the integration of the principles of universal design into all aspects of the design profession. Shortly before Mace's death on June 28, 1998, on the occasion of the first international conference on universal design, he was honored by designers from all over the world who had embraced his vision of designing for all people.

—*Joy E. Weeber*

See also Accessibility; Accessibility Codes and Standards.

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MACKENZIE, CLUTHA (1895–1966)

New Zealander blind activist

Clutha Nantes Mackenzie spent his youth in New Zealand as a farmhand and sailor, though his father was a senior politician and diplomat. Clutha lost his sight in 1915 during a World War I battle in Turkey. He went to St. Dunstan's in England for rehabilitation and practiced writing and magazine editing. His future wife, Doris, was a St. Dunstan's volunteer. Clutha returned to Auckland, New Zealand, and worked from 1923 to 1938 managing the Jubilee Institute for the Blind, fund-raising and campaigning for blind people to live independently. His autocratic style caused some problems, but his work was successful and he was knighted in 1935. His international career included lecturing and fund-raising across the United States, then six years in India, where he opened St. Dunstan's Center at Dehra Dun in 1943. He held a special government post to study and report on blind education and employment, and engaged in battles to determine which form of Braille would be adopted in India and internationally. In 1947, he toured China, producing a substantial report on blind people there. He advised other Asian countries, reported on blindness in Turkey in 1952, and a few years later was mobilizing services for blind people in East Africa. Clutha retired to New Zealand in 1958.

—*Kumur B. Selim*

See also Blind, History of the; Experience of Disability: India.

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MADNESS AND MENTAL DISTRESS

While Western understandings of disability have been subjected to fundamental reassessment in recent years, the medicalized individual model of "mental illness" continues to dominate mental health policy and practice internationally. It still shapes public understandings of "mental health" and governs the lives and experience of many mental health service users. In contrast, mental health service users/survivors and their organizations are increasingly expressing their concerns about medicalized individual models of "mental illness" and framing their experience in different terms. Yet traditional "mental illness" understandings of their experience seem, if anything, to be gaining ground. They have been exported to the majority world. They have been reinforced by the introduction of a new "recovery" model for mental health services developed in the United States.

THE MAINTENANCE OF MEDICAL DOMINANCE

The number and range of psychiatric diagnostic categories continues to mushroom. These increasingly cast broad socially related issues in medicalized terms, for example, attention deficit/hyperactivity disorder (ADHD) and posttraumatic stress disorder (PTSD). The needs of a growing range of groups, notably children and young people and older people, are being framed in psychiatric terms. While making clear that it cannot "treat" them, psychiatry has also categorized a growing range of people and behaviors under the heading of "personality disorder." Some of these are closely associated with violence and homicide. This has reinforced traditional associations of mental health service users with dangerousness, which has resulted in pressure for increasing restrictions on their rights, most notably in North America and the United Kingdom.

A growing focus on and recent developments in genetics, the neurosciences, and pharmacology seem to have confirmed the ascendancy of the natural sciences in this field as the key source for understanding, interpretation, and "treatment" of "mental disorder." Doctors are still the most powerful professionals operating in this area. Understanding mental disorder in terms of physical processes fits with the large-scale use of drugs as the main and routine response to people's difficulties.

One of the consequences of the development of organizations and movements of mental health service users/psychiatric system survivors since the 1980s has been the emergence of new challenges to and new critiques of conventional medicalized understandings of "mental health." These have been qualitatively different from previous critiques of the dominant paradigm, such as "antipsychiatry" and the "social constructionism" of sociologists, which have tended to come from dissident professionals, competing professions (e.g., psychology), and related academic analysts. These new challenges have been based primarily on service users'/survivors' understandings of their own experience—their experiential knowledge.

It is important to emphasize, however, that so far, no equivalent of the social model of disability has been developed among mental health service users/survivors that could provide a systematic and philosophical basis for their activities. While it is still a focus for much debate and controversy, the social model of disability has offered disabled people just such a coherent basis for their philosophy, self-organization, and collective action, reflected in their focus on rights and independent living. The social model of disability, however, has not as yet adequately been extended to address and explain the related, but also distinct, issues facing mental health service users/survivors. Thus, while "mental health" issues and the situation of mental health service users/survivors have sometimes been incorporated in the social model of disability by its proponents, so far this model has not been accepted widely by mental health service users/survivors as providing a satisfactory conceptual framework for their experience.

It is not clear why, as yet, mental health service users/survivors and their organizations have not developed a coherent alternative to the medicalized model of "mental illness." While the latter may be the only model for understanding with which many mental health service users/survivors are familiar, there also seems to be an unwillingness on the part of many activists to develop an explicit alternative. One view is that this may be linked with fears that to do so would be interpreted from outside as an attempt to deny their difficulties or difference and lead to their being further marginalized as lacking in insight and rationality.

Mental health service user activists have tended not to challenge the dominant medicalized framework explicitly. They have themselves frequently continued to operate within a framework of terms such as *mental health, mental health problems, difficulties,* and *issues.* However, they have also shown a growing unease with the traditional medicalized model, particularly as it has been linked with an increasing emphasis on social control and the extension of restrictions on mental health service users' rights and freedom.

For a growing number of mental health service user activists, the inherent problem with a medicalized approach to "mental health"—even the descriptor is itself medicalized and value laden—is that it is based on a *pathologizing* construct. The underlying construct that dominates "mental health" policy, provision, practice, and service users is one of "psychopathology." It is possible to be persuaded that this is not the case, because terms such as *mental illness, mental disorder,* and *psychopathology* are less often and less explicitly used nowadays. But the origins and meanings of the terminology remain unchanged. The legal base that operates tends to be the same. Law and policy rest on the premise that there is something "wrong" with the person. He or she is "ill." The individual's experience, behavior, perceptions—the person *him-* or *herself*—is pathologized. This is how people also come to understand themselves as mental health service users.

DEVELOPING ALTERNATIVE APPROACHES

The lack of a clear and agreed-upon conceptual framework has not stopped mental health service users and their organizations from developing their own alternative culture, discourses, and schemes for support. These have generally been based on nonmedicalized models, highlighting a holistic, complementary approach to providing support for mental health service users/survivors. Such schemes have placed an emphasis on peer and self-advocacy, self-defined needs, self-education, self-management, and self-support. They have led to the development of self-run crisis houses and refuges, survivor-led supported housing schemes, environmentally friendly employment, training and skill exchange schemes, programs employing mental health service users as mental health workers, crisis cards and advance directives, mutual aid and self-help support groups, and peer counseling. However, the lack of a clear and agreed-upon philosophy underpinning these developments has sometimes made it difficult for service users/survivors and their organizations to avoid being co-opted and their goals and ideas subverted by dominant medicalized service systems and their agendas, with which they have frequently worked in close association.

Mental health service users/survivors and their organizations have also developed their own alternative terminology, framed in terms of "madness" and "mental distress" rather than "mental health" or "mental illness." Survivors' use of terms such as *mad* and *distress* seems to reflect a desire both to move beyond the medicalized individual understanding of their situation and experience and, in the case of *mad,* also to reclaim language that continues to be used to marginalize and demean them. *Mad* is just one of a constellation of pejorative terms used to describe mental health service users and the behaviors associated with them—a constellation that includes terms like *loony, crazy,* and *nuts.* Such terms are also still used widely in popular discussion to mean weird, frightening, outlandish, unpredictable, and irrational.

MADNESS AND DISTRESS

In different cultures and historically, madness has been interpreted and understood in many different ways. It has been associated with magical powers, the supernatural, divine intervention, possession by the devil, violence, irrationality, spirituality, and special gifts and insight. It has been seen in both negative and positive terms. If once it was treated in the West as a condition of the whole person—body, mind, and spirit—more recently it has generally been diagnosed as a disorder of the brain. Responses have been spiritual, secular, and morally based, according to the society in which madness is identified, based on both superstition and elaborate theories. It has also long had a parallel embodiment in the law, in terms of "insanity," "incapacity," and "lack of responsibility." Such legal status has served both as a basis for taking control of people's money, goods, and affairs and for the imposition of "treatment" regimes, including confinement, restriction of rights, and compulsory "treatment."

Mental health service users/survivors have yet to develop their own clear and agreed-upon definitions of *mad* and *distress,* although the terms have come to be widely used within their movement. Members of Mad Pride, a U.K. survivor network that organizes events and direct action and also produces publications, highlight their pride in being mad. This pride may be in being different, in surviving madness, in surviving the mental health system, in having unusual sensitivities or capacities, in having capacities to an unusual degree, or in having a different way of life or approach to life—an approach that may be unconventional or anarchic, open to a wider range of experiences, or experienced more intensely.

Madness can be viewed as an equivalent of "psychosis," although not all survivors would be happy with the concept's being appropriated in this way. As mental health service users/survivors discuss it, madness may have many expressions. It may be a one-off experience, episodic, or long-term. In all these cases, people may report positive aspects of their madness. They may value their experience and perceptions, discovering helpful aspects, for example, to hearing voices or learning how to live with them. They may feel that their positive qualities and abilities are linked with and inextricable from the fact that they experience madness. Such experience, however, may also be negative and costly, restricting what people can do, linked with difficult and painful thoughts and feelings and associated with crises and problems.

Mental health service users talk about both "mental" and "emotional" distress. Such distress is associated with pain, sorrow, and anguish. It is difficult to conceive of distress as a positive, although it may be seen as part of a learning process, or as a predictable human response, for example, to loss and bereavement. Anxiety and depression are two common expressions of such mental distress. Distress may be a short-term/crisis event or a long-term state. People may also experience physical distress. A distinction may need to be drawn between mental and physical distress, but it is also possible that one may be interlinked with the other.

Mental health service users/survivors have a tendency to combine the two terms *madness* and *distress* when they are seeking to offer their own conceptualizations of their identity and situation. This seems to relate to a sense that neither term adequately carries the full range of experience and meanings that they wish to convey (and that are associated with being on the receiving end of mental health services). Just as distress may not always be "maddening," so madness may not always be distressing. Thus, "madness and distress" may represent a single construct rather than two. It is important to take account of this, because there is some tendency to treat "madness" and "distress" as mirroring traditional medicalized psychiatric and psychoanalytic concepts of psychosis and neurosis.

Treating the two sets of terms as interchangeable in this way is unlikely to be helpful or accurate. One of the aims of survivors in developing new language has been to challenge rather than retain traditional categories. Treating "madness" and "distress" as distinct and separate categories is likely to reinforce existing (unhelpful) distinctions between the worried well ("us") and the mad ("them" and "other"). The terminology of mental health service users/survivors is intended to be inclusive rather than divisive. In this, it reflects the same concern as that expressed by many members of the disabled people's movement, to avoid being "impairment specific," or, in this case, to privilege diagnostic categories and to focus instead on shared concerns and common processing.

It is also questionable whether there are clear boundaries between ideas of "madness" and "distress" or "distress" and "madness" that could demarcate a distinct group of mad people or madness. The boundaries are likely to be as imprecise and socially constructed as those that relate to perceptions of physical and sensory impairment. It is also helpful to remember that the terminology of mental health service users has an underlying political purpose. The term *psychiatric system survivor* highlights this. It was developed to emphasize that what individuals in this group have in common is primarily their (frequently oppressive) experience and (hopefully) survival of the psychiatric system.

THE EMERGENCE OF A NEW SOCIAL MODEL

Mental health service users/survivors and their organizations are showing increasing interest in the social model of disability. This seems to relate to their growing focus on the barriers and restrictions to their rights they currently face. These do not seem to be diminishing significantly and in some cases are experienced as increasing. Mental health service users/survivors experience disproportionately high levels of poverty, unemployment, homelessness, and social isolation. They are subject to high levels of stigma, institutionalization, and imprisonment. In Western societies, black and minority ethnic mental health service users/survivors face additional discrimination and disadvantage. Policies of psychiatric decarceration (without the provision of adequate alternative support services) have led to political pressure internationally for the extension of restrictions on mental health service users'/survivors' rights and compulsory "treatment." This provides the context for their growing interest in a "social model of madness and distress."

The terminology of "madness and distress" provides a helpful nonmedicalized framework for a social model. Such a social oppression/barriers approach to understanding "mental health" represents a break with traditional social approaches. These have tended to focus on social factors in the generation and conceptualization of "mental health problems" rather than on social oppression. Discussion of a social model of madness and distress is still at a relatively early stage, but it has already highlighted two issues that need to be addressed. First, some mental health service users/survivors do not see themselves as having any kind of "impairment" or equivalent. They may not accept the idea of "madness" as a discrete, objective state, or they may reject the idea of it as a negative or a problem. Instead, they interpret madness as essentially a consequence of societal responses to particular people, perceptions, or situations. The view of some disabled commentators that impairment may most helpfully be understood (like disability) as socially constructed—as *perceived* impairment—may offer a helpful way of taking account of this viewpoint.

Second, some mental health service users/survivors have emphasized that psychiatric labels and diagnostic categories have traditionally been attached not only to people whose behavior is seen as pathological, defective, or different but also to those whose behavior, perceptions, or attitudes are defined as deviant, dissident, or nonconformist. Demonstrating compliance (rather than resistance) continues to be an effective way for service users to be seen as getting "better" or "recovering." It is important to note, for example, that some women's sexual behavior and the sexuality of gay men, lesbians, and bisexuals have until recently been formally and specifically identified and "treated" in the West as forms of psychopathology. This had an extreme expression in the former Soviet Union, where political dissidents were consigned to the psychiatric system.

Thinking about a social model or approach to madness and distress is still at an early stage, and it would be wrong to suggest that as yet any clear or agreed-upon definitions have been developed. Such discussion is, however, developing. Such a social model is likely to be located within the framework of a social model of disability that is extended to accommodate it. Its increased adoption is likely to have at least three significant effects. First, judging from the experience of the social model of disability, such a social approach to understanding is likely to alter the focus in mental health policy and practice and among mental health service users/survivors. It is likely to shift it from a preoccupation with individual deficiency and blame to broader social concerns. It will draw attention to restrictions imposed on mental health service users' rights and the barriers and discrimination they face—which medicalized responses have generally failed to do. It is also likely to encourage reconsideration of "mental health" issues in terms of (ongoing) support and "independent living" rather than in terms of "treatment," "cure," and "recovery."

It is also to be expected that if it is possible to develop such a social model, which carries credibility and consensus among mental health service users/survivors, it will offer them (in the same ways as the social model of disability has helped disabled people) a clearer and more consistent philosophical basis for their activities and resources. This is important given the limits of such resources and the resistance of the psychiatric system to reforming its tendency to incorporate and tokenize the efforts of service users/survivors working in partnership with it. A social model of madness and distress is also likely to strengthen links and understandings between mental health service users/survivors and other disabled people, as well as increase the sensitivity of mental health policy to social model–based disability policy. On this basis, the concept of madness and distress can be expected to have increasing currency and significance.

—Peter Beresford and Peter Campbell

See also Mental Health; Mental Health: Law and Policy; Mental Illness; Psychiatric Survivor Movement.

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MindFreedom Online, http://www.mindfreedom.org

MAINSTREAMING

The term *mainstreaming* emerged within the educational jargon associated with the 1975 Education for All Handicapped Children Act (EHA, P.L. 94-142), the early U.S. legislation subsequently reauthorized as the Individuals with Disabilities Education Act (IDEA) in 1990. Mainstreaming was a component of the principle of the least restrictive environment (LRE) clause of the EHA, which aimed to promote the social acceptance of students identified for special educational services. However, the context was one in which students identified as needing special education services were typically removed from the general education classroom and, depending on need, reassigned to resource rooms for 21 to 60 percent of the school day or to disability-specific classrooms when student needs exceeded placement for more than 60 percent of the school day. Students with mental retardation were placed in an MR class, those classified with educable mental retardation were assigned to an EMR class, those with emotional disturbance (as per the vernacular of that era) were assigned to an ED class, those with health impairments were placed in an OHI class, and so forth. These labels—*Resource, MR, EMR, ED, OHI*—were affixed to classroom doors in much the same way other doors read *First Grade, Second Grade, Library,* and so on. In turn, this context normalized practices such as placing students beside placards that read "Resource Class," "MR Class," "OHI Class," and the like when they posed for their annual class pictures. Likewise, students became known as LD, MR, or ED students. Despite early warnings by a handful of special educators about the negative effects of the overuse of labels, most general and special educators seemingly viewed the labels as nothing more than benign markers—mere terminology formulated through the legislation of the EHA.

Decades would pass before the critical insights of scholars exposed the language of special education as a powerful mechanism that enforced subjectivities associated with assigned labels and the presumption of stigma. Although touted as a policy that guaranteed all students would have access to the least restrictive environment, this naive interpretation of the law became a controversial and contested practice by both general and special educators.

AIMS AND INTENTIONS

The vexed meaning of mainstreaming was compounded by the ambiguities of the EHA and the subsequent state and local interpretations that followed. Moreover, the EHA had unwittingly authorized the creation of two separate systems of education (which continue today), each with its own funding structures, policy and practice standards, and, most critically, distinct teacher preparation programs. In practice, the aims and intentions of mainstreaming were difficult to articulate as the goals that were established quickly proved antithetical to the everyday demands of schooling. Special education advocates urged a three-pronged approach to mainstreaming in which physical, social, and academic considerations would be merged. Thus, a disabled student would have access to receive his or her education in proximity to the *place* where other students received their education—regardless of the child's disability. *Place* was clarified as meaning the same building and same neighborhood school, regardless of its population as a preschool, elementary school, junior high school, middle school, high school, or technical school. *Social* suggested participation in the common social activities of the school in nonacademic settings, including interactions in the hallways, cafeteria, library, and playground—that is, interactions within the general social milieu of the school. The third prong of mainstreaming was specific to instruction and the general curriculum. During the 1970s, the general education curriculum was less restricted by mandates for standardization of instruction and educational outcomes than is the current curricular context. It was argued then that because students in regular classes are not all taught the same things at the same time, modification of the nature, method, rate, and procedures was commonplace for all students, and, hence, it was equally an option for students identified with special needs.

In practice, general educators rarely considered these integrative criteria, as mainstreaming proved antithetical to the everyday demands of schooling. Instead, the return of special education students to the general education setting was authorized only on the condition that the students demonstrate the "right" to return. The motivation for this approach to mainstreaming was bureaucratically driven—it was a means to ensure that general education teachers would not be stressed by the demands of disabled students who, as a consequence of mainstreaming, might jeopardize the learning of nondisabled students. A rights discourse soon emerged, but it was one that pitted the rights of the general education students against those of special education students. Fear led to educators' claims of "injustice" and imagined harm inflicted on the rest of their students as a consequence of the perceived negative impact of mainstreamed students. Moreover, citing the lack of credentials, general education teachers claimed they were ill prepared and actually unable to accept disabled students back into their mainstream classrooms. Arguing to these same ends, professional teachers' organizations warned their members to be on guard against the "hazards" of mainstreaming. In 1975, the same year the EHA was authorized by Congress, the president of the National Education Association described the "plight" of a teacher who is "suddenly and for the first time presented with a blind child, a spastic, an emotionally disturbed child—or even all three—as additions to the 40 'normal' students" (quoted in "NEA Warns" 1975). The NEA urged its members to support mainstreaming only if the plans in their districts met several specifications that guaranteed a "favorable" learning experience for both handicapped and nonhandicapped students.

Implicit within this debate was the belief that the learning problems of disabled children stemmed from individual pathology rather than from instructional or institutional pathology. For the most part, general educators held firm to the belief that despite procedural safeguards, the general education setting was not an appropriate place for disabled students, arguing, "If they can't do the work, they don't belong here."

PROCEDURES AND PRACTICES

Mainstreaming proved to be one of the many paradoxes associated with the implementation of the EHA. Because special education was mandate driven, policy heavy, and procedure intensive—and thus a highly bureaucratized approach to education—legislation, litigation, and fiscal concerns easily diverted its educational aims. Compliance with the law focused on the formulation of paper trails to document adherence to the letter of the law. Meanwhile, the spirit of the law became increasingly more illusory. Mainstreaming was a sort of no-man's land, ill defined and poorly articulated by both general and special educators, in which neither would agree to assume responsibility for the mainstreamed student. After a tremendous investment of effort toward the identification, assessment, referral, and placement of students into special education, neither general nor special education teachers were persuaded by the logic of orchestrating these students' return to general education. Once a student was identified with special education needs, he or she was removed from the general education classroom in order to receive "specialized" instruction in separate self-contained classrooms with specially trained teachers. The processes of identification, assessment, referral, and placement, although hailed within a rights discourse of "hard-won educational access," in fact often resulted in restricted access to general education. It was paradoxical that once a student was physically relocated to special education, his or her "right" to return to general education was authorized only on the condition that the student demonstrate the ability to meet the existing academic goals in place for nondisabled students.

Another related paradox emerged as educators questioned why a student would want to return to general education if his or her academic success was all but ensured in special education through the development of an individualized education program (IEP). Identified students received their education in what was often characterized in the special education literature as a "learning-intensive environment." The norm for this setting included small class sizes, specialized instruction, paraprofessional support, modified curriculum, and prescriptive technology targeted to meet individual student needs. This learner-centered setting stood in opposition to the teacher-centered general education classroom, which was neither intimate nor individualized. In fact, this was a persuasive selling point, both for the recruitment of special educators and for the parents of identified students, who tended to overlook the isolation their children would experience in separate self-contained classrooms. Moreover, because instructional remediation was predicated on a positivist approach to intervention, with treatment aligned to a medical model, it was assumed that this more "scientific" and "prescriptive" approach to learning would promote "individual" gains in ways uncommon to general education.

Indeed, the approach to learning in special education was one in which tasks were broken down into various component parts, each of which was then indexed in a hierarchy of simple to complex learning objectives. Students moved through the learning of bits of discrete knowledge on the assumption that more complete learning would result from this incremental approach. Exclusively behavioral models for learning—including task analysis, direct instruction, drill and practice, and rote memorization—formed the core of special education instruction. Accompanied by the use of reward systems and token economies, these practices reinforced the view that student learning in bits and pieces took precedence over contextualized learning within a broader holistic and emancipatory framework. The pedagogy, methodology, and learning context in special education and that common to the mainstream setting proved to be worlds apart.

Government-sponsored research on effective educational practices was another legitimating force that helped to shape the chasm between general and special education. Federal dollars allocated to university researchers privileged positivist methods over integrated and holistic approaches to learning, which in turn advanced a reductionist approach to learning and prompted calls for even greater specialization among professionals. Unwittingly, this government-sponsored research reified the belief that a "highly qualified teacher" is most capable of educating disabled students. Curiously, the link between the university-based researchers and their institutions' agendas specific to the expansion of their own teacher training programs was never questioned as a conflict of interest. The long-term effect of an overreliance on the traditional empirical research generated by many of the nation's largest academic programs in special education was the reinforcement of the beliefs that some students really *do not belong* in regular education and that some, but *not all,* teachers are responsible for all learners.

In time, this research fed the deeply entrenched attitudes that continue to divide general and special educators today. It is a belief that has proven to be one of the greatest obstacles to the inclusion of disabled students in public education. Ultimately, the goal of successfully mainstreaming identified students proved increasingly more difficult to realize as these students fell further and further behind their general education peers on both social and academic measures. The initial belief that identified students might eventually rejoin the mainstream when their learning deficits had been remediated was all but extinguished by shifting attitudes relative to who does and does not *belong* in the mainstream classroom.

—Linda Ware

See also Education, Primary and Secondary; Education and Disability; Race, Disability, and Special Education; Special Education.

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MANAGED CARE

For persons with physical and mental disabilities, managed care presents both a threat and an opportunity. Persons with disabilities have much to gain from truly and responsively integrated managed care health delivery systems. However, persons with disabilities also bring atypical, complex, and, in many cases, long-term service needs that managed care organizations may be reluctant to address because of the increased clinical and financial risks these needs represent.

The origins of managed care can be traced to the late nineteenth century, when a small number of physicians in several U.S. cities agreed to provide prepaid medical care to members of fraternal orders, unions, and other associations of workers. The physicians gave the members of these organizations unlimited access to the health care services they provided in exchange for a small annual fee per member. In the early twentieth century, railroad, mining, and lumber companies organized their own medical services or contracted with medical groups to provide care for their workers. During the Great Depression of the 1930s, prepaid contracts between employers and employee associations were relatively common. Starting in the 1970s, the federal government and many large private companies began encouraging their workers to join prepaid forms of health care groups. Despite this encouragement, however, prepaid group practice grew slowly. In the mid-1980s, employers increasingly turned to managed care to contain the spiraling cost of providing health care benefits to workers. During the 1990s, managed care enrollments soared. Today, the vast majority of privately insured Americans, and a sizable fraction of those in the government-sponsored Medicare and Medicaid programs, are covered by some form of managed care.

Despite the large number of persons enrolled in managed care programs, it is difficult to define precisely what managed care is. The definition of managed care has changed significantly through time as the concept of managed care has evolved. Currently, managed care can be broadly defined as any organized system of health care that attempts to reduce or eliminate services that system representatives deem ineffective or unnecessary in order to hold down costs while at the same time maintaining high-quality health care. Most managed care is carried out in one of two basic types of health care organizations: health maintenance organizations (HMOs) or preferred provider organizations (PPOs).

Managed care organizations use a variety of methods of financing and organizing the delivery of health care to control costs. Specifically, managed care relies primarily on three strategies for success: selective contracting, innovative economic incentives, and utilization review.

To develop selective contracts, managed care organizations use health care claims data to compare the prices that different hospitals and physicians charge for the same treatments in order to identify the lowest-priced providers. In highly competitive health care markets with many providers, large managed care organizations with hundreds of thousands of enrollees can selectively contract with individual hospitals and physicians and receive substantial discounts for the provision of health care to their members. The providers are willing to give deep discounts to these organizations to avoid losing large numbers of patients. Providers also can retain or build a greater market share by giving these discounts.

Managed care organizations frequently provide innovative economic incentives to patients and physicians to encourage them to select less costly forms of health care. For example, organizations may require patients to obtain preauthorization before using hospital emergency rooms to receive care for specific conditions. They also may discourage patients from using higher-priced health care institutions such as costly teaching hospitals for routine care. To control costs, some managed care organizations, such as HMOs, put their physicians on fixed salaries. They can then adjust the salaries up or down annually based on performance, rewarding those physicians who contain costs and punishing those who do not.

To conduct utilization reviews, many managed care organizations have established their own sophisticated internal computer information systems that monitor provider prices and the quality of health care received by their enrollees. Many have also developed a variety of utilization review programs that include such elements as preadmission screenings (to determine whether a patient should enter a hospital or receive treatment elsewhere), surgical second opinions, and ongoing reviews of high-cost cases (such as patients with HIV/AIDS and those receiving complex cancer care).

Of the three strategies described above, the evidence to date clearly shows that selective contracting has been the most effective in lowering costs for managed care organizations. The evidence on innovative economic incentives is weaker, and evidence on the effectiveness of utilization review is virtually nonexistent.

Initially, managed care organizations targeted generally healthy populations, placing emphasis on maintaining health and preventing disease. Recently, however, managed care has moved into less traditional markets, including managing health care for individuals with chronic illnesses and various disabilities.

Managed care has the potential to be of great benefit to people with disabilities in comparison with traditional fee-for-service systems or typical government-sponsored programs. By its very nature, managed care tends to decrease or eliminate individuals' incentives to overuse services. It generally reduces patient out-of-pocket expenses and other financial barriers to health care. Managed care also has the potential to achieve better coordination of patient services. Given that most managed care organizations use the primary care physician to direct and structure the patient's total treatment, in theory the services provided should be more logical, customized, and prompt than they would be under other systems. Thus, under managed care, persons with disabilities should experience less frustration and confusion from splintered service provision, which can be commonplace in public programs. Managed care, through its use of internal computer information systems, also has the potential to monitor the quality of care and assess the performance of both individual patients and their physicians more efficiently. Finally, some managed care organizations provide transportation services for patients between their homes and the facilities where they receive care. These services may be vital for patients with major disabilities, especially those who live in areas without any public transportation.

Managed care also poses a number of formidable problems for people with disabilities, however. For example, managed care organizations may design and direct their marketing programs to attract only generally healthy populations. They may overtly and covertly discourage enrollment of individuals who are likely to be users of costly health care services. Because patients with disabilities may be frequent users of specialists and other high-cost medical services, managed care organizations may view them as undesirable patients.

As noted above, managed care organizations typically use primary care physicians as "gatekeepers" to control access to care. These physicians may not have the necessary experience or expertise to address the unique needs of people with diverse physical and mental disabilities. Further, they may not have the time or inclination to provide care to such patients.

With their emphasis on primary care and cost containment, managed care organizations may not provide people with disabilities adequate access to needed specialists who are qualified to diagnose and treat their special health care conditions. For example, managed care organizations may stop referrals to psychiatrists, who tend to provide more comprehensive treatment than other mental health professionals. In addition, the complexity of managed care organizations' referral procedures and complaint and grievance processes, and the materials that describe these aspects of managed care, may create tremendous barriers for individuals with cognitive or learning disabilities.

Because managed care organizations deal primarily with the needs of healthy people, they may use definitions of "medical necessity" that work against people with disabilities. For example, they may apply criteria that call for "substantial improvement" or "restoration of function" as conditions for the authorization of treatment, medication, or medical equipment. This may discriminate against individuals with certain types of physical or mental disabilities who cannot meet these standards.

Managed care organizations may have narrow short-term business perspectives that ultimately may result in decisions that harm people with disabilities. Because many of these organizations operate on a for-profit basis and so must generate an appropriate return on equity to their owners or shareholders, administrators may be under great pressure to hold down short-run costs. To do so, they may deny patients access to ongoing ancillary services, such as speech, physical, and occupational therapies, or they may withhold costly medical equipment from individuals with disabilities who truly need them. These patients may suffer in the long term because of these shortsighted decisions.

To date, no rigorous scientific evaluations have conclusively demonstrated that managed care has improved the quality of life or the health outcomes of persons with disabilities.

—Ross M. Mullner and Kyusuk Chung

See also Health Care Systems; Health Management Systems; Political Economy.

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MARTHA'S VINEYARD

See Deafness, on Martha's Vineyard

MATERNAL IMAGINATION

Maternal imagination is the concept that oddities in infants occur as the result of thoughts by the mother during parturition. Although the interpretation of maternal imagination as a root cause for birth anomalies does not wholly refute the idea of supernatural causation, it does signal a move toward scientific formulations of the etiologies for congenital disabilities. Any kind of parental blame spells difficulty for disabled persons, who may thus have their lives less welcomed than those of others. Maternal imagination is different, however, from the perception that corporeal differences are signs from a supernatural realm or harbingers of danger.

The theory of maternal imagination hinges on an understanding of women's bodies as highly susceptible to powerful external events, and tales about such susceptibility abound in the literature. According to such stories, a pregnant woman exposed to traumatic or highly sensitive stimuli can translate those impressions to the developing fetus. A pregnant woman who is startled by a frog, for instance, could imprint her impression onto the body of her child; that is, her child's body might manifest physical evidence of the event, such as webbed toes or fingers or a froglike head. A woman who gazes too obsessively at a portrait of Christ might be shown her excess by giving birth to a bearded child. Thus, perceived corporeal strangeness in the infant also reflects back to the mother a "lesson" concerning her affect and demeanor. Contemporary scholars discuss how explanations based in maternal imagination theory nonetheless bestow on mothers an extreme amount of control over the plasticity, form, and shape of their children's bodies. While the theory holds woman culpable for the appearance of congenital disability, it does usurp a small aspect of the patriarchal belief in the supremacy of male seed in the gestation process.

This early etiological theory of disability was most influential during the early European Enlightenment, which occurred from the late sixteenth to the early eighteenth century. Nonetheless, one can find similar theories of women's impact on parturition across histories and cultures. The early Latin story of Marulla and Cinna, who gave birth to seven monstrous children, provides a prime example of the adulterous mischief of mothers reflected in the strange aspects of their children, but it is not a matter of the sensibility or emotional experiences of a mother imprinting themselves onto a life-form. Instead, Cinna bears the blame for producing strange children by deliberately cavorting with one who is a "natural" and "black" or "red" children by crossing codes of color conformity: "Two sisters, one black, the other red, are Crotus the flautist's and Carpus the bailiff's. You would now have a troop as numerous as Niobe's, if Coresus and Dindymus had not been eunuchs."

Debates about the prevention of birth defects continue to emphasize the behavior and habits of the mother during pregnancy. Many environmental causes or congenital properties are assigned to maternal habits and modes of existence; for example, low birth weight in newborns is now frequently determined to result from maternal stress. Babies that are deemed to mix skin tones in racially polarized societies can be held out as a matter of maternal impropriety. In Third Reich Germany, German mothers of *mischling* children, whose fathers might be African, Jewish, or Romany, were publicly shamed and punished. The children themselves were frequently sent to institutions that participated in genocidal "cleansing" of the German "race."

Throughout the Renaissance and premodern period, "monstrous births" were often attributed to maternal imagination, although they were sometimes linked to other "mechanical causes," such as a narrow uterus or inappropriate sitting positions of gestating mothers. The stuff of bawdy songs and legend, such births were sensationally cataloged in publications called "wonder books." Fortuno's *Monstrum* (Italian, 1646) and Pare's *Of Monsters and Marvels* (French, 1585) contain well-known and quite remarkable examples. The wonder book collected instances of strange and unnatural occurrences for prurient audience interests in observing disability. These early Enlightenment books served to mediate between more metaphysical systems of disability interpretation implied by ideas about divine or satanic intervention in fetal developmental processes. While fanciful to a viewer from the twenty-first century, they indeed anchor developing empirical systems of medical observation. Wonder books served as transitional texts between supernatural explanations and more "naturalistic" explanations for what we recognize as congenital disability today, while unsure of any belief for supernatural purposes.

One perspective always absent from the wonder book was that of the "monstrous" individual—instead, each figured as a "marvelous" specimen. We can start to piece together a tradition of voiced commentary by subjects in dramatic and poetic traditions. In Shakespeare's *Richard III,* the protagonist contemplates his own birth predicament as "scarce half made-up." Abandoned at birth, Quasimodo, the title character in Victor Hugo's classic novel *The Hunchback of Notre Dame,* is sealed off from contact with other townspeople. In a journalistic interlude quoted verbatim by William Carlos Williams in his epic poem *Paterson,* George Washington visited a man with severe hydrocephaly to trade quips on late-eighteenth-century American politics. In each of these instances, an individual deemed a "monstrous birth" begins to give voice to a nuanced, self-reflexive perspective. Such entries in the Western literary canon also forward these perspectives as disruptive moments to competitive versions of the normalcy of a national "stock" in which early modern nations, with census taking of disabled persons, engaged.

The debate over maternal imagination as a reliable, scientific barometer for birth anomalies largely circulated around medical theorizing about the degree to which fathers could be held culpable for "disastrous" births. Marie-Helene Huet discusses these issues in detail in her book *Monstrous Imagination* (1993). If the theory of the supremacy of male seed provided masculinity with a controlling role in the course of pregnancy, then such an emphasis helped make male partners more central to procreation itself. However, such centrality in the reproductive process came with its own costs. If the birth of a disabled child was viewed as a "failure" or developmental mishap, to what degree did the male partner share the blame in such an event? Maternal imagination has been discussed as a desperate resolution to this conundrum without relinquishing men's centrality in pregnancy. A mother's influence over extreme birthing results would expand only during instances of congenital disability. In fact, as in contemporary examples of the births of disabled children, fathers often abandoned households after the births of children with medically remarkable distinctions. In this context, then, the idea of maternal imagination might be exculpatory for fathers in order to dissuade them from abandonment.

However, there have also been efforts—particularly among feminist critics—to interpret maternal imagination as an opportunity for reading women's expanding agency in their own reproductive lives. For instance, a value in the idea of inherited traits could go astray for a woman who gave birth to a child in whom a family resemblance was not forceful. This might be the situation, for instance, in cases of Caucasian women giving birth to racially mixed children or in cases of severe disability. In order to distance themselves from the social opprobrium of sex outside of marriage, women sometimes actively sought refuge in claims to maternal imagination. For instance, in one famous case, Marjorie Sheldrake, who gave birth to a "severely deformed" child in England in the mid-eighteenth century, argued against the charge that she had had intercourse with a man other than her husband by claiming maternal imagination. Given that she was scheduled to go on a trip to Australia after giving birth, Sheldrake claimed that images of kangaroos and other exotic scenes that she contemplated during pregnancy directly influenced the development of what would have been an otherwise paternally mimetic infant. While such recourse to the influence of exotic cultures may seem fraught with racial and cultural anxieties about difference, such arguments provided women with access to less severe forms of public disapproval and familial suspicion.

At root, the theory of maternal imagination developed as a reaction to widespread patriarchal suspicions that women's sexuality was untrustworthy. Because femininity's association with irrationality and embodiment led to explanations of female volatility, maternal imagination functioned as a symptom of many superficial ascriptions. An equation of failed differentiation informed these explanations. Whereas male subjectivity relies on perceptions of bodies as whole, coherent, and autonomous, women's bodies, in their many sexed differences, often appear unstable by contrast. Power structures, such as patriarchy, may directly define women's bodies as excessive, or as what Julia Kristeva (1987) has theorized as abject. Abjection is a compulsive rejection of body types that are determined to exceed acceptable mandated standards for participation in social life. They appear to espouse a refusal of normative boundaries and strict cultural assignment.

A gender theory of body difference can also be critical for assessing the different reactions to disabled bodies in culture insofar as cognitively, physically, and sensorially impaired bodies, by definition, resist normative classifications. The classic 1896 textbook *Anomalies and Curiosities of Medicine* begins with a section devoted to menstruation as the matter of a medical anomaly. Many bodies present radical challenges to Euro-American investments in the myth of a narrow bodily spectrum of variation. In this sense, maternal imagination and the often radically divergent bodies that result threaten to expose premises of bodily integrity that inform models of standardized embodiment. Pregnancy itself, harboring multiple bodies and presenting quickly growing elements, challenges boundaries of singularity and body life. Indeed, arguments about the modifications of environments that best suit pregnant bodies abound. A famous contemporary account of maternal imagining during the experience of inhabiting a multiplying can be found in Julia Kristeva's "Stabat Mater" (1987).

—*Sharon L. Snyder*

See also Family; Gender; Models.

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MAUGHAM, W. SOMERSET

(1874–1965)

British novelist and playwright

W. Somerset Maugham was born in Paris in 1874, the sixth and youngest son of the solicitor to the British embassy. His mother died when he was 10 years old, and he was sent to live with an uncle in England. After attending university, Maugham studied medicine for six years in London, qualifying in 1897 as doctor from St. Thomas' Medical School, but he abandoned medicine after the success of his first novels and plays. Maugham had considerable success first as a playwright and satirist and later as a novelist and short story writer.

Loss and disability strongly influenced Maugham's work. He had a severe stammer that left him afraid to speak. He led a double life both in sexuality and, for a brief while, occupation. He continued for many years both his marriage and his affair with an American man; he also worked as a British intelligence agent during World War I. Perhaps the most profound life event he experienced was the death of his mother when he was a child, an event from which he claimed he had not recovered some 50 years later. Themes of disability and uncontrollable longing are vividly portrayed in his classic novel *Of Human Bondage,* which was published in 1915. The protagonist, Phillip Carey, is a medical student who is embarrassed and publicly humiliated by his professors and fellow students because of his clubfoot. Carey conducts an ill-fated relationship with a selfish waitress who reappears at the end of the novel with all the signs of tertiary syphilis. The mixing of sexuality, disability, and subcultures is more clearly developed in this novel than in the works of other authors using similar themes.

—*Joseph A. Flaherty*

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McDONALD, ANNE (1961–)

Australian disability activist

Anne McDonald was born with athetoid cerebral palsy and was originally diagnosed as having profound intellectual impairment. She is unable to walk, talk, or use her hands effectively. At the age of three she was placed in St. Nicholas Hospital in Melbourne, Australia, a government institution for people with severe intellectual disabilities; she stayed there for 14 years. She later wrote:

> The hospital was the state garbage bin. Very young children were taken into permanent care, regardless of their intelligence. If they were disfigured, distorted or disturbed then the world should not have to see or acknowledge them. You knew that you had failed to measure up to the standard expected of babies. You were expected to die. . . .
>
> Nurses were discouraged from cuddling children. A crying child needed to be punished for its own good, so it would learn to accept the absence of affection and be happy. Punishment consisted of locking the crying child in a small dark storeroom. The hospital defined a happy child as a quiet child. Silence was not only golden but sullen; the nurses never saw the looks we gave them when a child was put away. (Crossley & McDonald 1980:16)

In 1977, when McDonald was 16 years old, Rosemary Crossley taught her to read and to communicate by spelling. Because of her severe physical disability McDonald needed someone to support her arm while she pointed at letters on an alphabet board. Once she was able to make her wishes known, she sought her discharge from St. Nicholas. The hospital authorities denied her request on the grounds that the reality of her communication had not been established. McDonald instructed a lawyer to take an action for habeas corpus in the Victorian Supreme Court. She won the case and was released from the hospital in 1979. In 1980, she and Crossley coauthored a best-selling book, *Annie's Coming Out,* which was made into an award-winning film of the same title (released in the United States as *Test of Love*). She later graduated from Deakin University.

McDonald's story contributed greatly to the move to community care for people with disabilities, which started with the closure of St. Nicholas Hospital in 1985 and subsequently spread throughout Australia. McDonald has been a notable campaigner for the rights of people with expressive communication impairments, helping to establish the Communication Aid User Society, the world's first organization founded by people without speech, in 1981. Her 1993 statement on the right to communicate has been adopted by the U.S. organization TASH (the Association for Severe Handicaps):

> The right to communicate is both a basic human right and the means by which all other rights are realized. All people communicate. In the name of fully realising the guarantee of individual rights, we must ensure
>
> - that all people have the means of communication which allows their fullest participation in the wider world;
> - that people can communicate using their chosen method, and
> - that their communication is heeded by others.
>
> Where people lack an adequate communication system they deserve to have others try with them to discover and secure an appropriate system. No person should have this right denied because they have been diagnosed as having a particular disability. Access to an effective means of communication is a free speech issue. (pp. 21–22)

In a 1992 address to TASH, McDonald said:

> For people without speech, talking is often dependent on the generosity of others, either in providing interpretation or facilitation or in giving up time to listen. While this is inevitable, there needs to be an irreducible right to make one's opinions known on issues concerning your future well-being. At the moment social conversation and medical consent are equal in the sight of the law, both depending on the accidental availability of communication partners with the necessary skills and commitment.
>
> There is no right to be heard. There is no right to an interpreter. There is no obligation to listen.
>
> While social interactions will always be dependent on the politeness and tolerance of individuals, it should be possible to legislate for a right to communicate in formal situations such as courts, hospitals and schools. Without such legally enforceable rights, people without speech are at the mercy of decision-makers who can arbitrarily decide to disallow communication.
>
> Communication falls into the same category as food, drink and shelter—it is essential for life, and without it life becomes worthless.

—Chris Borthwick

See also Activism; Advocacy.

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▣ McMILLAN, MARY L. (1880–1959)

American physical therapist

Mary Livingstone McMillan, "Molly" to her friends, was the founder and first president of the American Women's Physical Therapeutic Association, which is today known as the American Physical Therapy Association (APTA). Born in Hyde Park, Massachusetts, McMillan was raised by cousins in Liverpool, England, and graduated from Liverpool University in 1905. Her interest was attracted by the new field of physical culture and corrective exercise, which she studied along with such medical subjects as neurology and anatomy. After several years of working with polio and scoliosis patients as well as patients living with the aftereffects of industrial accidents, McMillan returned to the United States, where in 1918 she became the first volunteer to respond to the U.S. surgeon general's call for reconstruction aides to work with injured veterans at Walter Reed Army General Hospital. Later in 1918, she was asked to move to Reed College in Portland, Oregon, to organize three-month training programs for 200 new reconstruction aides needed for the war effort. This successful effort led to her recall to Walter Reed to establish an army-based education program. (The fact that she worked at the two "Reeds" has led to much confusion about McMillan's efforts and which of the two programs she founded was the first.)

After World War I, McMillan was the driving force behind the formation of a professional organization for physiotherapists. Following a meeting of some 20 women and a few physicians at Keen's Chop House in New York City, the forerunner of the APTA was founded with McMillan as its first president. The organization's structure was similar to that of the British Chartered Society of Trained Masseuses, and standards for training and ethics were important elements of the fledgling association. Along with guiding the new organization, McMillan published her book *Massage and Therapeutic Exercise* in 1921. She went on to teach at Harvard University until 1932, when she went to Peking Union Medical College to become director of physical therapy under the auspices of the Rockefeller Foundation. Caught in Manila at the outbreak of World War II, McMillan was interned at the Santo Tomas prisoner of war camp. While there, she set up clinics to treat the wounds and disabilities of combatants with whatever was on hand. Like many others, she developed severe nutritional deficiencies during her stay in the camp. Later she was transferred to the Chapei prison camp near Shanghai, where she remained until 1944, when she was repatriated on the Swedish American ocean liner *Gripsholm.*

At her death in 1959, McMillan left a large part of her estate to fund a scholarship program for all levels of education for physical therapy students. The program is administered by the APTA, which has also honored her memory with the establishment of the Mary McMillan Lectureship, which began in 1964.

—Helen J. Hislop and
Suzann K. Campbell

See also Physical Therapy.

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MEDICAL FUTILITY

Medical futility is a term used to describe situations in which medical investigations and treatments have little or no beneficial effect on a patient. A futile treatment is one that will not cure the patient's illness or improve the patient's quality of life. When treatments are said to be futile, health professionals owe no duty to provide them to patients, and, it is argued by some, doctors can refuse to provide such treatments even when patients or substitute decision makers request them. *Medical futility* is therefore an extremely controversial term, primarily because health professionals can use it as a way of closing the debate about treatment provision and resource allocation. It is also controversial because it has proven extremely difficult to define.

ETHICAL UNDERPINNINGS OF MEDICAL FUTILITY

Concepts of futility can be found in the earliest writings on medical ethics. In the Hippocratic corpus, physicians were encouraged not to treat patients who were overmastered by disease. Similarly, in Catholic bioethics, physicians are not bound to provide "heroic" or "extraordinary" treatments—that is, treatments that are rare and expensive, that offer little hope of benefit and involve significant pain or inconvenience to the patient.

The term *extraordinary treatment* has also found its way into legislation. For example, in the Northern Territory of Australia, the Natural Death Act 1988 (NT) states that

> "extraordinary" treatment means medical or surgical measures that prolong life, or are intended to prolong life, by supplanting or maintaining the operation of bodily functions that are temporarily or permanently incapable of independent operation.

However, in the past two decades, the terms *heroic* and *extraordinary treatment* have been used with decreasing frequency. By the 1980s and 1990s, commentators began to rely more often on the term *medical futility.*

APPROACHES TO DEFINING FUTILITY

There are two main approaches to defining medical futility. One is the *quantitative* approach, by which a treatment is judged to be futile when it fails (or is known to fail) to achieve certain physiological goals. This could also include those treatments that have a very poor probability of success or that will fail to postpone the onset of death. Second is the *qualitative* approach, which looks not only at physiological success but at quality-of-life factors, such as comfort, well-being, and cognition. The simplest definition of futility using this approach is treatment that cannot return a patient to consciousness or that cannot end the patient's dependence on intensive medical care. Included in this assessment would be treatments that may have success in prolonging life but do so at a great cost to the patient's quality of life, for example, by inflicting enormous pain and discomfort. The qualitative approach therefore focuses on the ends or goals of medicine, those being primarily the absence of disease or disability. If a treatment will not be able to achieve these ends, then it can be considered futile.

PROBLEMS WITH MEDICAL FUTILITY

Clinical Uncertainty

The first problem with the concept of medical futility is that all assessments of quantitative futility are uncertain. While evidence-based medicine has improved our understanding of the success of treatments across populations of patients, it remains extremely difficult to judge the possible outcomes of treatment for individuals. Additionally, there is no consensus as to when the probability of a treatment's success will be low enough for the treatment to be classed as futile. As Kerridge, Mitchell, and McPhee (1997) point out, some doctors might think a treatment is futile when it has zero chance of success, whereas others might make the same judgment when the treatment has a 10 percent chance of success.

Discourse That Disguises Value-Laden Judgments

The assessment of medical futility, particularly of qualitative futility, is laden with value judgments about the quality of a patient's life. Physicians consider factors such as the pain that will be caused by a treatment, the level of awareness of the patient, and the patient's age. The ethical integrity of the medical profession may not provide a sufficient safeguard to prevent improper discrimination in this context.

Problems of hidden values are exacerbated in the end-of-life context, particularly in regard to decisions concerning the artificial feeding and hydration of patients in permanent vegetative states. If a person is in a permanent vegetative state, it might be argued that it is futile to continue artificial feeding and hydration because such treatment will not return the patient to sensate awareness. Nevertheless, it can equally be argued that the treatment is not futile (and in fact works extremely well) because it continues to keep the patient alive, even after the death of the higher brain. This example illustrates the fact that applying the term *futility* does not by itself resolve the underlying conflict about whether such treatment should be provided. Other considerations, such as the best interests of the patient or substituted judgment, are determinative.

Universally, common-law courts have found that artificial feeding in such circumstances is futile and have authorized its withdrawal. For example, the Supreme Court of California said such feeding was futile in *Barber v. Superior Court of the State of California* (1983). Similarly, the House of Lords found in *Airedale Trust v. Bland* (1993) that the continued artificial feeding of a patient in a permanent vegetative state served "no therapeutic purpose of any kind" and that it is the "futility of treatment that justifies its termination." Critics of these decisions have argued that the language of futility has shifted impermissibly from an examination of futility of treatment to consideration of whether the lives of the patients are futile.

RESOLVING DISPUTES ABOUT FUTILITY

Given that a purely objective and noncontroversial definition of futility does not seem to be possible, it is logical to assume that disputes about futility will continue. How are such disputes to be resolved?

If the determination of futility were limited to qualitative knowledge of medical probabilities, it might be arguable that debates about futility should be confined within the medical profession. Conversely, if the definition of futility includes consideration of factors of quality of life, medical professionals should be the only people to contribute to the debate.

Increasingly, it appears that the courts are being asked to resolve disputes about whether treatment should be provided to patients when health professionals have deemed that such treatment is futile. In the United States, much commentary was generated by the case *In the Matter of Baby K* (1994), which involved a decision by a hospital not to resuscitate a baby born with anencephaly (a congenital malformation where the upper brain, skull, and scalp are missing). The child had frequent presentations to the hospital (from the nursing home where it resided) because of breathing difficulties. The hospital believed that respiratory therapies were futile given the baby's inability ever to achieve cognition or awareness. The child's mother disagreed and insisted on treatment for the child. The court found that the hospital's decision breached the Emergency Medical Treatment and Active Labor Act, a statute aimed at ending the practice of patient dumping; the act requires hospitals to stabilize patients before moving them to other institutions.

Some commentators have seen the *Baby K* decision as an unnecessary expansion of patients' rights, so that patients (or their representatives) can demand and receive unnecessary, expensive, and unethical treatment. Others have argued that the decision is limited in scope, noting that it focuses on the narrow question of statutory interpretation and has not always been followed in later decisions.

Similar cases have arisen elsewhere. In the United Kingdom, futility arguments were raised in the case of *Glass v. The United Kingdom* (2004). In this case, doctors had decided to enter a not-for-resuscitation order on the chart of a disabled child without the consent of the child's mother. The child was also given diamorphine against the mother's wishes. The child had been treated for complications arising from surgery, and the doctors believed that resuscitation and aggressive respiratory treatment were futile. The mother disagreed with the doctors' assessment. After a fracas between the child's relatives and medical staff, the child was resuscitated and, eventually, discharged from the hospital. After the Court of Appeal of England and Wales refused to review the hospital's decision, the mother successfully sued the U.K. government in the European Court of Human Rights. That court found that the doctors' failure to gain consent from the mother or from a court meant that the family life rights of the patient and his mother had been breached. This case clearly demonstrates the problems with both quantitative (given the boy's survival) and qualitative (given the dispute between the family and the doctors about the child's quality of life) approaches to judging medical futility.

THE WAY FORWARD?

Given the failure to find an acceptable definition of medical futility, some commentators have suggested that what is needed is a process whereby disputes can be mediated and consensus can be achieved regarding the meaning of whether a particular treatment is futile. This approach has been adopted by the American Medical Association's Council on Ethical and Judicial Affairs and has also been legislatively recognized. For example, the Texas Advance Directives Act of 1999 provides for a process of ethical review of futility determinations that includes dispute resolution services when doctors and families cannot agree about whether treatment is futile.

—Cameron Stewart

See also Consent to Treatment; Refusal of Life-Sustaining Treatment.

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MEDICAL MODELS

See Models

MEDICAL THEATER

The term *medical theater* refers literally to the operating room—the operating theater. More broadly, the term is also used to refer to the places and practices that surround demonstration as a method of dissemination of medical knowledge. By drawing attention to theatricality, the term *medical theater* brings into view the different agendas and power positions that crisscross medical environments.

Medical practices are not fixed; they are subject to historical changes, and they have not always been aligned with issues of visibility. In *Discipline and Punish,* Michel Foucault (1977) describes the changes in machinery and practices that influenced the hospital's move from a place of thick walls and shelter, as a place apart and out of public view, to a place characterized by a regime of visibility that allowed observation of patients, complete with theatrical spaces created specifically to allow doctors to view patients and to instruct trainees. This new regime of visibility allowed for physicians' engagement with individual patients at the same time the patients themselves became site—places within which and on which symptoms could be observed. In the history of disability representations, psychologist Jean-Martin Charcot and his performances of hysteria in the Salpêtrière in the 1870s can illustrate this point. Charcot investigated women diagnosed with hysteria, fainting attacks, or spontaneous paralyses, parading them around his amphitheater. By presenting that these women were not consciously in control, that they were not faking their attacks, Charcot established the legitimacy of psychological conditions and their effects on the physical body. The price paid for this achievement, however, was the further disempowerment of these women, who became puppets with disheveled clothes in a male-dominated theater of stares.

The original medical theaters where dissections were publicly performed were amphitheaters, architectural forms that echoed the Greek theater tradition. The architecture also echoed Greek concerns of the public sphere: knowledge circulated from the staging area to the benches, and back—the patient's body was the scene of the action, but not the action itself.

The transformation of individual bodies into "data," or into forms of knowledge, is the economy initiated in this theater. The individual patient becomes a barrier breached, the patient's life a collection of data: heartbeat, blood pressure, lines on computer monitors, relations of blood chemicals, lung capacity. These disembodied data as representations of a patient's life are familiar from medical television shows and films. In *Flatliners* (1990), for instance, the resting green luminescent line of the heart monitor signifying death becomes the central metaphor of the film. Successful television shows such as *CSI: Crime Scene Investigation* offer a narrative of the anatomy theater and dissection in stylish images, bright colors, and clean arrangements. In *CSI,* the body on display is broken down, anatomized, atomized, into microsites of narratives. Bullets are tracked through flesh; a burst vein fills the screen, zoomed into by computer graphics; skin appears under the microscope, dramatizing the story that happened outside on the streets of Las Vegas anew in the confines of the medical theater and its laboratory stages.

Within this economy of the medical theater as medical practice, the "ideal" body becomes the object of knowledge: The symptoms of the bodies on display within this theater are interesting insofar as they shed light on the general body, the nonspecific body, the universal or "normal" body. Statistics set boundaries and norms within which the body in the medical theater is aligned. In some instances, these statistical demands and their effect on aesthetics and "proper bodies" lead to strange acts: medical practices that invade bodies, often of disabled people, in order to normalize. Thus, limbs are straightened or lengthened, often under excruciating pain; ears are repositioned, fat sucked, breasts enhanced.

In art practices, the boundaries between the "diseased" and the "normal" can become unstable and can be queried. The film *Crash* (1996), directed by David Cronenberg, reconceptualizes the medical theater. In the film, which is based on J. G. Ballard's novel by the same title, traffic accidents and the unhealed flesh of survivors become eroticized. New alignments between metal and body, unnatural openings into previously "whole" bodies become the focus of the camera, identified with the central character's desirous gaze. Within the medical setting, in the hospital bed—with its paraphernalia of bandages, metal cages, and blinking instruments—sex is used as a counterpoint to death. The medical theater here is the liminal space. But disability remains negative in this economy of eroticized wounded bodies; it is the fluidity of bodies that is valued, their ability to be wounded and to heal. For disability politics, the film offers a different vision of fetishized flesh, but not a pathway to a rethinking of disability as lived reality.

The medical theater is not without an audience—Charcot's pupils eagerly drank in the sight of their powerful professor handling fainting women. In *CSI,* detectives follow action with bated breath as the stage machinery of the medical theater distills "evidence" out of the wounded and dead bodies. Historical studies of anatomy practice discuss the growing public attraction of these spectacles of medical display, and history of medicine scholars have excavated the extravagant and (to modern sensibilities) strange practices surrounding medicine in the seventeenth and eighteenth centuries. For instance, Gonzalez-Crussi (1995) describes the Bolognese amphitheater in the seventeenth century as a site of theatrical spectacle, decked out magnificently for the occasion. In these rites of knowledge and bodies, the professors appeared in long crimson robes, flanked by assistants, to take up a position on the stage next to the cadaver. In contemporary displays of the rites of the medical theater, the clothing and procession are less extravagant, but TV series such as *ER* have educated the public to the less ponderous but still strictly followed fashions and practices of the medical theater today. Within disability history, the various dramatizations of the life of the "Elephant Man" hinge on the display of John Merrick—first by the freak show and then by the medical establishment. Bernard Pomerance's play *The Elephant Man* (1979) presents the problems of seeing beyond the roles of doctor and patient, of achieving human contact within the machineries of hospitals, fund-raising, and differing class demands and life paths.

Disability culture has also embraced the medical theater as an important site of political artwork, criticism, and revolt. Many of the skits and stand-up comedy routines performed at disability arts cabarets include references to encounters between medical personnel and disabled people in the medical theater. The medical theater here becomes a performance form that is highly aware of the power differentials, the "genres," the stories and the predetermined performance scripts that surround the doctor-patient encounter. Most disabled people have intimate knowledge of these visual and performative practices of the medical theater. In particular, if they have rare congenital impairments, they might have been required to undress in front of doctors and medical students; photos might have been taken, and demonstrations held over their mute, or even their protesting, bodies.

Traditionally, the diagnostic gaze of the medical practitioner can roam freely across the displayed bodies of patients, and only rarely are its intrusive and objectifying powers acknowledged in the everyday encounter. In disability culture's revision of the medical theater, the object of the gaze speaks back or subverts the agency and power of the scrutinizing gaze. Performers such as Bob Flanagan, Mat Fraser, Angela Ellsworth, Victoria Halford, Ron Athey, and Greg Walloch have used the encounters between doctors and patients as well as the paraphernalia of the medical environment as starting points for their explorations.

—Petra Kuppers

See also Disability Culture.

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MEDICINE

MODELS OF DISABILITY

In the medical and rehabilitation sciences, various models of disability have been proposed. These models help in the conceptualization of the medical aspects of disability and serve to guide research and educational efforts in rehabilitation medicine. In the United States, the Institute of Medicine of the National Academy of Science and the National Institutes of Health make use of a model that defines the development of a disability as a four-step path with three transitions. The process begins with the *pathophysiology* of the condition—that is, the basic disturbance at the level of molecules, cells, or tissues that results in clinical manifestations of disease. The presence of the disturbance itself may not result in disability and in fact may not be manifested clinically all the time. Modern medical sciences have made significant advances in understanding disease at this level, as illustrated, for example, by research into the genetic basis of disease.

When molecular and cellular alterations reach a certain threshold, the person may develop *impairment*—that is, the inability of a physiological or body system to perform the function for which it was designed. Thus, an impairment of the neuromuscular system may be manifested by muscle atrophy and weakness, and a loss of joint range of motion is a sign of an impaired skeletal system. Along the same lines, diabetics who cannot control and regulate their blood sugar levels have impaired metabolic and endocrine systems. When the impairment limits the person's ability to perform basic functional activities, such as climbing stairs, running, or jumping, a *functional loss* has occurred. Individuals need to be able to perform many functional tasks in order to be independent at home, perform the duties of a parent, work, and function in society. If a functional loss is severe enough and limits the person's ability to do such tasks, a *disability* has developed. Obviously, disability cannot be looked at from a medical or biological point of view only. In this model, disability is the final outcome, and it is defined not only by the biology of the disease or injury but, more important, by the interaction between the biology and the environment surrounding the person as well as the demands of the social and occupational activities of the person. In other words, an impairment or functional loss may not become a disability if the environment facilitates the task at hand (for example, by removing barriers to mobility) or reduces occupational demands (for example, by allowing the person to work from home). Disability is not necessarily permanent; it can be reversed if its determinants can be altered.

The elimination or treatment of factors that convert a functional loss into a disability or an impairment into a functional loss may result directly from medical intervention that limits tissue damage (e.g., thrombolysis in acute stroke) or replaces damaged tissue (e.g., joint replacement surgery). The latter, for example, eliminates pain and damaged tissue, restores joint integrity, and allows for physical therapy for the restoration of muscle strength and endurance. Thus, the functional losses and impairments are eliminated or minimized. This illustrates that the current conceptual model of disability is dynamic, and we should not assume that nothing can be done about the problem.

In this context, it is important to highlight the role that assistive technology, used in centers for rehabilitation medicine, can play in the conversion of a disability to a functional loss or in reversing a functional loss to the level of impairment. Assistive devices include mobility aids, computers to enhance communication and cognitive functions, and memory aids that can replace biological or mental functions and at least partially restore activity and participation. For example, when a person with muscular dystrophy loses muscle mass and the ability to walk, he or she may use a wheelchair to participate in community activities. In this case, the use of a device to assist in mobility replaces the functional loss and minimizes the disability.

A more recent model of disability, favored by some authors and adopted by the World Health Organization, is also based on various levels or steps but begins with the *person* as the central element. This level is roughly equivalent to the level of pathophysiology in the model described above. The person depends on having biological, physical, and psychological integrity to perform *activities* (a level roughly equivalent to the impairment and functional loss levels of the previously discussed model combined). One example of the importance of activity for disability is the beneficial effect of physical activity (e.g., walking, running) on a variety of chronic diseases. Well-conducted studies have shown that the regular practice of physical activity or exercise is associated with reduction in the incidence of heart disease, stroke, some types of cancer, diabetes, obesity, depression, and other conditions. Further, regular exercise of moderate intensity reduces mortality from many of these conditions in both men and women and, more important, delays the development of disability by several years.

Finally, it is not enough for the person to be capable of being active; rather, the ultimate objective is for the person to be a *participant* in his or her community and in society in general (i.e., for the individual to interact with the environment in performing certain tasks). Although there are important similarities between the two models, the latter model is less medically oriented and is characterized by a more holistic, participatory approach.

Independent of the model used, the important issue is that, in the practice of medicine, we need to understand the factors, biological and otherwise, that contribute to the development of disability. Medical and rehabilitative interventions must be based on this knowledge and understanding. Many of these factors are not biological or medical, and therefore many interventions must include other aspects of health.

THE INTERSECTION BETWEEN MEDICINE AND DISABILITY

An analysis of the relationship between disability and medicine is relevant for several reasons. Most obvious is the fact that the road to disability often begins with an acute illness (e.g., a stroke), injury (e.g., traumatic brain injury), or the development of symptoms and signs of a chronic illness (e.g., rheumatoid arthritis). In all of these situations, the affected person is likely to need the services of a medical professional. For many young and healthy individuals, this could be their first experience as hospital patients. Further, even those who have permanent but stable disabilities are likely to require medical services at different points in their lives. For example, disabling conditions resulting from spinal cord injury (e.g., tetraplegia and paraplegia) are associated with a high incidence of such medical complications as infections of the urinary tract, pressure sores, osteoporosis below the level of the injury, and pulmonary diseases. Persons with these conditions become regular users of the medical services available in their communities and develop relationships with health care providers. Another example is the patient with peripheral vascular disease and poor circulation who undergoes an amputation below the knee. Such a patient requires rehabilitation, including the use of an artificial limb, but also careful medical monitoring of the condition of the nonamputated leg, because many such patients develop complications during 5 to 10 years postamputation.

In any of these instances, various medical professionals with different areas of specialization evaluate the patient, establish a diagnosis, and initiate treatment and rehabilitation. These are important encounters, because medical interventions represent one of the first opportunities to control or reverse the physical and psychological conditions that, if left unattended, may lead to the development of a new disability or the worsening of an existing one. In addition, these critical opportunities represent times when professional medicine can display shortcomings. Although many medical specialists do not necessarily recognize the fact, acute therapeutic interventions can alter significantly, either positively or negatively, the pathway to disability. In other words, limiting tissue damage and disease activity in the early stages is the first step in the restoration of form and function. Medical professionals' failure to recognize this principle has led to undesirable outcomes and been the source of much criticism of the medical model of disability. On the other hand, inappropriate medical interventions can also contribute to a problem by delaying tissue healing and by imposing unnecessary restrictions on a patient's activity and community participation. History reveals many instances in which medical interventions, although well-intentioned, did more harm than good. In this context, one of the most noticeable weaknesses of the medical approach to disability has been the failure to recognize the importance of the environment as well as the psychosocial forces that define disability.

Two factors that have contributed to an increase in the prevalence of disability in recent years are worthy of attention. One of these is the success of the health care system in providing advanced medical interventions and using modern technology in acute settings. Advances in science and medicine have been published at an unprecedented rate since the middle of the twentieth century. These developments have resulted in a reduction in mortality associated with accidents, injuries, and acute and chronic illnesses. Paradoxically, the increase in survival rates, a positive outcome in and of itself, may have contributed to an increase in the incidence of disability, given that many patients now survive life-threatening injuries and diseases associated with permanent impairments and functional losses. This increased prevalence of disabling conditions requires a change in our medical practice, better educational programs for medical students and residents (postgraduate trainees), and novel research programs to generate new knowledge and successful interventions. Some of these needs are not being met, and the medical profession must make an effort to fulfill them if it intends to serve well an increasingly large segment of the population.

The dramatic demographic changes registered during the late twentieth and early twenty-first centuries have also contributed to an increase in the prevalence of disability. Increasing numbers of people survive to advanced adult age, and life expectancy is significantly longer today than in the past in all continents of the world with the exception of Africa. The World Health Organization has predicted that the aging of the world's population will continue for the next few decades, resulting in an increase in the number of people in the older age groups, particularly those older than 85, including centenarians. Further, the incidence of functional losses and disability increases with advanced age in both men and women. This is in part due to age-related physiological losses but also to the increased incidence of chronic illness in the elderly. The elderly seek health care services more than do the members of any other age group, bringing to the attention of their physicians, primary care doctors, and specialists not only their medical needs but also their functional limitations. Studies have shown that the elderly fear functional dependence more than death. This preference expressed by patients is a strong statement against the traditional medical approach of treating symptoms and diseases in isolation, without considering their functional consequences. A change in paradigm is needed to place the person's ability to participate in society at the forefront of medical interventions and to integrate the environment in the analysis of the health care and medical needs of patients.

TEACHING MEDICAL STUDENTS AND SPECIALISTS ABOUT DISABILITY

The changes mentioned above highlight the need for a health care system that is knowledgeable about and accessible to persons with disabilities. Although many medical specialties (e.g., developmental pediatrics, geriatrics, neurology, neurosurgery, oncology, orthopedics, and psychiatry) have developed an interest in disability, the only medical specialty that has included disability as a central theme in its philosophy of care, mission, educational and training programs, research agenda, and clinical services is the specialty of physical medicine and rehabilitation (PM&R, also known as physical and rehabilitation medicine, rehabilitation medicine, or physiatry). In fact, PM&R was born, to a very significant extent, out of the needs of patients with permanent disabilities caused by war-related injuries, because the other medical specialties available at the time did not offer effective therapeutic alternatives after the acute stage.

In the United States, physicians specializing in PM&R (physiatrists) must complete four years of postgraduate residency training. They learn to evaluate, treat, and rehabilitate people with disabilities using a holistic approach and are trained to pay particular attention to the restoration of form, function, and freedom to the patient. Thus, the specialty is defined by its comprehensive approach and interest in function and not by the need to attend diseases of a specific organ or body system. Furthermore, in addition to attending to the biological and physical needs of the patient, physiatrists place special emphasis on psychosocial, emotional, and vocational issues that may be important determinants of the level of disability. It is interesting that the consequent lack of identification with a specific organ or body system (unlike the identification of cardiology with the heart and ophthalmology with the eye, for example) has made the process of communicating the nature of the specialty more difficult. For those without disabilities, the concept of function may not be all too obvious.

Unfortunately, the specialty of physical medicine and rehabilitation is not very popular among medical students and is usually not included as part of the regular curriculum in most medical schools. Furthermore, conceptualization of function and disability is poorly disseminated within the field of medicine in general. Thus, standard medical textbooks such as *Harrison's Principles of Internal Medicine* do not include disability in their indexes. More frequently, disability awareness comes from firsthand experience. It is not unusual to find students whose interest in the specialty of PM&R resulted from their having lived with relatives with disabilities. Medical students interested in the field have to use some of their elective time to do special rotations in physiatry in order to learn more about it. It could be argued that this deficiency of information and knowledge about disability and rehabilitation, characteristic of many medical school graduates, explains the lack of appreciation and understanding that many physicians have in relation to disability issues. Further, more often than not, postgraduate residency training in many medical specialties fails to provide students with practical experiences in the diagnosis, treatment, and rehabilitation of disabling conditions. Nevertheless, recent data indicate that, despite the above-mentioned limitations, the medical specialty of PM&R is growing in many countries and regions of the world. Currently, there are approximately 8,000 board-certified physiatrists in the United States and 15,000 physiatrists in Europe. In addition, the numbers of medical graduates enrolled in PM&R residency training programs in the United States and Europe are 1,200 and 2,000, respectively. Greater availability of well-trained medical professionals could significantly enhance access to quality services focused on disability issues.

Another opportunity to educate physicians and other health care professionals has resulted from recent changes in the financing and management of health care systems. These changes may have the unintended consequence of enhancing the general understanding of disability and rehabilitation issues among health care providers outside the world of rehabilitation. Financial concerns with the cost of health care have forced acute care hospitals to reduce the length of the hospitalization for many diseases and surgical cases. To accomplish this goal, hospitals have begun transferring patients to other, lower-cost, facilities as soon as their medical conditions are stable enough to permit continuation of their treatment and recovery elsewhere. As a consequence, rehabilitation facilities have become important providers of subacute medical and rehabilitative care much earlier in the recovery (postinjury or postsurgery) process, and physicians and administrators in acute care facilities have been forced to learn more about the needs of people with conditions that require rehabilitation and patients with disabilities, particularly in the early stages of episodes of care.

HEALTH CARE SERVICES FOR PEOPLE WITH DISABILITIES

Modern health care systems are multicomponent organizations that integrate different levels of care across geographically separated campuses. Many patients needing multiple levels of care are transferred from one location to another, and then another, and so on. Most of the services for people with disabilities have been consolidated in entities known as *nonacute, postacute,* or *continuing care* health care systems. These systems have important distinguishing features that should be understood.

Acute medical services, including the acute hospital, an emergency room, operating rooms, ancillary services such as radiology and clinical laboratory services, and outpatient clinics, are usually available all on one campus. On the other hand, nonacute health care systems organized with the rehabilitation continuum in mind may provide services on multiple campuses, including the rehabilitation unit or hospital, nursing homes, day hospitals, and outpatient clinics, as well as in patients' homes. Acute care facilities provide important services for people with disabilities. The presence of a disability and the rehabilitation needs of the patient are sometimes important determinants of the nature and success of the intervention in the acute hospital, but most of the time they are not the center of attention. In the acute care hospital, more often than not, the need to restore form and function is a secondary consideration. The opposite is true in the various levels and facilities of care that form part of the nonacute system. In the majority of cases, people with disabilities access services in the nonacute system because of the disability, and the health care professionals make the disability and its determinants the center of attention and clinical activity. The need to include the home of the patient as a component of the system is a formal recognition of its important role in the final outcome.

An important difference between a typical acute medical intervention and treatment received in the medical rehabilitation context is the emphasis that the latter places on the interdisciplinary team. Although recently many medical specialties have begun to develop and implement versions of the team concept, medical care for people with disabilities in rehabilitation settings has always been characterized by the interrelatedness of the interventions of a large group of health care professionals. The team approach is one of the central tenets in the practice of clinical rehabilitation and the delivery of medical services for the disabled. In addition to the physician, the rehabilitation team may include individuals in all or some of the following health professions: occupational therapy, physical therapy, speech language pathology, psychology, neuropsychology, recreational therapy, rehabilitation nursing, nutrition, and social work. Fragmented medical care in which multiple specialists intervene with a patient without coordinating their services has no place in rehabilitation medicine clinics and centers or in medical programs for the disabled. The coordination of services takes place not only through daily communication among the members of the team but also through formal team meetings in which members discuss the goals and progress of the patient. In a very real sense, the patient and his or her family are also part of the team, and family meetings are held to discuss the patient's progress and to get family members' opinions on issues confronting the patient. Although some of these interactions and activities take place also in the acute care setting, they are more formally planned and executed in the rehabilitation setting.

Two of the main objectives of the rehabilitation process are the return of the person to his or her home and, if possible, the return of the person to his or her previous level of employment. To meet these objectives, medical professionals must develop a good understanding of the social and occupational environments of the patient. Such understanding may not be necessary in acute care settings, but it is almost always required in nonacute health care systems. For example, many of the rehabilitative and therapeutic interventions may have to take into consideration the architecture and physical barriers of the patient's house and the physical and psychological demands of the patient's job. Again, disability is defined by the interaction between the biological and physical domains and the environment, and even in the case of static and permanent biological dysfunctions, alterations in the environment can reduce negative impacts on function and lessen the degree of disability. In this context, it could be said that therapeutic and rehabilitative interventions should be directed toward the environment: enhancing the person's ability to overcome environmental barriers or reducing the magnitude of the barriers themselves.

THE MEDICAL RESEARCH AGENDA AND DISABILITY

Research is needed to generate new knowledge that medical professionals could use to understand the natural world and apply to the solution of clinical problems. In medicine, new knowledge is generated through research studies that can be divided into three general categories: basic science research, clinical research (including clinical trials and outcomes research), and health services research.

The goal of basic medical science research is to increase understanding of health and disease at the mechanistic level. Important basic science questions address how the human body works and what happens when a disease develops at the molecular and cellular levels. Many of these questions are relevant to a variety of clinical issues and help us understand problems at a very fundamental level even though they do not address or test immediate solutions to clinical issues.

Clinical research, on the other hand, is designed to test ideas with the potential to treat or cure disease in humans. Thus, researchers test drugs, new surgical interventions, and new technologies to assess their value in preventing illness, treating disease, and alleviating pain and suffering. This type of research is unique in that it requires the voluntary participation of human subjects. The patient or person with a disability has an opportunity to be part of the process and contribute to a better outcome. The clinical research enterprise has a solid base in areas such as cardiovascular disease and cancer but is not well developed in rehabilitation medicine. Advances in the rehabilitation of people with disabilities will depend on the establishment of a clinical trials network, so that new treatments can be tested on large numbers of individuals.

Finally, health services research deals primarily with issues related to the delivery of health care and the factors that determine the efficiency and effectiveness of health care systems. Current health services delivery models may not be adequate for people with disabilities, and more creative ways of providing services are needed. For example, new technologies such as tele-rehabilitation could help medical professionals to deliver services in patients' homes and reduce dependence on clinic and home visits.

In many ways, all of these types of research are important for persons with disabilities because many of the treatments developed in the context of acute care interventions might find application in rehabilitation centers. For example, understanding the basic events leading to brain damage after an injury or stroke could help with the development of ways to protect healthy tissue surrounding the affected area. Further, tissue engineering could potentially be used to replace tissue that has been damaged or lost due to illness or injury, as in degenerative arthritis. Stem cells that have the capability to differentiate into different types of cells represent another potential source of "new tissue."

Clearly, significant efforts in basic science are needed to accomplish these goals. Further, no discovery is incorporated in standard medical practice until appropriate clinical trials have been conducted to prove the safety and effectiveness of treatment based on the discovery. Therefore, clinical trials and outcomes research studies must also be part of the research agenda addressing disability issues. New pharmacological agents developed using this model could be effective in treating medical complications that are frequently seen in association with disabling conditions such as spasticity (a velocity-dependent increase in muscle tone) in stroke survivors and tetraplegics. Advanced prosthetic (artificial limbs) and orthotic (braces) devices for those with mobility problems and amputations, which clearly benefit consumers, are developed and tested using this approach.

Finally, the organization of a system of care for people with disabilities should take into consideration the special needs of this population; therefore, health services research is needed to help define the characteristics of such a system. This concept has been tested in the Model Spinal Cord Injury System, a network of centers in the United States dedicated to the care of patients with spinal cord injuries. These centers provide and coordinate emergency and acute medical care, rehabilitation services, psychosocial and community reintegration programs, and long-term follow-up focusing on the special needs of patients after spinal cord injury. During the past 35 years, researchers have developed and tested each of these levels of care and special programs with the needs of persons with spinal cord injury in mind. It is worth noting that these centers must integrate not only different levels of care (e.g., acute neurosurgical interventions with rehabilitation goals) but also administrative, research, and educational efforts for health care professionals, patients, and patients' families.

In general, the medical research agenda does not include enough research initiatives that have at their centers the purpose of ameliorating disability. Traditional medical research models used, for example, in acute care hospital settings are more oriented toward the biological and physical aspects of disease. These are clearly important, but in the future, the roles of environmental and psychosocial factors will have to be integrated with these two aspects. An example of this integration is the proposed future agenda for the Model Spinal Cord Injury System, which includes attempting to integrate basic science, clinical research, and health services research. This agenda, with minor modifications, could serve as an example for research agendas concerning other disabling conditions. It has been proposed that the Model

Spinal Cord Injury System centers conduct research related to the following general areas:

- Neuroscience and nerve regeneration
- Pharmacological interventions, including randomized controlled clinical trials
- Biotechnology interface projects
- Preventive health and wellness
- Subjective well-being and consumer satisfaction
- Bioethics
- Health care models
- Bioinformatics, collaborative patient, and research databases

This proposed new research agenda will take advantage of the dramatic advances in science recorded in the twentieth and twenty-first centuries and apply this new knowledge to the enhancement of the quality of life of people with disabilities. Disability should not be defined by medicine; instead, the medical profession should be considered an important partner capable of making a significant contribution to the understanding and transformation of disability.

—*Walter R. Frontera*

See also Health; Health Care and Disability; Models; Professions.

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MEDITATION

See Mindfulness Meditation

MELANCHOLY

The word *melancholy,* which refers to a state of low spirits, sadness, and anxiety, comes from the Greek terms *melas* (black) and *chole* (bile). The historical meaning of the concept of melancholy has been superseded by modern terms such as *depression;* whereas *melancholy* is now used to refer to a state of lingering sadness, from antiquity to the development of prepsychiatric medicine the term was used to describe a medical condition.

In antiquity, the word *melancholy* referred to a medical disturbance of the mind and the soul that was contrasted with other states of madness, such as *mania,* a chronic mental disorder without fever, and *phrenitis,* an inflammation of the brain with fever. The specificity of melancholy was believed to be related to its cause in the body: black bile. Like the three other bodily humors—blood, yellow bile, and phlegm—black bile was understood to affect the body as well as the soul; in excess, it was seen as the cause not only of melancholy but also of cancer, elephantiasis, and hemorrhoids.

The Hippocratic corpus mentions black bile, but melancholy is not prominent. One of the *Aphorisms* (6.23) states that "if sadness and fear last for a long time, the state is melancholic." A treatise from the Aristotelian tradition, *Problem XXX,* which connects the melancholic state to exceptional men, was very influential. In the treatise *On Black Bile,* Galen focuses on the physiological aspects of this humor. The twofold nature of black bile—that it is both necessary to life and yet in excess so potent that it is able cause anthrax, elephantiasis, and melancholy—is clear in this text. The cure for melancholy aims at reducing black bile through purgation with white hellebore. Other authors show more doubts about the possibility of a cure. Aretaeus of Cappadocia (1856) gives a vivid account of persons suffering from melancholy:

> And they also become peevish, dispirited, sleepless, and start up from a disturbed sleep. Unreasonable fear also seizes them, if the disease tend to increase, when their dreams are true, terrifying, and clear: for whatever, when awake, they have an aversion to, as being an evil, rushes upon their visions in sleep. They are prone to change their mind readily; to become base, mean-spirited, illiberal, and in a little time, perhaps, simple, extravagant, munificent, not from any virtue of the soul, but from the changeableness of the disease. But if the illness become more urgent, hatred, avoidance of the haunts of men, vain lamentations; they complain of life, and desire to die. (pp. 299–300)

On the physical side, the skin of melancholics was said to become green-black, and they were said to have great appetites while remaining emaciated.

During the Middle Ages, the whole theory of the bodily humors was systematized, and the melancholic emerged as one of the four temperaments—that is, a type of person with characteristics, both physical and mental, determined by the melancholic humor. Robert Burton's *Anatomy of Melancholy,* first published in 1621, is emblematic for the Renaissance: The author organizes the classical sources about melancholy around scrutiny of himself. Although alternative ideas concerning the treatment of melancholy were put forward, the ancient theories were influential well into the nineteenth century.

—Anne-France Morand

See also Humors, Theory of.

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MENTAL HEALTH

The concept of mental health has changed radically in the past decade. Mental health disabilities are no longer perceived as chronic, disabling conditions; rather, they are seen as limitations in the quality of life of affected individuals. In some nations, public policy legislation—such as the Americans with Disabilities Act (ADA) of 1990—has favored this reconceptualization of mental disability.

Despite these new perspectives in the understanding of mental disabilities, some dilemmas still are observed in this matter. In some countries and sectors of society, a disparity still exists between the perception and approaches to the management of chronic illnesses. In this regard, some chronic medical illnesses, such as diabetes and epilepsy, are treated intensively and acutely at every relapse; in contrast, this approach is not always afforded to certain chronic psychiatric disorders, such as schizophrenia. This type of discriminatory practice is also observed among countries, including the United States, where no parity exists between medical/surgical illnesses and psychiatric illnesses with respect to medical insurance coverage.

This dilemma, of course, is related to stigma, fear, and ignorance. It may not be the patient but society at large that discriminates, fears unknown illness, and feels guilty of conditions that still are not well-known. This is what has also happened in the past vis-à-vis epilepsy, leprosy, plague, and other similar conditions. Incidentally, this situation is similar to the one observed when people from different races, ethnicities, and cultures interface with people from the majority culture. In general, persons tend to be afraid of those who differ from them in religion, economic ideology, skin color, language, or culture. This type of phenomenon leads to fears, persecution, discrimination, racism, oppression, and even wars in some instances.

During the past two decades, major research advances have taken place in the field of psychiatry and behavioral sciences, particularly with respect to neurosciences and the management of mental illness. As the public begins to conceptualize many major mental illnesses as "brain diseases" instead of as the results of parenting problems or weak character, stigma is reduced. As new discoveries take place, new and promising perspectives also evolve, thus leading to progress in the way that society perceives psychiatric disorders at a worldwide level.

Mental illness ranks first in causing disabilities among many industrialized nations, including Western European countries, Canada, and the United States. In this respect, mental illnesses currently cause more disability than cancer and heart disease combined. Schizophrenia, bipolar disorders, and depression now account for 25 percent of all medical disabilities across major industrialized nations. This situation has major implications, not only from the point of view of pain and human suffering but from an economic viewpoint as well. For instance, in 1999, the economic cost due to loss of productivity as a result of mental illnesses in the United States was $63 billion. In the United States, 5 to 7 percent of adults currently suffer from serious mental disorders, and 5 to 9 percent of children suffer from serious emotional disturbances that severely disrupt their social, academic, and emotional functioning.

This situation is currently producing major public policy dilemmas in many industrialized countries. In the United States, for instance, one in every two persons in need of psychiatric treatment does not receive it, especially in inner-city and rural areas. This happens for several reasons; quality of care may be inadequate, diagnoses may sometimes be inaccurate, medication dosages may be insufficient, or the length of treatment may be too short. This circumstance is even worse with respect to ethnic and racial minority group members in the U.S. population. Stigma is definitely still a barrier to psychiatric care as well as to quality of care. Unquestionably, societal stigma and shame concerning mental illnesses lead to ostracism and discrimination vis-à-vis mental patients. Patients sometimes internalize this situation and thus develop low self-esteem and hopelessness; suicide may even result.

Despite these serious public policy dilemmas, the past decade has also seen major psychosocial research advances to complement the biological research, leading to new approaches in rehabilitation of the mentally ill, particularly the chronic mentally ill, and to major advances in the conceptualization and understanding of current mental health disability management. These new principles in psychiatric rehabilitation have shed new light on methods of intervention and have led to new perspectives with respect to early intervention and treatment of mental health disabilities.

A rehabilitation approach has recently been developed in which the patient becomes the center focus of the rehabilitation process. In this context, all key domains of the person's life—that is, the physical, emotional, intellectual, social, and spiritual needs of the person—are addressed from a rehabilitation point of view. In a well-integrated manner, all these personal dimensions are attended to from a rehabilitation viewpoint, with priority given to the rehabilitative expectations of the patient suffering from a given psychiatric illness or condition. This rehabilitative approach is geared toward involving the patient actively in the entire rehabilitation process. Active involvement also includes full patient empowerment—that is, the patient is provided with full information about the nature of the illness, its symptoms, its course, and potential sequelae.

In this context, hope becomes an inherent and essential aspect of the rehabilitation philosophy. Thus, the approach to the rehabilitation process becomes a core element with respect to the positive expectations of the patient and the outcome of his or her illness management. The whole rehabilitation process currently focuses on maximizing the patient's strengths, especially from a competence and skills point of view. Therefore, skill development, enhancement, and training are central to this new ideology.

The patient's environment extends itself to accommodate the factors that play a role in the mental health disability; thus, "limitations" substitute for "handicaps." Full focus is given to the patient's environment as a potential resource element. Possible resources include people such as the patient's family members and other persons in the environment, programs, services, and infrastructures that can play a positive role in the patient's rehabilitation process. In this regard, employers, coworkers, friends, religious institutions (e.g., churches and synagogues), landlords, and community centers all become potential resources on behalf of the patient's rehabilitative outcome.

Currently, vocational assessment of the patient is seen not as a way of coping with the mental health disability but as a way of maximizing the patient's opportunities in life; limitations in the patient's quality of life supersede acceptance of handicaps caused by the psychiatric illness or condition. Incentives for full rehabilitation opportunities aimed at helping the patient return to full- or part-time employment becomes the goal rather than the occasional expectation. The patient is offered full opportunities for maximum achievement and enhancement of his or her quality of life.

During the past decade, two new concepts have enlightened the rehabilitation process and the conceptualization of mental health disability: the concepts of *patient satisfaction* and *quality of life.* Although patient satisfaction has been addressed previously on many occasions, only recently has it come to be considered a quality indicator in the assessment of treatment outcomes. Likewise, quality of life is currently accepted as the major component in treatment outcomes. In this context, a successful and appropriate rehabilitation process has become an integral part of illness management.

The treatment of chronic psychiatric conditions depends less on the management of symptoms than it does on the intensive management of acute phases. Likewise, relapse is now perceived more as an expression of an acute phase of the illness than as a manifestation of a long-term disabling condition.

Research and educational efforts have resulted in numerous clinical advances in recent years, but further progress is still needed in this regard. Additionally, it is urgent that society face the current public policy dilemmas affecting mentally ill patients. Certainly, isolated state hospital facilities were not the appropriate answer to the need to provide humane care for the mentally ill, but neither are the streets of urban metropolises or the prison system.

—*Pedro Ruiz*

See also Mental Health: Law and Policy; Mental Illness.

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MENTAL HEALTH: LAW AND POLICY

Historically, severe mental illness has been merged with global incapacity. From at least the time of classical Greece and Rome to the European Middle Ages, families were expected to control, house, and provide for those afflicted with severe mental illness or intellectual limitation, and the freedom of these individuals was subject to whatever limitations were set by their families. By the fifteenth century, however, in Western

Europe the "insane" were increasingly confined to specialized institutions, a movement that grew substantially until the mid-twentieth century. Individuals with severe mental illness might be incarcerated in such facilities indefinitely, but they were not necessarily stripped of their titles or property. However, it was generally held that during the period of "insanity"—which might be lifelong—they could not exercise many of the rights of ordinary citizens, and (if they owned substantial property) guardians were appointed to act in their stead. (One interesting distinction was made in thirteenth-century England, where the property of those born severely mentally retarded—"congenital fools"—instead reverted to the king.)

Thus, those identified as severely mentally ill were considered unable—simply by virtue of being ill—to enter into business contracts, execute wills, or otherwise control their property. The laws of the Roman Catholic Church also dealt with issues such as the effect of "insanity" on the validity of matrimonial consent and whether an "insane" person could receive church sacraments.

Perhaps because of the lack of effective treatment and the chronic nature of many severe psychiatric disorders, questions of why and under what circumstances property and civil rights should be given up by the severely mentally ill were not seriously addressed until the mid-twentieth century. Prior to that time, there was little legal oversight of the treatment of those hospitalized for severe mental illness, and virtually all such patients were hospitalized at large, state-run institutions. Beginning in the latter half of the 1950s and early 1960s, coincident with the "deinstitutionalization" of psychiatric patients and in the context of large-scale social changes that led to marked liberalization of civil rights for many groups, those identified as severely mentally ill were nonetheless recognized as having the legal ability to exercise all the civil rights (e.g., the right to vote, the right to not be subject to treatment without informed consent, the right to refuse certain treatments) accorded other citizens in the United States and several other countries. Thus, a conceptual and legal shift occurred, from status as psychiatric patient being sufficient to establish absence of legal *competence* to a more nuanced view that focused evaluation is needed to determine if and to what degree mental illness might affect an individual's specific clinical *capacity* to exercise his or her rights. Only disability severe enough to compromise such capacity could negate a person's exercise of such rights.

GUARDIANSHIP

The roots of guardianship of the estate of an incapacitated individual can be traced to classical times, as noted above. Over time, the concept of guardianship has evolved dramatically, so that in some cases guardianship of the person (for example, the power to make health care decisions) is distinguished from guardianship of property (sometimes also called *conservatorship*). Guardianship may also be general (plenary), or it may be restricted to certain classes of decisions, with the ward retaining decision-making power for others. The issue of incompetence and hence need of a substitute decision maker can be based on legal definition *(de jure),* for example, if the individual is a minor, regardless of cognitive status; in other cases, proceedings can be based on the finding of actual *(de facto)* incompetence. A ward's status of incompetence can be reversed either through a change of legal status (e.g., reaching the age of majority) or through the ward's prevailing in a "restoration" hearing.

There is still significant variability among jurisdictions in the basis for appointment of a guardian, but a shift appears to be taking place from simply equating mental illness to need for guardianship to focused evaluation of the functions the individual can (or cannot) perform, with the determination based on the degree and kind of deficits identified.

CIVIL COMMITMENT

The shift described above has played out in a number of areas of mental health law. The justification for civil commitment has in large part moved away from a *parens patriae* model, in which the sovereign, or the state, is responsible for the well-being of citizens, much as the father is responsible for his family (note the gender bias), and thus is empowered to force treatment on those judged to be in need of it. This has been supplanted in large degree by a "police power" model, in which evidence of an individual's danger to self (by self-injury or inability to provide basic necessities of life) or to others (by violent behavior) is required for involuntary hospitalization. In other words, an earlier model based on social norms of which behaviors were acceptable and which merited confinement and coerced treatment has been superseded by a model in which individual liberty, within very broad bounds, can be abridged only when evidence exists of clear and significant risk of social disruption, such as threat to the physical safety of a citizen. Less severe behavioral problems, even when accompanied by suffering and risk of lesser degrees of harm (such as financial irresponsibility or disruption of the family situation), are insufficient to justify involuntary hospitalization. Indeed, physical freedom is considered so fundamental that in *Addington v. Texas* (1979), the U.S. Supreme Court held that "civil commitment for any purpose constitutes a significant deprivation of liberty" and, hence, due process protections must be in place to ensure that "the individual suffers from something more serious than is demonstrated by idiosyncratic behavior" before his or her freedom can be abridged. Under such circumstances, because the individual disproportionately bears the cost of an erroneous determination, the state must prove the need for civil commitment at least to a standard of "clear and convincing evidence."

Often associated with this deference to physical liberty is the concept of "least restrictive alternative." First explicated in the case of *Lake v. Cameron* (1966), this principle dictates that an individual's physical freedom should be restricted as little as possible consistent with physical safety and that practitioners consider the full range of services available (such as outpatient treatment, partial hospital programs, nursing homes) before mandating inpatient treatment, with precedence granted to the setting that interferes least with physical freedom consistent with safety.

TREATMENT RIGHTS

Personal autonomy is considered a higher social good than health. Disagreeing with medical advice is not necessarily evidence of impaired judgment, and in general, the patient is free to decline treatment even when the treatment is necessary to prevent serious harm or death. Conversely, it is generally incumbent on the treatment provider to obtain permission from the patient (or the patient's substitute decision maker). For permission to be valid, the patient must be able to render *informed consent.* This concept has three components: competence, sufficient information on which to base a reasoned choice, and freedom from coercion.

Competence can be a purely legal distinction (see above); in such a case, the consent is obtained from the patient's parent or guardian. Competence can also be questioned based on, for example, the presence of mental illness. Again, however, mere presence of a mental disorder is insufficient to undermine the individual's autonomy. Under such circumstances, the legal system may either make treatment decisions or determine who should act in the patient's stead.

Specific tests differ among jurisdictions, but in general to demonstrate incompetence one must show that the individual's reason for refusal of treatment is irrational. If that is so, for most health care decisions a substitute decision maker (often but not necessarily the patient's spouse, parent, or other family member) may be employed. In some cases, the individual may have previously executed a document spelling out what treatments he or she would wish (or refuse) in the event that he or she becomes severely ill. Although such contracts may not in the end determine treatment, they may be used as part of the fact base to determine the individual's wishes.

Involuntary treatment with psychotropic medication is often (by statute) handled differently from other interventions. In that case, the court (or other fact finder) might use information such as the patient's prior experience with the medication, the patient's perceptions of its purpose and effects currently, and the preferences regarding treatment previously expressed by the patient. If the patient's refusal of treatment is considered not to be competent, generally it must be further demonstrated that the proposed treatment's benefits outweigh its risks and that the underlying condition is sufficiently grave as to merit treatment over the patient's objections.

One seeming peculiarity in regulation of involuntary psychiatric treatment is that many jurisdictions now separate issues of involuntary *hospitalization* from issues of involuntary *treatment.* The presence of a disorder, even one sufficient to cause an individual to behave dangerously, does not inherently establish that the person's ability to make treatment choices is severely impaired, although this is in fact often the case. Commitment generally requires the presence of a mental illness plus some evidence of dangerous behavior, whereas involuntary treatment requires, in essence, the individual's lack of ability to make reasoned treatment choices—two separate concepts that may require two separate judicial determinations.

It is interesting to note that there has been judicial reluctance to identify a corresponding "right to treatment," even for those involuntarily hospitalized (*O'Connor v. Donaldson* 1975). Indeed, U.S. courts have paid great deference to professional judgment, requiring only that the patient be provided safe conditions, freedom from bodily restraint, and "training or 'habilitation'" (*Youngberg v. Romeo* 1982).

OTHER COMPETENCIES

Mental illness may potentially—but not necessarily—undermine a person's ability to exercise specific abilities, such as to validly enter into a contract, marry, write a will, or testify in court. The issue becomes whether mental illness has negated some element specific to a given function. For example, to execute a will competently, one must understand that one is making a will, understand the nature and extent of one's property, and have knowledge and understanding of one's heirs ("the objects of their bounty"). Great weight is placed on the will, and generally a rather strict ("clear and convincing") proof is required to invalidate it. A rather similar analysis generally informs the judgment of competence to contract; that is, the contractor must be sufficiently aware of the contract's elements and be able to make rational decisions based on them.

CRIMINAL LAW

Analogous to civil law, within the criminal law a number of kinds of competencies are noted specifically: competence to waive certain protections (e.g., one's rights under *Miranda v. Arizona* 1965) or appeals, to enter a plea, to confess, to testify as a witness, to represent oneself, and so forth. As with civil competencies, it is necessary to evaluate specifically the impact that mental illness might have on the legal tests, which may differ substantially from jurisdiction to jurisdiction. Most fundamental is the issue of competence to stand trial. The defendant's mental status *at the time of trial* must be such that the individual has "sufficient present ability to consult with his attorney with a reasonable degree of rational understanding and a rational as well as factual understanding of proceedings against him" (*Dusky v. United States* 1960).

In practice, therefore, competence to stand trial has several components, and a number of instruments have been devised to aid clinicians in assessing them. One major domain consists of knowledge of the relevant legal facts and procedures, such as the roles of courtroom personnel; awareness of legal protections, such as right to counsel and protection against self-incrimination; the charges and their potential penalties; and potential legal strategies, such as an insanity defense or plea bargaining.

A second component is the ability of the defendant to participate meaningfully in planning legal strategy. This includes such functions as the ability to weigh alternative defenses and potential outcomes rationally, the ability to collaborate with counsel regarding trial strategy, and the ability to challenge adverse witnesses realistically. Although the defendant's ability to provide counsel with a coherent accounting of the defendant's version of events is desirable, the courts have held that amnesia for events does not equate with lack of fitness to stand trial.

The last component of fitness or competence to stand trial is the degree to which the defendant is willing and able to mount a strong defense, unimpaired by the presence of mental illness that might, for example, make him or her plead guilty to a crime out of delusional guilt. Although a high standard of proof "beyond a reasonable doubt" is necessary for conviction of a crime, a lesser standard, "preponderance of evidence," is sufficient to establish competence to stand trial. A similar standard is generally used to determine other competencies relevant to criminal law, as noted above.

MENTAL HEALTH LAW, DISABILITY, AND DISCRIMINATION

The current relationship between mental illness and the definition of disability will not be discussed here;

suffice it to say that it is a complex relationship that may vary considerably depending on the legal context in which the issue is raised.

Arguably, to date the most sweeping legislation related to the rights of the disabled in the United States is the Americans with Disabilities Act (ADA) of 1990. Many mental illnesses may be considered as disabilities under the act, primarily excepting disorders of impulse control, current substance use disorders, and certain sexual disorders (paraphilias), as well as homosexuality (which is not a mental disorder). To qualify as a disability, the disorder must substantially limit one or more of the individual's major life activities. Of note, the act states that the disability so defined need not be current, as long as the individual has "a record of such impairment; or . . . [is] regarded as having such an impairment."

Title I of the ADA deals with issues of employment, Title II with public services, Title III with public accommodations and services by private entities, and Title IV with access to telecommunications. Under Title I, the ADA specifies that a disabled individual (as defined above) who, "with or without reasonable accommodation, can perform the essential functions of the employment position" comes under the ADA's protection.

Building on Title II, in the 1999 case *Olmstead v. L.C.,* the U.S. Supreme Court held that "states are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated." In that decision, the Court held that "unjustified placement or retention of persons in institutions . . . constitutes a form of discrimination" that the ADA prohibits and philosophically appears to have been influenced by the "least restrictive alternative" concept explicated in *Lake v. Cameron.* However, the Court deferred to the states the decision as to what community resources might be appropriate, addressing only the issue of equitable provision of existing services rather than what services ought to be available.

—*Stephen H. Dinwiddie*

See also Americans with Disabilities Act of 1990 (United States).

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MENTAL HEALTH PARITY

The term *mental health parity* refers to the effort to treat mental health financing on the same basis as financing for general health services. Under the concept of mental health parity, health insurance and health plan coverage for treatment of mental illness would be equal with coverage of treatment for all other illnesses, using the same terms and conditions. Mental illness would be recognized as an issue equal in importance to physical illness.

Advocates for mental health parity, such as the National Alliance for the Mentally Ill (NAMI), believe that mental illnesses are real illnesses, that treatment works, and that there is no medical or economic justification for health plans to apply different terms and conditions to the coverage of treatment for mental illness than they do to coverage of treatment for physical illness.

President Bill Clinton signed the Mental Health Parity Act (P.L. 104-204) into law in 1996. With the leadership of Senators Pete Domenici (R-NM) and the late Paul Wellstone (D-MN), this law created a standard of parity for annual and lifetime dollar limits.

The law applies to employers that offer mental health benefits but does not mandate such coverage. Mental health advocates such as NAMI are concerned that the law allows health insurers to employ cost-shifting mechanisms, such as adjusting limits on mental illness inpatient days and outpatient visits, limiting prescription drugs, raising patient copayments and deductibles, and modifying the definition of *medical necessity.*

The U.S. General Accounting Office (GAO 2000) has found that lower limits for inpatient and outpatient mental illness treatments have continued in spite of the law, and, in some cases, insurers have actually expanded such measures to help keep costs down. The law does, however, apply to fully insured state-regulated health plans and self-insured plans that are exempt from state laws under the Employee Retirement Income Security Act (ERISA), which are regulated by the U.S. Department of Labor. Existing state parity laws are not preempted by the federal law. That is, a state law requiring more comprehensive coverage is not weakened by the federal law, nor does the federal law preclude a state from enacting stronger parity legislation. The law includes a small-business exemption for firms with 50 or fewer employees and an increased cost exemption for employers that can demonstrate a rise in costs of one percent or more due to parity implementation. The GAO also found that 86 percent of surveyed health plans are complying with the law. Noncompliance may be the result of a lack of effort on the part of state insurance commissioners, the Centers for Medicare and Medicaid Policy, and the Pension and Welfare Benefits Administration to educate employers about the new law.

Evidence shows that the effects of mental health parity laws on costs are minimal. By introducing managed care or increasing its level, insurers can significantly limit or even reduce the costs of implementing mental health parity. In plans that have not previously used managed care, introducing parity simultaneously with managed care can result in an actual reduction in costs.

Given that recent studies have shown that parity laws do not increase costs significantly, and given that extensive limits on mental health benefits can create major financial burdens for patients and their families, mental health parity represents an important way in which society can advance the concept of comprehensive health care.

—Richard Huston Sewell

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MENTAL ILLNESS

Mental illness is a contentious concept. Some argue that it is a pathophysiological condition that resides in the individual, whereas others assert that it is a set of behaviors produced by and interpreted in the individual's physical, social, and cultural environment. The public health viewpoint integrates these two positions. For public health scholars and practitioners, mental illness is characterized by a set of conditions and behaviors that result from the interactions among the individual, society, and the environment.

From a medical perspective, mental and behavioral disorders are understood as clinically significant conditions characterized by alterations in thinking, mood (emotions), or behavior associated with personal distress and/or impaired functioning. Mental and behavioral disorders are viewed not just as variations within the range of "normal," but as clearly abnormal or pathological phenomena. However, a single occurrence of abnormal behavior or a short period of changes in mood does not, of itself, signify the presence of a mental or behavioral disorder. In order to be categorized as disorders, such abnormalities must be sustained over specific periods (for example, two weeks for a depressive episode) or be recurring, and they must result in some personal distress or impaired functioning in one or more areas of life.

Mental and behavioral disorders are also characterized by specific symptoms and signs, and they usually follow a more or less predictable natural course, unless interventions are made. Not all human distress is mental disorder. Individuals may be distressed because of personal or social circumstances, for instance; unless all the essential criteria for a particular disorder are satisfied, such distress is not classified as a mental disorder.

Diverse ways of thinking and behaving across cultures can influence the ways in which mental disorders manifest, but these ways of thinking and behaving are not, of themselves, indicative of disorders. Thus, culturally determined normal variations must not be labeled mental disorders. Nor should social, religious, or political beliefs be taken as evidence of mental disorder.

Two systems of classification of mental disorders are widely used for both clinical and research purposes. The World Health Organization's (1993) International Classification of Disorders (ICD-10) categorizes both physical and mental health disorders. The American Psychiatric Association's (2004) *Diagnostic and Statistical Manual of Mental Disorders* presents a classification system used only for mental disorders. Medical professionals use these two coordinated classification systems to categorize mental disorders, based on criteria sets with defining features, for diagnosis, treatment, research, and reimbursement purposes.

DIAGNOSING DISORDERS

Practitioners identify and diagnose mental and behavioral disorders using clinical methods that are similar to those used for physical disorders. These methods include the careful and detailed collection of historical information from the individual and others, including the individual's family; a systematic clinical examination for mental status; and the administration of specialized tests and investigations, as needed. Advances made in recent decades have helped to standardize clinical assessment and improve the reliability of diagnosis. Structured interview schedules, uniform definitions of symptoms and signs, and standard diagnostic criteria have made it possible for practitioners to achieve a high degree of reliability and validity in the diagnosis of mental disorders. Structured interview schedules and diagnostic symptom/sign checklists allow mental health professionals to collect information using standard questions and precoded responses. The symptoms and signs have been defined in detail to allow for uniform application. Finally, diagnostic criteria for disorders have been standardized internationally. Mental disorders can now be diagnosed as reliably and accurately as most of the common physical disorders.

PREVALENCE OF DISORDERS

Mental and behavioral disorders are found in people of all regions, all countries, and all societies. They are present in women and men at all stages of the life course. They are present among the rich and the poor, and among people living in both urban and rural areas. Recent analyses conducted by the World Health Organization (2001) found that neuropsychiatric conditions, which included a selection of these disorders, had an aggregate point prevalence of about 10 percent for adults. The WHO estimates that about 450 million people suffer from neuropsychiatric conditions, including unipolar depressive disorders, bipolar affective disorder, schizophrenia, epilepsy, alcohol and selected drug use disorders, Alzheimer's and other dementias, post-traumatic stress disorder, obsessive-compulsive disorder, panic disorder, and primary insomnia.

Prevalence rates for the disorders examined differ depending on whether the focus is on a point in time (point prevalence), a period of time (period prevalence), or the whole life of the individual (lifetime prevalence). Prevalence figures also vary based on the concepts and definitions of the disorders included in the study. When all the disorders included in the ICD-10 are considered, relatively high prevalence rates have been reported. Surveys conducted in developed as well as developing countries have shown that more than 25 percent of individuals develop one or more mental or behavioral disorders in their lifetimes.

Most studies have found the overall prevalence of mental disorders to be higher among women than among men. Much of this difference is accounted for by the differential distribution of disorders, however. Severe mental disorders are about equally common among men and women, with the exceptions of depression, which is more common among women, and substance use disorders, which are more common among men.

CATEGORIES OF MENTAL DISORDERS

The ICD-10 lists 10 major categories of mental disorders under Section F as follows:

F00–F09: Organic, including symptomatic, mental disorders

F10–F19: Mental and behavioral disorders due to psychoactive substance use

F20–F29: Schizophrenia, schizotypal and delusional disorders

F30–F39: Mood (affective) disorders

F40–F49: Neurotic, stress-related, and somatoform disorders

F50–F59: Behavioral syndromes associated with physiological disturbances and physical factors

F60–F69: Disorders of adult personality and behavior

F70–F79: Mental retardation

F80–F89: Disorders of psychological development

F90–F99: Behavioral and emotional disorders with onset usually occurring in childhood and adolescence

The ICD-10 provides clinical descriptions and diagnostic guidelines for all of these diagnostic categories. Some of the most important clinical categories are described below (these descriptions are based on those provided in World Health Organization 1993).

F00–F09: Organic, Including Symptomatic, Mental Disorders

This category comprises a range of mental disorders grouped together on the basis of their having in common a demonstrable etiology in cerebral disease, brain injury, or other insult leading to cerebral dysfunction. The dysfunction may be primary, as in diseases, injuries, and insults that affect the brain directly and effectively, or secondary, as in systematic diseases and disorders that attack the brain only as one of the multiple organs or systems of the body that are involved.

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded. The impairments of the cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behavior, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

F10–F19: Mental and Behavioral Disorders Due to Psychoactive Substance Use

This category contains a wide variety of disorders that differ in severity and clinical form but are all attributable to the use of one or more psychoactive substances, which may or may not have been medically prescribed. Identification of the psychoactive substance should be based on as many sources of information as possible. These include self-report data, analysis of blood and other body fluids, characteristic physical and psychological symptoms, clinical signs and behavior, and other evidence, such as a drug being in the patient's possession or reports from informed third parties. Many drug users take more than one type of psychoactive substance. The main diagnosis should be classified, whenever possible, according to the substance or class of substance that has caused or contributed most to the presenting clinical syndrome.

F20–F29: Schizophrenia, Schizotypal and Delusional Disorders

This category brings together schizophrenia (the most important member of the group), schizotypal disorder, persistent delusional disorders, and a larger group of acute transient psychotic disorders. Schizoaffective disorders are included here in spite of their controversial nature.

F20: Schizophrenia

The schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception, and by affects that are inappropriate or blunted. Clear consciousness and intellectual capacity are usually maintained, although certain cognitive deficits may evolve over the course of time. The most important pathological phenomena include thought echo, thought insertion or withdrawal, thought broadcasting, delusional perception and delusions control, influence or passivity, hallucinatory voices commenting on or discussing the patient in the third person, thought disorders, and negative symptoms.

F30–F39: Mood (Affective) Disorders

This category contains disorders in which the fundamental disturbance is a change in affect or mood to depression (with or without associated anxiety) or to elation. The mood change is usually accompanied by a change in overall level of activity; most of the other symptoms are either secondary to or easily understood in the context of the change in mood and activity. Most of these disorders tend to be recurrent, and the onset of individual symptoms can often be related to stressful events or situations.

F30: Manic Episode

The underlying characteristics of this disorder are elevated mood and an increase in the quantity and speed of physical and mental activity. Elation is accompanied by increased energy, resulting in overactivity, pressure of speech, and a decreased need for sleep. Normal social inhibitions are lost, attention cannot be sustained, and there is often marked distractibility. Self-esteem is inflated and grandiose, and overly optimistic ideas are freely expressed.

F32: Depressive Episode

The individual usually suffers from depressed mood, loss of interest and enjoyment, and reduced energy leading to increased fatigability and diminished activity. Marked tiredness after only slight effort is common. Other common symptoms are reduced concentration and attention, reduced self-esteem and self-confidence, ideas of guilt and unworthiness, black and pessimistic view of the future, ideas or acts of self-harm or suicide, disturbed sleep, and diminished appetite.

A depressive episode may also be diagnosed when a chronic depression of mood lasts at least several years but is not sufficiently severe, or does not include sufficiently prolonged individual episodes, to justify a diagnosis of severe, moderate, or mild recurrent depressive disorder.

F40–F49: Neurotic, Stress-Related, and Somatoform Disorders

When nervousness, anxiety, and depression are persistently or episodically combined with irrational fears, obsessive thoughts, fatigue, and a number of different somatic disturbances for which no cause can be found, the condition is called *neurosis*. Stress-related disorders are characterized by the development of anxiety, dissociation, and other symptoms that occur within one month after exposure to an extremely traumatic stressor, such as death of a parent or spouse, loss of a job, or diagnosis of a life-threatening illness. The common element in somatoform disorders is the presence of physical symptoms that suggest a medical problem when, in fact, these symptoms are not explained by a general medical condition, the direct effects of substance use, or another mental disorder. An example is hypochondriasis (the preoccupation with the fear of having a serious disease based on the misinterpretation of one's bodily symptoms or functions).

F42: Obsessive-Compulsive Disorder

The essential feature of obsessive-compulsive disorder is the recurrence of obsessional thoughts or compulsive acts. Obsessional thoughts are ideas, images, or impulses that enter the patient's mind again and again in a stereotyped form. They are almost invariably distressing, and the patient often tries, unsuccessfully, to resist them. The patient does, however, recognize them as his or her own thoughts, even though they are involuntary and often repugnant. Compulsive acts or rituals are stereotyped behaviors that are repeated again and again. They are not inherently enjoyable, nor do they result in the completion of inherently useful tasks. Usually the patient recognizes this behavior as pointless or ineffectual and makes repeated attempts to resist performing the behavior.

F43: Reaction to Severe Stress, and Adjustment Disorders

This category includes disorders identifiable not only on the basis of symptoms and course but also through the existence of one or the other of two causative influences: an exceptionally stressful life event producing an acute stress reaction or a significant change leading to continued unpleasant circumstances that result in an adjustment disorder. The stressful events or the continuing unpleasant circumstances are the primary and overriding causal factor; the disorder would not have occurred without their impact.

F43.0: Acute Stress Reaction

An acute stress reaction is a transient disorder that develops in an individual without any other apparent mental disorder in response to exceptional physical and mental stress and that usually subsides within hours or days. Individual vulnerability and coping capacity play roles in the occurrence and severity of acute stress reactions. The symptoms typically show a mixed and changing picture and include an initial state of "daze" with some constriction of the field of consciousness and narrowing of attention, inability to comprehend stimuli, and disorientation. Autonomic signs or panic anxiety (tachycardia, sweating, flushing) are commonly present. The symptoms usually appear within minutes of the impact of the stressful stimulus or event and disappear within two to three days (often within hours). Partial or complete amnesia for the episode may be present.

F43.1: Posttraumatic Stress Disorder

Posttraumatic stress disorder (PTSD) arises as a delayed or protracted response to a stressful event or situation (of either brief or long duration) of an exceptionally threatening or catastrophic nature that is likely to cause pervasive distress in almost anyone. Predisposing factors, such as particular personality traits or previous history of neurotic illness, may lower the threshold for the development of PTSD or aggravate its course. Typical features include episodes of repeated reliving of trauma in intrusive memories ("flashbacks"), dreams, or nightmares occurring against a persisting background of a sense of "numbness" and emotional blunting, detachment from other people, unresponsiveness to surroundings, anhedonia, and avoidance of activities and situations reminiscent of the trauma. There is usually a state of automatic hyperarousal with hypervigilance, an enhanced startle reaction, and insomnia. The onset follows the trauma with a latency period that may range from a few weeks to months. The course fluctuates, but recovery can be expected in the majority of cases. In a small proportion of cases the condition may follow a chronic course over many years, with eventual transition to an enduring personality change.

F48.0: Neurasthenia

Considerable cultural variations occur in the presentation of neurasthenia, and two main types occur, with substantial overlap. In one type, the main feature is a complaint of increased fatigue after mental effort, often associated with some decrease in occupational performance or coping efficiency in daily tasks. The mental fatigability is typically described as an unpleasant intrusion of distracting associations or recollections, difficulty in concentrating, and generally inefficient thinking. In the other type, the emphasis is on feelings of bodily and physical weakness and exhaustion after only minimal effort, accompanied by a feeling of muscular aches and pains and inability to relax. In both types, several other unpleasant physical feelings are common, including dizziness, tension headaches, and feelings of general instability. Worry about decreasing mental and bodily well-being, irritability, anhedonia, and varying minor degrees of both depression and anxiety are all common.

F50–F59: Behavioral Syndromes Associated with Physiological Disturbances and Physical Factors

This category encompasses behavioral problems that are related to physiological factors, such as sleep and sexual disorders. Sleep disorders include insomnia, substance-induced problems with sleep, sleepwalking, breathing-related sleep disorders, and circadian rhythm disorders. Sexual problems such as pain during intercourse, aversion to sexual activity, premature ejaculation, male erectile dysfunction, and lack of sexual desire are examples of disorders that often have physiological components.

F60–F69: Disorders of Adult Personality and Behavior

This category includes a variety of conditions and behavior patterns of clinical significance that tend to be persistent and appear to be expressions of the individual's characteristic lifestyle and mode of relating to him- or herself and others. Some of these conditions and patterns of behavior emerge early in the course of development as a result of both constitutional factors and social experience, whereas others are acquired later in life. Specific personality disorders, mixed personality disorders, and enduring personality changes are deeply ingrained and enduring behavior patterns that manifest as inflexible responses to a broad range of personal and social situations. They represent extreme or significant deviations from the way in which the average individual in a given culture perceives, thinks, feels, and (particularly) relates to others. Such behavior patterns tend to be stable and often encompass multiple domains of behavior and psychological functioning. They are frequently, but not always, associated with various degrees of subjective distress and problems of social performance.

F70–F79: Mental Retardation

Mental retardation is a condition of arrested or incomplete development of the mind that is especially characterized by impairment of skills manifested during the development period, skills that contribute to the overall level of intelligence (i.e., cognitive, language, motor, and social abilities). Retardation can occur with or without mental or physical condition. Degrees of mental retardation are conventionally estimated through the use of standardized intelligence tests. These can be supplemented by scales designed to assess social adaptation in given environments. These measures provide an approximate indication of the degree of mental retardation, but the diagnosis also depends on the overall assessment of intellectual functioning by a skilled diagnostician. Intellectual abilities and social adaptation may change over time, and even an individual with very poor abilities may improve as a result of training and rehabilitation. Diagnosis should be based on the individual's current level of functioning.

F80–F89: Disorders of Psychological Development

The disorders included in this category have three things in common: (a) onset invariably during infancy or childhood, (b) impairment or delay in development of functions that are strongly related to biological maturation of the central nervous system, and (c) a steady course without remissions and relapses. In most cases, the functions affected include language, visuospatial skills, and motor coordination. Usually the delay or impairment has been present from as early as it could be detected reliably and will diminish progressively as the child grows older, although milder deficits often remain in adult life.

F90–F99: Behavioral and Emotional Disorders with Onset Usually Occurring in Childhood and Adolescence

F90: Hyperkinetic Disorders

Hyperkinetic disorders are characterized by early onset (usually in the first years of life), lack of persistence in activities that require cognitive involvement, and a tendency to move from one activity to another without completing any one, together with disorganized, ill-regulated, and excessive activity. Hyperkinetic children are often reckless, impulsive, and prone to accidents, and they frequently find themselves in disciplinary trouble because of unthinking breaches of rules rather than deliberate defiance. Their relationships with adults are often socially disinhibited, with a lack of normal caution and reserve. They are unpopular with other children and may become isolated. Impairment of cognitive functions is common in such children, and specific delays in motor and language development are disproportionately frequent. Secondary complications include dissocial behavior and low self-esteem.

F91: Conduct Disorders

Conduct disorders are characterized by repetitive and persistent patterns of dissocial, aggressive, or defiant conduct. Such behavior amounts to major violations of age-appropriate social expectations; it is more severe than ordinary childish mischief or adolescent rebelliousness and is of an enduring nature (six months or longer). Features of conduct disorder can also be symptomatic of other psychiatric conditions, in which case the underlying diagnosis should be preferred.

THE CONTEXT OF MENTAL ILLNESS

The preceding discussion has summarized the psychiatric/medical approach to and classification of mental illness. In contrast to this approach, a growing literature in the social and behavioral sciences argues as follows:

> 1. *Mental illness* is a term that refers to a broad range of conditions and behaviours. For this reason, the concept of mental illness is too amorphous to be useful except as a way of speaking about the aggregate subject matter of psychiatry.
> 2. The attribution of madness to aberrant thoughts, feelings and behaviours is not inherent to the condition but is rather contingent on the social and cultural context within which these thoughts, feelings and behaviours occur.
> 3. The attribution of madness depends not only on the setting but also on the person's personal and demographic characteristics such as race, ethnicity, poverty, age and sexual identity which accentuate or ameliorate the process of stigmatization. (Aneshensel and Phelan 1999:5–6)

Based on these arguments, scholars are paying increased attention to the study of behaviors and "normality" within specific groups and social and cultural contexts. In sum, these arguments have led Horwitz (2002) to the following definitions:

> Mental diseases are conditions where symptoms indicate underlying dysfunctions, are distinct from other disease conditions, and have certain universal features. Mental disorders include all mental diseases as well as psychological dysfunctions whose overt symptoms are shaped by cultural as well as natural processes. Finally, mental illnesses refer to whatever conditions a particular group defines as such. In contrast to the concepts of "mental disease" and "mental disorder" which have valid and invalid applications, the concept of "mental illness" refers to the actual labelling process in any group and so cannot be true or false. (p. 15)

—R. Srinivasa Murthy

See also Behavioral Disorders; Bipolar Disorder; Depression; Madness and Mental Distress; Normality; Schizoaffective Disorders; Schizophrenia; Stigma.

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MENTAL RETARDATION, HISTORY OF

From ancient superstition to modern science, from old to modern empires, the history of intellectual disability is largely one of expanded possibilities rather than total change. Stigma, exclusion, invisibility, abandonment, impoverishment, even systematic extermination of intellectually disabled children and adults persist today as they have throughout history. At the same time, acceptance, visibility, inclusion, support, and self-advocacy have also become increasingly available to at least some of those same individuals. Simultaneously, one can find in the current circumstances of intellectually disabled people the echoes of the worst atrocities and best achievements that history has to offer.

Like most forms of disability, intellectual disability has gone under many names. At various times, and in various countries, people judged to have some type of difficulty with learning and abstract thought have been called fools, natural fools, idiots, cretins, aments, simpletons, imbeciles, and morons; they have been described also as fatuous, feebleminded, mentally defective, mentally retarded, learning disabled, and developmentally disabled. The question arises as to whether there is something stable, something physiologically persistent, behind those terms and the historical contexts within which their usage arose and declined. Regardless of how one answers that question, the need for a history of intellectual disability that recognizes the complexity of interaction between the name and the thing being named is clear.

The history of intellectual disability, then, should include the evolution of both the concept itself and the narrative of those to whom the concept has been applied. To use a term that is now avoided but was once the professional term of choice in the English-speaking world, the history of "idiocy" (i.e., the use of the term) is different from the history of idiocy. Until recently, however, the historiography of intellectual disability has emphasized the conceptual development and programmatic innovations over the daily lives of those with the disability. As one historian has put it, the "social marginality" of people with intellectual disabilities has, until recently, been carried over into an "academic marginality" where historians seemed to feel that people who could not learn were also not worth learning about (Digby 1996:1). In part, this simply reflects the evidence that is available. For the premodern eras, for example, we have much more evidence about the conceptual developments than about what life was like for intellectually disabled people and their families. In general, we know more about what philosophers and politicians of a given era and culture proposed for definitions and policies than we do about the quotidian reality of those covered by the definition and affected by the policies.

PREMODERN ERAS

What sparse evidence there is supports the notion that intellectually disabled people have been recognized as part of societies from the earliest times. In many cases, that recognition was harsh and violent. Early laws in ancient Greece and Rome, for example, established procedures for the killing or abandonment of infants judged to be too deformed or intellectually disabled to be valued as human. At the same time, however, scholars also point to evidence of early nomadic tribes who continued to transport members of their clans even when they had congenital physical and intellectual disabilities (Goodey 1995; Scheerenberger 1983). There is also evidence that in the Greek and Roman societies some of those with intellectual—and other—disabilities who survived into adulthood became servants or slaves in the households of the ruling classes, where they were relatively well cared for compared with the majority of the poor and oppressed (Rose 2003). The Roman philosopher Seneca complained, for example, about the blind and fatuous servant his wife kept at home even as the woman's impairments became more severe. Indeed, anthropological evidence from non-Western cultures suggests that the treatment of intellectually disabled people in preliterate societies was probably tremendously varied. As one of the anthropologists who first focused on the evidence has put it, "Nothing can be more certain than the conclusion that how the mentally retarded are seen and responded to in the non-Western world is a complex and variable matter" (Edgerton 1970:537).

Throughout the Middle Ages in Europe, this variety persisted. At the same time, as disabled beggars wandered from town to town, free but unsupported, church-related hospitals developed that provided both sanctuary and care to intellectually disabled individuals abandoned by their families. While infanticide continued to receive religious tolerance, if not sanction, the court jester tradition also placed great value on having natural fools always present and cared for, but without any real location within the social hierarchy—constant outsiders. One historian of the period notes that the custom of keeping a natural fool was so popular in Germany that by the early sixteenth century, "one finds them in the household of almost any rich and powerful family" (Midelfort 1999:248). For the most part, both intellectual and physical disability were seen in the Middle Ages as part of the "hodgepodge of normality" that made up everyday society. "There was an acceptance, at times awkward, at times brutal, at times compassionate, a kind of indifferent, fatalistic integration, without ideology but also without confrontation" (Stiker 1999:65).

By the thirteenth and fourteenth centuries, legal distinctions began to appear between lunacy and idiocy. The idiot (or "natural fool") was someone incapable of abstract thought from birth, whereas the lunatic became deranged sometime after birth. Still, even with these new distinctions, the conceptual evolution of terms and explanations for intellectual disability are much less varied than was the actual treatment of people with that impairment. Consistently, from Plato to Locke, the effort was to label and exclude those who were visibly and congenitally different. Whether seen as a joke or punishment of the gods or a materialistic imbalance of the bodily humors, the birth of a child with noticeable disabilities gave permission—even responsibility—to dispose of that which was something other than fully human. However, early on, the focus was on visible difference. The changeling, for example, was the visibly disabled child of nondisabled parents. The terms of reference were many and confusing.

It is with the empiricism of John Locke, however, that the understanding of idiocy moved from a primarily visible difference associated with congenital anomalies to include those who looked "normal" but lacked the capacity for abstract or "natural" reason. The expansion was important and laid the conceptual groundwork for the subsequent emergence of a new social response based in diagnostic expertise and therapeutic efficacy. If idiocy was not always apparent or visibly monstrous, then identification through testing and intervention through training became vital for both the protection of society and the remediation of the individual.

THE MODERN ERA

As it did with other areas of human endeavor, the Enlightenment brought a wave of scientific interventionism and governmental reform to the social awareness of intellectual disability. The emerging field of psychology built on the newly empirical approaches to the mental as well as the physical to make optimistic claims of precise identification and gradual improvement. Classification typologies became increasingly elaborate, with growing emphasis on close clinical observation and physiological examination. The official social response gradually moved on the one hand from the custodial to the therapeutic and on the other hand from tolerant neglect to aggressive confinement.

Perhaps the most famous and influential "experiment" in the development of this new psychological training occurred in France at the very beginning of the nineteenth century. When a strange, uncivilized boy was captured in southern France (the so-called Wild Boy of Aveyron), a young doctor, Jean Marc Gaspard Itard, undertook to teach this "noble savage" using the careful training of the senses consistent with the radical empiricism of Condillac and other French philosophers. Although Itard ultimately regarded his experiment as a failure, because of the lack of sufficient progress by the boy he named Victor, others took over his methods and achievements to proclaim a new therapeutic regime that gave hope for the remediation or cure of at least some types of idiocy. Throughout the remainder of the nineteenth century, there was a rapid spread of specialized idiot asylums in both Europe and North America led by a new professional class of institutional psychologists who made claims of cure or dramatic improvement through early and intensive instruction and regimentation. People such as Samuel Howe and Edouard Séguin in the United States, Johann Guggenbühl in Switzerland, Carl Saegert in Germany, and William Ireland and John Langdon Down in England began congregate residential facilities for the education and training of intellectually disabled children and young adults.

By the last quarter of the nineteenth century, this wave of optimism had subsided but the institutions continued to expand. Even with this rise of institutions, most individuals with intellectual disabilities remained the responsibility of their families or the communities where they lived. Outside the walls of the new institutions, intellectual disability remained primarily an economic problem of poverty and dependence. With the progress of industrial urbanization and the need for a stable workforce, unemployable intellectually disabled people were also portrayed as a social problem: the source of the crime and degeneracy that was seen as a growing threat to the commonweal.

THE TWENTIETH CENTURY

For much of the twentieth century, emphasis remained on classification and control of the intellectually disabled rather than on education and support. Early in the century, the intelligence test developed by Alfred Binet for the Paris schools was rapidly put to use in the United States in schools and other institutions. Here finally was an operational application of Locke's definition. What came to be called IQ (or intelligence quotient) tests were efficient, supposedly objective instruments that could identify those children who were intellectually inferior even when their physical appearance was "normal" and their intellectual inferiority mild. So precise were these new tests that a new level of mild feeblemindedness could now be identified. The psychologist Henry H. Goddard coined the term *moron* to refer to these individuals, who were said to have a mental age between 7 and 12 years. *Feeblemindedness* became the generic term in the United States for all types and levels of intellectual disability.

The rapid adoption of the IQ test not only made the placement of students into the newly emerging special education classes efficient and "scientific," it also supplied more than enough evidence for eugenicists to bemoan the growing "burden of the feebleminded" as a plague on modern civilization in both moral and economic terms. The new field of psychometrics combined with the new obsession with the scientific study of heredity to produce the pseudoscience of eugenics, whose purpose was to limit the spread of feeblemindedness through incarceration in custodial institutions and involuntary sterilization. It was a practice that reached its logical extreme with the perversions of Nazi medicine, but it was pursued to greater or lesser degrees by almost all industrialized nations and continued well into the 1960s and 1970s in many countries.

Post–World War II Developments

Throughout the 1950s and the 1960s, the familiar strands of segregation and exclusion of intellectually disabled people continued to interweave with strands of community presence and family support. By the 1960s, several parent advocacy organizations had coalesced to form a national presence in both Europe and North America, lobbying for expanded educational programs and family support. By 1970, the institutional growth in the United States had crested at just under 200,000 individuals. Buttressed by journalistic exposés and lawsuits documenting patterns of institutional abuse and neglect, a slow trend called *deinstitutionalization* began to move intellectually disabled people from institutions to the community. Individuals with intellectual disabilities themselves began to organize self-advocacy groups protesting discrimination and exclusion. Programs to support the integration of intellectually disabled children and adults in home, school, workplace, and community became the official policy in most countries in Western Europe and North America. Still, by the end of the twentieth century, thousands of individuals were still living in large, segregated facilities. In the latest terminological change, *intellectual disability* has begun to replace *mental retardation* (in the United States) and *learning disability* (in Great Britain) as the term of choice.

—Philip M. Ferguson

See also Alfred Binet; Down Syndrome; Henry Herbert Goddard; Johan Jacob Guggenbühl; IQ; Edouard Onesimus Séguin.

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MERCY KILLING

See Euthanasia

MICHAEL IV, EMPEROR (?–1041)

Byzantine ruler

The Byzantine Emperor Michael IV (reign 1034–1041 CE) suffered increasingly severe epileptic fits during his reign, and his attendants made efforts to hide his condition from the public. During public audiences and other ceremonies, they watched closely for signs of an impending fit and immediately let down curtains to hide him when they saw such signs. When out walking or riding, he was surrounded by guards who usually managed to conceal him if he became ill. The contemporary courtier and chronicler Michael Psellus, who described Michael IV's reign impartially and in detail, noted that the emperor recovered quickly after his fits. Michael IV came to power in very dubious circumstances and without any significant preparation, yet Psellus considered that he conducted himself well as emperor. Even with his condition steadily worsening, "he still supervised the whole administration of the Empire, just as if no illness were weighing upon him at all" (Psellus 1966).

—*Kumur B. Selim*

See also Epilepsy.

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MIDDLE EAST AND THE RISE OF ISLAM

HISTORY OF ARAB/ PROPHETIC MEDICINE

After the prophet Muhammad's death in 632 CE, a great expansion of the Arab Empire took place throughout the eastern Mediterranean. Under the Umayyad caliphate, local political structures remained intact, but by the Abbasid caliphate, the capital of the Arab Empire's administration became centralized in Baghdad (762 CE).

What is known about medicine and disability before Islam and during its expansion is difficult to summarize, as medical approaches were not monolithic but varied and often contradictory. There is a general consensus, however, that healing the sick was, and continues to be, considered in all legal schools of Islam, one of the highest forms of serving Allah (God), second only in importance to performing religious rituals. Despite medicine's high place in Arab-Islamic culture, the Qur'an itself seldom speaks directly of medicine except for references to the curative properties of honey, instructions for ways to wash for prayer when ill, and statements that the sick, lame, or blind are not inherently at fault for their disability. Muslims consider the text to embody the guidance and wisdom that restores and maintains both physical and psychological health. The Qur'an does not espouse a mind-body doctrine of the body, but it does use metaphors of disability such as deafness and blindness in references to God's decision to make some individuals struggle to reach the truth. Mostly, attitudes about and treatment of disease and disability in Islam are embedded within the historical development of Muslim political expansion and rule rather than derived from the sacred text. Following from this, the force and contributions of Islamic medicine during the medieval period were felt by both Muslim and non-Muslim residents of the Arab Empire.

The early ninth century marked the Hellenization of Islam, with translations of Greek, Syriac, Sanskrit, and Pahlavi medical texts into Arabic and subsequent commentaries and expositions by Arabic and Persian physicians. By the end of the ninth century, nearly all of Galen's writings had been translated into Arabic, reflecting the significant influence of his medicine in Arab scientific circles. As such, the Arab-Islamic medical tradition is based on the Graeco-Roman one, with humoral theory at its core.

Several physicians who wrote original treatises and compendiums on medical topics are worth mentioning due to their handling of disability and its treatment.

Al-Razi (Rhazes), a well-known Persian clinician who lived from 865 to 925 CE, wrote *Al-Hawi fi l-tibb (All-Inclusive Work on Medicine),* a 24-volume encyclopedia of medicine. Among other things, this work deals with hereditary diseases, diseases affecting women, and eye diseases. Ibn Sina (Avicenna) wrote *Qanun al-Tibb (Canon of Medicine),* a 14-volume work that investigated the contagious nature of pulmonary tuberculosis, described the symptoms and complications of diabetes mellitus, and examined various psychological illnesses. The *Canon* became the most authoritative reference book in European universities until the seventeenth century. Finally, Abu al-Qasim al-Zahrawi (Albucasis) lived in Cordoba, Spain, during the tenth century. Regarded as an expert pharmacist-surgeon, he wrote a manual on surgery called *Al-Tasrif li-man `ajaza `an al-ta´lif (Recourse of He Who Cannot Compose a Medical Work of His Own)* that included sections detailing methods for amputating limbs and removing foreign bodies. These books were later translated into Latin for widespread use in Europe.

As opposed to the formalized form of Islamic medicine, *Tibb al-nabi* (prophetic medicine) consists of popularized answers to medical issues drawn from the sayings of the prophet Muhammad and his companions in the Hadith. A popular statement of Muhammad's that is stressed in this type of medicine is, "God has sent down a treatment for every ailment." Other statements refer to the restoration of health by God's will. For instance, the question was raised in this literature as to whether or not God would, on Judgment Day, conclude that a person with an amputation tried to escape His will. Although natural causes of illness are recognized, God is said to inflict illness so as to test the individual's strength and ultimately restore his or her faithful character. As such, according to some sayings in prophetic medicine, illness has a redemptive quality to it. Other sayings, however, cite health as the means to strengthen faith and as a reflection of the blessing of God.

In prophetic medicine, prayer rituals and the physical positions they entail are said to provide physical, moral, spiritual, and psychological healing by distracting the individual from pain. They also are believed to exercise the body and ease ailments of the stomach, heart, and intestines. Such integrity of the body is central to prophetic medicine's message. Differences in medical approaches, however, sometimes exist within and between the Hadith of the two major sects of Islam, the Sunni and Shia. Despite their goal of imparting a religious value to medical practices, medical discussions of the Hadith are not considered part of sacred law. This collected medical advice, excluding magic and extensive use of amulets or charms, reflects the preventive approaches and medical treatments commonly practiced by the general population.

Throughout Islamic history, health concerns, both physical and mental, have been imbued with ethical, moral, and religious value. This social outlook has underpinned the establishment and operation of Muslim medical institutions. For example, multifunctional hospitals comprising libraries, pharmacies, and several wards were most often established by rulers, administrators, or other wealthy individuals and were managed by *awqaf* (charitable, religious endowment) foundations on land set aside for such purposes. Hospitals for specific ailments were also founded in this way. According to most schools of thought in Sunni Islam, the endower could participate in the administration of the donated property. This precept tended to encourage the proliferation of private endowments.

The first of their kind, institutions for lepers and the blind were built in Damascus under the Umayyad Caliph al-Walid (reign 705–715 CE). Guides were employed to help blind patients. Often patients were given stipends when they were discharged to help them return to work. Such treatment stands in sharp contrast to the situation in Europe, where lepers were burned to death by decree.

Islamic hospitals proliferated during the Abbasid caliphate (750–1257), especially under Harun al-Rashid, who established the first hospital in Baghdad. Men and women were treated separately. Special hospitals were established for mental patients during this time, as well as homes for orphans and older women. In addition, large hospitals included quarters for mental patients, and some used music therapy as a form of treatment. Treatment of mental illness was considered vital for maintaining one's honor and preserving a sound mind. These were thought of as fundamental rights in Islamic law that the state should protect. These institutions seem to have been inspired by earlier Christian efforts that established hostels for the insane and blind in the Middle East before and during the early medieval period.

Visiting the sick at home or in the hospital is encouraged in the Hadith, and the sick are asked to pray for others in return due to their presumed pure state of being. The ethics of medical care and visitation motivated the foundation of mobile dispensaries during the Abbasid period. These dispensaries extended accessibility to medical services throughout the countryside. In addition, it was decreed that physicians must visit jails, and physicians' services were made more accessible in general through the location of clinics near mosques.

MEDICINE IN MEDIEVAL ISLAMIC HISTORY

Prevalent Ailments and Disabilities

Blindness was perhaps the most common disability in the medieval Islamic world and the one most written about in Islamic medicine. It is discussed in a variety of medieval texts, including theological, philological, historical, legal, and literary. Discussions of the visually disabled dealt not only with questions of a physical nature but also with issues of spiritual blindness. Discussions of blindness also intersected with debates in Islam as an oral versus a written culture.

A number of words in medieval Arabic describe blindness, including *a'ma, makfuf, kafif,* and *darir.* The first of these words means complete disappearance of vision, the next two refer to someone who has lost his or her sight, and the last is the most polite, meaning one whose vision has gone or whose injury has resulted in blindness. The word *akmah* refers to those who are blind from birth and alludes to darkness, but most words for blindness point to physical covering or injury, not symbolic darkness or mental confusion.

From the time of the prophet Muhammad's death until the thirteenth century, contagious diseases such as trachoma, conjunctivitis, and smallpox most often caused visible disabilities. During the expansion phase of Islam, Arabs often contracted eye diseases while traveling, on pilgrimage or as a result of the slave trade. Blindness was also caused by old age, corporal punishment, and battle injury, as well as by marital practices of co-sanguinity. Starting in the tenth century, one way to dethrone a ruler was to blind him. Yet stories abound in the Hadith about blind men becoming devout believers, commanding men in battle, or predicting significant events. For example, Abu Sufyan, the father of the first Umayyad caliph, is said to have lost one eye at the Battle of Attayif and the other at Al-Yarmuk.

Because of the high prevalence of eye diseases, dissection of the eye was permitted as an exception for the pursuit of medical knowledge. For the same reason, specialization in and writing about ophthalmology emerged before other medical specializations. Hunayn ibn Ishaq, an early translator of Greek texts, wrote essays on ophthalmology that were collected in a volume called *Kitab al-`ashr maqalat fi l-`ayn (Book of the Ten Treatises on the Eye),* which became the basis for further research and commentary on the subject for rest of the medieval period.

Under Mamluk rule of Egypt and Syria (1250–1517 CE), the text *Nakt al-humyan fi nukat al-`umyan* by al-Safadi (d. 1361) formed an authoritative study on blindness and the blind. This biographical dictionary mentions elite blind individuals including scholars, Qur'an reciters, lexicographers, and famous poets as well as beggars who feign blindness or are truly impaired. In other types of literature of this period, blind people are treated with other physically disabled and marginal groups, referred to generally as *ahl al-ahat* (those with a physical impairment). Blindness is treated in one of two ways: as a simple difference, such that individuals who are different in this way are not excluded from society, or unfavorably, with the blind categorized along with women and beggars. Questions about the status of a blind person as a suitable witness or transmitter of the traditions posed legal controversies that ultimately stemmed from these two approaches.

The greatest concern related to blindness in Islamic legal and literary texts of the late medieval period is the problem of mobility and the dependence of the blind person on a guide's vision for description, transport, and social interactions. As Fedwa Malti-Douglas (2001) notes, such discussions point to the integration of blind individuals in society and how to best facilitate it. Another concern with similar implications is the act of eating, particularly at a communal meal. A final topic of discussion is the virility of the blind man, which is often presented in a positive, desirous light.

In addition to blindness, discussions about disability in the texts focus on such issues as disabilities of an orthopedic nature, especially in their relation to war or punishment. For instance, the Qur'an sanctions amputation for theft but exempts from such punishment a person who steals due to dire need. Crippling from stoning during battle is also noted in Islamic texts.

In general, the average life span during the medieval period was no more than 35 years, and infant mortality rates were very high. Leprosy, tuberculosis, typhus, scurvy, dysentery, malaria, and paralysis have also been chronicled during medieval Islam. Epidemics of plague also occurred at various points during this period, causing extremely high mortality rates.

Medical and Social Treatment of Disability and Disease

Before and after the advent of Islam, disease and disability in the Arab-Islamic world were treated in ways not unlike those seen in other societies of the time. In fact, the Islamic medical tradition necessarily integrated contributions of other cultures with the expansion of Arab territory. Islamic culture taught that all should be treated with justice, including those with disabilities, in order for balance in society to be achieved. Just as the balance of the humors formed the basis for the medical treatment of disability and disease, this social balance formed the moral basis for the system of charitable works and mutual responsibility in Islamic societies.

Cauterization, cupping, bleeding, setting of bones, and herbal remedies were widely used to treat disability. The populace attributed deviations from general health not only to imbalance of the humors but also to malevolent, supernatural forces or spells; this was especially the case with mental illness. On the other hand, disability was sometimes viewed as conferring luck or blessedness on a person, who could also be seen as having special insight or as being protected from the evil eye. Specific folk treatments varied according to region, ethnic tradition, and the availability of particular medicinal/magical ingredients, but they largely included amulets marked with Qur'anic passages or incantations.

Aside from the controversial issue of blindness, political leaders were generally not barred from ruling due to disability. For example, the Caliph Uthman was said to have scars from smallpox. Although others debated the point, al-Safadi claimed that prophets could be blind but not deaf, as this would hinder the central, oral character of Islamic cultural transmission. Famous poets, philosophers, and other literati were also known to have various disabilities. Records show that women cared for wounded soldiers and for those who became disabled by fighting in wars.

Mental illness is acknowledged and discussed in the Qur'an and Hadith, and during the medieval period, doctors were often appointed to visit asylums to care for patients there. Suicide is forbidden by Islamic law. Although there are no direct or explicit phrases in the Qur'an or Hadith that refer to this issue, the judgment rests on the idea that Allah created life and therefore humans do not ultimately own it. Aside from mental illness, the psychological state of a sick person should, as much as possible, be one of reservation, restraint from complaint, attempts at cheerfulness, and deference to God.

DISABILITY IN THE CONTEMPORARY ISLAMIC WORLD

With the advent of the modern period, particularly after the Napoleonic invasions of Middle East territories in the late eighteenth century, the Ottoman Empire began to accept Western medical approaches as a way to modernize the regime. This integration continued during the period of colonialism and has continued in postcolonial Middle Eastern and other Islamic societies. Still, humoral medicine and Islamic medical texts have continued to influence the treatment of disease and disability even up to the present day.

People in the Islamic world, which entails a vast territory, currently seek both biomedical and traditional folk remedies to address illness and disability. Acceptance of the disabled population varies depending on the country and the conflicts therein. For the general Muslim population, having a disability exempts one from making pilgrimage to Mecca, considered one of the five pillars of Islam.

Organized groups of disabled individuals currently advocate for greater rights and support; these include the National Association for the Rights of Disabled Persons and Youth Association for the Blind, both based in Beirut. Much of the work done on behalf of the disabled community in Islamic countries is organized, administered, and funded by nongovernmental organizations in connection with these grassroots organizations.

Disabilities that commonly exist today in the Arab world and in other Islamic countries include infectious diseases such as tuberculosis and AIDS, chronic illnesses such as heart disease and diabetes, congenital disabilities, cognitive and mental disabilities, and war-related injuries, including quadriplegia, paraplegia, and various amputations related to land mine injuries. Religious debates continue among Muslim jurists on the topics of organ transplantation and genetic engineering.

—*Sandy Sufian*

See also Disability Culture; Religion.

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MILAN CONGRESS ON THE DEAF

See Deafness, Milan Congress of 1880 on

MINDFULNESS MEDITATION

There are two broad forms of meditation, and although one must be careful not to see them as dichotomous, most forms of contemplative practice across cultures and various traditions tend to correspond loosely to one of these two broad forms. One form emphasizes a single point of focus, excluding all other mental content. This point of focus might be an object, image, thought, prayer, or chant. This form of meditation, referred to as *Samatha* in the Buddhist tradition, emphasizes single-pointed concentration as a means of closing out all distractions and disturbances, resulting in a profound sense of tranquility and calm. The other form of meditation, referred to as *Vipassana* or "mindfulness" in the Buddhist tradition, has a very different emphasis. Mindfulness meditation involves an *inclusive* approach to one's ongoing experience and promotes insight through awareness of the present moment. This inclusive awareness occurs through one's nonjudgmental acceptance of everything that arises in the mind and body as one observes each moment as it arises and then dissipates. One accomplishes this by using the sensations of breathing as a means of staying in the present moment. The breath offers a practical means of centering oneself, as it is something that is always present; it also offers a constellation of subtle sensations and movements when experienced through careful attention.

The formal practice of mindfulness can be conducted in a number of ways, including being very still, as in the traditional sitting meditation, and in a form often called *walking meditation.* However, since not everyone can walk, and since the spirit of this method of meditation practice does not depend on walking per se, the term *walking meditation* is really a misnomer. More precisely, this form of mindfulness is *moving meditation,* in which one slowly and deliberately moves one's body (or part of the body) in space, focusing on the sensations of one's breathing and the physical sensations associated with movement. Access to such moving meditation is universal, although the nature of the movement may differ radically in form and degree among different individuals.

The body of research and theoretical literature on the relationship between meditation and health promotion has been growing rapidly in recent years. Recent interest in meditation in relation to health has focused a great deal on mindfulness meditation. This increased attention stems from the realization that an expanded conceptualization of health involves perceiving it as a multitude of experiences that are undergoing continuous change. In order to actualize such an approach to health, however, one must gain an *awareness* of the multitude of changing experiences one is a part of at any given moment. Mindfulness meditation is one means of practicing this awareness.

Methods of contemplative practice that foster self-awareness pose a universal challenge. Because the experience being fostered by any form of meditation is the *process* of attention, without a specific goal or end point, nobody, in fact, has a relative advantage. Because meditation is not based on any external criteria for “success,” it constitutes a welcome paradox in that it is an intensely personal experience that is universally accessible. Individuals who make certain types of adaptations to various meditative practices will likely encounter the same discoveries and frustrations as those who make very different adaptations. Although each person accesses the contemplative process somewhat differently, all enter onto the same path.

Meditators tend to understand, through direct experience, that when it comes to practicing a greater awareness of one’s mind and body, the challenges are similar from person to person regardless of individual differences. Whether one walks or uses a wheelchair, sees clearly or has a visual impairment, has free movement or chronic pain, the process is very much the same. As such, meditation is an inclusive process that each person must embark on for him- or herself, pursuing no goals, casting no judgments, and accumulating no achievements. It is this process of personal observation that lends meditation its “universal design.”

—Daniel Holland

See also Complementary and Alternative Medicine.

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MIR NASIRUDDIN HARAWI

(?–1708)

Afghan Sufi

The Afghan Sufi Mir Nasiruddin Harawi, living at Burhanpur in northern India, appears among the Persian accounts of Sufism, with the usual attributes of piety, independent thinking, charitable giving, rejection of gifts to himself, and vigorous rebuttals of overtures by wealthy people. As a Sufi, Mir Nasiruddin was unusual in that he had been severely disabled since his youth, with paralysis of his legs and left arm. His right arm still functioned, and he worked as a Qur'an copyist, earning enough to keep himself alive. People revered him for his abstemious life, but Mir Nasiruddin gave them a hard time if they were among the powerful. When he denounced the governor of the province, Munawwar Khan, for greed and abuse of power, Munawwar responded correctly by asking the Sufi to guide him, but Mir Nasiruddin did not soften easily. He cited himself as an example of disobedience to Allah, which had resulted in his being crippled. This was not orthodox Islamic teaching, but his aim was to put the fear of God into the governor. He is also reported to have turned down a grant of land from the emperor Aurangzeb.

—Kumur B. Selim

See also Middle East and the Rise of Islam.

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MIRACLES

Western cultural traditions historically linked with Christianity have, from an early period, associated particular classes of disability with miraculous healing: the blind see and the lame walk more readily in the New Testament than in the Old. In addition to cures of the lame, deaf, dumb, and blind, stories of miracles encompass the relief of ailments ranging from leprosy to that ultimate disability, death.

Patterns established from the earliest centuries continued through the Middle Ages and, in some cases, continue to the present. In medieval miracles, disabilities seem to have been linked to gender and status. In a sample of nearly 3,000 cases (mainly from medieval England), 20 percent of the disabilities linked to "crippling" ailments (usually of the legs) were reported by lower-class women, but only 14 percent of men of the same social level reported crippling ailments; very few upper-class women, and only 7 percent of the men of this class, reported such disabilities. A second very common disability was reported as "blindness," which affected some 16 percent of all women and 11 percent of men from the lower classes, whereas only 3 percent of upper-class pilgrims reported this ailment. This suggests that the lame and the blind pilgrims at medieval shrines were generally of the lower classes and predominantly women. This could be accounted for by the lower classes' limited access to medical treatment (which was costly), poor environmental and living conditions (cold, damp quarters; dietary deficiencies), and perhaps a tendency for more women than men to suffer conversion reaction symptoms. On the other hand, upper-class folk distanced themselves from the lower by reporting symptoms that were often quite specific (suggesting that their position enabled them to consult with doctors) or by reporting "miracles" that had nothing to do with healing; this type was reported by only 3 percent of women and 13 percent of men of the lower classes, but was claimed by 23 percent of the upper-class males.

The most common disabilities, then, resulted in afflictions of the limbs and blindness, reputedly "cured" by a saint or at a holy shrine. It should be understood, however, that the medieval concept of a "miracle" was quite flexible: a miraculous cure could be (a) partial or incomplete, (b) delayed or gradual, or (c) temporary, with succeeding relapses. Even under these conditions, the "cure" was considered a miracle and recorded as such. As for the underlying mechanisms that may explain some of these releases from disability, many of the afflictions reported seem to have been self-limiting, chronic but subject to remission, and psychogenic.

Today's reported cures from places such as Lourdes follow, in general, the same pattern as that suggested by medieval data: The element of hopeful expectation that precedes a pilgrimage, the atmosphere of heightened emotion at the holy place itself, and the sight of examples of canes and crutches left by "cured" visitors create a psychophysiological context in which some disabilities seem to be, at least partially or temporarily, relieved. Apart from the religious context, in the world of modern medicine the curative efficacy latent in the mind of the patient has come to be appreciated; accordingly, medical professionals now tend to treat the whole being while attempting to alleviate the pain and suffering of physical disability.

—Ronald C. Finucane

See also Religion.

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MOBILITY AIDS

Mobility is a fundamental human need, an important component of the achievement of other goals of independence. Assistive technology—that is, technology that assists individuals with disabilities in being mobile—includes devices that aid in ambulation, wheeled bases that provide mobility for individuals who do not use their lower extremities for ambulation, and personal transportation vehicles used in the community.

Individuals with disabilities may use devices such as lower limb orthotics to enhance their stability during ambulation. Individuals may use lower limb prosthetics if they have acquired disabilities through amputation or if they were born with partial limbs.

Stability during ambulation can be enhanced through the use of common devices such as canes and walkers. Canes are available in several designs, from a single tip to a "quad"-tip base for added stability. Different styles of walkers are also available; some have four rubber feet, whereas others have two rubber feet and two wheels to enable the user to shift the device forward more easily during ambulation. Some walkers are equipped with baskets for carrying objects and fold-down seats for the convenience of users who may need to sit and rest during the course of travel.

A variety of manual wheelchair bases are available to enable individuals to move about in the community. For decades, manual wheelchair design was dominated by heavy, chrome-plated frames, but today many lightweight options exist, with designs utilizing alternate materials such as aluminum, titanium, and composites.

Powered wheelchair frames, which are also available in a variety of styles and materials, enable users to achieve independent mobility if they can operate a standard joystick or specialized controller.

For the users of either manual or powered wheelchairs, proper seating and positioning are required to ensure the maximum opportunity to use the bases independently and without complications such as pressure sores and scoliosis. Commercially available modular seating components and custom-fabricated cushions that exactly match the contours of individual users make such proper seating and positioning possible.

Personal vehicles can also be considered devices that serve as mobility aids for individuals with disabilities. Adaptive equipment such as accelerator and brake buildups, lever controls, and steering wheel posts may be installed in automobiles to enable individuals with disabilities to operate them safely. High-tech joystick controllers may also be installed to allow individuals to operate the acceleration, braking, and turning functions of motor vehicles.

Safe restraint is important for all users of personal vehicles. For individuals who use mobility bases, the type of securement used to anchor the base to the vehicle must take both safety and independence issues into account.

Assistive technology and universal design features of public transportation vehicles also help individuals with disabilities to achieve independent mobility in the community. Examples include buses with front-end kneel-down capability and airplanes with increased clear space for maneuverability.

—Glenn Hedman

See also Wheelchair; Wheelchair, Electric; Wheelchair, History of.

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MODALITIES

The term *modalities,* as used in physical rehabilitation, refers to techniques of application of therapeutic heat and cold, whether by direct transfer of heat from a warmer body to a cooler or by conversion of another form of energy to heat. Direct methods of heat transfer include convection, conduction, and radiation. Examples of these methods include Fluidotherapy, hot packs, and infrared bulbs, respectively. Diathermies (from the Greek *dia,* "through," and *thermi,* "heat") are examples of heating by conversion and include ultrasound, shortwave, and microwave diathermy. Ultrasound converts a high-frequency sound wave (i.e., a longitudinal compression wave) into heat. Shortwave uses radio frequency electrical currents. Microwave is an electromagnetic wave, similar to radar, that is transmitted even in a vacuum. The direct methods of heat transfer are also direct methods of cooling, but in the reverse direction; that is, the human body, or some part thereof, is the warmer body from which heat is transferred to the cooler, as with cold water or cold packs. The latter transfers heat by conduction and, to some extent, radiation. If the cold water is moving, then all three modes of transfer are involved, especially convection.

Physiological effects of heat that may be therapeutically useful include increased extensibility of structures made from collagen, such as burn scar and joint capsular contractures, relief of muscle spasm (but not spasticity), relief of pain, and possibly increased blood flow (but see the discussion of contraindications below). Physiological effects of cold that may be useful include decreased blood flow, prevention of swelling in acute trauma (if combined with rest, compression, and elevation), pain relief, and temporary relief of spasticity. For example, an ice pack applied to the muscles in the calf may remove clonus, a manifestation of spasticity, for up to 90 minutes. This, combined with prolonged static stretch, may improve gait in patients with stroke or central cord syndrome.

Vigorous heat has the following characteristics: The highest temperature is at the site of the pathology; the temperature is brought rapidly to tolerance levels and held there for relatively long periods, such as 20 minutes. Vigorous heat is reserved for chronic processes. It can be achieved in deeply located structures only with the diathermies; however, vigorous heat should not be considered synonymous with the diathermies, as superficial structures, such as burn scar, can be heated vigorously with superficial heating agents.

On the other hand, mild heat can be used even in acute processes, because the acutely inflamed tissues are not heated to tolerance levels. For example, a hot pack can be used over lumbar musculature in spasm associated with a herniated disc because the depth of penetration of the hot pack is only a few millimeters and is not close to the pathologic area. Paraffin is particularly suitable for burn scar, as it helps soften the scar as well as make it more extensible and amenable to stretching therapy.

General contraindications to heat include lack of sensation in the area to be treated, obtundation (dulled or reduced level of alertness or consciousness) of the patient, ischemia in the area to be treated, and cancer in the area to be treated (although special oncology centers may use heat as an adjunct to radiation or regional chemotherapy). General contraindications to cold are the same, except for the cancer; safety in the latter has not been established.

Specific contraindications to shortwave and microwave include the presence of pacemakers and metallic implants. Application near the eyes should be avoided, even with shielding, which does not provide adequate protection. Ultrasound can be used in the presence of metal implants, but safety in the presence of synthetic resins has not been established. Any of the diathermies should be used only with great caution, if at all, in pregnant women.

—Barbara deLateur

See also Occupational Therapy; Physical Medicine and Rehabilitation; Physical Therapy.

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MODEL OF HUMAN OCCUPATION

The model of human occupation is a theoretical framework developed in occupational therapy to guide services for disabled persons. It is the most widely used model in occupational therapy and is also used by other rehabilitation professionals. As its name implies, this model focuses on occupation, which is defined as the individual's engagement in work, play, or other daily living activities within his or her physical, temporal, and sociocultural context. The model seeks to explain how impairments affect the way persons engage in and experience their occupations. It focuses on how persons are motivated toward and choose what they do, how they organize their everyday behavior patterns and routines, and how performance is shaped by subjective experience.

According to the model of human occupation, the choices people make to engage in occupations emanate from a drive for action mediated by thoughts and feelings about personal effectiveness, what is important and meaningful, and what is enjoyable and satisfying to do. The model highlights how impairments can influence and resonate with a person's sense of personal effectiveness and what a person holds as important and enjoyable. It proposes that people organize their actions into recurrent patterns that are regulated by habits and roles. Habits are learned ways of doing things that unfold automatically. Roles are internalized attitudes and ways of behaving that serve as a framework for looking out on the world and for acting. The model underscores the ways in which impairments can disrupt or pose challenges to developing habits. It also calls attention to how societal attitudes can hinder access to roles. This model conceptualizes the capacity for doing things as involving not only objectively defined abilities and impairments, but also subjective experience. Thus, the model emphasizes the lived experience of impairments as a major factor in what a person can and cannot do.

The model of human occupation conceptualizes the physical and social environment as providing opportunities, resources, demands, and constraints that may affect each person's motivation, patterns of action, and performance. As with personal factors, the model underscores how the impact of physical and social environmental characteristics can be altered when a person experiences impairments. It also recognizes that physical and social environments can present significant obstacles, ranging from architectural barriers to social injustice.

More than 20 assessments have been developed (including substantial empirical validation) for use with the model of human occupation. The assessments emphasize capturing the disabled person's experience and point of view. Although some involve observation of the disabled person, most are designed to give the disabled person an opportunity to report directly his or her own perceptions, perspectives, desires, and priorities. Services based on this model do not focus on changing impairments per se; instead, they focus on how a person can be supported to achieve the kind of life he or she wants. The model emphasizes that services should be based on the client's desires and experiences. It emphasizes that achieving change ordinarily involves both physical and social environmental alterations as well as changes within the individual (e.g., changes in attitudes, habits, roles, and ways of performing).

To date, more than 300 works have been published relating to the model of human occupation. Approximately one-third of these report on empirical studies that have examined the theory and/or utility of the model.

—Gary Kielhofner

See also Employment; Occupational Therapy; Work Incentives.

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▣ MODELS

A model is a conceptual tool. Models are useful for making sense of reality and for achieving consensus. They help us to see both the forest and the trees, and they ensure consistency of terminology and usage. In the field of disability, the debate over models and definitions has been particularly heated and long running. This entry explores why models of disability are important and then analyzes four different models, selected on the basis of their influence and significance. The final section of the entry explores how models have been applied in practice and presents recommendations about resolving the models debate.

THE IMPORTANCE OF MODELS

Disability is a complex, multidimensional, scalar concept. Whereas human beings have had impairments throughout history and prehistory, understandings and definitions of impairment and disability have varied in different societies and at different times. No universal, global definition of disability is possible, and there are many different and often incompatible approaches to the problem. Key terms—such as *impairment* and *disability*—are defined in various ways and for different reasons within individual cultural contexts, which can cause confusion. Additionally, translations between languages, cultures, and contexts contribute another layer of complexity.

Disability models are parts of a larger system of understanding and knowing the world. For example, a model is based on a set of definitions and leads to particular schemes of classification and measurement. A model is therefore a map of the relationships among concepts, a way of describing and explaining the complex phenomenon that is disability. For policy makers, a model may be part of the process of

Table 1 Definitions: Nagi's Model (1965)

Term	*Definition*
Pathology	Interruption in body processes
Impairment	Anatomical or physiological abnormalities and losses
Functional limitation	Restrictions on ability to perform normal role tasks and obligations
Disability	Pattern of behavior

distinguishing between disabled people and nondisabled people, which might be important in allocating welfare benefits or entitlement to services to individuals or in planning provision for populations. For clinicians and rehabilitation professionals, a model may be part of the process of assessing interventions, which may enable judgments as to whether a therapy or training method reduces pathology, increases functioning, and affects social roles. For social scientists, a model may clarify the causes of disadvantage, help analysis of the relationship between individuals and wider social environments and cultural contexts, and prioritize changes aimed at reducing social exclusion or disadvantage. For disabled people themselves, a model is a way of understanding the world that has implications for explaining the disability experience and hence has impacts on personal identity and political action.

To be effective, a model needs to be clear and simple. Yet clarity and simplicity make any model vulnerable to challenge. Particularly in regard to a complex and contested phenomenon such as disability, any model may be criticized for not providing a full picture. This explains why debates around models of disability are so important and sometimes so bitter. The challenge to traditional models of disability lies at the heart of the challenge of the disabled people's movement, particularly in the United Kingdom. The self-organized groups that developed among disabled people in the United Kingdom, the United States, and many other countries during the 1970s and 1980s were not just campaigning for better social provision or social inclusion, but for a radical redefinition of disability itself. In other words, the debate about models is not just an abstract academic problem of definitions and classifications; rather, it is a question of political struggle and personal identity.

NAGI'S MODEL OF DISABILITY

The dominant North American model of disability was developed by the sociologist Saad Nagi (1965) in the context of rehabilitation. Nagi's definition of impairment includes congenital abnormalities that may not be associated with pathologies and allows for variation of impairment along many different dimensions, which may influence the nature and degree of disability. Not every impairment results in a functional limitation, and functional limitation can arise from nonimpairment causes. Nagi's definition of disability, particularly as later refined (Nagi 1977, 1991), is dynamic and allows for social context. Patterns of behavior associated with disability are influenced by impairment and limitation, by the individual's own reaction to and definition of the situation, and by the reactions and definitions of others. Nagi (1991) later clarified that environmental barriers are an element in disability. Nagi's model has been used as the basis for the Americans with Disabilities Act, for almost all disability social policy in the United States, for statistics at United Nations and European Union level, and in many other contexts.

THE ICIDH

The International Classification of Impairments, Disabilities, and Handicaps, or ICIDH, was developed by Philip Wood, Elizabeth Badley, and Michael Bury for the World Health Organization in the 1970s and published in 1980. This model distinguishes among impairment (the medical problem), disability (the resulting functional limitation), and handicap (the social disadvantage resulting from impairment or disability that limits or prevents the fulfillment of the individual's social role). Impairment is a necessary, but not sufficient, cause of disability, whereas disability in turn is necessary but not sufficient for handicap. The aim of the developers of the ICIDH was to make the social context of disability clear. Previous

Table 2 Definitions: ICIDH (1980)

Term	*Definition*
Impairment	Loss or abnormality of psychological, physiological, or anatomical structure or function
Disability	Restriction or lack of ability caused by impairment
Handicap	Disadvantage for an individual in fulfilling appropriate roles

approaches had been dominated by a narrow focus on health and disease, whereas the new model used the handicap concept to emphasize social disadvantage.

It has been argued that this model, although not without its problems, has been a useful tool in assessing the social needs of disabled people. Despite the utility of the ICIDH for assessing the social needs of disabled people and situating persons with impairments in a wider social context, it has been widely contested by disability movements, particularly in the United Kingdom. The British Council of Disabled People—and subsequently other national and international movements—has rejected the ICIDH, labeling it a "medical model" or "individual model" or "personal tragedy theory." Critics have claimed that the causal relationship in the ICIDH starts with individuals and their impairments, which cause their disabilities or incapacities, which then make them vulnerable to handicaps or social disadvantages. This is seen as "blaming the victim" and as placing insufficient emphasis on the social barriers that cause problems for people with impairments. For many disabled activists, the term *handicapped* is offensive; it is associated with outdated social attitudes and organizations and is linked to the idea of begging and dependency through an association with "cap in hand." It should be noted, however, that this is a false etymology, as the term *handicap* derives from horse racing, not begging.

Although the framers of the ICIDH intended to create a social model, in practice approaches inspired by the tripartite definition tend to slip into individualist and medically focused remedies. Questions of social context and meaning are often neglected when the model is operationalized. The ICIDH has perhaps unfairly attracted and focused the generalized opprobrium directed toward traditional approaches to disability. Many disabled people have experienced negative cultural stereotypes and assumptions based on the medicalization of disability. Undoubtedly, the idea that disabled people are defined by their mental or physical deficits is a major obstacle to both self-esteem and social inclusion. But the framers of the ICIDH explicitly wanted to challenge this medicalization, and the ICIDH is not the cause of the widespread devaluing of disabled people. Opponents of the "medical model" have created a straw man that stands for medicalization, prejudice, and the devaluing of disabled people. It is difficult to find any authors who espouse such a "medical model" or deny the importance of social barriers and discrimination in the lives of disabled people.

THE SOCIAL MODEL

The social model of disability was developed by the Union of the Physically Impaired against Segregation (UPIAS), a small group of disabled people in England in the 1970s. Inspired by Marxist politics, UPIAS retained a concept of impairment (physical impairment) but stressed that disability should be defined as the relationship between people with impairments and a society that excludes them:

> the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Disability is thus a particular form of social oppression. (UPIAS 1975:14)

Disabled Peoples' International (DPI) revised these definitions slightly in 1982 as shown in Table 3.

Michael Oliver used these definitions in *The Politics of Disablement* (1990), a book that was a founding text in disability studies. However, Oliver usually used the terms *medical tragedy theory* and *social oppression theory* in preference to *medical model* and *social model.* UPIAS and Oliver—and authors and organizations that followed them—succeeded in stressing the social structures and social barriers that oppress people with impairment. Disability is an additional burden that is imposed on people with impairment. Thus, the social model soon became reduced to a

Table 3 Definitions: Social Model, DPI Version (1982)

Term	*Definition*
Impairment	Functional limitation within an individual caused by physical, mental, or sensory impairment
Disability	Loss or limitation of opportunities to participate in the normal life of the community on an equal level due to physical and social barriers

slogan: "Disabled by society, not by our bodies." Social model approaches became associated with political campaigns for antidiscrimination legislation and barrier removal. The corollary of this approach was an increase in the tendencies to minimize the significance of impairment and to make social oppression the basis of disability as a political identity.

These tendencies are responsible for several logical flaws of the DPI version of the social model. First, the definition of impairment is circular: Impairment is defined as a functional limitation caused by impairment. Second, unlike the UPIAS definition, there is no mention of impairment in the definition of disability. This leads to the difficulty that other social groups—such as people who experience racism or sexism or poverty—could be included within the social model definition, even if they do not have impairments. In the attempt to decouple disability from impairment, impairment ceases to be a qualification for being a disabled person.

The British social model is not the only version of the social approach. For example, in the United States, a focus on social oppression and social barriers is encapsulated in the "minority group model," as theorized by Harlan Hahn (1988) and others. This suggests that people with disabilities (as defined in the Nagi model, for example) form a minority group that experiences oppression. The minority group version of the social model also places highest priority on barrier removal and other social change rather than medical or rehabilitation interventions. In the Nordic countries, a "relational model" similarly situates the experience of disabled people in a broader social context.

Most disabled-led political campaigns worldwide give highest priority to the improvement of the quality of life of disabled people through the reduction of discrimination and barriers. British activists have gone further than others in actually redefining the word *disability* to refer to oppression or barriers rather than to "impairments." Whereas activists in most other English-speaking countries favor the term *people with disabilities*—to signal that functional limitation is only one aspect of a person's overall identity—Britain has favored the term *disabled people,* to signal that people are disabled by society. Representatives of the British Council of Disabled People campaigned for the world body—Disabled Peoples' International—to follow their lead in rejecting the ICIDH definitions when it was formed in 1981.

In practice, the distinction between the "barriers" and "minority group" versions of the social model is not clear. In other documents, the U.K. disability movement referred to itself as a minority group from the outset, even though the formal definitions do not include this conception. As observed earlier, without a conception of a minority group of people with impairments who face oppression and barriers, the DPI model runs into the major difficulty that it does not specify the class of people it defines. Equally, U.S. discussions of the minority group model make it clear that people with disabilities are excluded by social barriers and an oppressive social relationship, although this model is weaker than the U.K./DPI version in not defining disability as barriers and oppression.

However, the implicit combination of "barriers" and "minority group" approaches within most social models does conceal tensions. In policy terms, should political action be directed at removing structures and barriers to promote equality of opportunity, or should it be directed at benefits and protections for a disadvantaged class of individuals? In terms of identity politics, the choice is between an attempt to minimize the differences between disabled and nondisabled people and the drive to celebrate disability identity, cultural distinctiveness, and disability pride.

Conversely, the social model has been criticized for neglecting the role of impairment and personal experience, and for being difficult to apply to groups of disabled people other than the people with physical impairments by whom it was devised. Often, these criticisms have come from within the disability movement

Table 4 Terms: ICIDH and Social Model, Thomas Version

ICIDH	*Social Model (Thomas Version)*
Impairment	Impairment
Disability	Impairment effects
Handicap	Disability

or disability studies, as activists or researchers have tried to operationalize the social model or think through its implications.

Some have claimed that there is no intrinsic contradiction between the ICIDH and the social model of disability, only a difference in terminology: Where the ICIDH talks about *handicap,* the social model uses the term *disability.* In attempting to deal with the common critique that the social model ignores impairment, Carol Thomas introduced an additional level of "impairment effects" into the social model binary in her book *Female Forms* (1999). She defines these as restrictions of ability that are caused by impairment, not by social relations. Although Thomas might resist this implication, the consequence might be to generate a familiar tripartite structure, as shown in Table 4. However, "handicap" (ICIDH) is the experience of disability in a social context, whereas "disability" (Thomas) places the causal emphasis on the society or environment that excludes or oppresses the individual who has an impairment by failing to meet that person's needs by actively discriminating unfairly against him or her.

THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH

A recent revision of the World Health Organization approach has attempted to bridge the impasse between "medical model" and "social models" by sidestepping the definition of the word *disability.* The International Classification of Functioning, Disability, and Health (World Health Organization 2001), sometimes called the ICIDH-2 but better known as the ICF, uses *disability* to refer to the entire process rather than to any element in the chain. It is described as a "biopsychosocial model" in an attempt to offer a way forward from the increasingly sterile debate over models and definitions. The ICF sees disability as the outcome of interactions between the features of the individual and the physical, social, and attitudinal world.

As well as avoiding the "disability" controversy, this approach has the dual advantage of stressing the social context in which individuals are enabled or excluded while not ruling out the roles of bodies and medicine. No comprehensive analysis of the ICF has been conducted to date from a disability studies perspective. However, initial reaction from several authors has been skeptical, given the model's origins within the discredited ICIDH schema. Professionals, researchers, and policy makers have welcomed the ICF. More than 150 papers have been written on or about the ICF, none of which has used it as a medical classification. This suggests that the ICF avoids the problems of the ICIDH and can be operationalized as a classification of participation and environmental interaction. DPI is a full supporter of the ICF and has officially adopted it for the UN Disability Convention.

MODELS IN PRACTICE

It has been demonstrated that the debate about models is as much about politics and identity as it is about definitions. The original ICIDH model was developed by experts to help researchers and policy makers. The UPIAS model was developed by disabled people themselves as a tool for social change. For activists, the medical/social model divide stands for the rejection of traditional approaches to disability that revolve around curing or preventing impairments. The "medical model" is equated with medicalization and the prejudice that suggests having an impairment makes an individual inferior, incapable, and dependent. The social model mandates and places high priority on barrier removal and social inclusion rather than medicine or rehabilitation. Instead of special provision based on impairment, the social model suggests that barriers should be removed so that disabled people can access mainstream services. Rather than counting the numbers of people with impairment, the social model suggests that the focus should be on discrimination and prejudice.

The social model has implications for personal identity as well as for policy and practice. It has

Table 5 Disability as the Outcome of Interactions: Terms in the ICF Model (2001)

Body function and structure
Activity
Participation
Environmental factors

proved hugely effective in enabling people with impairments to move from a position in which they believe they themselves are the problem to a position in which they identify society as the problem. Psychologically, individuals move from a poor self-image based on self-pity to a strong political identity based on anger against a disabling world. For many, this is also a move from being an isolated individual to being a member of a vocal minority group, based on solidarity, resistance, and pride. The self-esteem benefits that the social model has for individual adherents help explain why the social model is an article of faith for many in the U.K. disability movement and why debates about revising or replacing the social model have been so heated and acrimonious.

UPIAS activists never denied that impairment is important. They did not argue against medical care, only against the discriminatory ways in which it is delivered. Yet the consolidation of the social model through identity politics has led some activists to express opposition to any impairment-based approach. For example, there has been rejection of medical research, therapies, and attempts to prevent impairment; opposition to surveys of the numbers of people with impairment; and rejection of mono-impairment organizations as well as services provided to people on the basis of impairment distinctions. Because the social model has become a litmus test for progressive approaches to disability, particularly in Britain, interventions based on the ICIDH definitions have been rejected. For example, a government advertising campaign to challenge prejudice against disabled people used the slogan “See the person, not the disability.” The disability movement rejected the initiative because, activists argued, the slogan should have been phrased “See the person, not the impairment.” Equally, the 1995 Disability Discrimination Act (U.K.) has been challenged by many activists because it rests on a definition of disability as a medical condition.

Yet applying and implementing social model approaches is difficult in practice, and sometimes impossible. Unless impairment is part of the definition of a disabled person, no protected class can be identified in legislation. Without counting people who have impairment, it is difficult to predict the numbers of users of services and to create adequate provision. The implementation of universal design and the barrier removal mandated by antidiscrimination legislation have led to huge improvements in environmental access. However, some argue that an entirely barrier-free world is a utopian dream, for several reasons: because the natural environment cannot be made accessible, because it is impractical to make many existing buildings or systems accessible, and because different impairments necessitate different accommodations, some of which may be mutually contradictory.

The social model has huge rhetorical power as a social critique and mobilizing force. It also has great moral power: If society has constructed disability, then it has a duty to remedy the situation and remove barriers. But the model is difficult to operationalize and implement, and it is misleading as an explanation of the social world. The ICIDH may have been more coherent, but it failed to place a high enough priority on addressing the social factors that cause problems for people with impairments. Moreover, the ICIDH was never likely to inspire political allegiance or radical action by and on behalf of disabled people. In practice, the ICIDH and similar models risk collapsing disablement back into impairment-based approaches and neglecting the broader structural causes of the disadvantage faced by disabled people.

The ICF was developed over seven years with continuing input from DPI, the European Disability Forum, and a variety of other organizations of and for disabled people. The ICF has been adopted by DPI because it highlights the role of environments, accommodations, and discriminations. To date, it appears that applications of the ICF have avoided collapsing the social aspects of the experience of disability into individual, medical explanations. Yet the social model approach remains favored by disabled people’s organizations in the United Kingdom and is influential worldwide.

Disability is a complex, multidimensional, scalar concept. As Irving Zola (1989) and many other authors have pointed out, impairment is part of the human condition. Over a lifetime, all individuals experience limitations, vulnerabilities, and permanent or transitory illnesses or impairments. Impairment per se cannot therefore be the defining criterion for a disabled person, although the presence of impairment—or belief that it is present—is necessary for a person to be defined as disabled. The category "disabled people" exists only because social definitions and thresholds have been adopted. Different definitions and thresholds will result in the category's being larger or smaller, excluding or including people with different impairments and experiences. Disability categories play wider roles in social policy, as Deborah Stone has demonstrated in her book *The Disabled State* (1984).

It should be accepted that models and definitions are relative and contingent. Disablement is always a combination of the individual and the structural, the biological and the social. Different questions—medical, psychological, social—have to be investigated at different levels of a disability model. Disabled people experience a combination of bodily restrictions and social barriers, and the two factors cannot easily be extricated from each other. Where the social model would make a polar distinction between "impairment" and "disability," in practice impairment is always already social, and impairment is always implicated in disability.

Therefore, models should not become the touchstone of progress. It may be impossible to choose one model for every situation. A model is not an end in itself, but a means to an end. Models do not matter, in themselves, but are often taken as proxies for wider political or academic affiliations and strategies. Many commentators believe that the debate over models has now become an obstacle to the development of disability studies and achievement of the equality and inclusion of disabled people. Good initiatives have been created on the basis of "medical models" and failures have resulted from "social models," as well as vice versa. Rather than using the concepts "medical model" and "social model" as ways of judging "reactionary" and "progressive," activists and scholars need to pay attention to the details of the research, policies, or provisions that are being attempted. Two fundamental questions underlie all such interventions:

1. *Will this intervention improve the quality of life of disabled people?* Rather than focusing on ideological judgments about models, critical evaluation should explore the outcomes of interventions in terms of the quality of life of disabled people. Quality of life can be improved through the reduction of pain and suffering, the improvement of physical functioning, the provision of aids and adaptations, the removal of social and environmental barriers, and the reduction of discrimination and oppression.
2. *Is this intervention targeting the most appropriate level of disablement?* This question draws attention to the complexity and multidimensionality of disablement. Difficulties arise when medical or individual solutions are offered for problems that are social and structural—and vice versa. Disablement involves medical, psychological, and social aspects, and it cannot be reduced to any one of these dimensions.

Efficiency and appropriateness are major criteria for assessing particular proposals.

—Tom Shakespeare, Jerome E. Bickenbach, David Pfeiffer, and Nicholas Watson

See also International Classification of Functioning, Disability, and Health (ICF/ICIDH); Social Model: Sweden.

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MODERNITY

Modernity expresses the self-definition of a generation about its own technological innovation, population makeup, and "progressive" social organization schemes. To participate in modernity is to conceive of one's society as engaging in organizational and knowledge advances that make one's immediate predecessors appear antiquated or, at least, surpassed. The eminent Victorians thus appeared old-fashioned to a new generation of "moderns" at the beginning of the twentieth century, and the motto of poets of the time was to "make it new." The ubiquitous emphasis on "newness" within modernity signaled an *epistemological break* with the certainties of premodern societies.

Modernity for U.S. and British citizenry of the first half of the twentieth century meant new formats for new thoughts—innovative ways of writing and thinking, the infusion of women's views into university life and male-dominated labor markets, short skirts and short hair, rapid urbanization, a jazz era, and silent film narratives, among other products and technologies. As William Carlos Williams, a preeminent "modern" physician-poet, put it in his poem "To Elsie" (1923): "The pure products of America go crazy." Williams thus conjoins mass production with the now destabilized institutions of family and social life that occur in the wake of the first "modern" war, World War I. The dedicatee of the poem, Elsie, was a "broken-brain" nanny who came to work for the Williams family from an institutional orphanage as an adult ward of the state of New Jersey. The poem thus invests modernity in her figure and makes her into an emblem for speed and productivity in modern America gone awry. Elsie—at least in Williams's celebrated poem—indicates the degree to which the modern age became obsessed with human "defects." Disabled people were continually represented as somehow mis-fit or displaced in the midst of a press to standardize public and private spaces. Their bodies and minds were thought to fall too far short of an idealized, albeit elusive, body—one that would be measured, weighed, surveyed, and assessed for "baseline" capacities.

Thus, the "modern era" (generally identified here as synonymous with the age of industrialization) segmented bodies into their constituent parts. This process of segmenting bodies sought to make labor power more efficient while also rendering any single body replaceable. Assembly lines for autos, such as those instituted by Henry Ford and celebrated as egalitarian mergers of human and machine by the muralist Diego Rivera, implied better practices and technologies for all. But they also further entrenched citizens within a deepening nexus of debt and consumption—conscription to labor power. Ford declared that each worker should earn the purchasing power to drive an automobile even as he would spend his workweek toiling on an assembly line to make cars for others.

Under modernity, technologies develop that yield advantages of speed or efficiency over older terms of labor and consumption that rapidly disappear on a historical horizon. These technologies result in revised workplace organization, often displacing workers with established expertise, at the same time they introduce modifications to the organization of everyday life. From movable type to steam engines, from the telegraph to the advent of photography, technological innovations alter modes of inhabiting environments and daily living for entire population groups. Such innovations also precipitate the mass exclusion of whole communities under various rubrics of inferiority—namely, immigrants, people of color, lower-class people, and disabled people. Often marginalization occurs on the basis of a mutual referencing strategy that is bound up with disability definition. In other words, individuals situated in categories of incapacitation or insufficiency to the demands of a modern world rarely find themselves referenced by only one stigmatizing category. Instead, their bodies become identified as hosting multiple insufficiencies that are often believed to be "biological" in nature.

Behind the development and introduction of technologies are the investments of an increasingly global capital that targets markets and labor pools. The marginalizing strategies of modernity ultimately sought to produce what Marx called "surplus labor pools": labor rendered "superfluous," "expendable," or "excessive" to the needs of capitalist markets. In reality, modernity oversaw strategies of worker disqualification where entire populations found themselves sidelined from the demands of labor. All "inferior" peoples of the modern period presumably shared a natural incapacity to function competitively in the labor market, and, consequently, they were relegated to segregated communities, reservations, almshouses, and workhouses, and—particularly in the case of disability—confinement in colonies, "training centers," and institutions.

To operate within modernity also means to participate in the belief that one finds bold contrast between modern conceptions of the cosmos and the worldview of premoderns or "ancients." "God is dead," declared Friedrich Nietzsche (1844–1900), a famous German philosopher of modernity, not hesitating to add that this was because his contemporaries had killed God off with their own disbelief. In the field of philosophy, premodern beliefs yield to modern dismay about how social systems, from organizations of class privilege to theories of heredity, determine a great deal of life experience for any one individual. Nietzsche himself proposed that modernity is typified by crises in systems of morality, so that once belief is crushed there can be no restoration. Of course, he discussed the fact that many of these crises in self-perception occur due to advancements in knowledge and an uncritical embrace of new technologies.

For example, Copernican proofs that the earth revolves around the sun heralded revolutions in reasoning about the universe and the not-so-central place of humans within it. Charles Darwin's (1809–1882) theories of natural selection, demonstrating as they do that a changing human species evolves among multiple shifting life forms, precipitated the arrival of a fully "modern" sensibility. The founder of modern psychoanalysis, Sigmund Freud (1856–1939), who studied states of psychological aberrance in order to expand definitions of human existence, also typifies, in his work, the displacements wrought during modernity. His proposition that an unconscious conditions human behavior and actions likewise unsettled general Enlightenment faith in human rationality. In the film *Modern Times* (1936) Charlie Chaplin spoofs the users of high-speed contraptions; herein, products "gone crazy" not only foil the ambitions of their users, they also seem to have plans for the users that mechanize all involved.

As this entry has emphasized, technologies themselves participate in this decentering of human confidence in perception and planning. Modernity as a historical coordinate, a mere marker in a chronology of named epochs, depends on the distinction between new modes of existence as well as new perceptions of a self that attends to transport, architecture, mass events, and media that quite simply replace former ways of inhabiting space and experiencing time. Thus, some scholars will even go so far as to locate modernity with the advent of the printing press and the mass circulation of print information that brings about expanded literacy in a middle class during the fifteenth century.

The most prevalently cited examples include microscopic technologies that replace the human eye as an arbiter of evaluation and laboratory heredity texts that can prove parentage with or without testimony. Often bodies themselves experience a new inferiority as they come to be outdistanced by superior visual, aural, and detective devices of modernity. All bodies might come to be perceived as increasingly inadequate without supplementation, even as methods and mechanisms of enhancement, from telephones to typewriters, increase. The camera eye, for example, can seem to capture discrete elements of an activity and therefore offer a vantage point superior to any human eye. Eadweard Muybridge (1830–1904), an early technician of camera and motion, combined scientific experimentation with photography in a series of chronophotographic demonstrations. He famously showed that a horse becomes fully airborne during a cantor. The cinematic eye can therefore improve on the human gaze, wholly delimiting its privileged gaze on reality, just as Freud's modern concept of a human "unconscious" literally undermines the stated intentions of individuals. From a disability studies perspective, it should be noted that Muybridge also did chronophotographic studies of "nonnormative" human gaits, inaugurating an entire field of analysis, known as gait training analysis, that is linked to imaging devices. Likewise, early silent films turned on the "secret" knowledge offered by a camera that showed a beggar getting up and walking away with a charitable offering after having feigned paralysis or blindness. In each instance, the powers accorded to visual recording devices sought to break down, survey, and expose the exact source of dysfunction. This form of modern mechanization shifted conceptions of the body from an "organic" to an increasingly "artificial" entity. In the process, prior ideas about the body as a sacrosanct temple gave way to a more fluid and, ultimately, disposable material being.

This lowering threshold of respect wrought by modernity can be analyzed across numerous fields of inquiry. For instance, many scholars, particularly in the wake of Michel Foucault, connect modernity to medical practices that reference human anatomy as a result of the direct observation of dissected human corpses. The practice of anatomical dissection, with its violation of sacred beliefs about bodily boundaries, neatly encapsulates a change in sensibility toward behaviors that violate sacred prohibitions with the goal of knowledge about bodily mechanics. In his lectures on the topic "abnormal," Michel Foucault locates a rupture between agrarian communities and the arrival of a modern state in its imposition of psychiatric and confinement solutions for bodies deemed pathological. In this scholarship, confinement practices, as opposed to quarantine colonies (such as those for leprosy, tuberculosis, epilepsy, and "insanity"), initiate modernity as a matter of brutal concealments, torture, and controlling technologies that take place under professional purview. Foucault traces a shift toward modern practices when an ordinary "village idiot" becomes susceptible to medical interventions, experimentation, state management, and regulation—in other words, when mere madness becomes mental illness, a modern category to be officiated, contested, recorded, and detected. If corpses can be "cut up," then all bodies become potential targets for a host of modern interventions.

Certainly this clarifies the point that little consensus exists as to when modernity begins. However, histories on and about Western Europe do concur that a modern era arrives at the end of colonial invasion and expansion across the globe, with modernity coming at the end of a chronology that proceeds from the ancient world, the Middle Ages, the Renaissance, the Enlightenment, the Age of Exploration, and the period of colonial expansion. A British writer who straddled colonial expansion and World War I, Ford Madox Ford (1873–1939), wrote a four-volume epic in order to declare that with World War I there would be "no more parades," meaning that the idea of fighting for any heroic cause had been rendered obsolete—the antiquated product of a bygone era. For Ford, wars are fought on behalf of economic interests with little effective resistance to the military conscriptions of modern nation-states. Little meaningful celebration accompanied a "victory" for the living participants who survived such violent enterprises. In short, modernity means that heroism is dead.

In modernity, governance by distant colonizing powers yields to governance by locals, and the boundaries of nation-states are perceived to reflect oversight by resident officials as opposed to colonial military powers. Occurring in tandem with the arrival of modern warfare methods, those capable of enacting genocide on a massive scale, modernity has been thought to indicate awareness of the missionary conceit that colonial settlement plans and military ventures overseas constitute sources of "improvement" for nonmodern geographies. Thus, not only were bodies deemed insufficient, but entire nations could be imagined as "damaged goods." Irish poet William Butler Yeats's dictum that "the center cannot hold" in his poem "The Second Coming" presages the degree to which modern societies seem to experience themselves as fracturing along with the bodies housed within them. As the nineteenth century came to a close, numerous cries could be heard that even the most advanced nations were succumbing to the forces of degeneration. Nations continually assessed their "wealth" in terms of percentages of nondefective bodies inside their borders. As the 1927 U.S. health propaganda film *Are You Fit to Marry?* put it: "As goes its babies so goes the nation." In order to actively improve the "national stock," moderns sought to sequester as many deviants as possible. A dream of homogeneous futures guided much action during the modern period, and social marginals found themselves increasingly under siege by a variety of improvement schemes contrived by "progressives" and other professed social do-gooders.

In 1893, Edvard Munch painted *The Scream,* a figure that is often taken as a quintessential expression of modernity. Munch himself wrote that he had experienced intense fear during a moment of isolation while on an evening walk: "My friends walked on—I stood there, trembling with fear. And I sensed a great, infinite scream pass through nature" (quoted in BBC News 2004). In the painting, wavy lines and a red sky capture the sensation of terror he describes, and Munch's effort to capture his own feelings of besiegement by emotions struck a cord of sentiment for many denizens of the time. Joseph Conrad's 1902 novella *Heart of Darkness,* which is also taken as an emblematic text of modernity, matches the psychic journeying of a European protagonist with the atrocities he recounts having encountered on a colonial venture on the Congo while he drifts in present time in a boat on the Thames. He remembers native bodies tossed aside as mere labor power now exhausted, but he also emblematizes Africa as a site of disease. This would have been so for the European journeyers, such as those who often accompanied David Livingston, who lacked immunity as adults to a common West African childhood illness such as "yellow fever." "The horror, the horror," reputed to be the dying words of the character Kurtz, may refer to the protagonist himself, his venture, or the blissful ignorance of the ultrafeminine "intended," who, as the evident manifestation of civilized society, must be protected from men's savagery at all costs.

Until quite recently, with the dissolution of the Soviet Union, modernity had been taken, more or less, as the matter of an international consensus on nation-state borders. With a growing global practice of commodity capitalism, with capital's requisite ventures to open up consumer markets, modernity now is mostly associated with ever-increasing speed, both in the transport of financial exchanges and in cross-border communications. It is important to note the fact that modernity as crisis, where "the center cannot hold," operates differently across classes and privileged parties. In that sense, modern dislocations may be heralded as opening up new possibilities for those on the periphery—those previously excluded from the spoils of empire and the opportunities of education and leisure time. Hence, women in London and Chicago, African Americans in Harlem, and many others find potential for professional development and expression in the wake of the empire's crises in epistemologies and central governance. Likewise, and particularly for groups, institutions, and colonies of disabled persons, interior pockets of self-governance or incarceration may not yield as readily as schools, churches, or principalities, for example, to oversight from nation-state governance. Thus, they are already "colonies" as opposed to under the purview of central governance.

In sum, nearly all scholars of modernity agree that scientific methods serve neatly to mark a break between modern and ancient in that research designs precisely enable a new means for testing reality—from telescopes to electron microscopes, case notes, surveys, weights, and scales, along with systems for data analysis from means deviation equations to infrared scans. Yet unlike Enlightenment thinking about scientific experimentation, often now termed a mere "faith" in Enlightenment principles, citizens in modernity are wise to the ways that scientific development results in many means for mass destruction and population control alongside material improvements in the standards of daily living. In this respect, theorists of modernity seek out means for resistance, but not necessarily revolution, no longer believing that an equitable society can be gained through military struggle or transcendent social visions. Some have mourned this surrender of revolutionary universal programs as the final capitulation to capitalist logic. The failures of communism to provide fully desirable modes of inhabiting the world inform this pessimism and indicate, themselves, the difficulty in sustaining a belief in any effective counterforce to the new global inequities wrought by venture capitalism.

Inasmuch as modernity displaces a recent past, it is often associated with forward-looking progressive social policies that include modes of social engineering. For disability, then, modernity often indicates ideologies of eugenics and the promise to eradicate certain kinds of human "suffering" and "misery" through prevention and segregation campaigns. With this emphasis underwriting the schemes of modernity with respect to "deviant" bodies, one witnesses an explicit emphasis on bodily rather than social "renewal." Rather than work to make plastic environments more flexible—and thus habitable—modernity sets its sites primarily on the enhancement of individual physicalities and minds to fit inflexible locations. If those bodies fail in such efforts, then they are effectively extracted from participation. The body winds up as the barometer for all interventions—a surface to be molded by the forces of history come home to roost. Modernity can be viewed as a rather sinister program in this respect, one that is led by innovations in manufacturing and economic venues while neglecting the needs of populations that must navigate those very locations as well as many others.

At present, modernity no longer means "modern" as exemplified by the period subsequent to modern warfare, typified by two world wars, and succeeded by postmodernism. Today, theorists of modernity look for the effects of postnationalism in the face of uneven development. The underside of a belief in the goodness of modernity is perpetual interpretation of agrarian regions as underdeveloped. Modernity thus comes to define savage inequities on a global scale; infrastructure development such as roads, plumbing, mass transportation, and labor practices; and cultural biases in the provision of public education. Today, modernity most likely means the rapid-pace movement of global capital, industries run for the profit of invisible shareholders, satellite transmission of images, and immediate transglobal communication. Part of this fluid transcultural passage of capital also entails traffic in disability technologies and policies usually designed for Western contexts. Such an export economy of disability results in absurd situations: Wheelchairs designed for paved streets literally run aground and shatter when faced with the demands of other terrains, and disability service delivery systems designed for consumption practices in one capitalist context fail of inertia in other, less acquisitive, cultural venues.

This glimpse of the underbelly of modernity has come to the fore in influential scholarship and thinking of our own time. For instance, political theorist Zygmunt Bauman (1989) sees modernity through a much darker lens when he observes that Nazi genocidal procedures toward disabled, ethnic, and sexually stigmatized populations became an "inevitable" consequence of the modern regulation of bodies and measures taken for the sake of "population" control. Bauman inflects modernity as riddled with assembly lines and population demographics. Within such regulatory labor systems, some bodies find themselves excluded almost by definition. Within modernity, the rising prominence of labor capacity as synonymous with the privileges of citizenship came to eclipse older definitions of embodied difference (such as monstrosity or marvel). In their place, disability became increasingly tantamount to "incapacity to work." In other words, modernity oversaw a transition of the power of extreme alterity by promoting a domesticating mission that tended to denote disability as a mere loss of productivity. Disability theorists then must consider the ways in which modernity actually produces disability as a matter of displaced persons.

In many ways, disability groups are directly consolidated out of shared predicaments of modernity: those persons who have been displaced from mass transit, trampled in crowd control settings, and indentured for their subsistence to welfare schemes promoting absolute dependency. One thinks of the bodies that cannot make it across moving walkways at railway stations or of buses with steep stairs at their doors, with no alternative navigation pathway in sight. Under modern management practices, categories for "special assistance" get generated in order to accommodate for "normative" patterns and expectations necessitated by policies and practices that prove exclusionary but nonetheless may be insisted upon as mandatory. Voice technology ordering at drive-through restaurants, for example, excludes those who might order by sign language, gesturing, or pointing. Those who can't push open heavy doors must wait until someone comes along who can do so. Disability politics concerns itself with modern environments, from websites to cruise ships to personal facilities, that in demanding body conformities build exclusions into their offering and, therefore, quite undemocratically create groups of nonusers.

—Sharon L. Snyder

See also Citizenship and Civil Rights; Disability Culture; Inclusion and Exclusion.

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MOLECULAR, CELLULAR, AND TISSUE ENGINEERING

Molecular, cellular, and tissue engineering is an emerging discipline that addresses the principles and development of engineering therapies for restoring the structure and function of disordered molecules, cells, and tissues. Pathological disorders occur in biological systems at the molecular, cellular, and tissue levels in response to genetic alterations and environmental stimulations induced by chemical, microbiological, and physical factors. Engineering therapies are established based on the mechanisms of pathological disorders and principles of biomedical engineering (see Langer and Vacanti 1993; Liu 1999).

Molecular disorders occur due to mutation of genes or alterations in gene activity. Gene mutation often abolishes protein expression or generates malfunctioned proteins, whereas alterations in gene activity induce an increase or decrease in protein production. These changes influence cellular activities, such as cell proliferation, differentiation, apoptosis, migration, and adhesion, inducing or enhancing pathological disorders. For gene mutation-induced disorders, such as sickle-cell anemia, mutant genes can be identified, analyzed, and manipulated through the use of genetic technologies. A therapeutic strategy for such disorders is to replace the mutant gene with a natural or engineered gene, which can be expressed to correct mutation-induced disorders. An example of such a strategy is the introduction of an engineered beta A-globin gene into hematopoietic stem cells to treat sickle-cell anemia, which is caused by the formation of abnormal hemoglobin due to a single-point mutation in the beta A-globin gene (see Pawliuk et al. 2001). For disorders due to alterations in gene activity, such as atherosclerosis, genes involved in pathogenic processes can be identified and analyzed through molecular approaches. An effective engineering approach for such disorders is to introduce into target cells with genes encoding proteins that suppress pathogenic processes induced by altered gene activities. An example is the introduction of growth inhibitor genes into atheromatous cells to suppress cell proliferation and thus to reduce the progression of atherosclerosis, a disorder enhanced by the up-regulation of growth factor genes (see Dzau, Braun-Dullaeus, and Sedding 2002).

Cell and tissue injuries or disorders occur due to physical impacts, chemical toxication, ischemia, cancerous metastasis, and/or microbiological infection, resulting in disability of involved organs. A therapeutic strategy is to identify and collect functional cells from the hosts or donors, regenerate cells in vitro, construct cell-based tissues by incorporating cells into scaffolds of biological matrix or synthetic polymers, and replace disabled cells and tissues with regenerated cells or tissue constructs. Such an engineering approach can facilitate the regeneration of injured tissues and prevent permanent organ disability. Because stem cells, including embryonic and adult stem cells, are capable of self-renewing, differentiating, and repopulating, these are preferred cells for cellular and tissue engineering. An example is the repair of bone defects with bone stem cells from the marrow stroma (see Quarto et al. 2001).

For the past decade, experimental investigations have provided sufficient information for the establishment of molecular, cellular, and tissue engineering therapies. Clinical trials have been conducted to test the feasibility and effectiveness of these therapies. It is expected that molecular, cellular, and tissue engineering will contribute significantly to the treatment of human disorders and disabilities.

—Shu Q. Liu

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MONSTERS

For most of Western history, the monster exemplified one extreme form of what is now known as disability, the departure from expected physical type. Monsters included a variety of people and animals with dramatic and obvious congenital anomalies, such as conjoined twins and intersexuals, beings with too many or too few members, and the unusually short or unusually tall. Although even in its heyday, the medieval and early modern period, the category of the monstrous overlapped only imperfectly with disability, it nonetheless shaped modern attitudes toward people whose bodies lie outside the norm.

Medieval European writers derived the word *monster* from the Latin verb *monere,* which means “to warn.” In Christian Europe, as in the ancient world, monsters were originally understood as signs of divine displeasure, by which God informed human communities of His anger at their misdeeds and warned them of misfortunes to come if they did not mend their ways. At the same time, however, the term could signal another characteristic of monsters: the fascination they engendered. “Monsters are called monsters,” one seventeenth-century writer noted, “because everyone wants to show them to each other”—a play on the Latin verb *monstrare,* which means “to show” (see Daston and Park 1998:200). Thus, at the root of the premodern understanding of monsters lay two powerful ideas: spectacle and threat.

The idea of threat was at first the most powerful. For the Greeks and Romans, as for medieval Europeans, monstrous births were one type of portent or prodigy, a category that included celestial apparitions, comets, earthquakes, and unusual meteorological phenomena. As signs of divine wrath, they evoked terror and dread. In 1317, for example, when conjoined twin boys were born in the countryside outside of Florence, the city fathers refused to look on them out of fear, and a bas-relief depiction of the boys was placed over the gate of one of the local foundling hospitals to spur the population to live in conformity with God’s will. Many such children died in infancy—the Florentine twins lived only 20 days—and some were even killed at birth out of fear that they might harbor demons; having delivered their threatening message, they had fulfilled their purpose.

Even in the Middle Ages, however, we find other, less fearful reactions to people of anomalous appearance. The English chronicler Matthew Paris recorded the arrival in 1249 of an extraordinary young man in the Isle of Wight: "He was not a dwarf, for his limbs were of just proportions; he was hardly three feet tall but had ceased to grow. The queen ordered him to be taken around with him as a trick of nature to arouse the astonishment of onlookers" (quoted in Daston and Park 1998:190). Some 250 years later, around 1500, there is evidence of commercial display; parents or guardians of monstrous children took them from town to town, showing them for money, and some cities began to issue licenses or permits for spectacles of this sort.

Over the course of the sixteenth and seventeenth centuries, this practice became increasingly common. Adult men and women displayed themselves in inns, taverns, and fairs, advertising their unusual appearances and abilities in broadsides and flyers, and became the guests of princes and nobles. Petrus Gonsalvus, a native of the Canary Islands whose face was covered with long, silky hair, was raised at the court of Henri II of France and, together with his wife and equally hairy children, was memorialized in contemporary portraits that emphasized his noble bearing and exquisite attire.

This culture of display bespoke a different attitude toward monsters than the horror engendered by the fear of divine wrath. Philosophers and popular writers referred to people with unusual anatomies in terms of admiration and appreciation, describing them as signs of God's marvelous creativity and unceasing power for innovation; those who were lucky enough to view or meet many such individuals—medical men, collectors of broadsides, frequenters of fairs and taverns—prided themselves on their connoisseurship and their ability to make fine distinctions between the merely unusual and the absolutely unique. Like works of art, these special products of divine craftsmanship were collected, both alive and dead, by rulers and wealthy elites.

By the second half of the seventeenth century, scholars and medical men also were engaging in the intensive study and description of monsters as part of an effort to untangle the natural order of the world. This effort was not new. Medieval and Renaissance physicians and natural philosophers had also offered natural explanations for the birth of people of unusual appearance. The French surgeon Ambroise Paré invoked, among other things, the presence of too much or too little matter in the uterus, the effects of maternal imagination, and the workings of chance. But late-seventeenth- and eighteenth-century naturalists—the protagonists of the intellectual movement often known as the Scientific Revolution—increasingly understood nature in a new way: as governed not by general habits or regularities, violable in both principle and practice, but as governed by inalterable laws. This new investment in natural uniformity began to deprive monsters of their scientific interest and their appeal. They were seen increasingly as embarrassing mistakes that marred the natural order and uniform beauty of the world. In a world where the physical norm—a concept pioneered by the Belgian statistician Adolphe Quételet (1796–1874)—came quickly to be identified with the ideal, people with unusual anatomies were reconceived as ugly, abnormal, even pathological.

By the nineteenth century, the fear of monsters as portents of divine wrath had gradually lost its hold, and the reaction to monsters as abnormal, even repellent, coexisted with curiosity and fascination. The freak shows that flourished from the mid-nineteenth century to the mid-twentieth century, of which the most famous example in the United States was that operated by P. T. Barnum, were similar to the displays of armless men, giants, and hairy ladies at the fairs of seventeenth- and eighteenth-century Europe with respect to the crowds they attracted and the diversity of reactions they inspired. The same might be said of some more recent daytime television talk shows. For white, middle-class nineteenth-century Americans, people with unusual anatomies—many of them of exotic birth, like the "Siamese" conjoined twins Chang and Eng and the hairy Mexican Indian Julia Pastrana, advertised as the "ugliest woman in the world"—evoked fascination with the truly different and satisfaction with their own conformity to modern, "civilized" norms.

Perhaps the most dramatic change in attitudes toward people whose appearance challenged such norms, however, came in the years after 1900, as these people became increasingly subject to medical scrutiny. Although medical men had long presented themselves as experts on human anatomy, including anatomical irregularities, they had never claimed to be able to correct such irregularities—that was beyond their technical skill. Because monstrous people were not treatable, however different they might appear from others, they were not, by definition, ill. With new developments in surgery, however—anesthesia, antisepsis, new imaging technologies—doctors not only began to medicalize such conditions, describing them in terms of medical pathology, they attempted to intervene surgically to “fix” them. Intersexuals (long referred to as “hermaphrodites”) had their genitals normalized, and conjoined twins were separated in infancy. More recently, surgical and hormonal interventions have been deployed to normalize height as well.

In some cases, such interventions have met with dramatic success, increasing mobility and social acceptance. In others, the record is far more ambiguous, as in the case of conjoined twins “sacrificed” in separation operations. There is no question, however, that the medicalization of unusual anatomies has done little to lessen their stigma. Not only have people with such anatomies been reconfigured as victims and as patients—whether or not they are subject to cure—but the unquestioned power of effective reconstructive and cosmetic surgical techniques has reduced the range of appearances deemed socially acceptable, paradoxically enlarging the ranks of people who see themselves, or are seen, as “monstrous,” despite their having anatomies that would have evoked little reaction—or even positive reaction—in earlier periods. Thus, intersexuals are no longer seen as marvelous emblems of divine fertility; rather, they are viewed as physical deviants to be fixed at birth.

In sum, neither the fear nor the fascination engendered by people with socially challenging appearances has disappeared over the course of time. Rather, the fear and fascination have taken changing forms as the meanings associated with unusual anatomies have themselves changed. No longer seen as signs of divine wrath, symbols of an admirable natural diversity, or emblems of an imperfect and exotic Other, monsters are now interpreted in terms of pathology, dependent on the doctor’s extraordinary power to both harm and heal.

—Katharine Park

See also Freak Show; Normality.

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MONTESSORI, MARIA (1870–1952)

Italian physician and educator

Maria Montessori was born in 1870 in Chiaravalla, Italy, and died in 1952 in the Netherlands. She is known as the founder of a pedagogical method specifically intended for children between the ages of 3 and 12 years. Montessori studied engineering science, mathematics, physics, and medicine and became one of the first female physicians in Italy in 1896. She was also an active supporter of the international bourgeois feminist movement. During her tenure at the psychiatric clinic of the University of Rome, Montessori developed an interest in disabled children. In 1899, she and Giuseppe Montesano founded the Scuola Magistrale Ortofrenica, which was both an educational institute for disabled children and a training institute for instructors. In 1898, Montessori gave birth to their son Mario, who lived in a foster family until the age of 15.

Montessori was a lecturer of disability pedagogy from 1900 to 1918 at the Regio Instituto Superiore Femminile di Magistero in Rome. In 1907, she founded the Casa dei Bambini in the working-class neighborhood of San Lorenzo in Rome. Her pedagogical convictions and stimuli for the development of her own didactic material were inspired by Jean Itard (1774–1838) and Edouard Séguin (1812–1880). Above all, she relied on the concept of sensory-based instruction as a means for developing intellectual competence. With help of the so-called prepared environment, the child should, allowing for the greatest possible independence, foster his or her own development (the child's own inner "building plan"). The didactic material, which should be available once per group, serves as a "polarization of attentiveness." Further methodological principles include the age-mixed grouping of children and instructors' stepping back as much as possible to facilitate children's self-education.

Montessori traveled extensively and presented her work—with the support of her son—in order to disseminate her ideas. In addition, the worldwide Foundation for Instruction and Apprenticeship sponsored the publication of her pedagogy. In 1928, the Regia Scuola Magistrale di Metodo Montessori was established in Rome; in 1929, the International Montessori Association emerged in Copenhagen (this organization was later headquartered in Amsterdam). Maria Montessori was nominated for the Nobel Peace Prize three times.

—Vera Moser

See also Jean Marc Gaspard Itard; Edouard Onesimus Séguin.

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MOON, WILLIAM (1818–1894)

British evangelist and blind activist

William Moon, an Englishman who was partially sighted in childhood and blind in his teens, spent his life in Christian evangelism and enabling blind people to read. In 1847, he developed an embossed script based on Roman capitals that blind adults could learn to read in a few days and began a monthly magazine using the script. Moon's script facilitated the integrated education of blind children in many schools across Britain. One of his strategies was to teach sighted children to use the embossed material and then send them out to find blind people whom they would teach to read or blind children whom they could bring to school. From the 1850s onward, the script was transferred to India, China, Egypt, Australia, and West Africa by missionaries who included blind children in the schools they established and taught blind adults at home. Many of Moon's home teachers were blind men who walked great distances to serve other blind people. By 1880, Moon's annual report claimed to have reading material in 194 languages. Moon's script was the first reading system for the blind to be widely adopted across the world, but was costly to print. It was overtaken in the late nineteenth century by Braille, which was cheaper and could be produced by blind individuals for themselves. Moon's system is still used in Britain by people whose fingertips lack the sensitivity to use Braille.

—Kumur B. Selim

See also Agnes Gutzlaff; C. Colden Hoffman; Jane Leupolt.

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MOSCOW THEATER OF MIME AND GESTURE

Founded in 1962, the Moscow Theater of Mime and Gesture (Moskovskii teatr mimiki I zhesta) was the first professional deaf theater in the world. The theater has been in continuous operation for more than 40 years and has staged more than 100 classic and modern plays by Russian playwrights and playwrights of other nationalities. It has won many Russian and international theater contests and has toured in many countries.

—*Anna Komarova and*
Victor Palenny

See also National Theatre of the Deaf (United States).

MOVEMENT OF DISABLED PEOPLE, GERMANY

See Advocacy Movements: Germany

MULTIPLE SCLEROSIS

Multiple sclerosis (MS) is the most common demyelinating disease of the central nervous system, named for focal scars in the brain, spinal cord, and optic nerve. Myelin insulates the impulse-transmitting extensions (axons) from nerve cells and promotes fast transmission of electrical impulses. Demyelination results in slowing of impulse conduction. Clinical manifestations include sensory, motor, visual, gait, balance, bladder, speech, swallowing, sexual, mood, and cognitive disturbances, as well as spasticity, weakness, and fatigue. Ultimately, demyelination can result in axon loss, causing permanent damage. Diagnosis of MS is based on clinical presentation, nerve transmission, spinal fluid, and imaging studies.

Jean Martin Charcot provided the first clinical-histological description of MS in 1868. Since then, theories regarding the etiology of MS have included abnormal sweat suppression, toxins, poor circulation, allergy, and viruses. The prevailing theory today is that MS is an autoimmune disease—that is, the body attacks its own nervous system—that may occur preferentially in genetically susceptible people. Immune function in MS is studied in animals with experimental autoimmune encephalomyelitis.

MS most commonly affects women of childbearing age and of northern European descent. The best medical prognosis is in young women who first present with sensory symptoms and whose disease is relapsing-remitting (i.e., periods of exacerbation alternate with periods of improvement) rather than chronically progressive. Pregnancy does not affect long-term outcomes. MS does not alter lifespan. Psychological stress is suspected to exacerbate symptom severity.

Pharmacotherapy for MS includes medications to manage spasticity, pain, bladder dysfunction, sexual dysfunction, and fatigue, as well as corticosteroids to reduce exacerbation severity. In the 1990s, chemicals that modulate the immune system (immunomodulators), thought to alter the course of MS, were developed. Immunomodulators are used widely today, despite possible debilitating side effects. On the horizon are neuroprotective agents, stem cell transplants, and gene therapies.

The course of MS is highly variable. MS can result in a range of disability, from nearly none to the inability to write, speak, and walk. Physical therapy, occupational therapy, adaptive devices for ambulation and function in the home and workplace, and psychological and social supports are critical components of overall care.

As young adults adjust to new careers and families, those with MS must also adjust to loss of body function and the social stigma and losses of self-esteem, job opportunities, family time, and independence that come with it. Unpredictability of disease course makes acceptance and coping particularly difficult, both for the individual with MS and for the primary caregiver. Community support networks can help individuals with MS and their families adapt to disruptions in social, family, and work life, and can help to maximize both functional status and quality of life. In recent years, the Internet has increased the accessibility of individualized information on MS, clinical trials, and support networks.

Currently, there is no cure for MS. Its etiology—and whether more than one etiology could result in the clinical picture characterized as "MS"—has not been definitively determined. In the future, increased understanding of interactions among genes, immunity, central nervous system damage, clinical manifestations of disease, and psychosocial well-being will allow medical practitioners to provide maximally effective individualized treatment programs.

—*Dorothy Weiss*

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MURPHY, ROBERT FRANCIS

(1924–1990)

American anthropologist and disability scholar

Robert Murphy was one of the most influential scholars in the field of disability studies. His work proved critical to the disciplinary beginnings of disability studies as a field that challenged the medicalization of human differences as pathology. In 1976, at the age of 52, Murphy was diagnosed with an inoperable spinal tumor and later became increasingly paralyzed. At the time, he was already an established anthropologist at Columbia University and had spent many years (along with his wife, Yolanda, who was also an anthropologist) in the Amazon among the indigenous peoples. His most significant contribution to disability scholarship is the autobiographical work titled *The Body Silent,* in which Murphy takes up his experience with disability outside of more traditional narrative modes such as the first-person overcoming story. In doing so, he transforms disability into a journey of cultural discovery. As Murphy himself characterizes his efforts, "Since it is the duty of all anthropologists to report on their travels . . . this is my accounting." *The Body Silent* presents Murphy's accounting with the zeal of a field anthropologist investigating an unknown landscape or culture. Murphy thus successfully shifts the understanding of disability from a tragic encounter to one of profound intellectual value. His work moves disability out beyond an individual experience and into a profound analysis of societal and historical investments in bodies that exist outside of aesthetic and functional norms. Ultimately, Murphy's work transforms the disabled body from a socially bequeathed silence into a vehicle of social exposé.

—*David T. Mitchell*

See also Anthropology; Autobiography.

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MUSCULAR DYSTROPHY

The neuromuscular diseases (NMDs) are disorders of muscle or of the peripheral nervous system that cause generalized muscle weakness or paralysis but either mildly affect or completely spare the brain. The weakness most commonly results in inability to achieve or loss of independent ambulation, scoliosis (childhood onset), respiratory complications (which are generally preventable), and occasionally heart failure.

Before the French physician N. Andry's attribution of NMDs to muscle pathology in 1743, it was believed that they were caused by bony lesions. In 1853, the French physicians Duchenne and his colleague Jean Cruveilhier distinguished between generalized weakness due to muscle pathology and "paralysis" denoting muscle dysfunction on the basis of neurological disease. Duchenne described these disorders as resulting from febrile illnesses that affect the spinal cord (later called *poliomyelitis*), from syphilis, and from heavy metal toxins, and both paralyses and muscle diseases (from "impaired circulation or nutrition") could lead to fatty transformation of muscle. The most common and most rapidly progressive NMD has become known as *Duchenne muscular dystrophy.* However, it was not until 1868 that Duchenne distinguished muscular dystrophy, primarily a muscle disorder, from other NMDs. This was 16 years after the English physician Meryon's (1852) classical description of this condition and

32 years after its initial description in Italy (Conte and Gioja 1836).

Meryon (1852) described how a patient died at 16 years of age from acute respiratory failure during a febrile episode with "profuse secretion of mucus from the trachea and larynx" (quoted in Archibald and Vignos 1959). All NMDs cause death by respiratory complications due to weakness of inspiratory, expiratory, and throat (bulbar-innervated) muscles. Inspiratory muscle weakness can result in coma and death from carbon dioxide narcosis. Expiratory (essentially abdominal and chest) muscle weakness results in pneumonia and respiratory failure due to airway secretion encumberment from an ineffective cough. Bulbar muscle dysfunction results in death from massive aspiration of airway secretions; however, this is seen only in advanced bulbar amyotrophic lateral sclerosis (Lou Gehrig's disease) and virtually never in muscular dystrophy or other NMDs. In the case of myopathic disorders, heart muscle weakness (cardiomyopathy) can also result in death.

The inability to find very effective medical treatments or cures for any of these conditions and the failure to appreciate how respiratory muscles can be aided has resulted in therapeutic nihilism (see Dubowitz 1977). However, effective means of preventing or limiting musculotendinous contractures, prolonging ambulation, preventing scoliosis, and increasing limb function are now available; the use of specially designed robotics and computers can prevent morbidity and death and help to maintain a good quality of life for individuals with NMDs (see Bach 2004). The use of inspiratory and expiratory muscle aids can consistently and indefinitely prevent death from respiratory causes (see Bach 2002b), and effective regimens of cardiac medications have been developed that can prolong effective cardiac function for patients with myopathies (see Ishikawa and Bach 2004).

Respiratory muscle aids are devices and techniques that involve the manual or mechanical application of forces to the body or intermittent pressure changes to the airway to assist inspiratory or expiratory muscle function. The devices that act on the body include body ventilators that create atmospheric pressure changes around the thorax and abdomen and exsufflation devices that apply force directly to the body to mechanically displace respiratory muscles. Negative pressure applied to the airway during expiration or coughing assists the expiratory muscles as forced exsufflation just as positive pressure applied to the airway during inhalation (noninvasive ventilation through mouthpieces or nasal interfaces) assists the inspiratory muscles (see Bach 2002b). Despite the extraordinary efficacy of respiratory muscle aids in preventing hospitalizations, resort to tracheotomy, and death (see Gomez-Merino and Bach 2002; Bach et al. 2002; Bach 2002a), respiratory complications continue to cause death for the majority of patients with NMDs (Bach 2002b). This is because of a general lack of awareness of the availability of these aids and the medical community's low level of interest in helping patients with rare conditions that cause severe disabilities.

—John R. Bach

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▣ MUSIC

Ethnomusicologists have long understood that music can be the focus of highly autonomous cultural units whose rules and rituals—including their constructions of (dis)ability—may vary considerably from those of their host communities. What constitutes disability or impairment may differ greatly between a musical "world" and its extramusical environs. For example, in Japan and Ukraine of bygone eras, blindness was far from disabling for professional minstrels. In contrast, deafness, while regarded as a cultural identity rather than a disability by the Deaf, renders participation in music ("musicking") difficult. Nonnormate hand function typically regarded as minimally significant—left-handedness, small hands, single-finger mobility impairment (such as that experienced by composer Robert Schumann)—may be disabling for musicians. Addiction, epistemologically complex as regards disability, becomes exponentially more challenging taxonomically in music, where substance abuse may be regarded as a rite of passage, identification badge, or hearing (that is, musicking) aid.

Mobility impairments mandate either accommodations to facilitate normate musicking or at least nonnormate strategizing. While challenges to musicking with a disability are, ultimately, socially constructed, they may be formidable. Many remain unaddressed.

CLASSICAL MUSIC

Perhaps Western classical music's greatest advocate for disability accommodation was pianist Paul Wittgenstein. After losing his right arm in World War I, Wittgenstein commissioned five one-hand piano works; the concertos by Ravel and Prokofiev became standard repertoire, mostly for two-handed pianists. That compositions originally intended to accommodate Wittgenstein's disability have entered the twentieth-century canon—few modern concertos have—exemplifies universal design principles.

Ambulatory impairment barely impedes classical musicking, significantly affecting only instruments with pedals—keyboards and harp. Mobility-impaired conductors James DePriest and Jeffrey Tate use high stools on the podium. Renowned violinist Itzhak Perlman walks with crutches and performs seated; a colleague carries his instrument onstage. Recent improvements in concert stage/backstage accessibility are said to owe much to Perlman's prominence.

The most famous disabled classical musician was composer Ludwig van Beethoven (1770–1827). Gradual, ultimately profound hearing loss forced the composer to abandon instrumental performance and conducting. Contemporaneous biographical accounts take notice of his use of the adaptive technologies of his day, ear trumpets and conversation books. Many of the latter have been preserved, providing an exceptional biographical reference. Beethoven's compositional prowess was surely undiminished by his deafness. Whether some of his stylistic preferences were shaped by his hearing loss is a matter of speculation.

Contemporary Scottish percussionist Evelyn Glennie also has significant hearing loss. She eschews disability/Deaf identity. Her public statements could be interpreted as anti–Deaf culture; her official website (http://www.evelyn.co.uk) is inaccessible. She is a supporter of the Alexander Graham Bell Foundation, widely perceived as opposed to Deaf culture and a major advocate of orality and cochlear implants.

The late Canadian pianist Glenn Gould (1930–1981) was noted for his musical and personal eccentricities and abandonment of concertizing in favor of an exclusively recording career. His hypochondria and psychological dependence on prescription medications, which Gould obtained in great and often contraindicated variety and in large quantities by going to several physicians who were unaware of what others had prescribed, has been reliably documented. It is widely and exceptionally convincingly speculated that Gould had Asperger's syndrome, a high-functioning condition on the autistic spectrum and a diagnosis virtually unknown at the time of the pianist's death. Whatever Gould's cognitive differences and whatever the affect on his health and quality of life, it is precisely the iconoclasm of his music making—doubtless related to his unique cognitive makeup—that remains highly cherished.

POPULAR MUSIC AND JAZZ

Probably the most disabling aspect of Americanist global popular culture is the insistence that artists be exceptionally physically attractive by normate standards, particularly in youth popular music, where prominent figures with visible disabilities are virtually unknown, with such minor exceptions as late-disabled, established figures like Curtis Mayfield and Teddy Pendergrass, whose careers certainly declined postdisability. (Hidden conditions such as Karen Carpenter's anorexia and the substance addictions of Jimi Hendrix, Janis Joplin, Jim Morrison, Kurt Cobain, and others are common.)

More (under)class conscious musicians have been somewhat more accepting of artists with apparent disabilities. (Alt-)country has produced prominent singers whose impairments, although obvious, do not impede their performance: Vic Chesnutt (paraplegia) and Mel Tillis (speech disfluency).

Important jazz musicians have also been noticeably, although not musically, disabled. They include Benny Goodman band trumpeter Wingy Manone (amputee), pianist Michel Petrucciani (small stature, brittle boned), and blues singer-guitarist Brownie McGhee (mobility impaired). Others, including Charles Mingus (ALS) and Ella Fitzgerald (double amputee, owing to diabetes), were late disabled and continued to work.

Several jazz artists' physical impairments are incorporated seamlessly into their uniquely virtuosic styles. Pianist Horace Parlan, well-known for his work with Charles Mingus and also as a sideman for jazz legends Dexter Gordon, Archie Shepp, and Rahsaan Roland Kirk, had polio that left his right side affected, in particular his right hand, the fourth and fifth fingers of which cannot play at all. Parlan was fortunate that at age eight, piano teacher Mary Alston encouraged him to develop a uniquely personal technique rather than dismissing his musical aspirations. It is interesting to compare the careers of classical pianist Wittgenstein and jazz pianist Parlan. Wittgenstein's disability compelled him to commission a whole new one-handed literature, which, however, provided him only a minuscule repertoire. Parlan, working in an idiom whose essence is flexibility and improvisation, knew no such limits. He is able to play with his unique technique the entire jazz repertoire alongside legendary players.

Even more remarkable than Parlan was Roma guitarist Django Reinhardt. Badly burned at the age of 18, Reinhardt lost most of the use of the fourth and fifth fingers of his left hand. (The left hand uses fingers 2–5 to fret the strings, often simultaneously, when chords are played.) Even less able than Parlan to play with the conventional technique of his instrument, Reinhardt is known for having invented the single-string jazz guitar solo and revered as one of the greatest jazz guitarists of all time.

Singer Jimmy Scott, Billie Holiday's favorite, has Kallmann's syndrome, a hereditary hormonal condition that inhibits growth and prevents the male voice from deepening at puberty. Known for his work with Lionel Hampton, his newly revived career is currently at its peak, with international tours, recordings, and a recent biography.

MUTUAL ASSISTANCE AMONG MUSICIANS WITH DISABILITIES

The notable achievements of individual musicians with disabilities do not justify the lack of technological and other accommodations that would enable more universal musical participation. Organizations of disabled musicians in Canada and the United States provide important models.

Founded in 1988, the Vancouver Adapted Music Society (VAMS) is devoted to facilitating, through the development and commissioning of highly sophisticated technologies, musicking by people with "significant disabilities," mostly mobility impairments. Much of the new technology emphasizes composition and sound synthesis, although real-time performance aids have also been developed. VAMS views music making as inherently valuable rather than therapeutic or rehabilitative. Program participants tend to be avocational, rather than professional, musicians. In 1993, the organization's showcase band, Spinal Chord, recorded an all-original CD titled *Why Be Normal?*

Founded in 1986, the Long Island–based Coalition of Disabled Musicians (CDM) is concerned primarily with professional music making: Several members have acquired workplace disabilities that mandated career changes. CDM advocates and disseminates information about adaptive technologies, typically simpler if no less effective than those developed at VAMS, as well as nontechnological accommodations such as “tag-team performance”—that is, the use of several musicians in alternation as a strategy for dealing with fatigue issues. Like VAMS, CDM has a featured band, Range of Motion.

Organizations like VAMS and CDM have tremendous value for the advancement of music making by people with disabilities. In particular, the development of technologies for composition and sound synthesis and the emphasis of real-time performance address the needs of potential musicians with mobility impairments.

—*Alex J. Lubet*

See also Music and Blindness.

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MUSIC AND BLINDNESS

Blindness usually presents no obstacle to music making; indeed, the blind are often regarded as exceptionally musical. Nations have even reserved classes of musical employment for the blind, and blind musicians have often formed unions.

Blind musicians flourish where musical praxis is predominantly oral. Western classical music’s reliance on notation creates difficulties for blind musicians, and conductors present another problem. Still, notable blind classical musicians include composer-organists Francesco Landini, Louis Vierne, and Jean Langlais, and composer-pianist Joaquin Rodrigo. Louis Braille, inventor of tactile writing and music notation for the blind, was an accomplished organist.

FRANCE

Pierre-François-Victor Foucault (1797–1871) was a blind professional hornist in postrevolutionary Paris and husband of blind author Thérèse-Adèle Husson (1803–1831). Foucault and Husson were partially supported by Quinze-Vingts hospice for the blind, sponsored by French royalty since the thirteenth century. An 1825 census shows that 34 of 225 hospice members were professional musicians, including 9 women, most of Quinze-Vingts’s working blind. While music was considered a suitable occupation for the blind, Foucault’s colleagues defied hospice authority by serving as the house orchestra for the questionably reputed Café des Aveugles (Blind People’s Café), a manifestation of the tendency for the blind of Paris “to form a support network beyond the reach of an institution” (Weygand and Kudlick 2001:140), a transgression likely disapproved by hospice administrators. Braille entered Quinze-Vingts within a year of Foucault and Husson’s departure.

UKRAINE

Since at least the fifteenth century, Ukraine hosted a folk bardic tradition, with singers accompanying themselves on *kobza* (a lute that later evolved into the bandura) or *lira* (hurdy-gurdy). Blindness was obligatory for minstrels, and minstrelsy was reserved as a profession for the blind; artistry was a secondary consideration. Evidently, blind female minstrels sang a cappella and sang a repertoire different from that sung by men. Musical instruction was nearly universal for the blind, perhaps for all otherwise unable to work. Minstrels were associated with the Orthodox Church, but their social position was ambiguous; they were respected as workers and compensated as beggars.

Minstrels’ “remarkably democratic and egalitarian” guilds trained, protected, and policed the profession

(Kononenko 1998:xii). Apprenticeships included musical training as well as training in life/social skills and a secret language. Most guild members owned homes and raised families. Unlike most peasants, they traveled extensively. Minstrels hired sighted child guides, often with disabilities, who typically later became instrument builders, a skill acquired from their blind masters.

In 1939, Joseph Stalin convened a minstrel conference in the Ukraine. Fearing nationalism in minstrels' lyrics, he had all in attendance shot, nearly ending the tradition.

JAPAN

Japan's *biwa hōshi*—blind "lute-priests"—bear remarkable parallels to the minstrels of Ukraine. Even more than in Ukraine, in Japan the art and patronage of mendicant bards were religion based, with Indian and Chinese Buddhist antecedents perhaps as early as the sixth century BCE. The repertoire of the *biwa hōshi* syncretized Buddhism, Shinto, earlier local folk religion, historical narrative, and popular culture.

The principal function of the *biwa hōshi* evolved from spirituality to entertainment. Japanese attitudes toward blindness were complex and ambivalent, combining ancient beliefs that the blind have powers of divination and "extraordinary ability in communicating with invisible, yet very powerful, natural forces" (Matisoff 1978:30) and the Buddhist association of disability with negative karma. Disability was considered an opportunity to accumulate merit for future incarnations, fueling numerous morality tales in art and folk genres. Legendary *biwa hōshi* Semimaru has been described as "an archetype of the performing arts in Japan . . . a virtual 'patron saint'" (Matisoff 1978:6), inspiring stage works for Noh, Bunraku (puppet theater), Kabuki, and Butōh. Semimaru's status rose from local Shinto deity to bodhisattva, Buddha incarnate. The power that the *biwa hōshi* had over important popular narratives advanced his social position.

In the fourteenth century, *biwa hōshi* Akashi Kakuichi founded Tōdōza (the Proper Path Guild), which was eventually recognized by the government as a regulatory agency for blind lutenists. Tōdōza classified members "according to a system of four graded titles, divided into sixteen ranks" (Matisoff 1978:43). Beyond direct government control, the guild assumed the authority of "a country of the blind" (Matisoff 1978:43). Tōdōza was abolished in 1871, early in the modernist, pro-Western Meiji era.

The unionization of blind musicians in Ukraine and Japan implied broad societal consensus that certain categories of musical employment were apt and thus reserved for the blind, owing as much (or more) to extraordinary ability as to disability.

UNITED STATES

American democracy and market economics render impossible the existence of exclusivist guilds of blind musicians such as those established in Japan and Ukraine. The principal achievements of blind American musicians have been in forms of music with African American roots (although some notable blind exponents of these genres are neither American nor African descended). This is likely owing to the prevailing orality of African musical cultures and African American aesthetic preference for deeply personalized interpretation, often including improvisation. One ramification of the high value placed on individuality is that artists shape their interpretations around whatever idiosyncratic musical techniques emanate from their bodies, including vocal range, tone color, level of virtuosity, and the shaping force of a physical disability. African American music has produced distinguished musicians with a variety of impairments, including blindness.

Blindness has been particularly associated with the blues, especially older, acoustic varieties, the institution of the blind bluesman (blind blues musicians are apparently exclusively male) having nearly vanished in electric blues bands. Best known include Blind Lemon Jefferson, Blind Blake, Blind Willie McTell, Blind (or Reverend) Gary Davis, and Sonny Terry—the only one of this group whose sobriquet does not include "Blind." Although many acoustic bluesmen of this era were not blind, playing the blues appears to have been recognized as a suitable calling for blind musicians. Some, like Blind Lemon Jefferson, achieved considerable financial security and social status from their music making.

Although jazz makes greater use of notation than does blues, its prevailing orality/improvisation has made it an expressive medium for numerous blind musicians (not all African American), some of whom are acknowledged masters. They include pianists Art Tatum, Marcus Roberts, and George Shearing; pianist-vocalists Ray Charles and Diane Schuur; and saxophonists Rahsaan Roland Kirk, Lenny Tristano, and Eric Kloss. Among Motown's most illustrious performers and composers is Kennedy Center honoree Stevie Wonder. One of the best-known gospel groups in the United States is the Blind Boys of Alabama. Somewhat more removed from African American roots are folk musician Doc Watson and Latino vocalist-guitarist José Feliciano. Harder to characterize stylistically and largely forgotten musically but vital to disability history is composer-pianist "Blind Tom" Bethune (1849–1908), whose life is chronicled in three volumes by Geneva Southall (1979, 1983, 2002).

ELSEWHERE

Since the 1930s, the Royal New Zealand Foundation of the Blind has operated a program of music education and performances that has its origins in the pre-mainstreaming residential school system. A tradition of blind mendicant street ensembles, reminiscent of Japan and Ukraine, resides in Cuzco, Peru. The award-winning, extensively toured Light and Hope Orchestra of Cairo, made up entirely of women, is the world's only blind symphony orchestra. The South African Blind Musicians Association, which receives federal funding, performed at that nation's South African Music Week in 2002. The "blind-musicians" Listserv (blind-musicians-subscribe@yahoogroups.com) has worldwide subscribership.

Organizations of blind musicians have existed for centuries on nearly every continent. Blind leadership appears to be the rule in such organizations.

—Alex J. Lubet

See also Music.

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MUTATION THEORY

Mutation theory joined two seemingly opposed traditions of evolutionary thought at the beginning of the twentieth century. First, its practitioners accepted the primary contention of saltationist theory, which argues that new species are not formed, as Darwinism holds, through the gradual accumulation of variation over vast epochs, but instead are produced during sudden and unexpected shifts in the constitution of elemental species (a process referred to as *sports*). Second, unlike saltationists, who argue that some organismic variations are inherently undesirable, the first mutationists tended to hold the stricter Darwinian line that all differentiation is for the good of the organism/species. This argument was premised on the belief that more variation provides better opportunities for adaptation to a variable environment. This second emphasis has often escaped the reasoning of evolutionary theorists, many of whom have appeared to be perplexed that mutationists have claimed a Darwinian lineage (see Gould 2003:443). This important dovetailing of seemingly antithetical traditions made mutation theory one of the vanguard movements in twentieth-century evolutionary and, ultimately, genetic theory.

The first self-acknowledged theorist of mutation was the Dutch botanist Hugo de Vries. In his breakthrough two-volume work *The Mutation Theory (Die Mutation Theorie),* de Vries (1909) stubbornly insisted that he was first and foremost a Darwinian in spite of the fact that mutation functions as an expression of what the eugenicist Sir Francis Galton called *sports.* De Vries held that new species arrive suddenly and without prior precedent through the process of mutation, which he defined as "the change of one species into another [due to the formation of] a new center of analogous variations" (pp. 66–67). Rather than simply argue that species are discontinuous from each other—as in the case of neo-Lamarckism—mutation theory originated the idea that variations themselves are discontinuous, as in the cases of "dwarfism," "giantism," and "albinism." In the *O. Lamarckiana* species of plant that de Vries studied, these new species came into existence fully formed and viable while lacking all defining characteristics of the parent generation. Thus, de Vries's analysis focused on the creative force of discontinuity as a prime explanation for the origins of new species. This argument attempted to address a key lack in Darwinian analysis with respect to the incompleteness of the fossil record. Rather than insist that knowledge of the fossil record is insufficient to identify transitional stages in the gradual accumulation of incremental variations over time, de Vries's mutation theory insisted that no such gaps in the genealogical trees of organisms existed. Thus, what appeared to be absences in the fossil record could be marshaled as evidence in favor of a Mendelian and saltationist-based theory of evolution.

Mutationist theories developed after de Vries's work, such as Richard Goldschmidt's (1933) "hopeful monsters" and Gould and Eldredge's (1977) "punctuated equilibrium" theories, not only remained faithful to the saltationist basis for new species formation but also championed de Vries's devotion to the pure Darwinian belief that all variation proves beneficial, including above and below the organismic level. In doing so, mutationist theories have recognized alternative, viable organismic formations (often labeled "disabilities" at the human level) as examples of the creative force of new species coming into existence through mutation. This interpretation flies in the face of eugenicist—and geneticist—assertions that some mutations are monstrosities or organismic abominations. Those who have taken up this stance in favor of productive readings of mutation have been readily critiqued by a discourse that remains faithful to its investment in designating some organismic expressions "unnatural."

Rather than try to settle this dispute of more than 100 years' duration here, we need to ask this question: Why are efforts to embrace rather than malign the existence of recurrent forms of mutation so routinely banished from the theoretical canon of evolutionary and genetic traditions?

—David T. Mitchell

See also Charles Darwin; Evolutionary Theory.

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MUWAFFAK AD-DIN MUZAFFAR (1149–1226)

Egyptian philologist and poet

Muwaffak ad-Din Muzaffar was a blind Egyptian philologist and poet. Ibn Khallikan remarked that Muzaffar's treatise on prosody "testifies, by its excellence, the acute intelligence of the author." He quoted a little of Muzaffar's verse, in which the poet commented, rather wearily, on how strange sighted people found it that he could be in love: "You are in love, and yet you are blind! You love a dark-eyed nymph with rosy lips, yet you never saw the charms of her person; you cannot then say that they captivated your imagination." In a later era, the puzzled questioners might have listened to the radio and had the experience of falling in love with someone's voice; thus Muzaffar's reply, "I love through the medium of my ears," which Ibn Khallikan expanded with similar thoughts from earlier blind poets. The skills of memorizing and expounding Arabic literature, and expressing well-worn ideas about female beauty in neatly turned verse, continued in the thirteenth century to provide an opportunity for a few capable blind men to take part, without much disability, in the literary and courtly life of their times.

—*Kumur B. Selim*

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MYASTHENIA GRAVIS

Myasthenia gravis (MG) is a syndrome of fluctuating skeletal muscle weakness that worsens with use and improves with rest. Eye, facial, oropharyngeal, truncal, and limb muscles may be involved in varying combinations and degrees of severity. MG occurs throughout the world at any age from birth to the tenth decade. Today's overall annual incidence is 20 new MG cases per million individuals, with a remarkable increase with age. Current point prevalence rates of MG are in the range of 100–200 per million population.

The etiology of MG is varied, divided initially between those rare congenital myasthenic syndromes that are genetic and the bulk of MG that is acquired and caused by the body's own immune system attacking itself (autoimmune). The autoimmune conditions are divided into those that possess measurable levels of an antibody to a substance that allows communication between nerves and muscles (acetylcholine receptor, or AChR) and a smaller group that does not. The latter includes those MG patients who have antibodies to a chemical critical to normal muscle function (MuSK).

General treatment measures include rest, high-potassium diet, and avoidance of infections and drugs that exacerbate MG. Except for some of the congenital myasthenic syndromes, drugs that help overcome the diminished communication between nerves and muscles (anticholinesterases) are usually effective for temporary treatment of MG symptoms. Short-term immunological treatments for autoimmune MG emergencies such as breathing difficulties (crisis) include filtering the blood, plasmapheresis, and/or intravenous immunoglobulin. For long-term immunological treatment, therapies differ for early-onset MG, late-onset MG, and MG associated with tumor of the thymus gland, thymoma. Thymectomy is often effective for early-onset MG (before age 50). Drugs that suppress the immune system, including corticosteroids, are useful for late-onset MG and for MG associated with thymoma (following thymectomy). Most MG patients can be treated effectively, but more specific therapies are still needed.

—*John C. Keesey*

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MYOFASCIAL PAIN

DEFINITION AND SYMPTOMS

Myofascial pain is a chronic regional musculoskeletal pain syndrome characterized by the presence of trigger points, which are discrete areas of focal tenderness within a muscle that reproduce the patient's pain and have a characteristic referral pattern when palpated.

The characteristic symptoms of myofascial pain may begin after a discrete trauma or injury or may be of insidious onset. Patients note localized or regional deep aching sensations, which can vary in intensity from mild to severe. The myofascial trigger points of each muscle have their own characteristic pain patterns. Often associated subjective symptoms are present, such as abnormal sweating, vasomotor/ temperature changes, paresthesias ("pins and needles" sensation), edema (swelling), joint stiffness, impaired muscle coordination, decreased work tolerance, fatigue, and weakness.

CAUSE

Although many theories have been developed, no absolute answer has been reached concerning the cause of myofascial pain syndrome. The recent medical literature demonstrates that excess release of acetylcholine (the chemical responsible for communication between the nerve and muscle at the neuromuscular junction) may result in chronic muscle shortening, relative ischemia (diminution of local blood flow), and reduction of energy supply to the muscle.

In addition, in this chronic pain syndrome, neurochemical changes occur at higher-level pain-processing centers in the spinal cord and brain, rendering the nervous system more sensitive to pain. This results in a hypersensitivity to both painful and normally nonpainful stimuli.

PHYSICAL EXAMINATION AND TREATMENT

A comprehensive medical, neurological, and musculoskeletal physical examination is performed to identify underlying structural causes of regional pain, such as sciatica, bursitis, or tendonitis. Thereafter, careful palpation of the painful region is necessary to search for trigger points. Trigger points feel like ropy bands of muscle and are painful when pressure is applied. Pain is often referred distally (away from the area). Pain recognition by the patient is important to confirm that the trigger points are indeed the cause of relevant pain.

The treatment of myofascial pain may be either pharmacological (involving the use of medications) or nonpharmacological. *Pharmacological* treatments may include anti-inflammatory medications (for example, ibuprofen) to help treat any associated bursitis, tendonitis, or other inflammatory condition. Several different types of muscle relaxants are useful as well. Low doses of antidepressants have demonstrated utility in reducing pain even in the absence of clinical depression. In severe cases, botulinum toxin may be injected in the painful musculature. *Nonpharmacological* options include massage, ice, heat, acupuncture, and relaxation training. Trigger point injections are reserved for recalcitrant cases.

Rehabilitation and Exercise

Physical therapy is indicated both to provide local treatment and, most important, to ensure that the patient is educated in appropriate exercise, including stretching, graded strengthening, and aerobic exercise to decrease pain and improve function. An occupational therapist can be helpful in educating the patient on proper body mechanics and improving workplace ergonomics. Reinforcement of appropriate posture, stretching, and relaxation training can be helpful components of rehabilitation.

FUNCTIONAL OUTCOME AND DISABILITY

To date, few outcome studies have examined myofascial pain and its treatment. One research study found improvements in life satisfaction and coping skills as well as decreased sick-leave time after rehabilitation. Growing evidence suggests a link between arm pain and physical risk factors in the workplace. Therefore, possible ergonomic solutions may be forthcoming. No studies have yet been conducted regarding myofascial pain and disability.

—Joanne Borg-Stein

See also Pain.

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MYOPATHY

Myopathy is a general term referring to a disease of the muscle. Myopathies can be subdivided into hereditary and acquired variants. The hereditary myopathies include the various forms of muscular dystrophy, congenital myopathies, metabolic myopathies, and some mitochondrial myopathies. The acquired myopathies include a group of diseases known as the inflammatory myopathies, toxic myopathies caused by drugs or other chemicals, and myopathies due to endocrine dysfunction. All myopathies cause skeletal muscle weakness, which can cause disability.

The hereditary myopathies come from genetic defects affecting the expression of a protein, enzyme, or other structure within muscle. With the explosion of molecular genetics, many of these genetic defects and gene products have been identified. The three most common hereditary myopathies are all forms of muscular dystrophy: Duchenne dystrophy, myotonic dystrophy, and facioscapulohumeral (FSH) dystrophy. Both myotonic and FSH dystrophy are inherited in an autosomal dominant fashion, meaning that an affected parent has a 50 percent chance of passing the disease on to a child. The congenital myopathies are further classified by abnormalities seen on muscle biopsy. In the past, they were also distinguished from the dystrophies by nonprogressive weakness; however, it is now recognized that weakness does progress in some of these disorders.

The metabolic myopathies are caused by abnormalities in glycogen or fat metabolism in muscle, producing weakness, early fatigability, and muscle cramping. Mitochondrial myopathies are caused by abnormalities in the mitochondria, the energy source for cells. Unfortunately, there is no effective pharmacological treatment to reverse weakness caused by the inherited myopathies. However, the use of rehabilitation strategies limits the disability and handicap produced by these diseases.

The acquired myopathies are often treatable with medications. The inflammatory myopathies (dermatomyositis, polymyositis, and inclusion body myositis) are the most common acquired myopathies, with an incidence of 1–2 per 100,000. Dermatomyositis and polymyositis are autoimmune diseases, which can be treated with drugs that modulate the immune system (e.g., steroids). Inclusion body myositis does not respond well to pharmacological treatment. The endocrine myopathies can be treated through correction of the underlying hormonal imbalance, such as hypothyroidism or hyperparathyroidism. The toxic myopathies can be reversed through elimination of the responsible drug or the offending toxin (e.g., alcohol).

The disability associated with myopathies is caused by muscle weakness. Depending on the particular disease, the limb, trunk, breathing, chewing and swallowing, and ocular muscles can all be involved. Some of the myopathies have an abrupt onset with rapid development of weakness (e.g., dermatomyositis), whereas others present with gradual weakness (e.g., some cases of FSH and myotonic dystrophy). Onset can occur in childhood or adulthood. Disability and impairment due to limb muscle weakness can be minimized through the provision of appropriate assistive devices, braces, and alternate modes of mobility (scooter, wheelchair). Respiratory muscle weakness is often managed through the use of noninvasive ventilation and through assistance with coughing. Speech therapists can teach patients compensatory strategies to minimize swallowing and speech difficulties caused by bulbar muscle weakness. In some myopathies, cardiac muscle is involved as well as skeletal muscle, producing another source of disability, which may be managed through medications and/or pacemaker placement.

In the near future, advances in molecular genetics that have identified the causes of many of the inherited myopathies may translate into effective treatments that will reduce the disability caused by these diseases. Likewise, ongoing research on the pharmacological treatment of the inflammatory myopathies may reduce disability from these diseases.

—Lisa S. Krivickas

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N

NARCISSISTIC PERSONALITY DISORDER

Although prevalent in human society since the beginning of recorded history, narcissistic personality disorder has attained prominence as a distinct disability only in the past quarter century through the work of psychoanalysts. The disorder is characterized by most of the following: extreme sensitivity to slights, a grandiose sense of self-importance, a great need for admiration accompanied by a personal lack of empathy, a sense of being so special or unique that only high-status people or institutions are worthy of association, a sense of entitlement (unreasonable expectations of especially favorable treatment), and arrogance.

Rather than seeing them as people who were overly indulged growing up, contemporary psychoanalysts view such persons as having been partly arrested in their emotional development at a stage of early childhood. Seeking the parents' validation and a sense of personal specialness is within normal developmental bounds at age two or three. When such emotional supplies are not adequately provided to them in childhood, the inappropriate seeking of them well into adulthood is the hallmark of people with this disability. Treatment rests on the psychotherapist's tolerance of their self-centered behavior without gratifying it and promoting insight into the patient's exaggerated vulnerability to empathic lapses by the therapist and others in their world.

—*Jerome A. Winer*

See also Psychiatric Disorders; Psychiatry.

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NATIONAL ACTION PLANS IN NORWAY

See Norway: National Action Plans

NATIONAL CENTER FOR MEDICAL REHABILITATION RESEARCH (UNITED STATES)

The National Center for Medical Rehabilitation Research (NCMRR) has primary responsibility for medical rehabilitation research that is supported by the U.S. government's National Institutes of Health (NIH). The center's professed mission is to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of persons with disabilities. Research is emphasized that addresses the health-related problems of people with disabilities and that has implications for enhancing their daily functioning. The center pursues its mission principally by providing multiyear grants-in-aide to investigators located in universities, medical schools, and other institutions throughout the United States.

The *Research Plan for the National Center for Medical Rehabilitation Research* (National Institute of Child Health and Human Development 1993) describes a conceptual framework for identifying research that the NCMRR supports. Seven priority areas are the following:

Improving functional mobility

Promoting behavioral adaptation to functional losses

Assessing the efficacy and outcomes of medical rehabilitation therapies and practices

Developing improved assistive technology

Understanding whole-body system responses to physical impairments and functional changes

Developing more precise methods of measuring impairments, disabilities, and societal and functional limitations

Training research scientists in the field of rehabilitation

The NCMRR's annual expenditure in 2002 for research and research training was $57,659,000. The bulk of those funds supported research grants that originated with unsolicited, investigator-initiated applications for funding that then were submitted to peer review. A small percentage of applications were funded in response to solicitations that were announced by the NCMRR on topics of special importance to the center.

Established by legislation passed by the U.S. Congress in 1990, NCMRR is a component of the National Institute of Child Health and Human Development (NICHD), a part of the NIH. That legislation established two other entities, the National Advisory Board on Medical Rehabilitation Research, and the Medical Rehabilitation Coordinating Committee. The Advisory Board consists of 12 scientists and clinicians in medical rehabilitation, 6 people with disabilities who have been recipients of medical rehabilitation services, and 17 ad hoc members from government agencies that fund research or service programs of relevance to medical rehabilitation. Its principal functions are to recommend research initiatives that it believes the center should undertake and to advise the directors of the NIH, NICHD, and NCMRR on matters and policies relating to the center's programs. The Coordinating Committee is charged with making recommendations to the directors of the NICHD and NCMRR regarding the center's research plan and its activities that are carried out in conjunction with other organizational entities within the NIH and throughout the federal government.

The NCMRR's efforts are organized in terms of three programs. The Biological Sciences Program promotes basic research to provide the scientific underpinnings of clinical rehabilitation. Research supported by this program strives to understand the mechanisms of recovery from, and adaptation to, injury and disease. The Clinical Practice Program applies scientific findings to improve clinical practices in rehabilitation. Work supported in this area includes development of new therapeutic interventions, clinical trials of new interventions, and clinical studies to improve and validate existing rehabilitation practices. The behavioral science portion of the Behavioral Science and Rehabilitation Engineering Program supports research that is relevant to the development or redevelopment of individuals' emotional, cognitive, and behavioral functioning. The rehabilitation engineering component encourages applications of engineering and bioengineering principles to promoting the habilitation or rehabilitation of people with physical disabilities. Examples include research on various forms of assistive technology, including prostheses and devices for wheeled mobility.

—Marcus J. Fuhrer

See also National Institute on Disability and Rehabilitation Research (NIDRR) (United States); Rehabilitation Engineering; Research.

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NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH (NIDRR) (UNITED STATES)

The U.S. National Institute on Disability and Rehabilitation Research (formerly the National Institute on Handicapped Research and hereafter referred to as NIDRR) was established in 1978. The U.S. Congress adopted the Rehabilitation Comprehensive Services and Developmental Disabilities Amendments of 1978 (Public Law 95–602), which removed the engineering and training programs previously administered by the Rehabilitation Services Administration (RSA) in the U.S. Department of Health, Education, and Welfare and placed them in NIDRR located in the newly reorganized Department of Education under the Office of Special Education and Rehabilitative Services. The institute's name was changed to NIDRR by the 1986 amendments to the Rehabilitation Act. The mission of NIDRR is to contribute to the independence of persons of all ages who have disabilities by seeking improved systems, products, and practices in the rehabilitation process.

NIDRR is an old program. The official role of the U.S. government in vocational rehabilitation, prosthesis research, and other disability-related research dates back to the 1930s and 1940s. Much of the groundwork for the current system of rehabilitation research was laid in the 1940s by the National Academy of Sciences and the armed services response to the postwar needs of veterans. A large share of the initial research was conducted by the Department of Defense and the Veterans Administration (VA) on prosthetic devices. The Interagency Committee on Rehabilitation Engineering, a working group composed of representatives of the National Science Foundation, National Bureau of Standards, National Aeronautics and Space Administration (NASA), VA and other agencies, and the Senate Committee on Labor and Human Resources, was responsible for NIDRR's initial long-range plan. The Interagency Committee for Disability Research, which is coordinated by NIDRR, is responsible for reviewing proposed research projects and for identifying areas that overlap with ongoing projects.

NIDRR's initial research plan focused on functional areas of research needs including mobility, communication, function, education, employment, recreation, and activities of daily living. Using a competitive grant process, NIDRR program mechanisms included the following: rehabilitation research and training centers (RRTCs), rehabilitation engineering research centers (RERCs), spinal cord injury rehabilitation centers, centers for deafblind youths, and coordination with international rehabilitation research centers.

After the passage of the Americans with Disabilities Act in 1990, NIDRR increased its emphasis on research related to independent living and community integration. The most recent long-range plan for 1999–2003 was issued in 2000. The disability paradigm, which provides the value framework for the plan, maintains that disability is a product of an interaction between the individual and the environment. The plan listed the following research agenda areas: (a) employment outcomes, (b) health and function, (c) technology for access and function, (d) independent living and community integration, and (e) associated disability research areas such as statistics. The plan also listed priorities for related activities in knowledge dissemination and utilization and capacity building for rehabilitation research. RRTCs and RERCs continued to receive the largest percentage of NIDRR's resources with 22.8 percent and 10.78 percent, respectively, of the $70 million appropriated to NIDRR in fiscal year 1996.

In an enumeration of research and administrative accomplishments from 1993 to 2001, NIDRR identified both administrative reforms and research outcomes. Administrative reforms include reinvigorating the Interagency Committee on Disability Research, overhauling its peer and program review processes and implementing a Center of Excellence model that balances scientific rigor with consumer relevance. Research accomplishments include the following: (a) establishing the first RERC on telerehabilitation, (b) continued decrease of decubitus ulcers and other secondary complications of spinal cord injury, (c) expanding the Traumatic Brain Injury System and initiating a system in Burn Rehabilitation, (d) research support for the accessibility features in the Windows operating system, and (e) initiating voting research.

NIDRR has been involved in a number of science and technology policy issue areas and initiatives during this period including the President's Executive Memorandum on Technology Transfer, the President's Information Technology Advisory Committee and Section 508 and electronic accessibility in the workplace, and signing cooperative agreements with federal laboratories. NIDRR unleashed new international initiatives that included the Web Accessibility Initiative within the World Wide Web Consortium (W3C), and the establishment of an RERC on land mines.

—Katherine D. Seelman

See also National Center for Medical Rehabilitation Research (United States); Rehabilitation Act of 1973 (United States); Rehabilitation Engineering; Research; Telerehabilitation.

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NATIONAL THEATRE OF THE DEAF (UNITED STATES)

The National Theatre of the Deaf (NTD) is the world's first professional deaf theater company and the oldest continually producing touring theater company in the United States. NTD's influence is widespread and renowned: The company has trained most of the deaf theater artists working today, and a number of its alumni have started their own deaf theater companies across the United States and abroad. NTD has also educated generations of hearing audiences about American Sign Language and Deaf culture and provided intercultural experiences that bring both deaf and hearing audiences together. Despite the company's successes, some deaf audience members have criticized the company for gearing productions to primarily hearing audiences.

NTD was conceived and eventually founded by a hearing medical professional and several high-profile, hearing theater artists. Dr. Edna S. Levine, an expert in deafness and psychology as well as an ardent attendee of Deaf amateur performance events, originally conceived the idea for NTD in the late 1950s and early 1960s. She garnered the support of actor Anne Bancroft, who had consulted Levine for research about deafness for her role as Anne Sullivan, the visually impaired teacher of deaf and blind Helen Keller, in Broadway's version of *The Miracle Worke*r. Broadway directors Gene Lasko and Arthur Penn and Tony Award–winning Broadway set designer David Hays also lent their support. Early efforts foundered when the federal government turned down two different grant applications. Hays and Levine continued to pursue funding with the assistance of faculty at Gallaudet University; hearing administrator Mary Switzer of the Department of Health, Education, and Welfare; and deaf and hearing administrators of the Vocational Rehabilitation Administration.

This persistence and networking paid off in 1965 when NTD earned its first federal grant for the 1966–1967 season. Along with federal grants, NTD is supported by corporate donors and ticket revenue. The company's first home was the Eugene O'Neill Memorial Theatre in Waterford, Connecticut, moving to Chester, Connecticut, in 1983, and moving to its current home in Hartford, Connecticut, in 2000. Throughout its history, NTD has collaborated frequently with Gallaudet University faculty and students.

NTD's repertoire includes adaptations of canonical dramatic literature (both Western and non-Western), children's literature, poetry, letters, novels, and fables. The work has appeared on stage, film, and television. The company strives for cultural diversity, a goal furthered by exchanging company members with international deaf theater companies and the regular inclusion of international artists in their professional training programs. In addition, NTD has collaborated with hearing theater luminaries such as Peter Brook, Arvin Brown, Colleen Dewhurst, Bill Irwin, Marcel Marceau, Chita Rivera, Jason Robards, and Peter Sellers.

In addition to its theatrical productions, NTD has included a professional actor-training program (Deaf's Actors Academy, its earliest incarnation founded in 1967), a touring theater for young audiences (Little Theatre of the Deaf, founded in 1968), workshops for deaf playwrights (primarily active from 1977 to 1982), and educational outreach programs. NTD has performed in all 50 of the United States and on five continents.

To appeal simultaneously to both deaf and hearing audiences, NTD has developed a unique theatrical style, a seamless hybrid of corporeal and spoken languages in which audiences "see and hear every word." Because of his background and training as a set and lighting designer, David Hays recognized that the sculptural qualities of sign language theater had the potential to revolutionize theater aesthetics as a whole. In contrast to traditional Western theater's focus on spoken text and realistic acting styles, NTD's performance style emphasizes the spatial and dance-like qualities of human communication. The resulting style blends the spoken word, American Sign Language, sign-mime, invented theatrical sign language, music, and stylized individual and ensemble movement. A hallmark of NTD's style is the creation of visual scenic elements using only the actors' bodies, a few suggestive props, music, and unusual sound effects. NTD employs both deaf and hearing performers. Deaf performers most often portray main characters with hearing actors located on the stage's periphery voicing the main characters' lines, a technique called *shadowing*. Sometimes hearing actors play minor characters as well.

The NTD's performance style and repertoire have not succeeded without controversy. During its early years, while the company was in the process of inventing its theatrical vocabulary, deaf audiences complained that the American Sign Language used in the productions was unintelligible to them. They complained that the signing was performed too quickly and invented signs were cryptic. Furthermore, deaf audiences felt that the material was more often than not geared toward hearing audiences and that Deaf cultural issues went unexplored. Deaf audiences also tended to be suspicious of a company whose leadership was almost entirely hearing. To address these concerns, NTD began developing original work for deaf audiences about Deaf culture. As deaf theater artists became trained and experienced, they moved into leadership positions within the organization and took on more directing and design assignments. Complaints from the deaf community about the productions' unintelligibility have quieted as well. Audiences may have simply become accustomed to NTD's theatrical vocabulary as it has become more conventionalized and used by numerous companies. While the majority of NTD's audiences remain hearing (about 90 percent), over the years the company has dedicated portions of its season to work by, for, and about the Deaf community.

—Carrie Sandahl

See also Aesthetics; Dance; Deaf Culture; Drama and Performance.

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NAZISM

Disabled people have faced both neglect and oppression within different cultures and political systems, throughout history. Yet the period of Nazi control in Germany (1933–1945) is notorious for genocidal policies toward disabled people. In the postwar period, the magnitude and cruelty of the "Final Solution" or Holocaust of the Jewish people has overshadowed the parallel exterminations of disabled people, homosexuals, Gypsies, Communists, Jehovah's Witnesses, and other minorities. Reclaiming the story of the Nazi eugenic and euthanasia program has been an important part of the disability studies project and the political development of the disability movement. Where neo-Nazi groups have been resurgent in America and Europe in the late twentieth century, disabled people have been targeted for abuse, attack, and sometimes murder, showing the continued need for awareness of Nazi ideology.

THE NAZI VIEW OF DISABILITY

Social Darwinism—the application of Herbert Spencer's idea of "the survival of the fittest" (it was English philosopher Spencer who first used the phrase)—was widely accepted and promoted in the Germany of the 1920s. Adolf Hitler's political manifesto, *Mein Kampf*, adopted a strongly social Darwinist approach: "The strongest asserts its will; it is the law of nature" (quoted in Gallagher 1995, p. 21). One of his perennial concerns was with the biological basis of the German race. This took the form of perorations against Slavic or Jewish intermarriage with Germans, and the threat of "mongrelization." It also led Hitler to express prejudice against the weak, sick, and disabled. Thus, he expressed admiration for the Spartan city-state of classical times: "The exposure of the sick, weak, deformed children, in short their destruction, was more decent and in truth a thousand times more humane than the wretched insanity of our day which seeks to preserve the most pathological subjects" (quoted in Gallagher 1995, p. 21).

In his speeches and policies, Adolf Hitler negated both the Christian and humanist traditions, by explicitly promoting militarism and putting the good of the nation above the rights of individuals. For example, he claimed: "Nature is cruel; therefore we are also entitled to be cruel. When I send the flower of German youth into the steel hail of the next war without feeling the slightest regret over the precious German blood that is being spilled, should I not also have the right to eliminate millions of an inferior race that multiplies like vermin?" (quoted in Fest 1974, pp. 679–680).

Mein Kampf is full of prejudice against disabled people and expresses the view that disabled people should be prevented from reproducing. However, these views were not unique to Nazi ideologues: Beliefs about race and fitness had been popular since the late nineteenth century in German science and medicine. Old ideas were reinforced and emboldened by the development of the Nazi movement. During the 1930s, and especially after the takeover of power in 1933, propaganda against disabled people became more common. For example, the film *I Accuse* featured a husband who killed his wife, who was suffering from multiple sclerosis. This idea of mercy killing was to become a major element in the Nazi approach to disability. Other terms used in propaganda posters and films to describe disabled people included "useless eaters," "ballast existence," and "life unworthy of life."

NAZI ACTIONS AGAINST DISABLED PEOPLE

After 1933, eugenic laws were passed in Germany, which prohibited marriage for certain individuals and mandated sterilization for some. These laws were comparable to equivalent legislation in the United States and the Nordic countries. After the advent of war, a covert euthanasia program (T4) was authorized by Hitler, which led to the murder of 70,000 disabled people in six killing centers, largely by gassing them. The main targets for murder were individuals who lived in institutions, particularly people with learning difficulties or mental health problems. After complaints and concerns were raised among the public, the official euthanasia program was halted. However, it was replaced by other measures to murder disabled people and also people with tuberculosis and other diseases, particularly as the German army took over territory to the East—"wild euthanasia" as it was called. The technicians of the T4 program moved on to staff the new extermination centers, which murdered Jews and other minorities. Meanwhile, a children's euthanasia program murdered thousands of disabled children in hospitals, via starvation or lethal injection: this program continued until 1945.

The motivation for euthanasia was largely economic: In the context of war, it was an attempt to save money and resources by eliminating dependent people. The aim of racial purification was often subsidiary to the financial motive; for instance, disabled people outside institutions were less likely to be killed.

As well as official and unofficial euthanasia, disabled people were subjected to medical experimentation, particularly in the concentration camps such as Auschwitz. During the Nazi era, such research was conducted with little or no regard for the rights of the subjects, or concern for the origins of the medical specimens that were used. Corpses or body parts were sent to scientists from residential institutions, killing centers, and concentration camps. For example, Julius Hallervorden, working at the Kaiser Willhelm Institute for Brain Research in Berlin—now the Max Planck Institute—received more than 600 brains from institutions. He was very prominent in the field of neurology and gave his name to Hallervorden-Spatz disease. While the means and values of Nazi science may have been reprehensible, not all the findings can be dismissed as bad science. For example, alongside the eugenic and euthanasia programs, public health physicians were making major discoveries about the causes of cancer, linking tobacco to lung cancer for the first time.

This raises important questions about the extent to which all these developments should be attributed to the Nazis themselves. Hugh Gallagher (1995) argues that "although this program was authorised by Hitler and carried out under the auspices of the National Socialist government of the Third Reich, it would be a mistake to call it a Nazi programme. It was not. The program was conceived by physicians and operated by them. They did the killing. While many of these physicians were Nazis, many more were not. The program's sponsors and senior participants were the leading medical professors and psychiatrists of Germany, men of international reputation" (p. xv).

Nor was eugenics solely a Nazi ideology. In the United States, the Nordic countries, and across the world, involuntary eugenic sterilization was widely used during the twentieth century. However, in adopting official and unofficial euthanasia programs, the Nazi regime went further than any other.

It should be noted that the eugenic and euthanasia programs, although authorized by Hitler and carried out under the National Socialist government of the Third Reich, were largely conceived and carried out by senior medical professionals, not Nazi storm troopers or party ideologues. However, medical professionals were undoubtedly the professional group with the highest percentage of members of the Nazi party (approximately 50 percent). Many Nazi doctors escaped postwar prosecution, and some continued to take a leading role in German and international medical science after 1945.

THE NAZI ANALOGY

Referring to the eugenic and euthanasia programs carried out against disabled people during the Nazi era has rhetorical force in contemporary political arguments. For example, it is not uncommon for disability activists to label modern genetic research or screening services as "Nazi." Individuals who take positions that appear threatening or hostile to disabled people—such as the bioethicist Peter Singer—have been tarred with the "Nazi" epithet.

Equally, advocates of particular screening policies have used the Nazi example as a way of distinguishing between their own ideas and the discredited notions of eugenics that predominated prior to 1945. Distinctions between "bad science" and "evil eugenics" versus "good science" and "reproductive choice" are used to exonerate governments, medical professionals, and families from having immoral motivations or actions. Yet, on closer examination, freedom of choice is not always a reality, and the attitudes of doctors may sometimes sound implicitly or explicitly eugenic.

The descriptor "Nazi" has huge power, and it should be deployed with care and accuracy, not simply as a way of dismissing others with different views. Equally, when arguments about saving money by preventing the birth of disabled people—or about putting the interests of society above those of the individual—are being used by scientists and policy makers, then it is important to remember the past contexts in which these arguments were deployed. Understanding how the abuses of the Nazi era came about—and guarding against similar measures in modern medicine or social policy—remains vital in the twenty-first century, in democracies as well as in less liberal regimes.

—Tom Shakespeare

See also Bioethics; Eugenics; Eugenics: Germany; T4 Program.

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NCMRR

See National Center for Medical Rehabilitation Research (United States).

NESBITT, MURROGH DE BURGH (1889–1959)

South African independent living pioneer

Murrogh de Burgh Nesbitt lost his legs at 13, falling from a train on which he hitched a ride at Jagersfontein. The next 30 years of activity and adventure, overcoming physical obstacles and attitudinal barriers in others' minds, appeared in his much-reprinted autobiography, *The Road to Avalon* (1944), where Nesbitt also sketched his dream of a rural center for self-help rehabilitation, run by disabled people. The dream was realized in 1946, after publication of his first book. A further book (1958), including many descriptions and first-person accounts of people overcoming disabilities, described how the center "Avalon" was built and developed by Nesbitt, his wife Fraan, and a few companions, near Tulbagh in the Winterhoek Mountains, with fundraising and control vested in a committee of like-minded people at Johannesburg. However, by 1951, with Avalon in full swing, the original committee had largely been replaced, and the Nesbitts were ousted from Avalon. They moved to farming in the Orange Free State, living among the Basuto people. Murrogh Nesbitt was years ahead of his time in implementing ideas of self-help, mutual therapy, and the importance of disabled people as leaders and role models.

—*Kumur B. Selim*

See also Disability in Contemporary Africa.

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NETHERLANDS

See Experience of Disability: The Netherlands

NEURAL ENGINEERING

Neural engineering refers to a new discipline that has emerged by combining engineering technologies and mathematical/computational methods with neuroscience techniques. The objective is to enhance our understanding of the functions of the human nervous system. Neural engineering also holds promise to improve human performance, especially after injury or disease. As befits such a broad definition, the field is multidisciplinary, in that it draws from neurological sciences (especially neurobiology and neurology) but also from a diverse range of engineering disciplines, including computer sciences, robotics, material sciences, neural networks, signal processing, and systems modeling and simulation.

While the potential applications of neural engineering are very broad, the discipline offers particular opportunities for improving motor and sensory function after major human central nervous system illnesses such as stroke, traumatic brain injury, or spinal cord injury. In these illnesses, the new technologies can be applied to help reroute neural signals around damaged areas of brain or spinal cord, or to substitute one type of neural signal for another type that is lost after the injury.

A particularly innovative example relating to the descending control of muscle actions in spinal cord injury relies on the application of multi-electrode recording techniques to enable long-term, simultaneous recordings from clusters of neurons in the motor cortex during the performance of skilled voluntary movement tasks. These cortical signals can be used to drive assistive devices, to program electrical stimulation of muscles (functional electrical stimulation or FES), or to interact directly with computers as communication systems.

Leading investigators in this area are Andrew Schwartz (2004) from the University of Pittsburgh, John Donoghue (2002) from Brown University in Rhode Island, and M. A. Nicolelis (Patil et al. 2004) at Duke in North Carolina. Each group has developed impressive animal models that involve recordings from various cortical areas during normal voluntary behaviors. These neural signals are usually filtered and processed to allow them to be used to instruct computers, to control simple robotic devices, or to activate electrical stimulators to control limb muscles. Exemplar approaches includes studies in which primates can be trained to use cortical neuron discharge to control simple planar robots, or they can be used to activate neural stimulators to excite muscles and move joints.

Alternative approaches allow signals from skin or other sensory areas to be routed around damaged areas and to be delivered to the cerebral cortex by other means. For example, sensory signals from the eye or from skin can be detected by a range of electronic sensors then delivered to the cortex in the form of electrical stimulus trains.

Other potentially helpful applications of neural engineering include the development of novel recording systems to allow long-term recording from small groups of nerve fibers in peripheral muscle or skin nerves and the development of implantable stimulators for use in promoting recovery of walking in individuals with spinal cord injury or for the restoration of motor function after cortical damage sustained as a result of stroke. Neural cuffs placed around nerves innervating the foot sole can be used to sense foot contact during walking or to detect other phases of locomotion, allowing accurate programming of muscle nerve stimulation.

Clinical applications of neural engineering are increasing rapidly in number, and there will certainly be many new practical applications emerging over the next few years.

—William Zev Rymer

See also Bioemechanics; Spinal Cord Injury; Stroke; Traumatic Brain Injury.

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NEURASTHENIA

Neurasthenia literally means nerve weakness. Although the New York neurologist and electrotherapist Georg Miller Beard may not have coined the term, contemporaries certainly considered him to be the father of neurasthenia. Beard's publications on neurasthenia appeared from 1869 until 1883, the year that he died. His most influential books were *A Practical Treatise on Nervous Exhaustion (Neurasthenia): Its Symptoms, Nature, Sequences, Treatment* (1880), and *American Nervousness: Its Causes and Consequences* (1881). A German translation of *A Practical Treatise* already appeared in 1881; a French translation followed in 1895. In the meantime, the neurasthenia concept had become widely known on both sides of the Atlantic, including Russia and Italy but also in, for example, the Dutch East Indies. From the early twentieth century onward, the diagnosis would also be introduced in countries such as Japan and China.

The label of neurasthenia was applied to a whole range of physical and mental symptoms, varying from anxiety, despair, phobias, and insomnia to inattention, extreme fatigue, palpitations, migraine, indigestion, and impotence, among others. Neurasthenic symptoms were attributed to a lack of nerve force, stemming from excess demands on the brain, the digestive organs, and the reproductive system. These demands, in turn, were thought to result from the fast pace of modern, urban life. Beard had presented neurasthenia as a truly American disease that was more or less the acceptable by-product of American civilization, but in the European context, next to modernity, heredity and degeneration also figured as explanatory concepts.

The therapeutic repertoire included treatment with electricity; visits to spas, seaside resorts, or the mountains; psychotherapy in combination with a stay in a sanatorium of (mental) hospital; or the rest cure of the American physician Silas Weir Mitchell, consisting of seclusion, bed rest, electrical treatment, a nutritious diet, and massage.

Neurasthenia acquired many different faces, geographically, socially, and through time. Not only was neurasthenia appropriated in many different ways, its popularity as a diagnosis also varied significantly, as did the popularity of its various therapies. Beginning as an affliction of the elite and the educated classes, neurasthenia was later "democratized" to a certain extent, by including ordinary people. Male neurasthenic patients tended to constitute the majority. In America and Europe, neurasthenia's heyday continued into the first decade of the twentieth century. From the early twentieth century onward, neurasthenia shifted from a somatic into a psychic diagnosis. After World War I, the diagnosis of neurasthenia gradually became outdated, although it by no means disappeared, as witnessed by its inclusion in the 10th revision of *International Statistical Classification of Diseases and Related Health Problems* (*ICD-10*) and the fourth edition of *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*). Conditions similar to the ones that used to be called neurasthenia now tend to be labeled as chronic fatigue syndrome. In eastern Asia, neurasthenia is still a preferred diagnosis, presumably because of its somatic rather than mental connotation.

—Marijke Gijswijt-Hofstra

See also Anxiety Disorders.

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NEUROLOGICAL IMPAIRMENTS AND NERVOUS DISORDERS

Neurology is the study of human neuromuscular system, including the brain, spinal cord and roots, peripheral nerves, junctions between nerves and muscles, and the muscles themselves, in health and disease. Neurological impairment arises from an alteration of function in any of these structures and can result from a wide variety of etiologies, from inherited genetic conditions to obstructed blood flow to a particular part of the nervous system. Common neurological symptoms and related disabilities include problems with memory, attention, concentration, speech or language (aphasias); sleep disturbance; visual changes; dizziness or vertigo; fatigue; weakness; involuntary movements or muscle rigidity; pain; loss of sensation or abnormal sensations; and problems with coordination or gait.

Neurology has a long history, and knowledge of the structure and function of the nervous system, along with conceptions of neurological impairments and their related disabilities, can be roughly divided into three phases: the preclassical, classical, and scientific phases. During the preclassical period, from antiquity until the early nineteenth century, medical scientists described several neurological syndromes, including epilepsy (the "sacred disease" or "falling sickness"), migraine and cluster headaches, hemorrhagic stroke (apoplexy), paralysis, and a variety of psychiatric disorders. Anatomical knowledge during this period was largely limited to the gross anatomy of the brain, spinal cord, and peripheral nerves. Concepts of the nervous system's function were correspondingly guided by structural appearance, so that peripheral nerves were believed to be conduits for the flow of animal spirits or nervous fluid; or by extrapolation from simple observation or experimentation, such as the notion of reflex action. With a relatively short human lifespan, limited knowledge of the structure and function of the nervous system, and the absence of effective medications or interventions, neurological disability during the preclassical era frequently involved chronic pain, paralysis, social stigma, and institutionalization.

The classical period of neurology, from the early nineteenth century to the mid-twentieth century, witnessed a dramatic growth in knowledge about the structure and function of the nervous system, and detailed clinical descriptions for dozens of neurological disorders along with their underlying pathology. During this period, neuroanatomy advanced beyond the surface structure to the microscopic descriptions of the nervous system, including individual nerve cells (neurons) and their connections, and provided a foundation for the understanding of normal function and pathophysiology. Physiological concepts were still closely tied to general concepts of nerve impulses and reflex action, but were integrated with psychological notions of inhibition, association, and representation. Many neurological disorders were first described during this period, including the aphasias or disorders of language (Paul Broca, Carl Wernicke, Ludwig Lichtheim), several brainstem stroke syndromes, general paresis and tabes dorsalis (syphilis of the brain and spinal cord), movement disorders such as Parkinson's and Wilson's diseases, multiple sclerosis (Jean Martin Charcot), hemi-transection of the spinal cord (Charles Éduoard Brown-Séquard), and muscular dystrophy (G. B. A. Duchenne).

Although several anesthetics, aspirin, and potent anticonvulsants (phenobarbital and phenytoin) were also developed during the classical period of clinical neurology, disability was still largely related to the progressive or fixed paralyses, chronic pain, and institutionalization, with the addition of traumatic brain lesions resulting from war injuries and generalized syndromes related to combat and advancing technology ("railway spine," neurasthenia, shell shock).

The scientific phase of clinical neurology, dating from the early twentieth century until the present, has produced an explosion of detailed knowledge about the structure and function of the nervous system. Several innovations made this rapid evolution possible, including the development of information theory, storage, and analysis; techniques for molecular and genetic analysis; structural imaging of the nervous system from magnetic resonance imaging (MRI) of the entire brain to electron microscopy of individual neurons and their connections; and techniques for studying brain function such as electroencephalography (EEG), positron-emission tomography (PET), and functional MRI. Knowledge of the different organizational levels of the nervous system (genetic, molecular, membrane, cellular, and functional systems) is now integrated to provide a detailed account of many neurological disorders.

These techniques have also produced new concepts such as neurodegenerative disorders, autoimmune syndromes, disease-modifying drugs, and critical time periods for therapeutic intervention. Indeed, recent decades have seen the development of highly effective symptomatic treatments for many neurological disorders, as well as agents that alter the natural history of neurological diseases. Neurological disability has been likewise transformed by our ability to diagnose neurological disorders at earlier stages, detect and manage risk factors for stroke, alleviate the paroxysmal pain of migraine as well as the chronic pain of peripheral neuropathy, delay the progression of conditions such as Parkinson's and Alzheimer's diseases, and provide technologically advanced treatment or life support for patients with life-threatening neurological conditions.

Examples of common neurological disorders, their associated impairments, and treatments in Western medicine follow:

Movement disorders. Parkinson's disease, the most common movement disorder, involves three cardinal features, namely, tremor, rigidity, and bradykinesia, but it is frequently associated with fatigue, cognitive changes, and sleep disturbance. Medical therapy with carbidopa/levodopa and other dopamine agonists (medications that stimulate dopamine receptors) have significantly reduced these symptoms and their associated disability. Surgical treatment with deep-brain stimulators is available for severe cases.

Headache. Migraine is one of the most common headache syndromes and is frequently associated with severe pain, visual changes, dizziness, nausea, and vomiting, requiring several hours of rest for symptomatic relief. Development of a novel class of neurochemicals (serotonin agonists, or triptans) and the use of antiseizure medications to prevent migraines has significantly reduced the frequency, intensity, and duration of attacks.

Epilepsy. Recurrent seizures involve unpredictable lapses of awareness and are frequently associated with either subtle automatic movements or violent jerking movements of the entire body. They pose significant risks of bodily injury or death. In addition, personal and social activities including driving, employment, and interpersonal relationships are restricted in many cultures. Over a dozen new antiepileptic agents developed over the past 20 years have resulted in significantly fewer medication side effects and some improvement in seizure control. Epilepsy surgery for refractory cases has excellent prognosis in select patients.

Stroke. Temporary or permanent interruption of blood flow to an area of the brain typically can produce a variety of neurological symptoms including aphasia, weakness, visual problems, difficult swallowing, or paralysis, in addition to long-term neurological and medical complications. Recovery of neurological function is highly variable and depends on several factors. Acute intervention with thrombolytic agents (“clot busters”) or revascularization strategies can produce a significant improvement in neurological outcome, but these techniques are underused and limited to a very brief time window after the onset of symptoms.

Demyelinating diseases. Multiple sclerosis is a progressive, disabling autoimmune syndrome that typically affects young women and involves inflammatory lesions in the brain or spinal cord. Typical symptoms include cognitive difficulties and poor memory, loss of eyesight, weakness, incoordination, a decline in gait, incontinence, and prominent fatigue. New chemicals that modulate the immune system reduce the number of acute attacks, but their impact on long-term disability (i.e., average years before a patient is a wheelchair user) is not yet clear. Other medications can alleviate symptoms of profound fatigue and incontinence, improving the disability associated with these symptoms.

Dementia. The most common form, Alzheimer’s-type dementia, is increasing in both incidence and prevalence and typically involves loss of memory and higher intellectual abilities. Symptoms include a progressive loss of memory, difficulty with basic activities of daily living, loss of autonomy, and institutionalization in severe cases. Anticholinesterase agents mildly slow the progression of disease.

Radiculopathies. Symptoms of weakness, muscle atrophy, and numbness in the arms of legs commonly result from compression of a spinal cord root compressed by the bones of the vertebral column, osteoarthritis, or displaced vertebral discs (herniated or “slipped” disc). Physical therapy, anti-inflammatory agents, or surgical decompression or stabilization provide effective symptomatic relief.

Neuropathies. Injury to the peripheral nerves is most commonly produced by chronic disease (diabetes mellitus), toxins (alcohol), infection (leprosy, hepatitis), or repetitive mild trauma (carpal tunnel syndrome). Neuropathies can produce a loss of sensation in distal extremities, abnormal burning or lancinating pain, weakness, and a decline in gait. Minor trauma due to numbness in the feet can lead to major complications such as infection of the bone (osteomyelitis) or destruction of a joint (Charcot joint). Medical treatment of any underlying conditions producing nerve damage and the use of various medications for symptomatic relief can minimize related disability.

Motor neuron disease. Amyotrophic lateral sclerosis (ALS) is a relentlessly progressive disease typically affecting males in the fifth and sixth decades of life that involves symptoms of weakness and spasticity. Disability is typically associated with loss of use of the arms and legs, requiring the use of a wheelchair, as well as progressive weakness of the muscles of speech, swallowing, and breathing. Physical therapy is helpful in managing symptoms of muscle cramping and spasticity but does not have an impact on the overall disability or course of disease.

This brief list of neurological conditions highlights the variability of neurological symptoms and their extraordinary impact on human function, life, and culture. A historical view of neurological conditions and impairments also illustrates the evolving interaction between medical knowledge, technology, practice, and therapeutics across history.

—David Millett

See also Aphasia; Dementia; Diabetes; Epilepsies, Temporal Lobe; Epilepsy; Gait Analysis; Multiple Sclerosis; Neuropathy; Neuropsychiatry; Parkinson's Disease; Repetitive Strain Injuries; Stroke; Vestibular Disorders.

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NEUROPATHY

Neuropathy is a loss of the function of nerves. Symptoms depend on which nerves are damaged. The main motor symptom is weakness, whereas common sensory symptoms are numbness, paresthesias (abnormal sensations such as pricking, tickling, burning, or tingling), and pain. Neuropathy is a common neurological disorder resulting from damage to the peripheral nerves and thus is more often called peripheral neuropathy. Peripheral nerves include the nerves branching off the spine, nerves innervating the head and neck area, and the autonomic nerves regulating functions such as blood pressure and motility of the intestines.

Historically, in the eighteenth and nineteenth centuries, neuropathy was not recognized as a separate disease, but rather diagnosed as progressive paralysis together with many other diseases. In the nineteenth century, many different forms of neuropathy were described as ascending or descending according to the direction in which the disease progressed, because the common thought was that nearly all disorders of the nerves were based on inflammation. A second diagnosis often used was progressive muscular atrophy (degeneration). Due to the work of great nineteenth-century French neurologists such as Jean Martin Charcot and G. B. A. Duchenne, many new diseases were split from this general category of progressive muscular atrophy: various diseases of the muscles, the spinal cord, the brain, and the many diseases of the peripheral nerves, the neuropathies.

Neuropathies can be classified into mononeuropathies when one restricted area is damaged, polyneuropathies if there is damage of the nerves in more areas, and symmetric neuropathies with bilateral manifestations. Another classification is according to which type of nerve is involved. Sensory neuropathies account for damage to nerves carrying sensory information and motor neuropathies for those innervating the muscles.

Common causes of neuropathy are diabetes and alcoholism. Other causes include mechanical pressure such as repetitive strain injuries, direct damage, toxic substances, certain medications, inflammation, autoimmune disorders, and endocrine and hereditary diseases. Recent diagnostic DNA tests have greatly increased our understanding of the complexities of hereditary neuropathies.

Although there is a wide range of causes, the type of damage to the nerves is limited. The nerve is composed of a cell body and a fibrous extension (axon), which conducts electrical nerve impulses. Isolation cells (myelin sheath), which facilitate electrical conduction, surround most of the axons. In toxic or metabolic injuries (e.g., diabetes) the axons and the myelin degenerate, resulting in a numb feeling in the area, the so-called sock or glove hypesthesia. Degeneration of myelin can be due to hereditary, inflammatory, or autoimmune factors and usually shows patchy damage to the myelin sheath.

Treatment of neuropathies involves eliminating or regulating the causes. Surgery can help when a nerve is entrapped; optimizing drug treatment is required in the case of diabetes. Some drugs are prescribed to relieve symptoms such as burning sensation, pain, and painful contractions of muscles. Physical therapy and splints can also relieve the burden of muscle contractions. Some complementary therapies ([electro]acupuncture) can be useful in alleviating symptoms such as pain.

Most hereditary and autoimmune neuropathies are incurable and often show a gradual deterioration leading to a lifelong use of a wheelchair or chronic pain. The impairment of sensory neuropathies, such as those of diabetes or leprosy, can lead to secondary injuries, infection, gangrene, and limb amputation. Providing the means to increase quality of life and improve self-image and providing emotional support are critical for dealing with the disabilities of neuropathy.

—David J. Kopsky and
Jan M. Keppel Hesselink

See also Burns; Diabetes; Neurological Impairments and Nervous Disorders; Pain; Repetitive Strain Injuries.

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NEUROPSYCHIATRY

Neuropsychiatry is a nonboarded subspecialty of the medical discipline of psychiatry that focuses on the treatment of persons whose psychiatric symptoms appear to be most related to *documented* brain disease or brain injury. The term *neuropsychiatry* refers to psychiatrists who have had one or more years of postresidency training in a neuropsychiatry fellowship program or who have had some neurological experience. The qualification, *documented* brain disease, restricts the field of neuropsychiatry and limits the overlap with other related subfields of psychiatry, such as biological psychiatry, in that biological psychiatry attempts to define the biological abnormalities that correlate with mental illness in the otherwise normal brains of psychiatric patients. Because of this difference, patients treated by neuropsychiatrists not only have documented neurological disease but are often under the care of a neurologist as well.

The overlap with the subspecialty of neurology called behavioral neurology is therefore the strongest for neuropsychiatry. However, the differences between these two fields are more significant than their overlap. Behavioral neurologists diagnose and treat the cognitive and behavioral disturbances that correlate with the patient’s documented brain lesions. Neuropsychiatrists view these same brain lesions in the context of the patient’s total psychosocial context and also within the context of the remaining healthy part of the patient’s brain function, that is, the patient’s emotional reaction to his or her brain impairments. In this regard, neuropsychiatry overlaps to some extent with the medical field of physiatry, or rehabilitation medicine, and the psychological subspecialties of neuropsychology and neurorehabilitation.

Neuropsychology is more concerned with the precise measurable characterization of both cognitive and emotional symptoms of brain impairment using standardized testing materials and structured interviews to give as complete as possible a cross-sectional view of the patient’s function. Neurorehabilitation concerns itself with the application of new technologies to promote recovery of brain function or limit the progression of brain disease. Because the neuropsychiatrist has the larger psychosocial picture of the patient in mind and follows the patient longitudinally with relatively frequent follow-up visits, the final integration of the multifaceted care of the brain-impaired patient often falls into the hands of the neuropsychiatrist, which triggers an overlap with the legal and ethical aspects of medicine as a whole.

Therefore, the questions of medical as well as financial competency often arise in the course of the neuropsychiatrist’s longitudinal care of the patient as well as forensic issues related to legal state of mind during impulse dyscontrol in patients with disinhibition due to the progression of their brain disease. This is particularly true in the treatment of older patients who suffer from progressive dementias, and this triggers another overlap with the psychiatric subspecialty of geropsychiatry. Unlike neuropsychiatry, geropsychiatry is a fully established board-accredited subspecialty of psychiatry that specializes in the psychiatric care of older patients who may or may not have documented brain disease but do have psychiatric symptoms.

In the process of treating psychiatric symptoms of brain-impaired patients, both positive symptoms of delusions and hallucinations and negative symptoms of apathy and neglect, as well as mood symptoms such as hypomania and depression and dysexecutive symptoms such as poor judgment and impulse dyscontrol, neuropsychiatrists attempt to make use of the most recent work in integrative (clinical and basic) neuroscience. This includes neuropsychopharmacology, neuroimaging techniques such as single-photon-emission-computed tomography or brain SPECT, magnetic resonance imaging or MRI with its specialized techniques of functional imaging, magnetic resonance angiography, and diffusion tensor imaging, as well as positron-emission tomography or brain PET imaging, with radioligand binding, electroencephalography including EEG (electroencephalographic), MEG (magnetoencephalographic), QEEG (quantitative EEG), and EPs (evoked potentials), clinical neurogenetics, neural network theory, and medical informatics databases. In using these sources of clinical information, the neuropsychiatrist must rely on the expertise of the established practitioners, such as the neuroradiologist and the electrophysiologist, but because the neuropsychiatrist knows the larger history and psychosocial context of the patient and has generally spent more time with the patient in the clinic, it becomes his or her responsibility to make optimal use of this information in guiding the overall treatment plan.

The following are some examples of clinical problems that might be managed by a neuropsychiatrist: (1) a Parkinson's patient with delusions and hallucinations on high doses of dopamine-enhancing medications, (2) a Huntington's patient exhibiting violent behavior and personality changes, (3) a developmentally disabled patient exhibiting self-injurious behavior, (4) a dementia patient who is causing behavioral and social disruptions, (5) a postoperative neurosurgical patient with delirium and speech impairment, (6) a seizure patient with psychosis and/or depression, (7) a patient with recurrent seizures, (8) a patient with chronic fatigue syndrome and decreased cognitive function, (9) a patient with a traumatic brain syndrome with an unstable mood and cognitive impairments, (10) a poststroke patient with apathy, (11) a patient with both schizophrenia and dementia, (12) a patient with Tourette's syndrome and severe obsessive-compulsive disorder, and (13) physical violence in a patient with known brain disease.

A major contribution of neuropsychiatry has been the management of the violent patient with known brain disease. Neuropsychiatrists have been active in treating patients who exhibit patterns of violence related to different types of brain lesions. These include (1) violence related to hypomanic or manic behavior after right parietal stroke, (2) impulsive aggression in the setting of congenital brain abnormality or diencephalic injury, (3) reflexive aggression to transient environmental stimuli in patients with dementia, (4) violence emanating from a dysexecutive syndrome due to prefrontal cortical disease, (5) violence related to deepened affect or delusive ideation in patients with temporolimbic epilepsy, and (6) violence in childhood abuse victims who have experienced traumatic brain injury. Carefully crafted combinations of beta-blockers, anticonvulsants, antipsychotics, serotonin re-uptake inhibitor antidepressants or SSRIs, and psychostimulants have been used to enhance cortical control of limbic circuits for these patients. Decreasing the frequency and intensity of violent behavior in these patients is essential to effective nursing care and rehabilitation as well as outpatient management.

Neuropsychiatrists have helped to significantly reduce morbidity in stroke patients. Stroke is the third leading cause of mortality and morbidity in North America. More than 20 percent of stroke victims become severely depressed, greatly complicating their rehabilitation. Neuroimaging studies suggest that infarction of the left anterior cortex as well as left rostral prefrontal cortex and left rostral caudate area carry the greatest risk for poststroke depression. Vascular dementia is also receiving the attention of neuropsychiatry with extensive use of psychoactive agents especially anticholinesterase inhibitors to enhance cognitive function. Early treatment of stroke and vascular dementia patients with antidepressants and psychostimulants can substantially increase their success at rehabilitation. Also, since the psychiatric symptoms in vascular dementia can often be more disabling than the cognitive deficiencies, the neuropsychiatrist can play a substantial role in improving the patient's overall function. Neuropsychiatrists are also taking an active role in the treatment of other dementias particularly Lewy body dementia, which often presents with delusions and mood instability, and frontotemporal dementia, which frequently presents with anxiety, obsessions, and delusions. The patient's quality-of-life issues with these dementias often depend on the effective control of their psychiatric symptoms.

—Thomas Jobe

See also Delirium; Dementia; Epilepsy; Neurological Impairments and Nervous Disorders; Parkinson's Disease; Psychiatric Disorders; Psychiatry; Schizophrenia; Stroke; Traumatic Brain Injury; Violence.

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NEUROPSYCHOLOGY

Neuropsychology is the study of brain-behavior relationships. Clinical neuropsychology is an applied science dealing with the behavioral manifestation of brain dysfunction. Neuropsychological evaluation therefore entails assessing the various psychological/behavioral functions governed by the brain. Evaluations are useful in differential diagnosis among similarly appearing neurological disorders or between psychiatric and neurological conditions. Neuropsychological assessments often serve as the nucleus of rehabilitation and educational intervention plans and are instrumental in the evaluation of their effectiveness.

As with all psychological evaluations, neuropsychological assessment involves a process of answering clinical questions and responding to unique clinical situations that vary somewhat from patient to patient and across practice settings. The clinical application of neuropsychological principles can be used to determine the etiology and behavioral consequences of disabling conditions, as well as provide medical, rehabilitation, and psychiatric treatment recommendations. Treatment intervention is also an important and developing area within the specialty of neuropsychology.

Lezak (1995) delineated four knowledge areas important for neuropsychological practice: (1) clinical psychotherapeutic and assessment skills, (2) psychometrics, (3) neuroanatomy and functional neuroanatomy, and (4) neuropathologies and their behavioral effects. A fifth important knowledge area is a theoretical understanding of how the previous four content areas interrelate and interact. Such a conceptual framework helps the neuropsychologist integrate the historical information, medical material, current cognitive abilities, and general psychological functioning; provide an accurate description of a person's cognitive strengths and weaknesses; arrive at correct diagnoses (etiological conditions and anatomic location); outline the implications of the results for that person's functional living potential; formulate prognostications; and make clinically useful recommendations or design appropriate treatment interventions.

NEUROPSYCHOLOGICAL ASSESSMENT

There are three general reasons for conducting a neuropsychological evaluation: differential diagnosis, patient care, and research. The first step in the assessment process is defining the questions that need to be answered to meet particular clinical needs. Next, the neuropsychologist must determine what information is required and how best to obtain it. Neuropsychological testing might be only one of several methods used. In fact, a psychological test is simply a sample of behavior obtained under controlled or standardized conditions. Other methods of obtaining information about a person's past and present behavioral capabilities include the case history, clinical interview, mental status examination, direct behavioral observations, and reports of other people who are involved with the patient (e.g., spouse, children, friends, employer, and other professionals such as nursing staff or rehabilitation therapists). If testing is to be conducted, then test selection must be competently addressed. Structuring the testing session, administration procedures, scoring, and clerical issues also are important factors in the overall competent completion of the data collection phase of the evaluation process. Following data collection are the interpretation and application phases of the evaluation process.

A wide variety of cognitive and intellectual abilities are typically assessed during a neuropsychological evaluation. These include attention and concentration; learning and memory; sensory-perceptual abilities; speech and language abilities (sometimes including academic skills such as reading, spelling, and math); visuospatial and visuoconstruction skills; overall intelligence; executive functions (such as abstraction, reasoning, problem solving, behavioral self-monitoring, response discrimination, selection, inhibition, and mental-processing efficiency and flexibility); and psychomotor speed, strength, and coordination. Included are measures of sensory-perceptual input, the two principal central processing systems (verbal-language and nonverbal-visuospatial), executive organization and planning, and response output (motor abilities). Underlying them all are attention, concentration, arousal, and motivation. Although this list of cognitive functions might be organized or labeled differently by different neuropsychological schools of thought, these behaviors would generally be evaluated in most comprehensive neuropsychological evaluations. Frequently, aspects of psychological functioning (i.e., psychopathology, behavioral adjustment, and interpersonal issues) also are included in a neuropsychological evaluation.

Neuropsychological evaluation differs from other neurodiagnostic procedures such as computed tomography (CT) or magnetic resonance imaging (MRI) scans that examine the anatomical structure of the brain. With a neuropsychological evaluation, cognitive capabilities, from which inferences about the brain and its function can be derived, are examined. In this regard, it is similar to neurodiagnostic tests that assess other functional capabilities of the brain. For example, the electroencephalogram (EEG) and event-related potentials (ERPs) measure the electrical activity of the brain, and positron-emission tomography (PET) scans or single-photon-emission-computed tomography (SPECT) scans assess anatomical patterns of cerebral blood flow or metabolic activity. Among these, the neuropsychological evaluation is the only neurodiagnostic procedure that can evaluate how a person cognitively and behaviorally functions in real life. Neuroimaging studies may review a location of dysfunction, but two people with damage in the same brain region may have different behavioral manifestations of that damage. Neuropsychological examinations can identify and quantify those differences.

Neuropsychologists must be aware of the anatomic considerations and behavioral sequelae associated with various etiological conditions in the evaluation and interpretation of data. For example, some cognitive functions depend on well-defined anatomic structures (e.g., lower-level sensory-motor skills and even higher-level perception such as recognition of familiar faces dependent on functions of the sensory-motor strip and bilateral basal occipital-temporal regions, respectively). Other abilities (e.g., new learning, abstract reasoning, and speed of information processing) are diffusely organized or rely on complex interacting cortical and subcortical networks. The effects of brain injury can result not only in deficits in various cognitive abilities but also in the emergence of new behaviors or symptoms such as perseverations, unilateral neglect, or confabulations. Furthermore, congenital conditions (e.g., hydrocephalus, renal disease, William's syndrome) can result in similar deficits that result in learning disability and attentional disorders manifested in infancy and childhood.

NEUROPSYCHOLOGICAL INTERVENTIONS

In addition to neuropsychological evaluations, many neuropsychologists also provide intervention services. The neuropsychologist is informed by general psychological principles and knowledge of adjustment issues and mental health disorders, as well as by the influence of brain-behavior relationships on psychological and behavioral functioning. Treated patient populations include the spectrum of medical, neurological, and psychiatric disorders. Interventions often focus on adjustment, coping, and adaptation issues but may also involve attempts to remediate the adverse cognitive or psychological effects of various neurological disorders. Treatments include adjustment counseling, cognitive-behavioral therapy to deal with the emotional and psychological consequences of various neurological or medical conditions, cognitive rehabilitation therapies designed to enhance recovery or adaptation to cognitive limitation from various disorders, or family/marital therapy.

DIFFERENT PRACTICE SETTINGS

As the field of neuropsychology has grown, practice settings have diversified. Neuropsychological evaluations historically have been used to help determine lesion location in neurology and neurosurgical settings. That function has decreased in importance with the advent of such neuroradiological procedures as CT and MRI scans. However, evaluations remain a frequently requested procedure to help identify the pattern and severity of deficits associated with various brain lesions or neurological conditions. Neuropsychological evaluations are often an important factor in helping medical staff, patients, and families make decisions about treatment issues and placement after hospitalization. They are also important in educational planning and treatment planning for children with developmental and other disabilities. The assessment contributes to the diagnosis of subtle disabilities and clarifies the nature of any cognitive problems underlying learning disabilities.

In rehabilitation settings, neuropsychologists are most typically asked to detail and quantify a given patient's cognitive deficits, as well as explain how these deficits may affect the patient's daily life. Neuropsychologists help identify deficits that would be amenable to treatment and identify behavioral capacities that remain relatively intact and potentially useful in a compensatory fashion for other impaired cognitive functions. Finally, the neuropsychologist is asked to make treatment recommendations. These recommendations are typically for immediate treatment purposes (e.g., while the patient is in the rehabilitation treatment facility) as well as more long-term issues (e.g., are the deficits likely to improve, can the patient drive safely, can the patient return to work or school). In educational settings, neuropsychological evaluations can be important in identifying different learning disabilities, serve as an important ingredient in designing treatment and/or educational plans and in setting realistic goals, and help evaluate the effectiveness of various treatment interventions.

Neuropsychological evaluations continue to play an important role in the differential diagnosis between neurological and psychiatric conditions that may appear clinically similar (e.g., dementia vs. a pseudodementia secondary to depression or anxiety) but that have different prognostic implications and require divergent treatments. Finally, neuropsychological evaluations are appearing with increasing frequency in forensic settings where they are used to help document the presence or absence of behavioral impairments secondary to injuries (personal injury or medical malpractice cases) or in helping to evaluate issues of diminished capacity or disability and competency.

—Rodney D. Vanderploeg and
Heather Belanger

See also Dementia; Psychiatric Disorders; Psychology; Traumatic Brain Injury.

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NEUROSIS

Sigmund Freud's early work with neurotic patients was in a population that was totally disabled and dependent on others for care. Conversion hysteria was reportedly rampant in Europe at the end of the nineteenth century, and Freud's work as a neurologist exposed him to a large number of cases of total disability where no clear-cut organic etiology was evident. Neurotic patients with phobias, conversion symptoms, hysteria, obsessions, repetition compulsions, and inhibitions then and now range in functional level from highly successful to very disabled. The most severe cases are totally dependent on others for care and are still seen in long-term care facilities. Neurotic patients overlap with patients with personality disorders, and symptoms usually have a greater effect on the individual than on his or her friends and family. Some cases of conversion hysteria are still seen and may be more common in certain cultural settings. These patients, as a hundred years ago, are dependent on others, often family, for basic care and are disabled without clear evidence of depression or psychosis.

The extent of disability due to neurotic illness is difficult to quantify as the concept of neurosis has been replaced by a more descriptive diagnostic system. In the past, anxiety neurosis or panic attacks would have been seen as clearly disabling neurotic illness. For example, students who are unable to succeed due to neurotic issues often may end up underemployed rather than fully disabled. Adaptation to other illnesses is also an area where degrees of neuroticism may increase disability. Pseudo-seizures are a condition in which the patient usually unconsciously feigns a very realistic seizure episode witnessed by others. They continue to be a cause of diagnostic confusion and often are found in patients who suffer from genuine organic-based seizures. Disability post-myocardial infarction is also increased in patients with depression and preexisting neurotic illness. Currently, much of organized psychiatric research has focused on treatment and disability prevention in psychotic states and mood and anxiety disorders, and fewer resources have been devoted to the issue of neurotic illness. However, cognitive-behavioral approaches to anxiety, phobia, and dysthymia have led to good symptom improvement and time will tell if the associated disability will diminish with treatment. Also the improvement in anxiety phobia and dysthymia seen with the newer antidepressant medications suggests that neurotic illness may also share an organic substrate with the mental illnesses. Psychoanalysis continues to be used to treat a variety of neurotic illnesses especially when less intense and demanding treatment strategies have failed.

—*Dennis Beedle*

See also Anxiety Disorders; Behavior Therapy; Hysteria.

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NEW ZEALAND

See Experience of Disability: New Zealand

NIDRR

See National Institute on Disability and Rehabilitation Research (United States)

NIETZSCHE, FRIEDRICH

(1844–1900)

German philosopher

Friedrich Nietzsche, the *enfant terrible* of Western philosophy and culture, is usually hailed as the greatest forerunner of twentieth-century intellectual innovations, from psychoanalysis to postmodernism to cultural critiques of various stripes. Reared in pre-Bismarckian Germany, he quickly became its most vociferous critic and exile. His public debut began with an *éclat* over *The Birth of Tragedy out of the Spirit of Music* (1872) that cost him his reputation as the rising young star of classical philology at Basel. Thereafter, he drifted off into increasingly unruly and shrill philosophical and cultural writings, but never found much of an audience until shortly after his death. Once the darling of the Right, he remains the darling of the Left and an inspiration to all counterculturalists.

His writings are treacherous things, open to misreading and misappropriation. As in other matters (such as questions of race, gender equality, power, and violence), so too here Nietzsche can easily be taken to task for his merciless indictments of human disability. After all, doesn't he declare the better part of humanity shriveled and impaired, both psychologically and physically, and for that reason unworthy of life and hence worthy of extermination? And wasn't he from the first happy to view ugliness and deformity as sure signs of degeneracy—as, for instance, in his lifelong crusade against Socrates, that "monstrosity *per defectum*"? In that case, one would have to attribute to Nietzsche not only a distasteful prejudice but something like a pathological obsession. Max Nordau's ([1892] 1993) inclusion of Nietzsche in his gallery of European degenerates seems all too justified.

Nevertheless, several factors tell against these conclusions. First, Nietzsche's true meaning is notoriously hard to locate amid the polyphony—or cacophony—of his writings. Second, much of the time disability, like disease and weakness, seems to be a metaphor for culture, not a reference to the empirical body or to nature. "Nothing is beautiful" or "ugly" intrinsically, "there is no health as such [*an sich*]," and even the infirm demonstrate a will to life and to power that has to be affirmed and admired, yet everyone alive is diseased. How stable is Nietzsche's apparent indictment of disability and disease? If his prescriptions were taken seriously, the entire human race would have to be eradicated. A likelier conclusion is that Nietzsche is embarrassing, not perpetuating, a widespread cultural idiom, by bending it back upon itself. To be sure, this does nothing to erase the prejudice from his texts, although it does a lot to emphasize its untenability.

—James I. Porter

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NIRJE, BENGT (1924–)

Swedish activist

Bengt Nirje is internationally known for his work in promoting self-determination among people with intellectual disabilities. Born in Sweden and educated in comparative literature, law, and philosophy, Nirje's first work with people with disabilities was with the Swedish Red Cross and later with the United Nations where he was a welfare coordinator. As director of the Swedish Parents' Association for Mentally Retarded Children (1961–1971), he formed social clubs for persons with intellectual disabilities. These social clubs gave people with intellectual disabilities opportunities to exercise control over their leisure activities, including the right to take risks and make mistakes.

Nirje was deeply concerned with the lack of power and participation in normal community life experienced by people with intellectual disabilities. His work to formalize the principle of normalization led to the first English publication on the principle in 1969. This paper was highly influential throughout the Western world, particularly with respect to residential care and treatment of people with intellectual disabilities. Nirje's legal advocacy has resulted in the enactment of progressive legislation and policies reflecting the concept of normalization throughout Europe and North America. Nirje is one of the founders of the self-advocacy movement.

—Katherine E. McDonald

See also Niels Erik Bank-Mikkelsen; Normalization.

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NONTI NATAKAM (TAMIL CRIPPLE DRAMA)

The *nonti natakam* (cripple drama), also sometimes *ottraikkaal natakam* (one-legged drama), is a genre of Tamil drama or street theater originating in southeastern India in the seventh century or earlier, having a lame rogue as hero. The protagonist becomes obsessed with a prostitute, engages in crime to fund the habit, is caught stealing a horse, and is punished by amputation of a leg (sometimes also an arm). Next he comes under the influence of a holy man, renounces evil, and regains his limb(s) by intervention of the god Subramaniya (Murukan). This provides a serious frame while lending itself to bawdy, slapstick, and farce as the hero hops about on one leg recounting his sexual and criminal adventures. Disability is clearly portrayed as a consequence of wrong conduct, from which repentance leads to healing. There are also nonti natakam giving Muslim or Christian accounts of similar themes in southern India. These minor dramas can also be linked to broader themes of bandit heroes and kings with physical deformities in Tamil literature, as well as with East Asian and European medieval farce.

—Kumur B. Selim

See also Drama and Performance.

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NORMALITY

Defining normality has presented a puzzle to medicine and society for decades. Health and normality remain obscure concepts particularly in the medical field, which is historically reductionistic and its practitioners trained to recognize and treat pathology. Constructing concepts of normality requires philosophic inquiry as well as experience with general populations of people rather than those presenting only for treatment. As public policy has developed around concepts of disability, the implications for definitions of normality are profound.

The word *normality* derives from the Latin word *norma*, which referred to a tool used to show a square angle and by extension to mean a rule, standard, or principle. Over time, the definition of normal came to mean ordinary, usual, or "naturally occurring." Interestingly, if one applied the "naturally occurring" definition, many individuals born with "anomalies" or "birth defects" or with behaviors different from mainstream could be considered normal. But most societies did not take this definition. Instead, a departure from the typical physical or behavioral characteristics was usually seen as abnormality or deviance.

Although terms such as *normal* and *normality* serve some purpose in medicine and the study of human behaviors, they also perpetuate labeling and discrimination. The utility of the normality concept can be seen in how it benefits or contributes to the well-being of and services to the full range of human beings. Several attempts at defining normality are worth reviewing to examine examples of traits felt to be abnormal. Two different models to normality relevant to disability are the medical and social. Both have merits as well as limitations; attempts at integrating these models would be useful.

Offer and Sabshin (1980) reviewed four perspectives on normality, originally designed for purposes of examining mental health. These perspectives are rooted primarily in the medical model but allow an attempt at integration with the sociological. In their first definition, normality as health, normality is seen to exist in the absence of disease in terms of noticeable pathology and corresponds to medicine's concern with treating patients with observable signs and symptoms of illness. Such a perspective tends to be binary and reductionistic: One is either normal or has a disease. This view obscures the continuum of physiology and functionality that exists in almost every human physical and mental attribute. More important, this view does little to advance the principles of prevention or early intervention in the pathological progression of an altered physiological state.

A good example of the weakness of this approach is seen in the evolution of fetal alcohol syndrome (FAS) in the past two decades. Physicians first diagnosed that condition by a set of criteria including appearance (small head/body, certain facial characteristics), behavioral disorder such as attention deficit, heart defects, sight/hearing problems, and joint anomalies. Useful as this diagnosis is, it did not draw sufficient attention to the fact that maternal alcohol use can be hazardous to the developing fetus. In fact, low levels of maternal alcohol intake, below that seen in typical FAS, can cause milder problems for the fetus and newborn child.

Vitamin deficiency is another good example in which a disease state (e.g., scurvy from the absence of vitamin C) obscures the wide variation in vitamin C intake and blood levels, some of which are dangerously low and interfere with optimal functioning, but not to the extent of meeting the criteria for disease. Clinical medicine sometimes recognizes this problem by employing the term *subclinical* disease, again trying to use categorical distinctions rather than a continuum model, which would show the range of vitamin C levels and note the points within that range where various symptoms of pathological processes may emerge.

A second perspective is normality as utopia. Offer and Sabshin (1980) date this idea back to Sigmund Freud, who wrote, "A normal ego is like normality in general, an ideal fiction." This perspective highlights the ideal form and being, and it recognizes the diverse, interrelated mechanisms that define functionality.

A third perspective is the one most commonly used in medicine today: normality as average, based on the principle of the bell-shaped distribution around a central point where the greatest number (median) or average (mean) of findings (e.g., height, weight, IQ) occur. Various statistical measures further define *deviance* from this center point with boundaries that encompass various percentages of population (e.g., 2/3, 98 percent). By such methods, one can look at the "tails" or outliers in this normal distribution as being so many standard deviations away from normal. If one measures vitamin C intake as an example, this method captures disease state but also reflects subclinical deficiencies.

While there are many limitations to normality as average, there is also inherent value over other definitions of normality. Using this definition and applying it to medicine can define illnesses such as coronary artery disease, obesity, and blindness better than simply deciding when one has it or does not. For example, using a continuum model, we can see that adolescents start depositing plaque on their arteries and that this process continues through life. This allows intervention at any level as well as monitoring for later intervention. Similarly, an individual did not become *morbidly obese* (defined as twice one's "ideal weight") overnight. There was a progression, likely started in childhood, whereby the individual gradually gained weight to the point of severely limiting mobility and causing added health risks. Similar examples of this continuum of a trait can be found for vision, blood sugar levels, intelligence, movement, height, and many other traits that appear first in "normal" form before becoming pathological.

A variation on normality as average is to consider two bell-shaped curves, one representing the distribution of a characteristic, for example, hearing acuity of individuals with known hearing impairment, and compare them with a representative group from the general population without known or perceived hearing loss. The hearing-impaired group will have a narrower curve that will overlap with individuals in the general population on one end of the curve. This overlap consists of a group of individuals who may not be diagnosed as having hearing loss, but indeed show the common characteristic of hearing reduction with age. An interesting part of this example is that such hearing loss with age is considered part of "normal aging."

The continuum method allows for interventions and prevention as can now be seen with worldwide attention to the diets of children in Western countries and its relationship to adult obesity. However, when certain conditions or traits are congenital or currently irreparable (e.g., Down syndrome), intervention or prevention to a more "normal" state is not always possible, and using this as a benchmark might be damaging to a disabled individual.

A final perspective is normality as a transactional system that recognizes that behavior or traits cannot be examined by themselves but only in the context of other systems. It also implies that culture and context help determine what we define as normal: How and what we consider normal varies over time and space, with values shifting according to culture, gender, ethnicity, national origin, and age.

The social model of disability holds that it is society that defines, stigmatizes, and discriminates against the disabled by setting norms for and values on physical appearance and behaviors. This reasoning leads to the conclusion that it is not the physical aspects of the person, per se, that lead to damage. Rather, when a society or culture labels disabled bodies as inferior or diseased, it leads to reduced self-worth as well as devaluation and marginalization in society. The social model conceives of bodies as bearers of differing value as defined by society that acknowledges and distributes economic and social capital depending on these values. People with speech impediments, for example, are made to feel inferior, which directly affects their social interactions, often reduces their capacity to get around in the world, and clearly limits their employability. Social practices from genetic testing and subsequent abortion to devaluations of disabled people throughout childhood and adult life reflect a social definition of normality that can marginalize disabled people and reduce their sense of self-worth.

The social model is critical of the medical model, which is seen as objectifying and reducing the body to objects and conditions to be analyzed, diagnosed, treated, and rehabilitated along with prognostications that often emphasize the negative. What the social model often lacks, however, is a view of how the individual interacts with changing societal values and how technology, medicine, and changing social norms interact to determine the extent to which disabled people can navigate through society and the extent to which they are viewed as "normal." In different times and cultures, individuals with auditory or visual hallucinations have been viewed as having distinct talents and have been seen as healers or savants. At other times, these individuals have been viewed as dangerous and valueless to society. Similarly, people with seizure disorders have been seen as having special gifts and vision; conversely, such people also have been viewed as incapable of the most basic tasks including driving.

The industrialization and urbanization of society also affect the view of disabled people as normal or abnormal increasing the requirements for social maintenance and employment. Individuals with schizophrenia reportedly do better in developing nations and agrarian areas in part because these societies have roles in which the person can fit and provide some sense of belonging and utility within their community.

Three features of human existence are frequently the subject of controversy and labeling: physical characteristics, cognitive/learning capacity, and behavior. One common characteristic that illustrates the many uses and misuses of normality is weight. What is viewed as ideal or normal body size has shown tremendous variation over time and place. In Western society, being "stout" or obese by current standards was formerly a sign of good health and wealth. Since access to a good food supply had been for millennia a sign of one's status in many societies, appearing too lean suggested poverty or ill health. Today in Western society, "thin is in" to the point of encouraging youth to be anorexic and to where liposuction to remove fat is very big business. While this culture of starvation applied primarily to women over the past three decades, it now also affects men. However, in many non-Western societies women are desired for being more full bodied, and there is likely a relationship between this and fertility. Chinese society has been characterized as being very tolerant to the point of extolling the virtue of fatness in men as they age; recent studies show that in China this is also true for women and interestingly, obese men and women among elderly Chinese have lower rates of depressive symptoms. Morbid obesity carries considerable stigma and prejudice in many countries. It is also associated with varying disability such as decreased ambulatory capacity, and when the morbidly obese person enters into health care their providers frequently mirror these societal attitudes.

Cognitive capacity, particularly as measured by intelligence testing, has survived a storm of attacks based in part on how we measure and react to definitions of normal intelligence. The concept that intelligence could be or should be tested began with a nineteenth-century British scientist, Sir Francis Galton, who had training in both biology and early forms of psychology. Galton was strongly influenced by the revolution caused by the 1859 publication of Charles Darwin's *The Origin of Species*, which examined the relationship between heredity and human ability or disability. The general attitude of the time held that the human race had a very small number of both geniuses and idiots, while the vast majority of the human race comprised equally intelligent people. This thinking is typical of the binary method of medicine, which divided the population into disease or normal with the variation of adding "supernormal" or geniuses in this case. Galton believed that mental traits are based on physical factors—inheritable traits—the same as eye color or blood type. With the help of a statistician, Galton discovered the concept of normal distribution or the bell-shaped curve, with most of the population falling between two extremes. He published his ideas on hereditary intelligence in a book titled *Hereditary Genius*, which is recognized as the first scientific investigation into the concept of intelligence. James McKeen Cattell, a student of Galton's, led a brief and intense period of intelligence testing in the United States; this testing quickly fell into disfavor when it was shown that scoring high on the Galton test did not predict whether a student would do well on schoolwork. In France, Alfred Binet devised tests of intelligence and used them to compare "average" students with known "mentally handicapped" students. He found that certain tasks could distinguish the two. Binet calculated the normal abilities for students at each age, resulting in a tool to identify the developmental age of each student.

The idea that a test could determine a child's "mental age" became extremely popular. Just before World War I, German psychologist Wilhelm Stern suggested a better way of expressing results than by mental age. Stern determined his results by finding the ratio between a subject's chronological age and mental age. A 10-year-old scoring one year ahead of chronological age (110) would be less significant than a 5-year-old scoring one year above her chronological age (120) would. Later an American psychologist, Lewis Terman, coined the term *intelligence quotient* (IQ), identifying 100 as average. This method of IQ testing was first put to mass use in placing draftees in World War I in the United States. After the war, many companies and most school systems in the United States began using some form of IQ testing.

The designers of IQ testing had reservations on the potential misuse of testing. As early as 1922, a well-known social commentator, Walter Lippmann, wrote: "One only has to read around in the literature of the subject . . . to see how easily the intelligence test can be turned into an engine of cruelty, how . . . it could turn into a method of stamping a permanent sense of inferiority upon the soul of a child." With the beginning of the civil rights movement, the potential misuse of IQ testing for racist purposes became apparent initially with African Americans and later Latinos. Questions about the reliability and validity of testing and the role of heredity versus environmental enrichment and language curtailed the widespread usage. However, school systems still use IQ testing as one factor in determining the need for special education. Such usage might be valuable, but the stigma associated with the testing implies that students placed this way are innately less intelligent and, more critically, may never be capable of being "mainstreamed" back to regular classrooms.

The concept of intelligence and its measurement has continued to evolve, despite problems and testing misuses. In 1983, Howard Gardner argued that "reason, intelligence, logic and knowledge are not synonymous," setting forth a theory of multiple intelligences. Gardner defined seven distinct intelligences: logical-mathematical, linguistic, spatial, musical, bodily-kinesthetic, intrapersonal, and interpersonal intelligences.

The concept of multiple intelligences helped broaden the idea of intelligence from a mathematical and verbal understanding to one where many inherent abilities of humans may be considered and valued. Implicit in this approach is that disability in one area of intelligence may not be associated with other areas, or more practically, individuals with certain mental disability may also have rich, useful, and enriching capacities in other mental areas.

Classifying behaviors as abnormal poses a very difficult problem for sociologists, anthropologists, and cross-cultural psychologists, and it again begs the question of the value of such classifications. Within most cultures, there are individuals who are so out of sync with the accepted range of behaviors that they pose a threat to themselves or others. Inherent in the act of classifying behaviors is the use of taxonomy of behavioral descriptions as an instrument to define and therefore punish, exclude, or incarcerate a group whose behaviors constitute a threat to the status quo or to the local governance.

For example, homosexual behaviors were frequent parts of polytheistic and pagan ceremonies, and it is likely that homosexual practices were condoned in early societies. The ancient Greeks welcomed homosexuality along with other hedonistic behaviors, though marriage and producing children held higher value, making it "normal" only as an occasional activity for young boys or for older men after they produced children. Interestingly, the Greek military viewed homosexuality as positive in that it encouraged morale and camaraderie. However, men who were exclusively passive partners in homosexual encounters were stigmatized and even banished from the military as having become women. By the sixth century, the popularity and power of Christianity led to condemnation of homosexuality as well as prostitution and other hedonistic activities, although little was done to enforce this code even among priests and monks. Tolerance of homosexuality continued in most of Europe in certain circles until about the thirteenth century. The Inquisition and the Protestant Reformation resulted in strong penalties in different European countries including castration, imprisonment, and death. The death penalty for "sodomites" was imposed in the United States by the military as early as the eighteenth century, a sentence that Thomas Jefferson changed to castration in 1779.

By the close of the nineteenth century, medicine, including the newly developed field of psychiatry, was competing with religion and law over which had jurisdiction over sexuality in general and homosexuality in particular. As with the medicalization of alcoholism, this was progressive, as a "sick person" was better than a sinner or criminal.

Some forces within psychiatry were more liberal in their view of homosexuality. In 1901, Havelock Ellis considered homosexuality to be inborn and therefore not a disease. He also recognized the contribution homosexuals made to society. Sigmund Freud saw all humans as innately bisexual and their sexual preference was made according to experiences in early development. While he advised acceptance, he noted that homosexuality stemmed from arrested development. In his "Letter to an American Mother" (1935), Freud, in keeping with his view of psychoanalysis toward promoting mental health through self-understanding, wrote about homosexuality:

> If [your son] is unhappy, neurotic, torn by conflicts, inhibited in his social life, analysis may bring him harmony, peace of mind, full efficiency whether he remains a homosexual or gets changed.

Psychiatry and psychoanalysis did not always follow Freud's more accepting view. In the 1940s to the early 1960s, these fields developed complex developmental theories explaining the pathological development leading to homosexuality. Alfred Kinsey's empirical studies of sexual behaviors of Americans revealed findings that could not be discerned by clinicians working exclusively with individuals seeking their services. His studies revealed that a significant number of his research participants reported having engaged in homosexual behavior to the point of orgasm after age 16 and that 10 percent of the males in their sample and 2 to 6 percent of the females (depending on marital status) had been more or less exclusively homosexual in their behavior for at least three years between the ages of 16 and 55.

The *Diagnostic and Statistical Manual of Mental Disorders*, second edition (*DSM-II,* 1968) of the American Psychiatric Association (APA) listed homosexuality as a disorder, but the *DSM-III* (1975) did not. This change in thinking was supported by insiders within the APA but also was in response to growing numbers of gay and lesbian advocates who protested and disrupted the APA through the 1960s and 1970s. In 1973, the APA removed homosexuality from the *DSM.* However, to permit payments for treatment by insurance companies, the *DSM-III* included the category "ego dystonic homosexuality" and listed the criteria as (1) a persistent lack of heterosexual arousal, which the patient experienced as interfering with initiation or maintenance of wanted heterosexual relationships, and (2) persistent distress from a sustained pattern of unwanted homosexual arousal. While this had impact on American opinion, it did not change the values and rules of much of the larger society including the American military, which has continued to discharge homosexuals from service. These considerations strongly influence psychiatric views of the criteria for mental illness and normality as will later be demonstrated. The World Health Organization's classification, the International Classification of Diseases (ICD), in its diagnostic manual used in much of the world, continued to list homosexuality as a diagnosis until 1992 with the publication of ICD-10.

An example from the former Soviet Union demonstrates the misuse of psychiatry to serve a government's purposes in a more striking way through its implicit authority to determine normal versus pathological behavior. By the early 1960s, one of the most prestigious psychiatric institutes in the Soviet Union added a criterion for schizophrenia very different from any previously proposed: "dissident behavior" and coined a new type of schizophrenia, which was called "sluggish schizophrenia." Using this criterion and diagnosis, a number of radicals were hospitalized in psychiatric institutions and given treatments with severe side effects under the auspices of curing them of their "illness." Many Western counties and human rights watch groups made challenges to this diagnostic method and practice. However, this policy continued for more than two decades when, with a more open emigration policy in the Soviet Union, the practice was discontinued. Unlike the case of homosexuality where psychiatry was used to bolster general public opinion, the mislabeling of dissidents as schizophrenics was not in concurrence with society but was enforced by the existing regime.

Psychiatry's role in defining normal behavior is part of the larger ways in which society and culture define what are its shared beliefs and behaviors and the "proper" way an individual conducts himself or herself within a society and family. Many aspects of social behavior are usually considered including dress, posture, hairstyle, smell, gestures, facial expression, and use of language. Cultures also have specific codes for the context within which behaviors are appropriate so that different behaviors are condoned depending on gender, age, privacy, work, home, family, friends, and strangers, for instance. Some cultures while having very strict taboos on behavior also include special days of celebration (e.g., Mardi Gras, Halloween, New Year's Eve) in which behavioral norms are deliberately flouted. Some very restrictive cultures may place an onerous burden of conformity on certain demographic groups such as women, so that any deviation from these "normal" role expectations is seen as deviant and deserving of punishment.

As psychiatry and the social and behavioral sciences consider normality, they are increasingly addressing the context of behavior. Delusions, for example, are a criterion for many psychotic disorders. However, Western psychiatry has included in the definition of delusion that it be a "false and fixed belief" and also that it is a belief not commonly held by other members of the individual's cultural group. This added definition allows many unique cultural-religious views of the world without labeling them as psychopathology. Individuals who feel they have been "bewitched," possessed by an evil spirit, or that God is punishing them for their sins are no longer diagnosed as psychotic if these thoughts are consistent with the beliefs of their cultural or religious background. Likewise, hallucinations, defined by Western medicine as a sensory experience without sensory input (e.g., hearing voices or seeing things), has usually been seen as one sign of a psychotic experience. It is now recognized that "normal" individuals partaking in religious experiences with or without hallucinogens can have hallucinations that are not part of a larger psychiatric disorder.

Beyond questions of psychiatric disorders, there are more common behaviors related to disabled individuals that are sometimes considered abnormal in a manner that threatens their dignity. These behaviors include drooling, incontinence, and being physically and cognitively dependent on others. These acts are sometimes incorporated under the heading of "activities of daily living" and if an individual cannot perform them, it is assumed he or she does not have a good quality of life or is not "normal." Rehabilitation aims to improve or restore function on all levels possible. While it is hard to reject maximizing each person's potential, dwelling on a failure to reach a certain level of performance or function perpetuates the stigma attached to disabled people. Likewise, as elderly persons lose the capacity for performing these activities they are often seen in Western society as pathological and a burden, a factor that can be associated with increased interest in euthanasia. For disabled people, as well as other marginalized groups, the political revolution they are likely to lead is one in which difference is not labeled as deviance or abnormal.

—Joseph A. Flaherty

See also Eating Disorders; Health; IQ; Models; Obesity; Psychiatry; Stigma.

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NORMALIZATION

Normalization, or the normalization principle, has been the most significant driving force in the ongoing closure of state-run or state-funded institutions for people with a disability, especially those with a developmental disability in the Western industrialized world.

Its influence is also permeating the policies of developing countries that are increasingly embracing human rights principles. For instance, the normalization principle resonates closely with the UN Standard Rules for the Equalization of Opportunities for People with a Disability.

Possibly the first reference to the concept of normalization was by the Committee for the Partially Able-Bodied, established by the Swedish Government in 1943. This committee was appointed to create better opportunities for the productive ability of partially able-bodied persons, who, because of physical or mental occupational impairment or social affliction, can be expected to have more difficulty than others in acquiring and maintaining employment. This goal was consistent with Sweden's development of modern social services to replace the earlier philanthropic and public protective interventions that were seen as inadequate. In particular, segregated services, such as institutions for people with disabilities and social disadvantage, were being rejected. The committee's report, published in 1946, stated that "this 'normalization' of conditions of life, education, employment exchange etc. of the partially able-bodied must be a great achievement."

These developments in Sweden in the 1940s concentrated specifically on people with limited impairments but had little impact on those with more severe developmental impairments. Many of this population were placed in large institutions. However, in the 1950s and 1960s the normalization principle, as presented by the Committee for the Partially Able-Bodied, was frequently cited as a principle that should also be applied to persons with intellectual and other developmental disabilities. The immediate effect was a restructuring of the institutions toward a more normal life for their residents, but this did not lead to increased contact between persons with a disability and those in the local community.

Historically, for the institutional population, the scene shifted to Denmark where a strong advocate for people with an intellectual disability, Niels Erik Bank-Mikkelsen, was instrumental through his support for parent advocacy groups in achieving an act of Parliament that used the term *normalization*. This act supported the creation of situations for people with disabilities as near as normal as possible, irrespective of whether it occurred entirely or partially within an institution or in the general community.

While the act was strongly supported by large numbers of families who wanted their child with a disability living closer to home or at home, it attracted hostility from vested interest groups, including professional staff, who feared a loss of their jobs. It was significant that the enactment of the act was helped by the ever-improving Danish economy.

When Bank-Mikkelsen spoke of normalization, he was not inferring that people with disability were abnormal and nondisabled people were normal, nor did he want to imply that the special nature of people with disabilities should be made "normal." To him, the goal of normalization was not to normalize these people but to normalize their living conditions.

Undoubtedly, Bank-Mikkelsen's passion for strong advocacy for disadvantaged people was significantly influenced by his experiences during the German occupation of Denmark in World War II. He was imprisoned for his activities in the resistance movement. Bank-Mikkelsen's work soon had an international impact. In 1962, U.S. President John F. Kennedy established an advocacy committee on mental retardation, members of which visited Denmark and other Nordic countries. Bank-Mikkelsen contributed one of the chapters of the President's Committee's final report released in 1969. He also strongly supported an international conference held in Copenhagen in 1964, which saw the formation of the International Association for the Scientific Study of Mental Deficiency (IASSMD; now the International Association for the Scientific Study of Intellectual Disabilities, IASSID).

He also played an important role in the Legal Aspects of Mental Retardation symposium held in Stockholm, Sweden, in 1967 and sponsored by the International League of Societies for the Mentally Handicapped (ILSMH; now Inclusion International). The results of this symposium strongly influenced the 1971 UN Declaration on the Rights of Mentally Retarded Persons.

Through his travels to countries including Australia, the United States, Japan, and Saudi Arabia, Bank-Mikkelsen promulgated the tenets of normalization, with particular reference to the appalling conditions he witnessed in institutions for people with an intellectual disability.

The second significant person to contribute to the development of the principle of normalization was the Swedish scholar Bergt Nirje. Nirje, whose background was in the law and humanities, was deeply influenced by the work of Bank-Mikkelsen, whom he visited in 1963 as a preamble to speaking at a Nordic conference held in Oslo in that year. The theme of this conference was "institutions for mentally retarded persons." Nirje related that he was struck by the words in the Danish law that stated "to let the mentally retarded obtain an existence as close to the normal as possible."

Positions with the Swedish Red Cross and the UN High Commissioner for Refugees that involved visiting Hungarian refugee camps in the aftermath of World War II profoundly influenced Nirje's mission to oppose large "mass managed" institutions. He too contributed chapters to the report of the President's Committee on Mental Retardation.

As ombudsman and executive director of FUB, the Swedish Association for Persons with Intellectual Impairment (1961–1970), and coordinator of training and program planning in the Ministries of Health and Community and Social Services of the Government of Ontario, Canada (1971–1978), Nirje had the opportunity to develop his conceptualization of the principle of normalization. In 1967, in a paper presented to the First Congress of IASSMD held in Montpellier, France, he introduced the concept of the "normal rhythms of life," a concept that became embedded in the eight core facets of life that became the essence of his conceptualization of normalization. To Nirje, normalization means a normal rhythm of the day; implies a normal routine of life; means a normal rhythm of the year; calls for normal developmental experiences of the life cycle; calls for the valuing of individual choices; means living in a bisexual world; means applying normal economic standards; and calls for living, learning, and recreating in facilities similar to those others in the community enjoy.

Nirje (1969) summed up these elements into his overall definition of the normalization principle that "means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (p. 181).

In 1985, Nirje refined his definition: "The Normalization Principle means making available to all persons with disabilities and other handicaps, patterns of life and conditions of everyday living which are as close as possible to or indeed *the same as* the regular circumstances and ways of life of society" (p. 67). He further elaborated this statement by pointing out that

> the normalization principle rests on the understanding of how the normal rhythms, sequences and patterns of life in any cultural circumstances relate to the development, maturity of life of the handicapped, and on the understanding of how these patterns apply as indicators for the development of proper human services and actions. (p. 67)

Integration in society, Nirje maintained, is based on the recognition of a person's integrity, meaning "to be yourself among others—to be able and to be allowed to be yourself among others."

The next significant figure to contribute to the principle was Wolf Wolfensberger, who together with Robert Kugel, then chair of the President's Committee on Mental Retardation, edited its final report published in 1969 (Kugel and Wolfensberger 1969). Wolfensberger (1972), drawing on deviancy theory, proposed a reformulation of the definition of the principle as follows: "Utilization of means which are culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible" (p. 28). He specifically indicated that this definition was for purposes of a North American audience, and for broader adaptability to the general area of human management. He suggested that the normalization principle is culture specific and what may be typical in the Scandinavian environment would not necessarily apply in other cultures. Wolfensberger's elaboration was more detailed in its recommendations to service providers and facility managers than was Nirje's approach.

Wolfensberger became closely involved with the deinstitutionalization movement in North America, as did Nirje in Sweden and Canada. However, whereas Nirje concentrated on those structures that primarily affected the day-to-day lives of the person with the disability, Wolfensberger developed a quality control system that was directed specifically to program management. He devised two instruments for this purpose: The Program Analysis of Service Systems (PASS) and Program Analysis of Service Systems' Implementation of Normalization Goals (PASSING).

In the 1980s, Wolfensberger (1983) further elaborated the principle of normalization, subsuming and replacing it with the theory of social role valorization (SRV). In his earlier formulation, deviancy theory was the driving force, but this was replaced by social role theory. He defined SRV as "the enablement, establishment, enhancement, maintenance, and/or defence of social roles for people–particularly those at risk . . . by using, as much as possible, culturally valued means" (p. 234). He suggested people's roles can be enhanced by improving both their competencies and their social image.

Normalization, in its various interpretations, is a social science theory that has had a profound positive effect on the lives of people who were once removed and segregated from society. It remains relevant for the twenty-first century as thousands of people remain in institutions across the world. However, there are forces emerging that could see a return to institutional solutions to social problems.

—Trevor R. Parmenter

See also Niels Erik Bank-Mikkelsen; Bengt Nirje; Social Model: Sweden.

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NORSE SAGAS

Norse sagas are prose narratives written in Old Icelandic between 1190 and 1230 (the last years of the Icelandic Free State) mostly by unknown authors, concerning the lives of Norwegian kings, prominent Icelandic families, and legendary Norse figures as well as stories translated from Latin saints' lives and continental romances.

The Icelandic Family Sagas are set in tenth-century Iceland and are structured on a pattern of conflict (of honor or property) and revenge. The secondary literature on origins, structure, and plot themes such as feuding largely overlooks the great number of characters with impairments and disfigurements.

In the saga world, impairments were often acquired as Viking occupational hazards. That people with such impairments as blindness or the loss of a limb or eye were regarded as disabled was a social construct that related not to the denial of civil rights but to one's ability to acquire and defend property and dependents against aggressive neighbors. The measure of an Icelandic saga hero was in how he negotiated his impairment to obviate its disabling aspect. Impairments are thus the mark of outstanding characters—they were never sentimentalized.

The saga world regarded as impairments not only the loss of a faculty or limb but also sexual and temperamental quirks and foreign ethnicities. Of the three best-known and -loved eponymous saga heroes, Njál was never able to grow a beard, Egil was seven feet tall and swarthy, and Grettir was inarticulate and had a very small penis. Among the several saga heroes who are skaldic poets, Kormák looks Irish and is sexually dysfunctional, Björn the Hítárdalur Champion appears to be homosexual, Gunnlaug Snake's-Tongue suffers serial leg impairments, and Thormód Kólbrún's-Skald has a crippled right arm and stammers. Virtually all the Family Sagas include minor characters who are blind or have peg legs, and the simpleton is a stock character frequently made to play the fall guy. Women are not usually said to have any impairment other than blindness, and deaf characters do not appear.

The saints' lives treat impairment as an opportunity for a miracle cure, while legends and romances exploit impairment for fantastical prostheses or magical means to induce or cure dumbness. A subgroup of the Family Sagas, the so-called Contemporary Sagas set in the thirteenth century, describe impairment even more frequently, though this is usually the result of extra-juridical mutilation, and here we see impairments first associated with moral deficiencies, as came to be standard in modern times.

—Lois Bragg

See also Folk Belief.

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NORWAY: NATIONAL ACTION PLANS

Action plan is a term used in many countries and in many languages, typically referring to a package of objectives and activities that are intended to combine in ways toward accomplishing a larger goal. As in many other countries, Norway has had a series of action plans in many areas of sociopolitical life. One arena where Norwegian national action plans have received much national and international attention is in the area of disability. The national action plans for disabled people refer to three sequential four-year plans, covering a total period from 1990 to 2002, and with a general goal of improving the situation of disabled people. The first two plans were written by Norway's national Ministries, whereas the third and most recent one was also acted on by the Parliament and exists in the form of a white paper (*Stortingsmelding nr 8:1998–99*).

BACKGROUND AND CONTEXT

As a follow-up to the UN International Year of Disabled Persons (1981) and the subsequent Decade of Disabled Persons (1983–1992), Norway produced a national plan with the aim of working toward the newly formulated international goals of full participation and equality for disabled people. This first plan included a set of objectives and activities, but these were formulated in quite general ways and with unclear political commitment. While the government never admitted that this plan was unsuccessful in terms of its actual accomplishments, the first four-year plan of action (1990–1993) was in part a result of the fact that very few of the intended actions in the plan for the 1980s had actually been implemented. It was noted that there was a need for a more specific description of the intended actions, as well as a clearer and more binding political commitment. It is these two elements of concreteness and commitment that have shaped what became known as national action plans.

In Norway, all services for all citizens are the responsibility of the public sectors, with primary coordination at the local municipality level (*kommune*). Action plans for the disabled are not limited to activities in the area of health and social services, but include all spheres and sectors of public life. It is the national government that provides direction and guidelines, as well as having a monitoring role. Action plans could be interpreted as a signal that the Norwegian government is taking the social and political situation of disabled people more seriously, or at least is taking the actualization of stated goals more seriously.

USER INVOLVEMENT

Participation and influence of disabled people have consistently been a central principle in these action plans. Concretely, this involvement has occurred in two ways. First, the plans themselves are developed in cooperation with disabled people and their organizations, both through direct participation and also through a series of consultative hearings. The National Union of Disabled Peoples Organizations (Funksjonshemmetes Fellesorganisasjon) and the National Council for the Disabled (Statens råd for funksjonshemmete), which includes members from disability organizations, have also been involved in the drafting of these plans. The second way that disabled people are involved has to do with the actual actions stipulated in the plans, where user participation is mandated in a number of ways. One example is that research and development activities require user-collaboration as a prerequisite for receiving funding.

PLAN CONTENT

The content of these plans for action has been twofold. The first part is more principled in nature and describes overriding sociopolitical goals and general guidelines. The second part is the actual plan of actions to be carried out, containing the concrete activities and arrangements that the government is expected to implement, usually including specified sources and mechanisms for funding. The list of actions has been quite diverse in regard to purpose, form, and scope, and the number has increased with each plan. The 1990–1993 plan had a list of 53 actions, the 1994–1997 plan had 90, and the third had nearly 150 actions to be taken. While the range of types of listed actions to be implemented is rather diverse, they can be summarized in the following major categories: specified (earmarked) funding, incentive funding, innovative efforts, research and development work, and information projects.

Examples of activities receiving economic incentives include extending the range and type of respite services available to families with a disabled family member and smaller actions such as economic support for the production of "talking books." Examples of innovative actions are the establishment of a competence center to assist those with rare diagnoses and their families and smaller projects such as sign language theater. In the area of research and development, action plans have financed a range of projects, including a national research program on disability, one on the living situations of intellectually disabled people, and a number of smaller projects. Examples of information activities include projects aimed at improving access to information, such as sign language and subtitles on television. Other types of information projects are efforts aimed at informing public servants and the general citizenry about disability issues, especially those involved in local administration and community planning.

TIME LIMITED OR PERMANENT?

The activities stipulated in these action plans were intended to be time limited. However, many of the actions were deemed as successful and have been expanded or developed into permanent arrangements. Examples include the right to have a user-controlled personal assistant and functional assistants to assist at one's place of employment. In this way, action plans can be said to be vehicles for initiating and trying out different arrangements, as experimental steps as part of a longer-term strategy and goal.

EVALUATION

While several of the larger projects resulting from these action plans have been externally evaluated, the process of action plans itself has not been assessed. However, after the first two plans, the government Ministries reviewed results and experiences and emphasized in their conclusions that action plans made it easier to start up new initiatives. In addition, many actions and arrangements might not have taken place at all were it not for the framework of guiding principles and priorities described in the plans. The dual focus on concreteness and binding commitment was also seen as important.

However, there are some likely limitations to the "action plan approach" as a way of improving the situation of disabled people. First, disability politics risks becoming something outside of, or at least alongside, mainstream public sector policy. Having a special plan for a certain group of citizens reinforces their separateness and differentness. Another limitation might be that the overall effort behind these plans has been so all-encompassing and yet so detailed that the smaller bits may be easier to implement than addressing the larger, overarching challenges. Furthermore, there have been problems at local levels in joining the various actions together into a coordinated, comprehensive strategy. There is then a risk of increasing the gap between the societal goals of full participation and equality and the vast range of specific actions to be implemented. While it is difficult today to judge the overall effect of these national action plans, the hope that the various actions and activities would somehow combine toward a larger common effort remains to be realized.

—Kristjana Kristiansen and Jan Tøssebro

See also Participation; Social Model: Sweden.

"NOTHING ABOUT US WITHOUT US"

The expression "Nothing about us without us" has become one of the rallying cries of the international disability rights movement (DRM) and disabled people's organizations (DPOs). First coined in the early 1990s, the slogan's power derives from its location of the source of many types of (disability) oppression and its simultaneous opposition to such oppression in the context of control and voice. "Nothing about us without us" was adopted as a leading slogan by Disabled Peoples' International because it resonates with the philosophy of the disability rights movement. As Ed Roberts, one of the leading figures of the international DRM, has said, "If we have learned one thing from the civil rights movement in the U.S., it's that when others speak for you, you lose" (quoted in Driedger 1989:28).

"Nothing about us without us" can be considered a demand for self-determination. Self-determination is the essential theme that runs through all the work of the international DRM, regardless of political-economic or cultural differences. Control has universal appeal for DRM activists because the needs of people with disabilities and the potential for meeting these needs are everywhere conditioned by a dependency born of marginalization saturated with paternalism. The condition of dependency is presently typical for hundreds of millions of people throughout the world. Only in the past 25 years has this condition begun to change. Although little noticed and affecting only a small percentage of people with disabilities, this transformation is profound. For the first time in the thousands of years of recorded human history, politically active people with disabilities are beginning to proclaim that they know what is best for themselves and their community. This is a revelational claim aptly capsulized in "Nothing about us without us."

Since the late 1990s, the expression has become very popular and has been used by a variety of disability groups in trainings, articles, slogans, and titles.

—James Charlton

See also Advocacy, International; Disabled Peoples' International; International Disability Organizations; Ed Roberts.

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NOVEL, THE

"His wound gives him his narrative power." Arthur Frank is speaking of Tiresias, the ancient seer, who was blinded by the gods that he might "see" the future more clearly. Procne weaves the story of her sister Philomela's rape by King Tereus into fabric, her tongue having been cut out to prevent her telling the tale. Homer may have been blind, the better to remember the tale of the tribe and translate it into heroic dactyls. Such examples from classical literature suggest that the art of storytelling is intimately linked to a narrator's disability. Frank speculates that, at some fundamental level, the figure of the "wounded storyteller" may represent a "common bond of suffering that joins bodies in their shared vulnerability." But the wound may also extend to the story itself, a tale that is often of self-inflicted blindness (Oedipus), hubris-generated madness (Lear), and socially redemptive suffering (Quasimodo, Tiny Tim). Although disabled figures seldom appear as main characters, they often appear in cameo roles as grotesques or exotics necessary to the novel's plot. Given the preponderance of disabled figures in fiction, what is the relationship between the body of the story and the story of the body?

This question has been crucial for disability studies in the humanities. Disabled figures appear in many novels, such as Melville's one-legged Ahab, the invalid narrator of Charlotte Perkins Gilman's "The Yellow Wallpaper" and the limping Baby Suggs in Toni Morrison's *Beloved,* and most novels touch, in some way, on themes of illness, disfigurement, and mental illness. Certain genres—mysteries, Gothic novels, science fiction—are built around nontraditional bodies and extreme psychological states. We may not think of Milly Theale's lingering illness in James's *Wings of the Dove* or of Bertha Mason's madness in *Jane Eyre* as disabilities, but once we do, we begin to see the extent to which novels rely on a figure of bodily infirmity or cognitive incapacity. This linkage has spawned a considerable interest in the novel within disability studies. Foundational works such as Lennard Davis's *Enforcing Normalcy* (1995), Rosemarie Garland Thomson's *Extraordinary Bodies* (1997), Diane Price Herndl's *Invalid Women* (1993), and David Mitchell and Sharon Snyder's *Narrative Prosthesis* (2000) address not only the prominence of the disabled figure in fiction but also the cultural meaning of disability in a genre founded on an ideal of verisimilitude and fidelity.

Many critics see the novel emerging in the eighteenth century as an extension of Enlightenment rationality, a vehicle for chronicling the emergence of a new middle class. The novel's ability to represent ordinary people in ordinary circumstances made it a significant genre for validating a certain type of average individual, *l'homme moyen sensuel*, as the Realists called it. But as Lennard Davis has observed, *l'homme moyen* was also a product of medical and positivistic sciences that emerged in the early nineteenth century and that reinforced certain ideas of bodily or cognitive normalcy and excluded others. The sciences of eugenics, comparative anatomy, psychoanalysis, and phrenology provided a host of new (often suspect) diagnostic methods for analyzing various types of bodies and mental states for which the new technologies of photography and film provided visual support. This nineteenth-century "hegemony of normalcy," as Davis calls it, required a nontraditional or disabled body that could serve as a negative version of the statistical average. Often the disabled figure annexed other forms of deviance—racial, sexual, political—that threatened projects of imperialism and national consolidation. Thus, the disabled figure in fiction was a site for social anxieties within modernity for which there was as yet no name.

A key optic for regarding disability in nineteenth-century fiction is through gender. As women participated more forcefully in the public sphere, they found themselves portrayed as threats to patriarchal institutions, commonly represented in terms of irrationality and hysteria (the madwoman in the attic) or physical frailty (the invalid woman). Novelists such as Nathaniel Hawthorne, Émile Zola, and Gustav Flaubert often represented women as limited by their biology or subject to "female maladies" such as hysteria and neurasthenia. To some extent, this focus on female biology and psychology was prompted by scientists who were diagnosing women's illnesses and prescribing cures, the most famous of which was S. Weir Mitchell's "rest cure." As Diane Price Herndl (1993) points out, many nineteenth-century novels are centered around an invalid or dying woman whose representation reinforces female passivity and pathology at a moment when many women were gaining political and social power. But this passivity performs a critical function, as Herndl points out, because the invalid woman can serve as a challenge to representation itself. Invalidism, whether in the historical Alice James or the fictional portrait of Milly Theale, may offer women "a coherent and simple role in a world where multiple and conflicting roles are threatening or disappointing" (Herndl 1993). The unnamed narrator of Gilman's "The Yellow Wallpaper" uses her status as invalid to question the scientific definition of female biology offered by her doctor husband.

In the modernist novel, disability often serves as a sign of lack or absence, a figure for alienation in a world dominated by instrumental reason and commodity capitalism. In Ernest Hemingway's *The Sun Also Rises,* Jake Barnes suffers from a mysterious "wound" that has rendered him impotent. Edith Wharton's protagonist in *Ethan Frome* is a man who becomes seriously disabled in a suicide attempt in response to his arid, sexless life with a disabled wife. In *Lady Chatterley's Lover,* Clifford Chatterley is in a wheelchair, the result of a war wound that has rendered him, like Jake Barnes, impotent. In William Faulkner's *The Sound and the Fury,* Benjy Compson is mentally retarded, his broken, discontinuous narrative rendering the loss of family property but also the fragmentation and commercializtion of the American South. These modern texts thematize male inadequacy through disability that is a synecdoche for larger issues of world war, urbanization, and gender uncertainty.

Contemporary novelists have used disability to question the integrity of the unitary subject whose invention had been the focus of much previous fiction. Recognizing that the "normal" body is a variable fiction, novelists have represented the disabled body as a site of stigma but also of social critique. From William Burroughs's science fiction cyborgs—part technology and part human—or Katherine Dunn's carnival freaks in *Geek Love* to Toni Morrison's one-armed Nan in *Beloved,* disabled characters challenge certain humanist definitions of identity. Burroughs's cyborgs reveal the proximity of bodies to technology in the postwar era; Dunn's chemically altered grotesques expose the fictive nature of family and social institutions; Morrison's disabled African American women call attention to bodies that have historically been marked as other, culturally ostracized within racist culture. Rosemarie Garland Thomson (1997) notes that such representations in Morrison "enable [her] . . . to represent a particularized self who both embodies and transcends cultural subjugation, claiming physical difference as exceptional rather than inferior."

The pervasiveness of disability in the novel has produced several influential theoretical studies of narrative. David Mitchell and Sharon Snyder (2000) have suggested that not only do many novels feature a disabled character, such a figure provides a kind of "narrative prosthesis" for novelistic coherence itself. On the analogy of the prosthetic limb that provides an illusion of physical wholeness for the amputee, the disabled figure provides an illusion of textual embodiment that the novel must produce. And just as the wounded hero must be "cured" or brought back to health, so the disabled figure must be eliminated for the social body to be restored. The one-legged Ahab, whose megalomaniacal pursuit of the white whale for taking his leg, must be eliminated so that Ishmael's more recognizable humanist narrative can triumph. Physical and cognitive differences are the text's "cultural other" that must be brought under control by the narrative act. In Mitchell and Snyder's theory, the interrogation of the body's materiality coincides with an interrogation of the novel's materiality, its ability to complete a story that has a wound at its center.

Lennard Davis (1995) has argued that this wound is a historical phenomenon. He notes that theories of the novel that focus on its response to material conditions of emerging capitalism fail to recognize the impact of these conditions on the materiality of the body. Davis sees the modern novel as constructed around a dichotomy of normal-abnormal identities, one reinforced by positivist science in service to a national imaginary of typicality. For Davis, the disabled figure is foundational for undermining this imaginary. Since anyone can become disabled, the ideal of an average, typical, national body is suspect. The disabled figure "dismodernizes" the modern novel, establishing its formations in modernity but recognizing its deconstructive function in relation to the modern subject produced therein.

—Michael Davidson

See also Cyborg; Feminism; Invalid Women; Modernity; Representations of Disability, History of; Representations of Disability, Social.

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NURSING

Competent nursing has been central to the care of people with disabilities for many centuries. Up until the nineteenth century, people who were sick or disabled because of old age, mental illness, or physical disability were usually cared for by their families at home. For the poor sick and destitute, institutional care existed in local charitable guest- or poor houses. Professional nursing care by skilled nurses who were paid for their work, either in these institutions or through visiting nursing associations, grew during the nineteenth century. At that time, patterns of living and the provision of health care changed as a result of broader social changes, such as industrialization, urbanization, and changing work and gender relationships.

NURSING ORDERS

Nurses' role in care for the sick and disabled originated in religious orders, founded at the time of the Reformation and Counter-Reformation. Women and men who joined religious orders actively devoted themselves to poor relief and care for the sick. They viewed the care they provided as part of their religious practice and learned nursing skills through apprenticeship. With the foundation of the Daughters of Charity in France in 1633, cofounders Vincent de Paul and Louise de Marillac set a remarkable example of organized nursing care by lay women. The Daughters of Charity gained enormous social respect. Religious calling and spiritual commitment to God legitimized their role. So strong was the example that Roman Catholics and Protestants alike adapted to this model, and charitable nursing orders spread over Europe and North America through the next centuries, reaching a peak in the Evangelical and Missionary religious revival movements in the late nineteenth and early twentieth centuries.

Within a broader nineteenth-century humanitarian reform movement, previously unspecified groups of socially marginalized poor and disabled people were differentiated into distinct categories. Separate institutions emerged, for example, for the care of the sick and incurables, for insane persons, and for prisoners. In the new capitalist and industrial world, the emerging middle classes became concerned about the growing numbers of poor, which they perceived to be a source of social instability, fueled by fears of dirt, poverty, and contagious disease. In the New World, massive immigration created its own problems. Reform-minded middle-class citizens sought new and supposedly more effective ways to help the poor through rational control and scientific efficiency. Establishing good nursing care was one of them. Numerous associations for care of the sick emerged, who involved themselves with care of the sick in institutions, but some also provided care for people in their own homes.

Modeled after Roman Catholic sisterhoods and brotherhoods, the Protestants revived the function of the deacons and deaconesses. In 1836, Pastor Theodor Fliedner established one of the most well-known associations for care of the sick and dependent, the Deaconess Institute in Kaiserswerth, Germany. Within the protected structure of a motherhouse, the institute trained both nurses and teachers to work in its facilities. The work of deaconess nurses was not limited to care of physically sick or disabled people. People with mental illness were also included in the charitable effort. Within decades of its founding, the Kaiserwerth Institute included hospital care, a school for infants, an orphanage, and an asylum for women with mental ailments.

NURSING AS A PAID PROFESSIONAL OCCUPATION

The Kaiserswerth Institute served as an important inspiration to Florence Nightingale, who spent some time there in the mid-nineteenth century. She had an influential role in spreading and transforming the disciplined religious hospital apprentice training for nurses into a nonsectarian model that was fundamental to the emergence of nursing as a paid professional occupation. Most well-known for her work in the Crimean War, Nightingale fundamentally influenced the direction of nursing and nursing education in modern hospitals. Her authority evolved against the backdrop of a profound change in the public role of middle-class women.

The nineteenth-century humanitarian impulse that generated a new concern about the well-being of the poor provided a context for new caring roles for women. Their work and education became a matter of public debate, and an expanding economy created new work opportunities for middle-class women. They actively joined the humanitarian effort to uplift the poor and to help create a respectable working class. In this way, women not only created resources for a more meaningful life, but their philanthropic activities helped them to articulate the value of women's work in asserting a moral and ethical social influence, in fighting for temperance, for example, or in reforming hospitals and asylums. Based on a middle-class domestic ideology of women's special inclination for caring work, the new opportunities for women were considered an extension of women's traditional role in their families. Teaching, nursing, and social work became new areas of paid professional work for women. The women's movement, which obtained a more organized form in the late nineteenth century, provided a context for transforming a hitherto religious legitimization for women's work into a secular one. The idea that women had a special moral capacity and compassion, and the right characteristics such as devotion, sensibility, and sacrifice for caring work in a paid capacity, complementary to public roles of men, was a deeply gendered notion, reflecting the gendered beliefs of the time.

The projected image of the middle-class woman, trained in care of the sick, who brought order, cleanliness, and discipline to the unordered environment of large urban hospitals was a powerful one, and especially attractive to reform-minded physicians, who had their own interest in hospital reform. Influenced by the ideals of science, they sought to expand the application of medical therapeutics and technology. They had an interest in enhancing their research and teaching on hospital wards and valued the assistance of trained nurses who could help them to implement new therapies and maintain order on the wards.

NURSING EDUCATION AND WORK

The expanding demand for women with training in care of the sick grew from various sources, a boosting economy, the rise of a middle class that could afford to pay for private nursing, and the expansion of hospital care for a growing urban community and industrialized workforce that could no longer be cared for in their own homes.

Physicians sought to improve the image and reality of public hospitals and asylums alike, which traditionally had a poor reputation as stigmatizing places of last resort. In making hospitals attractive to a growing middle (and reputable) working class, the civilizing role of respectable nurses, for which high social regard had already been established in nursing orders and associations for care of the sick, became an inspiration to reform-minded doctors. The slight difference was that they were particularly interested in training these women themselves and bringing the nursing staff under their own control.

Initially, their interest matched feminist attempts to create work opportunities for women. The combined efforts of doctors, hospital administrators, and respectable ladies to reform hospitals resulted in the introduction of hospital-based training schools of nursing, a highly attractive model of nursing education that spread throughout the world, attracting large numbers of young, middle- and working-class women. The arrangement was that the women lived and worked on the hospital grounds, their reputations carefully protected through a disciplined system of supervision and regulations, in return for a nursing diploma after initially two, but later three, years of training. Doctors taught them the medical knowledge deemed appropriate and necessary, and usually a nurse superintendent oversaw the management of the school under the authority of the medical director of the institution. Soon, however, nurses expressed awareness of the challenges associated with a hospital-based program of education. Work conditions of the new student nurses did not differ much from their counterparts in domestic servant roles in terms of pay and working hours. The work nurses took up in private duty upon graduation was largely unprotected. This situation prompted nurses to organize themselves into professional associations and seek legal and social protection from the state through registration laws and licensing regulations.

NURSES AND CARE OF THE MENTALLY ILL

The introduction of diploma-based nursing education forcefully continued the cultural connection between nursing work and care of the sick and disabled. The introduction of trained nursing in asylums forms a salient example. Institutional care for the mentally ill became firmly established in the industrializing world in the nineteenth century. However, despite initial optimism about the improvement new institutions would bring, asylums soon grew into overcrowded, lower-class institutions for indigent insane and their social reputation was very poor.

When scientific psychiatry grew as a medical field in the late nineteenth century, psychiatrists had a vested interest in enhancing the status of asylums and introducing new therapies such as bed rest and hydrotherapy. They began to model the asylums after the influential example of the general hospital. A crucial factor in this transformation was the availability of competent personnel who could assist them in making the new therapies work. Inspired by the impact of the role of middle-class women in hospital reform and the effect of hospital nurse training schools, asylum physicians also began to argue for the establishment of mental nurse training. Nurses, trained in care of the sick, began to provide day-to-day care of the mentally ill, and asylums opened their own mental nurse training programs.

The care of large groups of mentally ill patients with difficult and often unpredictable behavior remained a burdensome task, however, and the limitations of high turnover of personnel and demanding work conditions characteristic of the general hospital nursing workforce were probably even more prominent in the asylums. At the turn of the twentieth century, a large part of the asylum population consisted of demented elderly, for example, who came to the asylum in the last years or last months of their life. Behavior of demented, confused, or agitated patients was difficult for nurses to handle, and communication with this population was a complex matter. Patients in a delusional, manic, or agitated state could be dangerously violent or unpredictable in their behavior. Asylum work was strenuous and not without risk. More stable patients, however, usually took part in hospital work and made an extensive contribution to the asylum economy. A gradual decrease in mortality rates, as in Dutch asylums, likely indicated that to some extent mentally ill patients did benefit from more competent and compassionate care, although generally circumstances in asylums remained challenging, reflecting the broader social difficulty of caring for the mentally ill.

Although the disadvantages of large institutions did not disappear with the introduction of systematic training of personnel, nursing work provided an opportunity for a decent social position for large groups of middle- and working-class women and men. The popularity of this training model for nurses may indicate that it served first and foremost as a new way to staff institutional care for the sick and disabled. This model of combined nursing education and work gradually changed in the second half of the twentieth century, as nursing education and work increasingly began to be separated and the necessity of a more advanced education for nurses became essential for expanding health services in the second half of the twentieth century.

PUBLIC AND MENTAL HEALTH MOVEMENTS

The devastating impact of World War I, with its aftermath of labor unrest and economic depression, combined with widespread tuberculosis and high infant mortality rates, reinforced the idea that in a democratic society basic needs of citizens had to be taken care of independent of the ability of individuals to pay for health services. Starting in the nineteenth century and expanding in the first half of the twentieth century, Western industrialized nations began to provide more consistent protection of its citizens through state regulated security and insurance plans for unemployment, old age, sickness, and disability. Although models and programs varied between countries, some form of regulated health insurance financed through private or public funds became the norm and had a permanent impact on the provision and development of health services and disease prevention.

Closely related to this idea was the belief that science, generating more effective and efficient ways to manage the social problems created by dependency, provided the foundation on which social policies and solutions should be based. The public and mental health movements arising in the first part of the twentieth century were a case in point. They reflected the growing confidence that professional and scientifically based efforts to enhance the health of the people, physically and mentally, would ultimately result in a productive and healthy population. Nurses took up an essential role in these movements, expanding and re-creating more independent careers in public and mental hygiene work, such as children's bureaus and vaccination programs, school health programs, visiting nursing societies, tuberculosis prevention, child guidance clinics, but also in factories, insurance companies, and boards of health and education.

CHANGES FOLLOWING WORLD WAR II

Following World War II, a growing health agenda originated from various sources. Increased international economic and social collaboration in health matters was reflected in the foundation of the World Health Organization (WHO) in 1948. The WHO noted that "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (Howard-Jones 1981:472). The new availability of antibiotic drugs fueled increased confidence in the advancement of medical knowledge and technology. Increasing national wealth provided an economic basis for expanding health programs. In the mid-twentieth century, hospital and medical care insurance legislation facilitated an enormous growth of hospitals and medical care services and generated an unprecedented demand for health care personnel.

During the 1940s and 1950s, every industrialized country faced an enormous shortage of nurses. As a more acutely ill patient population filled hospital wards, traditional patterns of staffing hospitals by continuously turning over nursing student personnel no longer matched required levels of care and clinical observation. More graduate nurses became employed in the hospital, while continued demand for more caretaking personnel was also filled through new diversification of the nursing workforce. As of the 1960s, academically based nursing education became more widespread, while new programs for nurse assistants and licensed practical nurses were also established to complement the work of the traditionally registered nurses. Nursing homes emerged for the care of chronically ill and disabled people, and the lower-qualified group of nurses became the workforce of choice in these new institutions.

While nursing adapted to increased demand, coming to terms with the new diversity in educational preparation of nurses was a complicated process. Through national and international nursing organizations, such as the International Council of Nurses (ICN), nurse leaders sought to establish minimal educational guidelines for professional nurses and expand nurses' role in health service, policy, and research, while seeking to maintain control over a continuously expanding nursing workforce. The higher complexity of nursing care required for a patient population that experienced new illnesses for which in the past no medical treatment had existed was not always well understood among health policy makers. Moreover, as health care advanced, chronic illness and permanent disability rendered new demands for skilled long-term care. The gendered context in which professional nursing emerged during the nineteenth century had generated beliefs that made it persistently difficult to articulate at a social level the essential value of nursing care in all of these situations.

Defining the responsibilities of the nurse, which had been a long-standing matter of debate within nursing organizations, regained relevance as the function of the nurse had to be articulated in new twentieth-century contexts. Virginia Henderson (1969:50), an influential nursing leader in the United States and a clinical nurse researcher, developed a powerful and influential statement that captured the essential role of the nurse in the assistance of dependent and disabled individuals:

> The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities contributing to health or its recovery (or to a peaceful death) that he would perform unaided if he had the necessary strength, will or knowledge.

Her view, articulated in *Basic Principles of Nursing Care,* became the basis for the ICN's vision on nursing and was translated into 12 languages, serving as a guide for nurses around the world.

PRIMARY HEALTH CARE

Not only the view on health and health services changed profoundly during the twentieth century but also the perspective on sick and disabled people themselves. Health is increasingly considered a basic human right. Moreover, health consumers now actively participate in health care politics, raising awareness and advocating for equal access and improvement of service. A strong consumer movement now advocates for consumer rights, resources, and responsibilities.

Demographic changes and a rapidly growing elderly and chronically ill population have shifted the emphasis of health services from merely disease prevention to health promotion. The argument that hospital-based care and medical services alone are not enough to maintain people's health gained momentum as of the 1970s. An emphasis on primary health care has emerged, in which community-based care and promotion of a healthy lifestyle have obtained central stage, enhancing an active role of people in maintaining their own health. Primary health care is a broad-based approach to health services in which promotion, prevention, cure, rehabilitation, and palliative support are equally valued. Nurses, both in staff positions and in specialized advanced practice roles such as clinical nurse specialist or nurse practitioner, have an essential role in patient advocacy and in bringing about the primary care philosophy.

CURRENT AND PERSISTENT CHALLENGES

Currently, nurses consider enhancing the integration of people with disabilities in the community and improving their quality of life essential tasks. As part of their academic education, nurses have gained knowledge and expertise in research and policy development. Nursing research is now a fundamental component of nursing practice. Over the past decades, nurses have made substantial contributions to knowledge of chronic illness and disability, supporting people with disabilities in improving their health and living conditions. Both nurses, as providers, and persons with chronic illnesses and disabilities, as consumers, experience the unrelenting reluctance of society at large to value the public need of basic care. As a nursing shortage once again is looming around the world, largely as a result of the profound effects of cost-containment and restructuring of health care during the 1990s, which eliminated thousands of nursing jobs, the persistent difficulty as much as the profound necessity of finding a balance in evaluating the cost and value of nursing care remains a prominent health care issue.

—Geertje Boschma

See also Health Care and Disability; Medicine.

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O

OBESITY

Obesity is a condition characterized by a larger-than-average amount of body fat (excess adipose tissue). While fatness has been associated with wealth and prosperity in historical contexts where continued existence was predicated on access to food, *obesity* is a medical term used to pathologize the fat body in a context of abundance of resources. In contrast to overweight, which is a Body Mass Index of 25–29 (BMI, or weight in kilograms divided by the square of height), obesity is a BMI of 30 or greater. (BMI problematically does not consider muscle mass and is only a crude measure of weight.) Obesity is considered a public health crisis/epidemic in the affluent West in the early twenty-first century, with more than one-third of all adults and one in five children categorized as obese. There was a huge jump in National Institutes of Health estimates of the prevalence of obesity in the United States from the 1960–1980 period, when 15 percent of adults were obese, to over 30 percent in the 1980–2000 period. However, the federal government's lowering of the baseline of standards for obesity made 35 million people who had not been considered fat before suddenly very much so.

The management of obesity fuels a multi-billion-dollar diet and fitness industry, extensive pharmaceutical research and development, lobbying for taxes and advertising bans on certain foods, efforts to improve nutritional labeling, and other interventions aimed at slimming down the public. The medical establishment links obesity to a host of health problems, including high blood pressure, diabetes, heart disease, stroke, gall bladder disease, and cancer of the prostate, colon, and breast. Sedentary lifestyles and increased consumption of inexpensive, fatty, processed foods are typically hailed as contributing factors, though heredity and genetic factors are thought to play some part as well. However, much medical research conflates obesity with these factors, further suggesting a causal relationship between obesity and the aforementioned health problems. Critics point out that the correlation is far too often misinterpreted as causation, and they propose instead that the stresses resulting from living in a society that stigmatizes fatness as unhealthy, immoral, and disgusting may in fact be the cause of ill health.

Since the early 1970s, members of several U.S. size-acceptance organizations, most prominently the National Association to Advance Fat Acceptance (NAAFA) and the Fat Underground, have been working to change the way society perceives of fatness, to cast off its stigma, and to combat discrimination. Their actions have been instrumental in the inclusion of obesity in the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990. Fat Americans are legally protected against discrimination so long as their condition substantially limits at least one of their major life activities or is perceived as doing so. Nonetheless, controversy abounds about whether the condition of obesity, over which individuals are usually thought to have some personal control, should be protected, and very few anti-obesity discrimination cases have been successfully argued. Several places in the United States have taken the plight of fat people who suffer discrimination more seriously, with Michigan, Washington, D.C., and Santa Cruz and San Francisco, California, offering anti-size discrimination statutes for protection.

—Kathleen LeBesco

See also Americans with Disabilities Act of 1990 (United States); Health Promotion; Normality.

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OBSESSIVE-COMPULSIVE DISORDER

Obsessions or compulsions, or more commonly both, are the hallmark of obsessive-compulsive disorder (OCD). Obsessions are recurrent and persistent ideas, thoughts, impulses, or images that are intrusive and inappropriate and cause marked anxiety or distress. Common obsessions include fears of harming other persons or sinning against God. Compulsions are repetitive, purposeful, and intentional behaviors or mental acts performed in response to obsessions or according to certain rules that must be applied rigidly. They are meant to neutralize or reduce discomfort or to prevent a dreaded event or situation, even though the sufferer generally knows the irrationality of these acts. Obsessions create anxiety, which is relieved by compulsive rituals such as checking, washing, counting, confessing, hoarding, and rearranging objects with symmetry and precision. These symptoms can cause functional disability as severe as psychosis and can make it virtually impossible to function at work or at home.

To receive a diagnosis of OCD, a person must have either obsessions or compulsions that cause marked distress, consume more than one hour daily, or significantly interfere with the person's normal routine, occupational functioning, or usual social activities and relationships. The person must recognize that the obsessions and compulsions are unreasonable. Many psychiatrically normal individuals—particularly children—have occasional obsessional thoughts or repetitive behaviors, but they tend not to cause distress or disability. Many people double-check locks or avoid stepping on cracks. These rituals are viewed as acceptable and desirable and are easily adapted to changing circumstances. To the obsessive-compulsive person, however, rituals are a distressing and unavoidable way of life. Data indicate that as many as 2–3 percent of the general population meet criteria for OCD at some point during their lives. Men and women are equally likely to develop OCD, although men have an earlier onset.

Recent developments in the treatment of OCD have improved outcomes and instilled a greater sense of optimism. The mainstays of treatment are pharmacotherapy and cognitive-behavior therapy. Behavior therapies, which tend to be more successful for ritualizers, emphasize exposure paired with response prevention. Proponents of behavior therapies state that 60–70 percent of the patients who persevere with the treatment improve markedly. New generations of drugs work well at relieving both obsessions and compulsions in nearly 75 percent of patients. Treatment is long term because patients tend to relapse when the drug is discontinued, often within weeks. Patients who complete a course of behavior therapy are less likely to relapse.

—Ahmed Okasha

See also Behavior Therapy; Behavioral Disorders; Psychiatric Disorders.

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OCCUPATION

In the context of disability and rehabilitation, the term *occupation* is most widely used and discussed in the field of occupational therapy. While various definitions exist, occupation generally refers to engaging in work, play, or activities of daily living. Work refers to activities (both paid and unpaid) that provide services or commodities to others, such as ideas, knowledge, help, information sharing, entertainment, utilitarian or artistic objects, and protection. Activities such as studying, practicing, and apprenticing improve abilities for productive performance. Thus, work includes activities engaged in as a student, employee, volunteer, parent, serious hobbyist, and amateur. Activities of daily living, play, and work interweave and sometimes overlap in the course of everyday life. Play refers to activities undertaken for their own sake. Examples of play are exploring, pretending, celebrating, engaging in games or sports, and pursuing hobbies. Play is the earliest occupation, persisting throughout life. Activities of daily living are the typical life tasks required for self-care and self-maintenance, such as grooming, bathing, eating, cleaning the house, and doing laundry.

Occupation is recognized as a basic human need and as a determinant of well-being. This need is reflected in the strong drive to do things and the fact that people flourish by engaging in practical, productive, and playful pursuits. The need for occupation entails the urge to do things, to discover, to exercise capacity, and to experience oneself as competent. It is considered to be the product of an evolutionary process in which the complex nervous system of humans gives them a pervasive need to act.

The term *occupation* derives from the Latin *occupare* and connotes taking hold of (i.e., occupying) time and place. Modern discussions of occupation highlight the fact that occupations are how persons fill their time. Humans mark the passage of temporal cycles by what they do. Such terms as *mealtime*, *playtime*, and *workweek* illustrate how the patterns of time and doing are intertwined. Human awareness of the future also means that much of what people do in the present is aimed toward some state of affairs they wish for at a future point. Therefore, occupations not only fill and mark time but also shape the course of people's lives over time. To a large extent, people engage in their occupations so as to locate themselves in an unfolding narrative with an eye toward a particular direction or outcome for that life story.

Occupation is also how persons make their place in the social world. Most of the occupations that people do are conducted among and with others. Occupations express and maintain the social fabric since they not only follow normative ways of doing things but also serve to perpetuate those same social patterns they reflect.

Occupation, disability, and rehabilitation were historically linked in the moral treatment movement of the seventeenth century. Moral treatment saw mental illness as a result of persons' loss of connection to the occupations that made up the mores or folkways. This perspective presaged contemporary views of disability as an interruption of a person's participation in life activities. Moral treatment emphasized using occupations (i.e., work and leisure activities) as ways to encourage and enable people to reconnect with the social world around them. The idea of using occupation as a therapeutic tool has continued in occupational therapy and other disciplines that use activities as a means of habilitation and rehabilitation.

—*Gary Kielhofner*

See also Employment; Job Training; Occupational Therapy; Rehabilitation; Work Incentives.

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OCCUPATIONAL THERAPY

Occupational therapy is a health-related profession that primarily serves persons with disabilities. It is concerned with the well-being of persons in their everyday occupations (i.e., work, play, and daily living tasks). The profession sees occupation as a necessary aspect of life, contributing to physical, emotional, and cognitive well-being. Occupational therapists work with individuals whose participation in occupation is threatened or hampered by impairments and/or environmental barriers.

The origins of occupational therapy are the eighteenth-century moral treatment approach. Moral treatment was a European movement that saw mental illness as a form of demoralization emanating from disruption of a person's connection with the mores or customary activities of society. Moral treatment consisted of inviting and supporting participation in everyday activities as a means of "remoralizing" individuals by reintegrating them into ordinary routines of living. Moral treatment exported to North America and practiced in the eighteenth and early nineteenth centuries. In the mid-1800s, overcrowding and underfunding of state hospitals led to its virtual demise.

In the early 1900s, a diverse group of people (architects, physicians, nurses, and leaders from the settlement movement and industrial arts) began developing a form of treatment that used participation in work, crafts, leisure activities, and self-care as a form of therapy. These early leaders included the psychiatrist Adolf Meyer and social activist Eleanor Clarke Slagle. William Rush Dunton, another psychiatrist and a descendent of Benjamin Rush (a physician and statesman who introduced moral treatment to the United States), was responsible for introducing and spreading literature and concepts from European moral treatment into occupational therapy. The early practice of the field (which quickly spread from application with persons who had mental illness to a variety of other impairments) focused on helping patients reclaim function and achieve satisfying everyday lives through active participation in work, self-care, and leisure tasks during their rehabilitation.

In mid-twentieth century, the field became more closely aligned with medicine and the medical model. As a consequence, more attention was paid to remediation of underlying impairments that contributed to disability. In the 1970s and 1980s, this emphasis on impairments was increasingly criticized from within the field. Consequently, leaders sought to return occupational therapy to a more holistic practice centered on the client's participation in everyday life occupations.

The contemporary focus of the field is, therefore, on the client's challenges or difficulties with participation in occupations. Occupational therapy services seek to enhance individuals' performance and satisfaction in work, play, and activities of daily living through reducing impairments and through personal and environmental adjustments. Services are offered to clients who range from preterm infants to the very old and to persons with any type of physical, sensory, cognitive, or emotional impairment. More recently, services are offered to persons whose work, play, and activities of daily living are disrupted by war, poverty, violence, and other social injustices. Occupational therapists are also increasingly involved with providing services to promote wellness and prevent loss of function.

Since the aim of occupational therapy is to enable persons to have satisfying and productive engagement in occupation, occupational therapists are trained to understand and address the interrelated biological, psychosocial, and environmental factors that contribute to occupational problems. The common denominator of occupational therapy practice is involvement of persons in occupations as a means to enhance their well-being. The profession is based on the premise that when humans engage in occupations using their physical and mental powers, they can positively affect their biological and psychological status. Consequently, occupational therapy focuses on empowering clients to actively influence their own rehabilitation process and outcomes, but selecting their own objectives for the kind of lives clients want to lead.

Occupational therapy ordinarily consists of one or more of the following elements. First, therapists provide direct opportunities for clients to perform occupations with an aim toward achieving personal change (e.g., development of new skills, learning to compensate for a permanent impairment, increasing self-confidence, and discovering new ways to achieve satisfaction in performance). The occupations that are used as therapy can include a wide range of activities (e.g., sensory-motor play, crafts, work tasks, group projects, leisure activities, school/classroom tasks, and self-care activities such as dressing or bathing).

Second, occupational therapists provide and train clients in the use of various technical devices that extend limited capacity or compensate for lost capacity. This technology ranges from simple adaptive equipment that has been modified to accommodate motor limitations to complex, computer-based equipment that is used for communication and environmental control.

Third, therapists help clients remove barriers to engaging in occupations by modifying how tasks are completed or through modifications of the environment. Tasks are modified through such strategies as simplifying steps, providing special sensory or memory cues, or altering expectations for outcomes. Environmental modifications include such things as removing architectural and structural barriers in the physical environment and changing attitudes of others toward disabled persons in environments where the person carries out occupations (e.g., home, school, and workplace). More recently, occupational therapy has increasingly included advocacy for social and policy change as a strategy for removing environmental barriers.

Fourth, therapists may enable persons to engage in occupations through counseling and problem solving that encourage the client to choose and participate in occupations. Because occupational therapy is based on the client's active involvement in doing things, the field pays particular attention to the client's perspectives and experiences in order to facilitate this involvement. Client centeredness is an important theme in occupational therapy.

In addition to working with individuals, many therapists have agencies, organizations, and entire communities as their clients. They may provide consultation services on program design, optimal environments, training and development of staff and families, prevention programs for workers, and education programs for community members, all within the context of maximizing occupational functioning of the target group.

There are occupational therapists practicing in more than 60 nations worldwide. Education ranges from occupational therapy assistants who earn two-year associate of arts degrees to therapists who earn professional doctoral degrees. In the United States, a graduate degree will be required for entry into the profession in 2007, but the most common educational background worldwide is the bachelor's degree. The World Federation of Occupational Therapists is a major international body that recognizes educational programs, although most countries have their own credentialing of educational programs and qualified therapists.

—Gary Kielhofner

See also Aids for Activities of Daily Living; Occupation.

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Websites

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World Federation of Occupational Therapists, http://www.wfot.org.au/

O'CONNOR, FLANNERY (1925–1964)

American author

Flannery O'Connor was born in Savannah, Georgia, the only child of a devout Catholic family. This background, as many critics have argued, shaped her later fiction writing as part of the southern grotesque. Her father was a realtor and her mother was a member of a prominent political family (her grandfather had been mayor of Milledgeville, Georgia, for many years). She graduated from Georgia State College for Women in 1945 and then attended writer's workshops at the University of Iowa. In 1950, she experienced her first bout with lupus—a debilitating blood disease that she inherited from her father. O'Connor used crutches for mobility from 1955 onward.

From the beginning, O'Connor's work demonstrated a somewhat perverse relationship between religious and disability themes. In her second novel, *The Violent Bear It Away* (1960), the main character, Francis Marion Tarwater, becomes a minister in his youth and later baptizes and drowns Bishop, the "idiot" son of his uncle. The act is performed in eugenic-like style as one of mercy to save the cognitively disabled character from Satan's temptations. Likewise, in her famous short story "A Good Man Is Hard to Find," a malignant criminal named "The Misfit" explains that the easy expendability of human life was brought about by Christianity when Jesus was raised from the dead. This miraculous act precipitated attitudes of false reverence for death and afterlife as mere inconveniences that can easily be overcome. In the story "Good Country People," the female protagonist dons an artificial leg as the result of a hunting accident. When she tries to sexually engage a country Bible salesman named Manley Pointer, he runs off with her prosthesis as punishment for her "licentiousness." Thus, O'Connor spent much of her writing career demonstrating the degree to which humans will torture, injure, and kill each other as an expression of their investments in religious "morality."

In the 1950s, she reflected directly on the social fate of disabled children by arguing that sentimentality expressed toward them—that which would deny their difficulties and suffering in a hostile world—is akin to beliefs that sent individuals to the gas chambers during the Holocaust. Furthermore, O'Connor insisted that the parents of disabled children would hesitate to dismiss such a comparison of cultural attitudes toward disability even though her parallel may seem extreme to many. In making this argument, the disabled author identified sentimentality as a key antagonist of disabled people with respect to more meaningful engagements with the experience of impairment. O'Connor died in 1964 at the age of 39 following an ill-fated surgery that reactivated her lupus.

—*David T. Mitchell*

See also Novel, The; Religion.

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ONTARIANS WITH DISABILITIES ACT OF 2001 (CANADA)

The recognition that people with disabilities are entitled to full citizenship and that government has an obligation to take steps to make that vision a reality is a relatively recent development in Canada. It reflects a transition from the view that people with disabilities are inadequate and require charity and beneficence to an acknowledgment that the obstacles for full inclusion are barriers that prevent people with disabilities from fully participating in all aspects of society.

The Charter of Rights and Freedoms provides constitutional protection to persons with disabilities by prohibiting discrimination on the basis of disability. Provincial and federal human rights legislation also prohibits discrimination on the basis of disability in a number of key areas including employment and the provision of goods and services to the public. However, the charter and human rights legislation require individual complaints to be filed for each act of discrimination and involve a lengthy legal proceeding. While human rights legislation may allow for systemic litigation and proactive approaches to prevent and remove barriers, the lack of a comprehensive barrier-removal statute was identified as an important deficit preventing the full participation of persons with disabilities. Requiring individuals to file complaints is difficult where people are afraid to disclose that they have a disability.

Between 1995 and 2001, the Ontarians with Disabilities Act committee, a province-wide coalition of people with disabilities and organizations representing people with disabilities, was formed to lobby for comprehensive barrier-removal legislation in Ontario.

Legislation was introduced in November 2001 and went into effect on September 30, 2002. It requires the provincial government, municipal governments, hospitals, educational institutions, and public transit organizations to develop barrier removal plans within one year. The plans must set out how organizations intend to identify existing barriers, how they plan to remove those barriers, and how they intend to prevent the creation of new barriers. There is no specific obligation in the legislation to remove a certain number of barriers or types of barriers within any time frame. The plans are to be developed in consultation with people with disabilities. The plans must be filed with the newly created Accessibility Directorate and will be available to the public. The legislation does allow the government to develop regulations and guidelines on the plans, but to date none have been developed. As of January 2003 the enforcement provisions of the legislation had not been proclaimed.

The legislation also permits the government to extend its application to the private sector, but again, this has not been done. The government is seeking voluntary compliance by the private sector. There are a number of other obligations placed on the provincial government, such as ensuring that all of their websites meet accessibility standards.

The legislation does not create an independent body, but it does enshrine in legislation the Accessibility Directorate as a part of the public service. It also creates a provincial Accessibility Advisory body, as well as requires municipalities of more than 10,000 people to create their own advisory councils.

The legislation specifically states that it does not in any way diminish or affect the rights of people with disabilities under the Ontario Human Rights Code.

The definition of *disability* in the Ontarians with Disabilities Act is inclusive and specifically includes mental disability and brain injury. The definition in the Ontario Human Rights Code was amended to be consistent with the definition in the Ontarians with Disabilities Act.

The legislation also requires that people with disabilities and other stakeholders must be given an opportunity to consult on any proposed regulations developed under the act. It allows for the development of guidelines and standards, although there are no timelines in place for them to be developed.

In a provincial election held in October 2003, the Ontarians with Disabilities Act was raised as an issue with the new government promising to strengthen the legislation within its first year in office. Consultations started in January 2004, and the legislation was passed and went into effect in 2005.

—*Patti Bregman*

See also Disability Law: Canada.

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OPPRESSION

Oppression occurs when individuals are systematically subjected to political, economic, cultural, or social degradation because they belong to a specific social group. In 1970, Paulo Freire argued that the experience of oppression is marked by dehumanization, conquest by the oppressed group, dividing and ruling by the oppressed group, manipulation, cultural invasion, "forcing the oppressed group to adopt the beliefs of the oppressors," exploitation, marginalization, power inequities, and violence.

OPPRESSION AND THE COMPLEX DISABLED PERSON

Oppression is often a topic when minority groups and the dispersion of power are discussed. In the African American civil rights movement, the women's movement, anti-apartheid movements, and many civil and human rights movements globally, oppressed people have sought to redistribute power and increase equality, all citing a common theme of oppression.

Many parallels have been drawn between the black community and the disability community in North America. The idea of the minority model being applied to both groups is anchored in the social model that has flourished in British and American disability studies. This model argues that social attitudes rather than physical or mental inabilities are the primary source of problems confronting disabled people. In addition, disability theorists argue that many aspects of the physical and social environment are determined by public policy and that policy is a reflection of pervasive societal attitudes and values. This may have a distinct impact on those who have intersecting identities that may be targets for oppression.

Consider, for example, a black woman who is disabled as defined by Western disability theorists. Persons such as this, who are members of more than one minority group, often experience tension, and they rank their membership in such groups in terms of the characteristics they consider most appealing and most central to their identity. What is appealing to a person is often dictated by the culture that the individual identifies with. Often, even within minority groups, the dominant culture influences beliefs about what characteristics are of value. Cultural invasion is a phenomenon discussed by Freire (1970) where the invaders, "persons outside of the oppressed group," penetrate the cultural context of another group, disrespecting the latter's potentialities. In this invasion, the invaders impose their views of the world—right and wrong, good and bad, inferior and superior—on those whom they invade, and they inhibit creativity by curbing expression of the less powerful group. Those invaded are then expected to pick up the values of their oppressors and accept them as their own. Many disabled blacks have internalized the views of the dominant group concerning both race and disability.

Oppression is expressed in the above instance by locating the sources of oppression within the body of the disabled person, thereby blaming the individual for experiences of oppression, because his problems are housed within him. This is done in an attempt to remove societal responsibility for barriers that may be placed on the oppressed group. The internalization of race hatred has been argued well; however, less theorized is the acceptance of dominant cultural views concerning disability status and the effect this has on the experience of oppression for persons who hold multiple minority status.

It is not enough that the skin is a culprit; now the biological traits beneath the skin have been targeted. Such an argument is not new to blacks as it was seen in the measuring of black skulls to prove innate inferiority and a lack of humanness in an effort to legitimize mistreatment of blacks based on race. Over the years, black theorists and scientists have taken up this argument to disprove it, but the same has not been successfully done for disability, and blacks have not openly recognized this similarity in a way that would spark revolution as it did in race politics. In turn, the dominant culture's ideas of the "normal-functioning body and mind" have become mainstream in black communities, and these ideas lend themselves to inadvertent oppression from a group that is familiar with the trauma of daily oppression.

Although incorporation of dominant beliefs toward the disabled has occurred, it is not an absolute within the black community. Blacks are also influenced by a historic ostracism based on race, and they have learned to accept a wider range of difference as normal and acceptable. Thus, disability oppression is often seen enforced on those whose differences lie outside the range that blacks have carved out as normal and functional, and it places those on the fringes at high risk for "majority norm enforcement."

If ethnicity complicates disability, then adding gender to the equation can certainly offer an additional dimension. Rosangela Berman Bieler, a Brazilian disabled woman, argued in 1998 that in spite of the similar discrimination that disabled men and women face, there is a point where they differ; that difference is seen in the cultural norms accepted by majority society concerning sexuality and affection in regards to disabled women. In a society where body defines you, the black and disabled female finds her body on the lowest stratum of beauty in terms of the dominant culture's standards.

Women of color with disabilities are not unique in their struggle to fight the stereotypes of asexuality and abnormality concerning the disabled female body, but an ethnic female does face the added stigma of being an "other," already considered less than the dominant culture's acceptability for beauty. Thus, not only does the disabled black woman receive societal messages that she is less than female because of her disability, she also receives the message that she is less than female because she is black. As a trinity, disability, blackness, and femaleness represent a union of oppression that is focused on the body of an individual who can be devalued from many angles. Her image is tarnished by her triple minority status, and it is acceptable to treat her as less than human.

THE UNIQUENESS OF DISABILITY OPPRESSION

Though oppression based on race and gender has similarities to oppression experienced by those who are disabled, disability oppression is unique in some respects: People are born black, or female, but can become disabled at any time in their lives. There is a fear associated with the unknown, and to distance oneself helps to keep a separation between what one currently is and what one does not want to be. This distance is seen in North America and also globally, and the fear of becoming disabled helps to keep disability oppression grounded in many cultures. The establishing of oppression based on the fear of a shift in social category separates disability-based oppression from race-based oppression; in other words, people do not wake up after 20 years of being white and suddenly possess the characteristics of blackness.

An additional unique characteristic of disability-based oppression is the need that a disabled person may have for personal assistance. This opens doors of oppression in different ways than does race or gender. Consider an individual who needs daily assistance with bathing or dressing. If the personal assistant refuses to help, or is late and services are not rendered, the disabled person is in a situation of less power, of less authority, of "dif-ability," and is thus oppressed based simply on the need for personal assistance. These occurrences are specific to those who have disability status.

CONCLUSIONS

When grappling with the existence of oppression, we must be informed by our surroundings, by the oppression that others have experienced and navigated through, while also being aware of the nuances that are present in oppression experienced in the context of disability. Oppression is not just an experience but also a social phenomenon that has been globally expected. There is always a group that assumes a subordinate position. The disabled community faces multiple levels of the expression of oppression, because disability inhabits locations that cross and encompass gender, race, socioeconomic status, disability type, lifestyle, age, religious beliefs, and nationality. It must be realized that disability oppression is not housed in genetics but lives in the cultural norms that have been accepted as mainstream beliefs in the societies in which we live. Mainstream cultural norms concerning disability must be altered in ways that will help eliminate disability oppression as a standard experience for the disabled.

—Nefertiti L. Nowell

See also Attitudes; Disability Culture; Disability Pride; Gender; Normality; Racism.

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ORALISM

Oralism refers to one of the two principal approaches to and philosophies of teaching language to the deaf; it is contrasted with manualism. Oralism assumes that speech is the most evolutionarily advantageous form of language and that the ability to use and/or understand spoken language is what separates humans from lower species. Thus, oralism devotes considerable attention to teaching deaf and hearing-impaired people not only how to produce speech but also how to read lips. Manualists take the opposite position, regarding sign language (in its various forms, from American Sign Language to Signed English, and their national variants) as "natural" languages, possessing all the important characteristics of any language, such as morphology, syntax, and markers for semantic and rhetorical intensifiers and connotations. In its earliest years, manualism also carried with it an evangelical mission, as a way of spreading gospel to those ordinarily considered excluded from its transmission.

In the nineteenth century, when the great debates between oralists and manualists first took shape, one of the most famous proponents of oralism was Alexander Graham Bell, whose invention of the telephone was in part a by-product of his work on creating communication systems for the deaf (Bell was married to a deaf woman). His father, Alexander Melville Bell, a famous teacher of elocution, developed a system called "Visible Speech," designed to assist in teaching deaf people how to acquire spoken language. The Alexander Graham Bell Association, a foundation named after him, continues today and is committed to furthering Bell's conviction that the proper way for deaf and hard-of-hearing (their term) people to communicate is through spoken language.

There were eugenic and racist elements to the oralism versus manualism debates, as well. Bell, for example, believed that manualism needed to be done away with in large part because it encouraged inbreeding between deaf people, thus leading to a greater possibility (in the case of hereditary deafness) of the continuation of deafness, since manualism allowed deaf people to remain segregated from the hearing. Also, by the end of the nineteenth century, it was the case that there was a racial gulf between oralists and manualists, and only people of color were being taught exclusively through manualist approaches (presumably because educators either believed them incapable of learning through oralist methods or because they did not see the reason for nonwhites to have the skills they associated with spoken language).

Oralism also became a platform for the development of the teaching of deaf people as a form of "women's work" in the United States: Because of the American Civil War, men, who were the principal teachers up until that time, were called to battle, and women took over some of these roles. After the war, the lowering of the age at which deaf children began to receive instruction and the economic advantages of assigning such work to women helped increase the role of women in this arena.

In recent decades, as deaf people became Deaf (i.e., assumed a cultural identity that involved pride in their status), oralism has become once again a more criticized approach to language education. Such larger educational movements as mainstreaming and inclusion are often seen as vestiges of or returns to the precepts of oralism, in that they do not create a space for Deaf people to enact their own linguistic culture and that they privilege speech over sign. Similarly, more recent debates over cochlear implant surgeries, particularly for children during their most sensitive years for language acquisition, revives the binary division between speech and sign that oralism raised almost two centuries ago.

—Bruce Henderson

See also Alexander Graham Bell; Deaf, History of the; Deaf Culture; Speech and Language Pathology.

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ORTHOPEDICS

The practice of orthopedics has a long history. From its first inception in France in 1741 to the present, orthopedics is a specialty that has evolved to fit the changing nature of disabling conditions with the rise of technology.

Despite its long history, prior to the nineteenth century very little orthopedic surgery was performed. Generally, orthopedics was confined to the correction of deformities by means of external apparatus, reduction in the case of dislocation, and amputation. With developments in other spheres such as anesthetics, antiseptic techniques, and X-rays, more surgical means were at the disposal of orthopedists. In the nineteenth century, orthopedics began to formally establish itself as a specialty, particularly in the United States. The American Orthopaedic Association was founded in

1887, its German counterpart in 1901, and the British Orthopaedic Association was established in 1918.

Specialist hospitals and clinics such as the Boston Orthopedic Institution and Fracture Clinics in Manchester and Liverpool were established in the late nineteenth and early twentieth centuries. While new techniques were created, such as surgery for open reduction of congenital dislocation of the hip and bone lengthening with direct skeletal traction, it was during World War I that orthopedic surgery came to the fore. Orthopedic surgeons' skill prevented permanent disability from skeletal injuries, halted deaths from gas gangrene through amputations, and mediated highly complex procedures on nerves and tendons. The need was so great that American orthopedists were imported even before the United States entered the war in 1917.

After the war, the orthopedic surgeons' focus concentrated once more on civilians. Hospitals that had housed disabled ex-servicemen were turned into institutions for disabled workmen and children. Surgery was conducted on tubercular joints so prevalent in Britain and other disabling conditions such as clubfoot. In the United States, until the development of vaccines in the late 1950s, orthopedists treated those who had contracted and recovered from paralytic polio with a variety of methods. As previously mentioned, discoveries in other spheres have had an impact on orthopedics; for instance, the development of sulphonamides and penicillin in the late 1930s and 1940s decreased the risk of bone infection in compound fractures.

The late 1950s and 1960s were a time of great change in orthopedics. Although artificial joints had been designed and implanted since the late nineteenth century, it was in the late 1950s that Sir John Charnley, at the Wrightington Hospital in Wigan, England, perfected his two component combination plastic and stainless steel hip replacement. His new procedure changed much of the focus of orthopedics to implanting devices that replaced worn joints affected by osteoarthritis. This innovation was taken up around the world, and other artificial joints were designed. Successful replacement knees were first inserted in 1968 and were followed by the shoulder, elbow, ankle, and hand. In Switzerland, the AO (Arbeitsgemeinschaft fur Osteosynthesefragen; Association for the Study of Internal Fixation) revolutionized fracture care, rejecting plaster casts for surgical intervention with a system of screws and plates. New materials have been developed for joint replacement surgery including titanium, combination alloys, and ceramics. High technology now plays an important role in joint replacement with new techniques such as minimally invasive surgery (MIS), which usually results in a shorter recovery time for the patient. These innovations have created even more specialization in orthopedics, which now includes approximately 12 specific areas of subspecialization including sports medicine and arthroscopy, trauma, tumor, and metabolic disease. Manufacturers play an important role in the marketing and promotion of orthopedic products, a multi-billion-dollar business.

—Julie Anderson

See also Accidents; Arthritis and Cartilage Diseases and Injuries; Disabled Veterans; Dwarfism; Surgery and Disability.

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ORTHOTICS

See Mobility Aids

OSTEOPOROSIS

Osteoporosis (porous bone), named in the 1820s by Alsatian pathologist Jean Georges Chrétien Fréderic Martin Lobstein "the Younger," is characterized by low bone mass and deteriorated bone tissue, causing fragile bones and increased risk of fracturing. Bone compression or fracturing most frequently affects the hip, spine, or wrist and causes loss of height and/or kyphosis (dowager's hump). Persons with severe osteoporosis may experience spontaneous and/or traumatic bone breakage; pain; mobility limitations; physical, emotional, or psychological disabilities; or death.

In 1940, Fuller Albright, a Boston endocrinologist, discovered a link between estrogen loss at menopause and "thin bone." Albright initiated estrogen treatments to osteoporotic women. Its use became widespread only in the mid-1960s when Robert A. Wilson, a Brooklyn gynecologist, promoted estrogen therapy, newly available in pills, as a cure for all menopausal deficits in popular and medical media. Researchers in the late 1970s associated estrogen treatment with reproductive system cancers, and its use declined. Osteoporosis remained obscure until 1984, when a Consensus Conference through the U.S. National Institutes of Health declared estrogen and calcium standard treatments.

Historically, osteoporosis was mostly associated with older women, but others at risk include aging men, persons with eating disorders, pregnant teenagers, and female athletes. Men generally have higher bone mass, lose bone density at a slower pace, and develop bone loss at older ages. Controversy remains about whether osteoporosis is a disease or a natural concomitant of aging.

Genetic, behavioral, and environmental factors and their interactions contribute to osteoporosis. All racial groups are susceptible, although incidence varies. Peak bone mass (PBM), the amount of bone tissue attained by adulthood, is a major determinant of fracture risk. Smoking, excess alcohol, excess caffeine, lack of or excess exercise, and lack of sunshine deplete bone tissue. Secondary osteoporosis may result from other illnesses (e.g., end-stage kidney disease), medical treatments and practices (e.g., removal of ovaries, institutionalization), specific drugs (e.g., long-term steroid use), and other hormonal and nutritional deficiencies (e.g., vitamin D, calcium, parathyroid hormone, calcitonin, and fluoride).

Bone densitometry proliferated during the late 1980s; campaigns to promote screening to measure bone mineral density (BMD) of older women further increased recognition of this "silent" epidemic and the estimates of persons affected. Definitions of osteoporosis and osteopenia (borderline low bone density) based on BMD criteria established by the World Health Organization resulted in the diagnosis of millions of asymptomatic patients. More than half of all women and about one-third of all men over age 50 are predicted to experience osteoporotic fractures during their lives. Incidence and cost estimates are widely employed by commercial, medical, and advocacy interests to influence governments and consumers.

Since the late 1990s, nonestrogenic drugs (e.g., bisphosphonates) have been widely prescribed to prevent and repair bone loss. In 2003, in the United States, the Women's Health Initiative clinical trials indicated increased risk of cancer and heart disease from use of estrogen with progestin. Postmenopausal women with osteoporosis are now advised to avoid long-term hormone replacement therapy.

Despite widespread bone densitometry testing in North America, many cases go undiagnosed, even when serious bone fracturing has occurred. Science cannot yet accurately predict which individuals with low BMD will develop fractures or become disabled, but geneticists and molecular biologists are pursuing subcellular studies. Programs to prevent falls play an important role in reducing incidence of broken hips, which often lead to disability and/or death in seniors.

North American patient activists and medical experts established voluntary agencies (e.g., National Osteoporosis Foundation, Osteoporosis Society of Canada) in the 1980s, which lobby governments, educate the general public, and provide services for persons with osteoporosis.

—Elaine Berman

See also Aging; Aging, International; Hip Fracture.

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OUTCOME MEASURES

Functional disability and quality of life are key outcomes that influence patients' demand for care, as well as their compliance and satisfaction with treatment. Over the past few decades, there has been a shift from traditional physician-focused assessment, with its dependence on physiological and radiological measurement, toward methods based on the belief that patients can provide accurate and meaningful assessments of their own health. Such measurements have found a natural home in the field of disability, where clinician-based assessments can give only a limited picture of the impact of illness on individuals. Indeed, clinical assessments have tended to overestimate the adverse effects of disability on self-reported quality of life. For example, in one study over 80 percent of patients with spinal cord injury anticipated average, or better, quality of life, while less than one-fifth of those treating them rated their potential health state so positively. Such a mismatch in perceptions of the impact of disability means that appropriate outcome measures must be developed that assess what is important to patients in terms of their own health-related quality of life.

Results from studies of patients with disabilities have often shown that they view their health in a positive way and that their self-reported quality of life is often very comparable to similarly aged people not reporting any disabilities. Manifestly, however, the impact of disability can also have dramatic negative consequences for patients, and appropriate outcome measures can be useful to assess patients' reactions to treatment and therapy. For example, the quality of life of stroke patients has been found to decrease over time, despite clinical assessments remaining stable. In trials of interventions, patient-based outcome measures can be used to assess their efficacy, and they provide an important addition to clinical assessments.

The increasing use of subjective health indicators has been reflected in the number of research papers reporting aspects of subjective health status or *health-related quality of life*. This reflects a growing interest on the part of physicians and health researchers in using the patient's viewpoint in formulating treatment plans and monitoring the quality of medical care outcomes. As more of the population experience the limitations of aging, chronic illness, and disability, due to increased lifespan, a need has developed for a more humanistic form of health care that incorporates a systematic assessment of the patient's perceptions.

Interest in subjective patient-based assessment accords with the World Health Organization's (WHO) now classic characterization of health, which incorporates autonomy and physical, mental, and social well-being and not merely the absence of disease. Health-related quality of life is a concept that attempts to encompass the spirit of the WHO definition of health by incorporating both personal health status and social well-being in assessing the health of individuals and populations. Although there is no agreed-on single definition of health-related quality of life, researchers for the most part concur on the components that should be included, such as general health, physical functioning, emotional state, subjective well-being, and social support.

Indicators of health-related quality of life typically incorporate patient views gained from interviews and/or focus groups. It is essential that, once a set of questions has been identified, the instrument has good psychometric and statistical properties. An instrument that evaluates outcomes of treatment must measure reliably and accurately what it purports to measure. Minimally, outcome measures should manifest the following attributes.

1. *Reliability.* The instrument should produce the same, or very similar results, on two or more administrations to the same respondents, provided, of course, there is good reason to believe that the health status of the patients has not changed. The difficulty with such a method of validating a questionnaire rests on the uncertainty of whether results that may indicate a questionnaire is unreliable are in fact an indication of real change in health status. Due to the potential difficulties in gaining an accurate picture of reliability in this way, many researchers adopt the Cronbach's alpha statistic, to determine internal reliability. Internal reliability refers to the extent to which items on a scale are tapping a single underlying construct, and therefore there is a high level of interitem correlation. Assuming that such high levels of interitem

correlation are not a product of chance, it is commonplace to assume that a high alpha statistic indicates the questionnaire is tapping an underlying construct and hence is reliable. However, due to many potential sources of variability, high internal reliability reported in only a single study should be viewed cautiously.

2. *Face validity.* Face validity refers to whether items on a questionnaire appear to make sense and can be easily understood. An instrument that contains ambiguities or illogical response categories is very unlikely to either be reliable over time or manifest high levels of internal consistency. In studies that are undertaken cross-culturally, it is essential that translations of an instrument have been validated and that translations of items should retain the original meaning.

3. *Content validity.* This refers to the choice of appropriate items in a questionnaire. Items included in a measure should reflect the underlying domain being measured.

4. *Criterion validity.* This is the ability of an instrument to correspond with other measures. However, finding a "gold standard" instrument is rare, and only really possible in instances where a shorter-form measure is being created from an established longer instrument. For example, results of the eight-item SF-8 have been compared with results from the 36-item SF-36 Health Survey.

5. *Construct validity.* This refers to the ability of an instrument to reflect previously hypothesized patterns of data. For example, physical health typically deteriorates with age, and any questionnaire designed to measure this should reflect this pattern in its results.

6. *Sensitivity to change.* Measures must be responsive, that is, sensitive to meaningful change. When evaluating health care interventions, responsiveness is a crucial aspect of a measures utility. It is possible, for example, to have measures that are reproducible and valid but not responsive. Gordon Guyatt and colleagues (Guyatt et al. 1989) give the example of the Sickness Impact Profile (SIP) in a controlled trial of different strategies for managing back pain. They found that while many parts of the SIP were useful in evaluating change, others were not. For example, they found that no respondent, either at baseline or at follow-up, endorsed the item "I do not feed myself at all, and must be fed," which produced results that are clearly reproducible but not informative in the context of that particular trial. Such unresponsive items cannot prove useful in detecting changes over time as a function of treatment. Consequently, when selecting a measure for inclusion in an evaluative study, researchers should select instruments that contain appropriate items for the patient group and that are likely to detect changes.

7. *Interpretability.* It is essential for measures to provide meaningful data. For example, in terms of change scores a number of instruments provide guidelines for interpreting changes that are important to patients, rather than simply being statistically significant. Minimally important differences (MIDs) are those changes that patients themselves have judged as being small but meaningful. These MIDs can be useful both for interpreting results of longitudinal data, and calculating sample sizes for trials.

The most commonly used measures are generic instruments that have been designed for use in any illness group, population, or sample, for example, the SF-36 and SIP. Such measures have gained widespread use, and consequently substantial amounts of data exist on reliability, validity, and sensitivity to change. Furthermore, data from general populations exist, enabling comparison of results with normative samples. Any given disease-specific measure is, by its very nature, less widely used but more likely to reflect concerns typical of the specific illness group for which it was designed.

—Crispin Jenkinson

See also Functional Assessment; Quality of Life.

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P

PAIN

Chronic pain may well be the most common cause of recurrent and permanent disability in the developed world today. According to a 1999 Gallup survey, 89% of Americans suffer from pain at least once a month, and 43 percent—some 83 million—report that pain frequently affects their participation in some activities. More than 26 million (15 percent) describe their recurrent monthly pain as severe. Pain accounts for an estimated 20 percent of health care visits and 10 percent of prescription drug sales. Yet less than 1 percent of the U.S. National Institutes of Health's budget supports research into the mechanisms and management of pain.

Pain is classified as chronic rather than acute when it persists beyond the normal healing period for any illness or injury and appears likely to recur or continue indefinitely. The insurance industry defines three months as the minimum for chronicity, but a period as short as two or three weeks can establish a chronic condition in many instances. Several organic diagnoses such as arthritis, cancer, diabetes, and herpes are associated with severe chronic pain.

Many Americans suffer, however, from disorders defined by the pain alone. These include migraine and other forms of chronic headache; low back pain; abdominal and pelvic pain; temporomandibular joint disorder; trigeminal neuralgia, an intense stabbing pain throughout the facial area, triggered by the fifth cranial nerve; fibromyalgia, defined as widespread musculoskeletal pain, often accompanied by fatigue; phantom limb pain; carpal tunnel syndrome (repetitive strain); and the causalgiform disorders (in current terminology, chronic regional pain syndrome [CRPS]). The latter are characterized by persistent burning pain, usually located in an extremity, which may be referred elsewhere in the body; allodynia, or painful sensation in response to an innocuous stimulus (such as light touch); and hyperesthesia, or severely painful sensation in response to a mildly painful stimulus (pressure or pinprick).

Regardless of its specific location and nature, chronic pain often takes over the sufferer's life. The individual finds it difficult and tiring to work, exercise, and participate in normal activities; withdraws from other people; and becomes both anxious in expectation of severe pain and depressed by its unrelenting persistence. Although many treatments are available, there is no one therapy that works in all cases, and many patients become angry and frustrated at what they perceive as the indifference or ignorance of the medical profession.

HISTORY

Nineteenth-century British, German, and French physicians were the first to recognize the problem of chronic "pains without lesion" and attributed them to a functional disorder or persistent irritation of the nervous system. Johannes Müller's concept of *Gemeingefühl*, or "cenesthesis," an individual's ability to correctly perceive internal sensations, was another of the creative etiologies proposed. S. Weir Mitchell, the American neurologist who observed many Civil War soldiers afflicted with causalgia, phantom limb pain, and other painful conditions long after their original wounds had healed, wrote movingly of their suffering. He described classic causalgia (the burning pain following a nerve injury) as "the most terrible of all the tortures. . . . Under such torments[,] . . . the most amiable grow irritable, the soldier becomes a coward, and the strongest man is scarcely less nervous than the most hysterical girl." Despite the odd and often hostile behavior of his patients, Mitchell was convinced of the reality of their physical suffering.

However, by 1900, specific diagnostic tests and signs had redefined the practice of neurology, leaving little room for unexplainable chronic pains without other physiological symptoms. At the same time, practitioners of psychiatry and the new field of psychoanalysis found that "hysterical" pains offered potential insights into mental and emotional disease. The contributions of neurophysiologists such as Charles Sherrington supported the concept of *specificity:* that "real" pain was a direct, one-to-one response to a specific harmful or noxious stimulus (although Sherrington himself insisted that the central nervous system integrated neural response from the periphery). The corollary of specificity theory was that individuals who reported pain in the absence of an evident cause were delusional, neurotically obsessed, or malingering (often the conclusion of military surgeons or those treating workmen's compensation cases): Their pain was "in the brain." As John Homans wrote of causalgia-like disorders in *The New England Journal of Medicine* in 1940, "That there is something basically at fault about the nervous system of certain of the individuals affected, is probable. Some . . . have grudges against the world, or are perhaps stupid, or even criminal."

This disparaging attitude toward patients with chronic pain persisted well into mid-century. A few researchers and clinicians—the surgeons Rene Leriche and William Livingston, the neurologists Alfred Goldscheider and Rafael Lorentè de No, and the anesthesiologist Emery Rovenstine—proposed alternatives to specificity theory or attempted new treatments before 1940. In the 1890s, Goldscheider endorsed Sherrington's insistence that the central nervous system integrated inputs from the periphery and proposed that pain was a result of the brain's recognition of spatial and temporal *patterns* of sensation. Leriche, based on his work with injured men during World War I, suggested that a nerve injury that damaged the myelin sheath surrounding the sympathetic nerves might create some kind of artificial synapse between these and contiguous sensory nerves, leading to sensations of pain in response to normal stimuli and internal physiological activity. Livingston, who worked with patients with industrial injuries in the 1930s, diagrammed a feedback loop within the nervous system, which he termed a "vicious circle," theorizing that continuing severe pain over a period of time led to functional and organic changes in the nervous system, producing a chronic pain state.

These ingenious ideas were largely ignored until World War II, when, for the first time in history, organized teams of clinicians had the opportunity to observe and treat large numbers of men with similar injuries. Henry K. Beecher, a Harvard anesthesiologist serving in Europe, was startled to realize that soldiers with serious wounds seemed to be in much less pain than surgical patients recovering consciousness in the recovery room. The GIs were slow to request morphine and often appeared quite relieved by a cigarette. Beecher theorized that, whereas pain for the surgical patient meant disruption of normal life and fears of serious illness, the soldier's painful wound meant his release from the battlefield to a hospital and increased chance of survival. The human experience of pain, he suggested, had to result from the fusion of a physical sensation and a cognitive and emotional "reaction component." The assumptions of specificity theory, based on laboratory experiments in which the reaction component was relatively neutral, could not be applied therefore to the understanding of clinical pain.

At Madigan Army Hospital in Washington state, the young anesthesiologist John Bonica participated in regular lunchtime discussions with colleagues—a neurologist, an orthopedist, and a psychiatrist—about the difficult pain disorders they encountered. He left army service with the conviction that interdisciplinary collaboration in both clinical and basic research would be essential to improving medical understanding of pain. Both Bonica and Livingston, who called the war years dealing with nerve injuries at Oakland Naval Hospital "the most exciting and productive of my life," founded multidisciplinary pain clinics at their home institutions in 1947. In 1953, Bonica brought together much of the current state of knowledge in his magnum opus *The Management of Pain.* One of the important points made in this book, paralleling Beecher's work, was that all clinical pain included both physiological and psychological components.

The Dutch neurosurgeon Willem Noordenbos extended the theory of pain as an integration of multiple inputs into the nervous system in his short but classic 1959 book, *Pain.* His model of a multisynaptic afferent system was "an extremely complicated nerve net in which, within limits, everything synapses more or less with everything else." His ideas appealed to the Canadian psychologist Ronald Melzack (who had been Livingston's fellow) and the British physiologist Patrick Wall, two self-described iconoclasts who met at MIT in the late 1950s. They drew together Goldscheider's, Livingston's, and Noordenbos's ideas with the available research evidence, rethought the problem, and proposed the gate control model of pain in their now iconic paper, "Pain Mechanisms," in 1965. Although the theory itself proved to be incorrect, the implication that laboratory and clinical observations together could demonstrate the physiological basis of a complex neural integration mechanism for pain perception inspired and challenged a young generation of researchers.

THE PAIN FIELD

Drawing on the upsurge of interest in pain generated by Wall and Melzack, John Bonica organized a meeting of 300 researchers and clinicians at an isolated convent in Issaquah, Washington. Under his leadership, this conference gave birth to an interdisciplinary organization, the International Association for the Study of Pain (IASP), and a new journal edited by Wall, *Pain*, marking the emergence of pain science as a professional field. National chapters of the association have been organized throughout Europe and Latin America; in Asia, Australia, and New Zealand; and in several African countries. The American Pain Society (APS) was founded in 1977. In 2003, the IASP had more than 6,700 members, representing more than 100 countries and 60 disciplinary fields. The next 30 years saw much new research on the problem of pain, stimulated by the availability of a dedicated research journal and by regular professional meetings and opportunities for interdisciplinary discussion between clinicians, neurophysiologists, biochemists, pharmacologists, molecular biologists, and psychologists.

Two major findings have emerged from this research. First, severe pain from an injury or other stimulus, if continued over some period, can alter the neurochemistry of the central nervous system, creating a sensitization of the central nervous system and significant neuronal changes that will endure after the initial stimulus is removed and that is perceived by the individual as chronic pain. Gary Bennett and Xie Yu-Kuan demonstrated this phenomenon dramatically at the National Institutes of Health (NIH) in 1989, using a rat with a constricted sciatic nerve. In 2004, Min Zhou and a team at Washington University in St. Louis identified two enzymes in the forebrain, adenylyl cyclase 1 and 8, that play an important role in central sensitization.

The second finding is that pain perception and response differ with gender and ethnicity and with learning and experience. Women appear to suffer pain more often and with greater emotional stress than do men, but some evidence shows that they may cope with severe pain more effectively. African Americans show a higher vulnerability to chronic pain and a higher level of disability than do white patients. These observations are borne out by neurochemical research; for example, Jon Levine and Christine Miaskowski at UCSF found in the early 1990s that males and females have differential analgesic responses to different types of opioid drugs.

In another set of experiments at NIH in the late 1990s, M. A. Ruda and her colleagues showed that animals that experience pain when very young show neuronal changes at the molecular level and appear more sensitive and hyperesthetic as adults. The clear inference of these studies is that no two individuals experience pain the same way. The clinical observations of Mitchell, Beecher, Livingston, and others are thus borne out by research evidence. Pain is in the brain after all, but in a physiological as well as psychological sense.

TREATMENT

Effective treatment of many chronic pain disorders remains problematic. There are more options than in the early 1900s, when opiate drugs or disabling surgery were the only alternatives, but no one method seems to work in all cases. Morphine and its relatives, including oxycodone, hydropmorphone, meperidine, propoxyphene, and codeine, remain the most consistently effective analgesics known. Since the introduction of the World Health Organization (WHO) analgesic ladder in 1986, an international group of pain specialists and policy advocates, led by Jan Stjernswärd, Mark Swerdlow, Robert Twycross, Kathleen Foley, Vittorio Ventafridda, David Joranson, and June Dahl, has campaigned for the removal of legal and attitudinal barriers to opiate use in severe chronic, particularly cancer, pain. But many patients and clinicians associate these drugs with an unacceptable loss of mental clarity and control. Drug regulatory authorities in most countries fear diversion to the criminal market and restrict and discourage the prescription of opiates. In the late 1990s, the diversion and illegal recreational use of Oxycontin, a slow-release formulation specifically designed for use in chronic pain, prompted a new outburst of public and regulatory concern in the United States.

Surgeons have progressively refined sympathectomies and other techniques—ligature, resectioning, or crushing of the nerve fibers—for blocking the transmission of pain signals to the spinal cord and brain since the 1870s, but in the 1920s, a few pioneers, including Leriche and Livingston, advocated the use of serial anesthetic blocks as a more humane therapy for intractable chronic pain. Livingston found that multiple injections of procaine, sometimes as many as eight over a period of two years or more, often ended the “vicious circle” and resulted in permanent remission. These methods were refined by Rovenstine, Bonica, Swerdlow, and other anesthesiologists and became the staple practice of pain clinics in the United States and the United Kingdom in the 1950s.

The search for pharmaceutical alternatives to the opiates has continued. Although many morphine derivatives were isolated by the 1960s, none had been found that combine analgesic efficacy with a complete lack of addictive potential. Clinical observations in patients with depression meanwhile had demonstrated that the tricyclic antidepressants, such as amitriptyline and imipramine, could relieve headache, postherpetic neuralgia, and other types of persistent pain. More recent research has suggested a number of new pharmacological strategies to develop drugs that will block or inhibit specific steps in sensory, inflammatory, or sensitization neural pathways: These include COX-2 inhibitors and N-methyl-D-aspartate (NMDA) antagonists.

Psychologists have developed alternatives to drugs for the treatment of chronic pain, based on learning and behavioral theory. Soon after the publication of the gate control model, Richard Sternbach argued that an individual’s perception of and response to pain were learned from prior experience—and, by implication, could be relearned. In the early 1970s, the psychologist Wilbert Fordyce and his colleagues at the University of Washington developed a therapeutic program based on operant conditioning, which helped chronic pain sufferers to work their way back to normal functioning by gradually increasing levels of activity. This method has often proved successful but is expensive and requires significant time investment. Cognitive-behavioral therapy, a related modality that emphasizes the teaching of self-management skills, emphasizes the patient’s own agency. The individual who has learned to cope effectively with his or her pain, using relaxation, distraction, and controlled exercise, is able to function better, may suffer less from anxiety and depression, finds the pain less intensive and less disabling, and discovers ways to lead a productive life. Yet some observers have criticized these learning-model programs for shifting so much of the therapeutic responsibility to the patient.

PAIN IN THE TWENTY-FIRST CENTURY

As the twenty-first century begins, pain has increasing salience as a scientific and health problem. In the late 1990s, the American Pain Society (APS) popularized the use of "Pain as the Fifth Vital Sign," and a campaign led by June Dahl prompted the Joint Commission for the Accreditation of Health Care Organizations (JCAHCO) to include pain assessment as a required standard. The U.S. Congress declared 2000–2010 the "Decade of Pain Control and Research" as a result of strong advocacy by pain professional groups, such as the APS and American Academy of Pain Medicine, and patient support groups, such as the American Chronic Pain Association. The Pain Care Policy Act, reintroduced in 2005 as H. R. 1020, would establish a new National Center for Pain and Palliative Care Research at the National Institutes of Health and a national awareness campaign within the Department of Health and Human Services.

Yet most medical students still learn little about pain; many medical specialists, in fields such as cardiology, oncology, gynecology, and gastroenterology, still pay relatively little attention to their patients' pain, and despite its high prevalence and debilitating effects, there is no definitive and completely effective treatment for chronic pain.

—Marcia L. Meldrum

See also Complementary and Alternative Medicine; End-of-Life Care; Health Care and Disability; Palliative Care.

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PALLIATIVE CARE

The term *palliative care* describes an orientation to the care of persons with life-limiting illness that encompasses physical, social, psychological, and spiritual dimensions. It is closely associated with the development of hospice services and is a model of care that has operated beyond the narrow confines of the formal health care system to involve local communities, charitable and philanthropic giving, and the efforts of volunteers. Palliative care services have considerable potential to serve the needs of people with disabilities with advanced illness, although so far and in most cases, they have tended to focus on the care of those with malignant conditions, to the exclusion of those with other needs.

The World Health Organization (WHO) first defined the term *palliative care* in 1989. The most recent definition of palliative care to appear from the WHO, published in 2002, states that palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten nor postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated; will enhance quality of life and may also positively influence the course of illness; and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

There is a global need for improved end-of-life care. Around the world, more than 1 million people die each week. It is estimated that 60 percent of these could benefit from some form of palliative care. Yet at the moment, only a tiny minority of dying people ever receive the support of hospice and palliative care services. Palliative care is hugely underdeveloped in most resource-poor countries, and it is still significantly constrained in many countries with otherwise "advanced" health care systems. There is a significant shortage of political leaders and "product champions" with an interest in palliative care and a dearth of national and international policies to promote its development. The creation of a trained multidisciplinary workforce to deliver clinical care, educational programs to support them, and an evidence base to highlight both unmet need and the efficacy of existing provision are all additional challenges. It is estimated that hospice or palliative care services now exist or are under development on every continent of the world—in around 100 countries. The total number of hospice or palliative care initiatives is in excess of 8,000, and these include inpatient units, hospital-based services, community-based teams, day care centers, and other modes of delivery.

The first attempt to develop a modern approach to hospice and palliative care was led by Dr. Cicely Saunders at St. Christopher's Hospice in South London, which opened in 1967. Based initially around an inpatient unit, soon followed by a home care service, it also delivered education programs and undertook research into the care of terminally ill people. From the outset, ideas developed there were applied differently in other settings. Within a decade, it was accepted that the principles of hospice care could be practiced in many locations: in acute and oncologic hospitals, in home care and day care services, and through ambulatory, outpatient, and "drop-in" services. Such approaches brought the new thinking about dying into the very heartlands of acute medicine and into domiciliary and long-term care settings.

Professional recognition of this emerging area of expertise was necessary if the work was to spread and the influence of hospice philosophy was to go beyond the confines of the voluntary hospice movement. Some claimed that specialization, the integration of palliative care into the mainstream health system, wider "coverage" of services, and the development of an "evidence-based" model of practice and organization were crucial to long-term viability. Meanwhile, others mourned the loss of early ideals and regretted an emphasis on physical symptoms at the expense of psychosocial and spiritual concerns. During the 1990s, there were claims that forces of medicalization and routinization were at work and even that the putative "holism" of palliative care philosophy masked a new, more subtle form of surveillance of the dying and bereaved in modern society.

At the same time, two forces for expansion were also clearly visible. First was the impetus to move palliative care further "upstream" in the disease progression and to make it available to those at earlier stages of a life-threatening illness, thereby seeking integration with curative and rehabilitation therapies and shifting the focus beyond terminal care and the final stages of life. Second, there was a growing interest in extending the benefits of palliative care to those with diseases other than cancer, to make "palliative care for all" a reality. So far, there has been greater success in the first of these; palliative care has found its way into the curriculum of health care professionals working in many settings, its services are delivered alongside and sometimes closely integrated with mainstream provision, and the palliative care "approach" is being fostered in many settings. Too often, however, access to specialist palliative care is confined to those with a cancer diagnosis.

Health and social care staff working in palliative care require training in the particular needs of people with disabilities in relation to advance health care planning, options for hospice and palliative care, and special concerns in consenting to care. People with disabilities, as well as their family members, companions, and surrogates (where applicable), require information and guidance on their rights to make informed health care decisions and on the availability of hospice and palliative care to manage pain and distressing symptoms, as well as psychosocial and spiritual distress in the context of advanced illness.

The lack of engagement between disability studies and studies in palliative care is striking. Yet both fields reveal some of the properties of social movements. In their early decades, modern hospice and palliative care services in the West were supported by wider forces: consumerism and increasing calls for autonomy among the users of health and social care; demographic trends, which created substantial numbers of individuals able to volunteer their labor in local hospices; and greater affluence, which led to an increase in charitable giving. This movement may well have contributed to a new openness about death and bereavement that was in evidence in the late twentieth century (in Britain, for example, the first person ever to be seen to die on television was in the care of a hospice). Inspired by charismatic leadership, the hospice movement condemned the neglect of the dying in society, called for high-quality pain and symptom management for all who needed it, sought to reconstruct death as a natural phenomenon rather than a clinical failure, and marshaled practical and moral arguments to oppose those in favor of euthanasia.

Hospice care and palliative care have a shared and brief history. The evolution of one into the other marks a transition that, if successful, could ensure that the benefits of a model of care previously available to just a few people at the end of life will in time be extended to all who need it, regardless of diagnosis, stage of disease, social situation, or means.

—David Clark and
Carol Thomas

See also Death; End-of-Life Care; Pain.

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PANIC DISORDER

Panic disorder (PD), a commonly observed mental disorder affecting up to 3 percent of the general population, is one of the most disabling conditions among the so-called common mental disorders. Approximately 60 percent of people suffering from PD show a severe or moderate level of disability and reduced quality of life, with relevant difficulties in important areas such as work, social relationships, marital life, and leisure. Disability related to PD may be due to several factors. First, the nature of symptoms themselves can result in overwhelming anxiety that impairs functioning, as can the fear of recurrent attacks and the presence of "anticipatory anxiety" (i.e., the anxiety related to the expectation of a new attack). Second, the frequency of "comorbidity" with other disabling anxiety or depressive disorders, particularly agoraphobia, complicates up to two-thirds of PD cases. Agoraphobia is characterized by anxiety about being in places or situations from which escape might be difficult or embarrassing (i.e., open or restricted spaces, crowded places, travelling in a bus, etc.) and by avoidance of such situations, with a consequent, often marked, restriction in lifestyle of people affected. Major depression is a frequent consequence of untreated panic disorder, and this adds to the symptom picture and adds considerable social-occupational disability. Finally, the chronic or recurrent nature of the disorder (up to 70–80 percent of cases) often leads to suicide attempts and to reduced self-esteem, which compounds the disability.

—Bernardo Carpiniello

See also Mental Illness.

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PARALYMPICS

The Paralympic Games or the Paralympics are the international multisport competitions for athletes with disabilities, which take place every two years, alternating between summer and winter sports. Roughly 4,000 athletes from around 140 countries compete in approximately 20 sports in the summer Paralympics, while roughly 500 athletes from around 40 countries compete in approximately four sports in the winter Paralympics. The *Paralympic movement* is a term that refers to the collective parties who contribute to the worldwide development of sports for persons with a disability, from developmental to the elite sport level. Historically, the idea stems from the use of sports for rehabilitation, but due to the increased participation and recognition of sports for persons with disabilities, the Paralympics and the Paralympic movement now play a vital role in facilitating sporting opportunities for all persons with disabilities and contribute to changing societal attitudes and perceptions of individuals with disabilities. In the past 50 years, this movement has seen a significant increase, and today, thousands of athletes participate in more than 300 international competitions every year.

HISTORY OF THE PARALYMPIC MOVEMENT

In 1944, Sir Ludwig Guttmann promoted sport as a form of recreation and rehabilitation therapy for World War II veterans with spinal cord injuries in Stoke Mandeville, England. In 1948, he organized a sports competition for athletes with disabilities, and with the gradual inclusion of other countries into these competitions, the Paralympic movement began. Olympic-style games for athletes with disabilities were organized for the first time in Rome in 1960. A number of different disability groups were merged in competition in 1976, and in the same year, the first Paralympic Winter Games took place. The number of participating athletes has consistently increased at every event since.

The Paralympic Games are multidisability, multisport competitions and have become the second largest sporting event in the world, only after the Olympic Games. The Paralympic Games have always been held in the same year as the Olympic Games, and since the Seoul Games (summer, 1988) and the Albertville Winter Games (1992), they have also taken place at the same venues. In 2001, an agreement was signed between International Olympic Committee and the IPC under which the city chosen to host the Olympic Games will also host the Paralympics. The Italian city of Turin will host the 2006 Olympic and Paralympic Winter Games, and in the summer of 2008, both the Olympics and Paralympics will be held in Beijing.

The word *Paralympic* was originally a pun combining *paraplegic* and *Olympic,* but with the inclusion of other disability groups and the close associations with the Olympic movement, it now relates to *parallel* and *Olympic,* to illustrate how the two movements exist side by side. Most sports at the Paralympic Games are the equivalent to the Olympic sports, but four sports are unique to the Paralympic Games (boccia, goalball, powerlifting, and wheelchair rugby). For current information about the Paralympic sports (summer and winter), please visit the International Paralympic Committee (IPC) website at www.paralympic.org.

To create a level playing field, Paralympic athletes are classified into one of six disability groups. The six disability groups are amputee, cerebral palsy, intellectual disability, visually impaired, spinal injury, and *les autres* (conditions that do not fit into the traditional classification system). In some sports, athletes compete in a class according to functional ability, for example, in Swimming. This means that an athlete who uses a wheelchair for mobility may compete not only against other wheelchair athletes but also against amputees or those with cerebral palsy, if they have the same or similar functional ability. In Athletics, however, classification is disability specific. This means that the disability groups only compete against other athletes with the same disability, for example, amputees against amputees.

As athletic opportunities have expanded and sport for persons with disabilities has matured, so have the number of participants at all levels of competition and the individual accomplishments of athletes with disabilities. Outstanding performances by athletes at Paralympic events are often only slightly behind those of able-bodied athletes and constantly improving.

THE INTERNATIONAL PARALYMPIC COMMITTEE

The IPC is the international representative organization of sport for athletes with disabilities. It supervises and coordinates the Paralympic Games and other multidisability competitions such as the World and Regional Championships as well as developing sporting opportunities around the world for athletes of all levels.

The IPC was founded on September 22, 1989, as an international, nonprofit organization formed and run by around 160 National Paralympic Committees (NPCs) and 5 disability-specific international sports federations (IOSDs). The organization has a democratic constitution and structure, made up of elected representatives. The current president of the IPC is Phil Craven, a former Paralympian and former president of the International Wheelchair Basketball Federation.

The IPC has a number of objectives and functions. Overall, the IPC aims to promote, without discrimination, the practice of sports for people with disabilities and to seek the expansion of sport opportunities for people with disabilities from a developmental to an elite level. To achieve these aims, the organization must coordinate the calendar of international and regional competitions, liaise with the IOC and other international sports bodies, and develop and encourage educational programs, research, and promotional activities. The IPC also currently serves as the International Sports Federation for 13 of the 26 sports. Other sports are either governed by independent sport federations or are part of a disability-specific IOSD program. All of these activities allow the IPC to achieve its mission: “To Enable Paralympic Athletes to Achieve Sporting Excellence and Inspire and Excite the World.”

Until 2005, the IPC was composed of the General Assembly (its highest decision-making body); the Executive Committee; the Management Committee; the Headquarters in Bonn, Germany; and the various standing committees and commissions. In 2005, the IPC underwent some structural changes; the Executive Committee was replaced by a Governing Board, and all members of the Governing Board are now directly elected by the General Assembly. There are four advisory councils in addition to several standing committees and commissions. They are governed under a new IPC constitution and a new electoral system. This will lead the 13 IPC sports toward more self-sustainability and eventually independence from the IPC. In addition to the NPCs and IOSDs, the sports and regional bodies will also become full members of the IPC. It is hoped that these changes will allow the IPC to lead the Paralympic movement more effectively and consistently in the future.

—Miriam Wilkens

See also Classification in Paralympic Sport; Physical Activity; Recreation; Sports and Disability; Sydney Paralympics.

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PARALYSIS

Paralysis, the relative absence of intentional movement of a part of or the whole body, has an impact on the social order. As Harold Garfinkel teaches, the entire social world, including the built environment, is based on an upright, bipedal, mobile body, with eyes in the front of the skull. Garfinkel illustrated this to his students by taking them to Rancho los Amigos, a hospital specializing in the rehabilitation of patients with spinal cord injuries. The objective was to learn the changed spatial perspective of the patients.

There are many causative conditions leading to paralysis. Among these conditions are stroke, spinal cord injury, a wide variety of congenital and neuropathic conditions and diseases, brain injury, and a host of other causes.

Paralysis is highly variable. Some people have a contracture in the shoulder and cannot move an arm. Others may suffer arthritis in the hip and cannot use a leg. Still others suffer from systematic neurological disease or injury and are totally dependent on others for movement, eating, toileting, cleaning, communicating, and, in some cases, breathing. For the most part, those who are totally dependent on others are the focus of this entry, which details the social impact of living within a paralyzed body. First, conversation and gaze will be topicalized. Second, lack of mobility will be discussed. Finally, the hope of practical sociology will be elaborated on behalf of paralyzed subjects.

This entry focuses on the interactional difficulties that have devastating economic consequences for totally and dependent paralyzed people. Most dependent paralyzed people lose their jobs and company or institutional medical insurance. The income stream plummets. People have to sell their homes and draw down their financial assets. Then, they move to apartments, often publicly assisted, and change to public medical insurance. These apartments are far from family support and lead to a sense of isolation and acute depression.

Families of dependent paralyzed subjects, who suffer the evaporation of financial resources, are extremely fragile in the United States. There is a frequent expression of resentment and cruelty toward paralyzed subjects. Some family members deal with their feelings by ignoring the subject, even when the subject requests assistance. Some declare ignorance as an excuse for not assisting in the care of paralyzed subjects. The care often falls on the parent or spouse. These caretakers are isolated within their family and suffer from the absence of psychological help and physical help.

CONVERSATION AND GAZE

General Properties of Being Voiceless

Paralysis of the voice and sound-making muscles radically distances the subject from participating in the social world. The paralyzed subject cannot solicit and maintain the attention of others by making sounds. Since the majority of social institutions are accomplished by speech, the paralyzed subject is routinely left out of these collaborative enterprises (e.g., conversations, parties, family, medical care, employment, organizations, friendships, banking and investment, and a host other everyday routines).

Here are some examples. In the daily flow of domestic activity in a house or apartment, the body without a voice quickly gets routinized as an object with no social reference. No one informs the body without a voice what is going on in the other parts of the dwelling and what people are doing. People will pass by, their eyes averted, and not address the voiceless. Questions about activities in the house, communicated by alternative means, are treated as pesky and are not answered. The subject without a voice soon comes to see himself or herself as treated like a piece of furniture.

Not only is the paralyzed subject removed from the ongoing interaction in the house, but the voiceless is subject to actions that are determined by others and not sanctioned by the voiceless. The voiceless subject will be moved, told "you are crooked," and then quickly and sometimes violently moved into the caretaker's perceived appropriate position. This will happen regardless of whether the voiceless subject is comfortable.

The caretaker(s) will frequently substitute their own judgment for that of the voiceless subject. The subject will be told he or she is fine and in no need of action, when in fact the subject is in immediate need of action. The words "you are fine" are often uttered in the face of an apparent request for action. Substitution of judgment can take many permutations, with people speaking and acting for the paralyzed subject without permission. The result is a decrease in the subject's autonomy.

If the subject demonstrates any displeasure with the failure to take proper action, such as getting red in the face or shaking the few working muscles, the caretaker will often infantilize the protest. The subject will be told, "You are not being a good boy." Caretakers will collaborate in characterizing the subject as "not a good boy" in endless rounds of conversation.

Adverse characterizations of the subject or patient are frequent in caretaking but routinely overlooked. Caretakers' utterances of phrases such as "you would be better off dead" or "death will be a gift" are not infrequent. Subjects' wives, husbands, children, and extended family members are not immune from getting involved with the talk of death, uttering phrases such as "why don't you just die!"

This kind of talk and reflexive attitude can infrequently lead to violence against and even the death of the paralyzed subject. Violence is usually written off as a result of stress, and there is certain stress within the family of the paralyzed subject. However, the focus on stress misses the widespread ambiance of the rhetoric of resentment, burdenship, and anger. Beyond the family and friends, this rhetoric of denunciation and violence seems widespread in general American culture.

Conversation

Sometimes, conversations are essential and cannot be avoided. If the paralyzed subject is lucky enough to be employed, most often in his or her preparalyzed position, the work product is produced by communication. Those who use the strength of their bodies are disqualified from employment as soon as they become paralyzed. Truck drivers, construction workers, repairmen, waiters, professional athletes, restaurant cooks, and others are out of luck if they become paralyzed. Only knowledge workers can continue to be employed after paralysis.

Knowledge workers, or those who are not employed in positions of physical labor, produce and distribute knowledge. Such work requires attending meetings and engaging in conversational interaction with others. The work is often computer based. Subjects with spinal cord injuries who can talk are able to do most of this work. Spinal cord injuries, especially at a lower level in the spine, do not affect the ability to carry on conversations. Those who suffer from neurological diseases or conditions that more generally affect movement in the body, including speech production, face a predicament in the information business. They cannot enter into conversations, produce utterances, or verbally acknowledge what they are told.

Conversation is a series of sequentially arrayed turns at talk. The turns are temporally tight, meaning there is no gap between them. The lack of a gap is a mutually read indication that each speaker is referring to the last turn or a formulated previous turn. The pace of natural conversation presents a huge problem for those who rely on computer-assisted speech and the few who use lipreading as their form of communication. Most people see computer-assisted, synthesized speech as a panacea for people with damaged speaking abilities. First, the person cannot type fast enough to keep up with the pace of conversational turn taking, with the exception of "yes" or "no." Any elaborate response cannot be formulated quickly enough to be designed to the previous turn at talk.

Some suggest that responses to verbal exchanges can be designed in advance. But stock answers do not respond to the particular verbal formulation of a questioner. Stock replies do not have built-in recipient design: The formulator of a question or a turn in conversation can easily anticipate the next turn at speaking, an answer built specifically to the previous turn at speaking, or to the inquiry. Preformulated turns at talk cannot adapt to the particular words used and to the specific setting of a verbal exchange. These predesigned turns at talk feel like heavy weights, encumbering natural conversation.

The ability to type is variously affected by paralysis. Some have full use of their arms and hands and can type as quickly as they are able. Such individuals have fewer problems keeping up with the pace and reference of a conversation. Others, including those who have neurological diseases or brain injuries, have more impaired arm and hand-finger movement.

Typing may be limited to a single finger input, to a scanning of words or letters. An orally held stick that is pushed onto letters on a keyboard may be used as a typing device. Head movement can be used to input letters; blinking of the eyelids can be used to input letters. There is a growing amount of technology that comes to the communicative aid of paralyzed people.

Still, despite these advances in technology, alternative computer input devices are painstakingly slow and cannot keep up with the pace of natural conversation. These devices, as cleverly engineered as they are, are frustrating to use because the conversational pace moves so quickly: By the time the computer speaks, the interlocutors have lost the specific turn at talk, and the reference of the comment is tapped out by an alternative device.

Finally, there are those paralytics who rely on lipreading to communicate. Lipreading is not fast but offers the maintenance of mutual gaze between conversationalists and the expression of facial gestures, intensifying the communication and slowing down the transition to the next turn at talk. Lipreading requires a lip-signer and a lip-reader, a person who assembles words or letters into sentences and then speaks the sentences on behalf of the lip-signer. This person is usually called a translator and is a side participant in the ongoing conversation. The translator can often connect the paralyzed subject's slowly formulated turn at talk to a previous turn at talk, to which the paralyzed subject designed his or her response. The role of an effective translator is difficult because the translator has to keep track of the ongoing conversation and translate what the paralyzed subject wants to say at the same time.

Translators can be great facilitators of communication, but it is also possible for translators to interfere with what the paralyzed subject intends to say. Once the translator becomes familiar with the subject's thought patterns, phrases, and vocabulary, the translator can and often does answer inquiries posed to the subject without getting input directly from the subject. This often leads to charges leveled by the subject that translators are speaking for him or her, saying things not intended. Control of communication is a continuing issue for paralyzed subjects.

MOBILITY

Paralysis is a big problem in a world constructed on mobility: in houses, offices, educational institutions, markets, planes, trains, motor vehicles, and social relations. As mentioned earlier, the whole constructed world is based on an upright postured and bipedal individual. Paralyzed subjects face a deficit in this world.

The paralyzed subject in a wheelchair, as well as his or her caretakers, becomes cognizant of every surface feature—for example, sand, grass, up and down hill angles, steps, rugs, step-downs and step-ups, uneven sidewalks, ice and snow, oil, curbs, edges of sidewalks, and other terrain. All of these details constitute hazards to safe wheelchair transportation. Nearly every wheelchair occupant has experienced being dumped out of the chair, landing violently on the concrete.

Just as automobile drivers are of varying quality, wheelchair pushers are spread out along the quality continuum. There are some pushers who regularly go over curbs and sidewalks, letting the wheelchair turn over. Others appear to have a spatial perception problem, regularly driving the paralyzed subject's knees and feet into walls and tables.

Often, those who push wheelchairs lack the American middle-class sense of personal responsibility and may repeatedly push the paralyzed subject's knees into solid objects. Wheelchair pushing often becomes an instrument of cultural and class differences.

Because the paralyzed subject cannot move, transfers are another area of danger for the subject and those who perform the transfer. The sites where transfers commonly take place are from wheelchairs to bed, from wheelchairs to the shower and toilet, and from wheelchairs to easy chairs. Paralyzed subjects frequently are dropped, and those facilitating the transfers hurt their backs and joints. Fortunately, there are mechanical lifts that help those who perform transfers to avoid the danger of injury. However, not all people can afford mechanical lifts.

Difficulty in movement contracts the spatial and social world. Previous routines of shopping, going to the bookstore, seeing a movie, going on vacation, and going to parties, barbecues, supermarkets, and meetings are seen as gigantic achievements. As such, they are avoided personally and perceived as an avoidable drain on caretakers. Despite this trend to avoid the above social situations, the paralyzed subject may desire to go to parties, for example. However, invitations are few, and when they come, they have the caveat, "I have steep steps to get into my house." Nevertheless, there are certainly enjoyable occasions at wheelchair-accessible houses and at hotels. But for the most part, there is a perceivable decline in invitations to social events. If the paralyzed subject had been a partygoer before, a feeling that one's social life has collapsed is inevitable.

The cure for feeling isolated and estranged from social life is to open one's home to parties and family social gatherings. Assuming the house has been modified to the requirements of a disabled, paralyzed person, it is a wonderful place to enjoy the fruits of social gatherings. However, remodeling houses for the disabled takes significant amounts of money. Few paralyzed subjects have access to these financial resources.

PRACTICAL SOCIOLOGY

Paralyzed subjects are great practical sociologists. They quietly and repeatedly observe the everyday routines of their households and of the individuals who are their caregivers. They are absorbed by these routines and family activities because they can interfere with getting attention. It takes attention and regard to participate in social settings. Getting this attention and participation is often problematic for paralyzed subjects.

Most paralyzed subjects did not realize before paralysis how much household activity is repeated in the same way, even institutionalized. This includes the routines of going to the toilet, preparing and eating food, reading the daily newspaper, cleaning rooms, going to bed and waking up, and the various tolerable limits in being called by the subject. There are certain times that are off limits, when the subject cannot call a caregiver, such as sleeping, no matter how many hours, and eating, showering, toileting, and free time.

Even gaze patterns are socialized. For most people, gaze is embedded in the project at hand because people have limited peripheral vision. Peripheral vision is developed through circumstantial training, such as hunting or operating a small sailboat. Paralyzed subjects notice how directed gaze is to the task at hand. They experience repeated frustration with signaling and maintaining mutual gaze. They attempt to set a behavioral code, such as the violent shaking of the head, as a solicitation for mutual gaze. However, this code is frequently overridden by emerging circumstances. The code is practically useless.

The situational opportunity for paralyzed subjects to develop into practical sociologists provides some hope and an instrumental sense of life. From observation and memory, they can anticipate problem settings and instruct their primary caregivers to ensure successful participation. They can also communicate what not to do. These "not to do's" have to be communicated neutrally and in a gingerly fashion, avoiding any sense of personal attack.

Although not every paralyzed subject has the patience and sense of a growing base of knowledge, practical sociology is the best way to avoid and repair most of the dire circumstances described here. Practical sociology does not require formal education in sociology, but it assumes a contemplative attitude. However, paralysis is often the harbinger of contemplation.

—Albert B. Robillard

See also Disability Management; Health; Mobility Aids.

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PARENTAL ADVOCACY

An advocate is defined as "one that pleads in another's behalf" and is often compared to a lawyer (*American Heritage Dictionary of the English Language* 1992).

In the case of parental advocacy for children with disabilities or special needs, the advocate is often responsible for pleading on behalf of a child from multiple perspectives. A traditional perspective would assume that the parent is responsible for "pleading on behalf" of the child in tandem with professional therapist(s) (e.g., the assumption being that there is only one perspective to consider, that of the child's success and "cure"). Current approaches through the field of disability studies allow for the incorporation of multiple perspectives on a "cause." By promoting parental advocacy, we can ensure that perspectives on the individual as a child, a family member, and a student or learner, as well as a person with a disability, are respected.

The treatment of children with disabilities has long been an issue requiring parental advocacy but has only recently been legitimized through public policies relevant to education and quality of life. Reading historical documents serves as a reminder of just how recently individuals with disabilities were stigmatized, and significant assumptions were made regarding future capabilities and life trajectories, based on initial status at birth or diagnosis at a young age. Parents were often encouraged to "give up" on their young children with disabilities and to "cut their losses" by institutionalizing children. A growing realization on the part of both parents and educators that such programs often were not in the best interests of the child and family has resulted in legislation that guarantees a "free and appropriate" education "in the least restrictive environment" to children age three and above and encourages states to identify high-risk children and children with disabilities from ages zero to three as well.

The growing fields of disability studies, special education, and child development/developmental psychopathology have all begun the process of researching how one determines the best educational programs for children across a wide range of developmental concerns and disabilities, but there is much work to be done in documenting which programs work for whom and how different programs meet the specific concerns of children and their families in terms of both educational and functional success. Within this cultural context (a relatively new area of study, with limited data on program success), what is the best way for parents to advocate for children and families?

PARENTAL ADVOCACY NEEDS

For any advocate to plead one's case, he or she needs information. This applies to parents of children with special needs in a broad variety of arenas. We compiled the following list of *some* types of information required by parents to be effective advocates for their own child and family:

Disability-specific information (the ability for parents to get such information will vary dramatically based on their child's identified special needs, as well as the age of the child. In some cases, diagnoses of children will not be made until the grade school level, if at all, making appropriate information-seeking difficult if not impossible.)

Knowledge of public policies and the child and family's legal rights, as well as the changes with age (Section 504 or the Rehabilitation Act; the Individuals with Disabilities Education Act [IDEA] and its components, including Individualized Educational Programs [IEPs]; Least Restrictive Environment; the Family Education and Privacy Act [FERPA]; most recently, the No Child Left Behind Act [NCLBA] and its implications for special education students; and potentially many other relevant policies dependent on the child's disability)

School district–specific information (within the legal parameters of the policies mentioned above, what are the offerings of the family's home school district? What is the range of possible placements? How do they change from pre-K to primary to middle and high school? How does the school district deal with behavioral or discipline issues for children with IEPs? How are children made eligible for special services within the district? How are school year programs extended through the summer to provide continuity? How are school or program transitions handled within the district? What types of assistive technologies are available?)

Statewide policies (statewide assessment, qualifications for state funding and special education initiatives)

"Out-of-the-box" information—Many types of "suggested" programs for children with special needs

(particular types of massage, yoga, or physical therapy for motor-related disabilities or regulation disorders; particular listening therapies for sensory or auditory processing disorders; etc.), as well as general programs of enrichment (music, fine arts, etc.), may be useful. Parents need information both about offerings of these programs, as well as data on effectiveness/actual effectiveness, and whether any data are available.

"Impact" and networking information—Finally, parents often find it useful to know about supportive services and resources in their own community (e.g., parent support networks) and more nationally (informational websites or chat groups).

As should be obvious from above, there is an overwhelming amount of information required to be an effective parental advocate for a child with special needs. Making the job even harder are some of the emotional issues regarding parental advocacy. Most parents did not expect to be raising a child with special needs, and there is a significant adjustment period required to cope with discovery of the child's needs. When one seeks information or services for a child with special needs, one suddenly enters a world of experts, from varying disciplines, with much jargon. Many parents are afraid of asking the "experts" questions, either because of potential reprisal (perhaps the district or private professionals will not treat my child nicely if I am seen as a "difficult" parent) or due to discomfort with feeling or being perceived as "stupid." Through parent information and support groups established throughout the country and funded by the federal government, parents are learning how to share information about their child with special needs, ask questions of professionals and school personnel, and bring relevant and important information about their child to the table.

Parents play a key role in providing information about the child's abilities, strengths and weaknesses, and interests. They have a unique expertise with regard to their own child and his or her role in their family. Parental insights complement information obtained by the school or the service provider and provide a broader picture of the child's capabilities and needs. Identifying specific ways for parents to be involved in the process is essential for developing a good educational program. The importance of collaboration on the part of parents and professionals, as well as key advocacy roles for both groups, cannot be overemphasized.

WHEN ARE PARENTAL ADVOCACY EFFORTS NEEDED?

Although parenting and advocating for a child is an ongoing process, there are certain distinct times when particularly intense efforts are needed. For example, two such times are (1) the period during which identification or "diagnosis" of a child's special needs occurs and (2) the yearly review or IEP meetings that document a child's educational progress and form plans and goals for the coming educational year. In addition to these two times, there is the ongoing supervision of the child's program, in terms of both meeting the child's educational and experiential goals, as well as the effect of the program on the child and family.

IDENTIFICATION OR DIAGNOSIS

In some cases, identification of special needs occurs at or prior to birth. In other cases, there is a growing realization either on the part of the parent or in an initial preschool or primary school experience that something is just "not right." Many parents discuss having gnawing levels of concern regarding specific behaviors, only to be reassured by pediatricians or other medical specialists. This is in part due to the very broad range of behavior in early development, which makes more subtle variations that may be indicative of special needs harder to detect. Most special educators, parents, and textbooks dealing with this issue recommend that in a "gray" instance, primary care professionals refer parents to early intervention specialists who can conduct evaluations and either reassure parents or provide needed services.

It is also the case that the reverse can happen—professionals at school or medical professionals can notice possible areas of developmental delay or learning differences and raise concerns to parents who have not yet been concerned (anecdotally, many parents of firstborn children with special needs mention this and state they had no "barometer" on which to judge their child's differences).

Once a developmental delay or other learning or social, emotional, or behavioral issue has been identified, parents are likely to be provided with a referral for evaluation. Key components of the parents' job at this point are twofold: (1) coordinating all needed evaluations and (2) providing accurate and complete information as part of the evaluation process. In general, gathering reliable data from children can be difficult; this is true for typically developing children and even more so for children with special needs. Indeed, the more profound the special need, the more potential for misinterpretation of child behavior and communication attempts. This makes the parents' role as "data provider" all the more essential. A good evaluation should include a parent interview both regarding the child's general abilities (birth history, meeting of developmental milestones, etc.) as well as a sense from the parent of just how typical the child's behavior has been during the evaluation and whether the child has demonstrated his or her true abilities, knowledge, and learning styles.

YEARLY REVIEW/IEP MEETINGS

Once a child is "in the system" (e.g., has received a detailed evaluation and been determined eligible for services), an initial IEP meeting will be held to create the child's program for the current or coming school year. In subsequent years, annual reviews and/or IEP meetings will be held to document progress toward educational goals and to form plans for the coming year. Parents must be notified about this meeting and may make plans to attend along with any key individual or individuals they would like to bring.

For most parents, IEP meetings are among the most stressful places they find they must advocate for their child. Anecdotally, many parents cite as particularly stressful the "litany" of data about their child and the technical format, focused primarily on weaknesses rather than strengths, given that the purpose of the meeting is to define need for services. Many parent information centers offer training on preparing for a meeting, particularly on the art of representing your child and family, as well as the importance of asking questions and getting accurate information. In addition, websites and information centers provide detailed checklists for preparation for IEP meetings, as well as reinforcing particular aspects of the family's rights (e.g., timing of information and receipt of reports, ability of parents to attend a meeting but withhold signature until all information is satisfactorily available for the child's program, etc.).

In summary, this entry merely scratches the surface for key factors underlying the necessity of parental advocacy in forming appropriate educational and quality-of-life goals for children with disabilities. Key needs of parents for information and support are discussed, as well as key times when parental advocacy efforts may be most important. An additional critical factor to be considered is the importance of advocacy and collaboration from other sources, such as the school and the community. A critical factor in future efforts should be the collection of evaluative data, both by individual and group methods, to ensure that we are all advocating for the best possible start for our children.

—Roberta L. Paikoff, Marian Casey, and Rhonda Wodlinger-Cohen

See also Advocacy; Childhood, Youth, and Adolescence; Family; Individualized Education Plan (IEP); Parenting; Special Education.

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Parent Advocacy Coalition for Educational Rights, www.pacer.org
Wrightslaw, www.wrightslaw.com

PARENTAL NARRATIVES

Mrs. Merrick explained that the appearance of her son, known as "The Elephant Man," was the result of her being frightened at a Victorian circus; Carry Nation explained that her husband's drinking led to their daughter's many health problems; Michael Bérubé explained that his son's Down syndrome was determined by the random replication of chromosomes at his conception. In all eras, parents of children with disabilities have explained. They have written and spoken their explanations as parental narratives, a genre somewhere between autobiography and biography, between memoir and witness. It is an enduring genre, often sharing shelves with adoption stories, mourning parent stories, and other vernacular efforts to recall the process of loving a child through unusual or difficult circumstances.

Several categories of parent narratives of disability can be identified. Inspirational or sentimental narratives are generally upbeat, intended to comfort and encourage others, especially other parents but also a more general readership, which may account for the frequent success of such books. A classic in the category, Dale Evans Rogers's *Angel Unaware,* published in 1950, was a best-seller for years; its frankly religious tone can strike many readers today as heavy-handed, but the book's ultimate message—that Robin Rogers's short life was worthwhile, her presence in the home a joy to her parents—countered medical advice and even other parents' more tragic constructions of disability in mid-twentieth-century America. The latter category, the parent confessional or pathographical narrative, is personal to the same degree as sentimental narratives but with the intent of warning other families and sharing grief. Heartbreaking accounts of learning the child's "hopeless" diagnosis are characteristic of this genre, for example, in Pearl Buck's *The Child Who Never Grew* (1950) or Michael Dorris's *The Broken Cord* (1989). Other parents take a more practical how-to approach to their story, attempting a more neutral voice as they pass along advice to a readership of new parents. Charles R. Callanan's *Since Owen,* from 1990, is among these works. Finally, more and more, some parents use their experience with a disabled child as a springboard toward exploring broader social or philosophical issues. Kenzaburo Oe's (1995) *A Healing Family* and Michael Bérubé's (1996) *Life as We Know It* are two recent exemplars of this approach. All these categories share the underlying impulse to say what others cannot or will not about disability and its effect on family life.

Such testimonies are not universally embraced. They are dismissed as unreliable evidence or, at best, anecdotal, imprecise, and self-serving documents. The ethical problem of consent is raised: Is the disabled child capable of giving informed consent for very personal details of her or his life to be revealed in print? And if so, is the parent's role too powerful, the relationship too emotionally fraught, to allow that consent to be given freely? Other critics fear that such narratives will be taken as sufficient substitutes for firsthand accounts of disability. Still others find that, by the time a parent is ready to write a memoir, his or her advice may no longer be useful to a new generation of parents encountering a much-changed landscape of laws, programs, and social attitudes.

Others, however, see parent narratives of disability as serving an array of useful functions. As Rapp and Ginsberg (2001:543) point out, because "the knowledge of what is entailed in caring for such children remains absent from the mainstream discourse, underscoring a sense of social segregation or stigma," parental narratives may bridge a destructive gap in common awareness. Parental narratives written in or recalling earlier times may work as a record of past conditions, valuable to historians but also to policymakers seeking models or measuring change. Parents themselves often report that the writings of other parents are more accessible, supportive, and relevant to their day-to-day decision making and coping than other formats, and parental narratives have historically encouraged, or even (in the case of *Angel Unaware*) directly funded, parent advocacy on behalf of social inclusion and community-based programs. As parental narratives are often (but not always) written in the context of developmental disability, they may add to a literature otherwise short on vernacular accounts.

The parental narrative literature is well developed in the United States and seems to continue growing: In 2002 alone, at least a dozen new parental narratives were published by American presses. Furthermore, online support groups are inviting millions of connected parents to tell their stories to each other, through listserv posts and web pages, unmediated by editors or publishers. What is less common is the parental narrative written in a non-Western cultural context (Kenzaburo Oe's work being a notable exception here); parents in emerging economies, finding their traditional sources of support lost without a strong system of alternatives in place, cannot access a rich array of published narratives for making sense of their circumstances. A wider range of cultural stories would also work to place existing Western narratives in a broader context than is now fully possible. Another opportunity for comparison is beginning to emerge in narratives written by adult children about their parents' disabilities (for example, Alzheimer's), a reversed situation that may produce an equally intense literature. The dimensions of intimacy, caregiving, and power inherent in family life, as they are experienced in the presence of disability, will thus long remain a fertile, complicated, and ethically challenging source of personal narrative.

—Penny L. Richards

See also Models; Novel, The.

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▣ PARENTING

A common misconception is that there are relatively few parents with disabilities. This assumption appears to perpetuate social obstacles—a lack of appropriate and accessible resources for parents with disabilities and their families. In fact, in the United States, parents with disabilities represent 15 percent of all parents of children younger than age 18. However, 24 percent of single parents, 18.7 percent of African American parents, and 16.3 percent of Hispanic parents have disabilities.

There is an overall lack of detailed national, regional, or local data on U.S. parents with disabilities and their children. Targeted national disability surveys, such as the National Health Interview Survey, focus primarily on the impact of the adult's disability on major life activities—such as work, education, managing a home, or personal care—but do not investigate the impact on parenting activities. As a consequence, national disability statistics provide only broad estimates of the numbers of disabled parents but little detail about their family lives. In addition, disabled parents and their children remain invisible in most public and private data systems' tracking services to parents or disabled adults in the United States. As a result, the need for specialized or accessible services for parents with disabilities tends to be underestimated.

An analysis of the 1993 Survey of Income and Program Participation, U.S. Census Bureau data by Linda Toms Barker and Vida Maralani, distinguished disabilities in parents as 40 percent sensory, 26 percent physical, 24 percent psychiatric, and 16 percent cognitive. The literature on parents with disabilities reflects a tendency to overgeneralize about them, often in a pathological direction. That is, negative assumptions about parents with emotional, psychiatric, or cognitive disabilities are generalized to parents with physical disabilities. Concerns about parents with acute disabilities such as a recent spinal cord injury are generalized to parents who have long-term stable disabilities, with coping skills and resources that have developed over many years. A focus on variation in disability issues should not obscure the profound effect of cultural, environmental, and psychosocial issues in the lives of parents with disabilities.

Unfortunately, parents with disabilities and their children face many social obstacles: Public policy and appropriate resources lag far behind the social changes that have led to the apparent increase in the numbers of parents with disabilities. The largest study on parents with disabilities to date was done for Through the Looking Glass by Maralani and Toms Barker and yields data from a national sample of 1,175 parents with disabilities. Although participants in the study tended to have more education, employment, and income than most individuals with disabilities, 23 percent had household incomes under $15,000 and 43 percent under $30,000. The many social obstacles and the lack of public resources mean that parents with disabilities and deaf parents in the United States face more out-of-pocket costs than other parents, while their incomes are lower.

In the national survey, transportation was cited by 83 percent as a problem for them as parents. Problems in housing accessibility was another key area that affected parenting. Another access problem was identified regarding adaptive parenting equipment, such as adapted cribs. Such equipment is still essentially unavailable on the market and is seldom reimbursed by public or private health or disability funding systems. Of the 240 parents answering what prevented them from obtaining such equipment, around half did not know how to find information about such equipment and had no way to pay for it. During pregnancy or childbirth, 62 percent of parents had found a lack of disability expertise on the part of professionals, attitudinal problems, and/or interference in the right to become a parent.

Deaf parents also report social obstacles. Ninety percent of deaf parents have hearing children and face significant communication problems with their children's schools, as well as a lack of culturally and linguistically appropriate services for their families.

Mothers with disabilities may face more complex social obstacles. Research by the Center for Research on Women with Disabilities (CROWD) at Baylor College of Medicine found that women with disabilities in the United States are more likely to remain in abusive relationships due to dependency. They report longer durations of physical and sexual abuse compared to women without disabilities and different forms of abuse, such as the withholding of personal assistance or adaptations. Intervention programs report that trauma and abuse experiences are particularly prevalent in mothers with intellectual disabilities. Despite these problems, CROWD research found that traditional shelters and agencies for battered women were generally not accessible for women with disabilities. Specialized services for mothers with disabilities in the United States seldom effectively address trauma issues.

In the U.S. survey of parents with disabilities, it was particularly concerning that 16 percent of these predominantly physically disabled, well-educated middle-class parents reported efforts to remove children from their custody. The literature on parents labeled with developmental disability cites a 25 to 60 percent rate of removal of their children. While 28 percent of adults labeled with "developmental disability" or "mental retardation" have children, only 14.4 percent of these adults have children living with them, apparently reflecting this high removal rate.

Through the Looking Glass's National Resource Center for Parents with Disabilities has identified significant problems in family courts and the child protection system for parents with disabilities. In child protection systems, there has been a tendency to assume that parents with cognitive or emotional disabilities cannot parent or benefit from services, based solely on their diagnoses. In family courts, there is often the assumption that marital custody by a parent with a physical or vision disability is "not in the best interest of the child," even when the primary relationship is between this parent and child. Both systems often do not evaluate actual parent-child interaction (or do so inadequately) and are unaware of disability adaptations, community supports, and relevant research. These problems are compounded by the lack of disability-appropriate preventive intervention in the United States. Similar problems in practice have been described by Gwynnyth Llewellyn in Australia (see McConnell and Llewellyn 200) and Tim and Wendy Booth in England (see Booth and Booth 1994).

The National Task Force on Parents with Disabilities in the United States has identified additional underlying social obstacles. Policies, programs, and funding streams tend to focus only on the parent or the child, rather than emphasizing the family as a unit. Relationships and interaction between parent and child should be more of a focus in research, evaluation, and services. Personal assistance services (PAS) usually only serve the individual with the disability but will not provide any assistance related to care of an infant or child. Both PAS and the availability of parenting adaptations are affected by the lack of inclusion of baby care or parenting as an "activity of daily living."

Since parents with disabilities are faced with so many social and environmental obstacles, adaptation emerges as a theme in their everyday family lives. In the 1980s, Through the Looking Glass documented the natural reciprocal adaptation process between parents with physical disabilities and their babies. This research evolved into a number of studies focused on developing and evaluating the effect of baby care adaptations for parents with physical disabilities. The studies found that such equipment can have a positive impact on parent-baby interaction, in addition to reducing difficulty, pain, and fatigue associated with baby care. By reducing the physical demands of caregiving, the equipment can be instrumental in preventing secondary disability complications. Prevention of secondary injuries prevents additional stress on the parent-child relationship. The equipment has also appeared to have a significant role in preventing or alleviating depression associated with postnatal exacerbation of disability, such as in multiple sclerosis. The research and clinical experience with parenting adaptations makes it clear that one cannot assess the potential of a relationship between a parent with a significant physical disability and an infant without first providing whatever adaptive techniques and equipment make it possible for interaction to occur and the infant-parent relationship to develop.

The incorporation of cognitive adaptations into prevention services for parents with intellectual disabilities has also been clinically documented as crucial to effective practice. Adaptations in communication are essential when evaluating or intervening with parents with cognitive or learning disabilities, visual disabilities, and deafness. Without adapted communication, parents may be mislabeled as "unable to benefit from services" and therefore vulnerable to loss of custody. Inappropriate and disrespectful services can create rather than resolve problems in parenting by individuals with intellectual disabilities. The Booths have eloquently described such problems with practice in England (Booth and Booth 1994).

Adaptations can remove disability obstacles to fair evaluation and effective services for parents with disabilities and their children. Disability-appropriate early intervention can achieve positive outcomes even in the most stressed families.

Parents with disabilities and their children demonstrate resilience and adaptability in the face of considerable social obstacles. However, parents with disabilities and their children are much more alike than unlike other families; parenting is about loving, guiding, caring, and nurturing, disability status aside.

—Megan Kirshbaum

See also Children of Disabled Parents; Childhood, Youth, and Adolescence; Family.

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PARKINSON'S DISEASE

Parkinson's disease (PD) was described in 1817 by James Parkinson, a London physician, whose "Essay on the Shaking Palsy" reported his observations on six patients. It is a disease of the brain characterized by degeneration of nerve cells (neurons) in an area of the midbrain known as the substantia nigra, which produce the neurotransmitter dopamine and transport it to the basal ganglia. The latter are paired groups of nerve cells in the base of the brain involved with movement. Parkinson's disease typically begins between ages 55 and 60 years. It is a common disease, affecting 1 to 3 percent of those older than age 60, and each year, between 5 and 25 new cases per 100,000 population are diagnosed.

The diagnosis is made be observing the characteristic signs described by James Parkinson. The classic triad includes slowness of movement (bradykinesia or akinesia), a slow tremor of the hand at rest, and a ratchety-like resistance when a limb is passively moved, known as cogwheel rigidity. Additional features include small handwriting (micrographia), a flexed posture, decreased facial expression, a soft-monotone voice, shuffling gait, and, as the disease advances, impaired balance with falls.

The cause of most cases of PD is not known. Approximately 5 percent of patients have PD on a primary genetic basis. These include an autosomal dominant gene, which codes for the protein α-synuclein, among others, and the *parkin* gene, which causes autosomal recessive, young-onset PD. Yet, most cases of PD are sporadic, and genes appear to play a contributory role but are not directly causal. Epidemio logic studies have demonstrated that environmental factors, such as being raised in a rural environment, drinking well water, having a prior head injury, and exposure to pesticides, are putative risk factors for PD, but none has been shown to be directly causal.

The treatment of PD is based on the deficiency of dopamine in the basal ganglia. The mainstay of therapy is levodopa, which is converted to dopamine by the remaining nigral neurons. It is combined with carbidopa to prevent nausea. As PD advances, the response to levodopa diminishes, and many patients no longer have a smooth transition between dosages, leading to fluctuations. During periods when levodopa is working, there is relative freedom of movement, alternating with times when levodopa does not work, characterized by an exacerbation of symptoms, including immobility. These fluctuations, known as "on-off," are further complicated by periods when there is an exaggerated, unwanted response to levodopa, producing excessive twisting movements known as dyskinesias.

In addition to levodopa, a number of other therapies can either be used alone or as adjuncts to levodopa. Dopamine agonists work directly on the dopamine receptor and, like levodopa, are often used as initial therapy. Anticholinergics are the oldest agents used for PD and help restore balance in the basal ganglia between dopamine and another neurotransmitter, acetylcholine. Amantadine is an antiviral agent, which was discovered serendipitously to have antiparkinsonian activity. Other medications are available to enhance the effectiveness of levodopa. When the symptoms of PD, particularly movement fluctuations, cannot be controlled adequately with medication, surgery is an option for selected patients. This involves inserting a permanent electrode into the basal ganglia and connecting it to a battery, a procedure know as deep-brain stimulation.

With modern therapy, most people with PD live a normal or near-normal lifespan. Yet, disability increases as the disease advances, while its rate and degree vary greatly among patients. There are currently no treatments that slow progression, but that is one of the most active areas of research. Throughout the course of PD, medical and surgical therapies are enhanced by rehabilitation directed at improving strength, flexibility, endurance, gait and balance, speech, swallowing, and the activities of daily living.

Although motor problems and their treatment are the main focus of managing PD, equal attention must be paid to the psychological and cognitive well-being of patients, as well as the needs of caregivers. Depression is very common in PD and is considered to have an organic basis and not simply a reaction to disability. With advancing disease, many patients develop cognitive impairment and often frank dementia, further contributing to disability and caregiver distress. The diverse and progressive symptoms and signs of PD emphasize the importance of a multidisciplinary approach for successful management.

—Stephen G. Reich

See also Epidemiology; Neurological Impairments and Nervous Disorders.

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PARTICIPATION

Participation has become a core concern of disabled people and disabled people's organizations because of the discrimination, barriers, and segregation that historically they have experienced and seek to overcome. Disabled people's political participation can only adequately be understood within a broader understanding of ideas of participation. *Participation* is a complex, ambiguous term without an agreed-on definition, to which disabled people have added their own meanings. Disabled people internationally have developed three particular focuses for their participation. These are as follows:

> participation in the support they receive, to ensure it meets their needs and is consistent with, rather than restricts, their human and civil rights (this aim is embodied in the disabled people's development of the international independent living movement);
>
> participation in society more generally, to ensure that disabled people are able to live in mainstream society on equal terms with nondisabled people, with equal access to mainstream employment, education, health, and other services and opportunities, instead of being segregated in separate structures and provision;
>
> political participation, to afford disabled people the same democratic rights as nondisabled people and equal opportunities to influence and take part in public life. These concerns are reflected in the rights-based approach of the disabled people's movement and its emphasis on disabled people's rights and responsibilities based on equal citizenship.

THE NATURE OF PARTICIPATION

Participation implies active involvement in the public and social sphere and refers to a range of involvements that individuals and groups may have in organizations, institutions, and decisions affecting them and others. There are many approaches to and understandings of participation and involvement. These have most often been framed in terms of the degree of involvement people have—from zero to control; from tokenism, through consultation, to a primary say in decision making. This was notably expressed in Sheri Arnstein's (1969) "Ladder of Citizen Participation." Participation is crucially judged by the extent to which people can exert influence and bring about change.

The concept of *public participation* developed in the context of land-use planning in the 1960s, became a key concern of community development, and is central in a growing number of discussions and developments, including the emergence of new social movements, postmodernism, public policy and services, the rekindling of interest in citizenship, "human need," "social exclusion," and the search for a new more participatory politics.

Because participation is an inherently political concept, it is contentious, without a clear or agreed-on definition. There is also no consensus about terminology, with different words used, including *citizen participation, self-advocacy,* and *consumer involvement,* sometimes synonymously, sometimes to impart different meanings.

COMPETING APPROACHES TO PARTICIPATION

Generally framed in terms of "consumer" or "user involvement," the idea of participation reemerged internationally toward the end of the twentieth century as a key idea, policy, practice, and goal, particularly in the fields of public policy, health, and welfare. This renewal of interest in participation relates to two frequently opposed and broader developments. First is the development of increasingly powerful and influential movements of disabled people and other long-term recipients of health and social care, with their own democratically constituted local, national, and international organizations and groupings. Second has been shifts in ideology and economics, which have resulted in a expansion of interest in the market and individual responsibility, linked with the philosophy and rhetoric of consumerism, highlighting individual choice and involvement.

This has resulted in two competing understandings of user involvement, which are often confused—the first from the disabled people's and related movements, committed to people speaking for themselves and securing and safeguarding their human and civil rights, choices, and quality of life, and the second from states and service systems, including private providers, reflecting consumerist concerns of improving the efficiency, effectiveness, and economy of services. The first approach starts with people's lives, the second with the concerns of service systems. These two approaches to participation—the "democratic" and the "consumerist"—do not sit comfortably. One is managerial and instrumental in purpose, without any commitment to the redistribution of power or control; the other is liberational, with a commitment to empowerment.

They are also associated with different strategies for participation. The consumerist preoccupation with service user feedback is reflected in an emphasis on consultation and data collection exercises focusing on the planning, management, and market testing of specialist services. The frequent experience of disabled people is that such exercises have very limited effects on improving their lives and support while making significant demands on them. Their concern is with bringing about direct change in people's lives, through collective as well as individual action. The disabled people's movement bases its approach to participation on the social model of disability, using both constitutional and direct action. It has prioritized independent living, civil rights legislation, and the provision of adequate support for organizations controlled by disabled people themselves.

DISABLED PEOPLE AND PARTICIPATION

Participation makes possible the negotiation of different, often competing interests. Participation is also an idea inseparable from issues of power and inequalities of power. As a constituency, disabled people are still relatively disadvantaged, in terms of income, class, status, and power. This is one reason why it is helpful to consider *who* is being involved, when exploring the policy and practice of participation. The equal inclusion of people in participatory developments has so far been a major and unresolved problem. The evaluation of participation is still at an early stage. Different approaches to participation also frame people in different categories. Thus, public policy initiatives have generally been framed in terms of "public participation"; regeneration, community, and international development initiatives have been framed in terms of "community" involvement; and health and welfare initiatives have been framed in terms of "user" and "patient" involvement. Typically, disabled people have not been equally included as members of the public and communities and therefore may not be equally represented in such categorization. Thus, policy for participation can reinforce the broader exclusions and discrimination that disabled people face.

Disabled people, like some other new social movements, have developed an approach to participation based on identity. They also emphasize participation in their own self-organization, highlighting their local, grassroots, and "bottom-up" approach to collective action. In their self-organization, they have generally developed their own representative structures to ensure accountability, but they also emphasize and prioritize the role of direct democracy in their broader collective action and campaigning.

While participation is generally associated with the public sphere, it is also affected by people's circumstances and responsibilities in the *personal* sphere. This can limit the participation of many groups, notably women, because of the care and support responsibilities that continue to be placed on them disproportionately and disabled people, if they are denied appropriate personal support or their access requirements are not met.

Two components are essential if disabled people are to have a realistic chance of participating and all groups, regardless of the nature of their impairment, are to have equal access to involvement. These are *access* and *support.* Both are essential. Experience indicates that, without support, only the most confident, well-resourced, and advantaged people and groups are likely to become involved, while without access, efforts to become involved are likely to be arduous and ineffective. Access includes equal and ongoing access to the political structure at international, national, regional, and local state levels and to other organizations and institutions that affect people's lives. Support includes increasing people's expectations and confidence; extending their skills; offering practical support such as child care, information, advocacy, and transport; enabling people to get together in groups; and ensuring that women, minority ethnic groups, and others facing discrimination can get involved on equal terms.

PARTICIPATION IN CONTEXT

While participation is generally presented in positive terms, it also has a regressive potential. Participatory initiatives can frequently serve to obstruct rather than increase people's involvement. They are sometimes used to tokenize and co-opt people, delay decisions and action, and legitimate predetermined agendas and decisions. This has been identified as a major problem in international development, where indigenous involvement sometimes serves to put a participatory gloss on policies imposed from outside, beyond local control. This relates to a more general and fundamental tension that exists when arrangements for participatory or direct democracy exist in political structures based primarily on a system of representative democracy. So far, little work has been done to explore if and how these two approaches to political participation may be reconciled. As a result, some disabled commentators see participation as a necessary but not sufficient condition for their liberation, arguing for an emancipatory, as well as a participatory, politics.

—Peter Beresford

See also Decision Making; Patient-Professional Relationships; Political Participation; Voting.

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PASSING

Although passing originally defined any form of pretense concerning identity, its meaning today refers increasingly to identity disguise motivated by social injustice and oppression. Passing is one strategy for managing what Erving Goffman (1963) calls the stigma of spoiled identities—those identities discredited by law, opinion, or social convention. For example, when in the minority and powerless, Jews pretend to be Christians, blacks pass as white, gay and lesbian people masquerade as heterosexual. Similarly, people with disabilities find ingenious ways to conceal their impairments and to pass as able-bodied. Disabled people who pass are often accused of leading an existence that endorses deception, accommodation, and betrayal, despite the fact that passing is necessary only because of the inequality and injustice of society. They supposedly deceive society at large, acquiesce to its injustices for personal gain, and betray other disabled people who are unwilling to pass. A more complex consideration of disability passing, however, focuses on the psychological and physical price paid by those who pass as well as on the knowledge they have acquired about the organization of human society. On one hand, to free themselves from curiosity, prejudice, economic disadvantage, and violence, disabled people develop sophisticated tactics designed to help them blend into society, but these tactics may also exact a heavy toll on individuals both mentally and physically, leading to psychological crises and secondary health problems. On the other hand, passing represents a vivid understanding of everyday life and its conventions. Those who pass treat social situations that others consider natural and normal as calculated, artificial, and subject to manipulation, thereby demonstrating their knowledge about social organization and human perception. Passers are skillful interpreters of human society. They recognize that in most societies, there exists no common experience or understanding of disability on which to base their identity. For where a common acceptance of disability exists, passing is unnecessary.

Passing is one strategy useful to manage the loss of self created by the oppression of people with disabilities. Temporary passing is empowering, producing brief moments of freedom from the prejudice and morbid curiosity often found to surround disability. Pretending to be able-bodied is one way of performing normalcy, of inserting oneself in society and escaping the alienating experience of being disabled. In the long term, however, disabled people who try to pass may feel guilty or become depressed about constructing their acceptance by society on the basis of pretense. They also internalize prejudices against disability, seeing their hidden identity as wrong, lacking, or shameful. For both the physically and mentally disabled, passing often requires overcompensation that exacerbates already existing conditions. A woman with chronic fatigue or post–polio syndrome may extend herself to the limits of endurance to maintain the appearance of able-bodiedness, but the result will be a worsening of her condition, sometimes permanently. The college student with a learning disability may discover that passing adds levels of unbearable stress to an already difficult classroom situation. Moreover, those who pass often find that keeping their secret requires solitude. Passing is a solo experience for most people. The feelings of relief that accompany coming out as disabled often derive from the discovery that one is no longer alone and that other disabled people exist on whom one may depend for acceptance, friendship, and love.

Passing requires a working knowledge of human society often unavailable to the majority of people. It entails a conscious engagement with and obedience of social rules, creating the impression of being able-bodied by close attention to the details of everyday life. Passing also requires individuals to make quick calculations in unexpected situations to avoid exposing their identity. Those who pass have a gift for dealing with unstable social situations from which we all might learn; they create a zone of comfort that blankets disability with the appearance of normalcy, making an art of helping nondisabled people feel more comfortable with the presence of disability. Passing also depends on special insights about the ways that human society and perception are organized. A blind woman pretends that she can see by giving the impression that she is sighted. Her role-playing is intentional and precise and will be successful only if she has both acute knowledge of the behaviors that define sightedness and the capacity to reproduce them. Sighted people need not pretend to see and would not be able to do so if required because the knowledge of seeing is unnecessary to their existence. A deaf boy may pass by asking questions to which he already knows the answer and by attending to subtle cues about how he should react in conversation, while a hearing person has no need to learn such nuanced behaviors. Passing involves playing roles, but its essential character is less a matter of deception than of an intimate knowledge of human ability and its everyday definition. Those who pass understand better than others the relation between disability and ability in any given situation. As careful strategists of social interaction, they know what sightedness looks like, though they may be blind; they know what conversation sounds like, though they may be deaf.

The limits of disability passing are often thought to rely on the visibility of an impairment. People with visible disabilities do pass, however, and often with relative ease because a common knowledge of disability does not exist in many situations. Both this ignorance about disability and the general anonymity of modern life produce opportunities for passing. People in public, disabled and nondisabled alike, prefer not to be noticed, with the consequence that disabled people may pass as able-bodied simply by obeying the unconscious laws of anonymity. Moreover, people with disabilities are often recognized by their tools rather than their impairments. A power chair of unusual design may not present as a wheelchair. A blind person without a white cane or whose guide dog is not the expected breed may not be perceived as blind. Similarly, when people with disabilities make their behavior conform to expectations about disability and then reverse these expectations, their status as disabled is placed in doubt. The individual who enters a bookstore in a wheelchair but stands to take a book off a shelf will confuse those who lack knowledge about disability. Passing demonstrates that the visibility or invisibility of an impairment is a less significant factor in the recognition of disabled people than the fact that a common experience of disability is rarely available in society.

Disabled people who pass understand more vividly than others that society possesses no common experience of disability. The lack of common knowledge underwrites passing, for widespread understanding and acceptance of disability would render passing not only impossible but unnecessary. While people with disabilities who pass have an understanding of both disability and its able-bodied counterparts, able-bodied people often have little idea of the conventions shaping either their own abilities or the disabilities they shun. The sighted are blind to blindness, and the hearing, deaf to deafness. When the able-bodied attempt to pass as disabled, for example, they rarely succeed, producing unconvincing versions of disability recognizable only by their exaggeration, and yet disabled persons are able to pass where the nondisabled fail. Disabled people who pass have a double experience of the oppression of disability from which both disabled and nondisabled people might learn. Like all disabled people, those who pass experience the oppression of disability on a daily basis, but they also have an intimate knowledge of just how little the habits of everyday life relate to disability. If their knowledge of human society were more widespread, disabled individuals tempted to pass might move from the desire to pass to the desire to unlearn passing and call upon others to recognize and accept their disabilities.

—Tobin Siebers

See also Inclusion and Exclusion; Stigma; Visibility and Invisibility.

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PATIENT-PROFESSIONAL RELATIONSHIPS

Patient-professional relationships involving disabled people and their health care providers is an area characterized by diverse perspectives. Research has shown that patients' relationships with professionals are critical to the outcomes of their health care. In addition, these relationships often influence patients' willingness to return for health care should the need arise. A number of theoretical models have been developed and used to build and maintain positive patient-provider relationships. These include models of patient-provider communication, interactive reasoning models, and client-centered models, among others. According to these models, key elements of the patient-provider relationship include the necessity for rapport, empathic understanding, mutual trust, empowerment, and reciprocal communication. However, models of the patient-provider relationship tend to differ with respect to the degree to which they emphasize a directive versus a nondirective or client-centered approach to interaction.

In directive approaches, the professional assumes the role of expert, and his or her role is to provide an informed viewpoint, structure, and direction to the treatment process. Providers who favor a directive approach also tend to favor a problem-solving, logical-deductive approach to treatment. Client-centered or empowerment-oriented approaches tend to be less directive and less structured. Professionals in favor of these approaches tend to seek the patients' views about the presenting concerns and encourage patients to control and direct their own care.

For disabled people, the nature of their relationships with health care professionals is critical. The attitudes and emotions that accompany these relationships, as well as the settings in which these interactions take place, affect the degree to which health care is viewed as relevant, useful, and ethical. A number of researchers, educators, and activists have examined and critiqued relationships between disabled people and health care professionals. Some of the more prominent voices in this analysis include Ian Basnett, Sally French, John Swain, John McKnight, Susan Wendell, Susan Lonsdale, Barbara Altman, and Peter Coleridge, among numerous others. Existing literature from this perspective includes testimonials and research reports that highlight the negative aspects, weaknesses, and areas for improvement within patient-professional relationships. These reports range from expressions of marked dissatisfaction with professionals to analyses and discussions of injustice, stigmatization, and victimization by professionals toward disabled people.

Like many relationships, the evolution of patient-professional relationships has involved a number of interacting variables. These include the personal characteristics and individual differences among and between professionals and patients. Larger contextual forces are also involved that address the societal norms of power, control, and hierarchy characteristic of the medical model of care. This model focuses on treatment or cure of damaged or failing body parts or systems. The implication of such an approach for disabled individuals is that body parts or systems that do not function as well as those of the nondisabled need to be remediated or fixed. If the impairment cannot be fixed, then the individual is somehow lacking or not whole.

Examples of these experiences are provided by number of writers and researchers, including but not limited to Susan Wendell (1996) and Susan Lonsdale (1990). Susan Lonsdale has interviewed a number of disabled women and found that they related many harmful experiences of hospital treatment and medical care. Visits to health care professionals were described as frightening in childhood. Women recalled being asked questions that were experienced as inappropriately personal and insensitive. They recalled being photographed unclothed and being pressured to walk naked in front of medical students. Peter Coleridge (1993) believes that the self-image of many disabled people has been damaged from their frequent involvement with professionals. This harm occurred particularly during childhood when necessary experiences of play, enjoyment, and discovery were attenuated or altogether replaced by stress, medical exams, and rehabilitation programming.

The negative impact resulting from objectification of the body and the medicalization of disability is also experienced by individuals with fluctuating or broadly defined chronic illnesses, such as arthritis, lupus, and multiple sclerosis. Individuals with these conditions, which are sometimes referred to as emergent or invisible disabilities, have been labeled as being depressed, anxious, or otherwise neurotic. Because their symptoms do not fit into neat diagnostic slots, professionals opt for psychiatric diagnoses of their secondary concerns and do not accurately assess the underlying disability. This invalidation is also evident in the early diagnostic labels given for less visible disabilities. For example, multiple sclerosis was once referred to as malingerer's syndrome or housewife's syndrome. Similarly, people with difficult-to-diagnose or poorly understood conditions, such as chronic fatigue syndrome, chronic pain, and fibromyalgia, have often faced ridicule, misdiagnosis, denial of care, and other stigmatizing attitudes and behaviors from professionals. For example, individuals with invisible disabilities have described a number of difficulties obtaining social services. Caseworkers with no knowledge of these conditions have denied benefits based on judgments that these conditions are not legitimate disabilities. These problems have a sharp impact on patient-professional relationships and can harm patients at a time of great vulnerability. Yet, it is not simply that professionals deny that these are disabilities or refuse services, important though those are. The larger issues of how disabilities are recognized and legitimized for treatment by society and the health care professions are relevant. To some extent, professionals reflect the societal awareness at the time. This is a problem since society can delay in understanding and recognizing emergent disabilities, especially ones that are not readily visible such as chronic fatigue syndrome. Thus, professionals are not the only individuals who bear the responsibility to address and correct this process.

For example, on average, individuals with chronic fatigue syndrome and fibromyalgia have seen 10 or more physicians, and it has taken five years or more to obtain a diagnosis. Many with these conditions have been told erroneously that their conditions were due to stress, mental illness, or lifestyle. The implication of these messages is that that the person's experience of his or her condition is not valid, that the individual is to blame for his or her condition, and that it is the responsibility of the individual to overcome it. As a result of these experiences, many people with poorly understood disabilities have developed a tendency to mistrust and doubt their health care providers. Discrimination is often multiplied for disabled people of lower socioeconomic status, as well as for those who are considered members of racial and ethnic minority groups.

As a support group facilitator, the second author has had many conversations involving the same recurrent theme—mistrust of health care providers. One individual with fibromyalgia commented, "Doctors don't know what they're doing. . . . Every time I ask my doctor something he has to pull out a book and look it up, or, says I don't know, or that's a bad idea!" A law enforcement officer with an invisible disability related during one physician's appointment that he asked his doctor about an alternative medicine therapy. The physician remarked, "I think you're reading too much." Another person related that three separate physicians are treating her because she does not believe any one physician knows how to help her.

Moreover, patients report that health care providers are often not aware of the physical and logistical challenges they face, including challenges involving mobility and transportation, limited or absent health care insurance, job schedules, and economics. Failure to arrive at scheduled appointments on time is often not tolerated or is interpreted by professionals as selfishness, disorganization, or noncompliance with treatment recommendations without appreciation of challenging complexities in the environment.

In addition, a number of disabled individuals have encountered paternalistic attitudes in their relationships with health care providers. Many report not being asked for input or concerns about health care or service needs. The professional reviews the patient's situation, makes a determination, and sets a plan of action. Then the patient is directed to follow a protocol. Another example of paternalism is evidenced in attempts by professionals to protect patients by failing to provide them with complete information about their condition or by deliberately excluding them from involvement in key decisions. For example, some patients have learned by accident that health care providers or legal advisers have "sugarcoated" or hid the severity or consequences of a situation because they felt that they (the professionals) knew what was best for the person. For example, a disabled woman was going through a difficult divorce. Her attorney insisted on closed-door negotiation with her ex-husband, his parents, and his attorney but advised the woman not to attend because he thought the situation would be too stressful for her because of her disability. Years after the divorce was finalized, this woman is still discovering the adverse consequences of her lack of direct involvement in these negotiations. Many of these consequences involve economic issues.

Medical perspectives that grow out of societal attitudes toward persons with disabilities can have a negative effect in patient-professional relationships. Contemporary writers argue that pejorative and misinformed notions of disability, often characterized as the tragic view (or personal tragedy view) of disability and impairment, have been reinforced by health care professionals. This view and its reinforcement have developed through health care workers' professional training, through their traditional approaches to practice, and through their biased interactions with disabled individuals. Health care professionals' contact with persons with disabilities is often limited to times when disabled individuals are most recently injured or acutely ill.

This tragic view holds that disability is something that should be avoided, reduced, rehabilitated, eliminated, or normalized by adopting as much of the lifestyle and behavior of a nondisabled person as possible. This view of disability is so prevalent that it has affected decisions and values about birth and the right to life. Writers have argued that the abortion of impaired fetuses is not commonly challenged within the United States. Gynecologists are now being sued if they do not appropriately screen for and detect impairments and abnormalities, including having one extra finger or toe. Physicians and society as a whole put pressure on women to undergo prenatal screening and to terminate pregnancies in which medical pathology has been detected. Notwithstanding considerable scientific evidence to the contrary, the idea that disabled people and their parents cannot sustain a joyful, fulfilling, or adequate quality of life is prominent within the tragic viewpoint.

RESEARCH

Individuals writing from the perspective of disabled people are not alone in their observations. Similar observations have been made in a smaller body of research and writings documenting the attitudes and behaviors of health care professionals. The literature indicates that the power imbalance that characterizes the medical model of care may, in part, contribute to the injustice, dominance, and delegitimization experienced by disabled people in their relationships with health care professionals. Writers and researchers such as Sally French, John Swain, and John McKnight have defined and discussed extensively the elements of power that are central to patient-provider relationships. The first involves the power of knowledge and skills possessed by professionals by virtue of their education and training. Professionals possess the power to evaluate the impairments that disabled people have and label their problems and needs based on their own perceptions of those needs. They also recommend specific treatments and evaluate the compliance and effectiveness of those recommendations.

According to Heather Coates and Alan King (1982), the professional's observations are often viewed as accurate, objective, and therefore superior, whereas the patient's perceptions are viewed as subjective and therefore inferior. Professionals not only possess power when working as individuals within clinical settings, but some groups, particularly physicians, also possess power collectively in that they are viewed as a high-status and economically and politically influential group within society. Professionals are more often consulted in the process of making public policy decisions that have a wide range of social and economic implications, including decisions involving abortion, genetic and stem cell research, cloning, and the sale of tobacco, alcohol, and other products, just to name a few. Professionals, rather than patients, are also called upon to make decisions that help insurance companies decide whether a patient deserves benefits or whether that patient is capable of returning to work.

As observed by Barbara Altman, Sally French, and others, practices that involve professional power encourage, maintain, justify, and enforce the dependency of disabled individuals on professionals and professionally driven institutions. Nursing homes, residential facilities (such as those for foster children or individuals with chronic illness, mental illness, or developmental disabilities), and day care programs, many of which provide specialized forms of transportation, embrace rigid treatment protocols, structures, and routines and fail to involve consumers meaningfully in daily decisions, and operations serve to foster and reinforce this dependency. These structures can encourage dependency, resentment, or both within patient-professional relationships. Systems and practices that are set up to encourage dependency have secondary effects on some disabled people. These consequences may involve internalized oppression in which the disabled person accepts his or her role as a dependent, disempowered individual. Ultimately, this process makes it more difficult for the recommendations made by professionals to be successfully embraced, and it makes it more difficult for the disabled person to achieve independence.

Over the past four decades, there have been efforts to counteract existing social norms through movements such as the disability rights movement, the independent living movement, and the patient power movement. These social movements are covered elsewhere in the encyclopedia.

WORK IN PROGRESS

Disability advocates and progressive health care educators and providers have formed a number of initiatives to improve patient-professional relationships. Values emanating from these movements and from client-centered models of care emphasize nonhierarchical, egalitarian relationships between consumers and professionals in which the role of the professional is limited to providing the patient accurate and balanced knowledge and information. Key decisions pertaining to health care, treatment, and participation in all other domains of life are within the control of the patient. Other recommendations to improve patient-professional relationships that have emerged from these movements and have been put in place to some extent include training health care professionals to understand the broader psychological, social, and economic influences of health and disability outside the health care system. For example, health care professionals from all disciplines have benefited from increased understanding of the role of physical aspects of the environment that prevent access to full participation in community and occupational settings. A final contribution that has emerged from these movements is the recommendation and practice of employing more disabled individuals in the roles of health and social service professionals.

One significant step toward incorporating these recommendations into real-world practice has involved the establishment of centers for independent living and other centers that embrace peer-facilitated models of care and the empowerment of disabled people by disabled people. Many disabled people prefer professionals who treat them as partners in their health care, legal situations, and in their search for social services. Many patients take the time to learn as much as they can about their disability, legal issues, treatment advances, and research updates. The most empowered patients expend the energy to learn about disability-related social services and attend self-help or support groups.

It appears that the most satisfied patients are the ones who feel empowered and know how to advocate for themselves in their relationships with professionals. Relationships with professionals work when disabled individuals have health care providers, legal advisers, and social service advocates who not only appreciate these qualities but also promote them. Individuals fortunate enough to find such relationships discover that they can have useful and relevant conversations with the various professionals in their lives. They can express their ideas and concerns about their situations in a trusted atmosphere without fear of being ridiculed.

In general, advocacy groups promote the value that patients take charge of their disabilities and become an integral component of their health care. In sum, health care professionals can occupy an important role in the lives of disabled individuals, and the way in which they regard and choose to relate to disabled individuals inevitably affects their well-being in emotional, social, economic, and political arenas. Well-intended professionals can provide valuable services that are nonetheless useful in the context of asymmetric relationships. There are some circumstances and cultures in which people may not be ready or accepting of an egalitarian or empowering approach. In sum, professionals who are sensitive to these issues and able to custom-tailor their approach to the client's needs may share in the most positive outcomes with their clients.

—Renee R. Taylor and
Sabrina Dudley Johnson

See also Attitudes; Decision Making; Health Care and Disability.

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Research Group on Rehabilitation and Independent Living, www.rgril.ku.edu

PATIENTS' RIGHTS

When people with disabilities enter a hospital setting, they expect to be talked over, around, and about based on a perception by medical staff that they, by the virtue of their disability, are not capable of thinking or talking for themselves. This behavior on the part of medical staff is historic and reflects society's attitude about disability and infirmity. As a practical matter, rehabilitation hospitals present less discrimination than acute hospitals because rehabilitation settings are more used to dealing with people with disabilities.

People with disabilities and the organizations that represent them have been working over the past 40 years to change people's attitudes about disabilities. One of the major methods of choice has been to use the law to improve wheelchair accessibility, to eliminate discrimination in employment, to provide equal access to services to all people with disabilities, and to ensure communications access throughout the new electronic world. Unfortunately, we as a society were not able to reduce discrimination against people with disabilities without resorting to the use of the law, but that is how it is getting done. In what follows, I offer several examples of legal and institutional documents, which enumerate patients' rights in a disability context. Together they suggest a range of societal reactions motivated to protect the rights of those with disabilities both in a medical setting and in society at large.

When Americans with disabilities think about their legal and civil rights, they consider two milestones in federal law related to services and nondiscrimination. The two milestones are Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990. The Rehabilitation Act affects only recipients of federal funding, including most hospitals. The law, with respect to services, states that

> no otherwise qualified individual with disabilities . . . shall, solely by reason of his disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance. (29 USCA § 794, Section 504 of the Rehabilitation Act of 1973, as amended)

The regulations provide further clarification.

The kinds of discriminatory acts prohibited include actions that

> (1) directly or through contractual, licensing, or other arrangements, on the basis of disability:
>
> (i) Deny a qualified person with disabilities the opportunity to participate in or benefit from the aid, benefit, or service;
>
> (ii) Afford a qualified person with disabilities an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others;
>
> (iii) Provide a qualified person with disabilities with an aid, benefit, or service that is not as effective as that provided to others;
>
> (iv) Provide different or separate aid, benefits, or services to persons with disabilities or to any class of persons with disabilities unless such action is necessary to provide qualified persons with disabilities with aid, benefits, or services that are as effective as those provided to others;
>
> (v) Aid or perpetuate discrimination against a qualified person with disabilities by providing significant assistance to an agency, organization, or person that discriminates on the basis of disability in providing any aid, benefit, or service to beneficiaries of the recipients' program or activity;
>
> (vi) Deny a qualified person with disabilities the opportunity to participate as a member of planning or advisory boards; or
>
> (vii) Otherwise limit a qualified person with disabilities in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service.

In addition,

> In determining the site or location of a facility, an applicant for assistance or a recipient may not make selections (i) that have the effect of excluding persons with disabilities from, denying them the benefits of, or otherwise subjecting them to discrimination under any program or activity that receives Federal financial assistance.

In 1990, the ADA built on Title V of the Rehabilitation Act of 1973 and declared that regardless of funding, the provision of services available to the general public could not discriminate against people with disabilities. The ADA states the following:

> No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation. (42 USCA §12182(a), Americans with Disabilities Act of 1990)

And through regulation:

> (a) Prohibition of discrimination. No individual shall be discriminated against on the basis of disability in

> the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to), or operates a place of public accommodation.
>
> (b) Landlord and tenant responsibilities. Both the landlord who owns the building that houses a place of public accommodation and the tenant who owns or operates the place of public accommodation are public accommodations subject to the requirements of this part. As between the parties, allocation of responsibility for complying with the obligations of this part may be determined by lease or other contract. (28 CFR 36.201, DOJ, Nondiscrimination on the basis of disability in places of public accommodation)

Many states have a "Patient's Bill of Rights," applicable to both patients with and without disabilities, which builds on the Rehabilitation Act and the ADA. As an example, the Massachusetts "Patient's Bill of Rights" follows the subsequent concepts.

MASSACHUSETTS GENERAL LAWS, CHAPTER 111, SECTION 70E

"'Facility' shall mean any hospital, institution for the care of unwed mothers, clinic, infirmary maintained in a town, convalescent or nursing home, rest home, or charitable home for the aged, licensed or subject to licensing. . . ; any state hospital. . . ; and any private county or municipal facility."

"The rights established . . . shall apply to every patient or resident in said facility. Every patient or resident shall receive written notice of the rights established . . . upon admittance into such facility. . . . In addition, such rights shall be conspicuously posted in said facility."

"Every . . . patient or resident . . . shall have, in addition to any other rights provided by law, the right to freedom of choice in his selection of a facility, or a physician or health service mode."

"Every . . . patient or resident . . . shall receive from a person designated by the facility an itemized bill reflecting laboratory charges, pharmaceutical charges, and third party credits and shall be allowed to examine an explanation of said bill regardless of the source of payment."

"Every Patient or Resident of a Facility Shall Have the Right:

(a) upon request, to obtain from the facility in charge of his care the name and specialty, if any, of the physician or other person responsible for his care or the coordination of his care;
(b) to confidentiality of all records and communications . . . ;
(c) to have all reasonable requests responded to promptly and adequately within the capacity of the facility;
(d) upon request, to obtain an explanation as to the relationship, if any, of the facility to any other health care facility or educational institution insofar as said relationship relates to his care or treatment;
(e) to obtain from a person designated by the facility a copy of any rules or regulations of the facility which apply to his conduct as a patient or resident;
(f) upon request, to receive from a person designated by the facility any information which the facility has available relative to financial assistance and free health care;
(g) upon request, to inspect his medical records and to receive a copy thereof, the fee for said copy shall be determined by the rate of copying expenses;
(h) to refuse to be examined, observed, or treated by students or any other facility staff without jeopardizing access to psychiatric, psychological, or other medical care and attention;
(i) to refuse to serve as a research subject and to refuse any care or examination when the primary purpose is educational or informational rather than therapeutic;
(j) to privacy during medical treatment or other rendering of care within the capacity of the facility;
(k) to prompt life-saving treatment in an emergency without discrimination on account of economic status or source of payment and without delaying treatment for purpose of prior discussion of the source of payment unless such delay can be imposed without material risk to his health, and this right shall

also extend to those persons not already patients or residents of a facility if said facility has a certified emergency care unit;

(l) to informed consent to the extent provided by law;

(m) upon request to receive a copy of an itemized bill or other statement of charges submitted to any third party by the facility for care of the patient or resident and to have a copy of said itemized bill or statement sent to the attending physician of the patient or resident; and

(n) if refused treatment because of economic status or the lack of a source of payment, to prompt and safe transfer to a facility which agrees to receive and treat such patient."

"Any person whose rights under this section are violated may bring in addition to any other action allowed by law or regulation, a civil action."

The Massachusetts statute also establishes patients' rights in the doctor-patient relationship that mirror those enumerated above.

As a result of the various state and federal laws defining "patients' rights," hospitals have made public, through postings and pamphlets, their own patients rights policies. A typical policy, developed by the Spaulding Rehabilitation Hospital in Boston, is set forth as follows.

SPAULDING REHABILITATION HOSPITAL PATIENT BILL OF RIGHTS

"Spaulding Rehabilitation Hospital is committed to providing you with quality care and respecting your rights as a patient. The hospital completely supports the law known as the Massachusetts Patient's Bill of Rights. The following are your rights as a patient, established by the provisions of that law.

"Every patient or resident shall have the right:

- Upon request, to obtain from the facility in charge of his/her care the name and specialty, if any, of the physician or other person responsible for his/her care or the coordination of the care;
- To confidentiality of all records and communications to the extent provided by law;
- To have all reasonable requests responded to promptly and adequately within the capacity of this facility;
- Upon request, to obtain an explanation as to the relationship, if any, of the facility to any other health care facility or educational institution insofar as said relationship relates to his/her care or treatment;
- To obtain from a person designated by the facility a copy of any rules or regulations of the facility that apply to his/her conduct as a patient or resident;
- Upon request, to receive from a person designated by the facility any information that the facility has available relative to financial assistance and free health care;
- Upon request, to inspect his/her medical records and to receive a copy thereof in accordance with Chapter III, Section 70, of the Massachusetts General Laws, and the fee for said copy shall be determined by the rate of copying expenses;
- To refuse to be examined, observed, or treated by students or any other facility staff without jeopardizing access to psychiatric, psychological, or other medical care and attention;
- To privacy during medical treatment or other rendering of care within the capacity of the facility;
- To prompt, life-saving treatment in an emergency without discrimination on account of economic status or source of payment, and without delaying treatment for purposes of prior discussion of the source of payment unless such delay can be imposed without material risk to his/her health, and this right shall also extend to those persons not already patients or residents of a facility if said facility has a certified emergency care unit;
- Upon request, to receive a copy of an itemized bill or other statement of charges submitted to any third party by the facility for care of the patient or resident and to have a copy of said itemized bill or statement sent to the attending physician of the patient or resident;
- If refused treatment because of economic status or the lack of a source of payment, to prompt and safe transfer to a facility which agrees to receive and treat such patient. Said facility refusing to treat such a patient shall be responsible for ascertaining that the patient may be safely transferred; contacting a facility willing to treat such patient; arranging for transportation; accompanying the patient with necessary and appropriate professional staff to assist in the safety and comfort of the transfer, assure that the receiving facility assumes the necessary care promptly, and provide pertinent medical information about the patient's condition; and maintaining records of the foregoing.

The physician shall provide every patient or resident in the facility essentially the same rights."

There is a relationship in a rehabilitation hospital between dignity and rights. It is often said that one must "check one's dignity at the door" when checking into a hospital. The personal privacy of people in the hospital setting is frequently compromised during the provision of hospital services. Respecting the dignity of people in the hospital setting, through the exercise of courtesy, confidentiality, compassion, and the empowering of patients to make informed choices regarding their treatment, is essential in ensuring the rights of all people in the rehabilitation setting.

—Elmer C. Bartels

See also Americans with Disabilities Act of 1990 (United States); Decision Making; Rehabilitation Act of 1973 (United States).

Further Readings

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PEDAGOGY AND CURRICULUM DESIGN

Across the United States, disability studies courses continue to multiply in academic departments within institutions that have established disability studies programs and those in which program development is not currently a goal. Course offerings are found in the humanities, the social sciences, medicine, applied health and rehabilitation sciences, psychology, philosophy, architecture, law, policy, and business. Until recently, disability-related content was the exclusive domain of medicine, education, and the social sciences. Infused by the current wave of disability studies in the humanities, disability is now more likely to be understood as a product of cultural rather than purely biological forces. Recent course offerings include the following: Disability and Literature; Disability in American History; Cultural Studies/ Body Studies; Extraordinary Bodies; Disability and Culture: Race, Gender, and Sexuality; Women and Disability; Disability in Film; and Crip Cultures & Disability Studies. Judging by the titles alone, this sample evidences a strong bias toward the cultural branch of disability studies, but undoubtably, titles can be deceiving.

ACADEMIC COURSES AND PROGRAMS

In many universities, the process for new course creation can impede the development of new courses if it threatens existing, state-approved, or professionally sanctioned content. However, courses can be updated with little or no fanfare and pasted into an existing course title. For example, Normality, Abnormality, and Society, offered in the philosophy department at the University of Hawaii, Hilo, is suggestive of the first wave of disability studies when professionals set the parameters for inquiry into disability informed by a prevention/treatment/remediation paradigm. However, despite its retrograde title, the course, taught by Ron A. Amundson, a philosopher of science and a wheelchair user, is described in the course catalog (2002–2003) as

> a philosophical study of how human diversity interacts with social norms. Topics include health and illness, disability, gender, and sexual orientation. Perspectives from biology and the social sciences are included in a study of how beliefs about normality vary between cultures, change through time, and affect human relations.

The course is not included in a special disability program, nor is it part of a cluster of course offerings designed to provide a closer examination of disability informed by a disability studies. Like many of the new disability studies courses that dot the academic landscape, this course stands alone in a traditional academic department.

Where efforts are under way to develop disability studies programs, course offerings are plentiful and more diverse. Community Planning and Public Policy for Disability, offered through the Department of Environmental Design at the University of California, Berkeley, explores what society and local communities can do to address the needs of citizens with disabilities specific to policies, programs, and local planning. Although the content is shaped by cultural awareness and more progressive interpretations of disability, the course has as its foci the economics of disability and the politics of producing change, with special attention to transportation, housing, public facilities, independent living, employment, and income policies, with content that reflects the perspectives of disabled and nondisabled members of society. Although the disability studies concentration to be offered at the undergraduate level in American studies at the University of California, Berkeley has yet to be finalized, a wide range of interdisciplinary courses already exist. Because Berkeley shares a long history of involvement with the disabled community, many courses were offered well in advance of the recent efforts to create an undergraduate minor in disability studies.

INFLUENCES ON PEDAGOGY AND CURRICULUM DEVELOPMENT

In the example of disability studies, two significant influences on pedagogy and curriculum design are (1) the perspective on disability offered and (2) the context in which the course is offered. When the perspective on disability is informed by cultural criticism and theory, it is useful to consider its relationship to women's studies, African American studies, and queer studies, particularly as each emerged in the era of civil rights movements. However, arguing against the impulse to add disability to the "roster of the disenfranchised," Lennard J. Davis (2002) contends that because the category of disability is porous, it poses a significant challenge to identities that seem fixed. Thus, increasingly disability studies scholarship has moved away from particular claims to status as "another other," opting instead to unsettle fixed identity categories through a more complicated critique informed by disability studies.

GOALS AND OBJECTIVES FOR DISABILITY STUDIES CURRICULA

In its most simple statement of purpose, the goal for a disability studies curriculum is to unpack inadequate representations of disabled people wherever they exist. At the center of many new courses in academe are efforts to disrupt pity, fear, loathing, and overly romanticized and uninterrogated inspirational depictions of disability. Course descriptions are peppered with terms such as *excavate, examine, explore, investigate, interrogate, probe, appropriate,* and so on. Moreover, when the content is organized according to the strictures of cultural studies as a "strategic practice," risk taking and discomfort are likely to follow, according to the critical theorist, Lawrence Grossberg—in short, to radicalize rather than romanticize the content. Demands for authenticity remain a critical feature of the evolution of disability studies curricula. As a consequence, it is not uncommon to find disclosure as a unique feature of the pedagogy of disability studies in academe—with both sides weighing in on the issue. An early framing of the disclosure issue appeared in the *Chronicle of Higher Education* in 1999, when Leonard Cassuto posed the question, "Whose Field Is It, Anyway? Disability Studies in the Academy." The essay sparked a healthy debate among scholars relative to the issue of disability insider/outsider status and who is qualified to speak about disability. It was a timely exchange that provided the occasion to map disability studies as a field and, more subtly, to foreshadow a few of the ruptures in academic traditions likely to follow. Among the most challenging disruptions within the academy at the practice level include those relative to hiring and promotion, instruction, publication, student services, and physical plant design and construction.

In less than three years, issues of pedagogy and curriculum development have become increasingly more complicated and turbulent. The recent publication of *Disability Studies, Enabling the Humanities* provided the occasion for Georgina Kleege and Brenda Brueggemann to consider their own classroom context and their teaching of disability content as professors with visible disabilities. Kleege voiced resentment over the assumption that her own personal experience "augments" her teaching and, more pointedly, that there is pedagogic power in exposing her disability to nondisabled students. Her refusal turned on the unintended effects of naive or well-intentioned approaches that cast her as the "goodwill ambassador sharing the quaint beliefs and customs of my alien world." It is also through her candid exchange with a student depicted in this essay that Kleege articulates the development "over time" of her own disability identity. The impulse to incite activism within a disabled community was revealed to be a latent issue—an insight that only insiders can substantively debate—and one with important implications for K–12 curriculum development. In a variation on us/them positioning still erupting in academe, Brueggemann turns the issue on its head to reveal that the "sword cuts both ways." Initially exasperated by students in her freshman composition class and their resistance to get "in" her disability content, Brueggemann recounts her own resistance to get "in" their abilities. Acknowledging the pedagogic tensions and reflecting upon them, both Kleege and Brueggemann informed their own practices and raised new points to debate as a field.

Arguing against the tradition of silence on the issue of pedagogy among cultural studies theorists, Henry A. Giroux (1995) cited academic elitism, the rewards of disciplinary policing, reluctance to cross academic borders, careerism, and competitiveness as the some of the barriers to probing the relationship between pedagogy and cultural studies. Composition studies, Giroux contends, is one of the few fields in the humanities to seriously contend with pedagogy. However, it is clear that many disability studies scholars have broadened the debate of what is political at the heart of pedagogy and curriculum development. Particular claims to postdisciplinary knowledge is not the ultimate goal for disability studies, at this juncture; there remains too much to be learned from the lives of real people articulating and renarrating lived experience *within* rather than outside history.

DISABILITY STUDIES AND THE PEDAGOGY OF INCLUSIVITY

As academic courses continue to develop and programs gain in popularity, sustained success turns on the pedagogy of inclusivity as the catalyst to sustain explorations into disability studies; to encourage enactment of policies that affect enrollment, hiring, access, and course offerings; and to foster the continuous examination of what counts as knowledge. At the present, those institutions that embrace a pedagogy of inclusivity herald disability studies as more than academic antics in pursuit of another other; rather, these institutions recognize the importance of reimagining the ways disability affects all our lives. In contrast, institutions that practice a pedagogy of exclusivity endorse traditions whereby elitism, entitlement, exclusion, and privilege prevail. Knowledge is more likely inherited rather than interpreted, leaving little appreciation for reflection on the recent ideological shifts that inform disability studies. That is not to say that disability studies courses would not, on occasion, appear in such institutions; novelty or fad-driven courses advance the economic interests of all institutions. But it is to remind us that there are real and measurable political implications for offering disability studies in the first place. Disability studies will be greatly undermined as a viable academic pursuit if institutions fail to simultaneously engage rigorous self-examination of existing policies relative to access and the inclusion of disabled people in the academy regardless of their status as faculty, student, staff, or visitor. A pedagogy of inclusivity would pursue fair representation of disability not only in the curriculum but throughout the university: indeed, no minor undertaking.

DISABILITY STUDIES IN THE CONTEXT OF K–12 EDUCATION

In K–12 educational settings, where disabling constructions are manufactured and conveyed through pedagogy and practice institutionally endorsed by local, state, and federal mandates, the context is thick with a pedagogy that pathologizes difference. Despite the growing legitimization of disability studies in higher education, many teachers are unfamiliar with the field and its implications for K–12 education. Were this encyclopedia entry written 10 years into the future, it would include samples drawn from K–12 school-based curriculum projects in which disabled youth spliced together lived experience, dreams, desires, and reflections on their subject positions in schools. The goal would be nothing short of locating students' experience *within* rather than outside history and, as a consequence, substantively reshaping the extant curriculum.

Given that education, health, and human services are the primary service providers for the disabled community and in schools, an important concern for professionals might be to address why the most recent wave of disability studies has emerged from within the humanities and outside the professions. Or, how can this new wave of disability studies inform and shape the education and training of future educators and school-based professionals? More to the point, how might this scholarship influence disabled students in K–12 educational settings to locate themselves in the curriculum in ways that have yet to emerge? Given that the professions have a high stake in preserving status quo assumptions about disability as pathology, it is highly unlikely that such questions will be considered in the absence of rigorous self-engagement with interdisciplinary disability studies and collaborative planning initiatives. The National Endowment for the Humanities (NEH) has taken the lead to provide funding for such initiatives discussed below.

Emerging K–12 Initiatives

Recognizing the value of cross-disciplinary and interdisciplinary scholarship, the NEH has previously sponsored focus grants and summer institutes for higher education faculty and for secondary educators that focused on disability studies. Although these are quite recent initiatives, it is clear at this stage that efforts to import coursework from academe into K–12 contexts will prove challenging unless the disjuncture between these two competing contexts is explored toward ends that promote reciprocal gains. *A Collaborative Inquiry on Understanding Disability in Secondary and Post-Secondary Settings* (2000) attempted to identify intersecting interests toward the realization of reciprocal goals, but what became apparent was how much a difference disability can make depending on one's context. K–12 teachers work in contexts in which disability is more than a theoretical concern, and although many are unaware of disability studies scholarship, their instructional context continues to include greater numbers of disabled students. This distinction served to complicate the project of articulating shared goals as most universities are situated at the exact opposite extreme and enroll far fewer disabled students—and, for the most part, only those likely to succeed.

"Integrating Disability Studies into Secondary Education," a five-week summer institute for secondary teachers, was cosponsored in 2003 by the University of Illinois, Chicago and the National Endowment for the Humanities. Both general and special educators were treated to a rigorous course of study that stood quite a field from the usual technicist fare that drives in-service "training" for teachers. Exposure to new ways to imagine the lives of their disabled students, informed by a broad survey of humanities content and interactions with disabled artists and performers, led many of the participants to confront, for the first time, the obvious contradictions in K–12 education as it currently exists. For these teachers, five weeks of interactions with wholly new content that, without malice, served to underscore the inadequate representation of disability in their teaching and daily practice was just a beginning. Once these educators returned to their schools, the hard work began as they continued to deconstruct and critique disability in the schooling context. Again, what became apparent was that pedagogy and curriculum development relative to disability studies in the instance of K–12 settings are quite distinct from that in postsecondary settings. Working in isolation to reassemble new images of disabled people and their own students to reflect newly acquired political understanding of disability proved a formidable challenge. Embedded in relationships with content, processes, and policies over which they exert little authority, K–12 educators face an incredible responsibility when attempting to dissolve the boundaries between schooling and popular culture, inherited social scripts, and the limits of their own professional knowledge base. Only through persistence and a long view of the change process can K–12 educators advance disability studies in their everyday practice. Educators' attempts will be greatly enhanced if postsecondary faculty maintain outreach to K–12 contexts as a necessary component of academic disability studies.

—Linda Ware

See also Disability Studies; Education and Disability; Mainstreaming; Special Education.

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PEDIATRIC REHABILITATION

The term *pediatric* refers to medical aspects of children and *rehabilitation* to the medical field of helping people with disabilities acquire greater function. Both are terms of professionalization, in which a field of training, research, and patient care has been assembled by its practitioners and recognized by society at large. As a consequence, this entry refers primarily to the profession, which cares for children with disabilities using medical techniques, following a primarily first world, modern model. In other cultures and at other times, care for children with disabilities has been provided.

In a formal sense, pediatric rehabilitation is comparatively young. It falls against the backdrop of the development of pediatrics from the mid-nineteenth century and the development of rehabilitation largely over the last two-thirds of the twentieth century.

Western medical systems have identified the unique aspects of pediatric conditions of disability from their inception. Certainly, case examples of children with disabilities and the adults they became exist from at least ancient Egypt. Hippocrates, Galen, Soranus, and other ancient authors identified certain conditions of a disabling nature in children and offered interventions appropriate to the time. In the Middle Ages, hydrocephalus, or swelling of the head, in newborn infants was recognized and treated by surgeons. With the earliest texts devoted exclusively to children's medical disorders, disabling conditions were identified and explained, and cures were suggested from Thomas Phaire's *The Boke of Chyldren* (1544) onward. However, it was not until the aggregation of children's care in a coherent way, at the beginning of the nineteenth century, that Western medicine began to identify and react to challenges peculiar to children with disabilities in an articulated fashion.

For much of its history, pediatric rehabilitation was closely related to institutions of chronic, "inpatient" care. In Paris, for example, the Hôpital des Enfants Malades, founded in 1802, was the first hospital dedicated to sick children, using the medical model. In this way, it was distinct from other institutions, which cared for abandoned, poor, or orphaned children. Within its walls, children with acute conditions were gradually separated from those with chronic conditions. Among the latter, those with conditions such as spinal tuberculosis, paralyses, Huntington's chorea, and skeletal anomalies gradually received medical care intended if not to cure then to improve the quality of the child's functional life.

Clearly, part and parcel of the institutionalization process was segregation, social control, and stigmatization. Children with chronic conditions, deemed amenable to intervention, were taken off the streets and away from begging for charity. In this sense, state-sponsored charity for children supplanted spontaneous, private intervention. But the impact on the children, including separation from able-bodied peers, enforced perception of difference; usually, isolation from family was nearly complete. From within the field of pediatric rehabilitation, these effects have been historically downplayed in comparison to the described benefits of concentrated resources, efficiency, and opportunities for learning. Collecting such children together in inpatient and outpatient settings fostered the growth of expertise in their medicalized conditions and care. Thus, pediatrics, pediatric orthopedics, pediatric rheumatology, pediatric neurology, pediatric neurosurgery, pediatric psychiatry, pediatric rehabilitation, pediatric occupational and physical therapy, and other specialties were born and grew.

In the United Kingdom, as in France, figures such as William John Little identified conditions such as cerebral palsy with more or less clinical coherence. This process of medicalizing conditions—identifying a constellation of signs and symptoms and then tracking the natural history of those signs and symptoms from origin to conclusion under a medical rubric—allowed physicians to gain control of knowledge about the children with these conditions. Similarly, conditions from meningomyeloceles to traumatic brain injuries to learning disabilities have been identified, catalogued, and allocated medical resources for intervention and research.

The multidisciplinary growth of the care of children with disabilities is exemplified by figures who wrote pioneering works on their conditions. As well as English surgeon William John Little, in Germany, orthopedist Jacob von Heine (1800–1879) worked with children with paralyses and poliomyelitis, writing on their conditions in 1860; in Vienna, psychiatrist Sigmund Freud (1856–1939) worked with children with cerebral palsy (1897) prior to developing psychoanalysis; and in the United States, the seminal figure in internal medicine, William Osler (1849–1919), wrote an observational study on children with cerebral palsy (1889) and later became the fourth president of the American Pediatric Society. Beyond the frame of medicine proper, other parts of society in other countries followed the French government in allocating central resources to the care of children.

In the United States during the 1920s and early 1930s, the White House advanced elements of a children's agenda; the presidents both convoked symposia for policy creation and created a "Children's Charter" (1928) to begin to identify the needs of children with disabilities, under the auspices of physicians interested in their care. Following his own bout with poliomyelitis, Franklin D. Roosevelt helped create the private philanthropy, the National Foundation for Infantile Paralysis (NFIP), later to become the March of Dimes. From its inception in 1938, the NFIP helped fund both care and research into pediatric rehabilitation. The impact of sequential epidemics of polio continued to bring the care of children with chronic conditions to the attention of reformers, government agents and agencies, and health care practitioners.

In 1947, physical medicine and rehabilitation (PM&R) as a field was formally recognized with its own certification board. Dr. George C. Deaver, commonly identified as the first pediatric physiatrist, influenced training, certification, and philanthropy to aid in the care of children with disabilities from his professorship at New York University and the (Rusk) Institute of Rehabilitation. In 1946, he organized the Advisory Council to the National Easter Seal Society. In these early stages, Deaver was joined by specialists from child neurology (such as Bronson Crothers), neurosurgery, orthopedics, and pediatrics to form the American Academy for Cerebral Palsy (later the American Association for Cerebral Palsy and Developmental Medicine) in 1947. Deaver and others subsequently fostered fellowships in pediatric rehabilitation in the 1950s. In these early years, training was often received as much from the therapists working with the children directly as from the senior physicians "directing" their care.

With further disparate developments in funding, research, and care models, the fields of pediatrics and PM&R began to establish joint residencies in the 1970s on an ad hoc basis. Similarly, PM&R programs created one-year fellowships for those trained primarily in adult PM&R to specialize in the care of children. By the 1980s, numbers of physicians identifying themselves as primarily pediatric rehabilitation specialists reached sufficient levels to form a Pediatric Rehabilitation Special Interest Group (SIG) in the American Academy of Physical Medicine & Rehabilitation (AAPM&R).

Over the past 30 years, pediatric rehabilitation has become a more formalized endeavor. Today, in the

United States, for example, one can enter pediatric PM&R from more general training in PM&R (largely adult) or a dual background in pediatrics and PM&R. Professional political movements over the past 20 years have resulted in a subspecialty examination process begun in 2004 under the aegis of the American Board of PM&R and with the acceptance of the American Board of Pediatrics. Other countries vary from this model, sometimes markedly.

From the point of view of the trappings of professionalization, pediatric rehabilitation is a comparative newcomer to the world of medicine. The first journal confining itself to the topic is in its eight-volume *Pediatric Rehabilitation.* No formal and independent organizations exist solely to sponsor pediatric rehabilitation, although there are professional organizations devoted to individual conditions, such as the American Academy of Cerebral Palsy, or sections of umbrella organizations that address pediatric issues, such as the Pediatric SIG of the AAPM&R.

Providers of pediatric rehabilitation include physical, occupational, and speech language therapists, nurses, social workers, play therapists, teachers, physicians, and others. In many of these fields, some formal training in pediatric rehabilitation is provided, but "specialization" occurs with experience and clinical setting. For physicians, that specialization previously occurred with similar on-the-job training and inclination. However, increasing recognition of the specific nature of such work has promoted certification in many fields. As in all matters with economic consequences, supply and demand in the marketplace change the value of certification. In the United States, while there are fewer children overall with rehabilitation needs compared to adults, there are far fewer specifically trained providers. Those with partial training are still very much in demand.

While there is a core of conditions generally treated by pediatric rehabilitation professionals, concentrating on physical disabilities, practitioners often apply rehabilitation concepts to almost any condition, which might consequently be improved. Conditions traditionally falling under the purview of pediatric rehabilitation include cerebral palsy, neural tube defects (e.g., spina bifida or meningomyeolocele), traumatic brain injuries, amputations, burns, congenital conditions, strokes, neuromuscular disorders, cancers, and a variety of others; in addition, many pediatric conditions, including those related to sports, are treated in outpatient clinics by rehabilitation personnel. There is much room for growth, quite apart from patient numbers.

As in many specialties, pediatric rehabilitation, as a concept, may be effectively applied to many conditions not now generally using it. Thus, standard treatments do not apply full rehabilitation models to children recovering from cardiac surgery as they would in adults. Newborns with complex conditions are only rarely specifically targeted for coordinated rehabilitative care beyond the intensive care unit. But expectations and market forces are gradually changing these limits. Similarly, rehabilitation as a field grew out of therapeutic associations often viewed as "marginal" in the late nineteenth century. As a medical specialty today, it often is amenable to alternative forms of treatment. This is particularly true as conditions treated by rehabilitation practitioners rarely have "cures."

Pediatric rehabilitation uses tools—including rehabilitation; physical, occupational, and speech-language therapies; gait analysis; casting; bracing; orthoses and protheses; electrodiagnosis; physical modalities; pharmaceuticals; and injections—to assess and improve the overall function of children. While the tools are similar to those of rehabilitation physicians for adults, the perspective is often different. In part, this is because of the neurodevelopmentally moving target of the child. Unlike adults, whose physical, mental, and sensory development has plateaued in a gross sense, children are still actively, often aggressively, changing in those respects. Thus, an adult with a low-level cervical spinal cord injury would learn to operate a wheelchair, transfer himself or herself, and so on. For a child, depending on his or her age, this might at first be difficult, but then increasingly possible, and then be complicated by growth and the shifting proportions of the child's body parts. Pediatric rehabilitation providers have to take account of such changes.

In addition, that children are still being educated by society—in a formal school setting—requires that pediatric rehabilitation providers interact with teachers in a fashion that their adult counterparts usually do not have to do. In one sense, this is a salutary symbiosis, as the educational program can be changed to take account of static or evolving impairments. On the other hand, it adds a layer of complexity onto a rehabilitative plan.

Families also play a huge role in pediatric rehabilitation. While parents can sometimes need as much support as the child, they are usually extremely strong advocates and caregivers. In current clinical models, the pediatric rehabilitation specialists are supportive partners to the child and family rather than directors of care. Siblings, like their parents, also need attention, which can be hampered by the physical and emotional demands of a child with a disability.

Research into exclusively pediatric rehabilitation conditions and settings is only slowly growing. Health services research, for example, has been struggling to identify care delivery mechanisms designed specifically for this sector despite exclusion by adult modeling. Clinical research also has met challenges. Since the numbers of children involved are fewer than adults and the reimbursement for their care, at least in the United States, is less consistent, research has sometimes lagged. As is true for its adult cognate, pediatric rehabilitation has also struggled to identify means to measure outcomes of children treated with rehabilitation techniques. A further challenge is the relative infrequence of such pediatric conditions. Low numbers make it difficult to generate statistical proof of treatment efficacy. Nevertheless, taking advantage of related basic sciences, pediatric rehabilitation internationally continues to doff its empirical roots and to seek out theoretical underpinnings for functional intervention and evaluations of outcomes. In this goal, pediatric rehabilitation is following the paths of previous specialties from ophthalmology to adult rehabilitation.

—Walton O. Schalick III

See also Bronson Crothers; Cerebral Palsy; Childhood, Youth, and Adolescence; Physical Medicine and Rehabilitation.

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PEER SUPPORT

Peer support involves a process of giving and receiving help among individuals who are in similar situations. A peer can be defined as a person of equal standing with another—someone who is equal to another person in some important respect such as age, social class, or experience. A peer can also be defined as a friend or companion. Peer support can vary greatly from one circumstance to another, but central to peer support is the ability to understand someone else's situation because of some shared experience. Through this common understanding, peers are able to share stories, exchange information, and often, once the relationship has become solid enough, challenge each other when they are in conflict. Peer support stresses experiential and not professional knowledge. The very value of peers is that they do not have professional training or use professional jargon: They speak from their experience and from a similar status.

The relationship between peer support and disability involves discussing the history of peer support;

how peer support occurs across types, structure, and settings; and the benefits and conditions necessary for peer support to be effective.

HISTORY OF PEER SUPPORT

The concept of peer support in the United States can be traced back to the establishment of Alcoholics Anonymous in 1935, which was formed under the assumption that persons who experienced and overcame alcoholism would be most effective in assisting others who were trying to do the same. The concept of peer support inherently allows individuals to be seen as resources. Specific to the area of disability, peer support offers an alternative to traditional ways of viewing disability as a deficit or problem in need of treatment. Because of societal discrimination, disability can often be an isolating social status. The availability of peer support can provide an antidote to stigma through affirming the very characteristic for which individuals with disabilities have often been disrespected. Furthermore, peer support can be an empowering experience for those who have faced discrimination and marginalization. Such a relationship can provide a positive and/or critical alternative way of looking at the world. For these reasons, peer support has emerged as a central guiding force in many disability-related organizations and services. Peer support relationships involve people with disabilities or family members or caretakers of people with disabilities.

Peer support has grown most visibly through the formation of a number of disability-related organizations across the United States. For example, peer support has been the foundation of the self-help movement and, more specifically, organizations such as Recovery Incorporated, a nonprofit peer-based organization that began facilitating weekly support group meetings for people with mental illness in 1937. As another example, United Cerebral Palsy was created as an organization in 1949 when two families with children with cerebral palsy came together to create a network to allow families to stay together and improve the lives of children with disabilities. Support groups have been a core service of this organization as they strive to help families share resources.

In the United States, the revolutionary thought of the 1960s continued to foster ideas related to peer support, as a rise in service delivery by paraprofessionals and nonprofessionals increased interest in the concept of peers supporting each other. An excellent example of this is the Center for Independent Living (CIL) movement. Led by Ed Roberts in Berkeley, California, a group of students with disabilities organized to pressure the University of California at Berkeley to become more accessible and to provide more supports for students with disabilities. In 1972, the Berkeley Center for Independent Living was founded as a community-based organization, with peer support as one of its central values. Today, more than 400 CILs exist around the United States, and peer support remains a core service for most local chapters.

During the 1980s, peer support continued to make its mark, as seen through the development of the Mood Disorders Association, a nonprofit, peer-based organization that was started in 1982 by and for mental health consumers. As another example, Americans Disabled for Accessible Public Transit (ADAPT) was founded in 1983 to promote advocacy in the disability community through civil disobedience to achieve the goal of public accessibility. Many other large organizations for people with physical disabilities, such as the National Spinal Cord Injury Association and chapters of the Paralyzed Veterans of America, have made peer support one of their major activities.

Peer support has been a strong component of independent living organizations around the globe. For example, independent living organizations in Sweden and Canada have used peer support as a mechanism for bringing people with disabilities closer to independence. Similar to the United States, international peer support developed strongly in the 1960s and 1970s. For example, in 1962 in the United Kingdom, a group of parents of children with disabilities formed the Society for Autistic Children, which later became the National Autistic Society, and includes a telephone support service for parents of children with autism. In Australia, peer support was part of a larger community health movement during the early 1970s. During this time, under the Whitlam administration, local community health projects were directly accountable to the communities they served. There was community involvement at every level of service development and delivery. This involvement opened channels of communication among service providers, bureaucrats, and consumers in areas such as disability and mental illness. Founded in the 1970s, GROW is one example of such organizations that flourished and presently runs peer-led groups for those with mental illness in many countries. More recently, peer support has reached other nations such as Thailand, where, in 2000, people with disabilities were trained as peer counselors. Thai individuals with disabilities have continued with training that focuses on how to establish and maintain an independent living center.

TYPES OF PEER SUPPORT

Peer support can take multiple forms, including peer support provided on an individual basis and that provided in a group setting. Individual peer support can include peer education, peer counseling, and peer-mentoring relationships. These relationships may involve sharing similar experiences and offering advice based on these experiences. As an example, individuals with newly acquired spinal cord injuries may serve as mentors to new patients, so that both can share emotional experiences as well as information regarding resources they have attained since their injuries.

In contrast to individual approaches, peer support groups are often composed of people with disabilities who have common difficulties. Created around common core issues, these groups then meet regularly to discuss their problems and strategies to deal with them. To provide an example, one peer support group among people with psychiatric disabilities announced that their group had two goals: serving as a source of friendships for participants and seeing that interpersonal skills learned via the group process would generalize to other relationships beyond the group.

STRUCTURE OF PEER SUPPORT

Across these forms of peer support, the structure of peer support relationships can also vary. Relationships can range from formal to informal and can occur across or within diverse programs. Regular contact between the supporter and supported can occur face-to-face and may involve educational or recreational activities. Contact can also be less frequent and may involve a simple phone call whereby the supporter is simply “checking in.” Last, support can be shared over the Internet in the form of listservs, chat rooms, and other online communities. Online support can be a particularly valuable resource for people with disabilities who face barriers regarding physical accessibility, transportation, and personal attendant care (for example, those who live in rural communities). One peer-mentor program had a variety of mentors “on-call” for consumers to contact as needed. In contrast, one peer support group was more formally organized, as the group included two meetings each week. One meeting was structured by the group. It included both time for each member to talk and also a facilitated discussion around some issue. The second weekly meeting was a recreational activity.

SETTINGS OF PEER SUPPORT

Peer support in its many forms and with its many structures can also be incorporated in a number of environments, including educational settings, employment settings, rehabilitation hospitals, independent living centers, health promotion centers, and supported living/supported housing settings. For example, one peer-mentor program, set up with individuals with violently acquired spinal cord injuries, is based in the rehabilitation setting. This program consists of, among other things, recreational activities, including wheelchair basketball, camping, and sailing. As another example, one supported housing program for individuals with HIV involved a series of groups. These groups were developed to focus on specific needs, such as cooking, emotional and addiction recovery support, information sharing about opportunistic infections, treatment protocols, and medication and alternative holistic therapies. Needs were identified in the group setting, and all community members were asked to contribute to solving them.

BENEFITS OF PEER SUPPORT

The little research that has been conducted to evaluate peer support programs has found positive results. Broadly, peer support seems to benefit the people being supported, those doing the supporting, and the broader community. In terms of individuals being supported, a number of psychological effects have been demonstrated. First, peer support in general seems to promote a sense of empowerment among the group of people with disabilities. When people are faced with a stressful situation, especially when they acquire a new disability, they prefer the company of those facing the same stressful event. Peer support helps people feel validated when they are able to share emotional reactions with others having similar experiences. Furthermore, people are given the opportunity to learn from the peer providing support. They are given the chance to develop skills that have proven effective for someone else in their life situation. They can also learn to advocate for themselves and may experience enhanced feelings of self-worth because someone similar cares about and understands their situation.

Peer support may also help the peer doing the supporting. In general, research conducted across a variety of populations has found that helping others can help you. Specific to disability, peer supporters can experience a heightened sense of self-worth as they are able to share their valuable knowledge and presumably help someone else in the process. They may also feel and explicitly acknowledge a strength of their disability (perhaps for the first time), as it has given them the tools to assist someone else through a difficult time. Furthermore, peer supporters often feel great satisfaction knowing they are helping someone else. This experience has also been cited as a catalyst toward career development.

Finally, the broader community can benefit from peer support in a number of ways. First, peer support can demonstrate to the community a positive contribution that peers with disabilities can provide. Furthermore, it seems to be a mechanism for building capacity for change. When people are sensitive to and aware of common needs and common rights, they have the opportunity to make appropriate social change; they can work together to develop appropriate solutions to complicated social issues and problems. For example, advocacy groups can be built based on common interests and can evolve from peer support relationships and groups. Advocacy groups facilitate change in certain areas.

As an example of the variety of benefits that peer support can yield, one peer support program among persons with psychiatric disabilities reported that participants maintained their independent or semi-independent living and increased their use of community resources. The participants also experienced greater social support networks and social and leadership skills. Furthermore, their likelihood of hospitalization decreased, and they reported high satisfaction with the program.

Benefits include that peer support is more cost-effective than that provided by professionals. Peer support also allows more people to receive assistance more frequently: Assistance becomes a part of individuals' natural networks rather than something they receive only when going to see a professional in an office.

Though advantageous in many situations, effective peer supporters require adequate support themselves to avoid burnout. Often, a strength of peer support is that peers have not been formally trained as clinicians or practitioners and therefore speak to their peers from their own experience. This strength also presents a limitation in that they need to be supported in dealing with others' problems, as this can be an overwhelming burden. Support can be provided to peer supporters in a number of ways, from structured contact with professionals to more informal contact with other peer supporters.

It is imperative that peer relationships, whether individual or group based, are comfortable for all involved and that they make individuals feel that it is acceptable to talk about their problems or sources of stress. A supportive environment is key to an effective peer support relationship.

Given the hundreds of millions of people with disabilities in the world and the limited number of professionals, peer support is a vital resource for people with disabilities. Peer support helps people with disabilities cope with everyday concerns, enabling them to validate their strengths and to move forward to improve their lives. As this review as shown, peer support can take many forms, yield many benefits, and lead to the development of advocacy efforts.

—Erin Hayes and
Brigida Hernandez

See also Advocacy; Empowerment and Emancipation; Leadership.

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Websites

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Mental Health Consumer Net Connections, www.mentalhealthconsumer.net/peer-support.html

National Self-Help Clearinghouse, www.selfhelpweb.org/what.html

PEOPLE FIRST®

People First® is an international self-advocacy organization with chapters all over the world. People First® groups are run by and for people with intellectual disabilities to work on civil and human rights issues. People First® groups are always led by people with intellectual disabilities. They have four guiding principles:

1 Speaking for ourselves
2. Solving problems—making decisions
3. Knowing our rights and responsibilities
4. Contributing to our community

Most People First® groups elect officers to run their meetings and have facilitators or advisers who assist group members. Facilitators help the group without taking control. People First® groups work on a wide variety of issues, including closing institutions, housing, employment, voting, and sexuality and social relationships. People First® groups fight prejudice and discrimination against people with disabilities. They also combat overprotection by parents and professionals. Those who participate in People First® find that their lives are enriched. They have more friends and colleagues to socialize with and help them to solve problems and meet individual goals.

PEOPLE FIRST® HISTORY

In 1968, a meeting was held in Sweden at a parents' organization for children with developmental disabilities. The organization had a motto—"we speak for them," meaning the parents spoke for their children. However, people with disabilities who attended the meeting wanted to speak for themselves. They started their own self-advocacy group. Similar groups quickly spread to England and Canada.

In November 1973, individuals with disabilities living at the Fairview Hospital and Training Center in Salem, Oregon, attended a conference in British Columbia, Canada. The conference was organized and run the British Columbia ARC. The conference was for people with disabilities, but it was run by professionals. The group from Oregon wanted to start a self-advocacy group by having a similar conference, but they wanted it to be organized and run by people with disabilities. They wanted support from professionals only when it was requested. During a meeting on January 8, 1974, they discussed how to name their group. Everyone disliked being called by negative labels such as "retarded," so they decided to call themselves "People First."

In October 1974, the first People First® Convention was held in Oregon. It was attended by 560 people.

Within five years, Oregon People First® had 1,000 members. People First® groups also began in Nebraska, Kansas, California, and Washington state. Self-advocates from 42 other states were seeking help in starting their own groups. The first international self-advocacy conference was held in Tacoma, Washington, in 1984. International conferences have since been held in London, England (1988); Toronto, Canada (1993); Anchorage, Alaska (1998); and Northampton, England (2001).

CONCLUSION

As of 2004, there are People First® and self-advocacy groups in 43 countries with an estimated 17,000 members. It has been estimated that there are more than 800 self-advocacy chapters in the United States with a national organization called Self Advocates Becoming Empowered (SABE). Although not all self-advocacy groups choose to call themselves People First®, this group continues to be a dynamic and visible arm of the international self-advocacy movement.

—Pamela Block and
Tia Nelis

See also Advocacy; Citizenship and Civil Rights; Empowerment and Emancipation.

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PERL, OTTO (1882–1951)

Author and cofounder of the Self-Help Alliance of the Physically Handicapped

Otto Perl was a German author and cofounder of the Selbsthilfebund der Körperbehinderten (Self-Help Alliance of the Physically Handicapped) (1919–1931), the first emancipatory self-help organization representing the interests of the physically disabled in Germany, which was also called the "Otto Perl Alliance." He was born on October 19, 1882, the son of a small farmer, in the state of Saxony. With nine siblings, he grew up in rather simple rural circumstances.

From the age of 13, he suffered from a stiffening of joints. In 1898, he began an odyssey through German so-called invalid institutions and cripple homes. In 1919, he became part of a small circle of founders of the Self-Help Alliance for the Physically Handicapped in Berlin. From 1922 until 1924, he was acting deputy of this first organization to represent the interests of people with birth defects and physical disabilities in Germany. After completing his studies at the gymnasium in 1919, he studied philosophy and economics in Berlin. In 1926, he lived in his own room for the first time in his life, in an institute in Nürnberg, and published his book, *Krüppeltum und Gesellschaft im Wandel der Zeit* (*Crippledom and Society in Changing Times*). He fought against institutionalization and demanded the right for self-determination. However, he limited his demand for education and job training to the "mentally normal" but physically handicapped person, in contrast to the "mentally handicapped," and already in 1926, he showed a thinking that alarmingly coincided with the Nazi ideology for selective care.

In 1946, a year after the end of the National Socialist regime, he described himself as a victim of Nazi encroachments, yet in 1935, he had demanded the separation of the "mentally sound" and the "mentally degenerate" and unmistakably applauded the National Socialists for their measures to control hereditary biological problems. Otto Perl died on October 17, 1951, at the Kaiser-Friedrich-Siechenhaus (Kaiser-Friedrich-Institute for the Invalids) in Wittenberg.

—Petra Fuchs

See also Deinstitutionalization.

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PERSONAL ASSISTANCE AND DIRECT PAYMENT

Personal assistance services are the most critical services for individuals with disabilities and are often considered to be one of the individualized supports essential for community life. Personal assistance is defined as one person assisting another with the tasks that individuals would normally do for themselves if they did not have disabilities (Litvak, Zukas, and Brown 1991). Personal assistance services are founded upon principles of universal access; information access, including for children and youth; community access; empowerment; and opportunities for full lives (Racino and Litvak 1999). In the United States alone, personal assistance services affect the lives of more than 9.6 million citizens with disabilities.

The 1991 Resolution on Personal Assistance Services, passed at the International Personal Assistance Symposium, upholds the basic human and civil rights to full and equal participation in society called for in the Americans with Disabilities Act (1990) and the United Nations Universal Declaration on Human Rights. Personal assistance services "shall enable users to exercise their rights and to participate in every aspect of sociocultural life including, but not limited to home, school, work, cultural and spiritual activities, leisure, travel and political life" (Litvak and Kennedy 1991). The right to these services is part of what it means to be without discrimination based on color, race, creed, gender, religious background, income and social class, cultural or ethnic origin, geography, or sexual orientation (World Institute on Disability 1991).

Personal assistance services (PAS) are consumer-directed services (Heumann and Racino 1992; Flanagan and Green 1997), and their growth has indicated a need for development based on the individual and for models that take into account unserved or underserved groups or populations. These groups may include people who need technological assistance and those with mental retardation and physical disabilities, brain injuries, psychiatric disabilities, and other cognitive disabilities (Racino 1993, 1995a, 1995b), in addition to youth and those who belong to cultural and ethnic minorities (Egley 1994). Adaptations may vary substantially by disability field, in part due to the organization and funding of services in countries such as the United States. Leaders internationally in PAS by field include Boston University's Center for Psychiatric Rehabilitation and Judi Chamberlin, as well as consumers such as Lori Stewart, one of the independent living leaders who is a psychiatric survivor. Personal perspectives were shared internationally through the 1991 symposium (Weissman, Kennedy, and Litvak 1991).

Critical aspects of personal assistance services are that it must be available up to 24 hours a day, 7 days per week, to people of all ages, and with access to governmental payments (independent of marital status and not as a disincentive to employment). In addition, selection of personal assistants must be the choice of the service user and include family members (World Institute on Disability 1991). Agency models of assistance, while supported, are more expensive and offer far less user control of services. More than 30 specific services have been surveyed in the United States, including personal, household, cognitive, transportation, and short-term (respite, emergency) services (Egley 1994), and they have been reviewed in the context of specific population groups (e.g., on issues such as involuntary care). Models of assistance include work site support (e.g., supported employment and worker-directed PAS) and have been approached through the individual life course theory (Kasnitz 1993), among others (e.g., Beach Center on Families, University of Kansas, lifespan theory, consumer empowerment theory).

Personal assistance services have been studied and investigated over the past decade, including through a congressionally funded U.S. Center on Personal Assistance Services, based at the World Institute on Disability. Original nationwide work in the field was conducted by Simi Litvak, Hale Zukas, and Judith Heumann (1987) in the report *Attending to America,* based on the independent living paradigm developed by Gerald DeJong, a supporter of personal assistance in long-term care (DeJong, Batavia, and McKnew 1992). The centers also developed from their international roots (e.g., Judith Snow and circles of support [Canada]) with national support, such as the Consortium of Citizens with Disabilities (e.g., Marty Ford of the Arc), state-level field models in severe disabilities (O'Brien 1992), the aging and university communities (Heumann and Racino 1992), and local/ state independent leaders throughout the United States.

New models of youth personal assistance services include peer-to-peer support; self-determination; career development; in-school support; youth lifestyles, including dating; and social relationship facilitation, if desired. Program models of PAS for independent living have been identified as varying based on the degree of consumer choice, often involving variations of state administration in relationship to the service user (Egley 1994). Among other findings (e.g., costs of PAS), "available data have indicated that different models do tend to serve different population groups, but offer no evidence that models and populations are closely or inherently linked" (Egley 1994:18). Major systems concerns in the United States revolve around systems coordination, eligibility, access, service limitations, assessment, workforce, liability, service quality, and long-term services coordination.

Through the past decades, PAS leaders have reviewed the development of the diverse fields (e.g., community integration, supported housing and living) and led national policy at the level of their relationships with organizations such as the National Council on Disability. Margaret Nosek, at ILRU-Texas at the Baylor College of Medicine, has assessed independent living programs on the basis of program age, consumer control, and budget; framed PAS in the community integration context (Nosek and Howland 1993); and supported U.S. and worldwide PAS development at the public policy levels (e.g., Nosek 1991). Leaders such as Ed Roberts have provided the inspiration for the continued development from the independent living movement's early roots.

Direct payments to service users have been the theme of funding in the field of independent living (Brown 1993), while other fields have pursued cash subsidies as part of service packages (Bradley, Knoll, and Agosta 1992 [family support services]) and explored the options of direct payments (Ridley and Jones 2003 [mental health]). In addition, major efforts nationwide in the United States have been placed on modifying public sources of funding for Medicaid, especially for community services (Doty, Kasper, and Litvak 1996; Racino 2000a, 2000b). In the field of mental retardation and developmental disabilities, individualized funding tied to the person has been the major focus in reform for the past several decades (see also Racino 2000a, 2000b; Lord and Hutchinson 2003). In the United Kingdom, direct payments to people with disabilities to purchase their own support services were attributed to importation from the United States and Canada (Maglajlic, Brandon, and Given 2000).

Debates by the late 1990s moved on the services front to privatization in the context of supporting the individual person (vouchers, grants, and service choice; Glover 1999) and less so to the family-user-government relationships. By 2000, the first international conference on individualized funding and self-determination was held in Seattle, Washington, and the Internet hosted sites worldwide on the topic (e.g., European Network on Independent Living, Centre on Human Policy, Syracuse University, Instituto Universitario de Integración en la Comunidad in Spain, the Australian Society Association for the Study of Intellectual Disabilities, Community Living Society of Canada, and Hester Adrian Research Centre in the United Kingdom).

International models of personal assistance services, which were also presented in 1991 at the International PAS Symposium, include housing and personal assistance services in Sweden (Tucker and Kleinman 1990), especially the Stockholm Cooperative Model for Independent Living (Ratzka 1991). Service brokerage with a component of individualized funding began in Canada (Salisbury, Dickey, and Crawford 1987), which has strong proponents for individualized funding and support approaches and links easily with the United States and United Kingdom (Centre for Research and Education in Human Services 1993). Independent living has been pursued in diverse parts of the world, from Japan and South Africa to Norway and New Zealand, and these roots are critical for the future development of PAS.

Today, the support and empowerment paradigm has influenced the development of PAS, including "model variation" based on community membership, person-centered and support approaches, the continued expansion to and from other population groups (e.g., HIV-AIDS), systems reform of state-federal-local financing, and diverse contexts such as those of abuse and rights abridgements. Personal assistance services, with its roots in the independent living movement, has reached new generations and holds a promise beyond its beginnings for personal and community futures in the years yet to come.

—Julie Ann Racino

See also Advocacy; Assistive Technology; Decision Making; Empowerment and Emancipation.

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PERSONAL CARE ATTENDANTS

Personal care attendants (PCAs), also referred to as personal assistants, are individuals who provide help to people who have difficulty performing, or are completely unable to perform, daily living activities by themselves due to a disabling condition or injury. Until recently, the use of PCAs was associated with only the most severely physically disabled population (e.g., people with paraplegia or quadriplegia). However, PCAs are increasingly employed to assist other populations who require extensive supervision or help with daily living activities, such as people with cognitive impairment and frail elderly individuals who are at risk for nursing home placement.

While historically, the majority of PCAs were untrained independent direct care providers, a rising demand for workers who provide assistance services has led to the development of training programs by community colleges and other organizations that certify paraprofessionals in the health care field. The duration of such programs may be from several weeks to several months. In many programs, the titles *PCA* and *certified nursing assistant* (CNA) are synonymous. Like CNAs, PCAs are hired by home health agencies and nursing homes, although many certified PCAs retain independent status.

PCAs are central to the "personal assistance service (PAS)" model of providing help to people with disabilities in the home setting, a mainstay of the independent living movement. The PAS model is in contrast to the home health agency-based model of home care delivery historically associated with the aging service system.

The PAS and agency-based models represent different and incompatible philosophies of service delivery. Proponents of PAS view home health agency-based workers to be part of the medical model of service delivery, in which health care providers define, direct, and deliver services to the individual. Agency supervisors hire, train, pay, and, if necessary, fire the home health aide or homemaker who is the direct provider of care. Under the medical model, the service recipient assumes the passive role of patient, with little input into the nature of services provided and little control over the direct provider of care. Activists and supporters of the independent living movement argue that the medical model entails the sacrifice of personal control as a condition of service receipt. Thus, this model is perceived to foster dependency, which is antithetical to the concepts of empowerment and independence—major goals of the independent living movement.

In contrast, control resides with the service recipient, termed *consumer* or *client,* in the PAS model of service delivery. Under this consumer-centered model, the person with disability interviews, hires, trains, manages, and, if necessary, fires the direct provider of services, generally a PCA. While the title "personal care attendant" is still widely used, members of the independent living movement and its broader counterpart, the disability rights movement, perceive the word *care* to hold connotations that are more appropriate to a medical model approach. *Personal assistant,* on the other hand, conveys a broader role that encompasses assisting consumers to meet work-related and social needs.

The duties of the PCA, or personal assistant, in the PAS model are defined by the consumer in accordance with his or her needs. Payment is either out of pocket or from third-party payers to the consumer who, in turn, pays the assistant, thus reinforcing that accountability is to the consumer in a clearly defined employer-employee relationship.

In general, two features of the PAS model increase the likelihood that service recipients will have their needs met over the more traditional agency-based model. First, the job of the PCA is defined by the consumer, not an agency, and redefined according to the consumer's changing needs. Control over job description such that the highly specific needs of the individual are met empowers the person with disability to participate in life's activities to a far greater extent than the more limited agency-based model, in which tasks performed by the PCA are fixed and typically confined to the client's home.

A second beneficial feature of the PAS model is the additional amount of coverage allowed by the organizational structure of the program. The elimination of administrative overhead associated with agency-directed services results in cost savings that can then be used to purchase additional hours of PCA service delivery.

The majority of third-party funding for PCAs is through states' Medicaid personal care optional benefit. Currently, only 28 states have this option available, although recent emphasis on community care for people with disabilities has heightened interest in expanding the Medicaid personal care option. An obstacle to expansion of this option is concern regarding the feasibility and desirability of the PAS model for elderly persons with disabilities. Advocates argue that the principles of autonomy, control, and independence are appropriate for older as well as younger individuals who need help with tasks essential to everyday life. Furthermore, an alliance of the two constituencies could greatly enhance opportunities for political action in securing the expansion of long-term community-based services in a manner that maximizes the potential for community rather than institutional living, as well as participation in the mainstream of community life.

For some elderly people who need extensive help, PCAs are a feasible and not prohibitively expensive alternative to nursing home placement. However, there is no doubt that some elderly people lack enthusiasm for the personal assistance model, generally because of discomfort with assuming the role of employer or supervisor. In response to this discomfort, many independent living centers offer training to people with disabilities on how to manage their PCA.

Other concerns that have served to impede widespread use of PCAs are fears of client safety, exploitation, and even abuse. Such fears stem from the fact that independent PCAs often lack the training that agency-based workers are required to receive as a term of their employment. In addition, attendants are often hired in response to newspaper ads placed by clients and consequently are not subject to background checks. Despite these potential drawbacks, several large-scale studies comparing the personal assistance model to the agency-based model have found no difference in the instances of abuse, exploitation, or adverse consequences associated with lack of training reported by consumers of the two models of service delivery. In fact, several studies conducted to date have concluded that clients of PAS are more satisfied with care arrangements than are clients of agency-based services.

Another unique feature of the PAS model of care, as offered under the Medicaid personal care option by a number of states, is that family members of the person who requires help are eligible to serve as PCAs. Studies have shown that people with disabilities who employ family members as their personal assistants are most satisfied with the quality of the job performed. This finding has allayed fears among Medicaid program administrators that family members will take advantage of a personal care benefit, by receiving payment for a service they would have performed anyway. Research has shown, however, that payment to family members enables them to stay out of the workforce, assisting their loved ones in performing daily tasks while still earning much-needed income.

Other labor issues associated with the PCA position include low pay and few or no benefits. However, a survey of Medicaid PAS programs conducted by the World Institute on Disability in the 1980s revealed substantial variation in wages and benefits offered to attendants, with independent PCAs in some states earning more than agency-based workers in other states.

With the aging of the population and increase in life expectancy for people with disabilities, it is likely that the demand for PCA services will increase in the near future, particularly by frail elderly people who desire to "age in place" despite disability. As this profession evolves, it is likely that associated wages and benefits will improve, as will its stature in the health care field. An adequate supply of PCAs will be essential to fuel current trends toward the development of home-based alternatives to nursing home care.

—Susan M. Allen

See also Caregiving; Personal Assistance and Direct Payment.

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PHANTOM LIMB PAIN

The term *phantom limb* has been used since the 1870s largely to describe the experience of pain and other sensations from a limb that has been removed, although it has also been applied to sensations seemingly coming from dead tissue. American Civil War surgeon and physiologist Silas Weir Mitchell coined the term after working with amputees in Philadelphia but was not the first person to write about the phenomenon. Early descriptions of phantom limbs appear in the works of Ambroise Paré (mid-1500s), René Descartes (mid-1600s), Charles Bell (early 1800s), and many others. The historical literature even reveals a self-description of a phantom limb by William Porterfield, a highly regarded Scottish physician who described his illusory sensations in 1759.

Different people living at different times had different motives for writing about this disorder. For Paré, a Renaissance barber-surgeon, the important thing was not to be fooled by "false" sensations. His fear was that sensations from dead tissue might dissuade well-meaning surgeons from performing life-saving amputations on riddled, gangrenous limbs. For Descartes, the great French philosopher, phantoms were used to argue that sensory information can be grossly misinterpreted and that the human soul receives information from the brain. Bell, in contrast, used phantom sensations of limbs in various positions to support a sixth sense, his muscle or proprioceptive sense. From his studies of sensation and movement, he became convinced that the brain not only sends messages to the muscles but also must receive feedback from those muscles to manipulate the limbs effectively.

As for Silas Weir Mitchell, he was both a surgeon and a humanist. He viewed phantoms an all-too-common horror of war that demanded compassion from the public and considerably greater understanding by the medical community. He even presented a fictional case involving a wounded medical officer in a popular magazine, hoping that "George Dedlow's" plight would move people to take the mental consequences of amputation more seriously.

Much was learned about phantom phenomena even before the twentieth century, including the fact that phantoms can follow amputations of more than just limbs. Descriptions of phantom breasts and even penises can be found in the early literature. So can recognition of the fact that phantoms can be brought on by loud noises, changes in the weather, emotional turmoil, and physical (including electrical) stimulation of the nerve trunk. Perceived changes in the size and position of a missing part have also been studied, as has the time-since-amputation factor.

The literature on phantom limbs now encompasses hundreds of papers and many books. These writings describe a multitude of treatments that have been tried, often with only temporary success. They include nerve resection, cauterization, narcotics, anesthetics, nerve blocks, acupuncture, and more radical amputations. Like Paré, Descartes, Bell, and Mitchell, people today are still trying to understand the relative contributions of signals from remaining nerve stumps, the roles of associative learning and memory, and the actions of the creative brain in this perplexing disorder. The hope is that, with more knowledge, there will be more effective treatments.

—Stanley Finger

See also Amputation; Pain.

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PHYSICAL ACTIVITY

An important aspect in improving the health of people with disabilities is to encourage higher levels of physical activity. Not only is physical activity important from the standpoint of promoting a higher quality of life by reducing secondary conditions and maintaining functional independence, but it is also essential in terms of reducing health care expenditures. Several reports have noted that a sedentary lifestyle can precipitate functional decline in people with disabilities and that physical activity must be a targeted health priority to prevent a progressive loss in health and function.

TERMINOLOGY IN PHYSICAL ACTIVITY

Physical activity involves all forms of bodily movement produced by contraction of skeletal muscle that substantially increases energy expenditure. Subcategories of physical activity include leisure-time physical activity (LTPA), which is a broad descriptor of the activities one participates in during free time, based on personal interests and needs. A structured form of physical activity is generally referred to as *exercise*, which is different from other forms of physical activity by its well-planned, structured, and consistent body movements and repetitions. Other kinds of physical activity include work-related activity or household activity. Gardening, cleaning, and working in physically demanding jobs (e.g., construction, janitorial) are all considered forms of physical activity. Among people who have a disability or are injured, therapy or rehabilitative exercise could also be considered a form of physical activity.

Physical Fitness. Physical fitness is defined as a set of attributes that people have or achieve that relates to the ability to perform physical activity. Components of physical fitness include cardiorespiratory endurance, muscular strength and endurance, flexibility, body composition (ratio of lean muscle mass to body fat), balance, and respiratory function. Certain individuals with disabilities will require a greater amount of each component depending on the various secondary conditions that may be associated with their disability. For example, persons with post–polio syndrome may require respiratory exercises to maintain the strength of the pulmonary musculature. Individuals with multiple sclerosis often have difficulty with gait and balance and would benefit from an exercise training program that targeted these areas.

Exercise. This is a subset of physical activity that is planned, structured, and consists of repetitive bodily movement that is done to improve or maintain one or more components of physical fitness. Examples of structured exercise that people with disabilities often participate in are chair aerobics, swimming, and handcycling, among others.

Moderate-Intensity Physical Activity. This term is used in the *Healthy People 2010* document to describe any type of physical activity requiring three to six times the energy required at rest. Since the definition has been developed for young individuals without disabilities, it is not clear if a "moderate" level of physical activity would be different for persons with disabilities.

Vigorous Physical Activity. This term is also used in the *Healthy People 2010* document to express any physical activity requiring seven times the energy required at rest. Similar to the definition for moderate intensity physical activity, this definition has been established for younger populations without disability.

Many activities that people with disabilities perform require a higher level of energy expenditure (i.e., transfers, walking with crutches or pushing a wheelchair, carrying various items). It is possible that moderate or vigorous physical activity has a different connotation for people with disabilities and does not fall in the same range that describes these activities for the general population. For example, carrying a bag of groceries from the store to the car may be considered a "moderate" activity for the general population but a "vigorous" activity for someone with reduced gait efficiency. More research is needed to evaluate the intensity level of various instrumental activities of daily living and general physical activities in persons with various types of physical, cognitive, and sensory disabilities.

PUBLIC HEALTH INITIATIVE IN PHYSICAL ACTIVITY

As a result of several landmark studies that have shown a graded, inverse relationship between physical activity/fitness and the incidence of morbidity and mortality, public health officials and federal agencies are recommending that all Americans, including persons with disabilities, engage in a minimum of 30 minutes a day of moderate aerobic exercise. The American Heart Association, National Institutes of Health, Centers for Disease Control and Prevention, Surgeon General's Office, and the American College of Sports Medicine have all developed position statements that call for Americans to achieve a higher level of physical activity. One of the historic documents published by the Surgeon General's Office in 1996 was a report titled *The Surgeon General's Report on Physical Activity and Health.* This report emphasized that physical inactivity is a major contributor to heart disease, adult onset diabetes, and colon cancer and that the risk from inactivity is similar to that of smoking. Today, physical activity has been recognized by numerous public health organizations as an important vehicle for improving the health of the U.S. population.

Despite strong endorsements from the Centers for Disease Control and Prevention (CDC), National Institutes of Health, Surgeon General's Office, and American College of Sports Medicine, most Americans are still not obtaining the recommended amount of physical activity that is necessary for maintaining health, and the level of physical inactivity among persons with disabilities is significantly higher than that of the general population. This represents a significant public health issue for people with disabilities.

OVERVIEW OF PHYSICAL ACTIVITY AND DISABILITY

For close to a half century, exercise has been promoted as one of the most powerful health promotion strategies for reducing chronic disease (i.e., heart disease, diabetes) and functional limitations. The first 25 years of research in exercise physiology contained only a handful of studies that investigated the effects of exercise on people with disabilities. Several of these studies were conducted on children with cerebral palsy and other neuromuscular disorders, primarily in Sweden and other Scandinavian countries. It was only until the mid-1980s that a growing number of researchers began to investigate the effects of exercise on people with disabilities in both children and adults.

The research literature on physical activity, exercise, and disability continues to expand. Exercise-related studies are being conducted to determine the effects of various interventions using cardiorespiratory, strength, flexibility, and balance training to enhance overall health and function. While there are numerous short-term studies demonstrating the positive effects of exercise on improving various health outcomes in people with disabilities, longitudinal studies are still lacking.

Low Physical Activity Participation among People with Disabilities

Federal officials and members of the public health community are growing increasingly concerned that as persons with disabilities age, they will have increasing difficulty performing activities of daily living (ADL) (i.e., dressing, showering) and instrumental activities of daily living (IADL) (i.e., ambulation, doing laundry, grocery shopping) at a much earlier rate than the general population. Persons with physical disabilities are often faced with various environmental challenges (i.e., navigating ramps and curb cuts, performing transfers) as a result of their impairment (i.e., paralysis) and/or associated secondary conditions (i.e., spasticity, weakness, pain, fatigue). The high incidence of physical inactivity observed in persons with disabilities, combined with the natural aging process, presents a greater risk of premature physical decline and accentuates the importance of physical activity in maintaining health and function.

Despite calls for higher levels of physical activity from major federal and private agencies, the vast majority of persons with disabilities are not obtaining the recommended 30 minutes a day of physical activity necessary for conferring health benefits and preventing or mitigating secondary conditions. Several reports have noted that people with disabilities have a disproportionately higher incidence of physical inactivity compared to people without disabilities. The *Healthy People 2010* document reported the prevalence of physical inactivity among people with disabilities to be substantially higher than in people without disabilities, 56 percent versus 36 percent. And in data collected at the National Center on Physical Activity and Disability (NCPAD), very low levels of physical activity were reported among various subgroups of disability. As noted in Figure 1, individuals with stroke, type 2 diabetes, and arthritis were significantly below the recommended 30 minutes a day of moderate exercise recommended by the CDC and other federal agencies.

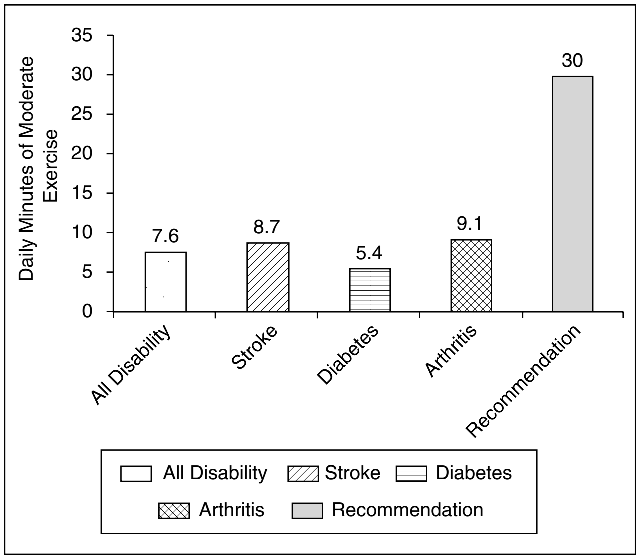

Figure 1 Daily Physical Activity Reported by People with Disabilities

Source: Data from the National Center on Physical Activity and Disability (www.ncpad.org).

Physical Activity and Reduction of Secondary Conditions

Numerous laboratory and field-based studies have quantified the many health and fitness benefits associated with physical activity. Among studies with disabled populations, benefits of endurance and strength training include reduced fatigue, reduced pain, improved fitness, and general well-being. Implicit in these reports is the notion that the health and fitness benefits associated with physical activity most likely follow a dose-response relationship. Most experts agree that any amount of physical activity is beneficial and that even minimal amounts of physical activity are better than no physical activity at all, and increasing amounts of physical activity accrue greater health benefits provided it is done safely. Vigorous physical activity performed in excess amounts (usually greater than one hour) increases the risk of injury. Physical activity must be conducted in a manner that allows maximum benefits at the lowest possible risk. Given the progressive nature of certain disabilities (i.e., multiple sclerosis) or physiological changes that occur after injury (i.e., spinal cord injury), greater attention must be provided by exercise specialists to ensure that the program is safe and effective in enhancing overall health. Shoulder injuries are common in chair users and have prompted researchers to develop alternative ways to exercise that will reduce the stress on joints and muscles that are used for ambulation.

Physical Activity, Functional Status, and Disability

Given the empirical evidence linking physical activity with functional status and overall health, as well as the fact that impaired health and functioning can impede participation in physical activity, one can postulate a downward cyclical pattern in both health and functioning that results from prolonged physical inactivity. The onset of disability often results in greater effort required to engage in physical activity, thereby causing persons with disabilities to remain sedentary. Physical inactivity over prolonged periods results in the development of secondary disabling conditions and further functional loss, which in turn results in greater effort to participate in physical activities.

The relationship between physical functioning and physical activity is a reciprocal one; physical functioning provides the individual with the capability to engage in physical activities, whereas physical activity helps to maintain and, in some cases, improve physical functioning. This reciprocal relationship, coupled with the high prevalence of physical inactivity among persons with disabilities, has profound implications for rehabilitation practice, especially in evaluating intermediate and long-term outcomes of clinical practice. For rehabilitation to play a role in the long-term maintenance and enhancement of physical functioning among persons with disabilities, monitoring of physical activity by both rehabilitation professionals and individuals with disabilities must be part of the recovery and maintenance process. The development of a standardized tool for assessing physical activity levels of people with physical disabilities can serve the purpose of monitoring physical activity patterns at both the individual (clinical application) and population levels (public health surveillance level).

Barriers to Physical Activity Experienced by People with Disabilities

Despite the plethora of evidence supporting the benefits of regular physical activity for improving health and function, people with disabilities are not engaging in physically active lifestyles at the same level as their peers. This may be due, in part, to the many environmental barriers to physical activity that people with disabilities are often confronted with, including inaccessible equipment and programs, transportation difficulties, limited income, unsafe neighborhoods, and a variety of personal barriers such as chronic health conditions and beliefs that exercise will not benefit their health.

Accessibility of fitness and recreation programs and facilities is a critical issue affecting the participation of persons with disabilities in fitness and leisure activities and ultimately affects their ability to improve their health and quality of life. A common barrier in the disabled population is the lack of attention given in promotional campaigns to the needs of persons with disabilities. Public health messages encouraging people to become more physically active usually recommend walking a minimum of 30 minutes a day most days of the week. Unfortunately, this recommendation is unattainable by many people with disabilities and chronic health conditions who are unable to walk (i.e., spinal cord injury, multiple sclerosis), have difficulty walking (i.e., back pain, obesity, heart condition, arthritis, frailty), live in neighborhoods where it is unsafe to walk, or are not allowed to walk without supervision. Campaigns to increase physical activity must present a more inclusive image by providing people with disabilities greater opportunities to improve their health besides walking. For this to occur, personal and environmental barriers must be eliminated so that access to various types of physical activity can be engaged in by a significant percentage of the disabled population.

Resource on Physical Activity and Disability: NCPAD

Through a grant from the CDC and the National Center on Birth Defects and Developmental Disabilities, the National Center on Physical Activity and Disability (referred to as NCPAD) was established in 1999. This information and resource center offers people with disabilities, caregivers, and professionals the latest information on fitness, recreation, and sports programs for people with disabilities. NCPAD's aim is to collect and synthesize various types of information on physical activity, rehabilitation, and disability and to disseminate this information to fitness and health professionals. With advances in technology, the NCPAD website at http://www.ncpad.org contains various types of readily accessible information on exercise and disability. The center also publishes a monthly electronic newsletter and sends out monthly features via e-mail on new topics and information related to physical activity and disability.

SUMMARY

The evidence concerning the benefits of physical activity is compelling. Among people in the general population, participation in habitual physical activity extends life, prevents multiple chronic conditions, and has beneficial effects on many systems of the body. Physical activity epidemiologists have noted that approximately 250,000 deaths in the United States annually can be attributed to a sedentary lifestyle. It is considered one of the leading preventable causes of death in our society.

It is unfortunate that most, if not all, of the physical activity longitudinal research has been conducted on nondisabled populations. While there is good evidence from short-term clinical studies demonstrating the benefits of physical activity among various subgroups of disabled populations, there is a dearth of longitudinal data on the long-term effects of physical activity in this cohort. Future longitudinal studies must be conducted on various subgroups of individuals with disabilities to determine the magnitude of health benefits that might be accrued from a physically active lifestyle.

—James H. Rimmer

See also Activities of Daily Living; Exercise and Physical Activity; International Classification of Functioning, Disability, and Health (ICF/ICIDH); Recreation; Sports and Disability.

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PHYSICAL MEDICINE AND REHABILITATION

Until the beginning of the twentieth century, people with disabilities were generally scorned, pitied, demeaned, and, in some societies, killed. As recently as the 1950s, they were "imprisoned" without trial in places such as "The Home for the Incurables" and custodial facilities. Even when kept at home, they were often isolated and "hidden" from outsiders. Still, "custodial care" too often is considered first, before placement at home.

There were isolated instances of medical people who showed an interest in "cripples," but they were rare. In general, medical students and others were taught that it would be uninteresting and demeaning, if not futile, to be involved in the care of such people (as well as the elderly and chronically ill).

The main thrust toward the organized care of people with disabilities came because of (1) the great drama of polio, a sudden event (paralyzing and sometimes fatal) affecting a president, Franklin D. Roosevelt, and very frequently children, and (2) World Wars I and II. In both instances, the nation decided that care must be given and that there should be an attempt to reintegrate people with disabilities into the community.

This idea of allowing people with disabilities to participate and contribute in the community was not entirely original at that time. At the beginning of the twentieth century, bureaucracies were intended to facilitate employment of people with disabilities, especially if they had been in the military.

In most wars, relatively few numbers of disabled people had returned home; however, with the discovery of antibiotics and better trauma care, more veterans of World War II survived, and there was a national outcry that these people, these heroes, should not be "discarded."

In military hospitals, some physicians took it upon themselves to develop a system to help these veterans (largely men). It was soon discovered that it would be necessary to deal with issues of functional loss and frequently with overwhelming psychological and sociological issues. Social work, nursing, and other allied health personnel were found to be necessary in carrying out this work as a collaborative effort.

A solo physician could not address these needs alone, so "collaborative medicine" practices were developed to unite the physician with a team of medical consultants as well as nurses, physical therapists, social workers, speech pathologists, occupational therapists, vocational counselors, and various technicians. The approach had to be nonautocratic and non–male chauvinistic.

At the same time, the Veterans Administration (VA) system was developed, and most of its 172 hospitals included this potential for a rehabilitation system.

In the meantime, celebrity status was given to polio, especially because of the effect it had on Franklin D. Roosevelt, and huge amounts of money were raised as a bulwark for a national effort to provide care for this population.

These movements required physicians able to practice physical medicine and rehabilitation (PM&R), so the demand grew.

At about this time, a philanthropic couple in New York, Mary and Albert Lasker, became very interested in health. At some point, Albert Lasker decided that although he and his wife could contribute large sums of money to worthy causes, they could multiply this amount hundreds of times by "lobbying" in Washington, D.C., to get the government more involved in health.

Their main contribution to society was providing the impetus for the formation of the National Institutes of Health. They discovered that in Washington, D.C., there was a small agency headed by Mary Switzer that attended to some aspects of people with disabilities, especially vocation. Switzer was an intelligent, charming, and convincing woman with New England force and directness blended with Irish charm.

The Laskers also discovered an extraordinarily capable and charismatic man, Dr. Howard Rusk, who had built a rehabilitation center in New York at the NYU Bellevue Medical Center on 34th Street. He was an internist but had helped invent the techniques of PM&R and promulgated its principles. He had built the rehabilitation center at Jefferson Barrack Hospital in Missouri during the war. Dr. Rusk and Switzer, united by the Laskers, mesmerized the Congress and generated millions of dollars for Switzer's agency.

Mary Switzer's agency developed a mandate to deal with disability very broadly—educating a whole nation about people with disabilities. At that time, few hospitals or medical schools had shown much interest in people with disabilities, but their interest was piqued when money appeared on the horizon. Not only did Ms. Switzer supply funds for programs to train residents in the specialty of PM&R (physiatrists), but she also offered funding for stipends for medical students to train. Training residents made it possible to send physiatrists where there were few or none, and good and early care could be made available. Even now in the United States, if someone becomes disabled, he or she may go to the person considered the best doctor in town and find that the doctor has never seen a similar case and has no knowledge of rehabilitation. Switzer's impact on medical students started with her mandatory summer fellowship. Eventually, mandatory rehabilitation rotations were added for students in medical school.

Switzer also established regional research and training centers, which became very important, and some eventually evolved into centers for spinal cord injury and stroke. In each of these instances, a grant went to a comprehensive center and gave it status along with the obligation to have links to other states and to spread knowledge about aspects of disability beyond the original centers.

All of this made PM&R much more visible—to the medical and lay communities. Progress has been slow in coming, however, partly because physiatrists have not made an effort to explain who they are, what they do, and what their background and education are. Many physiatrists will not even use the word *physiatrist* but will simply say they care for the disabled. This does little to spread the word about the field of PM&R.

EARLY EFFORTS IN REHABILITATION MEDICINE

The first major thrust toward thinking about bringing people with disabilities into the mainstream of society was accomplished by Jeremiah Milbank, a wealthy 30-year-old New York lawyer who had been interested in helping the "crippled beggars" in the streets of New York. He allied his thinking with ideas from Germany, Canada, and France. Even before World War I, he had joined a few pioneering thinkers who were pushing to create self-sufficiency. They decided to create a rehabilitation facility in New York: the Red Cross Institute for Crippled Soldiers and Sailors. (It opened just after the war began.)

At the same time, the Army Surgeon General was encouraging growth of allied health assistance. Soon before World War I began, the American Occupational Therapy Association was formed. Milbank developed a program to educate the country about the potential of people with disabilities by providing medical/vocational assistance, training professionals, publishing literature, and establishing media contacts.

In about 1920, the state of Ohio created an organization to work with crippled children, and the Shriners opened hospitals for the care of these children.

Simultaneously, care providers saw a growing alliance in care among medical, surgical, and vocational/psychological/sociological health care providers, which set the stage for progression toward the collaborative approach of physiatry. Nonetheless, by 1920, there were few people in the field of rehabilitation.

Physical therapy began to develop and became recognized by physicians as vital to their team. In 1926, Dr. John Stanley Coulter pioneered PM&R in the United States and became assistant professor of physical therapy at Northwestern University Medical School.

In 1928, President Hoover established a "Children's Charter" highlighting the need to attend to the needs of crippled children.

In 1929, Dr. Frank Krusen established a Department of Physical Medicine and Rehabilitation at Temple University. He then joined the Mayo Clinic in 1935, organizing and directing the Mayo Clinic Graduate School of Medicine's first three-year fellowship in physical medicine.

In 1935, Dr. Henry Kessler wrote about the absolute necessity of the development of the rehabilitation movement around a comprehensive medical, sociological, psychological, and vocational model. He built a center in New Jersey and published eloquent reports and papers.

Dr. Kessler objected to the Workmen's Compensation Program, which made it more profitable to neglect the disabled than to restore them to activity and productivity.

In 1936, the American Academy of Physical Medicine & Rehabilitation was founded, and Dr. Krusen was elected as its first president. He wrote definitive texts, and his trainees were the first doctors trained to care for the disabled.

In 1942, Dr. Howard Rusk started the Army/Air Force Convalescent Center at Jefferson Barrack Hospital in Missouri. The plan was that "convalescent time" could be "rehabilitation time." In New York, Dr. Rusk learned how to proceed from the Milbank Institute for the Crippled and Disabled and was able to broaden physical medicine in his burgeoning "convalescent program." In the meantime, Dr. Krusen was a consultant in PM&R to the U.S. Army. He also continued to stress the need of education in PM&R.

In the war years, Bernard Baruch established the Baruch Committee on PM&R. He laid the groundwork for a great expansion in rehabilitation. Mr. Baruch gave grants for educating individuals and established major centers in research and patient care at Columbia, the Medical College of Virginia, and NYU. Concomitantly, the number of occupational therapists and physical therapists continued to grow and receive acceptance as key personnel in military hospitals.

The collaborative approach was even more firmly demonstrated through the founding of spinal cord injury centers at Hines VA (Illinois), the Bronx (New York), and Van Nuys (California). Dr. Paul Magnuson, who became the second medical director of the VA system, was first in charge of education and research and then headed the Dean's Committee System, which linked VA hospitals to academic centers. He later founded the Rehabilitation Institute of Chicago.

In 1947, the denouement in officially recognizing PM&R occurred with the approval of the American Board of Physical Medicine & Rehabilitation by the American Medical Association (AMA). The first three certificates of specialization went to Dr. John Coulter, Dr. Walter Zeiter, and Dr. Frank Krusen.

THE PM&R FIELD TODAY

The vision statement for the Academy of Physical Medicine & Rehabilitation, the major professional organization for physiatrists, is as follows:

> The American Academy of Physical Medicine and Rehabilitation will be the leader in assisting PM&R physicians to acquire the continuing education, practice knowledge, leadership skills, and research information needed to provide quality patient care, and to represent the best interests of patients with, or at risk for, temporary or permanent disabilities.

The distinction of the field of PM&R lies today in its ability to deal with the technical issues involved in diagnosing and treating disabilities/functional loss in ways that can in great breadth affect the quality of life of the individual patient. The training of physiatrists gives them a unique ability to unite in consideration of the basic pathology, the psychology of the patient, the social environment and the effects of existing attitudes allied to the patient, and what might appear to be a "new identity."

They have particular skill in bringing together all the facts at hand and being able to turn to members of the coalition who are best equipped to explain and deal with these matters. It is understood that there must be a sense of equality among members of the team and universal, mutual respect for the talents of all involved. Citizens in the United States are well aware of the need for "coordination" in health care and certainly in the case of people with disabilities; good care cannot be given without such talent available. In all health care, these premises are valid.

> Life is short, the art long, occasion sudden, experience fallible and judgement difficult. Not only must the physician show himself prepared to do what is needed, he must make the patients and attendants and the surrounding circumstances cooperate with him. (Hippocrates, 1st Aphorism)

—Henry B. Betts

See also Decision Making; Professions; Rehabilitation Medicine, International.

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▣ PHYSICAL THERAPY

Physical therapy is a health profession serving persons of any age or health status with compromised physical functioning or the desire to improve their current physical functioning. Typical clients are persons with compromised quality of life as a result of impairments, functional limitations, and disabilities caused by disease or injury. Physical therapists complete an examination of the individual and work with the person to determine goals that are reached primarily through exercise prescription and functional training to improve movement. A key component of patient management is education to promote physical health and to prevent injury and disability caused by abnormal posture and movement. Other problems such as pain may be addressed with treatments, including mobilization of soft tissues and joints, electrotherapy, and other physical agents.

Although the use of exercise as part of a healthy lifestyle is ancient in its origins, modern physical therapy developed in response to the needs of injured soldiers. The first physical therapists in the United States were trained to work with soldiers returning from World War I and were called "reconstruction aides." Some worked in hospitals close to the battlefields in France to begin early rehabilitation of wounded soldiers. Typical patients were those with amputated limbs, head injuries, and spinal cord injuries. As the field developed in the early part of the twentieth century, physical therapists also attended to the movement needs of those affected by polio epidemics. In this instance, strength was impaired by damage to cells that activate muscles to create movement. For these clients, physical therapists developed programs to strengthen muscles when possible and helped patients learn how to use the remaining musculature to accomplish functional mobility activities.

Physical therapists now practice in a wide variety of settings, including private practices, hospitals, rehabilitation centers, nursing homes, public schools, and home health agencies. In all of these settings, therapists work with the other members of the health care team toward common functional patient goals. Typical clients are individuals with back pain, elderly persons with arthritis or balance problems, injured athletes, infants with developmental disabilities, and persons who have had severe burns, strokes, or spinal cord injuries. For all of these individuals, physical therapists are the experts in examining and treating musculoskeletal and neuromuscular problems that affect how people move and perform physical functions such as standing up, walking, and lifting. Persons whose endurance for movement is affected by heart or lung problems or other illnesses are also helped by exercise and education to build activity tolerance, improve muscle strength, and move efficiently during functional activities. Individuals with limb deficiencies are taught to use prosthetic replacement devices.

Examination of the individual begins with identifying the client's perceived problems with functional activities and his or her movement goals for reducing disability and improving quality of life. Adults with the types of impairments and functional limitations described above can be taught how to recover or improve movements impaired by disease and injury. On the other hand, infants born with developmental disabilities are helped to learn movements they have never done before, with an emphasis on functional mobility for satisfying participation in family and community activities.

New areas of practice are continually developing. For example, the scope of practice of a growing specialty in women's health includes concerns of women such as incontinence, pelvic/vaginal pain, prenatal and postpartum musculosketelal pain, osteoporosis, rehabilitation following breast surgery, lymphedema, and education for prevention, wellness, and exercise. All females across the lifespan, from the young athlete to the childbearing woman to the menopausal and elderly woman, can benefit from physical therapy.

In addition to working with individuals and their family members, many physical therapists have agencies or organizations as their clients. In the role of consultant, they perform services such as advising clients on preventing back injury in workers or designing workplace environments to prevent repetitive use injury. Physical therapists also teach in higher education institutions, specialize in areas such as the training of high-performance athletes, consult with public school teachers to educate children with disabilities, and provide consultation to fitness centers on developing workouts for clients who already know they have joint or back problems.

Physical therapists (also called physiotherapists) are at work in countries all over the world. The World Confederation for Physical Therapy is a nonprofit organization consisting of 82 national physical therapy associations. The confederation represents 225,000 physical therapists worldwide. In the United States, the American Physical Therapy Association represents 64,000 physical therapists and physical therapist assistants. The organization's mission is to further the profession's role in the prevention, diagnosis, and treatment of movement dysfunction and to enhance the physical health and functional abilities of the public.

The Commission on Accreditation in Physical Therapy Education accredits educational programs for physical therapists who are trained at the master's or doctoral level and for physical therapist assistants who complete a two-year associate's degree program. Physical therapy professional education involves grounding in basic sciences such as anatomy, physiology, and movement science followed by clinical science courses on the musculoskeletal, neuromuscular, cardiopulmonary, and integumentary systems. Education for the profession culminates in clinical fieldwork training involving internships of various lengths up to about a year. Although a graduate-level college degree and state licensure are required for practice in the United States, physical therapy education in many countries takes place in polytechnical institutions.

—Suzann K. Campbell

See also Activities of Daily Living (ADLs); Health Care and Disability; Occupational Therapy Physical Activity.

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PHYSICIAN-ASSISTED SUICIDE

Defining physician-assisted suicide might initially appear a straightforward task, as it is an expression that concatenates three terms, each of whose meanings are clear and uncomplicated. However, even the most basic etymological exploration reveals a concept that sustains an inherent contradiction that is only the beginning of the problematization of what remains likely the single most critical issue in biomedical ethics. Said contradiction lies between the notions of "suicide," the killing of oneself, and "assistance," the implication of another in that killing, which by definition renders the assistant an agent and, at times, depending on the circumstances of that killing, even the sole agent in homicide, which may or may not be regarded as justifiable. In the simplest and most literal terms, then, *assistance* and *suicide* combine as—or at least approximate—an oxymoron, although one whose practice, whether legal or illegal, is far from unknown. Furthermore, moving only slightly beyond the most basic sort of definition, physicians are universally known to be admonished to "do no harm," a responsibility that is necessarily, at the very least, difficult to reconcile with deliberately putting a "patient" to death.

A major complication in defining physician-assisted suicide is that it is frequently conflated and even regarded as being synonymous with euthanasia or "mercy killing." The terms are (obviously) not (entirely) synonymous. The former assumes as an absolute given the agency of a medical doctor. The latter does not, and this has often been borne out in practice. While it is customary to presume that both terms assume the consent and even the explicit request of the person who is killed, there is neither anything inherent in the notion of euthanasia to safeguard that presumption, nor in the case of either term is it possible to arrive at an unproblematic definition of consent given the abject vulnerability of a person whose circumstances lead to an intentional death being contemplated.

In practice, those seeking assistance in suicide typically do so either because their physical impairments are such that they render the act of self-killing impossible and/or they are unable to legally and/or easily procure adequate quantities of toxic substances that would facilitate a relatively painless demise. Generally, "patients'" motivations fall into two, often overlapping, categories: (1) those whose impairments are so significant that they find the activities of daily living impossibly difficult without substantial, though possibly unavailable, assistance and (2) those who find their physical/emotional pain unbearable.

How any society responds to the question of physician-assisted suicide provides an important window into how it prioritizes the value and quality of life of its individual members, one that forces an examination of praxes of family units, health care delivery systems, educational programs, and social service networks. The desire to die is often the ramification of the unavailability of entirely feasible if currently/apparently unavailable enhancements to the quality of life, including disability accommodations, educational and professional opportunities, emotional and logistical support, and palliative medical and/or psychological care. In that context, the provision of and advocacy for the alternative of a quick, easy, and economical death as a solution to life's challenges requires the utmost scrutiny.

Laws regarding physician-assisted suicide are sometimes ambiguous. In the United States, the practice is legal only in the state of Oregon. It is also a lawful practice in the Netherlands, Belgium, and Switzerland and was permitted for nine months in the Northern Territories of Australia, ending in 1997. The practice is legal, though, owing to social opprobrium, practically nonexistent, in Japan. Whether physician-assisted suicide is right or wrong, its availability anywhere implicates medical doctors and biomedical ethicists who condone the practice.

In the United States, physician-assisted suicide achieved its greatest notoriety through the infamous "Dr. Death," Jack Kevorkian, a pathologist who claims to have illegally assisted in dispatching over 130 "patients," many obviously and almost surely treatably depressed, others with conditions such as fibromyalgia, which threaten neither life nor general health and for which palliative treatment is frequently available. Since 1999, Kevorkian has been serving a 10- to 25-year prison sentence for second-degree murder, the result of his participation in an assisted suicide.

—Alex J. Lubet

See also Death; Ethics; Euthanasia; Quality of Life.

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PINEL, PHILIPPE (1745–1826)

One of the founders of modern psychiatry

Philippe Pinel is considered by many to be the father of modern psychiatry. After the French Revolution, he was appointed physician to the infirmaries at the Bicetre Hospital, which at that time housed 4,000 criminals, pensioners, and the sick, including many with syphilis. Pinel focused his attention on the ward housing 200 mentally ill men where he instituted a strict nonviolent, nonmedical management of patients that became known as "moral treatment." Although he gave due credit to his mentor, Jean Baptiste Pussin (1745–1811), who had freed patients from their shackles and invented the straightjacket, it was Pinel who was credited for the improved management of the mentally ill. After he moved to the Salpêtrière Hospital, he worked to assure that the shackles were removed from patients there. Pinel also put an end to the bleeding, purging, and blistering "therapeutic" interventions for the mentally ill. He focused his energies on careful diagnosis developed through close contact, observation, and extensive conversations with patients. He kept careful notes on his patients, which served as the basis of his book, *Traité medico-philosphique sur l'alienation mentale; ou la manie* (1801), translated in English as *Treatise on Insanity* (1806). In 1795, he was appointed to the chair of medical pathology, which he held for 20 years, and was also named chief physician of the Salpêtrière, which he kept until his death.

Pinel created an inoculation clinic at the Salpetriere, where the first vaccination was given in Paris in 1800. In 1798, he published *Nosographie philosophique ou methode de l'analyse appliquée à la médicine,* which was, for the time, an authoritative classification of diseases. He was elected to the French Académie des Sciences in 1804 and to the Académie de Médicine in 1820. His treatise on mental illness has had a long lasting influence on French, English, and American psychiatry. He has been immortalized in paintings, prints, and by a statue situated outside the Salpetriere.

—Claude Wacjman

▣ POETRY

Poetry seeks to explore and validate the lived experience of moving through the world with a disability. Sometimes referred to as crip poetry, disability poetry embodies a disability consciousness; it is informed by and contributes to disability culture.

Like the rest of the disability arts movement, crip poetry rejects the view of disability as a shameful, pitiable, tragic, and individual phenomenon. Fundamental to crip poetry is an understanding of disability as a social construction. This is not a denial of the pain and functional limitations that may come with impairment—in fact, disability poetry is often informed by a heightened awareness of those aspects of impairment. But crip poetry is also sharply aware that a major part of the impact that disabilities have on lives results from the ways those human differences are interpreted culturally and responded to by society, so often with prejudice, marginalization, and discrimination. Lynn Manning's poem "The Magic Wand" explicitly addresses this point when it describes the transformation the persona undergoes, "from black man to blind man," through the simple act of unfolding his white cane.

Disability poetry can be characterized by several characteristics: a challenge to stereotypes and an insistence on self-definition; foregrounding of the perspective of people with disabilities; an emphasis on embodiment, especially atypical embodiment; and alternative techniques and poetics.

One of the major impulses of crip poetry is to resist stereotyping and the limits of the socially imposed "handicapped" identity through a process of self-definition. Disability poetry often explicitly rejects social pressure to pursue a forever-elusive "normality" and instead finds value and strength within disability experience, not *in spite of* impairments but *because of* and *through* them. This can be seen in Cheryl Marie Wade's "I Am Not One of The," in which the persona forcefully rejects the labels that are applied to her.

The speaker of this poem rejects the euphemistic labels applied to her by a world that would prefer to not discuss disability and rather simply stereotype her. Instead, she articulates an identity for herself. She claims a kinship with disabled people through history, including those hidden away, left to die, even executed for their disabilities. Each time she rejects the euphemism, she replaces it with images that confound common expectations for people with disabilities—images of strength, of action, of sexual attraction and pleasure. The poem situates people with disabilities not in the margins but in the center of human experience ("I'm the first cell divided," "I've been forever I'll be here forever"). By the end of the poem, she has claimed negative terminology ("gimp," "cripple," "crazy") for her own, transforming the terms with the final, triumphant assertion: "I'm the Woman With Juice."

Disability has typically been described by nondisabled people. Another characteristic of disability poetry is that not only is it situated within the lived experience of disabled people, but it specifically comes from the perspective of people whose bodies and minds have been deemed anomalous. Whether from wheelchair height or through impaired eyes or ears, crip poetry foregrounds an alternative perspective. Sometimes, that alternative perspective is specifically addressed in the poem, as in "Harvest" by Stephen Kuusisto, when the speaker seeks to "admire the white moon of the morning, / even if my eyes tell me there are two moons."

Embodiment is another characteristic of disability poetry. Crip poetry demonstrates an awareness of and sensitivity to the body, which may not be unique to poetry within a disability aesthetic but is certainly present. This is not to suggest that disability poetry is simply participating in a larger poetics of embodiment, which centers the body as the source of artistic production but also expects bodies to conform to nondisabled expectations. Instead, with its attention to alternative ways of being in the world, crip poetry seeks to redefine what it means to have and be a body in the world. In Mark O'Brien's poem "The Man in the Iron Lung," the speaker describes his dream life in "the body electric," which "inserts itself in the map of my mind." As it "whooshes beautiful lies of invulnerability," it forces its way not just into his lungs but into his sense of who he is. Eli Clare describes a far different anomalous embodiment in "Learning to Speak": "I practiced the sounds *th, sh, sl* / for years, a pianist playing endless / hours of scales. I had to learn / the muscle of my tongue."

Because of this emphasis on exploding the limits of acceptable bodies in the world, embodying poems through performance is an important part of disability poetry. Disability is centrally about bodies, how they look and act, and how they are construed, so this embodiment is a crucial strategy. People with disabilities are often told to disregard their flawed, unsatisfactory bodies; paying the attention that poems evoke and reward is a powerful antidote, one that is intensified and multiplied through performance. And, as with other disability arts, events that include the performance of crip poetry are an important site for the continuing development of disability culture.

Alternative poetics can be found in disability poetry as well. Anomalous ways of moving through the world can lead to formal differences in poems; for example, using a respirator to breathe has significant potential to influence rhythms and use of the line. Cerebral palsy had a significant impact on the poetry of Larry Eigner, including the length of his poems—it was difficult for him to put a new piece of paper in his typewriter—and his distinctive use of space on the page. It is important to note that alternative embodiment, cognition, and rationality do not guarantee alternative poetics, but anomalous ways of encountering the world seem likely to influence a disabled writer's poetry.

—Jim Ferris

See also Art Therapy; Disability Culture; Representations of Disability, History of.

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POLIO

Although forgotten by many, polio was during the past centuries one of the most widespread and devastating diseases, leaving many persons with residual functional limitations. The disease is not completely eradicated, however, with a few new cases in some countries in Asia and Africa during recent years. The major health problem is the late effects of polio with reduced muscle functions and other symptoms leading to increased disability decades after the initial period.

DISEASE AND PREVALENCE

Polio (or poliomyelitis) is a virus-spread disease whose only known host is man. There are three types of polio virus (1, 2, 3), which is spread mainly through fecal-oral infection, usually through the water system. Polio has been accompanying man for a long time, and archaeological dig-outs from Egypt have identified skeletons with changes after polio, from more than 13,000 years B.C., and there are hieroglyphic stones with persons seemingly affected by polio. It has been an endemic disease, but with increased hygiene, epidemics started. Large epidemics occurred in Scandinavia, North America, and Australia in the 1940s and later. The virus has a seasonal variation, with a start in late summer and continuing during fall and declining in midwinter. The typical picture of a polio case starts with an initial infection with slight upper respiratory infection, general malaise with slight fever, fatigue, or gastroenteritis. The disease could stop here (so-called abortive polio), but often within a few days up to a week, the meningitis would start. Fever occurs with headaches and a stiff neck. While the fever is still rising, the paralysis starts to occur, and after a few days, the fever goes down but usually the paralysis stays. The paralysis is characterized by flaccid, asymmetric paresis. The most common form is spinal polio, where the legs often are involved and the breathing muscles are often affected, giving reduced pulmonary function. Cranial polio could affect the facial nerves but also the lower cranial nerves. The so-called bulbar polio results in paralysis of the throat and eventual paralysis of the swallowing process, with the gathering of secretion in the throat and lungs, eventually suffocating the patient. The centers for breathing and circulation in the brainstem could also be affected. Cerebral polio is similar to other types of encephalitis, with a drowsy-person "slow cerebration," but could lead to coma and death. The start of the vaccination era halted this.

The first vaccination was developed by Dr. Jonas Salk, who developed a vaccine that was a mixture of the three virus types, which were killed with formalin. Vaccination trials started, and the vaccine was available in 1955, which ended the epidemics in the Western world. A new vaccine developed by Dr. Albert Sabin (approved for use in 1961), which was made of weakened virus strains and given orally, gained popularity and is now the dominating vaccine in the world.

During 2002, around 500 confirmed cases were reported to the World Health Organization (WHO), and polio was still present as an endemic in Pakistan, Afghanistan, India, Nigeria, Niger, Egypt, and Somalia, with a few cases in Ghana and Lebanon. The number of persons who have had polio and are thereby at risk for late effects of polio is not known, but WHO estimates that there are up to 20,000,000 survivors in the world today. The risk for developing post–polio syndrome is not known, with reports ranging from around 25 percent up to 75 percent. This means that 5,000,000 to 15,000,000 persons might need to be in contact with the health system now and in the next 50 years for problems due to the late effects of polio.

CONSEQUENCES OF POLIO

Polio survivors may experience different types of health problems. Dominating are new or increased muscle weakness, general fatigue, pain in muscles and joints, and, for a smaller group, breathing problems. There may also be reduced tolerance to cold.

The muscular symptoms are connected to the initial loss of nerve cells in the anterior part of the spinal cord. During the recovery, after the initial infection, there is a more or less pronounced reinnervation by terminal sprouting from still-functioning motor units—a motor unit is the nerve cell, with its nerve and nerve branches and the muscle cells (fibers) connected to that nerve cell. In that way, one of the same nerve cells may have innervated several times the normal number of muscle fibers. This process leads to recovery of muscle function, which even could become normal or near normal in a polio-affected muscle. Besides that, the other compensatory mechanisms are increased size of the muscle fibers (hypertrophy), which can be double the normal cross-sectional area in muscles used in daily life. Over time (often 20–30 years after the initial polio infection), these compensatory processes may not maintain the muscle strength. This may be due to several factors, as further loss of nerve cells in the spinal cord (aging and/or overload) and less efficient reinnervation. Still, there is evidence of an ongoing reinnervation also at that age, with motor units that may contain five or even more times the normal number of muscle fibers. There may also be immunological factors involved in the deterioration of function.

Fatigue is a common symptom and can be muscular due to muscular overload or reduced physical fitness due to a low level of activity; it can also be of a central origin, to which damage in the central nervous system by the polio affection may contribute. Pain may be due to overload of muscles or joints and connected to physical activity. Persons with previous affection of respiratory muscles may experience further breathing problems.

These impairments may lead to different levels of activity limitation, especially mobility, as the lower limbs are usually more commonly affected than the upper limbs. This may then lead to limitations in activities in household work, work, leisure time, and so on. The person will suffer an increasing amount of disability. This situation has been named post–polio syndrome and is especially defined by increasing muscle weakness.

HEALTH CARE

This new or increased disability situation requires medical analysis to understand the background factors for that particular person and the possibility to give symptomatic help. Pain relief is important. Physical training may have positive effects on muscle strength and general fitness. Still more important is advice about the proper level of physical activity in daily life to facilitate adaptation to a new life situation. Technical aids are important for some persons, especially mobility aids such as canes, crutches, wheelchairs, or adapted cars. Orthoses may be given or renewed, especially in some cases of reconstructive orthopedic operations. Screening for reduction in breathing function is important since some persons may require assisted ventilation. Some people have been dependent on ventilators since the initial infection; others need night ventilators. There may also be psychological crises connected to the increased disability situation.

Although acute polio occurred quite recently in the Western world, knowledge about care for acute disease has disappeared, and the teaching in medical schools about the late effects is scarce. Therefore, not many health professionals have knowledge about the disease and the effects that might come with time. For polio survivors, this can be a frustrating experience when changes are occurring in their bodies and they seek advice. This can lead to unnecessary contacts with different specialists in the health care system and might prolong the correct diagnosis. Special clinics have therefore been created to handle the late effects of polio.

POLIO SUPPORT

In many countries, there are support groups available for polio survivors. They can serve many purposes: They give emotional support to the polio survivor and next of kin, provide information about the disease, help the polio survivor obtain health professionals who are knowledgeable about the disease, and lobby for more interest in the polio disease. The support groups are also involved in trying to get a more accessible society and provide information about disability rights in the society where they are active. Polio support groups have also been of great value, and the “polio-movement” is considered strong in many Western countries. However, new cases have appeared in several developing countries in the later decades, and it may be expected globally that there will be a large number of polio survivors with medical and disability problems for another half century.

—Gunnar Grimby and
Katharina Stibrant Sunnerhagen

See also Developing World; Disease; Infectious Diseases.

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POLITICAL ECONOMY

The political economy of disability seems like an arcane topic until we realize that the inexorable growth and aging of the world population, particularly those with physical and mental disabilities, is putting enormous strains on governments, economies, and political systems in the developing and industrial worlds. Who will take care of these people? What systems can be put in place to deal with the problem? Who will pay for this and how? What will the burden be on our children and grandchildren? Disability is an issue that forces people to reassess their values and make painful decisions on how to allocate scare resources.

DEFINITION

Political economy is a perspective used in analyzing how money and politics shape behavior in social institutions such as health and welfare systems. Political economists emphasize that studying the interdependent operation of government and the economy is essential for understanding the survival and growth of a nation and the configuration and operation of its institutions. Political economists are equally concerned about how the demands of citizens influence government and economic institutions such as the National Health Service in the United Kingdom, splintered capitalistic health care systems in the United States, and government-run, public health–oriented systems in Cuba. Interestingly enough, the vast disparities in per capita expenditures across nations do not seem to have similar large effects on health outcomes as measured by mortality, morbidity, and disability. In fact, the most expensive system of all, the United States, leaves more than 60 million citizens totally uninsured or dramatically underinsured and does not produce longer life expectancy than that of many other countries. Differences between these systems can be explained by differences in values and economic and political systems. At the root of the issue lie different decisions on how to identify and manage risk, how to allocate scarce resources to those in need, and whether to believe in some sort of safety net. The tagline always is, What do people need? What do they want? Who is going to pay for this? And how much? The consequences of these decisions are far reaching because they speak to idealism, values, quality of life, and cross-generational responsibilities.

THE STATE

Because of global urbanization and changing values, people less often are living in extended family systems where the family as a unit cares for the weak and vulnerable. Consequently, the elderly and disabled are increasingly being thrown to their own devices and become more a concern for the state. In the microcosm of Cook County, Illinois, for example, more than half of the 4,000 current inmates of the county jail are judged to have mental illnesses, often complicated by the dual diagnosis of alcohol and drug addiction. In this case, the justice system is being used as a “dumping ground” for those with serious mental illnesses because their families are unable or unwilling to care for them, and there is no county or state mechanism for dealing with these people in the existing mental health system. In Africa, AIDS has become a similar unmanageable problem for families and governments with meager resources to prevent the problem or care for those with a prevalent, deadly condition. Where AIDS used to be a condition that killed rather quickly, modern treatments and drug regimens have extended life expectancy but often in a disabled condition. These HIV-positive individuals lose their capacity to work and parent, thus requiring constant care and medical attention. The burden on families is enormous. In those regions where HIV prevalency is at or above 40 percent, entire generations are being decimated, with dire consequences for the oldest and younger generations. These examples are illustrative of an international phenomenon. While responsibility for caring for the vulnerable is being transferred from the family to the state, the political and economic systems of most countries are not prepared to deal with these problems. People are living longer, and the numbers of disabled people are growing. Individuals typically have not saved enough for old age or anticipated disability. Families often do not have the resources or are not willing to pay for the care of their older and disabled members and do not want taxes raised in any form to do so. All of this leads to a crisis in the welfare state of industrial countries and insurmountable pressures on the economies of developing countries. As populations age and the number of young workers paying taxes decreases, something has to give. Savings and taxes must go up or the type, quality, and amount of services decrease.

VALUES

Disability exacerbates the pressures put on social institutions by aging and vulnerable populations; raises difficult ethical issues such as abortion, euthanasia, and physician-assisted suicide; and questions the basic values of a society. Disability symbolizes the debate over quality of life for individuals and their relatives and questions judgments about the lived experience of disabled persons. Is living with a disability an unbearable experience to avoided at all costs? Should individuals or their relatives be able to end their lives? If so, under what conditions, and who is to decide? What values and principles underlie these decisions? These are questions that disquiet individuals, family, and the state. For all of the espousal of family values and respect for elders, adult children are not eager to care for elders in their own homes and are reluctant to pay for expensive assisted care living. The trend in North America and other industrialized, urban countries is for more elders to live by themselves or in institutions, particularly if they are disabled or at the end of life.

Research studies complicate these discussions. There is growing evidence that many individuals with persistent and severe disabilities report a good or excellent quality of life even though external observers might judge otherwise. Many disabled people are as happy and enjoy life as much as those without disabilities. Like anyone else, they have no desire to be discounted, be left alone to fend for themselves, or die. Given the aging populations in the world, the trend is that more people will live longer with disabilities exacerbating the existing problem and placing more strains on families and welfare systems. Faced with these issues, disabled people are becoming better organized and more vocal. They are joining forces with the elderly to exert more political pressure on the state to address their needs. Almost every disability group has an organization that lobbies for their cause, be it Alzheimer's disease, multiple sclerosis, arthritis, asthma, depression, or intellectual disabilities. It is also clear that these people do not want to be made dependent. They want to make or at least actively participate in decisions that affect their quality of life and future.

These issues directly address the values of human life and to whom. Utilitarian philosophers have examined these problems through the lenses of an individual's worth to society and contribution to the common good. Economists have spent considerable time assessing the economic value of human life based on age, sex, education, ability to participate in the labor force, and capacity to pay for and consume goods and services. While both of these approaches are informative in exploring disability in society, the political economy of disability adds to the discussion by analyzing the interrelationship between disabled people and political and economic institutions. This is important because the political and economic institutions and values that undergrid them will determine how disabled people are treated in a society.

Political economic values and institutions vary from state to state. In the United States, considerable emphasis is placed on rugged individualism, capitalism, "free markets," and an "American" form of democracy. As a consequence, American funding for and support of disabled people is generally related to an individual's ability to work and be economically productive. In this sense, men are favored over women and children. American pundits say that American health insurance is wonderful as long as you do not have a serious or persistent health problem. This is really true for disabled people. Health insurance companies and the government try to limit the numbers and types of disabled people they cover. This is euphemistically called "cherry picking." The disability system is disjointed and often profit driven or risk aversive. Since there is no integrated "safety net," disabled people frequently fall between the cracks and have to rely on family and friends, live in an institution, or live alone poor. Investigations after the incredible loss of life among the elderly and disabled in the recent, severe summer heatwaves in Chicago and France indicated that thousands died because they were living alone, no one checked in on them during this dangerous time, they were unable or afraid to go out for help, they did not drink enough water, and they did not have fans or air-conditioning. In France, this occurred during the national vacation time when the vulnerable elderly and disabled were left alone. These problems are intensified because these vulnerable citizens are usually poor, so they cannot purchase assistive care if the family is not present. Disabled people are either poor to begin with or the loss of work and cost of dealing with their health and disability problems deplete their resources. These dynamics illustrate the dilemma that citizens face. Either they must care for their elderly and disabled in the family, or there must be an effective state system to do so.

Absent either solution, these vulnerable populations will suffer and even die as in the case of the Chicago and French heatwaves.

THE MARKETPLACE

On the other hand, because there are large numbers of disabled and dependent elderly people, private insurance money, public funds, and personal resources to pay for health care and rehabilitation goods and services, a large industry has developed to define and respond to this multibillion-dollar annual market. Historically, disabled individuals received benefits if they or their work were important to the national economy: members of the armed forces, merchant seamen, railroad workers, miners, and members of the government. More recently, disability benefits were expanded to a much larger population through social security, social welfare programs, and employer-based private insurance. As a consequence of extended coverage, demand for disability-oriented health care and rehabilitation goods and services grew enormously. A massive health care market niche for rehabilitation was created.

In the past, families, local communities, and charitable organizations cared for disabled people. Now, disability has become part of the capitalistic, free-market system where health care and rehabilitation goods and services have become commodities for sale, frequently at a profit. This increasing commodification and privatization of goods and services enabled remarkable growth in the hospital, medical goods, pharmaceutical, insurance, and rehabilitation industries from the 1980s to the present. Not only are these industries some of the fastest growing in the world's stock markets, but they are also among the most profitable. As health care and rehabilitation goods and services became privatized, industry focused on forming companies to serve a need and to make a profit. At times, it is unclear which goal predominates. Certainly, the size of corporations has grown through mergers and acquisitions, expansion of the market through advertising, and development of new products. Concurrent with the privatization of health and rehabilitation care has been the corporate abuses of the past 10 years. Executives of large health care companies have been accused and convicted of accounting irregularities, fraud, questionable marketing practices, and overpricing. The corporate jet, multimillion-dollar salaries, stock options, and golden retirement "parachutes" have become staples in the health care corporate world. HealthSouth is an example of such a multi-billion-dollar company.

While the corporatization of health and rehabilitation care has resulted in remarkable advances in health care and rehabilitation, it has driven up the cost of care to unprecedented heights, creating an expanding chasm between those who can afford these goods and services and those who cannot. These forces raise fundamental questions about capitalism and democracy. What should be expected for all citizens as a minimum standard? Should there be a social safety net? Should health care and rehabilitation be for profit industries in the private sector funded by government and private insurance? How will access for all and equity be effected? The critical issue concerns who will protect the vulnerable populations of any nation.

FUNDING AND RESPONSIBILITY

While the issues are becoming clearer, their solution is not. The problems of an aging population and increases in the numbers of disabled citizens are apparent. How to structure a system that deals with these issues and pays for them is not. It is clear that the very wealthy can afford to pay for their own care. What to do about those who cannot pay for this care out of pocket affects every nation in the world. The existing models are no system (e.g., Sudan, Cambodia), national health insurance (e.g., Canada, United Kingdom, France, Sweden), mixed systems (e.g., Switzerland and Japan), and a strong public health and primary health care system with family support for the elderly (e.g., Cuba). Of those countries with some sort of system to deal with the elderly and disabled, each has attractions. The most attractive in terms of national policy are those that provide universal coverage at some minimum level. This is clearly the most equitable solution, but the problem is funding. Who will pay for it?

The funding issues immediately raise questions of responsibility. Whose responsibility is the care of the elderly and disabled, and how should it be financed? While this is a contentious issue in many societies and raises unavoidable cross-generational tensions, there are but a limited number of solutions. Resolution of the problem will probably involve a combination of strategies. Expectations will have to be lowered. People will not receive services that they and/or the nation cannot afford. Expectations of what constitutes a materially "good life" will have to diminished—hence current attention being given to "simplifying life" and spirituality. Taxes to support an adequate welfare system will need to be increased. The age of retirement will need to be increased as populations age into their 80s and 90s. Social security and retirement systems were designed during a time when life expectancy was in the early to mid-60s. These systems cannot sustain early retirement and life expectancies projected for an additional 30 years. Immigration will continue to be a "hot button" issue. As populations age, more young people will be needed to work, pay taxes, and provide the goods and services required to sustain the elderly and disabled population. Since birth rates are unlikely to increase dramatically, permitting the immigration of healthy, skilled young workers is the likely outcome. This, in turn, will make societies more multicultural and intensify tensions between race/ethnic groups.

Rationing of health and rehabilitation care is inevitable. Today, rationing occurs through the use of health maintenance organizations (HMOs), managed care organizations, queuing in National Health Insurance systems, and copayments for diagnostic and surgical procedures and for drugs. As costs of these goods and services continue to increase, more intense rationing will occur. The heated debate that will ensue will be over universal health coverage, inequities in the access to care and the rationing system, what constitutes minimum standard care for all, and how much care is enough. The economics of the situation will dictate limits on demand.

INFRASTRUCTURE AND STEWARDSHIP

Here the expressed the rights, needs, desires, and demands of the individual collide with the greater good of the community and all the citizens of the state. Sometimes, these perceived needs and demands are in concert; other times, they are not. In ethical terms, should the needs and wants of the individual supersede those of the larger community? The debate is tinged by value systems. In the United States, great emphasis is placed on the rights of the individual, whereas in European and Asian societies, more relative importance is given to the primacy of the community. Hence, the discussion will be framed differently in different countries.

These issues of demand for and allocation of scarce resources in society further lead to discussions of infrastructure and stewardship. The quality of life of elderly and disabled people is contingent on their access to care, ease of use, appropriateness of treatment, and cost of care (particularly pharmaceuticals). The present U.S. and national health care systems of most countries are not constituted to meet the increases in demand of elderly and disabled people. Consequently, they must be restructured. More physicians and health care workers knowledgeable with geriatrics, physically accessible facilities, transportation to and from places of care, home care services, redesigned accessible living quarters, and affordable drugs and assistive devices are needed. These adjustments need not cost more money, but they do require a reallocation of resources. For example, new buildings, homes, apartments, and health clinics can be constructed with a universal design in mind. Social support systems for these populations who can often be isolated need to be encouraged through more family involvement, community activities, friendship networks, and community-based home visiting programs.

Finally, the disabled and aging populations of the world suggest the problem of stewardship. If citizens want to leave the world a better place for having been there, they will have to rethink how they treat their physical and social environments and the people they leave behind. There are many communitarians and community leaders who are calling for a renewed emphasis on respect for our physical and social environments and other people. This requires a rethinking of how we use precious resources and deal with our families and neighbors. All citizens of the world have an obligation to be trustworthy stewards of their own worlds and social lives.

—Gary L. Albrecht

See also Economic Analysis of Disability; Health Management Systems; Managed Care; Social Support; Values.

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POLITICAL PARTICIPATION

Grassroots political activism by people with disabilities formed the basis of the disability rights movement in the United States, leading to the passage of the Americans with Disabilities Act and other important laws. Despite these policy gains, however, recent research indicates that people with disabilities remain underrepresented in the political process, raising concerns that their needs and interests are often neglected and ignored by politicians and elected officials. The lower levels of political involvement can be largely explained by economic and social disparities faced by people with disabilities, which often create barriers that make political participation more difficult but can spur some people to become disability activists. While there has been only limited research in this area, several studies shed light both on overall political participation among people with disabilities and on disability activism.

OVERALL POLITICAL PARTICIPATION

Overall levels of political participation among people with disabilities are significantly lower than among nondisabled individuals in the United States. In addition to being less likely to vote (for further information, see the Voting entry in this encyclopedia), people with disabilities are also less likely to work with others on community problems; write or speak to public officials; attend political meetings; contribute money to political causes, parties, or campaigns; write letters to newspapers; participate in political protests or demonstrations; or otherwise work to change government laws or policies. The following comparisons come from nationally representative surveys conducted in the United States in 1998 and 2000 (see Table 1).

Table 1 Comparison of U.S. Political Participation by People with and without Disabilities

	People with Disabilities	*People without Disabilities*
Number of political activities in the past year (0–9 scale)	1.86	2.33
Political activities (in percentages)		
Voted	61.9	70.9
Written or spoken to elected representative or public official	31.2	41.4
Worked with others on community problem	22.1	29.0
Contributed money to organization trying to influence government policy or laws	16.9	24.3
Attended political meeting	13.1	16.6
Contributed money to political party or candidate	13.2	17.4
Written letter to newspaper	8.2	8.9
Otherwise worked with groups or on one's own to change government laws or policies	15.3	19.4
Participated in protest or march	4.0	5.5

Women with disabilities have slightly but not significantly lower levels of overall political participation than do men with disabilities, reflecting economic and social disparities due to gender as well as disability. Nonetheless, they are about as likely as men with disabilities to vote, write letters to newspapers, and work with others on a community problem and are actually more likely to take part in political protests or marches.

Many people with disabilities face considerable barriers, such as the lack of accessible transportation, stigma, and discrimination, that discourage them from taking part in political activities. At the same time, however, such obstacles motivate others to become and remain politically active, particularly on disability rights issues. The factors affecting political participation in general can be divided into three categories: resources, recruitment, and psychological engagement. Resources include money, education, time, and civic skills that facilitate participation—for example, the ability to speak in public or write an effective letter to a public official. Recruitment networks expose people to requests for participation, and psychological engagement includes interest in political issues, feelings of political efficacy, and other psychological factors.

People with disabilities tend to have fewer resources, including lower average levels of income, education, and civic skills, which help account for their lower levels of political participation. They are also less likely to have vehicles they can drive, which curtails their ability to engage in many types of political activity outside the home.

People with disabilities are also less likely to be recruited for political activities, reflecting their generally greater social isolation. This is due in part to transportation constraints and to the fact that people with disabilities are more likely to live alone and are less likely to have jobs, socialize with friends or family, attend religious services, or regularly attend groups where recruitment can occur.

Less than half of people with disabilities are employed, and these low employment levels contribute to their low levels of political participation. Employment provides not just income and recruitment opportunities that increase participation but also opportunities for developing civic skills through activities such as leading meetings, giving presentations, or participating in decisions at work. There is, in fact, no political participation gap between employed people with and without disabilities, and the particularly low participation level of women with disabilities is partly explained by their especially low employment levels.

Regarding psychological factors, there is mixed evidence on whether people with disabilities express the same general level of interest in political issues as people without disabilities. People with disabilities are more likely to express interest in public health care issues and to identify with the Democratic Party but have a similar average score on a liberal to conservative scale. When asked how disability has affected their political views, about half of people with disabilities say that it has had no effect. Among those who say it has affected their views, about half say it has increased their interest in disability-related issues, while smaller percentages say it has made political participation more difficult, has made them more cynical and antigovernment, or has made their political views more liberal.

The psychological impact of living with a disability can be especially strong in the first few years after onset, as individuals undergo a major life transition and learn to cope with disability-related problems and their new status. This can be exacerbated by the often greater demands on time, energy, and financial resources during this period and helps explain why political participation is particularly low in the first few years after disability onset.

Feelings of political efficacy are another important psychological factor that helps explain the lower political participation levels among people with disabilities. Compared to people without disabilities, they report lower average levels of both internal political efficacy (the belief that one is competent to participate in politics) and external political efficacy (the belief that the political system is responsive to people such as oneself). The lower levels of internal efficacy are largely explained by lower levels of education and employment, but the lower levels of external efficacy are not explained by other factors and appear to be directly related to the experience of living with a disability. Individuals with disabilities are also much more likely to report that people with disabilities do not receive equal treatment from public officials or have equal influence in politics. Combined with their low external efficacy levels, these responses indicate that people with disabilities tend to feel that the political system is not responsive to their interests. Such perceptions may result from internalized "social constructions" of disability, which are popular images of disability that are shaped by public policies that send negative messages (for example, by stereotyping people with disabilities as dependent and needy).

Low levels of political efficacy can be part of psychological responses to the experience of living with a disability. Among the variety of responses that individuals can have to disability, Renee Anspach (1979) and other writers have described how some people with disabilities have a negative self-concept and respond to stigma, discrimination, and other disability-related problems by developing an attitude of fatalism and helplessness. This discourages political involvement and can lead people to withdraw from society.

Other psychological reactions to disability do not discourage political participation. Some people react to the experience of living with a disability through "normalization"—trying to emphasize their similarity to people without disabilities while ignoring or minimizing stigma, discrimination, and other disability-related difficulties. Such people accept society's devaluation of people with disabilities and try to maintain a positive self-concept by de-emphasizing their disabilities. An extreme form of this response is characterized by "role distance," where people with disabilities try to separate themselves as much as possible from others who have disabilities and only associate with nondisabled people. Those who normalize may engage in standard political activities such as voting but avoid political activities directly related to disability issues.

DISABILITY ACTIVISM

While the experience of living with a disability leads some people to retreat from society or practice normalization, it motivates others to become politically active in an effort to end discrimination and improve conditions for people with disabilities. The percentage of people with disabilities who said they took some sort of action on a disability-related issue in the course of a year is shown below (based on U.S. national surveys in 1998 and 2000):

Political activity on a disability issue (as part of one or more of the political activities listed earlier)	10.1 percent
Took action against private organization on a disability issue (e.g., talking to business owners, filing lawsuits)	8.6 percent
Either of above	14.8 percent

(Note: This does not equal the sum of the two previous activities because overlap has been eliminated.)

Four basic perceptions appear to be linked to disability rights activism. First, there must be recognition of the importance of disability-related problems. This is undermined by normalization where people minimize or rationalize such problems. Second, in contrast to people with a fatalistic response, activists believe that many disability-related problems are not an inherent part of living with a disability and can be eradicated. They also perceive that their problems are widely shared and have a strong sense of identification with others who have disabilities. Finally, activists perceive that many disability-related problems require political, rather than purely individual, solutions. They emphasize changing policies, practices, and laws, rather than relying on self-help strategies such as developing a "positive attitude" or learning how to put nondisabled people at ease.

People who become politically active on disability issues are more likely to meet regularly with disability groups. Such groups can provide members with role models, education on disability issues, recruitment networks for political activities, and a supportive environment for the development of a sense of identification with others who have disabilities. It is important to note, however, that not all politically active people who work on disability issues work through groups. Some people are politically active on their own, engaged in private struggles to change laws or policies as a result of discrimination or other negative experiences they have had.

Disability activists are more likely than other people with disabilities to say that they have directly experienced disability discrimination. This partly reflects a broader definition of discrimination. For example, activists tend to define discrimination not just in terms of intentional behavior but also in terms of policies or practices that have discriminatory effects, such as architectural standards that create inaccessible buildings. Disability activists also express greater life satisfaction and a greater sense of control over their lives and have higher levels of internal and external political efficacy than other people with disabilities. At the same time, they are less likely to believe that people with disabilities get equal respect from public officials, which helps motivate their activism.

The most committed activists have lived with their disabilities for a longer period of time on average, consistent with findings on the psychological impact of disability onset. While some people describe becoming activists after being galvanized by a particular experience (for example, an act of discrimination or denial of needed services), others describe going through a slow process in which they gradually learn to come to terms with living with a disability, fully accept themselves, and identify with others who have disabilities. Early in this process, they may go through stages of fatalism, role distance, and/or normalization but then learn to develop broader views of disability and discrimination, as well as an appreciation for the value of political action.

Those who have become leaders in the disability rights movement, in particular, have learned to reject the medical definition of disability in favor of a sociopolitical definition that views environmental and attitudinal barriers as helping create disability. Some people originally join disability groups for nonpolitical reasons (for example, for recreation or needed services) but become politically active after being exposed to new issues and meeting politically active people who serve as role models. The gradual politicization of many activists suggests that there are no apparent prerequisites for who can become active in disability rights politics and that circumstances—the types of groups, information, and opportunities that are available—often play a large role in politicization.

In conclusion, overall political participation is lower among people with disabilities than among the general population. This disparity is accounted for by factors such as lower resource levels, fewer recruitment opportunities, and lower political efficacy levels. The barriers that discourage many people with disabilities from fully participating in political life, however, also motivate others to become politically active on disability issues. While some people view their disability-related problems only as personal matters, many others perceive political dimensions in the problems they face. Disability groups can play a particularly important role in this respect by providing role models, building group identification, and increasing exposure to political information and opportunities for participation. Overall political participation among people with disabilities can also be encouraged by policies that decrease social isolation and increase resource levels—for example, by creating better educational and employment opportunities. Greater political and civic participation among people with disabilities will help them achieve equality, ensure that their voices are heard, and strengthen our democratic institutions.

—Lisa Schur

See also Activism; Participation; Voting.

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POLITICS OF DISABILITY: INTERNATIONAL

The politics of disability refers to the ongoing debates over how disability definitions and programs shape what constitutes disability, who is identified as being disabled, and what resources a society will allocate to disabled people. Disability politics have come to the forefront as increasing demands are made on state welfare systems and as nations experience serious problems in coping with their aging and disabled populations.

This entry conceptualizes the politics of disability internationally and in a social and cultural context. First, at the fundamental level, the very existence of disability as a category of knowledge should be clarified. This is important in an international context because the social and cultural context in which disability is framed has political consequences. Several authors report that the distinction between disabled and nondisabled people is not known in certain social and cultural contexts and hence of no political consequence. Second, in the study on the politics of disability, one would want to know how a person gets categorized as disabled (i.e., the process by which one is assigned and confirmed a label of disability and through which one acts as a disabled individual in a cultural and social context). Third, given the social existence of disability, the next level of analysis is to explain how the very distinction between disabled and nondisabled people, through processes of socialization and social exclusion, is maintained. This is a question of control and/or tolerance for change. Fourth, the politics of disability consists of the development of an ideology of thought, as found in the formulation of the social model of disability, and the building of coalitions to overcome the historical distinctions between disabled and nondisabled people. In processes of identity formation, cultural development in the so-called culture of disability, and social movement, power is used to redefine disability and the relations between disabled and nondisabled people. From a disability studies perspective, the question here is about the contours of a disability model that pertains to different cultures.

The questions above are directed with the goal of recontextualizing a Western perspective on disability. The intellectual benefit is to clarify meanings of disability in other cultures as well as providing directions of studying and practicing the politics of disability internationally.

THE POLITICS OF THE VERY EXISTENCE OF DISABILITY

The very existence of disability cannot be understood without taking into consideration the particular ways in which Western society has separated people with certain characteristics from the overall group, through defining a certain status as human beings, with rights and entitlements, and the right of society to take certain decisions. *Disability* as a linguistic term is a composite; it comprises people with a large variety of unrelated characteristics, yet through processes of separation and practices of defining society's responsibility to those who have been separated from the rest. This is, however, not a universal process. For example, Holzer (1999) observed that in Juchitán, Mexico, the distinction between disabled and nondisabled is not known. Such ethnographic examples may, however, make clear how the distinction *is* made in other cultural contexts.

The category of disability has taken form over the centuries. In the English language, the term *cripple* first took on connotations of designating *all* people with identifiable disabilities. But it is undoubtedly the notion of "handicap" that is perhaps best known for being able to apply a particular ideology to a group of people with varying types of disabilities, namely, the ideology of equal chances. This ideology was first developed in the United States, in the context of building a modern, industrial society. The term *handicap* appeared in public discourse around the turn of the century (e.g., in the *New York Times* in 1905). From the United States, the ideology of equality (through many different transformations known as integration or, more recently, as inclusion) reached most, if not all, societies in the world. The ideology of *handicap* reached Europe in the 1950s. However, it appears in legal texts much later (e.g., in Belgium in 1967). In France, the year 1975 constitutes the essential moment of putting in place the politics of *handicap.* From that moment on, *handicap* serves as a unified field of intervention that figures among other social politics. While *handicap* is no longer in favor in the United States and has largely been replaced by the term *disability,* at least in professional and legal language, the term *handicap* survived in many other countries. Because of the many shifts in language, the use of terminology in a text has become an object of careful explanation for many writers, as a matter of political consciousness.

THE PROCESS OF ACQUIRING PEOPLE BY A LABEL

Social scientists have studied the process by which people are enlisted by a label and the consequences of this enlistment for society. Perhaps the most early and well-known studies are in the area of mental retardation. According to one definition of mental retardation, the number of people who could be identified as mentally retarded could be as many as 16 percent of the U.S. population. The identification of people as mentally retarded evidently has direct consequences for the provision of services and the spending of public funds. Labeling people as mentally retarded added also to the stigmatization of people. This was the case with a disproportionate number of ethnic minorities identified as mentally retarded. This issue put into perspective the cultural inadequacies of tests and, more generally, the politics of testing.

The politics of testing in Jordan is put into perspective by what is being tested and what is left out. According to Turmusani (2003), the only national survey ever conducted in Jordan (in 1979) used a definition of disability based on the concept of visibility of impairment, meaning that persons with nonvisible or hidden impairments would not be perceived as disabled. The consequences are both positive and negative since they would not be discriminated against but also not be entitled to services. The political consequence at the national level would, however, be that disability would remain low on the public agenda.

In *The Disabled State,* Stone (1984) describes how the medical profession achieves and exerts power as the gatekeeper in the process of entitling a person with a particular label, thus giving way to a certain treatment by society. In many cases, the relation between society and disabled people is here defined in terms of employment as a contribution to society. Nonemployment can result from not being able to work, which can in turn be the result from a contribution to society. The distinction between "deserving" and "nondeserving" plays an important role in the determination of entitlements.

In a broader framework of the relationships between society as a governing body and disabled people, one can speak of a political economy of disability, which aim it is to explain the occurrence and the magnitude of the existence of disability. In such a perspective, societies are producing disability and disabled people. Disability in this perspective is the very outcome of historical, economic, and political processes that regulate.

At the more intermediate level, Barral et al. (2000) ask what social form do various organizations take that operate in the field of disability. What are the structural or psychological characteristics of the politics in which they are engaged, the status that is given to individuals who are active within these organizations and in the movements that intend to represent disabled people? By investigating the laws in different countries, one can glean at the ways in which "the national obligation" takes place. In France, this takes the form of a mission of prevention, follow-up, and rehabilitation to which private initiative and public action can be associated. On the other hand, it becomes necessary for the French state to install a way of controlling private initiative so that disabled individuals are given a republican guarantee.

THE DISABILITY MOVEMENT

The politics of disability transcends all times and societies. Indeed, the very existence or nonexistence of the category of disability is the result of a negotiation process among individuals in society, a political process with social consequences. However, in recent decades, a disability social movement has arisen in the aftermath of human and civil rights consciousness throughout the world. This development was both spurred by the aftermath of World War II and the development of the United Nations, as well as by the civil rights movements in the United States. In the early developments of the disability movement, Scotch (1984, 1988) researched how disabled people could define themselves as a minority and how a disability movement could emerge in view of its own historical past. In many countries, the movements have accomplished the passing of civil rights legislation, such as the Americans with Disabilities Act in 1990. In particular in the United States, the independent living movement became a strong advocacy and practically oriented means to implement the ideas of the disability movement. The prominence of disability advocacy and the passing of antidiscrimination legislation evolved differently according to the social and cultural contexts. In the United States, it is clearly connected with the civil rights movement and the prominence of individual development. In most of Europe, the development of a disability movement was less strongly developed, in part as a result of strong social security systems. Lee (2002) argues, mainly in reference to Great Britain, that the disability movement has been rather unsuccessful in reaching out to the disabled population as a whole. Moreover, the movement has been dominated and fueled by a very particular constituency, notably those with strong physical and sensory impairments, who are both relatively active and relatively young. On the other hand, the social disability movements in Southern African countries became strongly developed in conjunction with the struggle against apartheid. In still other countries, the (lack of) prominence of the disability movement could be clearly connected to military and government regimes (for examples on Asian countries, see Charlton 1998). The disability movement was supported by some slogans that intended to express the required attitude changes (e.g., "ability, not inability," "no pity," and "nothing about us without us"), expressing wide disparities in the political demands. Following Oliver (1990) and Lee (2002), it can be supported that the disability movement ought to be characterized as a new social movement. It is indeed internationalist, aims at empowerment and consciousness raising, offers a critical evaluation of society, lies at the periphery of the conventional political system, and can be seen to focus on the quality of life of a particular section of society.

The academic and theoretical framework in support of the social movement of disabled people and the emergence of what became known as "disability studies" has been the "social model of disability." This model was first launched primarily by sociologists and political scientists, some of whom had themselves disabilities and engaged as both advocates and academics. This model was usually defined in opposition to either an individual or medical model of disability. In terms of knowledge, an overall focus on the social construction of disability became central. In Britain, the social model of disability has been supported by Marxist ideas that explained the material conditions and the oppression faced by disabled people. In the United States, the social model became more readily interpreted in the analysis of ecologies (i.e., adaptations between people and their environments) and grew into increasing attention to the discriminatory impact of systems and of language use. This also grew into considerable attention to representations of disability in media, history, literature, and visual arts.

During the 2003 European Year of Disabled People, the key emphasis was on the ways disabled and nondisabled people could work together and on the issues of physical, social, and informational accessibility. Such a European perspective therefore frames disabled people as a political entity to be taken into account and also pushes attention to the politics of the environment as the source of disability. In particular, as a follow-up to the International Year, the European Union maintains its goals of achieving equal treatment in employment and adds goals such as reinforcing mainstreaming of disability issues in relevant policies and accessibility for all.

The proliferation of difference in postmodern times has led many groups to claim their own identities and social movements. For disabled people, this has consequences as such proliferation leads at first glance to "forgetting" the difference. Lee (2002) argues that as the environment becomes the focus, it is suggested that differences can simply melt away. This is a politically dangerous idea since it minimizes the necessary social care and accommodations that disabled people require. The difference of disability is equally challenged by the intersection with other groups, such as women, elderly people, and ethnic minorities. In many cases, coalitions with other groups appear to have political implications (for an example, see Iris 2003).

A future disability model that pertains to different social and cultural contexts and to the impact of globalization will have to respond to the fact that various forms of modern society are found throughout the world. In such modern societies, disability is understood with different degrees of emphasis on religious, biomedical, and social-political components. Such a future model could be called "cultural" in the ways it can integrate existing dichotomies that dominate the current understanding of disability. A cultural model would equally emphasize certain universal characteristics of the world today (such as the importance of information and the media) and of disability (such as its challenge of existing cultural orders and therefore its potentially transforming impact on society). Last, a cultural model would be sensitive to our modes of communication as these are affected by historical and cultural developments in the use of spoken and written language, visual imagery, technologies, and aesthetics. Research on the politics of disability that is steered by such a cultural model of disability would continue to emphasize how new modern societies create orders by overcoming old categories and developing new ones that once again produce disability.

—Patrick Devlieger

See also Activism; Developing World; Politics of Disability: International.

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POLITICS OF DISABILITY: POLICIES AND PROTEST

DISABILITY AND POLITICAL ACTION

People with disabilities frequently occupy marginalized social, economic, and political positions in contemporary societies, positions that are only likely to change through effective political action. In recent decades, people with disabilities have increasingly sought to participate collectively in decisions about public policy, both specifically about disability issues and more generally about issues related to participation in governance and the distribution of power. While people with disabilities are almost universally constrained by stigma and limited resources, their political status varies considerably across societies, according to how disability is socially constructed.

In the medical model of disability, which has been predominant in Western culture since the nineteenth century, disability is considered an individualized attribute dispersed across the general population rather than a commonly held position and thus is perceived as not naturally forming the basis for collective political activity. Many disability issues are nominally apolitical, as disability is viewed as inextricably linked to impairment and more a matter for professional treatment than for political action.

Within this construct, whether one has a disability has important consequences, and gatekeeping, the definition of who is and is not considered to have a disability, is considered to be a scientific interpretation linked to impairment and thus is typically managed by medical and rehabilitative professionals. People with disabilities themselves often are not considered to have an appropriate role in public debates over who is entitled to claim public benefits or other entitlements attached to the disabled status.

However, there are considerable political implications within the medical model of disability. Within this conception of disability, the primary question within the politics of disability is reallocative—to what extent public resources should be devoted to medical and rehabilitative services for treatment and to benefits accorded to maintain people with disabilities, who are judged incapable of self-sufficiency. Since disabled people are also considered to be incapable of self-advocacy within this context, such disability politics are typically engaged in by nondisabled advocates rather than by people with disabilities themselves. Thus, in many historical accounts of disability policy debates, people with disabilities are rarely characterized as major political actors, either individually or as an organized interest group. (A prominent exception is the case of disabled veterans, who typically self-identify primarily as veterans who have earned the right to social assistance through their service, rather than as people with disabilities who have needs related to their impairments.)

Taking the lead, rather, are organizations *for* rather than *of* people with disabilities—often charitable organizations or professional service providers led by nondisabled individuals. Political initiatives of this variety frequently emphasize the incapacity associated with disability, as well as the moral blamelessness of "deserving" disabled people, unable to help themselves, whose conditions have been acquired through no fault of their own. Such political discourse frequently features tales of woe about people, particularly children, whose lives will be ruined by their impairments unless help is given.

Many public officials are reluctant to appear insensitive to appeals by those perceived as helpless and blameless, and such political appeals have often been quite successful. At issue in such political discourse is often the moral entitlement of those who are "afflicted," which is based on their impairment being based on random victimization rather than their own choices and behavior. Thus, political debates over disability benefits frequently involve questions of moral entitlement. With the gatekeeping role usually taken by medical professionals, efforts have been made to medicalize a number of conditions to entitle those who have them to a flow of benefits and services earmarked for the "deserving" poor. Questions of personal responsibility may arise, with debates over public funding benefiting people with chronic conditions widely considered to be morally questionable, such as HIV/AIDS, psychiatric disorders, addiction to alcohol or illegal drugs, or learning disabilities.

Nonmedical models of disabilities are associated with quite different political forms, issues, and dynamics. A sociopolitical model of disability conceptualizes disability as a social and political construction that is the result of interaction between physical or mental impairment and the social environment. Technology, architecture, and spatial organization all reflect concepts of what is "normal" and how "normal" people function, as do cultural attitudes and institutional processes. These social characteristics help to define who is “disabled” and who is “normal,” as well as what constitutes an appropriate social response to those who have a disability.

The politics of disability takes far different forms within the sociopolitical model than would be expected in the medical model. Political issues are not simply reallocative, although disputes over resources are found here, too, but may also include conflict over what social roles can appropriately be played by individuals who have disabilities and how the state should support or restrict those roles through its policies. A sociopolitical model of disability would lead one to expect political conflict over issues such as the appropriate role for people with disabilities in education, employment, public services such as transportation, economic development, and participation in civic life. Organizations composed of people with disabilities are prominent in such political activities, groups whose membership and leadership are individuals who themselves have disabilities.

By characterizing the social isolation and enforced dependency of people with disabilities as the result of social choices rather than as inevitable results of impairment, the sociopolitical model suggests analogies between the social status of people with disabilities and other marginalized groups such as racial and ethnic minorities, women, or gays and lesbians. Within this political framework, disability politics can encompass disputes over civil rights (in the American context) or human rights (in the European context and in non-Western societies around the world). Similarly, politics encompasses conflicts over the role of disabled people collectively in the governance of service systems and other institutions addressing the disability community and the role of individuals with disabilities in shaping and controlling the services they receive.

In recent decades, as the dominance of the medical model has diminished, the sociopolitical model has become more prevalent. In such a sociopolitical model, people with disabilities may be grouped together into common medical, educational rehabilitative, human service, and custodial systems, but the establishment of such systems and the definition of who is to be considered disabled vary across cultures and historical periods. Gatekeeping under a sociopolitical model of disability is not solely the province of medical and rehabilitation professionals but can be contested by many within society, particularly by people with disabilities themselves.

DISABILITY IDENTITY AND POLITICAL REPRESENTATION

Disability politics increasingly involves advocates who have disabilities, although individuals with disabilities do not necessarily share the political perspective held by the majority of people with disabilities within a society. The label of having a disability may be taken or rejected by individuals with impairments as well as by others. In some instances, vanguard groups have celebrated their identity as people with disabilities, promoted disability culture, and embraced a belief in “disability pride.” For others, stigma is perceived as associated with disability. People may be reluctant to self-identify as disabled; they may seek to hide their impairment or to portray its effect on their lives as minimal. Even people with significant impairments that interfere with important life functions may not consider themselves to be in a similar situation as others with the same impairments, let alone with quite different ones, and may be unwilling to be visibly associated with them.

Even when individuals self-identify as disabled, having a disability does not in itself inevitably lead to participation in collective political action with others who have disabilities. Many political constituencies form on the bases of spatial propinquity and/or out of already socially cohesive groups. Because impairments are spread spatially and demographically throughout the general population, people with disabilities may not find themselves in naturally occurring communities of their peers; they typically grow up within families of people who do not share the experience of disability and must seek out others like themselves. Thus, while some disability advocates commonly refer to the “disability community,” those who actively identify with this community may include only a portion of the substantial number of people with disabilities in any society.

One issue that often arises within disability politics is that of who may legitimately represent the broader disability community, which is diverse in terms of impairments, demographics, socioeconomic status, and cultural perspective. This dilemma is reduced when diverse people with disabilities representing a variety of constituencies are engaged in politics, rather than a few token individuals purporting to represent a single disability community. At the high end of representation, for example, a total of approximately 47,000 Ugandans with disabilities serve in the country's governing bodies, including 40,000 who have been elected at the village level.

This strong national presence of persons with disabilities is unique, but increased political participation by people with disabilities has occurred in many nations around the world, often in accordance with growing democratization and concerns about representation of diverse minority interests. In the Soviet Union, along with a number of other political organizations founded in the wake of the Helsinki Accords in the late 1970s, the Action Group to Defend the Rights of the Disabled in the USSR was founded in 1978 to advocate for legal rights for Soviets with disabilities. In the Philippines, a national political party was recently established to represent the interests of disabled persons.

Many individuals with disabilities have challenged the legitimacy of political representation by anyone but those who themselves have disabilities. These advocates question whose interests actually are advanced by nondisabled service providers and contend that only people with disabilities should speak on their own behalf. Such issues of representation have been applied to parents or other family members of disabled individuals; some contend that parents should be viewed as a part of the "disability community" and allowed to represent that community in political forums, while others strongly disagree. These questions become even more complex when applied to individuals with severe cognitive or psychiatric impairments who may have difficulty articulating their own interests in political discourse. However, whenever disability is created as a social category, particularly through public policy and the provision of health and social services, those defined as having a disability have the potential to become a distinct political interest group that may become capable of mobilization and political action.

There are numerous examples of people with disabilities engaged in protests or forming organizations on their own behalf. In the past four decades, political activity by individuals with disabilities and organizations of disabled people has particularly increased, and much of that activity has been directed toward the goals of equal access, community integration, and independent living. Among the explanations that have been offered for this increase are emerging medical and assistive technologies that have supported independence for many people with disabilities, changing ideologies of treatment that have encouraged noninstitutional service strategies, and the models of other minority movements in the 1960s and 1970s that advocated for inclusion and social change.

LEGAL ADVOCACY

Some efforts to redefine the social position of people have occurred through legal advocacy in the courts, particularly in the United States. Enabled by the distinctive American constitutional and legal framework and building on the civil rights advocacy that fought racial segregation through federal lawsuits in the post–World War II era, a number of class action suits were successfully pursued in the late 1960s and 1970s on behalf of children denied public school education because of their disabilities, people with disabilities receiving inappropriate treatment in residential institutions, and others denied fair treatment because of their disabilities. These lawsuits were often the product of advocacy groups representing parents of children with disabilities working in partnership with public interest law centers.

Key judicial rulings have helped to establish legal protections for disabled people and foster the growing disability rights movement in the United States. In the American disability policy context, with its emphasis on civil rights, legal advocacy has been a crucial component in ensuring that broader public policies are applied appropriately to individual cases. Legal organizations such as the Disability Rights Education and Defense Fund and the Bazelon Center for Mental Health Law have been valuable resources in the protection of individuals with disabilities. Yet in the absence of more broadly based political advocacy, litigation-based political strategies tend to be episodic and non-self-enforcing and may have a limited capacity to effect institutional change. Such advocacy is most effective when it is part of a wider political mobilization of people with disabilities on their own behalf, a process that requires both social solidarity and collective action.

ELECTORAL POLITICS

Participation in electoral politics is a potentially important avenue for people with disabilities to secure their political voice, yet Americans who have disabilities are much less likely to register and vote than are nondisabled individuals. For example, in the 1994 election, 56 percent of people with disabilities were registered to vote, as compared to 71 percent of nondisabled individuals; only 33 percent of people with disabilities reported voting, as compared to 54 percent of nondisabled individuals.

While there has been little research on possible explanations for this pattern, one factor may be accessibility of the polling place, where individuals with disabilities may encounter a variety of architectural barriers. Another issue is the receptivity and responsiveness of election officials. At times, election officials may become sufficiently frustrated with meeting accessibility needs, so they urge the disabled voter to vote absentee, although some individuals with disabilities view absentee voting as an inferior form of participation. People with mental retardation, blindness, or deafness are sometimes subjected to challenges or have to encounter election officials who are uninformed about their accommodation needs or who resist taking the necessary steps to make the voting process or polling place accessible.

In addition to these physical and attitudinal barriers, policy barriers may affect participation. In the United States, 44 states disenfranchise some individuals with cognitive and emotional impairments, and England's Representation of the People Act 1983 disenfranchises people who have been involuntarily admitted to mental hospitals. Similarly, the constitution of Albania prohibits voting by individuals who have been adjudicated incompetent.

PEOPLE WITH DISABILITIES AS POLITICAL CANDIDATES AND ELECTED OFFICIALS

Persons with disabilities hold or have held elected offices in several countries, and this may help to shape the electorate's response to people with disabilities and the problem of disability. These include Joshua Malinga of Zimbabwe, who was mayor of Bulawayo; Joseph Sinyo of Kenya, a member of the national parliament; Kalle Konkkola, who has served on the city council of Helsinki, Finland; Midori Hirano, of Japan, who was elected in 1998 to the Kumamoto Prefecture; a Philippines congressman, Ernesto Herrera; and several individuals with disabilities who have served or are serving in the national parliament of South Africa.

Informal observations of U.S. politics indicate that disability is often an issue in campaigns, particularly contests for the presidency. In the 1996 American campaign, for example, the Republican Party candidate, Senator Robert Dole, was a World War II veteran who had lost the use of his arm from an injury sustained in combat, whose disability was labeled a badge of honor. The Democratic Party candidate, Bill Clinton, is not disabled, but the Democratic national convention featured an address by Christopher Reeve, an actor who had become quadriplegic after a riding accident. Reeve, a controversial figure in the U.S. disability community, issued a plea for funding for research to cure paralysis. In neither of these instances was civil rights for people with disabilities a major focus of the campaign message, although in both parties' campaigns, disability rights was a minor emphasis.

Because they tend to be less affluent than nondisabled individuals, people with disabilities around the world are less likely to have the wherewithal to contribute money, time, or other resources to political candidates. To the extent that these circumstances make their voice less likely to be heard in the electoral process, people with disabilities will be disadvantaged in democratic governance.

LOBBYING AND PRESSURE GROUPS

In addition to participation as elected officials or through political parties, disabled people in many nations have formed organizations whose purpose is to represent the disability community and influence governmental bodies responsible for the enactment and implementation of public policy. While there is a long history of political activity by and on behalf of people with disabilities, disability politics has become far more widespread in the post–World War II era, particularly in the last three decades of the twentieth century, building on the example of similar movements for self-determination and inclusion by other politically marginalized social groups around the world.

In recent decades, a number of umbrella organizations have been formed to coordinate political activity and speak with one voice on behalf of the disability community. In Great Britain, for example, the British Council of Disabled Peoples (BCODP) formed in 1981 to represent 80 organizations and approximately 200,000 Britons with disabilities. In the United States, the American Coalition of Citizens with Disabilities was organized in 1975, with 19 constituent groups. In Canada, the Coalition of Citizens with Disabilities (CCD) was founded in 1976 with affiliates from most Canadian provinces. In Denmark, De Samvirkende Invalideorganisationer (DSI) has been active for decades in promoting the integration into Danish society of Danes with disabilities.

Parallel to the formation of these national coalitions has been the creation of cross-national coalitions. Some international groups have organized around specific disabilities, such as the African Union of the Blind, founded in 1987, whose activities have been supported by the Norwegian Association of the Blind and Partially Sighted. In 1981, Disabled Peoples' International (DPI) was formed, an international cross-disability coalition of more than 110 organizations, including many from developing nations in Latin America, Africa, and Asia. DPI has been particularly active in advocating for disability rights in international governmental and particularly nongovernmental activities, as well as in supporting the development of organizations of people with disabilities around the world. Pelka (1997:103) quotes Joshua Malinga, a former DPI chairperson from Zimbabwe, who remembered the 1980 organizational meeting of DPI in Singapore: "It was at this meeting that most of us from Africa first understood what was meant by a 'disability rights movement.' We had never thought about disabled rights as a cause, to the disabled community as a community. . . . It was a shift from looking at disability as a health issue, to looking at it as a human rights issue."

Perhaps the most established political role for disability advocates has been in the United States, where a number of organizations maintain active lobbying roles in Washington and many state capitals. Representatives of disability organizations in the United States played an extensive and significant role in disability policy development in the 1970s and 1980s. In Scandinavian nations, disability policies have been shaped by disabled representatives of community-based disability organizations. Organizations of people with disabilities in many other countries, including Canada, Singapore, England, Ireland, and the Netherlands, have participated in the reformulation of outdated disability policies.

Most American disability policies since the mid-1970s, including the landmark Americans with Disabilities Act, have been drafted with the active participation of representatives of organizations of disabled people, and in the 1990s, many appointed government officials responsible for making and enforcing government disability policies were recruited to their posts from organizations of people with disabilities. In a number of instances, the prior connections among government appointees from the disability movement have meant that the long-standing absence of communication and cooperation among competing public bureaucracies has been overcome.

While access to positions of power and influence has had many important benefits for the disability community, it has often created dilemmas for those holding them, who must balance their loyalties to their constituencies with the practical considerations of public policy making. Nevertheless, since so many aspects of life for people with disabilities are shaped by public policy, institutionalized participation in policy debates within government appears to have incorporated the experience of disability into many policy decisions. Where regular participation does not occur, however, disability advocates may need to turn to more contentious nonelectoral political action to represent their own interests.

PROTEST POLITICS

Disability protestors have been willing to confront public officials, block traffic, occupy public places and government offices, or be arrested for their causes. In 1972, for example, members of the cross-disability group Disabled in Action blocked traffic in the New York financial district. In 1981 in Canada, coordinated national protests were organized by the Council of Canadians with Disabilities to advocate for a Human Rights Amendment to protect the civil rights of Canadians with disabilities.

Through much of the 1980s, members of ADAPT (originally Americans Disabled for Accessible Public Transit) chained themselves to buses and disrupted meetings of the American Public Transit Association to protest inaccessible public transportation. Following the enactment of the Americans with Disabilities Act, ADAPT changed its name to Americans Disabled for Attendant Programs and has conducted numerous protests against the unnecessary institutionalization of people with disabilities in nursing homes. In 1988, deaf students at Gallaudet University in Washington, D.C., forced the closure of their campus for a week, demanding that a deaf person be hired as university president. British organizations of people with disabilities have engaged in similar disruptive tactics; Gooding (1994:160) cites a 1993 *New Statesman* report of a national register maintained by the Direct Action Network of more than a thousand disability activists willing to take part in civil disobedience.

Typically, protests involve not just short-term objectives but also a sense of shared purpose based in a vision of an alternative to existing social arrangements. The goal of an inclusive, barrier-free society may motivate disability activists beyond the specifics of an exclusionary policy or demeaning practice. It is such a vision that will increasingly serve as the basis for disability politics.

—Richard Scotch and Kay Schriner

See also Activism; ADAPT; Advocacy; Disability Pride; Lobbying; Politics of Disability: International; Voting.

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POOR LAWS (UNITED KINGDOM)

The English poor laws consist of the parliamentary legislation, as well as subsequent practice, related to the public relief and control of the impoverished, including the disabled poor. The period from 1531 to 1834 is known as that of the *old* poor law, with an emphasis on parochial, predominately noninstitutional, provision (outdoor relief). From 1834 to 1929, the *new* poor law involved national supervision and extensive use of workhouses.

Responding to concerns about the social order and influenced by Christian humanism, the sixteenth-century elites passed legislation initially to punish vagrants but later to identify and relieve needy paupers. In 1572, England became the only country in Europe to permit parish authorities to regularly levy poor rates (compulsory property taxes). In 1598 and 1601, further legislation *required* parishes to levy rates, to punish vagrants, to provide outdoor relief (usually a pension) for those disabled to work, and to provide work for the able-bodied. Further legislation included a 1662 act establishing settlement laws limiting migration and providing a way for paupers to establish a right to relief in their "home" parish (usually where they were born), with the right to appeal to local justices of the peace.

In the seventeenth century, the system spread in practice throughout the country, and pension numbers and levels grew substantially. Disability to work was the test in practice, with the elderly, those disabled on the job, the feebleminded, and war widows given priority. Medical care was provided. Institutions were increasingly established (almshouses, workhouses). From 1593 to 1679, thousands of disabled veterans were relieved via a statutory, county-based pension system administered by county justices and paid for by taxes (after 1679, the central government took over this responsibility).

From 1700, workhouses increasingly included infirmaries that provided medical care. It has been argued that the sick and disabled had more control over their lives and bodies on out-pension (noninstitutional) than in-house (institutional). Others argue that the infirmaries provided much-needed medical attention for those with disabling conditions such as syphilis. "Out relief" continued, with relief manipulated by employers to top up and consequentially depress wages.

The costs of the poor law came under increasing scrutiny, with many assuming the poor were unwilling to work. In 1834, a new poor law was enacted that created a uniform national system, with parishes joining together in unions running workhouses controlled by Boards of Governors. Outdoor relief was significantly curtailed. The disabled had to be prepared to enter the workhouse to be relieved. Conditions within some of the workhouses were appalling.

In 1929, the Local Government Act officially abolished the Boards of Governors and workhouses, although many related aspects of the poor laws continued to be implemented for some time.

Throughout the history of the poor laws, the actions of the disabled poor themselves were an important factor in the growth of the system, as well as changes in practice, particularly at the local level. The disabled increasingly felt entitled to relief and negotiated as best they could to that end.

—Geoffrey L. Hudson

See also Poverty; Veterans.

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POPE, ALEXANDER (1688–1744)

Eighteenth-century English poet

Alexander Pope, eighteenth-century England's most celebrated poet and his generation's most frequently portrayed celebrity, dominated the emergent literary marketplace as the first self-supporting, nonplaywriting professional author while fascinating his audience as a spectacle of deformity. Characterizing the career of a wit as "a warfare upon earth" and complaining in his *Epistle to Arbuthnot* of "this long disease, my life," this master of the heroic couplet endured a war between an exceptional mind and a body lambasted as "at once resemblance and disgrace" of humanity's "noble race." Barely four and a half feet tall when grown—in Voltaire's words, "protuberant before and behind" (speculation as to the cause of his deformity has ranged from tuberculosis of the spine contracted from a wet nurse, to trampling by a cow, to excessive study)—and socially disenfranchised for his Catholicism, Pope transformed his marginality into a vehicle for self-reflection, self-representation, self-possession, and self-legitimation. His life's work was the ultimate couplet of deformity and poetic form. Mocked early on as "the ladies' plaything" for a best-selling translation of Homer appealing to a nonaristocratic and female audience (a serious attempt at post-Miltonic epic refracted in his mock-heroic mirror *The Rape of the Lock*), at his career's close, the Tory satirist cast himself as a hypermasculine epic hero embodying moral integrity in an age of beautiful hypocrisy. Radically conservative in his final nostalgic critique of British economic and imperial progress, innovative in his exploitation of the literary marketplace, Pope embodied, negotiated, and redefined the ambiguities of his age. When the curtain falls at the end of *The Dunciad* and "universal Darkness buries all," Pope's couplet art concludes triumphantly by envisioning art's destruction.

—*Helen Deutsch*

See also Poetry.

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POSSESSION

See Witchcraft

POSTCOLONIALISM

Only recently have scholars in both disability studies and postcolonial studies attempted to explore the intersections between these two areas of scholarship. Disability studies' scholars have ventured into global contexts to explore the intersection of disability and culture in comparative perspective and/or have explored the impact of globalization on disabled people internationally. However, they have only very rarely situated these same discussions within the political space of postcoloniality—a space that postcolonial scholars would argue provides a very different analysis of the global.

Postcolonialism, in its broadest representation, foregrounds the effects of imperialism and exploitation as a result of the colonization of specific cultures and societies, but this representation has itself been widely contested. While on one hand, the term *post* in *postcolonialism* clearly highlights a historical dimension to the discussion (i.e., "after" colonialism), this position has been contested by other postcolonial scholars who argue that colonialism has become transhistorical because the effects of imperialism and exploitation continue to affect the former colonies via the neoliberal policies of globalization. Other postcolonial scholars have broadened this focus to include discursive analyses of postcolonial culture that foreground contradictions, ambiguities, ambivalences, and ruptures. In this case, the *post* in *postcolonial* foregrounds a more nuanced discourse that supports "going beyond" materialist analyses of contemporary culture to foreground radical possibilities of movement, fluidity, and mobility that produce hybrid (postcolonial) subjects.

It is in engaging Otherness that scholars in both postcolonial studies and disability studies find common ground, especially in their deconstructive analyses of how representation, hegemony, and normativity produce both the postcolonial and the disabled Other. For example, postcolonial studies scholars have described how the colonized body has been constituted as the abject Other when situated in opposition to the “civilized, civilizing, [and] normal” body of the colonizer. Similarly, disability studies scholars have also demonstrated how the Western paradigm of knowledge has produced specific ideological representations of the “normate” through a series of exclusions that constitute the disabled Other as outside the purview of rights-bearing humanity.

These ideological representations of the colonized and disabled Other often draw on the presumed interrelationships between physiognomic factors and social/geographical environments. For example, even though John Langdon Down (Jackson 1999) recognized differences between those he termed “mongoloid idiots” and the “real Mongols,” he still saw what he claimed were unmistakable similarities and considered these combined physical and mental features of this ethnic group as pathognomonic of a distinct and prevalent class or type of idiocy. Even though this was refuted in later years, the racial assumptions inherent in his study continue to persist such that, on one hand, “mental defectives” became metaphorically as well as literally “a race apart,” and at the same time, the racialized Other was seen as “mentally defective” and in dire need of civilization via colonialism. As a result, just as it was imperative that attempts be made to tame the savage racialized Other in the colonies, the minds and bodies of the “idiot,” the “imbecile,” and the “feebleminded” were also to be subdued and domesticated in the segregated internal colonies of state institutions.

The oppressive interrelationship between disability and colonialism was epitomized in the freak show, a popular form of entertainment that had its heyday in the United States from 1840 until about 1940. Of particular interest to this discussion are those “freaks” who were exhibited as the exotic mode. This was a mode of presentation that accentuated the culturally strange, the primitive, the bestial, and the exotic. Promoters of the shows claimed that their exhibits came from mysterious parts of the world—darkest Africa, the wilds of Borneo, a Turkish harem, and an ancient Aztec kingdom. Many of these exhibits were non-Western people with demonstrable physical differences who were exhibited in the exotic mode by emphasizing their anomalies as well as their “strange ways,” and though they were nondisabled, they were exhibited alongside native-born Americans with disabilities. One of the most famous examples of such an exhibit was the “Hottentot Venus,” whose enlarged labia and buttocks were accentuated to foreground her savage sensuousness and mark her as measurably different from the European woman. Moreover, in another blatant distortion of presentation that brought together both disability and colonialism, native-born Americans with disabilities were misrepresented as savage foreigners (e.g., Ohio-raised dwarfs as the “Wild Men from Borneo”; African Americans with microcephalus from Alabama as members of the Ituri—a head-binding African tribe). While such exhibits at the freak shows were arguably presented as entertainment, at the same time, they also provided a quasi-scientific basis for the justification of both slavery and colonialism by depicting the nonwhite world as childlike, barbaric, and dangerous and therefore in desperate need of the civilizing influence of the West.

A critique of Western science and its devastating effects on both the disabled and the colonized Other is yet another commonality shared by both postcolonial and disability studies scholars. According to postcolonial scholars, Western medicine, armed with an enormous battery of tests and discursive practices that focused specifically on the physical and mental constitution of the colonized body, extended its reach beyond mere scientific interest to explore and use its knowledge to further the authority, legitimacy, and control of the colonial state. Describing a similar history of the asylum on Robben Island, South Africa, postcolonial scholarship describes how the racial superiority of the white settler over the African native was codified in the science of ethnopsychiatry. Unlike the European “madman,” whose insanity was seen as physiological, the African “madman’s” insanity was attributed to his racially determined incapacity to cope with the stresses of urbanization and civilization and was therefore provided physical rather than psychological therapy, with the therapeutic purpose of introducing the African to civilization. Such examples demonstrate how Western science used specific ableist and racist discourses to justify European control of its colonies even in the face of Enlightenment ideals of universal humanity.

With this oppressive context as their historical backdrop, postcolonial subjects have attempted to distance themselves from what they perceive as a stigmatizing context of disability and, in doing so, have failed to realize the emancipatory possibilities of forging a political alliance with disabled people. In fact, postcolonial scholars, for the most part, almost never recognize disability as a political construct and, as a result, seldom include disability in their analyses of difference. When disability does appear in their analyses, it is often used as a metaphor to describe the colonized condition.

For example, postcolonial analyses have explained how, under the censorship of Japanese colonialism, Korean writers often drew on the trope of disability to create characters who lacked freedom in bodily function and movement. Casting their literary work in metaphorical terms as the textual body impaired by the violence of colonialism, these writers overturned traditional views of disabled people as abject citizens by recasting them along with the colonized (disabled) nation-state as a bearer of rights. The silencing of these writers by colonial censors also represented a shared critical relationship with disability such that just as the physically disabled were constituted as objects of colonial hygiene and social control, these intellectuals were also constituted as objects of thought control and censorship. In this way, Korean writers produced literature that was encoded with anticolonial and anticapitalist messages of protest by using disability as the discursive means to articulate various positions of their colonial destiny, ranging from internal critique and self-criticism to objection of their unfree colonial situation.

The radical potential of disability in postcolonial literature is also echoed by various postcolonial literary critics. According to these analyses, because the postcolonial subject is forced to enter into a multiple symbolic order (e.g., colonial, native, and postcolonial/neocolonial contexts), he or she is forced to go through (as per Lacanian psychoanalytic theory) multiple castrations to achieve wholeness and, as a result, experiences symbolic deformity—entering into a condition, sometimes problematically described as “disability.” At the same time, some scholars also realize the radical possibilities for the “disabled” postcolonial subject in this context as it enters into a combat over meaning by using one cultural/symbolic system against another. This space where disability and postcoloniality intersect has been described as the “third dimension,” where the Self can no longer be contained within the simplistic binary of Self/Other, thereby producing an identity that is both ambivalent and muted. Located now at the point of slippage between identity categories, the disabled postcolonial subject appears as the “evil eye”—the figure that resists the image of totality that is critical in the myths used by both the colonizer and the colonized. However, some scholars have been quick to point out that postcolonial authors often fail to capitalize on this radical potential of disability in their novels and have instead characterized the disabled body as a docile body against which nationalist tensions can be arbitrated and against which a rationalist ideology can pull “a collection of disparate peoples into a self-identified nation” (Lacom 2002:141). In this way, national identity is consolidated so as to maintain the differentiation of the national “us” from aliens within and without. Unfortunately, such efforts fail to serve the interests of both the postcolonial and disabled subjects because they continue to support oppressive representations invested in tragedy and exoticism.

Just as postcolonial scholars have used disability as a metaphor to represent their oppression under colonial rule, disability studies’ scholars have also appealed to the metaphor of colonialism to depict and explain the social oppression of disabled people. For example, some scholars describe the harsh and delimiting educational segregation of students with disabilities in U.S. public schools as mimicking the historical trajectory of colonialism. Others point out that just as emerging European states drew on particular notions of normality to support their project of imperialism, these same states looked inward at the human variation among their own people and produced a form of internal colonization that supported a dehumanizing view of disability. In educational contexts, in particular, these oppressive beliefs about disability have resulted in disabled students experiencing a “pedagogy of control” that, according to authors, mirrors the forced labor and absolute confinement that was experienced by those living in the colonies. In addition, scholars have likened the struggles for equal schooling for disabled students as a decolonization effort that has sought to challenge the social hierarchies that have reduced disabled students to the status of defective and dependent citizens.

What is apparent in the previous examples is that the metaphoric representations of both the colonized and disabled Other hold emancipatory possibilities for each other. At the same time, these metaphoric discourses of Otherness sometimes fail to account for and/or describe the actual experiences of disabled postcolonial subjects living in the former colonies that constitute the so-called Third World. Already living in impoverished conditions in nation-states incapable of providing an economic safety net for even their nondisabled citizens, disabled citizens living in postcolonial contexts continue to struggle for survival amid conditions of abject poverty; unemployment; lack of adequate medical care, education, and assistive technology; and the denial of basic human rights.

These conditions have been exacerbated in recent years by the neoliberal policies of the World Bank and the International Monetary Fund, which support economic austerity measures to be implemented by countries that had defaulted in their payment of debts incurred as a result of more than a century of colonial economic exploitation. These austerity measures, called structural adjustments policies (SAPs), are specifically designed to cut public spending in the areas of health, education, and public welfare in an attempt to support sustained economic growth and eventually lead to a reduction in poverty. However, as a result of these policies, there has been a drop of 10 to 25 percent in average incomes, a 25 percent reduction in spending per capita on health, and a 50 percent reduction in spending per capita on education in the poorest countries in the world—material conditions that set the stage for the social construction of disability. In addition, the World Bank uses the concept of the DALY (disability-adjusted life years) to prioritize health interventions by calculating their relative cost-effectiveness measured by the number of DALYs saved through each intervention, where the cost of each intervention is weighed against the person's potential "productivity' (i.e., contribution to economic growth). Here postcolonial disabled citizens who are unable to work are awarded zero value and therefore have little or no entitlement to health services at public expense. In this context, postcolonial conditions are seen to once again support the oppression of disabled citizens.

—Nirmala Erevelles

See also Freak Show; Globalization; Poverty.

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POSTER CHILD

Poster children are persons with disabilities portrayed in the media (e.g., newspaper, television, and publicly displayed posters) to encourage the public to donate money to organizations set up to help persons with disabilities. Most of the general population views disability as a statistical tragedy and often is not familiar with anyone who has a disability. In portrayals of poster children, the emphasis tends to be placed on the difficulties these individuals face, and the language tends to be negative, referring to the persons with disabilities as victims and sufferers who spend their life waiting for a cure. Poster children tend to be children because it is easier to portray children than adults as innocent victims. The vivid portrayal of the "tragedy" of an adorable child with a disability touches the emotional hearts of the viewers by eliciting feelings of pity and guilt, which in turn stimulate individuals to donate money to help these "helpless" individuals.

Throughout the past century, the media have used poster children to collect large sums of money. During the nineteenth century, religion-based charities often took on the responsibility for persons with disabilities. The concept of the poster child was invented at the beginning of the twentieth century, when volunteer organizations were developed that depended on donations. In 1919, Edgar "Daddy" Allen, a businessman from Ohio, founded the Society for Crippled Children, today's Easter Seals, and during the 1920s, Franklin D. Roosevelt inspired the March of Dimes. Today, when 99 percent of families own televisions, telethons have become a popular method for reaching large numbers of potential donors. The telethons portray the struggles of persons with disabilities, most of them cute disabled children, and their families (e.g., Jerry Lewis's Muscular Dystrophy telethon on Labor Day).

Although these organizations are set up to help persons with disabilities, an increasing number of disabled individuals, including former poster children, criticize them. Common criticisms include the following: these organizations have developed into million/billion-dollar enterprises, which have lost sight of their original goals; the organizations exploit poster children; primarily nondisabled individuals run the organizations; and disabled people are not consulted on how the money is used. In fact, many disabled individuals oppose using contributed money for various types of therapy (e.g., surgery and physical therapy), preferring instead that it be used to provide disabled individuals with necessary aids to live full and productive lives and to make built environments more accessible. The organizations tend to deny the various criticisms or insist that the protestors' opinions are not representative of larger groups.

The portrayals of poster children may have a negative impact on disabled children, especially those without disabled adult role models, because the children may learn to view their disability as a defect that needs to be cured. By overemphasizing the struggles in their lives, the children may reject (this part of) themselves. This rejection in turn can lead to insecurity, depression, anxiety, or other types of psychopathology, thus affecting disabled individuals into adulthood. The portrayals can affect children directly, by being poster children or seeing the portrayals, and indirectly, by interacting with members of society who have seen these portrayals and adopted the perspective that disability is a defect.

—Ingrid C. Hofmann

See also Easter Seals; Telethon.

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POSTTRAUMATIC STRESS DISORDER

A person's life can be interrupted by sudden, unexpected, and uncontrollable events involving death, injury, inflicted pain, or threat to self-integrity. Such events are very distressing. With time and appropriate support from others, distress and sorrow subside in most survivors, leaving scars but no open wounds. Some, however, do not recover and develop prolonged and disabling mental conditions. Posttraumatic stress disorder (PTSD) is the prototype of prolonged psychological disturbance that follows a stressful event.

Known since ancient time and masterfully described following World War I, PTSD was formally delineated in a classification of mental disorder in 1980 (*Diagnostic and Statistical Manual of Mental Disorders,* third edition [*DSM-III*]). The definition was further refined in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*). Some PTSD symptoms are directly related to the triggering event. These include reliving the traumatic experience through distressing and intrusive flashbacks, nightmares, heightened sensitivity to reminders of the event, and fearful avoidance of places, situations, or mental representations of the traumatic event. Other PTSD symptoms resemble depression and anxiety: loss of interest in previously pleasurable activities, restriction of one's emotional life, irritation, trouble falling or staying asleep, jumpiness, and constant vigilance.

For PTSD patients, therefore, the traumatic event is ever present and extremely demanding. A war veteran with PTSD may feel that the war "never ends." Combat scenes may continue to intrude into his or her consciousness, and he or she might experience an overpowering need to remain vigilant and defensive (e.g., scan building roofs for potential snipers). Survivors of terrorist attacks will, similarly, feel that another attack is imminent and behave accordingly. Rape survivors with PTSD might find it difficult to freely engage in sexual activity—even with known and beloved partners. As in other anxiety disorders, PTSD patients are well aware of the irrational nature of their fears but are trapped and overpowered by them.

Because many PTSD symptoms evoke the traumatic event, a prevalent theory explains the disorder as an inappropriate acquisition of fear responses during the event. Specifically, it has been argued that those brain areas that mediate fear responses (such as the amygdala) come to control and dominate PTSD patients' emotional and cognitive life. Brain-imaging research has shown that trauma survivors with PTSD tend to activate the brain's alarm system whenever confronted with novelty or challenge.

PTSD does not develop in every survivor. Inherited vulnerability and lifetime exposure to trauma increase the risk of developing PTSD. Adequate support and a nurturing recovery environment in the aftermath of traumatic events help protect survivors from developing the disorder. PTSD symptoms can be alleviated by pharmacological agents from the family of selective serotonin receptor inhibitors (SSRIs) and by psychological treatment (such as cognitive or cognitive-behavioral therapy).

Some writers have challenged the validity of this syndrome, arguing that PTSD is an artifact that reflects skewed social perception of normalcy and pathology. Clinicians are well aware of the suffering of PTSD patients and, while admitting that the definition of PTSD might be imperfect, use this diagnosis and the related research findings in the best interest of their patients.

—Arieh Y. Shalev

See also Mental Illness; Psychiatric Disorders; Stress.

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POVERTY

A family is considered poor when their monthly income is less than the income threshold set by the particular country's census bureau. Poor families do not have adequate income to cover their basic needs, including food and shelter. People living in poverty are more likely to be unemployed, have limited education, and are more likely to lack health care. An increasing number of people with disabilities, including children and adults, live in poverty.

Poverty is both a cause and consequence of disability. Several reports have found a strong correlation between disability and poverty and have described them as being cyclical in nature. First, living in poverty has implications for being at increased risk for developing a disability. Pregnant women living in poverty are less likely to receive prenatal care and are at higher risk for having low-birthweight babies and birth complications that place them and their offspring at a higher risk for experiencing disabilities. Also, people living in poverty are more likely to have either insufficient or unhealthy nutrition and live in conditions that put them at high risk for exposure to malnutrition, hazardous working conditions, and unhygienic living conditions, increasing their likelihood of developing impairments. Second, having a disability can lead to poverty. It is estimated that people with disabilities are three times more likely to live in poverty than the population as a whole. Individuals with disabilities experience additional stressors and expenses related to daily living. These include expensive assistive devices/adaptive equipment for increased functioning, home modifications expenses, health care attendant costs, special services (e.g., interpreters), extra transportation expenses, and health care costs.

Individuals with severe disabilities are more likely to experience difficulty seeking and maintaining employment. They are more likely to receive welfare benefits and less likely to have health insurance. All of these difficulties, combined with the marginalization from community and social activities, increase the likelihood of leading a life of poverty. According to the 2001 census data for the United States, only 48 percent of citizens 25 to 64 years old with severe disabilities have health insurance compared with 80 percent of individuals with nonsevere disabilities and 82 percent of nondisabled Americans.

In the United States, at least half of the adults with disabilities who cannot work because of a chronic disease or disability receive federal cash benefits under Social Security Disability Insurance (SSDI) and Social Security Insurance (SSI), and some may qualify for Medicaid and Medicare. The paperwork and bureaucracy involved in receiving this income are complex. Even if an individual successfully obtains these supplements, the small monthly income is often not sufficient to cover living expenses. In brief, having a disability has three different types of consequences that increase the likelihood of experiencing poverty for the individual and the immediate family. These consequences include (a) the income lost due to incapacity and discrimination; (b) the direct cost of treatment, access, and accommodations; and (c) the indirect costs to family caretakers who are not necessarily directly affected by the disability. Caregivers may have to quit their jobs or accept only part-time jobs so that they can care for the family member with a disability.

Women with disabilities in general are also more likely to live in poverty than men. Disabled women, compared with men with disabilities, are likely to have fewer years of formal education, less likely to have health care and to be employed, and, if employed, likely to be earning less income. A similar outlook has been reported for the elderly with disabilities worldwide. It has been reported that the proportion of the elderly with disabilities living at or below the poverty line, with limited health care, limited income to meet their daily needs, and limited access to attendant care, transportation, and assistive devices, is higher than younger adults with disabilities.

Adults are not the only ones affected by the relationship of poverty and disability. Children living in poverty are particularly at risk for having a disability. For example, in 2003 in the United States, it was estimated that about 28 percent of children with disabilities were living in poor families compared with 16 percent of all children. Poverty affects a child's development and learning, and in turn, the presence or onset of a disability exacerbates poverty. Children living in poverty have a higher incidence of malnourishment and exposure to environmental toxins; furthermore, poverty contributes to other factors such as parental stress and reduced exposure to a healthy and safe learning environment. Children with disabilities living in poverty are more likely to be neglected and malnourished and are more likely to die young than nondisabled children. Antipoverty programs need to closely examine the needs of families with children with disabilities who may experience emotional and material hardships.

Researchers have also highlighted the relationship between race, poverty, and disability in the United States. Minorities with disabilities (including

Hispanics, African Americans, and Native Americans) are more likely to live in poverty than nonminorities with disabilities. Researchers have called this "triple jeopardy" or triple discrimination of race, poverty, and disability that increases social inequalities. Minorities with disabilities are at a higher risk for being discriminated against when looking for jobs compared to Caucasians with disabilities. They are likely to have less formal education, to be less integrated into the fabric of society, and to be more often marginalized from societies' social and economic life than are Caucasians with disabilities.

It has been shown that, worldwide, people with disabilities are poorer as a group than the general population and that people living in poverty are more likely than others to be disabled. Individuals living in developing countries in poor conditions are more likely to experience poor nutrition, dangerous work environments, limited access to vaccination programs, limited preventive health care and maternity care, poor hygiene and sanitation, war and conflict, and natural disasters that can cause disability and impairment.

In communities around the world, people with disabilities are among the poorest and most vulnerable of all groups. Individuals with disabilities are often stigmatized and abused and less likely to have social security and health care. Furthermore, the housing and environmental conditions in which poor people live and work make them and their children more vulnerable to mental and physical impairments.

According to the World Health Organization (WHO), it is hard to obtain an accurate estimate of the number of people with disabilities in the world. Disability rates may vary by the type of country, type of disability, and age group. Nevertheless, the percentage of disabled persons ranges from 0.2 to 20.9 percent of the population in a given country. It is estimated that more than 500 million individuals in the world have a disability, and about 80 percent of these individuals live in developing countries. The fact that developing countries have such a high number of people with disabilities is due, in part, to the large number of people who live in poverty. Many international efforts are under way to address poverty and disability. For instance, the Action on Disability and Development (ADD) and the Chronic Poverty Research Centre (CPRC) attempted to understand the relationship between poverty and disability and are sponsoring a multitude of efforts to address these issues. These efforts have included economic development initiatives to create new and safer jobs, campaigns to eradicate polio and other childhood diseases through appropriate vaccinations, campaigns to prevent malnutrition in small children, and educational campaigns about appropriate handling of hazardous materials.

A worldwide effort is led by WHO to eradicate polio and other preventable childhood diseases with vaccinations. Much of the WHO efforts are also concentrated in Asia and Africa. In addition, the Department for International Development is sponsoring numerous programs through the United Nations in developing countries to improve sanitation and the water supply, as well as decrease exposure to environmental hazards. More research needs to be done to address policy issues and examine the impact of current international efforts. Research endeavors also need to focus on practical strategies for reducing the poverty that people with disabilities face, instead of continuing to gather data to reaffirm the well-known link between poverty and disability. It is important to increase the inclusion of people with disabilities in policy and social change efforts concerning poverty and disability. Inclusive and participatory research is needed to empower people with disabilities during the process of gathering data and information, to assess progress, and to challenge the exclusion and marginalization that help perpetuate the link between poverty and disability.

—Yolanda Suarez-Balcazar and
Sharibeth Cooper

See also Education; Political Economy; Poor Laws (United Kingdom); Race and Ethnicity.

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PREMATURITY

Prematurity, as defined by the World Health Organization, includes infants born at < 37 weeks gestational age (GA). The prematurity rate varies between 5 and 7 percent in Europe and Canada, whereas in the United States, it is 8 to 10 percent in white and 16 to 18 percent in African American women. Despite improvements in obstetric care, the prematurity rate has not declined in the past 40 years. Prematurity remains the leading cause of mortality and morbidity worldwide and accounts for between 60 and 80 percent of deaths among infants without lethal congenital malformations.

Survival of preterm infants is directly related to the degree of immaturity and birthweight. Although only about 1.5 percent of all infants are of very low birthweight (VLBW, < 1500 g), this group accounts for a disproportionately high mortality and morbidity. Neonatal survival improves dramatically with increasing GA; currently, the survival is more than 50 percent at 25 weeks and more than 90 percent at 28 or 29 weeks GA.

Although recent advances in the care of infants have resulted in a significant improvement in survival, they have not been associated with a parallel decrease in the rates of subsequent neurosensory sequelae, which include cerebral palsy, mental retardation, blindness, and deafness. The rates of cerebral palsy for infants < 1500 g birthweight are between 13 and 90 per 1,000 live births, which is nearly 40 times higher than the rate of 2 per 1,000 in the general population. The rates of blindness for infants < 1000 g are between 2 and 8 percent. The current estimate is that 1 in 2 extremely low birthweight (ELBW, < 26–28 weeks GA) survivors will have a neurodevelopmental disability; the most immature infants often have multiple disabilities.

At mid-childhood, additional problems such as behavioral difficulties, inattention, and learning disabilities may emerge. Children who were ELBW have mean IQ and achievement scores that are 9 to 13 points below the normative mean. Nearly half of the ELBW cohorts require special educational assistance and/or repeat a grade. These difficulties have been shown to persist to mid-to-late adolescence. Even children who are normal neurologically and have intellectual scores within the average range do not perform as well as their term birthweight peers. Thus, there is an economic burden for remedial assistance over and above that for term infants. However, by self-report, adolescents born with ELBW placed a high valuation on their health-related quality of life, despite recognition of their disabilities.

In terms of general health, the high prevalence of recurrent illness and hospitalization in early childhood appears to decline as the children born prematurely grow older. However, although there is some catch-up growth, overall, ELBW survivors have lower growth attainment at adolescence and early adulthood. Disturbances in growth in the intrauterine and postnatal period may have long-term implications in terms of metabolic derangements, hypertension, and cardiovascular disease in adulthood.

It is important to emphasize that the morbidities described are more prevalent in the least mature infants. By and large, infants weighing >1500 g at birth or born above 32 weeks gestation do substantially better but may still have minor disabilities. Thus, prematurity is a major public health problem. The high disability rates are often compounded by psychosocial disadvantage.

To date, medical efforts to prevent premature birth have been largely unsuccessful.

—Saroj Saigal

See also Prenatal Testing.

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PRENATAL TESTING

Disability plays a major role in prenatal testing. This entry focuses on the principal diagnostic categories that contribute to risk of disability in prenatal testing and the major technologies that are used to assess prenatal and preconceptual risk of disability; full discussion of the social contributors to prenatal testing is beyond this brief essay. Prospective parents seek prenatal or preconceptual testing to determine specific anatomic or genetic diagnoses with which to assess risk of disability in their fetus or yet to be conceived fetus. Individual parents generally seek to optimize the chances of a "normal" (i.e., nondisabled) child. As access to prenatal information concerning fetal anatomic and genetic characteristics has increased, the gap between accurately predicting fetal anatomy or genetic mutations and predicting childhood disability has widened. This widening gap leaves parents to define the limits of hope for their offspring individually, based on heterogeneous information and experiences. In many industrialized countries, socioeconomically advantaged parents act on these risk assessments in decisions to terminate pregnancies. Some parents who have a specific disability and are faced with a relatively certain fetal diagnosis of the same disability (e.g., achondroplasia) will opt to continue the pregnancy based on their own life experiences. Alternatively, parents faced with a similarly certain but life-limiting disability (e.g., Tay-Sachs disease) may opt for pregnancy termination.

The major diagnostic categories in prenatal testing associated with a significant risk of disability are genetic, anatomic, infectious, and environmental. Genetic diagnoses include cytogenetic abnormalities (too many, too few, or malformed fetal chromosomes, e.g., Down syndrome) and inherited genetic diseases (e.g., cystic fibrosis). Diagnosis of either category of genetic disease requires access to fetal cells or DNA through amniocentesis, cordocentesis, chorionic villus sampling, or embryo biopsy. Anatomic diagnoses are established by antenatal ultrasound and include major birth defects (e.g., congenital heart disease or spina bifida) and prematurity. These diagnoses can also lead to the prediction of childhood disability (e.g., cerebral palsy in premature infants). Fetal infections (e.g., rubella or German measles) can be diagnosed using either maternal or fetal blood samples or amniotic fluid and can lead to the prediction of significant pediatric disability. Finally, fetal exposure to specific teratogens through maternal or paternal environmental exposure discovered through a careful medical history can increase the risk of childhood disability (e.g., fetal alcohol syndrome or birth defects due to paternal exposure to organic solvents). Each of these categories includes many conditions with widely varying outcomes in disability. This biologic heterogeneity in outcome can complicate parental understanding of disability risk.

The two most frequently used diagnostic methods for prenatal testing are antenatal ultrasound and amniocentesis. After ultrasound technology was developed during World War II to detect German submarines, early ultrasonographers in the United States began to visualize the fetus in "black and white pictures of things that looked like the clouds seen in hurricane reports," according to Lewis H. Nelson, president of the American Institute of Ultrasound Medicine. With rapid advancements in technology, accurate anatomic evaluation of individual organs (e.g., hearts or spinal cords) in fetuses as early as 8 weeks gestation has become commonplace. However, antenatal ultrasound has significant false-positive and false-negative rates. In addition, the anatomy of a fetus may not predict the disability of a child. For example, with enlarged chambers in the fetal brain midway through a pregnancy (hydrocephalus), the likelihood of adverse neurodevelopmental outcome (e.g., seizures, inability to read or talk, blindness, or deafness) is significantly increased. But some children with this finding are "normal," and the ultrasound test cannot distinguish those who will have from those who will not have disabilities.

Amniocentesis, or the removal of a sample of amniotic fluid from the womb, was first developed in 1950 by a Uruguayan obstetrician to measure pressure changes in the womb during labor. This procedure transformed obstetrics from an exclusively maternal discipline to a medical specialty that included prenatal testing for fetal chromosomal composition around 16 weeks gestation. Recent advancements now permit fetal chromosomal evaluation at less than 8 weeks gestation (by chorionic villus sampling) or prior to implantation in the womb of an embryo (by embryo biopsy). Diagnosis of disabling chromosomal and genetic conditions in the embryo or fetus prior to the legal definition of viability is feasible (24 completed weeks of gestation in the United States). However, like antenatal ultrasound, the biologic continuum of many genetic diagnoses plus the socioeconomic status of different families may lead to different degrees of disability in children with similar fetal genetic diagnoses. For example, children with trisomy 18 are frequently born with life-limiting birth defects that lead to death within hours to days after birth. However, some of these children survive for years. Parents faced with a fetal diagnosis of trisomy 18 may choose to terminate or carry the pregnancy depending on their perceptions of the disability these children develop. These techniques also provide access to fetal DNA that can be used for molecular diagnosis of specific gene defects. When unambiguous evidence is available correlating a specific gene mutation with disability, parents use this information to make decisions about the management of the pregnancy and the child. However, the ability to predict disability based exclusively on genetic information is limited due to the biologically complex interactions among gene mutations, environmental conditions, and genetic backgrounds (e.g., different ethnicities). For example, in Tay-Sachs disease, the neurodevelopmental progression of the disease is invariable and life limiting. In cystic fibrosis, while the diagnosis is equally precise, the disability outcome may be quite variable, with many affected individuals surviving and being productive well beyond age 30.

Preconceptual testing for predicting risk of disability in future children has also become increasingly commonplace. Using careful review of family histories of both parents and DNA testing for many different gene mutations, preconceptual testing attempts to reduce the risk of conceiving children who will be born with disability or become disabled. For example, if there is a strong family history of spina bifida or anencephaly, folic acid is recommended for prospective mothers prior to conception and for the first three months of the pregnancy. Epidemiologic studies have shown that this inexpensive nutritional supplement can reduce the risk of spina bifida and anencephaly by 75 percent. A more difficult problem with newer DNA technologies is the ability to predict the risk of disabling adult diseases (e.g., Alzheimer's disease, Parkinson's disease, or breast cancer) prior to conception. Available genetic testing technologies permit the identification of genetic predisposition, and risk can be reduced with strategies such as the selection of a genetically determined low-risk sperm or egg donor. In some conditions, pharmacologic, behavioral, or monitoring strategies can also be used to reduce the risk of disability.

Prenatal and preconceptual testing leaves parents with a conundrum that they must resolve based not only on test results but also on personal values, prior experiences, and, ultimately, hope. Parents use the input of medical providers, religious advisers, family members, financial consultants, the media, the Internet, and cultural expectations differently and selectively. Frequently, mothers and fathers differ in their perception of disability based on prenatal testing, and this difference will lead to conflict concerning consideration of pregnancy termination. Some parents will choose to rely on hope that their child will be less disabled than predicted, on hope that technology advancement will offer their child new strategies to reduce the impact of disability, or on faith that their child's disability will be a leavening factor in their lives. Other parents will choose to terminate a pregnancy rather than subject a child to multiple painful medical interventions without reasonable hope of the ability to overcome disability. While technology offers impressive anatomic and genetic precision for fetal evaluation, the biologic continuum of disability outcome associated with specific fetal anatomic and genetic findings, parental perceptions of disability risk, and the timing during pregnancy of the diagnosis all contribute to decisions that may alter significantly the population-based frequency of specific disabling conditions.

Prenatal and preconceptual testing provides a battery of powerful medical tools to predict risk of disability. Prenatal testing also provides an area for disability research to improve the capability of prenatal testing to predict disability, to identify strategies to understand mechanisms of disability, and to improve outcomes of specific disabilities. Such research is critical to ensure that parents optimize their children's futures rather than choose their future children. Prenatal testing must be viewed as information for parents that will help them decide wisely about their pregnancies, not simply make wise decisions prompted by medical providers. Given the significant contributions of genetic, environmental, anatomic, and infectious causes to risk and severity of disability and the substantial amount of prenatal testing provided to parents, the opportunity for improved understanding of disability has never been greater.

—F. Sessions Cole

See also Cystic Fibrosis; Down Syndrome; Prematurity.

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PRESSURE ULCER/SORE

Pressure ulcer/sore (PU) is a severe soft tissue breakdown most commonly reported in individuals confined to an unaltered body posture such as sitting in a wheelchair due to mobility impairment or staying in bed due to illness. Unrelieved pressure squeezes tiny blood vessels, which supply the skin with nutrients and oxygen. When skin is starved for too long, the tissue dies and a PU forms. The most frequently affected body locations are where soft tissue is overlying a bony prominence and where body weight is supported, such as the ischia and tailbone for sitting posture and the hip bone, back of the head, shoulder blades, spine, ankles, and heels for supine posture.

Persons with impaired nervous systems are not able to sense the need to change posture for pressure relief. Those in bed may get PU after as little as one to two hours, while those who sit in wheelchairs can get PU in even less time because the force on the skin is greater.

A number of factors predispose an individual to a high risk of PU. External factors include interface pressure, shear and friction, time remaining in a fixed posture, temperature, and humidity. Internal factors (i.e., sensory impairment, vascular disease, previous history of pressure damage, malnutrition, and dehydration) determine the level of loading tolerated by the tissue before damage occurs. In practical situations, these factors interact with each other, making an individual more vulnerable to PU formation. Increasing the time that pressure is applied without relief and the loss of muscle bulk and tone all make the tissues more liable to be damaged by a given level of pressure.

Among the above-mentioned factors, pressure, which is more concentrated over bony prominences, has been considered the single most important etiologic factor in PU formation. High pressure leads to impaired lymphatic circulation and hypoperfusion in the compressed tissue, resulting in an accumulation of toxic intracellular materials and a compromised blood flow, which further lead to tissue hypoxia, acidosis, interstitial hemorrhage, and cellular death. Both duration and intensity of pressure affect the amount of damage. Reestablished tissue perfusion after a long period of high loading will result in ischemic/reperfusion injury, which has been implicated in tissue damage. Studies have shown that muscle is highly susceptible to localized compression, eventually leading to tissue degeneration in the form of a deep PU that progresses toward the skin surface.

If pressure is relieved periodically, higher pressures can be tolerated for longer periods. This forms the basis of pressure relief regimens used in clinical practice, which involve regular turning, pushing up from the support surface, and the use of alternating pressure support systems. Short-term loading generally produces elastic deformation and rapid elastic recovery, whereas long-term loading results in marked creep and requires significant time for complete tissue recovery.

It is suggested that skin inspection be performed regularly and the frequency determined in response to changes in the individual's condition. Patients who are able and willing should be informed and educated about PU risk and prevention strategies.

—Mohsen Makhsous

See also Spinal Cord Injury.

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PREVENTION

Prevention: (noun) 1. action that stops something from happening; e.g., prevention of crime. 2. something that acts to prevent something: an action or measure that makes it impossible or very difficult for somebody to do a certain thing, or for something to happen.

In everyday language, the word *prevention* refers to stopping something bad or unhealthy from happening. *Promoting* or *encouraging* are the antonyms—actions that facilitate or help something to happen. The two ends of the spectrum are generally associated with negative outcomes, on one hand (prevention), and positive outcomes, on the other (promotion).

PUBLIC HEALTH PREVENTION

The traditional public health meaning of prevention refers to efforts to eliminate a negative health condition. For example, infants are immunized early in life to prevent certain childhood diseases. An overwhelming percentage of infants in the United States are now immunized, and this is clearly a public health triumph—one that few would question. Traumatic injuries, another example, are associated with several negative health outcomes, ranging from long-term limitations in activities to death. Public health interventions to prevent injuries include seat belt protection, swimming and diving safety, and bicycle helmet programs. Research has shown that a large percentage of neural tube defects could be prevented if women of childbearing age take 400 micrograms of folic acid each day by a combination of nutrition, food fortification, or vitamin supplementation. Obesity is another significant problem in the U.S. population, resulting most often from a combination of poor diet and lack of physical activity. Major public health programs have been implemented to prevent each of these—childhood illness, traumatic injuries, birth defects, and obesity through population-based programs—through immunizations, automobile safety, folic acid consumption, and appropriate diet and exercise.

"Prevention," as it pertains to disability, is a more complicated topic. Disability, by public health definition, is a negative health outcome to be prevented. Disability prevention is perceived by many in the disability community, therefore, as an attempt to prevent the person with a disability from existing. This interpretation can create an adversarial relationship between public health and the disability community—one that need not be present.

Public health does not inherently disrespect the experience of disability. In the pursuit to improve the health of the public, in the context of the history of public health, it is easy for public health professionals to forget that no accumulation of public health activities will eliminate all conditions that limit people's activities. Public health can, therefore, inadvertently frame messages designed to help prevent behaviors associated with disabling conditions so that they disrespect the human experience of disability—and those living with a disabling condition. Those messages, for example, proclaim the need for safe driving while showing someone in a wheelchair. The explicit connection disrespects the experience of disability and draws an inappropriate connection. Disability, then, is presented as equated with illness. To the extent that public health messages, in an effort to prevent the conditions associated with disability, equate illness with disability, they unwittingly demean people living with a disability.

People with disabilities can also contribute to an adversarial perspective. In their pursuit for inclusion, people with disabilities may believe that public health prevention activities are implicitly (or explicitly) trying to prevent them from being. Seeing the emphasis placed on primary prevention often leads those with disabilities to conclude that all public health activities are focused on trying to keep them from existing. Past experience is not balanced with current reality—the reality that public health emphasis on improving the health of people with disabilities is growing. There is no inherent conflict between primary prevention interventions that try to reduce disabling conditions and maintaining and improving the health of individuals who experience disabilities. Those who experience disabling conditions often have fallen through the primary prevention net—that is, all the public health activities did not prevent them from experiencing the disabling condition. They live with disabilities related to birth defects, developmental disabilities, injuries, chronic illness, or aging.

Primary prevention messages are equally important for people with and without disabling conditions. This is a crucial perspective for public health professionals, as well as individuals with disabilities and their families. Individuals with disabling conditions are just as vulnerable to cancer or heart problems, for example, as the rest of the population. Screening for breast or prostate cancer or cardiovascular problems should be a part of clinical preventive services for all of the population. Cancer research comparing women with and without disabilities show that women with disabilities are diagnosed later and treated less intensively than the general population. Even though they might see medical professionals more often, people with disabilities often do not receive these preventive services as routinely as the general population.

Part of the problem might be that clinical preventive services (e.g., shots, prostate or breast cancer screenings) are usually completed in the offices of family physicians or internists. Many individuals with disabilities use specialists as their primary care physicians. The specialists may be less aware of, familiar with, and sensitive to the need for clinical preventive services.

In addition, there are times when public health messages should be tailored specifically to reach people with disabilities. This is particularly important when people with disabilities could be at particular risk. For example, people with mobility limitations are at greater risk for weight gain than the general population due to their often reduced physical activity and poor nutrition. In fact, national data suggest that people with disabilities report significantly more obesity and less physical activity than the population without disabilities. Few public health messages, however, focus on this at-risk group.

Prevention and the Environment

There is another kind of public health primary prevention activity relevant to people with disability—environmental factors. Dramatic improvements in the health of the public have come about as a result of environmental changes. It is clear, for example, that more improvement in the health of a population occurs because of clean water and hygienic waste removal than because of any other contributors. Improvement of the health of the public has often been intimately tied to such environmental improvements. Changes in environmental conditions have been estimated to account for an overwhelming percentage of decreased mortality during the first half of the twentieth century. That is, environmental improvements have been primarily responsible for the increase in lifespan from 45 years in 1900 to 72 years in the year 2000. Toxic air, water, or food can decrease quality and quantity of life for the population, including those with disabilities. In addition, however, environmental factors such as a lack of curb cuts, negative attitudes of society, and government policies can dramatically affect the health and well-being of people with disabilities.

PUBLIC HEALTH PREVENTION PROGRAMS

Programs to implement primary prevention activities associated with disability were officially begun at the U.S. Center for Disease Control and Prevention (CDC) in 1988. The program focused on disability prevention using the traditional public health model—identify the condition, generate interventions to control or prevent the conditions, identify those at risk for the condition, and intervene. This approach has been used universally by public health agencies to protect the health of the world. Unfortunately, emphasis on primary prevention of conditions associated with disability has been the major focus but is only a small part of public health's responsibility related to disability. Many conditions are not prevented from occurring despite the best public health effort. Children are born with sensory, physical, and cognitive problems. Throughout our lives, we may experience traumatic injuries anytime, and chronic illnesses develop for many individuals as they age. Vernon Houk, a public health physician and CDC leader, speaking to one of the early disability prevention meetings, suggested that "people with disabilities form the only minority group to which anyone may join at any time with no intention to do so." Prevention of conditions associated with disability is one, albeit important, set of public health activities. Public health also has responsibility to people who live with disabilities.

SECONDARY CONDITIONS

The term *secondary conditions* is relatively new to the lexicon of public health and disability studies. While the term has created some confusion—in part because it is new and in part because the definition continues to be refined—the distinctions it creates are essential to the lives of people with disabilities. "A secondary condition is *any* condition to which a person is more susceptible by virtue of having a primary condition" (Lollar 1999). The concept of secondary condition does not reflect its importance but rather its temporal quality—that is, a secondary condition occurs after a primary condition.

There are fundamental distinctions between comorbid conditions and secondary conditions. Often, the science of public health addresses individual conditions in terms of risk, prevention, and intervention, as if those experiences occurred in isolation. That is seldom the case, of course. In some situations, conditions occur as comorbid health conditions—that is, they are unrelated; there is no association. An older person with macular degeneration (an eye disease) might also have arthritis. There is essentially no relationship between these two conditions, although the combined effect may be significant in terms of mobility and quality of life. In other cases, one condition creates risk for another. A person with paralysis, for example, may be at risk for pressure sores. One follows the other. An important characteristic of a secondary condition is that it can be prevented. Prevention strategies to avoid pressure sores would include shifting weight, repositioning, or having a good seating system. Some secondary conditions are unique to people with disabilities, while some are not. For example, because of a disability and its consequent isolation, a person might become depressed. An individual without disabilities may be depressed as well, though the underlying causes may differ. Common secondary conditions include depression, chronic pain, joint and muscle pain, sleep disturbance, obesity, fatigue, contractures, and lack of conditioning.

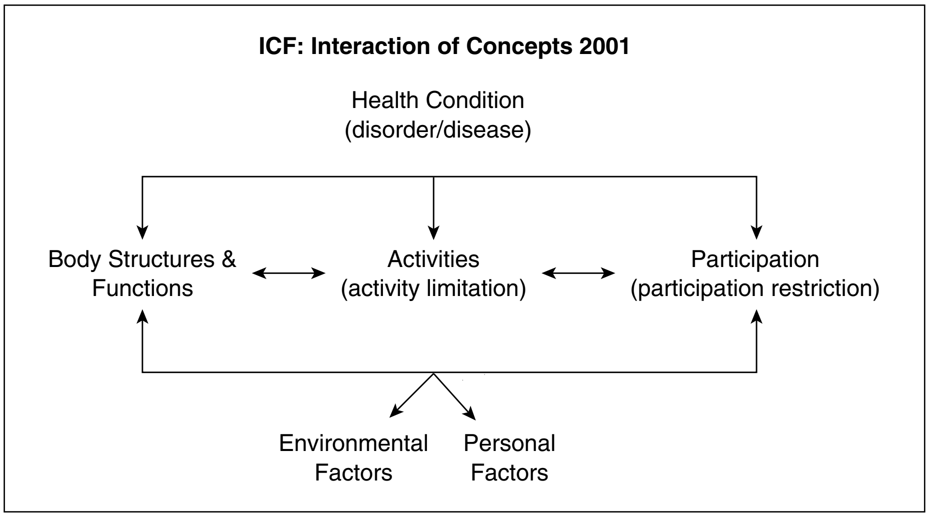

Figure 1 ICF: Interaction of Concepts 2001

The concept of secondary conditions, however, is now regarded as broader than associated impairments to include activity limitations and participation restrictions. Recently, the concept of secondary conditions has expanded: "Secondary conditions can create significant impediments to an individual at the level of *body system* dysfunction, *activity limitations* or *participation restrictions*" (Lollar 1999). This expanded notion of secondary conditions emerges from efforts over the past 25 years to reconceptualize the lived experience of disability. Until recently, the so-called medical model dominated how disability was described. The essential notion was that a problem at the body system level created inherent limitations in function—for example, the ability to pronate or supinate the hand. The medical model relies on an accurate diagnosis that allows problems to be "fixed." However, in disability, people's lives go on—"fixed" or not—and individuals generally demonstrate remarkable capacities to make do with what they have. The ability of individuals to deal with adverse circumstances and go on is mediated by many factors in addition to restoring function. One's financial resources, the kinds of activities one performs, and the supportive nature of the environment, as well as one's own resilience, may have more to do with quality of life and social participation than restoration of function. Thus, in recent years, scholars and advocates in disability have attempted to portray the multidimensional characteristics of disability as a way to understand how people carry out their lives or how they might be more successful in pursuing meaningful activities. This effort is described as a social model of disability.

This more dimensional portrayal of disability embraces the complex relationships of human experience and illustrates the potential impact of secondary conditions. The World Health Organization developed the *International Classification of Functioning, Disability, and Health* (*ICF*) as a companion to the *International Classification of Diseases* (*ICD*). The *ICF* creates a framework to "map" human experience. It is not designed to be used exclusively to model disability. The *ICF* creates a taxonomy to portray the relationship of human experience in related domains—body, person, and society. Health condition describes disease, injury, or disorder at the at the person level. Health conditions may result in changes of body structure and function. These can be described and measured; for example, macular degeneration occurs at the cellular structure of the macula, and its effect can be measured in altered acuity and central loss of visual field. Activities describe the things people do: walking, lifting, reading, driving, and preparing meals. And participation deals with the social roles that people carry out—going to school, working, voting, and having friends and relationships. The multiple arrows of Figure 1 illustrate the multidimensional characteristics of the concepts of the *ICF.*

For example, a disease or injury may create changes in body function and structure that, in turn, may or may not affect the performance of activities, which, in turn, may or may not affect social roles. In this model, the environment plays an important mediating role insofar as the environment can serve as either a barrier or a facilitator. An example helps to make these relationships substantially clearer. A person with macular degeneration (an eye disease) experiences changes in the structure of the macula. These changes can be measured in terms of visual acuity, that is, function. As a result of macular degeneration, then, a person may have difficulty reading print, driving a car, getting around in dimly lit environments, or recognizing faces at a distance. These are all activities. As a consequence of these activity limitations, a person with macular degeneration may be less inclined or less able to go out to dinner with friends. The print on the menu might be too small to read, steps could create hazards for falls, and an individual may not be able to get to the restaurant unless someone picks her or him up. These relationships are not inevitable or predictable. This model suggests multiple places where interventions may reside. For example, medical treatment may mitigate the effects of macular degeneration, low-vision services (technology) may improve function, and rehabilitation services might improve the performance of various activities (say, using a cane to detect steps). Moreover, the environment can have a major influence in reducing the negative outcomes of macular degeneration for the individual. For example, a robust transportation system would likely solve the problem of getting to the restaurant. Better light at the steps might improve safety and mobility, and a large-print menu might ease the difficulty and anxiety of ordering. Also, helpful and patient restaurant staff could make the entire outing more pleasant. In the *ICF,* the concept of environment has to do not so much with the built characteristics of the environment as with the environment as it is defined by social attitudes and public policy.

While the *ICF* allows us to map the course and dimensions of disability, the conceptual framework also helps to understand the role of secondary conditions in a complex system defined by our lives. The definition of a secondary condition emphasizes *any condition* that creates significant impediments to individuals at the level of body system dysfunction, activity limitations, or participation restrictions. Therefore, if we map potential secondary conditions against the *ICF* model, we can see that there may be secondary conditions at the body structure or function level (say, pressure sores or contractures), a secondary condition may occur at the activity level (e.g., personal care might be limited due to a fall), or secondary conditions can occur at the participation level if one is socially isolated or cannot get a job.

Consequently, the prevention of secondary conditions is embedded in more responsive clinical care. For example, physicians should routinely ask about weight, exercise, and pain among patients with disabilities, and broad health promotion activities should include or target people with disabilities in health messages. The prevention of secondary conditions may evolve from improved technology, for example, as wheelchair design and improved seating systems reduce contractures, pain, and skin abrasions. And secondary conditions related to social isolation and social roles (e.g., work) can be mediated by changes in the environment, as the built environment becomes more accessible, transportation systems more robust, and employers more welcoming.

—Donald J. Lollar and John Crews

See also International Classification of Functioning, Disability, and Health (ICF/ICIDH); World Health Organization.

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PRIMARY AND SECONDARY EDUCATION

See Education, Primary and Secondary

PRIVATIZATION

Starting in the late 1970s and continuing today, there has been a worldwide movement by countries to privatize government-owned industries and state-provided services. Starting with Prime Minister Margaret Thatcher, the rightist governments in the United Kingdom and the United States (under President Ronald Reagan); labor governments in Scandinavia, New Zealand, and Australia; socialist governments in Spain and Mexico; and the governments in the countries of the former Soviet bloc have all implemented privatization programs. This unprecedented growth in privatization will likely have profound and long-term impacts on the type, cost, and quality of social and health care services that individuals with physical and mental disabilities receive.

Privatization (or liberalization, as it sometimes is called) has strong political, technical, strategic, and ideological dimensions. It has been proposed as a strategy to meet an almost limitless set of objectives, from shrinking the overall size of government, to raising funds and lowering taxes, to enhancing the technical efficiency of specific public-sector services. For some, privatization is an end in itself; for others, it is the means to other valued outcomes.

The privatization movement raises a number of important fundamental public policy questions that governments and citizens must address. These questions include the following: How large of a role should governments play in their nation’s economies? What are the basic realms and responsibilities of governments? What specific tasks should governments perform for their citizens? Which tasks are best performed by the private sector? What role should governments play in regulating functions best implemented by the private sector?

The term *privatization* first appeared in the business and management literature in the early 1970s. Economic and social theorist Peter Drucker is credited with inventing the word. Since it was coined, numerous definitions of privatization have been proposed. Some of them have been very broad and vague, while others have been very narrow and specific. All of the definitions, however, have two common elements: a movement away from the reliance on government agencies to provide goods and services and a movement toward the private sector and market forces.

Privatization can take on a myriad of forms. They include governments: contracting with organizations in the private sector to purchase goods and services; providing grants and subsidies to individuals and organizations to encourage them to provide needed items; charging consumers fees for the use of particular services; encouraging volunteerism so that charities and other organizations assume a larger portion of the social burden; encouraging self-help services by individuals and groups; granting franchises to private organizations to provide particular services within specific geographic areas; issuing vouchers to consumers, authorizing them to purchase specific goods and services from government-approved private-sector companies; totally withdrawing from the provision of existing services; selling assets, such as land holdings, to the private sector to generate revenue or to spur development; and deregulation, the weakening or total elimination of legislative rules and regulations governing certain private-sector industries.

In the United States, most privatization to date has occurred at the local and state levels of government. Much of it has been through increased contracting with private-sector companies to provide such services as trash collection, fire protection, public health laboratory services, and the operation of correctional facilities. Also, several cities and states have established school voucher programs enabling students in public schools to enroll in private charter schools. Recently, however, there have been a number of proposals to partially privatize the nation's Medicare and Social Security programs.

Outside of the United States, privatization has taken place mainly at the national level and primarily through the sale of assets and the withdrawal of services. Many countries have concentrated their privatization efforts in the areas of telecommunications, energy production, and health care and community services. For example, Sweden, the world's traditional exemplar of the welfare state, has privatized much of its health care system, selling many of its formerly state-owned hospitals to private corporations.

Views about privatization's virtues and pitfalls vary widely. In most cases, the views are fundamentally ideological and political in nature. Conservatives in general and businesses in particular tend to advance positive arguments, while liberals in general and labor unions in particular are strongly opposed to any form of privatization.

Proponents of the privatization of health care argue that it enhances individual choice, fosters innovation, and reduces inefficiencies. They state that selling off government-owned hospitals brings much-needed money into state, county, and regional coffers. And privatizing local clinics removes their operating costs from public budgets. Proponents argue that private companies, or groups of physicians, who purchase these medical facilities can run them more efficiently, increase patient access, and provide better quality care. They also indicate that privatization can "free up" scarce government resources to provide services for the poor, to the extent that those individuals who are willing and able to pay for health services seek care outside the public sector.

In sharp contrast, opponents of privatization argue that although some health care programs may have serious problems and need attention, privatization is not a general solution to them. Critics say that privatization erodes the very principles of universality and social equity in the delivery of health care services. It creates an inappropriate "multitiered" health care system where the provision of care is based on the ability to pay, rather than on need. Such a system decreases the access of underprivileged groups to care and ultimately worsens health outcomes. Also, important preventive care and community public health services such as immunizations, which are generally not profitable, tend to be neglected. Critics further point out that privatization interferes with real accountability to consumers. Last, they argue that privatization hurts health care workers because it threatens their job security, pay and benefits, working conditions, and career opportunities.

Despite the large number and types of privatization programs implemented in countries throughout the world, it is notoriously difficult to assess their impacts. There have been few evaluations of the programs in terms of their stated objectives. Even in crude terms such as the number of privatized firms, the proceeds of sales, or the share of gross domestic product coming from the private sector, it is very difficult to get hard data and an overall picture. Many of the privatization programs have been implemented haphazardly and often with little consistency across different regions of counties. Furthermore, because every industry is different and because countries have their own unique cultures and traditions, no two acts of privatization are ever identical.

The effects of privatization on health care services and patient outcomes are also very difficult to assess. In several countries, privatization appears to have adversely affected the health of its citizens. For example, in Russia, after the collapse of communism, many former state-owned hospitals and clinics were privatized. Some of these private for-profit facilities offer the latest medical technology and high-quality health care but, unfortunately, at prices that few Russians can afford. At the same time, state-owned facilities are critically short of money and medicine, equipment and buildings are crumbling, and physicians and nurses earn near-poverty wages. The decline of these facilities has resulted in a rise in Russia's overall mortality rate and a decrease in average life expectancy unparalleled among developed nations in recent peacetime history.

Rural health care in the People's Republic of China is reported to have suffered because of privatization. As China moved toward a free market system, an increasing number of state-owned clinics have contracted out services, and a large number of privately owned for-profit clinics have been established. The for-profit clinics charge their own rates, which many of China's hundreds of millions of poor rural citizens cannot afford. The private clinics have also led to the decline in community public health services. Because it is not profitable, clinic physicians no longer trek to distant villages to vaccinate children or to exhort women to obtain prenatal care.

The health care system of Mozambique also appears to have suffered from privatization. After independence, the Mozambique government established a national primary health care system. The system was so successful that the World Health Organization considered it a model for other African nations. To undertake various development projects, Mozambique borrowed funds from the World Bank, the International Monetary Fund, and other international financial institutions. These institutions pressured the nation to adopt free market policies. Many local private organizations and foreign agencies began providing health care services. As a result, Mozambique now has a two-tiered health system where poor people continue to seek care in an underfunded, understaffed, demoralized government-run system, while a small group of largely urban, rich elites receives services from private for-profit clinics.

In summary, it is not clear how individuals with physical and mental disabilities have fared under these and other privatization programs. It is clear, however, that all privatization efforts must address the special and unique social and health care service needs of those with disabilities. To protect them and other disadvantaged groups, governments must maintain a safety net of services that they alone can provide. Last, although empirical studies do not provide clear evidence on the costs and benefits of privatization, public perceptions and pressures to improve government efficiency and hold down taxes will keep proposed privatization programs on present and future government agendas.

—Ross M. Mullner and
Kyusuk Chung

See also Health Management Systems; Managed Care; Political Economy.

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PROFESSIONS

Professions are a special type of occupation. The sociological study of professions examines the social forms taken when work is organized and controlled by experts. According to Freidson (1970a, 1970b, 2001), work ("the practice of knowledge") is best understood by constructing three ideal types (or conceptualizations) of work: free market, bureaucratic, and professional. Each ideal type represents a different form of control over work: (1) the consumer/buyer (free market), (2) managerial (bureaucratic), and (3) occupational (professions). In turn, each has its own characteristic ideology: the market in consumerism (or what Freidson terms "popularity generalism"), the firm in managerialism ("elite generalism"), and professionalism in "specialization." Freidson also identifies five "critical contingencies for establishing and supporting professionalism": (1) an esoteric body of knowledge requiring "considerable discretion"; (2) control by the occupation over its own division of labor, (3) its own labor market, and (4) its own training program; and (5) "an ideology serving some transcendent value." For Freidson, a major sociological question of our time is the "status of professionalism in advanced industrial society." However, and as noted by Abbott (1988, 2001), the concept "profession" is distinctly Anglophone, with the term having no direct translation in either French or German. Professions trace their early roots to the guild system in England. The general form, as we know today, emerged in the early to mid-1800s in England and the United States, with medicine serving as the prototypical profession. Studies of the historical evolution of medicine as a profession generally point to a period of rapid growth from the mid-1800s into the early 1900s, followed by a period of consolidating professional powers and privileges that lasted until the late 1960s. Beginning in the 1970s, traditional professional groups came under sustained attack by rival occupational groups seeking their place under the professionalism sun, a growing consumer rights movement, increasing encroachment by the state, and the aforementioned arrival of a for-profit marketplace. Social theorists in the 1950s and 1960s envisioned a groundswell of professionalism that would neutralize the evils of political authoritarianism and capitalistic exploitation—a vision that has not materialized.

AN EVOLVING SOCIOLOGICAL INQUIRY

Analysis of professions has undergone its own evolution. Early works such as Carr-Saunders and Wilson (1933) adopted a functionalist approach to social analysis, an analytical framework that reached its zenith in the 1950s and 1960s with the theoretical writings of Talcott Parsons. In 1970, Eliot Freidson published two watershed volumes, *The Profession of Medicine: A Study in the Sociology of Applied Knowledge* and *Professional Dominance: The Social Structure of Medical Care.* Freidson sought to critique the functionalist emphasis and to explain the rise of professional dominance and autonomy—with allopathic medicine serving as Freidson's occupational template.

Works critical of the "professional dominance approach" quickly followed. Notable was work by Margali Larson (1977), Paul Starr (1982), and Andrew Abbott (1988). Alternative theoretical frameworks included "deprofessionalization" (Haug 1973), "proletarianization" (McKinlay and Arches 1985), and "corporatization" (Light and Levine 1988). A vigorous decade-long debate between Freidson and his critics ensued, as insights into the nature of professions were extended to occupational groups other than medicine and to a more nuanced cross-national understanding of professional work (Hafferty and McKinlay 1993). Most recently, Light (2000) has extended his earlier work on corporatization into a more robust theory of "countervailing powers."

THE "REDISCOVERY" OF PROFESSIONALISM BY ORGANIZED MEDICINE

The failure of the Clinton Health Plan in 1994 occurred in the midst of what would be the United States' longest running bull (stock) market, thereby unleashing a deluge of investor dollars into a number of new corporations and corporate sectors—health care being one. What had once been defined almost solely by the pharmaceutical industry quickly came to include new market sectors such as “health care services,” “physician practice plans,” biotechnology, and, most recently, “genomics”—as purchasers and providers alike quickly staked out territory in a new “medical marketplace” (itself a new way of thinking and talking about medicine). The arrival of “managed care” and the development of varied strategies to alter both physician and patient behaviors were greeted with fear and distrust by organized medicine. Editorials, commentaries, and articles began to appear in authoritative medical journals (e.g., *JAMA, New England Journal of Medicine, BMJ*) about the “inherent conflict” between medicine’s “culture of professionalism” and the marketplace’s “culture of commercialism” and medicine’s loss of public trust. In turn, a number of medical organizations ranging from trade groups (e.g., Association of American Medical Colleges) to specialty societies (American Board of Internal Medicine) to accrediting agencies (American Council of Graduate Medical Education) began to call for a rededication to the principles of professionalism, for a more explicit presence of professionalism in medical education, and for the development of licensure and accreditation standards for professionalism. Similar efforts appeared in England and Canada.

MEDICINE AND THE "NEW PROFESSIONALISM"

This mingling of medicine and Wall Street, along with other social changes, brought about another call to professional arms, this one for a “new professionalism” or for a “reformulation” of old professional ideals. Traditional professional values or organizational forms such as a “autonomy,” “monopoly,” “hegemony,” and “hierarchy” were deemed “lacking” and/or “inappropriate” in a “new medical era.” Instead, the physician and patient were being cast as a “partnership of equals.”

MEDICINE AND THE SHIFT FROM IMPAIRMENT TO DISABILITY

The evolution of disability as a social form follows a somewhat similar path to that of professions and the sociological analysis of expert work. The growth of medicine as a scientific enterprise was both a cause and a consequence of a broadly based effort to “objectify” disease and to extend the influence of a distinctly biophysiologic account of “normal” and “patho” physiology. Behaviors and/or attributes that had been seen as personal shortcomings and/or moral weaknesses became markers of disease, a process sociologists refer to as “medicalization.” This increasing encroachment of medicine over domains of social life was not without detractors (Illich 1976). Nor were they without negative consequences, as advances in medical science seemed to be doggedly shadowed by the rise of treatment side effects, iatrogenic disease, and an appalling rate of fatal medical errors. Organized medicine, operating within an insular cocoon of elitism and arrogance, rebuffed criticisms. Earlier promises to place the patient’s welfare ahead of its own (e.g., altruism) slowly morphed into a less stringent promise that medicine would act in the best interests of the patient (paternalism). Organized medicine had become less responsive to the needs and concerns of patients.

A FUNDAMENTAL TENSION BETWEEN PROFESSIONALISM AND DISABILITY

The emergence of “disability” as a unique social form, distinct from that of “impairment,” reflects the emergence of a “social” versus a “medical model” of disability. This growing recognition of the barriers faced by people with physical and/or cognitive conditions was not defined solely by pathophysiology or rooted within the individual but could (and did) involve elements of social organization. This recognition, however, with its underlying recognition of a form of expertise rooted within the lived experience of disability, stands in conflict with professionalism—and not just “medicine’s version” (grounded in scientific expertise) but sociology’s as well (with its focus on “expert work”). Of the two, the conflict between the disability and medical professionalism is more stark. Sociological professionalism, on the other hand, is not so much “antidisability” as it is likely to view disability as part of a broader consumer rights movement than as a countervailing example of expertise grounded in knowledge.

Recent calls for a "patient-centered" medicine rooted in egalitarian notions of a "partnership among equals" have served to heighten this tension between traditional medical authority (e.g., the physician as expert—the patient as the object of that expertise) and the physician-patient relationship as a partnership of authoritative equals. The rise of genomics and the search for the "root causes" of disease also stand to re-excite tensions between the individual-medical and the social-discriminatory models of disability. While individual physicians may profess or "play at" partnering, the prevailing belief system within medicine is that medicine believes itself to be a "culture of no culture" (Taylor 2003) and therefore a domain where knowledge is neither relative nor culturally determined but rather exists as "fact" and therefore outside the relativizing presence of time, place, or social arrangement/forms. This cult of science, with its ideology of "objectivity," is not so much disdainful of the lived experience of patients with disabilities as it is truly uncomprehending about how "subjective experience" can be anything more than a source of distortion and bias. All of this is taking place within an occupational arena (medicine) that itself is currently undergoing a fundamental value shift via the "evidence-based medicine" movement. In this latest iteration of scientific objectivity, "truth" is to be based on "evidence" *rather than* "experience," whether that experience is the clinical type of practitioners or the "lived" expertise of patients.

The identification of disability as residing in social arrangements and structures (as opposed to individuals) also allows medicine to disavow expertise and authority in this later arena and thereby delegate "those problems" to other health care or social service workers, all the while maintaining occupational control over what medicine considers to be the defining issue—physiologic or cognitive impairment. While any such unbundling may invite other types of "experts" into the fray, it does not, necessarily, acknowledge patients as an *alternative and legitimate source of expertise.* As noted above, the sociological definition of professionalism stresses "esoteric knowledge" and "considerable discretion" with respect to its work. This stands at odds with the notion of physician and patient as equal partners or, better still, "equal experts." Patients may constitute competing sources of authority—"the market" for individuals with disabilities (as consumers) and professionalism for physicians—but this does not elevate experience to expertise.

However, as Western industrialized nations face the tsunami of an aging population, so will medicine and sociology face the conjoint social fact that age is more than a biological marker and that lived experience may well come to represent a new type of social authority.

—Frederic W. Hafferty

See also Medicine; Models.

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▣ PROGRESSIVE ERA WOMEN IN SPECIAL EDUCATION

While special education has taken significant advances in recent decades, throughout the world, its history did not begin in the 1960s. Generations earlier, reformers, often women, were beginning to establish the underpinnings of pedagogical and therapeutic approaches to children whose disabilities seemed to require alternative means of education, as well as the bureaucratic and professional cultures that have developed to provide those alternatives. These women worked in various national contexts, from a wide array of motives and backgrounds; they shared an era of innovation and unprecedented opportunity for women's participation in policy making and the development of theory.

The numbers of women activists who took a role in Progressive-era beginnings of special education are impressive and may be explained by several factors. Reformers in the Progressive era were often especially drawn to the problems of children in cities, immigrant children, and other young people in apparent crisis. Through the settlement movement and similar ventures, reform-minded women's groups sought reforms that some term "maternalist" because they imposed middle-class notions of femininity, hygiene, and domestic relations on the working-class objects of their charity. While many of these reforms seem uncontroversial today—child labor regulation, milk safety, kindergartens, urban playgrounds, and parks—others cast grave suspicions on families that could not easily conform to the domestic ideals proposed. And among the latter were measures to identify and segregate children with special educational needs, especially those associated with eugenic "defect."

Meanwhile, newly opened opportunities in medicine, education, government, and law gave some individual women professional credentials and expertise for establishing programs. Women working in the public schools as teachers and administrators saw the need for separate classes and methods for educating "misfit" students; women with medical training working in such positions as health inspectors, home visiting nurses, and clinic doctors saw the children unserved by public schools on account of their disabilities and the ways they might be otherwise educated. As the field of special education was new, it held great potential as a niche where professional women might gain positions of significant authority, without encountering resistant, entrenched networks. In addition, the specialties of pediatric medicine, public health nursing, and eugenics research were unusually accepting of women's expertise, with the added assumption that any endeavor that involved children or health appealed to a "natural" talent inherent in the female sex.

Among the many women whose names appear in the era's history of special education, only a few can be mentioned here. Italian doctor Maria Montessori (1870–1952) is best known today as a pioneer in early childhood education, but she derived many of her theories during her stint as director of the State Orthophrenic School in Rome, where she performed direct teaching with "feebleminded" children as well as developing a teacher training program. In London, Mary Ward (1851–1920) was a novelist from a literary family when she became involved in philanthropy, founding the Passmore Edwards Settlement (now the Mary Ward Centre); among its offerings, beginning in 1898, was an innovative model day school for children with disabilities. A year after the English school opened, Elizabeth Farrell began teaching an ungraded class of boys in the New York City public schools, using a self-developed curriculum that emphasized individualized, practical skill building. Farrell, who would eventually found the Council for Exceptional Children, was part of a cluster of socially active women centered around public health nurse Lillian Wald (1867–1940), who founded the Henry Street Settlement and mentored Lina Rogers (the first public school nurse in the United States) and Margaret Sanger (the birth control activist). Meanwhile in Providence, Rhode Island, two medical doctors, Mary S. Packard and Ellen Stone, conducted a summer camp in 1907 for children with tuberculosis, which would develop into school-year programming in specialized classrooms to serve students with special health needs. These stories must stand for those of many other women in the early twentieth-century history of special education.

—Penny L. Richards

See also Feminism; Maria Montessori; Margaret Sanger; Special Education.

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PROSTHESES

See Mobility Aids

PSYCHIATRIC DISORDERS

Psychiatric disorders are estimated to affect 20 percent of the adult population in America in any given year. Although less well developed for children, epidemiological studies estimate an annual prevalence rate of 20 percent for this population also. With more than 40 million persons affected annually by mental illness in the United States, it is likely that very few individuals have not had contact with a person with a psychiatric disorder. Psychiatric disorders exist along a spectrum from the very mild, with little or no evidence of disability, to the very severe, with profound disruptions in all areas of functioning, leading to severe, disabling consequences.

Based on functional impairment, it is estimated that 9 percent of the adult population has severe mental disorders. Prevalence rates in childhood are not predictive of adult prevalence rates. Many children with psychiatric disorders will recover from their disorders. Many adults with psychiatric disorders have their initial onset as young adults without a prior premorbid psychiatric disorder in childhood. Although prevalence rates in adult and child populations approximate each other, the numbers are not in and of themselves predictive of how psychiatric disorders impair or disable over the life course of an individual within a population as the correlation between symptoms and disability, while positive, remains weak. Some individuals can function well with severe symptoms, and others are genuinely disabled with few symptoms.

It is estimated that approximately 20 million adults in the United States have psychiatric impairment. Of this number, 4.5 million adults have persistent mental disorders that, by virtue of the severity of their symptoms, significantly disrupt or impair their ability to carry out activities of daily living (ADLs). ADLs include maintenance of personal care and hygiene, maintenance of school or job tasks, maintenance of household duties and responsibilities, and maintenance of interpersonal relationships. When these functions are disrupted by a psychiatric disorder, an individual is said to have a psychiatric disability. By understanding and measuring disruptions in ADLs, the extent of the disability can be measured quantitatively and qualitatively.

It is well documented that individuals with psychiatric disabilities manifest limitations in everyday functioning. In interpersonal situations, social cues are misinterpreted, yielding inappropriate responses to social situations. Minor stressors can lead to catastrophic emotional responses. Individuals can experience poor concentration, poor memory, lack of initiative, lack of affective expression, and indifference to socially appropriate expectations. These symptoms place the individual with a mental illness at a disadvantage in a society where cognitive and interpersonal skills are highly valued. In developing and agricultural societies, the World Health Organization (WHO) has shown that individuals can enjoy higher functioning in the presence of more severe psychiatric illness.

The World Health Organization's *International Classification of Impairments, Disabilities and Handicaps* has stated that psychiatric disability is a predictable consequence of having chronic severe mental illness. With disability, there are always quantifiable restrictions and lack or loss of the ability to perform specific roles and tasks.

PSYCHIATRIC DISORDERS

The fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) is the official diagnostic manual used in the United States for diagnosing psychiatric disorders. The content of the DSM-IV is exhaustive and far exceeds what can be covered in this review. It is an excellent reference text, comprehensive in its scope and readily available to anyone seeking a comprehensive text describing diagnostic criteria used to diagnose all psychiatric disorders.

Disorders that occur with the greatest prevalence and are likely to be associated with disability are the anxiety disorders, mood disorders, schizophrenias, and substance abuse disorders. The *DSM-IV* provides a comprehensive listing of diagnostic symptoms for each disorder listed.

As a group, anxiety disorders represent the most common psychiatric disorders. Symptoms include a subjective feeling of nervousness or fear in conjunction with specific physical symptoms. Physical symptoms include heart palpitations, shortness of breath, sweating, muscle tension, sleep disturbance, fatigue, urinary frequency, diarrhea, sensation of having a lump in the throat, and dilated pupils. These symptoms typically manifest themselves when an individual comes into contact with a specific object or situation. Persons with anxiety disorders frequently report avoidance as a means of symptom management. Although not fully understood, it is believed that this category of psychiatric disorders is caused by a dysregulation of the brain chemicals norepinephrine, serotonin, and gamma amino butyric acid (GABA).

Generalized Anxiety Disorder (GAD). Excessive worry and anxiety in addition to some of the physical symptoms listed previously characterize this disorder. The anxiety, worry, or physical symptoms are severe enough to cause impairment or distress in the individual's ability to carry out social or occupational functions.

Panic Disorder. Individuals with this disorder frequently report a sudden feeling of impending disaster or doom. Patients frequently report symptoms that resemble those reported by heart attack victims. These include but are not limited to palpitations, shortness of breath, dizziness, sweating, lump in throat, numbness or tingling in fingers or around the mouth, and chest tightness. Symptoms generally peak within 10 minutes. Chronic symptoms can lead to significant impairment in functioning as the individual attempts to avoid those situations psychologically linked to the panic attacks' occurrence.

Specific Phobias. This group of disorders is characterized by excessive fear of specific objects (simple phobia), situations that expose the person to the possibility of judgment or ridicule (social phobia), or situations where escape may be perceived as difficult by the patient (agoraphobia). This group of disorders constitutes the most common of all psychiatric disorders according to epidemiological catchment area (ECA) data. The avoidance or distress that occurs as a consequence of phobia can be debilitating.

Obsessive-Compulsive Disorder (OCD). This disorder is characterized by persistent and recurrent thoughts, impulses, or images that are experienced as unwanted or intrusive (obsessions). The person attempts to alleviate these thoughts and the associated anxiety by engaging in repetitive nonsensical behavioral rituals (compulsions) such as avoiding stepping on cracks in the sidewalk or excessive hand washing. Obsessions can impair concentration and thus lead to disability. Compulsions likewise can lead to incapacitating disability as the person's time is consumed by the performance of the ritualized behaviors.

Posttraumatic Stress Disorder (PTSD). This disorder typically follows exposure to a traumatic event that is life threatening, leading the person to experience intense fear, helplessness, or threat of losing one's physical integrity. The traumatic event is then reexperienced in a manner that is intrusive, occurring as flashbacks or recurrent dreams. Avoidance of events or places that may trigger memories, increased arousal (decreased need for sleep), or enhanced startle response are additional associated features. In its most severe forms, this disorder causes significant disability.

MOOD DISORDERS

This category of psychiatric disorders includes those disorders that have a disturbance of mood as the primary symptom. The mood may appear as excessively sad, as seen in depression, or as excessively happy, irritable, or grandiose, as seen in mania. When a patient experiences episodes of depression alternating with a single or multiple episodes of mania, the individual is said to have bipolar disorder. Prevalences for major depression and bipolar disorder in the general population are 4.4 percent and 1.2 percent, respectively.

The etiology of mood disorders is hypothesized to be related to a dysregulation of neurochemicals in the brain (norepinephrine and serotonin).

Major Depression. This condition refers to a mood disorder in which the patient experiences sadness, loss of interest, or loss of pleasure daily for a period of two weeks. During this period, the patient might experience crying spells, decreased or increased need for sleep, decreased or increased appetite, agitation, loss of energy, loss of sex drive, and thoughts of death. Untreated, this disorder can lead to significant time away from work and an inability to carry out ADLs, as well as result in suicidal behavior or completed suicides.

Manic Depression or Bipolar Illness. This disorder is characterized by recurrent episodes of depression alternating with mania. The depressive episodes are synonymous with the major depressive episodes described previously. Mania is characterized by persistent elevated expansive or irritable mood lasting at least one week or shorter if hospitalization is required. Other accompanying symptoms include inflated self-esteem, decreased sleep, engagement in high-risk behaviors, increased speech production, and goal-directed behavior. A variant of this disorder (Bipolar I), in which symptoms of mania are decreased in their intensity, is known as Bipolar II mood disorder. Both disorders can lead to significant disability if treatment is not accessed.

Dysthymia. This is a disorder that is experienced by the affected person as a subjective experience of a continuous low-grade form of sad mood lasting a minimum of two years but not meeting threshold criteria for the diagnosis of major depression.

Cyclothymia. This disorder is an attenuated form of bipolar illness. In this disorder, episodes of mania alternate with episodes of subsyndromal depression. Although less severe than Bipolar I, it is associated with significant disruption of social functioning and can lead to disability if undiagnosed and untreated.

SCHIZOPHRENIAS

This group of disorders includes a spectrum of disorders characterized by the presence of "psychotic" symptoms. The term *psychosis* is generally used to indicate a state of impaired reality testing, leading to severe impairment of social, personal, and occupational functioning. Whether schizophrenia is a single disorder or a series of disorders occurring along a continuum is unresolved. This disorder has a prevalence of 1 to 2 percent in the general population. It is characterized by symptoms that are referred to as "positive" and "negative." Positive symptoms include hallucinations, delusions, and bizarre associations. Negative symptoms include decreased motivation, decreased attention, and social isolation.

Although the cause of the disorder is unclear, it is believed to be due to a disruption of function of a main neurochemical known as dopamine. Dopamine interacting with serotonin, GABA, glutamate, and acetylcholine in such ways as to enhance the effects of dopamine on neuroreceptors appears to play prominent role in the etiology of this group of disorders. Environmental and genetic cofactors appear to play a significant role in determining who gets these disorders. Of all psychiatric disorders, the schizophrenias carry the highest level of morbidity and psychiatric disability as a group.

SUBSTANCE ABUSE DISORDERS

These disorders represent some of the most prevalent and psychiatrically disabling disorders known. Alcohol abuse and dependency affect 15 to 17 percent of the general adult population. Alcohol or another drug of abuse is involved in 50 percent of homicides and 33 percent of suicides recorded in the United States.

Substance abuse or dependency is typically seen as a comorbid condition in all of the major psychiatric diagnostic groups. Schizophrenia, bipolar disorder, and anxiety disorders are all associated with significant levels of comorbid substance abuse or dependency. Substance abuse contributes to the morbidity of psychiatric disorders by precipitating psychiatric disorders directly (e.g., substance-induced mood or anxiety disorders) or by exacerbating a pre-existing disorder in an individual. Failure to diagnose and treat substance abuse in patients results in treatment noncompliance, treatment failure, overutilization of mental health resources due to recidivism, and increased rates of suicide.

Typical substances abused by today's adolescent and adult populations include alcohol, cocaine, marijuana, ecstasy, heroin, and PCP. All have addictive potential, but addiction is not a prerequisite to these substances having a profound impact on the course and outcome of psychiatric disorders.

SUMMARY

When thinking about psychiatric disorders associated with disability, one should keep in mind specific characteristics held in common by all that can lead to functional impairment.

Many psychiatric disorders, when severe (as defined by the presence of psychotic symptoms), have symptoms such as hallucinations, delusions, disordered thoughts, poor concentration, and loss of reality testing. These symptoms can interfere with the patient's ability to make decisions, process information, problem solve, or follow instructions. Occurring singularly or in combination, it is not a stretch to ascertain that impaired functioning can be a consequence.

The life course of a psychiatric disorder may reveal the presence of intermittent or constant symptoms. Psychiatric symptoms can result in a person experiencing low self-esteem, loss of confidence, emotional fragility, and feelings of helplessness and hopelessness. The consequence of these symptoms can be a lack of initiative, lack of motivation, loss of confidence, and lack of pleasure, which can impair one's ability to perform tasks, function in required roles, or carry out the daily activities of living.

Because psychiatric disorders typically have their onset for many in the most productive years of life, many individuals experience interruptions in social and interpersonal development that lead to impaired social functioning, interpersonal dependency, and arrested achievement.

Many individuals with psychiatric disorders are in a double bind. On one hand, they have an illness that can profoundly impair them emotionally, interpersonally, and professionally. On the other hand, the stigma attached to mental illness prevents some individuals from accessing mental health systems where help is available that could reduce the disabling consequences of living with a psychiatric disorder.

It is not unusual for individuals with psychiatric disorders to have lower socioeconomic status, to experience social isolation and rejection, to have lowered expectations from family and friends, to have increased rates of substance abuse, or to have increased levels of homelessness and crime victimization. Clearly, morbidity associated with mental illness is significant and requires the collective efforts of our nation's health care system to find treatment strategies that are accessible, affordable, and tolerable, whether pharmacologically, psychotherapeutically, or psychosocially based.

Psychiatric disorders are treatable, and the cost in both financial and personal terms of not treating them can be monumental. It is estimated that more than $100 billion in direct (associated with treating psychiatric disorder) and indirect costs (associated with loss of productivity and other sequelae of being mentally ill) is spent yearly. Not treating these disorders can lead to major disruptions in interpersonal relationships, diminished socialization, loss of educational opportunity, and failure to maximally participate in society and make significant contributions.

Activities and interventions directed at reducing the potential for disability in at-risk individuals need to focus on those factors that can reduce the effects of psychiatric disorders as they are diagnosed or reduce the long-term effects of the disorders once an illness manifests itself. Thus, activities that focus on prevention by educating at-risk populations to seek mental health services can be effective. Education of the public at large that reduces stereotyping and stigmatization of those with psychiatric disorders can further enhance reduction of potentially disabling symptoms of mental illness by encouraging and promoting early diagnosis and treatment. It is not enough for those with mental illnesses to simply avail themselves to treatment; they must also comply with recommendations made by physicians and other mental health care workers if treatment is to be successful. Reduced morbidity or disability defines success in this case.

Many communities have underdeveloped mental health networks that can lead to reduced availability of mental health services. Inadequate funding, lack of qualified mental health professionals, and absent rehabilitation services can contribute to the disabling effects of mental disorders over time. Improved awareness by citizenry may lead to improved availability as citizens lobby their government officials for increased expenditures for the creation of more mental health service networks.

Even when available, mental health services are often underused. Access issues related to affordability of mental services can create opportunities for disability. For the working poor and minority communities, lack of adequate insurance coverage can prevent individuals from gaining access to treatment, thus contributing to the potential for disability. Stigma associated with having a psychiatric illness may also negatively affect access to psychiatric services.

Providing improved ways of funding services and educating the public on the importance of accessing these services can reduce disability. Addressing mental health availability and access issues through increased funding and education in conjunction with efforts to make mental health services more sensitive to the specific cultural needs of those being serviced will likely improve utilization. Improved utilization of mental health services offers the best possibility for preventing and controlling the disabling effects of psychiatric disorders, thereby improving outcomes for many with these disorders.

—Henry Dove

See also Bipolar Disorder; Depression; Mental Illness; Normality; Schizophrenia; Substance Abuse.

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PSYCHIATRIC SURVIVORS MOVEMENT

The psychiatric survivor movement consists of a loosely affiliated coalition of individuals who have used the psychiatric system and found it extremely lacking. Most members portray their experiences as harmful and disempowering and therefore have adopted the term *survivor* to indicate that fact. Reflecting a diversity that is characteristic of the nature of the movement, various factions may use different terminologies to describe themselves such as "ex-patients," "ex-psychiatric inmates," "consumers," "service users," and "psychiatrically labeled."

Because self-definition is a central theme within the survivor/user movement, it is accepted that participants will define themselves as appropriate, as opposed to having a medical authority "diagnose" their condition. Those who use terms such as *survivor* and *inmate* emphasize their militancy by taking up a decidedly antipsychiatric orientation, while those who prefer the term *consumer* may be less critical of psychiatry and more attentive to improving the quality of services. Even given these differences, a sense of the mental health system as broken and in need of repair infuses the whole movement. While the method and degree of repair may be somewhat controversial, the innate value of user input and control is an integral foundational belief for all factions.

A largely North American development of the late 1960s, the psychiatric survivors movement was heavily influenced by this era's emphasis on individual choice and civil rights. Its membership was collectively energized by negative experiences at the hands of the psychiatric system while incarcerated as patients; the survivor movement is rooted in self-advocacy. It is an important principle of the movement that practices that induce discrimination toward those labeled with a mental illness diagnosis must be changed so that a psychiatric diagnosis has no more impact on a patient's choices and rights than a diagnosis of arthritis or heart disease. Challenging their stigmatized status in society, the movement promotes the values of self-help and collective action while rejecting forced treatment of any kind. While it would be incorrect to characterize the survivor/user movement as antipsychiatric, it does negatively critique the dominant medical description of mental illness and demands a more holistic view of mental health disability or, as some survivors might say, "extra-ordinary mental experiences." As one pioneering survivor put it, "Because psychiatric ideology mystifies people's difficulties into 'illness' that only experts are thought capable of treating, we are all rendered a little less human" (Chamberlin 1990).

While there are overlaps in social and developmental histories, the relationship between the psychiatric survivors movement and the disability rights movement is a complex one. Kept separate by a theoretical and medical taxonomy applied to physical and mental impairments as if people were either "apples" or "oranges," interpretations of disability as different types of personal tragedies worked to draw attention away from shared situations and shared needs. In addition, some disabled people may have difficulty viewing psychiatric survivors as disabled because their impairment is not evident and may fluctuate. Alternatively, survivors may not consider themselves disabled because they reject the medicalization of their experiences.

STAGES OF DEVELOPMENT

Driven by their perception that the psychiatric system damaged its users, the psychiatric survivors movement began when clusters of ex-patients spontaneously gathered in small local venues. These early years were exciting but tiring times. Like other disabled people, psychiatric survivors were geographically and socially dispersed, suffering from economic hardships, accessibility issues, and stigmatizing social forces. Many people with psychiatric labels were still in state hospitals or on strong psychiatric medication. Promoting healing through consciousness raising, survivor groups worked to move themselves from the static position of victim/survivor to the active role of providing mutual support and advocacy. Common goals included fighting for patients' rights, eradicating stigma, ending economic and social discrimination, and creating peer-run support services. Out of these seemingly disconnected efforts, coalitions began to form, leading to regional associations in Oregon (Insane Liberation Front, 1970), Northern California (Network Against Psychiatric Assault, 1972), New York (Mental Patients' Liberation Project, 1971), and Massachusetts (Mental Patients Liberation Front, 1971). Early advocates such as Judi Chamberlin, Howie the Harp, Sally Zinman, Leonard Roy Frank, and Su and Dennis Budd staged civil disobedience actions, chaining themselves to the gates of psychiatric facilities and picketing American Psychiatric Association meetings.

Sponsored by a nonpatient professor and the New York City–based Mental Patients' Liberation Project, the first Conference on Human Rights and Psychiatric Oppression was held in 1973 at the University of Detroit. Fifty people from the United States and Canada, many working together for the first time, met to develop philosophical guidelines. True to the movement's core belief in self-advocacy and leadership, by 1976, the conference was limited to only patients and ex-patients.

The Madness Network News first went to press in 1972. Begun in San Francisco as a simple newsletter, it evolved into a newspaper that perpetuated and connected the growing survivor efforts in North America and throughout the world. *The Madness Network*

News existed solely on subscriptions and volunteer efforts yet became the voice of the ex-patients' movement, publishing a wide range of material that included personal experiences, art, and factual reporting. It ceased publication in 1986.

In the late 1970s, the federal government began to support the movement's efforts with small grants. The Community Support Program was developed within the National Institute of Mental Health to increase the involvement of users in the development of psychiatric services. Projects such as the "Alternatives" conference were begun with its assistance. The first national Alternatives conference was held in 1984 and has been held annually ever since. Offering workshops related to self-help and self-determination, the Alternatives conference is a great success, bringing together national and international leaders in the survivor/user movement with an annual attendance often exceeding 1,500.

Many of the early pioneers in the survivor/user movement were angry, promoting the complete abolishment of the psychiatric system. By 1980, some individuals were identifying themselves as "consumers" and had begun organizing self-help advocacy groups and promoting peer-run services. While still sharing many fundamental beliefs, consumer groups differed from earlier militant groups in that they preferred reform over abolishment, believing certain traditional services were necessary. Increasingly, these consumer groups have gained access to mental health policy-making and advisory committees. Many such groups have incorporated and now receive direct funding to provide peer-run services. These have proven to be effective, and the "consumer-driven" model is now generally accepted as key to the provision of mental health community services.

The California Network of Mental Health Clients (CNMHC) is an example of a mental health consumer organization. In 1987, it received funding from California's Protection & Advocacy agency. In 1989, CNMHC produced *The Well-Being Project: Mental Health Clients Speak for Themselves* (Campbell and Schraiber 1989), which included groundbreaking research on mental health services developed and implemented by mental health clients themselves. They went on to produce what some consider the movement's self-help bible, *Reaching Across: Mental Health Clients Helping Each Other* (Zinman, Harp, and Budd 1987). Today, user/survivor groups in California have a strong public position, and members sit on mental health–related planning boards and advisory councils throughout the state.

In more recent times, consumer/survivors have moved into paid jobs as "peer specialists" in their state-funded consumer organizations or as case managers in the mental health system itself. (*Prosumer* is a new term that attempts to capture the liminal position of those providing a service within the mental health system while receiving or having received services.) States may require boards that receive federal or state mental health funds to include consumer/survivors. Many states now have an Office of Consumer Affairs, which is headed by a psychiatrically labeled person. This infusion of survivor/user perspective can be attributed to the pioneering efforts of the psychiatric survivors movement, with its core belief in the importance of self-determination and the essential humanity of psychiatric system users.

The Bazelon Center for Mental Health Law was founded in 1972 by a group of committed lawyers and professionals in mental health and mental retardation who attempted to affect mental health service provision through individual and class action suits. In 1980, a group of these lawyers formed the National Association of Rights Protection and Advocacy (NARPA). One-third of NARPA's board of directors must identify themselves as current or former recipients of mental health care. Dedicated to promoting the preferred options of people who have been labeled mentally disabled, NARPA is committed to the abolishment of all forced treatment.

There are some disadvantages to this infusion of federal funds and the growing coalition with community mental health agencies. Many "consumer" groups have become dependent on state or federal money, while independent organizations have faded as volunteers are drawn to paid positions in publicly funded projects. A split has formed between "consumers" and "survivors," with the more radical groups, which relish their independence, warning against "sleeping with the enemy." While some say the independent psychiatric survivors movement is over, a few radical groups continue to directly challenge the fundamental principles of the psychiatric medical model. In 1988, leaders from several grassroots psychiatric survivor groups formed the Support Coalition International. Now an alliance of nearly 100 groups in 14 countries and known as the MindFreedom Support Coalition, it works to defend the rights of psychiatric survivors and to promote empowering treatment alternatives. The coalition has produced a journal since 1987. Originally known as the *Dendron News,* it advocates the global networking of "free minds."

HISTORICAL AND PHILOSOPHICAL ROOTS

Although the psychiatric survivors movement began in 1970, the earlier efforts and writings of former patients in the late nineteenth and early twentieth centuries challenged society's views on insanity and the use of asylums. A good example is the Alleged Lunatic's Friend Society, formed in England by ex-patients in 1847. Another example would be Mrs. Elizabeth Packard, who began publishing books and pamphlets that detailed her forced commitment in the Jacksonville (Illinois) Insane Asylum in 1868. Though she later founded the Anti-Insane Asylum Society, it never gathered significant public attention or support. At the same time, Elizabeth Stone worked in Massachusetts to change public opinion about mental states and to stop the incarceration of those unjustly labeled as insane.

With rapid and expansive industrialization, and as medical science became more elaborate and readily available, more people were given mental illness diagnoses while asylum populations mushroomed. At the dawn of the twentieth century, there were approximately 126,000 patients in 131 state hospitals, yet by 1940, there were 419,000 patients in 181 state hospitals. By the mid-1950s, New York state alone had 93,000 inpatients (Grob 1994). By 1943, with a U.S. patient-doctor ratio as strained as 277:1, a hospital could become more holding tank than medical treatment center. In 1908, Clifford Beers wrote *A Mind That Found Itself,* chronicling his own incarcerations in public asylums. Speaking out against mistreatment and neglect within the system, Beers founded the National Committee of Mental Hygiene, an organization that persists in its current incarnation as the National Mental Health Association.

Another landmark moment in the history of mental health advocacy occurred in 1961 with Erving Goffman's (1961) publication of *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates.* Goffman emphasized that institutionalization created the role of "mental patient" and challenged the central importance of diagnosis in predicting outcome. Many psychiatric survivor leaders continue to credit Goffman's work as significant in expanding the understanding of how a dependency on long-term institutionalization creates an inherently disempowering system of psychiatric care.

By the 1940s, invasive procedures such as insulin coma therapy, Metrazol convulsive therapy, electroconvulsive therapy (ECT), and prefrontal lobotomy had become popular treatments in psychiatric hospitals. These often damaging treatments created a tide of criticism among users and some professionals. Ken Kesey depicted these modes of treatment in a decidedly negative fashion in his 1962 novel *One Flew Over the Cuckoo's Nest*—a book he claimed to have modeled on his actual experiences as an orderly at the San Mateo Mental Facility. The 1970s movie rendition won five Academy Awards and strongly influenced the general public's view of the psychiatric system while fueling the antipsychiatry and psychiatric survivors movements.

In the 1950s, in response to the excessive and violent intervention plans developed in the field of psychiatric care, a critical analysis of psychiatry also began from within, among a small number of practitioners. This insider critique, most literally, authorized the knowledge base for what is recognized today as "antipsychiatry." Charging that the medical model attended almost exclusively to pathology, antipsychiatry accused the field of leaving its patients powerless and isolated. Antipsychiatry practitioners stressed the value of difference, attempting to reconfigure normalcy and deviance.

In 1965, R. D. Laing, Aaron Esterson, David Cooper, and supporters founded the Philadelphia Association, devoted to the creation of therapeutic communities that valued agency and experience as integral components of psychosis. In his influential

The Politics of Experience (1961), Laing declared that normality entailed intrinsic hidden losses, while madness, if we allowed it to unfold instead of subordinating its power beneath an array of medication and psychiatric technology, harbored potential benefits. As an alternative to medical intervention, he recommended initiation and guidance.

Current participants in the antipsychiatry movement also often reference *The Myth of Mental Illness* by Thomas Szasz. Szasz's popular work, although originally published in 1961, is still controversial and continues to be used as a focal point for the antipsychiatry movement. Remaining active, Szasz consistently proposes that psychiatric patients are not ill but are instead social misfits who receive poor treatment and eventually find themselves placed improperly in asylums.

In sum, a more radical faction of the psychiatric survivors movement eventually affiliated with antipsychiatry—both share critiques of a profession and systematically expose historical violence that occurred under its purview. The more moderate consumer groups reject the complete denouncement of the medical model, feeling some portion of traditional treatment to be helpful. They would emphasize the fact that many who have been diagnosed with mental illness relate experiences of real and terrible suffering that both psychiatry and community treatment ultimately helped to alleviate.

—Pam Wheelock

See also Antipsychiatry Movement; Psychiatric Disorders; Psychiatry.

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PSYCHIATRY

Psychiatry is the field of medicine that is devoted to the scientific study of mental illness and the evidence-based treatment of mental disorders. A physician must complete a four-year course of postgraduate training after college and medical school to qualify as a psychiatrist. Psychiatry is a board-certified medical specialty. The concept of mental disorder currently used in American psychiatry is defined in the fourth edition of the *Diagnostic and Statistical Manual of Mental*

Disorders (*DSM-IV*). It states that a mental disorder is a clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress, such as a painful symptom, or a disability, such as an impairment in one or more important areas of functioning or with a significantly increased risk of suffering death, pain, disability, or an important loss of freedom. The *DSM-IV* recognizes approximately 386 distinct mental disorders, each of which can be characterized by a set of criteria. Many other conditions may be included in subsequent editions of the *DSM* as their criteria become empirically validated. This current classification of mental disorders can be divided into broad categories that include dementias, cognitive disorders, mood disorders, anxiety disorders, dissociative disorders, personality disorders, eating disorders, sexual disorders, sleep disorders, developmental disorders, attention deficit disorders, and substance use disorders. Physicians who graduate from four-year residency training programs in psychiatry develop a high interrater reliability in assigning a *DSM-IV* diagnosis to a given patient and also in assigning a similar score on the Global Assessment of Function Scale (GAF), which provides a standard measure of symptom severity and degree of functional impairment for a given patient. This scale score, in conjunction with the multiaxial diagnostic system, provides a criterion-based approach to the measurement of progress of any therapy chosen for the treatment of the patient.

Mental disorders can be severely disabling and can be measured in terms of missed employment, accommodated employment, and full disability; approximately 20 percent of the U.S. population will experience some form of psychiatric disorder with related disability. By far, the disorders that account for the greatest impact on employability and workplace accidents are alcohol abuse and dependence, with a lifetime prevalence of 13.8 percent. Phobia, with a lifetime prevalence of 14.3 percent, and generalized anxiety disorder, with a lifetime prevalence of 8.5 percent, are also major factors in the workplace. Major depressive disorder and substance abuse and dependence have a prevalence of about 6.2 percent each. Other mental disorders that significantly account for psychiatric disability are dysthymic disorder, with a lifetime prevalence at 3.3 percent; obsessive-compulsive disorder, at 2.6 percent; antisocial personality, at 2.6 percent; panic disorder, at 1.6 percent; schizophrenia, at 1.5 percent; and bipolar disorder, at about 0.8 percent. A major concern for school-age children is attention deficit hyperactivity disorder, which has a prevalence rate of between 3 and 5 percent. Absences and suspensions from school have been positively affected by the widespread use of psychostimulants such as methylphenidate, which are effective in 70 to 80 percent of children with this disorder.

Historically, modern psychiatry grew out of the need for those who superintended the large asylums and mental hospitals (alienists) to develop common principles of care at the beginning of the nineteenth century. First in Europe, then North America, then spreading throughout the world, associations of asylum directors began to meet on a regular basis to discuss management and treatment issues and gradually assumed the name of psychiatrists (from *psyche* [mind] and *iatros* [physician]). At the beginning of the nineteenth century, psychiatry focused primarily on the social and psychological factors that were thought to underlie mental disorder such as immoral behavior, unrestrained ambition, or political and religious enthusiasm. This trend led to the formulation of moral therapy as the fundamental mode of treatment. During the second half of the nineteenth century, the pendulum shifted toward biological and brain-related causes of mental disorder, with the disease of neurosyphilis serving as the paradigm mental disorder. The two Nobel prizes specifically given for the treatment of mental disorders were awarded for fever therapy for neurosyphilis, developed by Wagner von-Jauregg, and psychosurgery for intractable psychosis, developed by Egaz Moniz during this era.

By the early twentieth century, the pendulum had shifted back in the direction of psychological causes of mental disorders with the success of the Austrian psychiatrist Sigmund Freud's psychoanalytic theories. This trend, also attributable to French psychiatrist Pierre Janet, culminated in the latter half of the twentieth century with an appreciation of the role of psychologically traumatic experiences, stemming from child abuse, adult trauma, and wartime experiences, as causes of mental disorder and led eventually to the addition of the category of posttraumatic stress disorder to the psychiatric nomenclature. However, with the advent of the psychopharmacology era in the 1950s, as well as the development of chlorpromazine as the first specifically antipsychotic medication and imipramine as the first specifically antidepressant medication, the pendulum began to swing back in the direction of brain-related research for mental illness. The research field of neuropsychopharmacology, which studies the mechanisms of action and brain circuits that underlie the efficacy of psychopharmaceuticals, paralleled the growing field of biological psychiatry, which studies brain circuitry thought to underlie the major mental disorders of schizophrenia, anxiety disorders, and bipolar mood disorder. By the 1990s, brain circuit and neural network models of mental disorders were proposed and tested both in animal studies and in human brain neuroimaging.

The success of the psychopharmacological revolution in psychiatry fueled the trend toward deinstitutionalization, which was further accelerated with the advent of the community mental health movement in the 1960s. In 1955, when chlorpromazine was introduced into the United States (following its introduction in Europe), there were approximately half a million psychiatric inpatients in public and private facilities. By the mid-1990s, that number had dropped to approximately 20,000. The treatment of three major mental disorders—schizophrenia, mood disorders, and anxiety disorders—all received a specialized psychopharmacology based on drug receptor theories unique to each area. Thus, for example, in the treatment of schizophrenia, high-potency phenothiazines such as fluphenazine and haloperidol replaced the first generation of antipsychotics because they were more potent blockers of dopamine. Since antipsychotic potency appeared to correlate with the degree the pharmaceutical blocked certain dopamine receptors in the brain, it was proposed that an excess of dopamine stimulation caused schizophrenia. These receptor theories have proven to be oversimplifications of the etiology of psychiatric disorders.

Despite these advances in the psychopharmacological area, the drawbacks of side effects such as tardive dyskinesia (embarrassing involuntary movements of lips and tongue), the lack of compliance due to cognitive slowing and restriction of affective tone, and treatment resistance led to a new wave of pharmacological innovation. Attempts at molecular engineering, to produce a safer congener of the pharmaceutical clozapine, which had superior efficacy and tolerability in the treatment of schizophrenia, produced a new family of atypical antipsychotics. These newer antipsychotics were better tolerated and had less potential of producing tardive dyskinesia. The additional features of blocking the 5HT2 serotonin receptor and the histamine receptors also proved effective in the treatment of the negative symptoms of schizophrenia not satisfactorily addressed in earlier generations of antipsychotic medications. The negative symptoms of schizophrenia, such as decreased intensity of pleasure or anhedonia, social isolation, affective flattening, poverty of speech and thought, inattentiveness, apathy, and negative behavior, are very disabling. How positive and negative symptoms link up over the natural course of schizophrenia and which brain circuits are involved in their production are questions currently under intensive psychiatric investigation in the area of schizophrenia research.

Comparable progress has been made in the psychopharmacology of mood disorders. Efforts to target the serotonin transmitter system in the brain and to avoid potential overdose lethality from a toxicity point of view led to the development of a generation of serotonin reuptake inhibitors (SSRIs) as well as norepinephrine reuptake inhibitors (SNRIs), both classes of which showed greater specificity in the enhancement of the synaptic concentration of these vital neuromodulators. Despite showing no greater efficacy in treating the fundamental symptoms of major depressive disorder than that possessed by their predecessors, the tricyclic antidepressants, the removal of histamine, and acetylcholine blocking characteristics liberated these newer psychopharmaceuticals from the bothersome side effects of excessive sedation, weight gain, and dryness of the mouth.

Diminution of these side effects was especially important in considering the use of different combinations of these medications, which is often necessary in severe cases of mental disorder and was virtually impossible with the older medications because of cardiac and other toxicities. Where the dosage of the primary drug has been optimized without full remission, then the choice of the second or third medications must be based on the likelihood of enhancing therapeutic effects while, at the same time, diminishing possible side effects and harmful drug-drug interactions. This problem is especially acute in the treatment of bipolar mood disorder, where a refractory patient may require more than one mood stabilizer, one or more antidepressants, and one or more antipsychotics. Added to this problem is the issue of comorbidity, both medical and psychiatric. The psychiatrist needs specialized expertise to effectively treat a patient who has multiple medical conditions requiring medical and psychiatric drugs with overlapping side effect profiles, if a patient has multiple psychiatric diagnoses requiring medications with overlapping side effect profiles, or if the patient is abusing an illicit substance while requiring a complex medical and psychiatric pharmacological regime. Also, if the patient is a member of a vulnerable age group at either end of the spectrum or belongs to a class of imperiled medical patients—for example, those with cancer, AIDS, or other chronic illness—then the choice of psychopharmaceutical agents becomes highly constrained by many physiological considerations. These problems have further reinforced the need for several psychiatric subspecialties such as child and adolescent psychiatry, consultation-liaison psychiatry, addictions psychiatry, neuropsychiatry, and geriatric psychiatry.

Despite these advances in psychopharmacology, psychiatrists are trained in several forms of psychotherapy. Psychotherapy is essential to psychiatry because even those mental disorders that respond reasonably well to psychopharmacological interventions require supportive psychotherapy as well as medication management to sustain patient compliance. No psychopharmaceutical is curative in the most complete sense, and all mental disorders have a psychological as well as a social aspect. The psychotherapies most used by psychiatrists include psychoanalysis, psychodynamic psychotherapy, cognitive therapy, cognitive-behavioral therapy, interpersonal psychotherapy, integrative psychotherapy, dialectical behavior therapy, psychoeducational therapy, group therapy, and brief dynamic psychotherapy. Certain mental disorders require mainly psychological and psychosocial treatment such as addictive disorders, eating disorders, personality disorders, dissociative disorders, developmental disorders, and the group of sexual disorders termed the *paraphilias.*

In diagnosing and treating the whole range of mental disorders, psychiatry, more than any other medical specialty, incurs an obligation to the greater society to protect those who might be injured as a result of a person acting under the influence of a mental disorder. This duty takes many forms depending on the mental health laws of the country or state in which the psychiatrist practices. The basic principles include involuntary hospitalization for endangerment to self or others, duty to warn a potential victim of a patient's homicidal tendency toward him or her, and duty to inform child protective services of probable child abuse. On the other side of the issue, the psychiatrist has a duty to protect a person who has allegedly committed a crime but who was acting under the influence of a mental disorder. In most criminal codes, this is an important mitigating factor. Because persons with mental disorders can be found in all walks of life and in all institutional settings, psychiatrists can be found in most large institutional concerns. Some of these subfields of psychiatry include forensic psychiatry, or psychiatrists who work primarily with the court system; prison psychiatry, an area of growing importance; military psychiatry, psychiatrists who handle issues of fitness for service; Veterans Administration psychiatry, psychiatrists who treat not only military posttraumatic stress disorder but also the entire spectrum of mental disorder; academic psychiatry, those charged with training the next generations of psychiatrists; and research psychiatry, psychiatrists who are funded by government or pharmaceutical companies to perform research on mental disorders.

—Thomas Jobe

See also Mental Illness; Models; Psychiatric Disorders.

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PSYCHOLOGY

Although psychology did not emerge as a discipline centering on the study of disability, its development as a field dedicated to the understanding of the human mind and behavior has inevitably led to the involvement of psychology in work with individuals with disabilities. Initial psychological models of understanding disability borrowed from the medical paradigm, which emphasizes individual-level factors, pathology, and abnormality. Thus, persons with disability have traditionally been defined as those possessing deficient physical and mental characteristics. Definitions of disability have evolved as historical events such as the World Wars, the eugenics movement, and the disability rights movement both shaped and have been shaped by the involvement of psychology in disability issues. Contemporary models of working with disability are progressing toward a focus on the role of environment in disability issues and an understanding of disability in terms of "differently abled" rather than as deviant from "normal" human functioning. In addition, current psychological practice and research seek to apply an interdisciplinary approach in work with persons with disabilities as a means to address disability issues in their entirety. Overall, psychology's role in disability work continues to generate new roles and responsibilities for psychologists in the areas of research, practice, and training. Doubtlessly, psychology will continue to experience the mutual influence of the changing zeitgeist as it relates to disability issues.

EARLY CONTRIBUTIONS

Much of the work that established psychology as a valid science simultaneously produced both theory and research methods that have aided in psychology's study of disability. In the late 1800s, experimental psychologists Hermann Ebbinghaus, Wilhelm Wundt, and Gustav T. Fechner developed observational methods of measuring psychological processes, including rudimentary forms of learning and sensory experiences. Fechner's work directly contributed to modern sensory screening. In fact, Fechner's techniques of testing vision and hearing are the same that are used in contemporary screening tests. Also, the work of Ebbinghaus, Wundt, and Fechner provided a basis for developing measurement techniques that aid in identifying intellectual, emotional, and other forms of mental disability.

When psychology surfaced as a new field of study, evolutionary theory was guiding much of the intellectual thought of the late nineteenth and early twentieth centuries. Consequently, evolutionary theory had great implications for psychology, which led to a focus on heredity and genetic superiority. In 1865, Sir Francis Galton observed that children of geniuses were more likely to be geniuses themselves than were other children and asserted that through controlled breeding, the human race could develop into one with superior intelligence. In the early 1900s, the development of intelligence tests provided psychologists with an apparently valid method of assessing an individual's intellectual functioning, thereby creating a means of identifying those whose propagation was less desired. It was at this time in the United States that the use of intelligence tests and the eugenics movement in the United States were growing.

PSYCHOLOGICAL TESTING AND THE EUGENICS MOVEMENT

The work of Alfred Binet in France established a standardized measure of intelligence based on average mental levels for various age groups. With this measure, a person would receive a score and be placed in a category according to his or her intellectual functioning. Henry Goddard further developed these categorizations by labeling each group. He is responsible for the term *moron,* which referred to adults who had scored similarly to 8- to 12-year-old children. According to Goddard, this category of individuals, though not the most severely intellectually disabled, posed a threat to society as they were more likely to survive and procreate than were those of lower intellectual functioning. Goddard proposed control of these individuals through strict monitoring and institutionalization.

Goddard continued his assistance of the eugenics movement by developing group testing procedures for the army during World War I. Through such testing, men were identified as having high or low intellectual functioning and accordingly assigned to "appropriate" positions. Men with lower intellectual functioning were systematically assigned to the front lines, as their likely deaths were not considered as great a loss as the death of an individual with higher intellectual functioning.

Henry Goddard's interest in eugenics coincided with the increased institutionalization of people with a number of physical and mental disabilities. In addition, in 1907, sterilization laws, requiring the sterilization of people with disabilities, were put into effect. Beginning in 1910, these laws were challenged by discoveries in genetics. Yet the momentum of the eugenics movement was not immediately slowed, and people with disabilities continued to encounter the effects of the movement for years.

POSITIVE CONTRIBUTIONS OF PSYCHOLOGY

The early 1900s was not merely a time in which psychology provided a scientific basis for discrimination against people with disabilities. Psychological testing did produce a standardized method with which disability could be assessed accurately, one that has remained useful in contemporary psychological research and practice. Moreover, the physician Edouard Séguin, produced work with individuals with developmental disabilities and demonstrated the learning capacity of these individuals. Thus, he directly contributed to the development of special education programs and influenced developmental psychologists' work with persons with disabilities.

VOCATIONAL REHABILITATION

In 1912, neuropsychologist Shepard Ivory Franz developed a training program for persons with brain damage, conducting some of the first disability work that provided evidence of reversing the psychological effects of brain damage. Franz's work marked an important shift toward applied psychological work with people with disabilities. However, the major impetus for psychology's involvement in applied work came at the end of World War I, when veterans with disabilities acquired during the war returned to the United States. Increased need for rehabilitative services for veterans prompted the 1920 passage of the Vocational Rehabilitation Act to "provide for vocational rehabilitation of persons disabled in industry or otherwise and their return to civil employment." This legislation marked the formal beginning of federal support for vocational rehabilitation in the United States.

The early to mid-1900s continued to be an era in which psychologists' primary role in disability was rehabilitative, and with World War II, the need for vocational rehabilitation increased. In 1943, the

Vocational Rehabilitation Act was passed and expanded services to include persons with intellectual and psychiatric disabilities as well as those with physical and sensory disabilities. This act helped to establish additional rehabilitation settings, such as schools and mental institutions, in which psychologists provided services to people with disabilities. Over time, many psychologists became involved in the National Society for Crippled Children and Adults. Founded in 1919, this broad-based organization, now Easter Seals, provided psychologists an arena in which they could discuss disability issues with people with disabilities, family members, and other professionals. Psychology's role in disability grew and led to the formation of a special interest group during annual conferences held by the American Psychological Association (APA) in the 1950s. By 1956, a new division of APA was originated, which focused on rehabilitative work with persons with disabilities. Division 22 was originally named the National Council on the Psychological Aspects of Physical Disability and exists today as Rehabilitation Psychology.

THEORETICAL DEVELOPMENT

While rehabilitation work was at the center of psychologists' involvement with disability during the first half of the twentieth century, concurrent developments in psychological theory provided a framework to guide psychologists' understandings of individuals with disability. These theories are based in the medical model, are individually oriented, and often focus on the individual's emotional and/or behavioral characteristics. Clinical and counseling psychologists have used them extensively in their work with people with disabilities, and their influence continues today.

Among the most influential of these theories is Freud's psychoanalytic theory, which originated in 1910 and was widely known and accepted by the 1920s. The theory was developed to explain and aid in the treatment of neurosis and thus emphasized abnormality. Psychoanalytic theory has undergone much criticism and reform since its origination. Psychologists whose practice is guided by this framework have maintained a focus on treatment of abnormalities, which has influenced clinical and counseling services provided to people with disability. Specifically, persons with psychiatric and emotional disabilities are considered to possess a deficiency that must be treated, much as a physical illness is treated by a medical doctor. Currently, individual adjustment to a disability is largely understood as the stages of coming to terms with an object loss. Because of its focus on individual limitations, critics of the psychoanalytic framework claim that this approach overlooks other important aspects of the person and his or her disability, including both abilities and environmental issues. Conversely, psychoanalysis provides helpful insight into a person's needs and motives, which enables a greater understanding of the individual experience of the psychiatric and emotional disability.

Other theories that arose at this time have a similar focus on individual characteristics and seek to influence the behavioral and mental processes associated with disability. Edward Thorndike's law of effect and B. F. Skinner's operant learning theory provided a theoretical basis for applied behavioral analysis. Applied behavioral analysis focuses on the careful use of rewards to develop specific desirable behaviors. It has been used to help develop many behavioral abilities of people with a variety of disabilities, especially including autism and other intellectual and emotional disabilities. These abilities include speaking, relating to others, and reducing self-injurious acts such as head banging. Applied behavioral analysis has been criticized for its narrow focus on a limited number of behaviors, its occasional use of punishment as well as rewards, and its inability to develop skills that can be used across many situations. More recently, applied behavioral analysis has been used as part of larger interventions to help youth and adults with physical, learning, and other disabilities accomplish educational, employment, and independent living goals.

In mid-century, Albert Ellis's rational emotive therapy and Aaron Beck's cognitive therapy emerged and have been widely used in clinical and counseling practice. These methods aim to challenge unhealthy thoughts and beliefs that are thought to cause emotional or psychiatric disability. These approaches have also been used in work with individuals with other forms of disability, particularly when the individual's stance toward his or her disability is a primary issue. In this case, the psychologist understands that the person's difficulty with disability stems from an unhealthy manner of thinking about his or her disability. According to these approaches, when these beliefs are challenged and replaced with healthy beliefs, individuals with disabilities are more able to think constructively about their impairments. Similar to criticisms faced by psychoanalytic theory, these approaches have been criticized for failing to address possible environmental issues that may contribute to a person's disability.

By the end of the 1950s, psychology's role in service to individuals with disabilities was established as one that incorporated testing, counseling and psychotherapy, and rehabilitative work. As these services were established, the political context within the United States was marked by an increasing awareness of and struggle against discrimination and the injustices that it produced.

PSYCHOLOGY AND THE DISABILITY RIGHTS MOVEMENT

With the *Brown v. Board of Education* ruling of the U.S. Supreme Court in 1954, separate schools for African Americans were declared unconstitutional, and the modern civil rights movement began. By 1964, the Civil Rights Act was passed, outlawing discrimination on the basis of race and consequently providing a model for disability rights legislation. Four years later, the Architectural Barriers Act, requiring access to federally funded facilities, became the first disability rights legislation in the United States.

Meanwhile, psychology was evolving with the changing political climate. Psychologists from various areas of specialization were becoming involved in advocacy efforts for minority groups, which evidenced a shift from a focus on solely individual characteristics to greater attention to environmental factors in the understanding of individual experience. In addition, there was more interaction between psychologists and individuals from other disciplines, further influencing psychological methods of service. Specifically, psychologists began seeing a need to merge traditional research and practice with newly emerging advocacy roles. A number of psychologists organized such efforts by developing the Division of Community Psychology, Division 27 of the American Psychological Association. This division (now the Society for Community Research and Action), among others, helped legitimize the role of psychologists as advocates by establishing a mission that emphasized psychologists' responsibility for promoting social justice.

During the 1970s, the disability rights movement gained momentum and continued seeking legislative protection for the rights of people with disabilities. The movement centered on concepts of the inclusion and autonomy of people with disabilities. In 1972, the Center for Independent Living originated in Berkeley, California, launching a widespread independent living movement. Legislation, such as the Rehabilitation Act of 1973 and the Education for All Handicapped Children Act in 1975, promoted antidiscrimination efforts by explicitly specifying the rights of people and students with disabilities, which aided in developing future legislation.

Psychologists were able to support the disability rights movement during the 1970s and 1980s by supplying empirical evidence for the necessity of inclusion and autonomy as well as develop techniques that would facilitate such inclusion. For example, psychologists produced methods of skill instruction to people with disabilities to aid in community living. They also created assessment tools to measure individual skill levels for people with disabilities. They conducted research that provided evidence of the benefits to both individuals and society when persons with disabilities lived in the community versus in institutions. Furthermore, the 1970s saw some of the first conferences on the psychological aspects of disability, which aided psychologists in working together to develop and implement beneficial services to people with disabilities.

The work of psychologists and other disability right activists in the 1970s laid a foundation for work in the 1980s. Much of the legislation that was passed during this time built on prior legislation. While psychologists continued to be involved in disability rights, other changes that society experienced in the 1980s further influenced how psychologists were involved in disability work.

CONTEMPORARY PSYCHOLOGICAL PRACTICE AND THEORY

A primary influence on psychology's role in disability in the 1980s was the progress in medical technology. Such progress led to a greater number of individuals surviving serious head injuries and other medical conditions and thus a higher need for psychological services. Neuropsychologists who had been trained in the new medical technology became involved in rehabilitation services with these individuals. Today, neuropsychologists continue to contribute to services for people with disabilities by studying the connections between the brain and behavior for those with disabling conditions. Knowledge acquired through these studies enables other psychologists and individuals from other disciplines to provide more appropriate services to these individuals.

In addition to the contributions of neuropsychologists, other clinical and counseling psychologists sought to enhance their methods of serving individuals with disabilities. Specifically, psychologists, such as Beatrice Wright and Hanoch Livneh, developed theory and practice that would address specific disability issues. They drew first on existing individually focused theories of personality and counseling and applied them to their psychological rehabilitation approach to help persons with disabilities. Building on the ecological tradition of Roger Barker and the socially relevant social psychology of Kurt Lewin and Tamara Dembo, Wright later called attention to the importance of improving societal attitudes toward and acknowledging the strengths of people with disabilities. She encouraged rehabilitation professionals to recognize that people with disabilities are not passive and should be actively engaged as "comanagers" of their own rehabilitation and affirmed as in charge of their lives more generally. These approaches incorporated both psychological and social aspects of disability. They explained how the interaction of these components could either promote or inhibit a healthy adaptation to disability. Carol Gill has advanced a positive view of the development of disability identity that describes how individuals with disabilities constructively come to terms with their limitations and engage society based on their own strengths. These developments in practice and theory have guided contemporary methods of counseling and psychotherapy services with people with disabilities.

Psychological views of family members of individuals with disabilities have also evolved. The blaming models of mid-century, such as Bettelheim's "refrigerator mothers" who purportedly caused autism, have been replaced by the more positive views underlying the work of Tamar Heller, Marty Krauss, and others. They recognize the substantial care and support provided by mothers and other family members to children and adults with intellectual disabilities. They are documenting the stress, coping, satisfaction, and fulfillment that can be part of living with and supporting family members with disabilities.

From the area of social cognition, Ronnie Janoff-Bulman, Shelly Taylor, and others have examined the important role that assumptions may play in how individuals respond to major life changes such as becoming disabled. "Positive illusions" can be a coping resource, for example. They also show that major traumatic events can affect views of the world by challenging long-held assumptions such as "The world is a benevolent place" and "I am a worthy person." They suggest that highly emotional events are of great importance in shaping the thoughts persons have about the world.

In their now-classic article on the social model of disability, Michelle Fine and Adrienne Asch recommended questioning the social attitudes and arrangements that limit the opportunities of people with disabilities. They suggest viewing people with disabilities as a minority group whose disabilities are not a matter of shame but a reality to address and who can contribute meaningfully and valuably when given equal access to education and employment and independent living. In that spirit, psychologists have also continued to work as researchers and advocates. In 1990, the U.S. Congress passed the Americans with Disabilities Act (ADA), which provides greater legal protection for the civil rights of individuals with disabilities. Psychologists were active in providing testimony in support of ADA and were influenced by its passage. Currently, psychologists have a responsibility to understand legislation protecting the rights of people with disabilities so that psychological services, research, and advocacy respect, examine, and build on this important legal foundation.

FUTURE DIRECTIONS IN PSYCHOLOGY AND DISABILITY

While psychology has progressed for more than a century and thereby has become a field more knowledgeable about and responsive to disability issues, criticisms of current psychological practice have pressed the field to further develop its involvement with individuals with disabilities. Specifically, some psychologists are challenging traditional definitions of disability, which have significant implications for current psychological practice.

Newer ideas of disability have stemmed from the social model of disability, which conceptualizes disability on a dynamic continuum. That is, the degree to which a person is considered disabled may fluctuate from day to day or from situation to situation depending on the interaction of environmental and/or individual factors. For instance, an individual who uses a wheelchair experiences the disability differently depending on whether he or she is attempting to enter a building that is wheelchair accessible or inaccessible with a wheelchair that can or cannot climb stairs. In essence, the lack of fit between the individual's abilities and the environmental characteristics creates an inaccessibility that becomes a part of the disability. The new social paradigm of disability has begun to influence psychology in the areas of training, assessment, research, and practice. For example, the nature, extent, and role of social support in the lives of persons with disabilities are emerging as areas of research interest with implications for community-based interventions.

Furthermore, although there has been an increase in studying individuals with disabilities, reform efforts suggest that there is also a need for an inclusion of persons with disabilities in areas of psychological study that are not particularly directed toward understanding disability issues. Similarly, psychological training programs are being challenged to address disability issues across the curriculum to enhance disability competence within the field. These methods of including disability issues in broader psychological practice have been recommended to ensure that the perspective of those with disabilities will be considered. This consideration will lead to better informed psychological practices for individuals with disabilities and to greater knowledge about the human condition more generally.

—Jaime Wernsman, Christopher B. Keys, and Scott Feldman

See also Professions; Psychiatric Disorders; Psychiatry.

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PSYCHOSIS

The term *psychosis* refers to an array of symptoms that relate to disturbances in how the brain processes perceptions and thoughts. A narrow definition of psychosis focuses on a cluster of phenomena known as positive symptoms. Positive symptoms include hallucinations and delusions. Hallucinations are said to occur when an individual experiences a sensory impression that has no basis in reality. This impression may involve any of the sensory modalities (i.e., hearing, sight, smell, taste, touch, or body position in space). Delusions are strongly held beliefs that are maintained despite a lack of supporting evidence. A delusional person may believe that others are reading their thoughts or plotting against them. Attempts to persuade the person that these beliefs are untrue generally fail and may even support the paranoia. In addition to hallucinations and delusions, persons with psychotic illness may have disorganized and confused thinking and may exhibit odd or flagrantly bizarre speech and behavior. These symptoms generally cause considerable disability, particularly in interpersonal relationships and work, and in most Western cultures, are associated with high unemployment.

Persons with psychotic illness may also develop what are known as negative symptoms that impair motivated and spontaneous behavior. Negative symptoms can make it difficult to conduct basic activities of daily living such as maintaining personal hygiene or attend to tasks such as grocery shopping and banking.

Psychotic symptoms may occur in a wide variety of mental disorders. Although most characteristically associated with schizophrenia, psychotic symptoms can also occur in severe mood disorders (e.g., major depression and bipolar disorder), as well as in response to underlying general medical conditions, in certain substance-induced disorders, and with some of the more severe personality disorders.

Psychosis caused by an underlying medical condition remits once the condition has been identified and treated. However, the 1.1 percent of the population suffering from schizophrenia may have psychotic symptoms throughout their lives. Following a first episode of schizophrenia, residual psychotic symptoms, negative symptoms, and a variety of cognitive deficits often persist and can cause significant psychosocial impairments. One of the best outcome predictors for first-episode patients with schizophrenia is treatment adherence, and there are compelling data to suggest that earlier, more intense interventions produce better long-term outcomes.

Psychotic symptoms resulting from a variety of disease states seem to share an underlying common mechanism, as they tend to respond as a group to specific pharmacological interventions. Despite the remarkable improvements that are developing in the treatment of psychotic illness, much remains to be learned about the brain mechanisms underlying psychosis so that more complete and predictable symptom abatement may occur.

—Thomas A. Simpatico

See also Psychiatric Disorders; Psychiatry; Psychology.

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PUBLIC STRIPPING

Term used by people with disabilities and disability studies scholars to describe a medical teaching and consultation practice in which disabled people, to receive medical care, were required to display themselves naked (or nearly so) in front of a well-dressed group of physicians, students, and allied health professionals. The practice, often referred to as *grand rounds* by medical practitioners, involves the presentation of a medical case with the actual person present not as a participant but as an object lesson for the assembly. The practice varied from institution to institution and from case to case, but the subjects of these demonstrations describe having hospital gowns and even undergarments taken off so that the professionals and students could examine them more freely. Many report having to walk naked in front of the physicians and others, having their bodies bent, probed, inspected, and exposed in mortifying ways.

The practice has not been limited to the grand-rounds setting. For example, psychologist Carol Gill reports that in 1993, on the popular NBC prime-time news magazine *NBC Now,* a physician pulled up the T-shirt of a 12-year-old girl with cerebral palsy and, without even speaking to her, displayed her scoliotic back to a national television audience.

Disabled people report feeling objectified by this experience, in which their perspectives on their impairment are completely ignored. But worse, they suggest, is the humiliation: These people, whose physical characteristics were the occasion for shame and oppression, were forced to denude themselves and parade those very characteristics for which they were singled out in front of a judgmental group of powerful people who treated them not like a person but like a set of symptoms, like an malfunctioning object.

By the twenty-first century, the practice has become less common, due perhaps to gradual changes in the culture of medicine as well as to changes in medical education, including the advent of advanced information technology. The practice and its impact on its disabled subjects has been explored extensively by crip artists, writers, and performance artists, including Cheryl Marie Wade, Greg Walloch, Mary Duffy, Carrie Sandahl, and Eli Clare.

—*Jim Ferris*

See also Stigma; Values.

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PUBLIC TRANSPORTATION

As societal divides between domestic and labor environments developed in the Industrial Revolution, public transportation systems were built to address the mobility needs of the labor force. Historically, these systems have been inaccessible to people with disabilities, making removal of transportation barriers a universal disability rights demand. A quick search of the Internet reveals more than 30,000 sites containing information about disability and public transit. Canadian and Australian authorities publish information about how disabled citizens and visitors may access their transit systems. In Great Britain, DAN (Disabled Action Network) has taken to the streets, winning a great victory in Nottingham in 1996. In South Korea, activists have documented their ongoing struggle in a documentary film. In all of these cases, the need for transportation has helped to create and fuel movements for disability rights, making public transportation the fight that is building the disability rights movement around the world.

In the United States, modern public transportation systems began to take shape at the dawn of the twentieth century. In 1895, New York City replaced its steam-powered lines with electric trains, and across the country, horse-drawn omnibuses and carriages were phased out in favor of electric-powered trolleys and streetcars. The first modern city bus, which seated 43 passengers and featured driver-operated doors, was manufactured in 1927. In 1933, Boeing unveiled the first commercial aircraft, which seated 10 passengers, featured upholstered seats and a water heater, and traveled at 155 mph. The development of these early public transportation systems unfortunately coincided with a period of disability history known as the “eugenics” era, in which disabled people were institutionalized, seldom seen in public, and sometimes even prohibited by law from using public streets and facilities. Invisibility led to exclusion so that early public transportation systems evolved for almost three-quarters of a century without considering access for people with disabilities. Transportation equipment and facilities were built without vertical access for people with mobility impairments and without communication access for people with visual or hearing impairments.

With the development of the independent living movement in the 1960s, a new way of thinking about people with disabilities and society emerged. Disability rights activists used the "social model of disability" to move the locus of "the problem" from individual or personal inadequacy (e.g., the inability to climb bus stairs) to society's systematic exclusion of people with disabilities through architectural and attitudinal barriers. In 1973, MAD (Metropolitan Area Disabled), a group of disabled people in Denver, Colorado, began to protest separate and unreliable service for disabled riders. In 1977, the same year that the first wheelchair lift–equipped fixed-route bus was run in San Diego, the Atlantis Community, a client-based organization that provided attendant services to people moving out of nursing homes, filed a lawsuit under Section 504 of the Rehabilitation Act of 1973, demanding access to Denver's public bus system. When a judge ruled against the Atlantis Community in 1978, a group of disabled activists and their allies closed down Denver's bus system for two days until they won agreement to equip all new buses with lifts. By 1982, disabled riders in Denver enjoyed accessible mainline bus service. This group formed the nucleus of what would become one of the most contentious of disability rights groups, ADAPT (American Disabled for Accessible Public Transit).

Throughout the 1980s, the nascent disability rights movement rallied around the demand for access to public transportation. Activists forced public officials to rethink policies that excluded people with disabilities from mainline public transportation systems by debunking inflated cost propaganda and showing that access to public transportation was essential for full participation in educational, social, and vocational activities—integral to connecting with others in the community and moving about freely.

Public transportation authorities through their national association, APTA (American Public Transit Association), vigorously opposed the concept of providing accessible mainline transportation to people with disabilities. Portraying the cost of equipping buses and trains with lifts and other accessibility features as an economic threat, transit authorities appealed to the courts for relief from federal regulations in favor of a "local option" that allowed localities to determine what service to provide to disabled riders. The courts concurred, and in the decade preceding passage of the ADA, most disabled riders continued to be relegated to separate and notoriously unreliable paratransit services, where ride denials were commonplace and spontaneous travel was prevented by laborious administrative and scheduling requirements.

The demand for accessible public transportation was sustained through community activism, protests, and court battles for more than 15 years. In Chicago, disabled riders, many of who were members of Chicago ADAPT, sued for access to the city's buses and rapid rail system under the state human rights law (*Jones v. CTA*). Their victory in 1988 was followed by a sister lawsuit against Chicago's commuter rail system (*Jones v. Metra*), which was also settled in favor of disabled plaintiffs. By the time the Americans with Disabilities Act (ADA) of 1990 was passed, almost half of the nation's bus companies were ordering at least some lift-equipped buses.

With the passage of the ADA in 1990, which established minimum accessibility requirements, many disabled people gained improved access to public transportation systems. Yet compliance has not been easy, and transit entities had to be taken to court, in some cases repeatedly, to enforce compliance. Others have used the "minimum" requirements of the ADA to circumvent accessibility for disabled riders. For example, many public bus companies purchased new inaccessible buses just before effective dates of transportation regulations, with useful lives of 10 to 12 years; this effectively postponed mainline access for a decade. For some, who depended on door-to-door transportation, the ADA resulted in less transportation when not traveling within the required radius of mainline.

"Full compliance" under the ADA does not always translate to equal or full access in practice. For example, as of 2003, the Chicago Transit Authority proclaimed that 35 percent of its stations were ADA accessible, yet the accessibility is unequally distributed, and some key access compliance continues to be deferred into the future. Over time, a key flaw in early disability rights thinking became apparent. Activists in the 1970s and 1980s envisioned a "common" disability population and deprioritized the needs of people with disabilities who could not be accommodated by mainline transportation systems. This includes, for example, people with respiratory impairments who cannot wait for buses in temperature extremes, people with chronic fatigue syndrome, and ambulatory disabled people who cannot stand for long periods of time. While complementary paratransit requirements were included in ADA regulations, service areas are based on travel patterns of mainline bus users, and the regulations allow transit agencies to charge double the standard bus fare for disabled people who cannot access mainline systems, thus effectively pricing public transportation out of reach for many people with disabilities, who remain the poorest minority group in America.

Even where technical compliance on fixed-route services has been achieved, disabled riders are often singled out, separated, and expected to participate in separate additional interactions. "Handicap" turnstiles, separate paths of travel, special call buttons, additional paperwork, separate boarding and debarking processes, and delayed exits from the system all add up to a multiplicity of separate policies and procedures that stigmatize disabled riders.

For many, the promise of the ADA remains out of reach. Just as disabled people were staking a claim to public transportation, funding for public transit declined and private vehicles became a staple of American life. The cost of modifying private vehicles for accessibility is often prohibitive; it is not unusual for modifications to double the cost. Most taxi services also remain inaccessible. Disability rights groups argued that making buses and trains accessible would provide reliable transportation to disabled people and reduce the human and social costs of failing to accommodate—the cost of maintaining millions in unemployed poverty who could work if they could obtain reliable transportation. Yet more than a decade after the passage of the ADA, 65 percent remain unemployed, a significant number cannot or do not drive, and in many parts of the country, people with disabilities, unlike their nondisabled counterparts, remain isolated and excluded from the mainstream of American life.

Despite disappointing progress at times, disabled people continue to press for access to all modes of public transportation. When the Supreme Court found that the Rehabilitation Act did not apply to air travel, disability advocates organized, and in 1986, Congress passed the Air Carrier Access Act (ACAA), which requires the implementation of practices and procedures to ensure access to air travel by people with disabilities, but stopped short of mandating the development of accessible aircraft. At the dawn of the twenty-first century, disabled people would win accessibility on American cruise lines and then go on to press for accessibility on foreign-flagged cruise ships in U.S. waters.

—Sharon Lamp

See also Accessibility; ADAPT; Air Carrier Access; Americans with Disabilities Act of 1990 (United States); Industrialization.

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Q

QUALITY OF LIFE

The measurement of quality of life has become central to the evaluation of health care. This has not always been the case; until recently, quality of life was addressed only through indirect inference from more traditional medical variables. The difficulty of defining quality of life in a meaningful and operational manner was in part to blame for the apparent unwillingness of the medical profession, and those allied with it, to engage in systematic evaluation of quality of life in the past. Indeed, the term *quality of life* is inherently ambiguous, as it can refer both to the experience an individual has of his or her own life and to the living conditions in which people find themselves. Consequently, definitions of the concept have varied widely, with some writers viewing quality of life as in some way akin to the Aristotelian notion of the "good life" and others defining it in terms of capabilities (i.e., having the ability to live a good life in terms of emotional and physical well-being). Within the arena of health care, the latter view has tended to dominate, and the term *quality of life* is typically used to refer to individuals' experiences of their own health.

Academic interest in quality of life grew after World War II, when there was increasing awareness, and recognition, of social inequalities. This provided the impetus to social indicators research, and subsequently to research on subjective well-being and quality of life. The term *quality of life* first appeared in the medical literature in the 1960s, and references to it have grown exponentially ever since. In 2003, the term appeared in more than 6,000 articles referenced on Medline alone. For the most part, health care scholars and researchers use the term to refer to outcomes based on patient self-reports. Historically, this had simply not been an integral part of how health was reported in the scientific literature. Undeniably, the patient's view of his or her own health had played some role in the medical consultation, but in terms of the health care literature, researchers did not begin collecting and reporting such data systematically until the late 1960s.

Within the arena of disability research and health care it has become increasingly commonplace to discuss *health-related* quality of life. Interest in health-related quality of life is in keeping with the World Health Organization's definition of health, which incorporates autonomy and physical, mental, and social well-being; health is not merely the absence of disease. The literature in this field covers a wide variety of areas, including role functioning (e.g., ability to perform domestic and work tasks), degree of social and community interaction, psychological well-being, pain, tiredness, and satisfaction with life. To some extent there is a tendency to equate quality of life with those factors of the health state that are not encompassed by traditional medical assessments. Such a view can lead to conceptual confusion and perhaps highlights more than anything else the difficulty in providing a simple definition of quality of life. Suffice it to say that health status and health-related quality of life have come to mean a combination of subjectively assessed measures of health, including physical function, social function, emotional or mental state, burden of symptoms, and sense of well-being.

Most early attempts to develop measures for assessing health-related quality of life included attempts to measure the specific impacts of disability. For example, the Katz and Barthel measures were designed to assess activities of daily living in patients undergoing rehabilitation programs. Measures of emotional health, such as the Beck Depression Inventory, were designed to assess mental health and to give an indication of the severity of depressive symptoms. However, questionnaires are now often specifically designed to cover a wide range of areas that may affect an individual's quality of life. Two broad categories of measures have emerged: those designed to evaluate health-related quality of life in any group of patients (indeed, in any population sample) and those designed to evaluate health-related quality of life in specific illness groups. The former group include measures such as the Sickness Impact Profile and the 36-item Short Form Health Survey (SF-36). These instruments cover a wide range of aspects of life that can be adversely affected by ill health, such as physical functioning, emotional well-being, and ability to undertake work and social activities. Disease-specific measures, such as the Arthritis Impact Scales Version II (AIMS II), the 39-item Parkinson's Disease Questionnaire, the Endometriosis Health Profile, and the 40-item Amyotrophic Lateral Sclerosis Assessment Questionnaire (ALSAQ-40), are designed for use with specific patient groups. They are intended to cover dimensions salient to particular patient groups; thus, like generic measures, they address areas such as physical and emotional functioning, but they also cover issues that may be predominant among patients with particular illnesses (e.g., feelings of loss of control, stigma).

A wide variety of uses have been suggested for quality-of-life data, but the most common applications are the assessment of treatment regimes in clinical trials and health surveys. Other applications include population and patient monitoring, screening, and improvement of doctor-patient communication. One of the most emotive uses of such data, however, is in the economic evaluation of health care, with some measures designed specifically to be used in cost-utility analyses—that is, analyses that attempt to determine the benefits of an intervention in terms of both length of life gained and quality of life. Perhaps the most widely used of these measures is the EuroQol 5D (EQ-5D), which addresses five dimensions of health: mobility, self-care, usual activity, pain, and anxiety/depression. Each of these dimensions is subdivided into three levels according to whether the dimension represents no problem, a moderate problem, or a severe problem. The five dimensions and the three-level classification system generate 243 health states, which the instrument's developers have extended to 245 through the addition of death and unconsciousness. The values attached to these health states, which are based on responses from surveys of the general population, are intended to reflect societal views of the severity of each state. The EQ-5D can produce the quality-of-life component for the calculation of quality-of-life-adjusted years (QALYs), in which quality of life is combined with years of life gained as a consequence of an intervention. Costs of treatment can be linked with the number of QALYs gained to give a cost per QALY.

Clearly, quality of life represents an aspect of health that is different from that generally measured using traditional methods of assessment, such as X-rays, blood tests, and clinical judgment. The latter have tended to dominate within health care and medicine in part because they are seen to be relatively objective. The measurement of quality of life incorporates the subjective views of the patient directly and can provide health care professionals with information that can supplement or, on occasion, contradict traditional assessments. For example, there is evidence that outsiders, such as doctors and relatives, view the quality of life of patients with serious disabilities more negatively than do the patients themselves. Also, in some instances, clinical assessments remain stable over time and yet patients report a worsening of their health. Such divergences between the perceptions of those in a given health state and the perceptions of outside observers highlight the limitations of basing assessments purely on observers' assessments. The main purpose of the health care system is to increase the well-being of those it treats. This can be achieved only if patient views are incorporated into treatment evaluations, thereby ensuring that health and medical care are fully evidence based.

—Crispin Jenkinson

See also Activities of Daily Living (ADLs); Citizenship and Civil Rights; Health; Participation.

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QUEBEC MODEL OF DISABILITY CREATION PROCESS

The disability creation process (DCP) is a conceptual model that enables one to identify and explain the causes and consequences of disease, trauma, and disruptions to the development of a person. It demonstrates that social participation is not only the result of our identity, our choices, impairments to our organs, and our abilities and inabilities, but also of characteristics of our living environment. For example, an individual's preparing meals or going to regular school may be influenced by the reinforcement of that person's capabilities and alteration of his or her functional limitations through rehabilitation, as well as through the reduction of obstacles caused by prejudice, lack of assistance or resources, and absence of accessibility within the home or school.

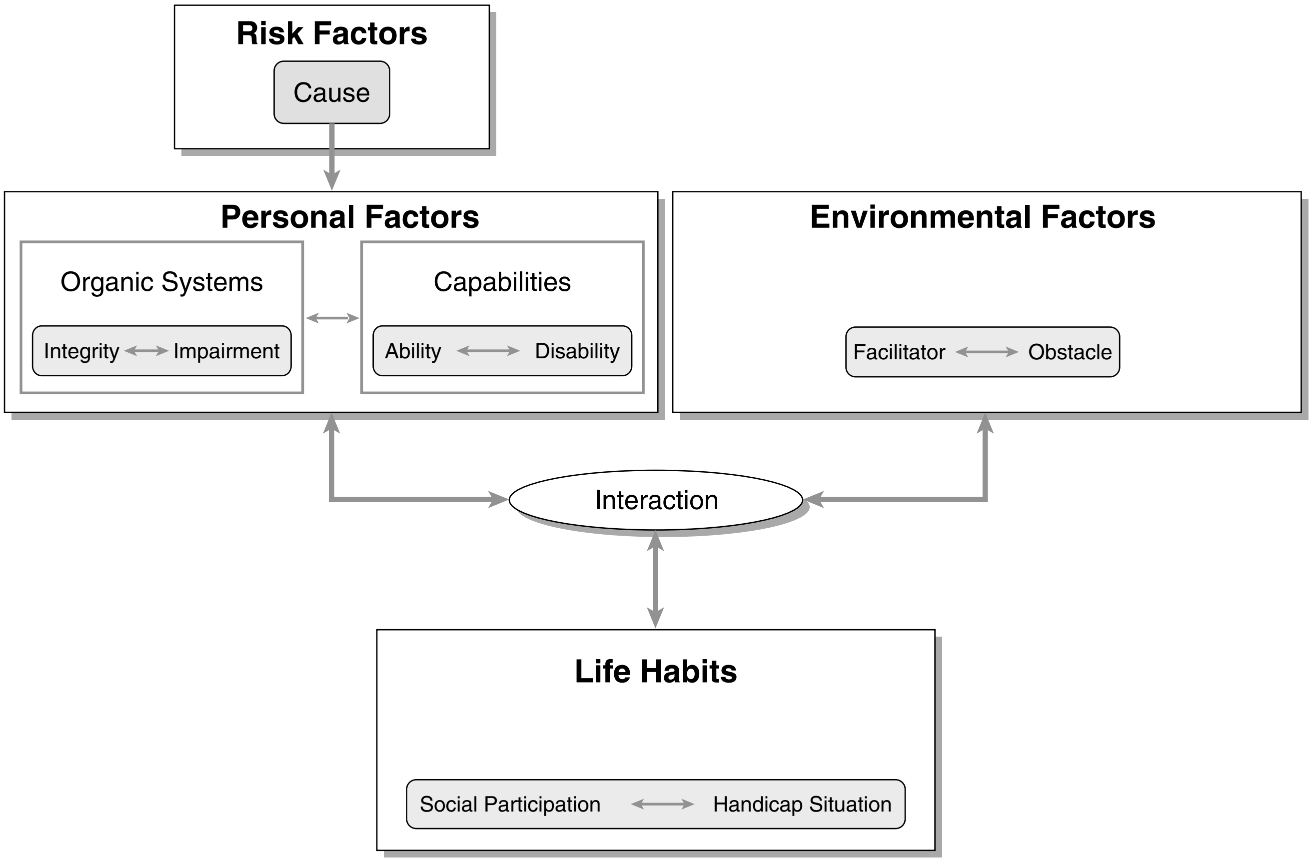

Figure 1 The Disability Creation Process: The Reference Model

The DCP model was developed based on the Quebec government's disability policy, "On Equal Terms," and on the recommendations of international experts, including the World Health Organization, the United Nations, Disabled Peoples' International, and the Council of Europe, at the Quebec Meeting on International Classification of Impairments, Disabilities, and Handicaps (ICIDH) in June 1987. By 1989, Patrick Fougeyrollas, a Canadian anthropologist, and the Quebec Committee on ICIDH published a conceptual framework illustrating the person-environment interactive process of the creation of social participation or exclusion. Throughoout the 1990s, they improved the DCP framework and classification, known also as the Quebec model, and urged the WHO and international partners to revise the ICIDH. From 1993 to 2001, this innovative conceptualization and its scientific applications influenced the revision process that culminated in the WHO's adoption of the International Classification of Functioning, Disability, and Health (ICF).

The DCP model differs from the ICF in its conceptualization of human development and adaptation as well as in its view of the disability process as an interactive person-environment relationship that creates the outcome of quality of social participation. Although the ICF has also adopted a universal, systemic conceptual framework, the DCP illustrates in a heuristic and pedagogical way the dynamics of the interactive process between personal factors (intrinsic) and environmental factors (extrinsic) that determines the situational result of accomplishment of life habits (daily life activities and social roles) corresponding to the person's age, gender, and sociocultural identity. The DCP concepts and taxonomies are mutually exclusive.

The DCP model distinguishes two intrinsic dimensions applicable to every human being: organic systems and capabilities (see Figure 1). The "personal factors" category is larger and more inclusive than the "organic systems" and "capabilities" themselves because other personal identity variables (age, gender, sociocultural identity) must also be considered in the explanation of the performance of life habits. The "environmental factors" category is clearly delimited and includes all dimensions of the context (social, cultural, political, physical, and so on) in which the person lives. The dynamic nature of the interactive process is symbolized by the bold double arrows in Figure 1. The point of central convergence, symbolized in the figure by the word *interaction,* aims at naming the continual relationship and influence of the three conceptual dimensions.

The International Network on the Disability Creation Process is a Canadian nongovernmental organization that promotes the use of the DCP model and the development of applications supporting the exercise of human rights and full citizenship for people with functional and organic differences.

—Patrick Fougeyrollas

See also International Classification of Functioning, Disability, and Health (ICF/ICIDH); Models.

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QUEER/DISABILITY STUDIES

As disability studies flourished in the late 1990s, the insights that emerged from points where the field intersected or converged with queer studies proved to be particularly productive. By the turn of the century, this convergence had generated a number of significant texts, events, communities, and institutions. Eli Clare's *Exile and Pride: Disability, Queerness, and Liberation* (1999) was a landmark text in this process, as were a number of edited volumes, including Raymond Luczak's *Eyes of Desire: A Deaf Gay and Lesbian Reader* (1993), Shelley Tremain's *Pushing the Limits: Disabled Dykes Produce Culture* (1996), Victoria A. Brownworth and Susan Raffo's *Restricted Access: Lesbians on Disability* (1999), Robert McRuer and Abby L. Wilkerson's "Desiring Disability: Queer Theory Meets Disability Studies" (2003) (a special issue of the prominent academic journal *GLQ: A Journal of Lesbian and Gay Studies*), and Bob Guter and John R. Killacky's *Queer Crips: Disabled Gay Men and Their Stories* (2003). An efflorescence of cultural work in many other locations both preceded and accompanied these important volumes, including individual memoirs such as Kenny Fries's *Body, Remember* (1997) and Daphne Scholinski's *The Last Time I Wore a Dress* (1998); performance art by Terry Galloway, Greg Walloch, Julia Trahan, and others; the online publication *Bent: A Journal of Cripgay Voices;* and the "Queer Bodies" study and education group, which focuses on queerness and disability, based in New York City at the Center for Lesbian and Gay Studies (CLAGS). A group of activists and academics in the United States initiated a queer disability Listserv on the West Coast in 2000 and, partially through this network, the first international queer/disability conference was organized. That event, which was held at San Francisco State University in June 2002, was attended by artists, academics, and activists, thereby bringing together (in sometimes contentious conversation) the three overlapping communities responsible for generating increased interest in the convergence of queerness and disability.

This wave of interest in queer/disability studies was facilitated both by the perceived connections between some lesbian/gay/bisexual/transgendered (lgbt) subjectivities and some disabled subjectivities and by the affinity certain strands of disability studies seemed to have with what had been known since the early 1990s as "queer theory." Among the perceived connections between lgbt and disabled subjectivities was the recognition that socialization for both people with disabilities and lgbt people often occurred in heterosexual and able-bodied families, isolated from queer and disability communities. Similarly, the rhetoric of coming out that developed in part to resist such isolation and that permeated the disability movement by the end of the century had clear, and sometimes acknowledged, antecedents in the gay liberation movement, and at its best did not signify discovery of some deep essential truth but rather coming out to a vibrant movement intent on collectively and often quite literally rebuilding the world. Both communities have faced ongoing medicalization or pathologization and arguably faced similar new dangers at the turn of the century, normalization perhaps at the forefront. Throughout the 1990s, lgbt communities debated the benefits and liabilities of the normalization process, weighing such factors as increased media visibility and tolerance against the potential loss of a flamboyant and critical militancy, the dangers of tokenism, and the ongoing marginalization of members of the community furthest from what Audre Lorde identified in 1984 as "the mythical norm." For both lgbt and disability communities, the danger of mutual recoil was perhaps the most problematic aspect of normalization: the possibility that acceptance for queers would come first to those perceived as least disabled and that acceptance for people with disabilities would come first to those perceived as least queer.

The origins of queer theory are multiple. Michel Foucault is often located as a founding figure of sorts, with special emphasis placed on *The History of Sexuality,* Volume 1 (1978). In that work, Foucault challenged the notion that sexuality has simply moved from a state of repression or secrecy to liberation and openness. He showed instead the ways in which sexuality in the modern era has emerged as a unique apparatus, composed of and by an array of discourses and institutional practices; he argued that it has not been repressed but *managed.* Foucault made it possible to understand how sexualities (and, indeed, forms of subjectivity and embodiment generally) emerge through the construction, categorization, and dissemination of the "normal" and the "deviant." Foucault's work had affinities with the work of several other gay and lesbian historians and sociologists, who were mostly working outside the academy in the 1960s and 1970s. From Mary McIntosh's groundbreaking "The Homosexual Role" (1968) through Jonathan Ned Katz's *The Invention of Heterosexuality* (1995), these scholars examined the ways in which understandings and experiences of sexual identity (including heterosexuality) are socially constructed, emerging from specific historical and cultural contexts. Since this body of work as a whole focused on embodiment, normality, and deviance as historical entities, other scholars more directly concerned with late-twentieth-century queerness and disability were able to access it to critique the ways in which the institutions and discourses of compulsory able-bodiedness and compulsory heterosexuality worked in tandem to produce and contain both able-bodied heterosexuality and queer disabled subjects who might confirm (by embodying a "deviance" that vouchsafed able-bodied heterosexuality's dominance) or trouble (by resistance to this function and refusal to be kept in place) the larger apparatus.

Queer theory also developed in relation to a late-1980s resurgence of radical lgbt activism, in particular activism that addressed the lack of attention that the medical establishment, the U.S. government, and the media were giving to the AIDS crisis. Although some disability activists resisted the incorporation of HIV/AIDS into the Americans with Disabilities Act (ADA), there were nonetheless many points of identification between AIDS and disability activism. Some AIDS activist groups, in fact, explicitly acknowledged their debt to the disability rights movement, and some disability rights groups, such as ADAPT, in turn developed strategies and styles that explicitly recalled or cited those of AIDS activists, especially activists in the AIDS Coalition to Unleash Power (ACT UP). AIDS activism in the late 1980s and early 1990s was flamboyant and confrontational, stopping traffic on Wall Street, storming the National Institutes of Health, staging a "kiss-in" in front of St. Patrick's Cathedral in New York City (Cardinal John O'Connor had opposed safe-sex education in both private and public schools). The demands of activists included increased funding for education and research; expanded access to treatment, especially for women, people of color, and the poor; and an end to the stigmatization of "AIDS victims," who themselves preferred to be called "people living with HIV/AIDS." AIDS activists, like other disability activists, were also media savvy, recognizing the importance of both challenging dominant media representations and documenting their own movement. A significant body of AIDS cultural theory—including Douglas Crimp's edited volume *AIDS: Cultural Analysis/Cultural Activism* (1987), Cindy Patton's *Inventing AIDS* (1990), Paula Treichler's *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS* (1999), and Cathy J. Cohen's *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics* (1999)—emerged from this period and provided an additional context in which queer/disability studies flourished.

Finally, queer theory also developed as an extension of feminism and, in some cases, as a partial break from feminism. Gayle S. Rubin's "Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality" (1984), specifically responding to what Rubin understood as the "sex panics" of the 1980s, called for new and autonomous theoretical tools that could account for, and counteract, the sexual stratification and oppression of our culture; feminism alone, in Rubin's estimation, was not adequate to this task. Similarly, writers such as bell hooks, Audre Lorde, Gloria Anzaldúa, and Cherríe Moraga critiqued white feminists for their universalizing of all women's experiences and for their explicit exclusion of women of color. In calling for a more fluid, oppositional, and coalitional feminism, these women of color either explicitly articulated their demands as "queer" ("We are the queer groups," Anzaldúa [1981:209] wrote, "the people that don't belong anywhere. . . . and because we do not fit we are a threat") or anticipated similar fluid and oppositional theories that would later emerge under the rubric of both queer and disability activism and theory. The call for autonomous or semiautonomous spaces and the simultaneous emphasis on specificity and coalition suggests that queer/disabled thought and activism, in particular, inherit these complex feminist histories. Queer/disabled individuals and communities have worked to secure recognition and respect for the full range of bodies and desires, and have resisted the ways in which they have at times been made invisible by larger lgbt and disability movements.

—Robert McRuer

See also Advocacy; Disability Studies; Gender.

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QUOTA HIRING POLICY

In many countries of the world, programs have been established to seek to create equitable employment opportunities for persons with disabilities. Known as *affirmative action, positive discrimination, employment equity,* or *quota systems,* these programs all have in common the goal of raising the workplace participation rates of disabled people to match those found in the nondisabled general population. In some countries, these programs encompass not just disabled people but other groups as well, such as women, visible minorities, and aboriginal peoples. This entry provides an overview of such programs found in the United States, Canada, France, and Germany.

UNITED STATES

In the United States, affirmative action programs flow from that country’s antidiscrimination legislation and are not based on the imposition of strict numerical quotas. The term *affirmative action* was first used in the United States in the context of civil rights legislation in the early 1960s. In March 1961, President Kennedy issued Executive Order 10925, which established the President’s Committee on Equal Employment Opportunity. The goal of the committee was to end discrimination in employment by the government and government contractors. The order required that every government contract contain the following pledge: “The Contractor will not discriminate against any employee or applicant for employment because of race, creed, color, or national origin. The Contractor will take *affirmative action,* to ensure that applicants are employed, and that employees are treated during employment, without regard to their race, creed, color, or national origin.” However, the term *affirmative action,* in this context, meant only that the organization should not discriminate.

In 1964, the U.S. Congress passed the Civil Rights Act, Title VII of which outlawed discrimination on the basis of race, color, or national origin in programs and activities receiving federal assistance. The act was amended in 1972 to include in this list religion, sex/gender, and national origin. However, in 1965, President Johnson noted that “fairness” means more than a commitment to impartial treatment. In his commencement speech at Howard University in Washington, D.C., that year, he said:

> You do not take a person who, for years, has been hobbled by chains and liberate him, bring him up to the starting line of a race and then say, “you are free to compete with all the others,” and still justly believe that you have been completely fair.
>
> Thus it is not enough just to open the gates of opportunity. All our citizens must have the ability to walk through those gates.
>
> . . . We seek not . . . just equality as a right and a theory but equality as a fact and equality as a result.

These concepts were embodied in Executive Order 11246, which President Johnson issued in 1965 and amended in Executive Order 11375 in 1967. These orders required that all federal government contractors develop “affirmative action programs” to “promote the attainment of equal employment objectives.” The orders authorized the use of goals but prohibited quotas in regard to race, religion, national origin, color, and sex. In 1971, President Nixon extended affirmative action by issuing Revised Order 4, which required that each contractor develop “an acceptable affirmative action program,” including “an analysis of areas within which the contractor is deficient in the utilization of minority groups and women, and further, goals and timetables to which the contractor’s good faith efforts must be directed to correct the deficiencies." Goals were not to be quotas; rather, they were to be seen as targets that were reasonably attainable.

In 1973, the U.S. Congress passed the Rehabilitation Act, in which Section 503 required government contractors to take affirmative action to employ and promote qualified handicapped individuals. The act also prohibited employment discrimination against qualified persons with disabilities. In 1990, the Americans with Disabilities Act (ADA) was signed into law. This legislation outlawed discrimination against persons with disabilities in employment and in the provision of goods and services. Provisions of the ADA cover both public and private employers. The law does not specifically mandate the creation of affirmative action programs, but the remedies available for violations of the ADA are the same as those available under Title VII of the 1964 Civil Rights Act. In cases of systematic discrimination, the courts may require that an affirmative action order be established, requiring the employer to establish outreach programs to increase the hiring and promotion of disabled people.

Affirmative action programs in the United States, then, are not based on one law but instead have evolved over the years through the adoption of a number of statutes, coupled with the issuance of various executive orders. In recent years, however, these programs have become the subject of much controversy in the United States. Critics of affirmative action contend that it is nothing less than discrimination in reverse, and that affirmative action policies amount to de facto quotas. Supporters of affirmative action programs argue that such efforts are necessary to balance the history of barriers faced by racial minorities, women, and persons with disabilities. A key element in the U.S. debate is the absence of an equality rights provision in the U.S. Constitution that would furnish a constitutional basis for the implementation of affirmative action programs.

CANADA

Canada's affirmative action program for persons with disabilities, known as *employment equity,* also flows from antidiscrimination laws. And, as in the United States, Canada does not impose on employers any requirement to hire specific numbers of disabled employees.

In 1978, Canada's federal Parliament passed the Canadian Human Rights Act. As originally enacted, the law outlawed discrimination in employment and in the provision of goods and services on 10 grounds: race, national or ethnic origin, color, religion, age, sex, marital status, family status, disability, and pardoned conviction. Some years later, sexual orientation was added to this list. This law provided that it is not a "discriminatory practice" for a person to "carry out a special program, plan or arrangement designed to prevent disadvantages that are likely to be suffered by, or eliminate or reduce disadvantages that are suffered by groups of individuals . . . when those disadvantages . . . would be based on or related to the prohibited grounds of discrimination." Thus, this antidiscrimination legislation first allowed employers to implement affirmative action *passively,* with no actual requirement to do so.

In 1982, Canada's Constitution was amended to include the Charter of Rights and Freedoms. Section 15 of the Charter, the equality rights provision, provided the constitutional underpinnings for the mandatory employment equity (i.e., affirmative action) programs that were soon to be enacted.

Despite the antidiscrimination legislation in place, it became evident that existing laws could not deal with structural or "systemic" discrimination that certain groups, including persons with disabilities, found in the Canadian workplace. In 1984, a Royal Commission on Equality in Employment, chaired by Madame Justice Rosalie Abella, issued a report that provided the philosophical rationale for affirmative action:

> Sometimes equality means treating people the same despite their differences, and sometimes it means treating them as equals by accommodating their differences.
>
> Formerly, we thought that equality only meant sameness and that treating persons as equals meant treating everyone the same. We now know that to treat everyone the same may be to offend the notion of equality.

In 1986, Canada passed the Employment Equity Act, which mandated the institution of *positive* policies and practices to ensure that persons in designated groups (women, aboriginal peoples, visible minorities, and persons with disabilities) "achieve a degree of representation in the various positions of employment with the employer that is at least proportionate to their representation (i) in the workforce or (ii) in those segments of the workforce that are identifiable by qualification, eligibility or geography and from which the employer may reasonably be expected to draw or promote employees." The law requires employers to eliminate structural or systemic discrimination and to institute measures that will ensure that persons who belong to one of the four designated groups subject to the law achieve a degree of representation in the various positions of employment with their employers that is proportionate to their representation in the workforce. The law also requires employers to prepare yearly plans that outline the employment equity goals that they propose to reach as well as timetables for achievement of those goals. The requirements of the Employment Equity Act apply to employers that have more than 100 employees and are under federal jurisdiction.

It is important to note that the Employment Equity Act does not contain any provision that actually forces employers to hire anyone. Rather, the law requires that employers prepare annual reports and send copies of those reports to the Canadian Human Rights Commission, the agency responsible for enforcement of the act. Although employers are not required to hire anyone, these reports are public documents, and employers' progress is subject to public scrutiny. Moreover, the Canadian Human Rights Commission may conduct audits of employers and may issue directions to them.

The affirmative action program in Canada has been subject to the same criticisms as such efforts in the United States. However, because of the existence of the equality provisions of the Canadian Charter of Rights and Freedoms, the Canadian program has not been subject to the same intensity of legal challenges that have taken place in the United States.

QUOTA SYSTEMS

In contrast to the programs in place in the United States and Canada, affirmative action efforts in many countries of Europe (France, Germany, Italy, Austria, Poland) do not flow from antidiscrimination legislation, but rather are based on strict numerical quotas. Thus, they are fundamentally different from U.S. or Canadian affirmative action programs, which rely on targets or objectives rather than on requirements concerning fixed percentages of the workforce. Moreover, the quota programs in Europe cover only disabled people, not a broader range of "designated groups" such as racial minorities or women. For the purposes of this entry, the systems in place in France and Germany are described briefly below.

France

In France, a law enacted in 1987 established a quota-levy program. The law stipulates that enterprises with 20 or more workers must have 6 percent of their workforces composed of disabled workers. The legislation also allows for the application of branch or enterprise agreements by which the company agrees to the recruitment and retention of persons with disabilities. These agreements may cover a single enterprise or an entire sector of economic activity. Most of these agreements include job retention objectives for injured workers.

A company that fails to observe its quota obligation is charged a levy commensurate to the number of workers by which it falls short of the quota. The levy averages 2,000 euros (approximately $2,300 U.S.) annually for each employee by which the company falls below the quota. The funds collected by the quota program are administered by the Association Nationale de Gestion du Fonds pour l'Insertion Professionelle des Personnes Handicapées, or AGEFIPH, which is made up of representatives from government, trade unions and employers, and organizations of persons with disabilities.

Germany

Germany has had a statutory obligation for companies to hire disabled workers in place since the end of World War I. In 1917, the German Parliament passed a law requiring companies to hire 1 disabled war veteran for every 50 employees. This was later broadened to require companies to fill 1 percent of all jobs with severely disabled persons, defined as war victims,

victims of industrial accidents, and other persons entitled to public pensions and compensation.

In 1974, the Severely Disabled Persons Act was enacted. This legislation provides, with some exceptions, that all companies with more than 16 employees must fill at least 6 percent of positions with severely disabled persons. This figure represents the proportion of severely disabled persons of working age in the German population as a whole. Under the legislation, severely disabled persons are defined as individuals who have been assessed with as a disability of 50 percent or more from any cause. Companies that do not comply with their quota requirements must pay a monthly levy of approximately 102 euros, or $120 U.S. Certain positions, such as part-time jobs of less than 18 hours weekly and jobs of less than eight weeks' duration, are exempt. It is noteworthy that the compensatory levy is payable solely on the basis that disabled persons are not employed in the firm; it is not predicated on whether disabled persons have actually applied for positions.

CONCLUSION

Despite the existence of quota and affirmative action programs, persons with disabilities continue to experience levels of unemployment far above those experienced by their nondisabled fellow citizens. Unfortunately, this is a statement that is valid for all countries.

Very little evaluative research has been conducted on this topic, so there is insufficient evidence to allow us to state with any certainty whether the affirmative action or quota system models are effective vehicles for the integration of persons with disabilities. However, what these programs have done is place the equity issue in the forefront of public awareness and encourage employers to embark on equity activities they might not otherwise undertake. Certainly in the North American context, it is rare to see a job advertisement that does not proclaim that the company is an "equal opportunity employer" or that it is dedicated to employment equity. Finally, it should be noted that the goal of both quota and affirmative action programs is the establishment of a workforce that accurately reflects the participation rates and percentages of disabled people in the general population. As such, these programs must be seen as works in progress.

—Carl Raskin

See also Disability Law: Europe; Disability Law: United States; Employment; Employment, International; Work.

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R

▣ RACE AND ETHNICITY

Historically, the two social categories of race and disability have had a contentious relationship. Race theorists have sought to distance themselves from any association with disability because such associations have supported, justified, and enacted centuries of oppression, exploitation, and even genocide against bodies marked as racial Others. Even today, the racialized body continues to remain central to the maintenance of a hierarchical social-political world order. For disabled people of color, the double jeopardy of both race and disability continues to locate them at the margins of society.

Despite their contentious relationship, the academic areas of critical race theory and disability studies draw on similar foundational concepts. Both begin with the assumption that race and disability are, in fact, social constructs. For examples, critical race theorists depict race as a product of "human rather than abstract forces," produced through a process often called "racial fabrication." Similarly, some disability studies scholars have described disability as "the attribution of corporeal deviance—not so much a property of bodies [but rather] . . . a product of cultural rules about what bodies should be or do." Both perspectives argue that race and disability are relational concepts. Some theorists, consequently, have argued that races are constructed relationally against one another rather than in isolation, such that the privileges that "whites" (i.e., Nordic Europeans) enjoy are linked to the subordination of people of color. Similarly, in the context of disability studies, scholars point out that "our construction of the normal world is based on a radical repression of disability."

Notwithstanding these commonalities, because disability has historically been associated with "deviance" and "the lack of intelligence," race theorists have attempted to distance race from these attributes. By doing so, however, race theorists have invoked the biological definition of disability as an abnormality rooted in the medical language of symptoms and diagnostic categories. It is this definition that disability studies scholars have critiqued, describing it as a "deficit" model, and have instead opted for an alternative definition of disability as a socially constructed category that has historical, cultural, political, and economic implications for social life. Drawing on this reconceptualization of disability, some disability studies' scholars have foregrounded the theoretical linkages between disability and race by arguing that disability is an ideological construction used to justify not only the oppressive binary cultural constructions of normal/pathological, autonomous/dependent, and competent citizen/ward of the state but also the racial division of labor and other forms of racialized oppression.

EUGENICS AND THE BIRTH OF A RACIST SCIENCE

Theoretical linkages between disability and race have historical roots in Enlightenment thought, where philosophers such as David Hume and Immanuel Kant sought to distinguish between what they thought of as "different breeds of men." Hume's naturalism drew him to identify what he termed nature's "original distinction" between "inferior" breeds of men that were nonwhite (e.g., the Negro) and an "eminent" breed that was white—distinctions that extended to their intellectual and moral aptitudes. Similarly, Kant, in pursuit of an objective scientific theory of human differences, established a meticulous conceptual distinction between "race" and "species" and gave credence to the argument of intergenerational permanence of racial traits. Such theorizations of human difference in the late eighteenth century occurred at the same time as slavery and colonialism were flourishing and served as justification for the brutal violence meted out against nonwhite people who were assumed to be subhuman.

Paralleling the social construct of race as a category of human difference, disability studies scholarship reports that during the latter half of the eighteenth century, "disability" became tied to discourses aimed at remediating, curing, and cataloging variation in human bodies. This argument does not imply that disabled people did not exist in earlier times. Rather, such arguments suggest that while disability in earlier times was seen more as an individual event, in the late eighteenth century, the disabled person was "seen, drawn, dissected, legally placed, morally and ethically determined" (Davis 1995) and, as a result, became associated with a genetic entity or group defect, which was, in turn, also linked to race, class, and gender differences.

Leading scientists of the late eighteenth and nineteenth centuries, such as Carl Linnaeus, Georges Cuvier, Charles Lyell, Charles Darwin, and J. F. Bluemenbach, made linkages between human character and human anatomy and drew on the racial politics of the time to link Africans and other nonwhite races and disability in demeaning ways. By the beginning of the twentieth century, the intimate relationship between nonwhite races and disability was institutionalized by the racist science of eugenics. The term *eugenics* was coined in 1883 in Britain by Francis Galton to describe a program of selective breeding. By the late 1890s, eugenics as a scientific idea crossed the Atlantic and found support in U.S.-educated society frightened by the radical changes in society brought about by economic transformations caused by industrialization and the cultural disruptions caused by new waves of immigration from southern and eastern Europe and the migration to the North of newly freed slaves from the South.

Amid these social upheavals, the fear of racialized Others was fueled by associations of race with genetic degeneration and disease. Medical historians and anthropologists define degeneration as losing properties of the genus. The fear of the loss of this generative force encouraged typological as well as physical and biological speculation and, in doing so, supported unscientific stereotyping of many human differences. As a result, degeneration became a compelling racial metaphor such that certain races were assumed to be intrinsically degenerate and, as a result, could never be improved in any way. Because racial biology was a science of boundaries between groups, the threat of degeneration was seen to occur when boundaries were crossed and certain races found themselves "out of place." This definition was extended to describe the urban poor, prostitutes, criminals, and even the insane, who were now also seen as a "race apart."

By hinting at the imminent possibility of social decay if these degenerate "bodies" were not brought under control, the segregation of race was regarded as a necessity because maintaining biological distance was critical to preventing degeneracy. This fear of degeneracy was attributed not only to nonwhite populations (e.g., African Americans, Mexican Americans, Chinese Americans, and Native Americans) but also to lower-class white populations. Fearing that lower-class whites may overpopulate the nation and weaken the superior stock of the dominant race, eugenicists deemed it necessary to "purg[e] the blood of the American people of the handicapping and deteriorating influences of defective anti-social classes" (Jackson 2000). Scholars have described this eugenic practice as "a white-on-white racial discourse" that required that whiteness be purged and sterilized until anyone who disrupted the social order was eliminated. Like degeneracy, disease was also something to be feared, especially when it was seen as the very embodiment of racial difference. Thus, for example, the travel memoirs of Mark Twain's *The Innocents Abroad or the New Pilgrim's Progress* have been interpreted as equating the Jew with disease and death. In Mark Twain's travel writing, the Jew was represented as illness incarnate. Since Jews were seen as intransigent to the assimilation process because they clung to their language, customs, dress, and habits, the

Jewish body was read in generalized terms as immutable, and by extension, what was translatable was his or her immutable relationship to disease, pathology, and death. Physically, Jewish bodies were described as repellant with "big heads, big mouths, everted lips, protruding eyes and bristle eyelashes, large ears, crooked feet, hands that hang below their knees and big shapeless warts or are otherwise asymmetrical and malproportioned in their limbs" (Twain, quoted in Gilman 1995, p. 107). In other words, the Jew's disease was written on his or her skin.

The association of degeneracy and disease with racial difference also translated into an attribution of diminished cognitive and rational capacities of nonwhite populations. Disability-related labels such as "feeblemindedness" and "mental illness" were often times seen as synonymous with bodies marked oppressively by race. As a result, the presumption of an inbuilt biological inferiority was seen to be both the cause and result of degeneracy. The most terrifying aspect of such biological deterministic ascriptions was that they attributed to nonwhite populations of African Americans, Native Americans, Mexican Americans, Chinese Americans, and Jewish Americans a shared incapacity to assimilate into dominant society—characteristics that eugenicists described as biological rather than cultural. Fearing that such characteristics could be passed down from generation to generation and further pose a threat to the dominant white race, "protective" practices such as forced sterilizations, rigid miscegenation laws, residential segregation in ghettoes, barrios, reservations and other state institutions, and sometimes even genocide (e.g., Holocaust) were brought to bear on nonwhite populations. Thus, disability studies scholars have pointed out that in an attempt to regulate and control differences seen as disruptive to the "natural" order in society, violent schemes were developed to expunge undesirable biological variations that were identified as uniquely racial.

Although the above discussion clearly designates the intricate interconnections between the social constructs of disability and race, it is this discussion that also foregrounds the real tensions between racialized and disabled bodies. Race theorists have critiqued eugenics as a racist science that falsely attributes racial differences as examples of biological defect. By doing so, disability studies scholars point out that race theorists run the risk of achieving "'liberation' from dehumanizing constructs by distancing people of color from their association with the bearers of 'more real' (or material) biological incapacities [i.e., disabled people]" (Mitchell and Snyder 2005). Such a project, contends disability studies scholarship, fails to recognize eugenics as a transnational ideology that used the social category of disability to produce constructs such as IQ (intelligent quotients) and practices such as institutionalization, sterilization, segregated education, and restrictive immigration policies that had detrimental effects not only on persons of color but also on disabled people—all of them grouped under the limited but all-encompassing heading of "defect." By regarding the category of "defect" not as a biological given but instead as a social construct invoked so as to regulate, control, and eradicate difference, scholars in both areas of race theory and disability studies can more effectively expose the oppressive violence enacted against humanity that was inspired by the eugenicists' worldview.

In addition, disability studies scholarship has described the trans-Atlantic cultural exchange in discourses of race in the early twentieth century as the "Eugenic Atlantic" in an attempt to demonstrate the parallels between race and disability as dehumanizing ideological practices that have had devastating material effects on both populations. Some disability studies scholars are critical of how most academic discussions of eugenics dedicated to the engineering of a "healthy" body politic have failed to describe disability as a social category that was "the hub that gave the entire [eugenic] edifice its cross-cultural utility." Thus, the use of term *Eugenic Atlantic* is instrumental in describing how "*the discourse of disability functioned in a diasporic manner*" in the transnational phenomenon that was eugenics and, as a result, permitted scientists and other professionals both in Europe and North America to justify oppressive social, political, cultural, and economic policies based on the argument that racial difference represented pathological defect.

THE ENFREAKMENT OF POPULAR CULTURE: DISABILITY AS RACIST DISCOURSE

Disability's central role as the ideological discourse deployed so as to legitimate racist oppression in the early twentieth century via the practices of colonialism and slavery was played out on hundreds of stages across the country in the form of freak shows. It was at these freak shows that race and disability were brought together via the creative, dishonest, and exotic maneuverings of opportunistic show managers. Scholarship on the U.S. freak show meticulously records the chicanery rampant in these shows where disabled people of color, especially those with mental retardation from other parts of the world, were exhibited in the exotic mode as "savages" and "cannibals." These studies cite several examples of occurrences such as the "Wild Australian Children," who were the African Americans Tom and Hettie, severely retarded microcephalic siblings from Circleville, Ohio; the "Wild Men of Borneo," who were Hiram and Barney Davis, listed in court records as "dwarfs" and "imbeciles" who came from a working-class farming family in Ohio; the "Last Ancient Aztecs of Mexico," who were El Salvadoran peasant children, Maximo and Bartola, bought by a Spanish trader on account of their "dwarfish and idiotic appearance"; and, perhaps the most famous of all, the "What is it? or The Man Monkey!" exhibit, who was William Henry Johnson, an African American from New Jersey with microcephaly.

Other freak show scholarship defines the public's encounter with the "freak" as one where the audience crosses both corporeal and psychic boundaries to experience the terror and the excitement of coming face-to-face with examples of "monstrous" humanity while being reminded of the "unbearable excess that has to be shed to confer entry into the realm of normalcy" (Adams 2001). If this is the case, it is possible to see the significant role that freak shows played in the ideological construct of racial discourses when the exhibits just described as both disabled and racially marked were exhibited as subhumans, cannibals, and savages. To give credence to these racist mythologies, disability studies scholars describe how show managers designed publicity materials, stage settings and props, and a colorful commentary to advertise and exhibit the exotic aspects of their exhibits while contributing to racist knowledge by linking race, disability, and subhumanness all together.

For example, publicity materials for the American Museum, responsible for exhibiting Johnson as the "What is it? or the Man Monkey!" took advantage of the public's interest in the relation of humans to primates to describe Johnson as the connecting link between human and ape. Foregounding his physical features that were a result of his microcephaly, Johnson's "keeper" is quoted as saying, "The formation of the head and face combine that of the native African and of the Orang Outang . . . he has been examined by some of the most scientific men we have, and pronounced by them to be a CONNECTING LINK BETWEEN THE WILD NATIVE AFRICAN AND BRUTE CREATION." Thus, one can see how freak shows drew on scientific discourses of disability, the racial politics of the era, and fears of a public steeped in eugenic thought to produce a discourse that justified and thereby propagated race and disability inequality.

Because persons of color were often seen to dominate freak shows, it is often assumed that a predominantly white audience was attracted to these shows to encounter the deviance of the racial freak. This was not always so. On the other hand, these shows were mostly frequented by populations who were otherwise disenfranchised in U.S. society and who derived some comfort from the sight of Other bodies radically different from their own. Other scholars point out, however, that encountering the freak show produced not just the repudiation of difference but sometimes a painful identification with the object of difference—the Freak. Thus, disability studies reports that when African American audiences came face-to-face with "Ota Benga: The Pygmy in the Zoo," they were faced with "the monstrosity of U.S. racism embodied in the spectacle of a black man in a cage." It is narratives such as these that demonstrate the very painful relationship between race and disability for African Americans, in particular, and people of color, in general.

RACIALIZED SUBJECT AS DISABLED CITIZEN: THE DISCIPLINARY PRACTICES OF THE NATION-STATE

Likewise, some critical race theorists have argued that for a nation to be itself, it has to be perceived as racially and culturally pure. Thus, to come into being, the nation-state embarks on an obsessive imperative of setting up a "stigmata of exteriority and impurity" and, in doing so, produces a double-edged racism—a racism of extermination to purify the social body from the dangers of inferior races (an exclusive racism) and a racism of oppression and exploitation to hierarchize and partition society (an internal racism). What these studies do not explicitly say is that, once again, the category of disability is deployed by the nation-state to police its borders to keep "unfit" immigrants from entering and to control "unfit" citizens who are seen as a threat to the nation-state.

For example, the nation-state supported immigration laws and regulations that drew on discourses of disability by requiring checks on the mental competencies of newer immigrants. Thus, scholars describe how immigrants were faced with batteries of tests at Ellis Island, in an effort to screen for "mental defectives." Similar practices have been reported in Canada, where immigration policies drew on the profession of psychiatry and invoked concepts such as lunacy and idiocy to exclude certain categories of citizens to maintain a more "sanitized" Canadian society. That these practices are not just historical but have contemporary relevance is apparent in Richard Herrnstein and Charles Murray's (1994) book, *The Bell Curve*, which recommended that immigrants be allowed into the country based on an IQ test. Critical of the 1965 Immigration Act that allowed previously excluded immigrants into the country to be unified with their families, Herrnstein and Murray argue that immigration should not be based on what they call nepotism but on competency. Herrnstein and Murray's arguments could be dismissed as the surviving relics of eugenic practices of the past that are now no longer in vogue, but recent policies related to immigration belie that claim. Thus, for example, Proposition 187, which denies vital and legally guaranteed services to anyone suspected of being an illegal immigrant, was passed with overwhelming support in California and funded by a foundation that backed race-based intelligence research. In the most recent election of November 2004, Arizona passed a similar bill that was on the ballot. Thus, once again, it is possible to see that social categories of race and disability are deployed together to police the boundaries of the nation-state.

Birth control is another example of how the ideological category of disability is deployed by the nation-state in its attempts to police the bodies of its racialized citizen-subjects in very intimate ways. At the height of the eugenics era, the state, drawing on eugenicist fears of the deterioration of the Caucasian race, sought to control the reproductive capacities of those it deemed "deviant" and therefore dangerous. Thus, in the early twentieth century, a large number of poor white people, along with Native Americans, Puerto Ricans, Chicanas, and African Americans, were forcibly sterilized in an era that was obsessed with issues such as "racial hygiene" and the spread of "feeblemindedness." While overt sterilization of these populations is no longer in vogue today, several scholars have argued that new discourses, such as "gene therapy" and "health care rationing," and new birth control technologies, such as Norplant and Depo-Provera, are imposed mostly on poor women of color on welfare who, because of their "dependency," are deemed to be unfit for reproduction. Thus, even though birth control drugs such as Depo-Provera were banned in 1978 because of the side effects, which included cancer, long-term sterility, and osteoporosis, to name a few, Depo-Provera reappeared in the late 1980s and was still being prescribed by doctors to poor women of color in cities and to Native American women living on reservations. In addition, current scholarship cites an early 1990s report on HIV-positive Haitian women held at the naval base at Guantanamo Bay being forced to choose between Depo-Provera or permanent sterilization while in captivity.

But the nation-state not only justifies its control of its citizens of color by deploying the category of disability; it also contributes to the construction of disabled citizens of color. In both urban and rural United States, for example, poverty conditions, lack of access to affordable health care, rampant unemployment, and violent neighborhoods contribute to the onset of disability in communities of color living below the poverty line. In addition, working-class communities of color, especially migrant workers—many of whom are considered undocumented immigrants—labor in factories, sweatshops, and nursing homes where wages are low and where working conditions can create disabilities. Moreover, in the armed forces, where many poor and working-class people of color enlist, deployment in a war also produces disability. In each of these contexts, then, there exists a population of disabled people of color who were either born with a disability or acquire a disability during their lifetime and who are therefore forced to negotiate double oppression on account of both their race and their disability. This experience of double oppression has been especially well documented in the United Kingdom by disabled scholars of color. In each of these accounts, what is often foregrounded is that their oppression, on the basis of disability, is often compounded by their racial affiliation in areas such as employment, access to culturally responsive services, and resources. Sometimes, they have even experienced social and cultural marginalization in both their racial/ethnic as well as disability communities. It is in such contexts that the need to examine race and disability in dialectic relationship to each other becomes a necessity for survival.

SPECIAL EDUCATION AS RACIAL GHETTO: THE DIALECTICS OF RACE AND DISABILITY

The dialectical relationship between race and disability is clearly foregrounded in the specific context of education. Advocates for the inclusion of persons marked by race and/or disability in educational contexts have drawn on similar philosophical and constitutional arguments to frame educational policies that support this inclusion (e.g., *Brown v. Board of Education* [1954] and the Education of All Handicapped Children's Act of 1975, now renamed the Individuals with Disability Educational Act [IDEA] of 1990). More recently, race and disability have once again reappeared together on the educational stage in recent court cases (e.g., *Lee v. Macon Board of Education,* Alabama), in which critiques have been made regarding the overrepresentation of minority students in segregated special education classes. This, however, is not a recent phenomenon. As early as 1968, educational research pointed out that nearly 60 to 80 percent of students labeled mildly mentally retarded were from "low-status backgrounds" and included African American, Latino, and Native American children. Nearly 20 years later, in the Woodstock Report of 1993, F. D. McKenzie, a former superintendent of schools in the District of Columbia, observed that although African American students made up approximately 16 percent of the school population, they made up 35 percent of the students assigned to special education classes.

This overrepresentation of students of color in special education classes can be accounted for in different ways. Recent scholarship has described how the predominance of asthma and lead poisoning among poor children contributes to neurological damage that manifests itself as mild disabilities and behavioral disorders in schools. In terms of race, 36.7 percent of African American children compared to 17 percent of Latino children and 6.1 percent white children have been identified as experiencing lead poisoning. Such statistics point to environmentally induced damage that is a direct result of inadequate housing, health care, clean air, and other basic necessities. Students of color also get banished to alternative schools (special education programs for students identified as "behaviorally disordered" or "emotionally conflicted") as a result of the new zero-tolerance policies that were put into place after the slew of school shootings by white students in middle-class suburbs in the United States. Ironically, once again, students of color, especially African American and Latino males, were the ones most often disciplined as a result of this law. According to a study undertaken in 2000, when all socioeconomic indicators are held constant, African American children were noted as being suspended and expelled at much higher rates than white students within the same schools. In both examples, what becomes apparent is that students of color are increasingly "pathologized" in schools—a practice that has become a lucrative business where professionals interact with these children armed with a battery of tests, boot camps, and other behavior management programs that are more profitable to the professionals than to their clients.

George W. Bush's plan for education, which claims to "leave no child behind," furthers supports the oppressive relationship between race and disability. One important aspect of the Bush Education Plan is Project Sentry, whose main goals are to identify, prosecute, punish, and supervise juveniles and to empower teachers to remove violent and disruptive students from the classroom. Such policies draw on philosopher Louis Althusser's concept of "interpellation"—where *interpellation* is the process by which individuals (subjects) are inserted into practices governed by the rituals of ideological state apparatuses (ISAs) such as schools. Thus, it could be argued that schools use the logic of disability to "interpellate" students of color into "disabled" subject positions that marginalize them in both educational and social life. In other words, understood in a racialized context, special education programs become the most effective way of disciplining, regulating, and controlling students of color and teaching them their places within a racial and class hierarchy. By bringing into line through special education those who comply with ideological mandates, as well as by excluding and containing those who insist on staking their claim for recognition as human beings, these policies become the most effective way of supporting the *racialization of disability* and the *disabilization of race* in the ghettoes of special education. Thus, it is in the interests of theorists working on race and disability to continue to pursue collective deconstruction of social categories of difference to ensure their collective empowerment.

—Nirmala Erevelles

See also Eugenics; Freak Show; Race, Disability, and Special Education; Racism; Stigma.

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RACE, DISABILITY, AND SPECIAL EDUCATION

The long-standing and problematic relationship between race, disability, and special education continues to be evident in the disproportionate placement of students from racial and ethnic minorities in special education programs. Landmark legal cases such as *Diana v. State Board of Education* (1970) and *Larry P. v. Riles* (1971–1979) challenged biases inherent in standardized testing procedures used to identify students as eligible for special education. In *Diana,* a class action suit was filed on behalf of nine Latino/Latina children who were forced to take an individually administered IQ test in English and, as a result, were classified as EMR (educable mentally retarded). Interestingly, when retested by a Latino examiner, only one of the nine children was classified as EMR. In a similar suit, *Larry P.,* the overrepresentation of minority children in EMR classes throughout San Francisco, was determined to be due to educational practices, including teacher bias. Both cases illuminated the role of school personnel, tests, and testing practices in erroneously labeling students of racial and linguistic minorities as disabled and placing them in segregated special education classes. These legal cases demonstrated how special education, like ability tracking, served as a mechanism to resegregate classrooms after the historic *Brown v. Board of Education* (1954) ruled that racially segregated schools were unconstitutional.

These cases drew attention to the ways that special education labeling and placement decisions reflected stereotypic beliefs about white intellectual superiority. Both *Diana* and *Larry P.* called into question the widespread use of "scientifically" objective measures to gauge intellectual ability. The intelligence quotient (IQ) score that had once been viewed as measuring innate, fixed, unidimensional, and naturally distributed "ability" along racial and class lines would now be cast in a different light. As a result of these cases, it became increasingly clear that evaluation instruments and their use falsely reinforced presumed intellectual hierarchies among racial and ethnic groups. Although tests continued to be seen by many as relatively neutral and valid, others came to view standardized tests as forms of institutionalized racism, based on cultural and linguistic biases and norms and predicated on the supposedly universal values and experiences of American, white, middle-class citizens. Because the special education eligibility process typically begins with teacher referral, the widening racial imbalance between the teaching corps and an ever-more diverse population of public school students remains a concern. Recent reports show that 90 percent of public school teachers in the United States are white, while 40 percent of public school students in the United States belong to racial/ethnic minorities. Because cultural, social, class, and linguistic biases often influence teacher perceptions of students' ability, students from racial/linguistic minorities continue to risk having their differences pathologized when measured against exclusionary and ethnocentric norms and standards.

Despite reforms, a disproportionate number of students from racial, ethnic, and linguistic minorities continue to be placed in special education classes. Since the early 1970s, the U.S. Office of Civil Rights (OCR) has reported a persistent problem of minority children being overrepresented in *certain* disability categories. Specifically, racial disparities are highly pronounced in categories requiring specialized clinical judgment. These categories include Mental Retardation (MR), Emotional Disturbance (ED), and Learning Disability (LD). Thus, "invisible" and more subjective disabilities of a cognitive and/or social nature are overly ascribed to racial and linguistic minority students, while less subjective categories such as blindness or deafness are ascribed proportionately to all student groups. In other words, overrepresentation is much more pronounced for more subjective special education labels than in diagnoses that are more obvious or objectively determined.

The most recent government reports reveal that although blacks constitute 14.8 percent of the population, they represent 20.2 percent of all students in special education. Black students remain three times as likely to be labeled MR as white students, two times as likely to be labeled ED, and almost one and a half times as likely to be LD. In fact, black students remain the most overrepresented of all groups in 10 out of 13 disability categories nationwide. Among these categories, MR remains most likely to be assigned to black male students. Furthermore, black students who attend school in wealthier communities are more likely to be labeled MR and assigned to segregated classes than those attending predominantly black, low-income schools. Thus, depending on context, both social class and racial biases can increase the risk of minority children being labeled and placed in segregated classrooms.

The category of LD has also been deeply implicated in the problem of overrepresentation. The label, which emerged during the 1960s, characterized a student with LD as having average or above-average intelligence, specific rather than generalized deficits, and a cultural/familial background unrelated to the academic difficulties experienced in school. This category became associated with white students to such a degree that students of similar levels of achievement were given different labels along racial, ethnic, and class lines. In fact, in the first 10 years following the emergence of the category (1963–1973), the vast majority of students labeled LD were white middle-class boys. Because students were placed in separate classrooms according to their label/disability category, special education became as racially segregated as general education had become with the practice of "ability" tracking.

In states with high Latino/Latina or Native American populations, these students are more likely to be overrepresented in special education.

Data on Latino/Latina students are complicated by the fact that they tend to be underidentified for special education in elementary school but overidentified in high school. Furthermore, students who are English language learners (ELL) or labeled limited in English proficiency (LEP) are overrepresented in special education, especially in the upper grades. Once labeled, minority students are educated in more restrictive/segregated placements in comparison to their white peers. An exception to this trend is the underrepresentation of Asian American students with disabilities. Stereotyped as the "model minority," Asian students are far less likely to be labeled in subjective categories of MR, ED, or LD than any other minority group. Further research is needed to determine if there are within-group differences, especially among newly arriving Asian immigrants, or if there are differences in schools with and without English as a second language (ESL) classes.

Inappropriate classification of racial/ethnic/linguistic minorities for special education leads to lowered achievement and poor postschool outcomes. Students in segregated special education classrooms are denied access to the general education curriculum and their typically developing peers. Often, the instruction provided in segregated classrooms results in poor transition outcomes after the child leaves school. Finally, the child is more likely to experience lowered teacher expectations as a result of being labeled. These factors combine to negatively affect the academic performance of students of color who are labeled disabled, who have higher rates of suspension, face more severe disciplinary actions, and experience a higher dropout rate compared to their white and/or nondisabled peers. It has been documented that failure to obtain a high school diploma further restricts occupational opportunities and leads to the increased likelihood of poverty. These problems are not diminishing but rather are starting earlier with children from economically poor, black, or Latino/Latina families being labeled with the ill-defined "at-risk" category even before they enter school.

Although many have suggested that socioeconomic status accounts for some or even all of the racial disparities in special education identification, the problem cannot be explained by any one factor. There remain large variations within district-to-district and state-to-state levels of overrepresentation in special education, suggesting that the degree of overrepresentation is affected by many variables and contexts. Southern states, for example, continue to have some of the highest incidents of disproportionality, regardless of social class, suggesting that overrepresentation is connected to a longer legacy of racial segregation. Moreover, there are substantial within-group differences, in terms of gender and age of diagnosis. Black females, for example, are less likely to be overidentified than black males but more likely to be labeled than white females and males. In addition, when language is taken into consideration, Latino/Latina students who are learning English are much more likely to experience overrepresentation. Such within-group differences point to an urgent need for more sophisticated research methodologies to fully understand the relationship of race, disability, and special education. Finally, in this era of high-stakes testing, we must also consider how many of our current educational practices are serving as tools of social control and exclusion rather than as tools of social transformation and democracy.

—Beth A. Ferri and David J. Connor

See also Learning Disability; Race and Ethnicity; Special Education.

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RACIAL HYGIENE (*RASSENHYGIENE*)

The German concept of "racial hygiene" was the predominant term for *eugenics* until the end of the

Third Reich (1933–1945). It comes from physician Alfred Ploetz (1860–1940), who founded the Deutsche Gesellschaft für Rassenhygiene (German Society for Racial Hygiene) in 1910, the main organization of the racial hygiene movement. It committed itself to the introduction of eugenic measures such as marriage bans, forced institutionalization, and sterilization of the supposedly hereditarily ill, alcoholics, and criminals. German racial hygiene, which presents a specifically radical variant of eugenics in comparison to international development, is rooted in racial anthropology. This approach influenced German eugenics/racial hygiene considerably. The French aristocrat Joseph Arthur de Gobineau (1816–1882) formulated the basic ideas of racial anthropology. He started from the assumption that only white, Aryan, Germanic, or "Nordic" races are culturally constructive; all other races are culturally destructive. Racial anthropologists were convinced that racial differences are objective facts. Skull measurements and the diagnosis of other bodily characteristics established so-called racial types, such as the white, black, red, or yellow race. Specific cognitive and spiritual qualities were attributed to individual races. Racial anthropologists believed that miscegenation would lead to the inevitable downfall of the Volk. A strongly hierarchically organized social model was therefore designed in which the upper strata of society dominated as the noblest race. Selection, the battle for existence, and measures against degeneration promoted the "Nordification" (*Aufnordung*) of the race. Racial anthropological approaches pushed forward nationalist thinking and were connected with an extreme anti-Semitism. Main representatives of this extreme line of thinking were engineer Otto Ammon (1842–1915) and doctor and philosopher, Ludwig Woltmann (1871–1907).

Racial anthropology gained influence in Germany before and during World War I in nationalist circles and also determined the eugenic/racial hygiene movement of the Weimar Republic. With their seizure of power in 1933, the National Socialists fell back on a multitude of already existing eugenic, racial hygienic, and racial anthropological proposals for the improvement of the *Volkskörper* ("body of the Volk"). In 1931, the Nationalsozialistische Deutsche Arbeiterpartei (NSDAP) (National Socialist German Labor Party) became the first party in Germany that incorporated racial hygienic thinking into its political program. It strove for a rapidly growing population that consisted of "racially pure," "hereditarily healthy," "Aryan," and productive individuals. To achieve this, the carriers of "foreign" blood should be eradicated. "Foreign" for the National Socialists included those who carried either "hereditarily" or "racially" so-called inferior blood. Many laws were enacted to fulfill these objectives. Already in July 1933, the *Gesetz zur Verhütung erbkranken Nachwuchses* ("Law for the Prevention of Hereditarily Diseased Offspring") was passed, which, in contrast to the drafted sterilization law of the Preußische Ministerialverwaltung (Prussian Ministry of Administration) from 1932, provided for compulsory sterilization. In November 1933 came the *Gesetz gegen gefährliche Gewohnheitsverbrecher* ("Law Against Dangerous Habitual Criminals"), which allowed not only the sterilization of repeat offenders but also the castration of sex offenders. In total, about 400,000 people were forcefully sterilized by 1945, more than in any other country in which a sterilization law existed. In addition, from the beginning, National Socialist politics were focused especially against Jews and gypsies. The first measures taken were the systematic destruction of the economic existence of the Jewish population and the racially biological registration of the Sinti and Roma (gypsies), who were confined in work camps as so-called asocial people and often also sterilized. In 1935, various laws followed that forbade marriage between *Deutschblütigen* (those of "pure" German blood) and Jews, as well as between the "hereditarily diseased" and "hereditarily healthy." In *Beratungsstellen für Erb- und Rassenfragen* (advice centers for heredity and race questions), hereditary and racial "inferiors" were identified. In this way, essential preconditions were put into play, leading to the Holocaust of the Jews and the "euthanasia" action on disabled people.

—*Volker van der Locht*

See also Eugenics; Eugenics: Germany; T4 Program.

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RACISM

Racism remains, in many minds, a term whose ultimate definition is but vaguely understood. Identification of absolute instances of racism is still contested in scholarship and public discourse much in the way that charges of ableism (or disableism, in some vocabularies) now often prove hotly contested. However, an examination of the development of racism can also demonstrate that a history of systemic discrimination against people with disabilities develops in a somewhat parallel manner. In both cases, the discrimination faced by these populations (not to mention those who find themselves marked as racialized *and* disabled) functions in a much more pernicious manner than mere active group snobbery. Before we can parallel these types of oppression, however, a working definition of racism should be outlined.

Scholars have suggested that formalized racism can be recognized whenever the following conditions exist: (1) publicly sanctioned restrictions on a group's ability to participate in wider social rituals and institutions, (2) formalized segregation policies, (3) demotion to lower caste/class status of a majority of group members, (4) active circulation of propaganda that bolster perceptions of inferiority, and (5) the deepening of legal prejudice over time and, perhaps most important, fears of reproductive contamination. The latter point is key because formal racism—at least our own modern variety—operates as a social guarantee that race purity will be actively policed and maintained. Prohibition from reproductive participation (i.e., miscegenation or sterilization laws) erupts from a belief that one group of individuals represents a biological threat to the integrity of the species. In other words, rather than subordinating an entire group on the basis of faulty beliefs, such as in cases of religious bigotry, modern racism may be said to operate on the principle of in-built inferiorities that cannot be overcome. Such differences (particularly of a visible, physical nature) become a racist formation when characteristics that might be considered "cultural" become associated with innate (i.e., biological) features. This is the key linkage between racist and ablest beliefs—group-based inferiority appears indelible and biologically encoded.

Scholars of the history of racism have placed the origins of such practices somewhere in the fourteenth or fifteenth centuries—specifically, in early modern Spain, when religious intolerance gradually transformed into forms of body-based intolerance. While religious antipathy for another group expressed itself in persecution based on adoption of the wrong faith, there was little sense that such differences were intrinsic to a population's bodily constitution. The key qualifier here depends on the capacity of a despised population to assimilate (even theoretically) to the persecuting culture's status—either through rituals of conversion, renunciation, shifts in habits, ways of communicating, and so on. If members find a way to become integrated into the dominant community, then a racist system may not be operative. Of course, this also suggests that modes of assimilation are primarily cultivated through efforts by members of stigmatized groups to actively participate in the devaluation of their former culture's values, aesthetics, attitudes, practices, and so forth. In other words, the demands of assimilation require a stigmatized member to recognize his or her prior self as inferior. There is a hierarchy of communities that individuals learn to solidify and substantiate in the process of assimilation.

Yet, in the case of racism, such an avenue of escape is closed. Members of the stigmatized group find themselves positioned in an impossible coexistence with the dominant group—specifically, an existence that requires their simultaneous sequestration and subordination. In such a situation, segregated locations—such as reservations or custodial institutions—become a metaphor for the group's individual as well as collective predicament. Identity itself becomes fixed, and ethnic or racial differences cannot be mobilized beyond the boundaries of deviancy established by the enforcers of the norms. No transcendence of one's racial circumstances avails itself, and thus cultural differences transform into markers for inferiority itself. Thus, the superiority of one group is based on a subjective valuing of arbitrary qualities it associates with itself in contradistinction to another (i.e., pigmentation). The presumed characteristics of the marginalized group become synonymous with subjective values of undesirability.

Just as Carolinus Linnaeus sorted vegetation into particular species groups in 1735, he also classified human populations into distinct racial types. While this racial taxonomy was not delineated as hierarchical, the characteristics attributed to each population supported perceptions of northern European superiority. The practice of drawing distinctions based on biological characteristics began as early as the fifteenth century in campaigns such as the Spanish policy of requiring blood certificates (or *limpieza de sangre*), where ethnic belonging became increasingly biologized. Such efforts, not coincidentally, paralleled the rise of modern nation-states, where connections began to be drawn between the attributes of individual physiology and the nation's body as a whole. In each of these cases, we witness the formation of investments in biological determinism where one's birthright preordains some members to increased social status; others inordinately comprise the lowest spheres of social hierarchy—including economic immobility and lack of access to influential social institutions. Thus, the Enlightenment arrived replete with ideological investments in "proving" that social hierarchies exist due to the in-built incapacities of some as opposed to the natural abilities of the fully enfranchised.

While formalized racism has been reported to exist on the basis of group-based limitations that cannot be overcome, physical, sensory, and intellectual differences—often designated today as disabilities—also began to serve scientific systems of differentiation. No longer did those labeled "deviant" exist within relatively amorphous groupings such as the "monstrous," the "crippled," or as "fools," but rather the eighteenth century oversaw the rise of individuated human taxonomies. Debates over the relationship of racial characteristics as environmentally produced effects of climate and geography ultimately lost support in the wake of more biologically determinist models. Thus, human divisions, as expressed in Linnaeus's racial classifications or in the arguments against polygenesis (the development of separate, distinct bloodlines across racial groups) offered by Blumenbach in 1771 and others later in the century, laid the groundwork for discriminatory beliefs about bodies/minds designated as inferior. Consequently, one can witness the parallel cultivation of empirically based hierarchies based on racial, ethnic, and functional identifications in this period. In all cases, a group's failure to thrive socially came to be increasingly associated with in-built insufficiencies rather than cultural inequalities.

Even within the most liberal schemes of their day, those identified as possessing inferior anatomies were used to justify "progressive" science. For instance, single bloodline arguments that situated all peoples as participating in a shared human origin (usually placed in Africa) positioned racial (i.e., "savage") and disabled (i.e., "feebleminded") populations as "proofs" of common human ancestry with animals. In *Descent of Man* (1871), Darwin, the great champion of shared species origins, employed racialized and microcephalic populations as key evidence of primordial "arrested development" in his influential, mid-nineteenth-century theory of evolution. Likewise, his cousin, Sir Francis Galton, coined the term *eugenics* (Latin for "good seed") by arguing that breeding practices in horticulture and animal husbandry could be applied to the artificial cultivation of superior races of human beings. In making such arguments, nineteenth-century science, particularly after the rediscovery of Mendel's recessive/dominant theory of inheritance, rejected a previous era's metaphorical investments in blood as a "carrier" of magical properties in favor of a more literal hereditary vehicle (i.e., germplasm and later genes).

Thus, the late nineteenth and early twentieth centuries increasingly paved the way for science to influence public policy with respect to restrictive legislation toward "flawed" biologies: Jim Crow–era miscegenation laws, marriage laws, coerced institutionalization, segregation, sterilization, and, ultimately, under German National Socialism, state-sponsored murder of disabled, sexually "deviant," ethnic, and racial populations. As historians of racism have argued, the great irony of such developments occurred with respect to "radical" social discourses of human equality and formal emancipation efforts to free marginalized populations from various forms of enslavement. Thus, racism, homophobia, sexism, and ableism all come to fruition as a "back-door" form of discrimination that undermines more egalitarian principles of "all *men* being created equal." The perpetuation of social inequalities, consequently, functions in tandem with scientific justifications of biologically based insufficiencies. The more we classify, the farther we seem to get from a realization of just societies. The history of racism helps to demonstrate—at least to this point—that empirically sanctioned differentiations between individuals and populations inevitably lead to more "modern" forms of inequality (i.e., ideologies and practices that sanction socially derived inequalities on the basis of biologically deterministic criteria).

Late twentieth-century arguments about the fiction of race have been recently championed as a reversal of such trends. If genetic variation between human beings is no greater than 0.01 percent, then investments in genes as the basis for population differentiation based on innate capacities may finally fail from lack of a true biological basis. However, given our modern predisposition for investments in differentiation inherited from the Enlightenment, new efforts to define a distinctive racial genome seem to renew, rather than undermine, biologically encoded distinctions across human communities. For instance, witness recent efforts to establish racial genome banks in order to sponsor a racially specific health care research industry. While science may have lost some ability to sponsor and steer state policy-making agendas since the heyday of eugenics, investments in empirical taxonomies of inferiority based on characteristics marked as racial and/or disabled still garner a great deal of sway over aesthetic and cultural value systems.

—David T. Mitchell

See also Eugenics; Race and Ethnicity; Race, Disability, and Special Education; Stigma.

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RAMABAI, PANDITA

(1858–1922)

Sanskritist and social reformer

Pandita Ramabai was a Sanskritist who earned the honorific "Pandita" from the male scholarly community of her time, an almost unique achievement. She travelled to Oxford to study medicine, but her health deteriorated, and impaired hearing prevented her from enrolling at medical college. Instead, Ramabai became an aggressive campaigner for the social uplift of women in India and established a home for child widows at Kedgaon. Ramabai embraced some Christian beliefs that she integrated with her personal selection from the ocean of Hindu faith and practice, thereby infuriating the orthodox of both religions. She started a mission organization with both Indians and Westerners working under her leadership, another scandalous arrangement in her time. A deaf widow who wanted to join the Kedgaon community had difficulty convincing Ramabai but eventually overcame her resistance and proved willing and competent at work and worship. Apart from her own substantial writings, there is a large hagiographic literature about Pandita Ramabai, in which her significant hearing impairment is almost entirely ignored.

—Kumur B. Selim

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RAPE

Rape is a sensitive and complex topic. A comprehensive discussion of rape must take into account the legal, medical, psychological, and emotional issues that result from this act. When exploring the experience of rape from the perspective of individuals with disabilities, the complexities increase, and several key issues emerge. One major problem is that numerous definitions permeate the literature for sexual violence, sexual abuse, sexual assault, and rape. While there is a sizable body of literature on rape and sexual abuse in the general population, there is very little literature on rape in the disability community.

The following discussion provides the reader with a better understanding of the issues surrounding terminology. In addition, it provides an overview of what is known about risk factors for rape in the disability community, as well as prevalence estimates of rape. The last section highlights gaps in our current understanding of rape and disability. Furthermore, it suggests directions for future research efforts. These include the benefits of using the social model of disability to understand how social and cultural forces negatively affect the abilities of disabled survivors of rape to move beyond this experience.

THE LANGUAGE OF RAPE IN DIFFERENT CONTEXTS

When attempting to understand rape, in any context, it is important to first identify the words used to represent this act, why they are used, and what they mean. This task is important because language has power, and the ways in which we use language give insights into the social and cultural meanings of behavior. Thus, the way terms such as *sexual abuse, sexual violence,* and *rape* are used gives us insights into how society views appropriate and inappropriate sexual behaviors within and across communities.

No formal definitions were identified in the literature for the term *rape* in a disability context. This is not to say that the term *rape* is never seen; rather, it is used as part of a larger discussion of sexual abuse. Within the disability context, rape is subsumed under the labels of *sexual violence* and *sexual abuse.* These definitions are critical for understanding how the intersection of rape and disability is interpreted across contexts (e.g., the legal system, the medical system, the social service system, and within a social network or societal context). One must also note that not only are definitions different, but the nature of the content is different as well. For example, a general definition of sexual abuse "includes molestation, incest, rape, prostitution, or use of a child for pornographic purposes" (*Columbia Encyclopedia* 2001). This definition provides a laundry list of inappropriate sexual behaviors but does not necessarily leave us with a better understanding of what sexual abuse means. A more useful definition for sexual abuse among individuals with physical disabilities comes from the Center for Research on Women with Disabilities. In this definition, sexual abuse is "being forced, threatened, or deceived into sexual activities ranging from looking or touching to intercourse or rape" (Cole 1984; Soeken et al. 1998; Nosek et al. 2001). When referring to individuals with developmental disabilities, sexual abuse has been defined as "occurring where sexual acts are performed on or with someone who is unwilling or unable to consent to those acts" (Brown and Turk 1992) or "being forced, threatened, or deceived into sexual activities ranging from looking or touching to intercourse or rape" (Young et al. 1997). "Sexual abuse of a person with learning disabilities can take place where that person's willingness is unacceptably exploited" is another definition that warrants inclusion in this discussion. This definition is useful in that it moves away from the complexities of consent. It acknowledges that while a developmentally disabled person may willingly engage in a sexual encounter, the act may still be abusive because of the motivation and position of the other person (McCarthy and Thompson 1996). However, from a disability studies perspective, it is troubling in that it seemingly negates a disabled individual's ability to consent in instances where he or she willingly participates in a sexual encounter that is not abusive.

Studies of sexual violence among nondisabled individuals distinguish between sexual abuse in childhood and sexual assaults and/or rape in adulthood. In studies of sexual violence among the disabled, this differentiation of terms does not occur. Specifically, in a disability context, *sexual abuse* is commonly used to describe sexual violence rather than *rape.* One possible explanation for this is the pervasive view of disabled individuals as childlike and powerless. Since sexual transgressions against children are defined as abuse, the able-bodied population perpetuates this usage for adults with disabilities. Another possible explanation for this misuse of terminology is that, like children, individuals with disabilities are viewed as asexual and undesirable.

The legal system offers definitions of two different types of rapes. The first type is simple rape, whereby the victim and attacker(s) have a prior relationship, there is a lack of force and resistance, and there is an absence of evidence corroborating the victim's account. The second type is aggravated rape, in which there is extrinsic violence, multiple assailants, and no prior relationship between victim and offender(s) (Estrich 1987). These distinctions become important in discussions of what happens within the legal system after a rape occurs.

Research conducted on rape within the general population shows that district attorneys are more likely to move forward in the prosecution of an aggravated rape than a simple rape. In cases of simple rape, societal attitudes about sexuality and promiscuity make successful prosecution difficult. In a disability context, the prosecution of simple rape is complicated further because of the societal misconceptions surrounding the sexuality and desirability of individuals with disabilities. In addition, able-bodied persons generally question the ability of a disabled person to consent to sexual activity and to act as a competent witness against the attacker.

THE STATISTICS OF RAPE WITHIN THE DISABILITY COMMUNITY

The overall prevalence of sexual abuse across the spectrum of disabilities is unknown. Research in this area suggests that women with disabilities are assaulted, raped, and abused at a rate two times greater than nondisabled women (Waxman and Wolfe 1999). According to the Centers for Disease Control and Prevention (CDC), the reported rates of sexual violence range from 51 to 79 percent against women with disabilities. When the discussion is limited to cognitively impaired individuals, there are wide variations in the reported prevalence rates of sexual abuse. For example, it has been suggested that women with developmental disabilities face a 68 to 83 percent chance of being sexually assaulted in their lifetime, a rate that is 50 percent greater than that for nondisabled women (Sobsey 1994; Waxman and Wolfe 1999). The CDC estimates that the reported rates for cognitively disabled individuals' lifetime experience of sexual violence range from 25 to 67 percent, which is significantly different than the aforementioned percentages. These variations result from differences in definitions of abuse, differences in populations sampled, and differences in research methodology (McCarthy and Thompson 1996). The discrepancies highlight the need for more research on this problem.

FACTORS PUTTING THE DISABLED COMMUNITY AT RISK

It is a common misperception that the disabled are not at risk of being raped. However, research has shown that disability is not a protective factor against sexual abuse. Rather, disability has been hypothesized to reduce an individual's emotional and physical defenses, making him or her more vulnerable to abuse (Nosek et al. 2001). Researchers have identified several factors that increase disabled individuals' vulnerability to sexual abuse, including dependency on others for long-term care, life in an institution, denial of human rights that results in perceptions of powerlessness, the perpetuator's perception of limited risk of discovery, the difficulty some survivors have in being believed, lack of education regarding appropriate and inappropriate sexuality, social isolation and increased risk of manipulation, physical helplessness and vulnerability in public places, and the emphasis on mainstreaming and integrating disabled individuals without evaluating their capacity to protect themselves (Andrews and Veronen 1993; Groce 2003). It has also been suggested that economic dependency greatly increases the risk of abuse among the disabled. Specifically, individuals with disabilities have fewer opportunities in the labor market than able-bodied individuals.

The overall lack of attention to the issue of abuse against the disabled by both violence and disability researchers has contributed to the invisibility and continuation of misconceptions regarding disability and victimization (Curry, Hassouneh-Phillips, and Johnston-Silverberg 2001). Moreover, while it is increasingly recognized among professionals that individuals with cognitive disabilities or mental illnesses are more vulnerable to sexual abuse and exploitation than the general population (Mansell, Sobsey, and Moskal 1998; Tharinger, Horton, and Millea 1990; Furey 1994), there continues to be limited recognition that the physically disabled are also at significant risk for being raped. For example, it has been suggested that the tendency for women with physical disabilities to be devalued by society is one reason that this group is not included in research on sexual abuse (Coleman 1997, in Curry et al. 2001). This assertion is indirectly supported by the fact that as recently as 2001, fewer than five studies examined the sexual abuse of individuals with physical disabilities (Curry et al. 2001).

Discussion regarding sexual abuse and the cognitively disabled focuses heavily on cognitively impaired individuals' ability to give consent and their competence to give evidence against their attackers. However, several dialogues are equally important and yet virtually absent from the literature. The first emerges from the recognition that discussions of disability and rape are specific to individuals within a disability category (e.g., physical or cognitive). There is little, if any, research that explores sexual abuse across disability types. This points to the need to explore what, if any, differences in service needs exist between physically disabled and cognitively disabled rape survivors. The second area that must be addressed is the identification of the emotional and psychological service needs of cognitively impaired individuals in the aftermath of rape.

GIVING VOICE TO RAPE SURVIVORS

The literature proves that we do not currently have a full understanding of disability and rape. Although sexual abuse and rape are increasingly recognized as significant problems for those with disabilities, research that gives a voice to the survivors of rape has not been conducted. The unique challenges that individuals with disabilities face in bringing charges against their attackers and accessing supportive services to assist them in moving forward with their lives are important topics that have been neglected. An integral piece to gaining understanding is a social model analysis of the intersection of disability and rape. A social model analysis lends itself to the identification and acknowledgment of social barriers surrounding rape: the barriers that isolate and impoverish disabled individuals and put them at risk for rape; the barriers to reporting rape; the barriers to prosecuting perpetrators of rape; the barriers to overcoming the physical, emotional, and psychological effects of rape; and the barriers to overcoming the shame and stigma that having been raped brings.

Proponents of the social model of disability view disablement as the consequence of society's failure to recognize and account for the differing needs of disabled people and to eliminate the barriers they encounter (Oliver 1996). One could also argue that society has failed to recognize that disabled individuals have significantly different risk factors for being raped. In addition, legal and social service systems are nearly impossible to negotiate for individuals with disabilities because they have different needs and abilities that these systems do not recognize. Therefore, a social model analysis challenges societal misconceptions about the disabled and calls for a better understanding of the rape experience within the disability community. The current lack of knowledge on this experience within the disability community denies rape survivors an opportunity to heal on multiple levels. First, it denies them the opportunity to find meaning through talking about their experiences. Second, it prevents them from accessing much-needed legal, medical, and social services following rape. Third, it prevents service providers from fully recognizing and understanding the barriers faced by this community in dealing with the experience of rape. Finally, this lack of understanding perpetuates the isolation of this already marginalized group of individuals.

Another crucial component of this analysis is the lived body experience of rape and disability. Throughout their lives, disabled people are routinely dehumanized by the medical system under the guise of correcting medical conditions and minimizing impairments. As part of this process, disabled individuals are forced to believe that they are not the experts on their bodies. Rather, it is the doctors and therapists who are the experts. This psychological framework, which leads many to try to escape their "deficient" bodies for normal ones, has significant consequences for the healing processes of disabled rape survivors. The reality of this statement is reinforced in the narrative of a disabled rape survivor. In the process of diagnosing her disability, she describes how she was accused of fabricating and exaggerating symptoms as a means of getting attention. The lack of support from family and the "experts" led her to question her authority over her body. Subsequently, while in college, she was raped. This experience, coupled with her lived body experience of disability, led to increased feelings of lack of authority over her body, which drove her to "escape" through drug use and other self-destructive behavior.

To truly understand the intersection of rape and disability, researchers must move beyond traditional research strategies that rely on surveys of service providers and family members of rape survivors. Specifically, researchers must engage in qualitative participatory research strategies that incorporate the experiences of disabled rape survivors in all aspects of the research design. It is only through the inclusion of those who have experienced both disability and rape that we can truly understand the experience.

—*Amy Paul Ward*

See also Child Abuse; Empowerment and Emancipation; Social Model; Violence.

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RAU, FEDOR ANDREEVICH

(1868–1957)

Director of the Arnoldo-Tretiakov School for the Deaf in Moscow

Fedor A. Rau was director of the Arnoldo-Tretiakov School for the Deaf in Moscow. He was also the founder of special education training at the university level and organized the first Russian congress on deaf education in 1910. From 1922 to 1948, he was the head of the faculty of deaf education in the Moscow

State Pedagogical University and the author of many textbooks and manuals for deaf schools, including the *ABC Book for Deaf Children* (1903).

—Anna Komarova and Victor Palenny

See also Natalja Aleksandrovna Rau.

RAU, FEDOR FEDOROVICH (1908–1977)

Speech therapy specialist

Fedor F. Rau was a professor at the Institute of Defectology (now the Institute of Special Education) and a speech therapy specialist. Together with N. F. Slezina, he developed the "concentric" method of speech therapy.

—Anna Komarova and Victor Palenny

RAU, NATALIA ALEKSANDROVNA (1870–1947)

Founder of a kindergarten for deaf children

Natalia Rau, Fedor Andreevich Rau's wife, founded the first kindergarten for deaf children in Europe in 1900. After 1917, she worked as an inspector for a deaf children's kindergarten. In 1922, she organized lip-reading classes for deafened and hard-of-hearing people. She wrote *Pre-School Education of Deaf-Mute Children* (1947).

—Anna Komarova and Victor Palenny

See also Fedor Andreevich Rau.

RAY, ISAAC (1807–1881)

Father of American forensic psychiatry

Isaac Ray was one of a handful of men in mid-nineteenth-century America who were largely responsible for establishing the first generation of public institutions specifically aimed at serving the mentally ill population. Along with his fellow asylum superintendents (e.g., Pliny Earle, Thomas Kirkbride, Amariah Brigham), Ray supported the early optimism about the curability of insanity if individuals were housed in specialized hospitals carefully constructed along specific architectural plans, supported with generous funding by the state, supervised by a new class of medical professionals with expertise in mental illness, and handled according to the latest principles of "moral treatment." For 20 years, Ray served as the superintendent of the Butler Asylum in Providence, Rhode Island. In 1844, he was one of 13 asylum superintendents to gather in Philadelphia and found the Association of Medical Superintendents of American Institutions for the Insane (now the American Psychiatric Association). Ray published numerous articles throughout his career that were intended for both an audience of asylum administrators as well as a more general readership of policy makers and influential philanthropists. Ray, who had a special interest and wrote extensively on the need for the reform of criminal insanity laws, is sometimes referred to as the "father of forensic psychiatry."

—Philip M. Ferguson

See also Institutionalization and Segregation; Mental Illness; Psychiatry.

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RECREATION

Recreation is any pleasurable activity that is freely chosen. It is an activity that diverts, amuses, or stimulates. It is an activity that refreshes and recreates, that renews health and spirits by enjoyment and relaxation. Recreation can be done alone or with others, it can be active or passive, and it can be artistic or athletic. Recreation has both intrinsic and extrinsic benefits.

Recreation is an important part of life for all people. It is a powerful force in people's lives. Recreation makes people feel good about themselves and helps people to stay socially connected to other people. Recreation is revitalizing and rejuvenating. Research shows that higher levels of involvement in recreation activities are associated with increased ratings of well-being and life satisfaction. Yet, people with disabilities are often less involved in recreation. Some people with disabilities do not have access because of a lack of exposure to and training in recreation settings. There are myriad reasons, but the fact remains that people with disabilities are involved in recreation less than their typical peers.

Recreation enhances self-esteem and the quality of a person's life as well as the ability to occupy one's free time in a socially valued and acceptable manner, which has a significant impact on where a person is able to live, whether he or she functions successfully in the community, and the quality of relationships that a person develops. Social and recreation experiences have the power to generate skills that can be transferred to work, housing, family relationships, and so on. Thus, recreation experiences can facilitate an individual's successful integration into other spheres of life.

In practice, there are three distinct types of recreation services. They include *inclusive recreation* (often simply called recreation), *special recreation* (sometimes referred to as specialized or segregated recreation), and *therapeutic recreation* (also called recreation therapy). Each will be described below.

INCLUSIVE RECREATION

Inclusive recreation includes pleasurable activities or experiences in naturally occurring environments alongside people with and without disabilities rather than in settings that only include people with disabilities. In inclusive settings, necessary accommodations and supports are provided to ensure that people with disabilities can be involved on as equal a basis as possible. Even when the disability is too severe to "level the playing field," some people with disabilities or their advocates may choose an inclusive recreation setting in which "partial participation" is allowed.

Including people with disabilities in the fabric of life strengthens the community and its individual members. Recreation in naturally occurring environments rather than in special, segregated settings can offer flexibility, choice, self-determination, individuality, and decision making. Inclusive recreation experiences encourage and enhance opportunities for people of varying abilities to participate and interact in life with dignity. The availability of inclusive recreation provides the right to choose from the full array of recreation opportunities offered in diverse settings and environments.

For inclusive recreation to be effective, necessary support, assistance, and accommodations must be provided. This support, assistance, and accommodation must be responsive to each person's needs and preferences. Types of support, assistance, and accommodations include but are not limited to qualified staff, adaptive equipment, alternative formats for printed or audio materials, trained volunteers, and/or flexibility in policies and program rules.

In addition, to facilitate inclusive recreation, environments should be designed to encourage social interaction, risk taking, fun, choice, and acceptance that allow for personal accomplishment in a cooperative context. All physical and programmatic barriers should be eliminated to facilitate full participation by individuals with disabilities.

Inclusive recreation means that all recreation programs are available to all people, regardless of ability level. Ensuring that all people have equal opportunity to participate in recreation activities of their choice can be difficult. A detailed, systematic procedure to facilitate inclusive recreation is outlined in the LIFE (Leisure Is for Everyone) materials and can be found in Bullock and Mahon (1997).

Not everyone believes that inclusive settings and experiences are the best for people with disabilities. Some believe that it is better for people with disabilities to participate in recreation activities alongside peers with similar abilities. In that case, there are many opportunities for recreation involvement in special or segregated settings.

SPECIAL RECREATION

Special recreation is the provision of recreation services and programs in settings only with other people with disabilities. Necessary accommodations and modifications are made to assist the person with a disability to enjoy the activity. Many of these programs occur in municipal parks and recreation departments. Examples of other special recreation programs/activities include the Special Olympics and Wheelchair Sports.

For those who believe that it is best for people with disabilities to be with other people of similar ability levels, there are special or segregated recreation opportunities. Many people believe that it is necessary to first learn skills and have experiences in separate settings and then move to inclusive settings. Others believe that requisite skills can and should be learned in inclusive settings. Whatever the belief, in the United States, it is required by law (Americans with Disabilities Act) that when separate recreation programs exist, there must be options for participation in regular, typical (inclusive) recreation as well. For example, a local parks and recreation agency can offer beginning guitar lessons open only to persons with severe mental retardation; however, any person with severe mental retardation must be allowed to participate in the regular guitar lessons alongside people without retardation, and appropriate accommodations must be made to facilitate participation in the regular (inclusive) setting. Most special recreation programs exist in municipal parks and recreation departments, YM/YWCAs, Boy and Girl Scouts, and similar programs. The Special Olympics is one of the best-known examples of a separate program.

There is another category of specialized recreation programs. These are competitive sport programs for people with disabilities, such as wheelchair sports, that are not available to people who do not have disabilities. Competitive sport for people with disabilities can be traced back to the 1870s in the United States with the beginning of sport programs for students at a state school for the deaf in Ohio. However, sport programs flourished following World War II as a part of the rehabilitation of disabled veterans in the United States and Europe. The disabled sport movement grew steadily and is now characterized by national and international competitive events, the best known and respected of which is the Paralympics, which is held in conjunction with the Olympics.

THERAPEUTIC RECREATION

Therapeutic recreation is the purposive use of recreation/recreative experiences by qualified professionals (therapeutic recreation specialists) to promote independent functioning and to enhance optimal health and well-being of people with illnesses and/or disabling conditions. Therapeutic recreation often occurs in hospitals and other treatment facilities.

Therapeutic recreation is founded on the basic premise that recreation has therapeutic value. Various researchers have found that recreation experiences can assist people to manage and reduce the impact of stressors in their lives, to cope with the transitions of aging, and to maintain overall physical and psychological health. The National Consensus Conference on the Benefits of Therapeutic Recreation in Rehabilitation (1991), funded by National Institute on Disability and Rehabilitation Research (NIDRR), found that recreation had therapeutic benefits in (1) physical health and health maintenance, (2) cognitive functioning, (3) psychosocial health, (4) growth and personal development, (5) personal and life satisfaction, and (6) societal and health care system outcomes (Coyle et al. 1991:353).

As therapeutic recreation has evolved over the years, several different models, or sets of assumptions and beliefs, have emerged. For example, the “medical model” is based on the assumption that growth and development are biological processes that occur in a predictable fashion, that there is a “normal” and an “abnormal” way to grow and develop, that health represents an absence of illness or symptoms, that illness represents a breakdown of biological processes, that the goal of treatment is the removal of symptoms of illness, and that the health care provider possesses the knowledge, expertise, and ability to restore the individual to a state of health.

Working within the medical model, the recreation therapist would take the role of the expert who determines the problems to be addressed, the desired outcomes of treatment, and the specifics of how the intervention will occur. The goal of the recreation therapist’s interventions would be to remove or reduce the symptoms of the illness. The client’s role would simply be to comply as closely as possible with the therapist’s instructions and recommendations.

In contrast, a more “wellness-oriented” model is based on the assumption that growth and development are unique to each individual and occur in response to both internal biology and a supportive and nourishing environment; that “health” represents a full and optimal expression of the individual’s capacities and uniqueness, that illness occurs in response to an interaction between internal and environmental conditions and represents a restricted or limited expression of the self, that the goal of treatment is to enable the individual to fully experience his or her own uniqueness and health, and that the health care provider cannot control the process of healing but rather can only support it.

The recreation therapist working within a wellness model would tend to take the role of a facilitator and supporter. The recreation therapist would collaborate with the client in defining the problem, the desired outcome, and the means of achieving that outcome. The client, rather than being asked to comply, would be asked to be essentially an expert on his or her own health and asked to join actively with the therapist in their common pursuit.

Historically, most recreation therapists have worked either in hospitals or long-term care settings. More specifically, most recreation therapists have worked in psychiatric services, physical medicine services, or nursing homes. Today, recreation therapists work in a broader range of environments, including inpatient health care (hospital) settings in many service areas, outpatient health care settings, schools, and community- or home-based contexts. These contexts are described in detail by Kraus and Shank (1992).

THE PROCESS OF THERAPEUTIC RECREATION INTERVENTION

The practice of therapeutic recreation encompasses a wide and varied spectrum of individuals, interventions, activities, and contexts. “Clinical process” in therapeutic recreation provides consistency—that is, regardless of the context or content of the intervention, recreation therapists follow a systematic sequence of assessment, planning the intervention, implementing the intervention, planning for transition, and evaluation to systematically document the outcomes of their interventions. These processes and activities maximize the likelihood that the services provided by the recreation therapist are individualized, purposeful, outcome focused, and, ultimately, effective.

Assessment is the first step undertaken by the recreation therapist because it sets the direction for the “purposeful intervention” by enabling the therapist to focus specifically on the strengths, needs, and health concerns of the individual being served. Assessment may be defined as a systematic process of gathering and synthesizing information about an individual and his or her world to determine the most effective course of intervention. Some assessments are standardized, while some are more flexible, allowing the therapist more latitude in how and when to administer them. Generally, it is recommended that more than one method or instrument be used to gain the most accurate and complete “sense” of the individual. An effective assessment will provide information about the individual’s functioning at the beginning of the intervention, his or her desires and goals for intervention, and some possible ways to structure the intervention. It provides a “baseline” against which to measure progress and outcomes.

The planning phase (sometimes called “treatment planning,” “individualized program planning,” or “care planning,” depending on the setting) is one in which the strengths, needs, and goals of the individual, as well as the expertise and contributions of the therapist, are organized into a coherent plan that maximizes the chance that the individual will reach her or his desired outcomes. This phase of the therapeutic recreation process is often as much an “art” as a “science,” as it involves creatively and sensitively combining many elements of skill, timing, and relationship to achieve a positive and meaningful goal.

Many settings have particular guidelines or requirements for the development and formatting of intervention plans. In some settings, the recreation therapist will develop specific “recreation goals.” For example, “the patient will be able to fish independently” is a possible recreation-based goal for an individual who has experienced a stroke and needs to master the use of adaptive equipment to continue his or her most valued recreation pursuit, fishing. In others, the recreation therapist will develop goals pertaining to aspects of functioning that are more generalized and are attainable through participation in recreation pursuits. For example, “the client will reduce perceived levels of stress through increased physical activity" is a possible goal for an individual who is experiencing symptoms of anxiety disorder.

The next phase of the therapeutic recreation process is implementation, or the actual delivery of services. Recreation therapists have a wide spectrum of options for their interventions, allowing them to tailor to the needs of the individuals being served. A significant portion of the recreation therapist's training is devoted to studying and mastering these intervention options. Interventions may be conducted one-on-one or in groups. Ideally, the needs and preferences of the client and the professional judgment of the therapist should drive the decision about how services are offered, and many times, a recreation therapist will have the opportunity to work with a client in both one-on-one and group contexts, as needed. Each modality has advantages and appropriate uses. One-on-one services allow for maximum flexibility in individualizing and contextualizing interventions and in truly moving at the client's own pace. They allow the therapist to devote all attention to the individual client, which may be important when a great deal of hands-on assistance is needed. Group interventions, on the other hand, allow for the development of interpersonal relationships and for the reinforcement and encouragement that arise from working together with a group of peers on a common goal or concern.

Services may be provided in a relatively segregated setting, as in a classroom or treatment center, or in an inclusive setting, as in a restaurant or movie theater. It is common practice in therapeutic recreation interventions to deliver interventions in both settings, in a sequenced manner, so that the client may receive instruction and rehearsal opportunities in the safety of the classroom but then will have the opportunity to master those skills in his or her natural environment, at first with support and then with increasing independence.

The next phase of the therapeutic recreation process is sometimes called *discharge planning* (in inpatient, residential, or medical model outpatient facilities) or *transition planning* (in educational contexts). It is a crucial part of the process that provides continuity, as it is the phase in which the individual and the therapist have the chance to look at what has been accomplished, what challenges will emerge in the future, and what supports are needed as the individual moves on to a more independent setting.

Ideally, transition planning should begin during, rather than at the end of, treatment, so that the client will have the opportunity to plan for and preferably visit or experience some of the settings that will be encountered in the next phase of his or her life. Comprehensive transition planning involves exploration of the places, persons, opportunities, and resources that will be part of the individual's life; exploration of the supports available; and identification of "next steps" for that person's development.

The final phase of the therapeutic recreation process is the evaluation of the effectiveness of the intervention. As discussed in the "planning" phase, the therapist does not wait until the end of the intervention to evaluate its effectiveness; rather, built-in mechanisms are already in place for evaluation or monitoring along the way. Various aspects of the intervention may be evaluated, depending on the requirements and needs of the setting, including attainment of identified goals, effectiveness of the intervention over time, satisfaction with services for clients and families, and cost-effectiveness of services.

CONCLUSION

There are increasing efforts to involve people with disabilities in recreation activities and programs. Whether it be inclusive recreation, special recreation, or therapeutic recreation, attention is being paid to the importance of choice to ensure individuality and dignity in the pursuit of pleasurable activity by people with disabilities. Within the recreation field, there is a recognition by professionals that extra efforts are required to ensure that people with disabilities have opportunities to be involved in activities and experiences that refresh, recreate, and renew health and spirits by enjoyment and relaxation of a full array of recreation offered in diverse settings and environments.

—Charles C. Bullock

See also Classification in Paralympic Sport; Exercise and Physical Activity; Paralympics; Sports and Disability.

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REFUSAL OF LIFE-SUSTAINING TREATMENT

A competent person has the right to refuse medical treatment, even when that treatment may be necessary to preserve the person's life or prevent serious illness or disability.

The right to refuse treatment stems from the right to control what is done to your body. This is sometimes referred to as the principle of self-determination or bodily inviolability. In the British common-law tradition, this is best illustrated by the law of battery, where it is said that the merest touching of a person's body without that person's consent is an actionable wrong. Similarly, in the American common-law tradition, it has been held most famously by Justice Cardozo in *Schloendorf v. Society of New York Hospital* (1914) that

> every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.

This common-law right to refuse treatment is also accepted in South Africa, Australia, New Zealand, and Canada.

A RIGHT TO MAKE AN UNREASONABLE DECISION

The right is so fundamental that a person's reasons for deciding to refuse treatment are not subject to review, no matter how objectively unreasonable the decision is. For example in the New Zealand case of *Smith v. Auckland Hospital* (1965), Justice Greeson stated that "an individual patient must, in my view, always retain the right to decline investigation or treatment however unreasonable or foolish this may appear in the eyes of his medical advisers." In Britain, Lord Donaldson, in the case of *Re T* (1922), stated that "this right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent."

In the American case of *Lane v. Candura* (1978), it was said that "the law protects [the patient's] right to make [his or] her decision to accept or reject treatment, whether that decision is wise or unwise."

The right to refuse treatment has other sources apart from the common-law principle of self-determination. In some cases, the right to refuse has been sourced in the common-law doctrine of informed consent or in rights to privacy. Constitutional guarantees of privacy and freedom of religion have also been found to support the right.

TYPES OF TREATMENT THAT MAY BE REFUSED

A person has the right to refuse all treatments, even minor or minimally invasive treatments that will preserve life. A commonly occurring example is the refusal of blood products, due to religious beliefs, such as those held by Jehovah's Witnesses and Christian Scientists.

People can also refuse artificial ventilation, resuscitation, and artificial feeding in circumstances where they will die without them. This position was accepted in Canada in *Nancy B v. Hotel-Dieu de Quebec* (1992), where the patient's right to refuse ventilation was held to be almost absolute. In *Bouvia v. Superior Court* (*Glenchur*) (1986), the Californian courts upheld the right of a cerebral palsy sufferer to remove a nasogastric tube that was keeping her alive. In *Blackman v. New York City Health and Hospitals Corporation* (1997), a competent 88-year-old woman who was on a ventilator and feeding tube was successful in seeking an order that all medical treatment being provided to her cease, barring treatment to alleviate pain.

Other examples of treatment that have been refused include operations to remove gangrenous limbs (see, e.g., *Lane v. Candura* [1978] and *In Matter of Quakenbush* [1978]) and the administration of psychotropic medication (*Fleming v. Reid* [1991]).

ADVANCE DIRECTIVES OR LIVING WILLS

It is possible to make a decision to refuse treatments that might be offered to you sometime in the future, when you may be unable to communicate a competent decision. Such decisions are most commonly referred to as *advance directives* or *living wills.*

In most common-law jurisdictions, advance directives can be made orally or in writing. To be valid, an advance directive must have been made by a competent person and must be specific enough to be able to be applied in the circumstances that have arisen. Ordinarily, clear and convincing evidence is needed show that the decision was based on an informed opinion and was intended to apply to the circumstances that arose. In addition, weight is also accorded to the question of whether the directive was made thoughtfully, seriously, and in circumstances free of the undue influence of others.

Many jurisdictions have also legislated for advance directives. Every state in the United States has advance directive legislation. Legislative schemes also exist in parts of Australia, and there are also moves toward introducing legislation in England and Wales.

LIMITATIONS ON THE RIGHT TO REFUSE TREATMENT

The right to refuse treatment is not absolute. The first limitation is that a patient be competent before his or her decision to refuse treatment is considered as binding.

The second limitation consists of public or state interests that may override a competent person's refusal. There are several situations in which the courts have upheld the state's interest in preserving life over the individual's right to refuse treatment. Among these are the interests of the state in compulsory vaccination (*Jacobson v. Massachusetts* [1905]), preventing children from becoming orphans when their parents are refusing treatment (*Holmes v. Silver Cross Hospital of Joliet* [1972]), and safeguarding the ethical integrity of the medical profession (*R v. Ashworth Hospital; ex parte Brady* [2000]). Over time, these state interests have become less likely to justify the overriding of a competent refusal of treatment.

Most troubling are those cases where the rights of pregnant women to refuse treatment are balanced against the state interest in protecting the unborn child. Earlier cases indicated that women could be forced to undergo procedures such as caesarian sections, if they were necessary to save the life of the unborn child (*Jefferson v. Griffin Spalding County Hospital Authority* [1981]). Later cases have shown a judicial reluctance to override the rights of competent women on grounds that it would be discriminatory to do so as it would severely limit pregnant women's rights of autonomy. This is the accepted position in many U.S. states and in the United Kingdom (*Re Fetus Brown* 689 [1997] and *St. George's Healthcare NHS Trust v. S; R v. Collins; ex parte S* [1998]).

The state's interest in maintaining order and discipline in prisons has also been used to override a prisoner's right to refuse treatment (including force feeding; see *Laurie v. Senecal* [1995]), but there is a wide variation in the types of rights enjoyed by prisoners across jurisdictions, and in some jurisdictions, it has been said that prisoners even have a right to die (*Reeves v. Commissioner of Police* [1999]).

The state also has an interest in preventing suicide. While committing suicide is no longer criminalized in most jurisdictions, assisted suicide remains a crime. The courts have limited the right to refuse treatment so that it does not extend to cover assistance from a third party to commit suicide. The right to refuse treatment only extends to the withdrawal of life-sustaining treatment, not active voluntary euthanasia. The courts have therefore been very careful to distinguish decisions to refuse treatment from requests for assisted suicide.

This is illustrated by *Rodriguez v. British Columbia* (*Attorney-General*), where a patient with amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, wished to have a physician supply her with a "suicide machine" that she could activate when she could no longer tolerate her condition. She sought a declaration that would invalidate the criminal provisions that made the aiding and abetting of suicide an offense.

The majority of the Canadian Supreme Court found that the provisions of the criminal law did not infringe on the guarantees of the Canadian Charter of Rights and Freedoms. According to the court, the criminal prohibition may have deprived the patient of her autonomy and caused her physical pain and distress, but such a deprivation was not found to have been contrary to the principles of fundamental justice, as secured by the charter. The court could not make fundamental changes to the long-standing and almost universal policy against euthanasia.

There are several difficulties with the prohibition against assisted suicide and its relationship with refusals of treatment—namely, the logical and legal distinction between the two. The courts have attempted to distinguish active euthanasia from treatment refusal on two grounds. The first ground is that the person is not suicidal because this individual does not desire death: he or she only wishes for treatment to cease. The second ground relied on by courts is to say that death is not caused by the person refusing treatment but by the underlying disease or disability.

Many commentators see these arguments as spurious. First, while it may be true that some patients do not desire death in refusing life-sustaining treatment, there are several cases where patients expressly stated that death was their aim (see, e.g., *State v. McAfee* [1989]). Second, to say that death is caused by disease or disability ignores the fact that the disease or disability would not have caused death without the treatment being ceased. Moreover, it ignores the active role played by physicians in actively helping the patient by administering sedatives or painkillers that accelerate the dying process.

Regardless of these logical problems, the law in several jurisdictions has upheld the distinction between refusing treatment and assisted suicide, accepting the former and criminalizing the latter.

—Cameron Stewart

See also Euthanasia; Physician-Assisted Suicide.

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REHABILITATION ACT OF 1973 (UNITED STATES)

The roots of today's rehabilitation system for civilians with disabilities in the United States, particularly those with work injuries, lie in the Smith-Fess Act of 1920. The act was based on the belief that, with professional training and intervention, people with disabilities could return to productive employment. Support for vocational rehabilitation (VR) programs grew during the years that followed until finally, in 1935, the law made the provision of VR services by each state mandatory.

During the next several decades, the act was expanded to broaden the definition of eligibility for rehabilitation services to include people with more severe, congenital disabilities, such as blindness, mental illness, and mental retardation. Services were expanded to include physical restoration and living expenses, as well as vocational evaluation and work adjustment. The act provided funds for graduate programs in rehabilitation and funded construction of rehabilitation centers and sheltered workshop facilities, although these activities are no longer funded. In 1973, the act was again amended to mandate that agencies establish an "order of selection" to ensure that people with severe disabilities receive services before individuals with less severe disabilities and to require that a written rehabilitation plan be developed to ensure that clients themselves have a strong voice in the services they receive.

The 1973 amendments also included Title V, the first civil rights legislation for individuals with disabilities. Passing with little congressional debate, Title V bans discrimination against people with disabilities in programs receiving federal financial assistance. Section 503 requires that federal contractors adopt affirmative action programs to hire individuals with disabilities. Section 504 requires that programs receiving federal financial assistance make "reasonable accommodation" for individuals with disabilities to participate fully in their programs and activities, in addition to the nondiscrimination requirements. For the first time, accessibility was required of federally funded transit systems, colleges and universities, health care institutions, and state and local programs that receive federal financial assistance. But for Section 504 to be implemented, federal agencies must adopt regulations implementing this legislation. When President Jimmy Carter refused to sign the regulations without significantly weakening the language, hundreds of individuals with disabilities protested. They occupied regional offices of the Department of Health Education and Welfare, the agency responsible for promulgating the regulations, until the regulations were finally signed into law.

In 1990, the Americans with Disabilities Act (ADA) was passed, which broadened these nondiscrimination and access requirements to include public services and other entities that did not receive federal dollars. The ADA's drafters incorporated many of the provisions of the Section 504 regulations into the act.

In 1998, the Rehabilitation Act and other employment programs were incorporated into the Workforce Investment Act (WIA). The goal of the WIA is to increase the employment, job retention, and earnings of people who participate in employment-related activities, including people with disabilities. The intent of the WIA is to create a user-friendly, one-stop system of service delivery through the coordination of multiple workforce development programs. This one-stop system must be designed to address the needs of all individuals and must be accessible to people with disabilities as required under the ADA and Section 504 of the Rehabilitation Act of 1973. The state rehabilitation program must be an integral part of this one-stop system.

Today, the Rehabilitation Act is guided by strong principles, including respect for the dignity of all individuals, personal responsibility, self-determination, and pursuit of meaningful careers; the act promotes inclusion, integration, and full participation of people with disabilities. The Rehabilitation Act contains seven titles that regulate and fund disability employment and independent living programs. Some of the key titles are the following.

Title I provides grants to each designated state agency, which employs rehabilitation counselors to provide job training, advanced education, job placement, postemployment support, assistive technology, and other services to assist individuals with disabilities to find and keep work.

Title III establishes the National Institute on Disability and Rehabilitation Research, to promote and coordinate research, demonstration projects, and training related to people with disabilities.

Title V requires affirmative action by federal contractors in hiring individuals with disabilities (Sec. 503) and nondiscrimination against people with disabilities in programs and activities receiving federal financial assistance (Sec. 504). In 1998, Section 508 was added to require that electronic and information technology purchased by or used in federal programs be accessible to people with disabilities.

Title VII regulates and funds independent living services and centers for independent living, which provide services and advocacy for individuals with significant disabilities. Chapter Two of this title provides services to older blind individuals.

—Bonnie O'Day

See also Accessible Internet; Americans with Disabilities Act of 1990 (United States); Vocational Rehabilitation; Vocational Rehabilitation: Law and Policy.

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Workforce Investment Act of 1998, 29 U.S.C. § 794d.

REHABILITATION COUNSELING

Rehabilitation counseling is a pragmatic, strength-based approach to counseling persons with disabilities. It shares similarities with certain aspects of a number of related disciplines, including physical rehabilitation and occupational therapy, psychiatry, psychology, nursing, and social work. Rehabilitation counseling is most commonly provided to individuals newly disabled by a physical event or injury or to those with a serious mental health or substance abuse problem. What makes rehabilitation counseling distinct from other disciplines is that it is activity focused, involving learning by doing within real-world contexts. Other disciplines tend to be therapy focused, usually occurring in institutional settings. The evaluation component of rehabilitation counseling typically involves the assessment of a client's problems or goals and the formulation of a treatment plan. The counseling component may seek to assist clients across a wide range of life domains, including activities of daily living, vocational functioning, social functioning, advocacy and resource acquisition, coping, and lifestyle change. The central aim of rehabilitation counseling is to empower clients to live more independently and satisfactorily while also advocating for clients' rights, needs, and hopes. Rehabilitation counselors help to reduce the cultural stigma that persons with disabilities experience. Generally, society views persons with disabilities as flawed and needy. This cultural milieu promotes feelings of dependence and inadequacy in persons with disabilities. Rehabilitation counselors counter these attitudes by helping persons with disabilities to function and excel in real-world educational, vocational, domestic, and familial contexts.

One of the hallmarks of rehabilitation counseling is that it is a pragmatic approach that facilitates rehabilitation through the use of techniques found across multiple fields. Frances Reynolds (1999) distinguishes it from other approaches to physical rehabilitation in that it may borrow techniques from a variety of orientations to facilitate adaptation and adjustment to a disability. For example, rehabilitation counselors such as Richard Hardy, Warren Rule, and John Cull have described using various psychodynamic approaches in rehabilitation counseling contexts. Hardy (1999) has also described the use of Gestalt therapy and hypnosis, while Joseph Ososkie (1998) has described existential perspectives, and Gerald Gandy (Gandy, Martin, and Hardy 1999) and a number of others have used cognitive-behavioral therapy and integrative techniques to facilitate a person's acceptance and adjustment to a disability. Nancy

Crewe (1997) has contributed a number of articles on functional assessment and outcomes rehabilitation counseling for individuals with spinal cord injury and traumatic brain injury that have provided valuable insight into the lives of persons with disabilities. Brian McMahon has written a number of articles about rehabilitation counseling and supported employment for individuals with a wide range of disabilities, including traumatic brain injuries that have moved the field toward a more empowerment-focused ideology (e.g., McMahon and Shaw 1996). In sum, the field of rehabilitation counseling can be characterized by a wide variety of approaches that are drawn from the distinctive psychological issues facing people with disabilities and from the theory, research, and practice of general counseling and psychotherapy. To an important extent, these approaches are framed by the goal of a person retaking his or her full potential and ability after the onset of a disability.

With respect to training and certification, two initiatives in the United States have worked to ensure that rehabilitation counselors are adequately educated and sufficiently competent to enter the profession: program accreditation and certification for practice. These two movements have helped set national standards for skill-level proficiency and knowledge adequacy of rehabilitation counselors. National standards include knowledge about vocational counseling and consultation, effective counseling, case management, service availability, medical and psychosocial aspects of disability, and history and systems of rehabilitation. A similar movement has taken place in Canada. Michael Leahy has written about perceptions of knowledge requirements among certified rehabilitation counselors in Canada (see, e.g., Leahy, Chan, and Magrega 1997). Domains of required knowledge identified by Canadian counselors were very similar to the domains of knowledge that U.S. rehabilitation counselors endorse, including knowledge of psychosocial aspects of disabilities and systems of rehabilitation.

Scholars such as Jared Schultz, Joseph Ososkie, and Elias Mpofu have commented on the state of the field of rehabilitation counseling. The field of rehabilitation counseling tends to serve a diverse population of individuals with disabilities using a wide range of approaches. In addition, rehabilitation counselors work in varied settings. These settings range from private settings, such as private rehabilitation centers and hospitals, health insurance companies, and employment counseling firms, to public settings that include the state agencies of rehabilitation services, the federal Social Security Administration, and other governmental organizations. For these reasons, these scholars argue that many may not understand the unique and cohesive mission and vision of the field. In addition to this challenge of understanding breadth, the field has been forced to confront changes in practice settings, evolving federal legislative regulations, and the certification movement. The field has attempted to respond to these challenges by explicitly defining major areas of required knowledge and skills. Recently, Leahy, Chan, and Saunders (2002), as well as others, have sought to describe the job functions and training requirements of certified rehabilitation counselors for the twenty-first century. One set of core job functions concerns employment and includes vocational assessment, counseling, and consultation to identify interests and competencies, provide job retraining and practice, identify potential job placements for clients, and, ultimately, increase client readiness for and likelihood of stable employment. Another central role of the rehabilitation counselor concerns promoting effective coping with daily and community life. It involves counseling activities that range from assessment of clients in terms of resource needs to case management. It also includes specific counseling interventions that are designed specifically for the consumer's abilities and environment. Rehabilitation counselors also conduct community-based rehabilitation service activities, where their knowledge of health care and disability systems empowers them to engage in professional advocacy. In sum, rehabilitation counselors work with the psychological, medical, functional, and environmental implications of disability to support and ready their clients for independent functioning and community integration.

Over the past 30 years, the profession has expanded outside of state vocational rehabilitation agencies and into schools, medical settings, mental health settings, substance abuse settings, geriatric settings, employee assistance programs, private practice settings, and community-based organizations. Relatedly, a growing number of integrative, community-based approaches to rehabilitation counseling have developed. These approaches seek to combine counseling and advocacy efforts. David Hershenson (1998) has described one approach that involves four elements of rehabilitation. These include restoring or replacing assets and skills, reintegrating identity and self-image, reformulating goals, and restructuring the environment. Lloyd Goodwin (1986) described another approach that involves eight dimensions of rehabilitation: supporting wholeness of the client, wellness, responsibility taking, prevention, uniqueness, disability as an opportunity for growth, healing and rehabilitation approaches, and environmental sensitivity. Other fundamental principles of rehabilitation counseling include normalizing roles and relationships within society, building informal and egalitarian relationships, emphasizing empowerment, focusing on present-moment concerns, and promoting community integration. Principles that have emerged more recently within rehabilitation counseling include multicultural sensitivity, evaluating outcomes, incorporating family members into treatment, and interdisciplinary collaboration. All these new approaches signify the strength of the rehabilitation counseling field as it evolves and adapts to new political, cultural, and fiscal contexts.

—Renee R. Taylor and
Curtis J. Jones

See also Community-Based Rehabilitation; Employment; Independent Living; Vocational Rehabilitation.

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REHABILITATION ENGINEERING

Rehabilitation engineering is a field that brings the art and science of engineering to the assistance of persons with disabilities. It encompasses engineering research and development activities but also includes direct engineering services to persons with disabilities.

Rehabilitation engineering is frequently viewed as a component of the more general field of biomedical engineering, which brings together engineering with medicine and biology. As a direct service to people, it is related to occupational therapy and, to some extent, physical therapy. Although examples of rehabilitation engineering are almost as old as civilization itself, the field was not identified widely as "rehabilitation engineering" until the 1960s, when health agencies in a number of countries began to recognize the benefits of engineering insights and methods in the provision of assistance for persons with disabilities.

DEVELOPMENT AND SCOPE

Limb prosthetics is a subspecialty of rehabilitation engineering. It is concerned with the replacement of arms, hands, and legs with artificial components. Since antiquity, specialists have provided artificial replacements for lost limbs, particularly limbs lost in the conflicts of wars. After World War II, persons with limb loss often reentered society successfully, and high-quality artificial limbs coming out of federally sponsored research and development programs in prosthetics at that time contributed to this success. Consequently, in the late 1960s, the generalizing concept of rehabilitation engineering evolved, based on the thought that if engineers could work creatively with rehabilitation physicians and clinicians to improve limb prosthesis outcomes, they probably would also be able, through engineering techniques and scientific principles, to assist with the rehabilitation process for many other disabling conditions. Thus, the generalized field of rehabilitation engineering was launched.

In the late 1960s, one of the original objectives for the new field of rehabilitation engineering, as proposed by James B. Reswick, was "to improve the quality of life of the physically handicapped through a total approach to rehabilitation, combining medicine, engineering, and related science." Today, this field is viewed much more broadly, placing many chronically disabling conditions under the possible purview of engineering approaches. Physical disabilities such as limb loss are only one aspect of this field that now also includes communication disabilities, sensory disabilities, cognitive disabilities, and the many disabling conditions resulting from spinal cord injuries, head injuries, strokes, blindness and visual impairments, hearing impairments and deafness, neuromuscular diseases, musculoskeletal conditions, arthritis, orthopedic disabilities (bone and joint), cerebral palsy, pulmonary insufficiencies, cardiac deficits, disabling conditions from birth, disabilities of aging, disfigurement, and numerous other traumas, conditions, and diseases.

TECHNOLOGY SERVES THE PROCESS

Rehabilitation engineering is connected with treatments and therapies (e.g., robotic-aided therapy). It is associated with the avoidance of secondary disabling conditions and with comfort and alleviation of pain (e.g., witness the significant role engineering played in the orthopedic success of total joint replacements). This field also has to do with access to medical and rehabilitation services, tele-rehabilitation, and a wide scope of health care and possible cures that may result from genetics and stem cell medicine.

PERSONAL AIDS

The possibilities and prospects of rehabilitation engineering are as broad as life itself, which makes them innumerable. There are walking aids, functional electrical stimulation of muscles, manipulation aids, and wheeled mobility (e.g., powered chairs such as the unique iBOT Mobility System). Issues to be addressed include proper seating and positioning in wheelchairs and elsewhere, and management of pressure on body tissues. There are memory aids, and self-care aids (e.g., for handling one's medical prescriptions), speaking aids, reading aids, writing aids, hearing aids, visual aids, eating aids, teeth hygiene, toiletry aids, bladder and bowel management, recreational aids, temperature and lighting controls, telephone controls, control of entertainment equipment, assistance for caregivers, and attention in general to as many aspects of independent living as are feasible and reasonable. Modern computer-based technologies and wireless communication systems are making many of the aids listed available and easily customized to individual needs.

ASSISTANCE ON A LARGER SCALE

Rehabilitation engineering deals with aspects of the built and natural environments that may be inhibitory to persons with disabilities. The elimination of architectural barriers, development of universal designs for home and public environments, and the arrangement for home and work site modifications are all within the domain of rehabilitation engineering. There is need for access to secure living quarters, access to transportation and travel, and access to education and employment opportunities. Access to information (e.g., the Internet) and to the origination of information is highly desirable. With the right technical tools, meaningful work can be made accessible. This kind of technology may also permit pursuit of hobbies and avocational activities that can be invigorating and life enriching.

MULTIDISCIPLINARY INVOLVEMENT

As a general rule, engineers in rehabilitation cannot be successful alone with their efforts. They need to work together with physicians, surgeons, nurses, therapists, prosthetists, orthotists, and people with disabilities, their family members, and friends. This need for multidisciplinary experience exists both for engineers who conduct research on new methods and technologies to better serve persons with disabilities and for engineers who directly delivery rehabilitation engineering services to people. Nevertheless, the two kinds of rehabilitation engineers—the service-providing engineer and the research and development engineer—work in fundamentally different ways.

RESEARCH AND DEVELOPMENT

The rehabilitation engineer who conducts research and development (R&D) work usually is employed by a company that designs and/or manufactures rehabilitation engineering equipment or is involved in R&D work through a university-based laboratory that is funded by research grants. The R&D employee usually is a research engineer or scientist, often with a Ph.D. in biomedical engineering or some related area of science or engineering. The researchers usually work closely with rehabilitation professionals and ideally may have disabilities themselves. The aim is to develop new knowledge (science and engineering) concerning rehabilitation processes and new superior ways to solve problems that persons with disabilities experience. Much of the R&D work in rehabilitation is what might be described as applied research and development. However, new approaches at the cellular and molecular levels, new concepts in tissue engineering, new nanotechnologies, and new biomaterials are basic research arenas that may open up completely new concepts in rehabilitation.

SERVICE PROVIDERS

Engineers who deliver service directly to individuals with disabilities work basically as clinicians. Through training and experience, through working with other rehabilitation professionals, and through close interaction with the persons being served, they can begin to help their clients with rational decisions about which rehabilitation engineering approaches and assistive devices may help them. Many providers of rehabilitation engineering services in the United States are credentialed by RESNA (Rehabilitation Engineering and Assistive Technology Society of North America). The positions examined are assistive technology practitioner (ATP), assistive technology supplier (ATS), and rehabilitation engineering technologist (RET). The credentialing process attempts to provide safeguards for clients and to increase client satisfaction.

Clients usually should have their medical conditions stabilized before being seen for rehabilitation engineering consultation. Modes of communication also need to be established beforehand, if possible, so that the client can interact in the discussions and in decision-making processes. After communication has been achieved, it is important to determine if the person is comfortable. If not, the possible causes of discomfort need to be investigated and eliminated. For example, good seating and positioning frequently need to be established to help clients relax and be more comfortable. After the client can communicate and is comfortable, an early step is to try to provide that person with independent mobility. From this point on, it is usually possible to begin to address the many individual and unique needs of each client. Inevitably, this process usually involves many compromises as well as medical, engineering, and financial constraints.

A HUMAN ENDEAVOR

In the end, rehabilitation engineering methods and techniques cannot rehabilitate a person with disability. True rehabilitation must somehow come from within the person with disability, aided primarily by human love and compassionate care. Nevertheless, if one is truly rehabilitated, the methods and techniques provided by rehabilitation engineering can indeed greatly enlarge the scope of his or her life.

—Dudley Childress

See also Activities of Daily Living (ADLs); Independent Living; Assistive Technology; Mobility Aids; Physical Activity.

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REHABILITATION ENGINEERING AND ASSISTIVE TECHNOLOGY SOCIETY OF NORTH AMERICA (RESNA)

The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) is an interdisciplinary association composed of individuals interested in technology and disability. Professionals in RESNA include occupational therapists, physical therapists, rehabilitation engineers, speech-language pathologists, special educators, manufacturers, and durable medical equipment suppliers. Consumers of assistive technology also belong to RESNA.

RESNA started in 1980 as early research and development work in the field began at federally funded rehabilitation engineering research centers (RERCs). Each RERC focuses on one specific area of assistive technology, developing new technology, training new professionals, and providing information to the public.

RESNA provides a forum for individuals with a common interest in a particular area of assistive technology, through special interest groups (SIGs). In addition, RESNA's professional specialty groups (PSGs) provide a way for specific disciplines to communicate with one another.

Through the Technical Assistance Project and Alternate Financing Project, RESNA provides assistance to the 56 state and territory assistive technology programs. These programs are funded under Public Law 105–394 to increase awareness of and access to assistive technology in each area.

Through its credentialing program, RESNA provides a mechanism for professionals to demonstrate a knowledge and skill base critical to the delivery of assistive technology services. Three credentials exist: assistive technology practitioner (ATP), assistive technology supplier (ATS), and rehabilitation engineering technologist (RET).

RESNA's international sister organizations—the Association for the Advancement of Assistive Technology in Europe (AAATE), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation and Assistive Technology Association (ARATA)—provide forums for similar work around the world. On August 26, 2000, the leaders of the four organizations signed the Tokushima Agreement to promote exchange of information and collaboration.

—Glenn Hedman

See also Rehabilitation Engineering Society of Japan (RESJA).

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REHABILITATION ENGINEERING SOCIETY OF JAPAN (RESJA)

The Rehabilitation Engineering Society of Japan (RESJA) was established in 1986 and is composed of approximately 1,000 members. RESJA's membership is interdisciplinary, including engineers, occupational therapists, physical therapists, speech therapists, educators, physicians, and consumers.

RESJA organizes an annual conference, the Japanese Conference of Advancement on Assistive and Rehabilitation Technology (JCAART). The conference provides a forum for the presentation of approximately 700 papers. An additional dissemination avenue is the *Journal of RESJA,* which is issued four times each year.

RESJA is organized around 10 special interest groups (SIGs). Current SIG topics include the following: automobile, communication, functional electrical stimulation, house design, seating, self-help devices, wheelchairs, special education, transfer aids, and devices to prevent pressure sores.

RESJA interacts with its sister organizations—the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), the Association for the Advancement of Assistive Technology in Europe (AAATE), and the Australian Rehabilitation and Assistive Technology Association (ARATA)—to advance assistive technology use worldwide. On August 26, 2000, the leaders of the four organizations signed the Tokushima Agreement to promote exchange of information and collaboration.

—Glenn Hedman

See also Rehabilitation Engineering and Assistive Technology Society of North America (RESNA).

Websites

Rehabilitation Engineering Society of Japan, http://www.resja.gr .jp/

REHABILITATION MEDICINE, INTERNATIONAL

Rehabilitation is used as a term for different medical, psychological, social, and vocational measures that aim to support a person with disability to regain as normal a life as possible. The ultimate goal for rehabilitation is that the person will participate actively in life roles of importance for that person. This entry concentrates on rehabilitation within medicine, with special emphasis on the situation in Europe.

GENERAL ASPECTS AND DEFINITION

For the development of rehabilitation, the concepts first given by the World Health Organization (WHO 1980) in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and recently (approved 2001) in the International Classification of Functioning, Disability, and Health (ICF) have played a great role. Rehabilitation works on all levels in ICF (body function and structure, activity, and participation), also taking environmental factors into account. Impairments (the level of body function and structure) can be treated to reduce or eliminate the reduction in function by pharmacological means, training through physiotherapy, occupational therapy, speech therapy, neuropsychological means, and so on, or they can be compensated for by assisted devices. Rehabilitation aims at reducing the activity limitations (the level of the individual) by training, changing an activity pattern (e.g., more appropriate way to handle objects for a person with joint disease), and using assistive devices and modifications of the environment (e.g., housing adaptation). Finally, the aim is to increase participation, where social and psychological factors play a great role and should include attention to the attitudes of relevant other persons. Emphasis may be placed differently on those three levels, depending on the phase and actual goal of rehabilitation, but all should always be kept in mind. In the early acute stage, measures to reduce impairment and limitation in basic daily activities may dominate, whereas in the more subacute stage of rehabilitation, reduction of activity limitation in a broader sense may be the dominant goal. The need for treatment of specific body functions (impairments) should therefore be analyzed in such a perspective. In a later stage, after an individual leaves the hospital, social aspects related to family life, occupation, hobbies, and leisure activities will be given an increasing importance for the rehabilitation efforts.

Rehabilitation measures and programs can be divided into different categories:

- separate rehabilitation measures, which may or may not be coordinated, such as physiotherapy, occupational therapy, and speech and language therapy;
- coordinated rehabilitation within different clinical specialities, but without participation of a clinical specialist in rehabilitation medicine;
- team-based rehabilitation in specialized rehabilitation units (clinics) and led by a specialist in rehabilitation medicine (in the United States, a physiatrist).

The activity of the rehabilitation team should essentially be goal oriented and should take account of the preferences and goals of the patient, who is an active participant in the rehabilitation process.

Many medical disciplines have a rehabilitation component within their work, but of special note are psychiatry, rheumatology, cardiology, neurology, orthopedics, and respiratory medicine. Specialized clinics are established by specialists in physical and rehabilitation medicine to address the needs of special groups of patients, where a broad and more timely approach is required. Thus, the medical speciality that is most greatly concerned with the medical rehabilitation of physically disabled people is physical and rehabilitation medicine. It goes under a variety of names in different countries, reflecting different priorities:

> Rehabilitation medicine: Hungary, Ireland, Luxembourg, the Netherlands, Poland, Portugal, Sweden, United Kingdom
>
> Physical and rehabilitation medicine: Official Title in the Union of European Medical Specialists (UEMS) and also in France, Germany, Denmark, Greece, Switzerland
>
> Physical medicine and rehabilitation: Austria, Belgium, Croatia, Czech Republic, Denmark, Estonia, Finland, Greece, Italy, Latvia, Liechtenstein, Lithuania, Norway, Slovakia, Slovenia, Spain, Turkey, United States

The term *physical medicine* is still used in some countries but represents a slightly different activity from rehabilitation medicine. In some countries, such as in the United States, a specialist in physical and rehabilitation medicine is named a physiatrist.

Definition

The speciality will hereinafter be referred to as physical and rehabilitation medicine (PRM). So what is PRM? The European Union of Medical Specialists (UEMS) section of PRM has defined it as follows:

> PRM is an independent medical specialty concerned with the promotion of physical and cognitive functioning, behaviour, quality of life (activities and participation) and with the prevention, diagnosis, treatment and rehabilitation management of people with disabling medical conditions and co-morbidity across all ages.
>
> Specialists in PRM have a holistic approach to people with acute and chronic conditions, examples of which are musculo-skeletal and neurological disorders, amputations, pelvic organ dysfunction, cardiorespiratory insufficiency and the disability due to chronic pain and cancer.
>
> PRM specialists work in various facilities from acute care units to community settings. They use specific diagnostic assessment tools and carry out treatments, which include pharmacological, physical, technical and educational and vocational interventions. Because of their comprehensive training, they are best placed to assume responsibility for the activities of multi-professional teams in order to achieve optimal outcomes.

There are variations from country to country, but the common aspect is the relationship of the rehabilitation physician to other members of the multiprofessional team. This is quite different from that found in acute medicine.

Aims of Physical and Rehabilitation Medicine

The concepts in the ICIDH, published in 1980 by WHO, have made a great impact on rehabilitation. However, the terms have changed in the recently published ICF. The overall aim of rehabilitation is to reduce or eliminate disability, as its definition in ICF still applies. Rehabilitation is a precise activity and is quite different from care and describes a goal-oriented activity. Similarly, it is quite different from "therapy," which contributes to the rehabilitation process in individual recipients but may not always be required for everyone. *Therapy* and *rehabilitation* are not synonymous.

Rehabilitation—WHO Definition. This is an active process by which those disabled by injury/disease achieve a full recovery or, if full recovery is not possible, realize their optimal physical, mental, and social potential and are integrated into their most appropriate environment.

Health-Based Rehabilitation: Working Definition. This dedicated, designated, multiprofessional activity, which takes an active and holistic approach to care and is centered on the individual needs of patients and carers, starts in earnest when the patient is medically stable and continues through community reintegration and beyond, is goal oriented, and is easily and appropriately accessible.

Rehabilitation Medicine. This is a consultant subacute speciality concerned with the secondary and tertiary management of the medical aspects of physical disability (especially in the fields of neurological and musculoskeletal disease, trauma, and amputation), which require specialist rehabilitation expertise.

Rehabilitation Therapy. This includes treatment provided by, or under the direction of, nurses, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists, dieticians, chiropodists, and so on. They each have their professional philosophies, but space prevents from describing each.

Medical practice is based on the concept of arriving at a diagnosis and providing a treatment that aims to cure the patient. In the context of medical and social progress and the increasing importance of degenerative diseases in medical practice, the relatively new concepts of improving quality of life and preventing deterioration and complications have assumed greater priority.

General Structure in Europe

The general structure of PRM services across Europe is fairly similar despite the differences between health care systems. PRM is recognized as a core service in each of the 19 member states of Europe and the new associate members also adopt the same principles. The names may be different from place to place, but the essential services appear in the following form.

> *General Rehabilitation:* Characterized by health professionals working within their professional roles in relative isolation from others.
>
> *Special Services:* Dedicated areas of working, where individual professionals have varying degrees of contact with others involved in the rehabilitation process—for example, continence and tissue viability services, dysphagia services, and so on. For specific conditions, such as multiple sclerosis, Parkinson's disease, and back pain, individuals may have a general clinical role working within a team and an extra responsibility to these respective patients.
>
> *Specialized Rehabilitation:* Dedicated multidisciplinary or interdisciplinary rehabilitation, where the team meets to define the rehabilitation objectives and activity and professionals work together to achieve the aims of the process. It is often inpatient based, but there are now a number of community teams working in this way.

The numbers of specialists in PRM across Europe varies considerably, and this depends to a large extent on geography.

Training in PRM

Specialist training covers a four- to five-year course in UEMS member states. The route to start training is slightly different in each country, but, despite different entry points to a four- to five-year training program, the curriculum has much similarity across the continent. The European Board of PRM has the task of harmonizing specialist training across Europe and has taken on the following roles.

- European examination for recognition of specialist training
- Continuing professional development and medical education with five yearly revalidations
- Recognition of the European trainer and training unit through site visits

The eventual aim of this harmonization is to produce specialists who can work across European health care systems and allow national medical authorities/employers the knowledge of the training content and experience of the specialists working for them.

DELIVERY OF REHABILITATION SERVICES

With such a burden of physical disability in the population, adequate and equitable delivery of health care to the disabled population is clearly a major logistical problem. Services provided in most countries are patchy, fragmented, and overall inadequate. Facilities are needed for both inpatients and outpatients, and the criteria for inpatient rehabilitation are as follows:

a. patients requiring 24-hour nursing and medical supervision for their rehabilitative needs;
b. patients with neurological and locomotor disorders who have the capacity for, require, and will benefit from rehabilitation (i.e., patients in whom the evidence shows that active intervention improves function and life satisfaction or prevents deterioration);
c. severely disabled patients, whose needs can only be met by a multiprofessional team practicing interdisciplinary rehabilitation;
d. patients with complex needs (i.e., requiring more than two professionals working in a team);
e. some very severely disabled patients with little hope of improvement in personal functioning but who require assessment and appropriate equipment and whose families require education for caring purposes.

A number of basic core services are required in each area. Logistics demand that rare and complex conditions require designated specialist services, and because they will not be available in each locality, an access network is necessary.

Acute Services

As the pressure on acute facilities increases, rehabilitation in acute hospital beds should be available to achieve optimal outcomes, reduce complications and disability, and allow a clear pathway for efficient ongoing rehabilitation after discharge. The barriers to achieving this are as follows:

- lack of recognition by the acute care team of what the specialist center can offer in addition to that provided by the acute physician/surgeon,
- lack of access (availability of services, waiting time to enter rehabilitation),
- financial restrictions (hospital/clinician/insurance).

Specialist Centers

Certain individual groups of both old and younger adults and children require dedicated centers/services for specialized rehabilitation, and the standards proposed by the British Society of Rehabilitation Medicine on the number of required beds per district for rehabilitation medicine only account for younger adults. These centers need both inpatient and outpatient rehabilitation facilities, which are separated from acute beds and long-term care facilities for the elderly.

Disease-Specific Clinics

Specific clinics and activities have been developed for managing certain long-term conditions, such as multiple sclerosis, epilepsy, Parkinson's disease, or inflammatory joint disease. In addition, back pain services have been set up, and these clinics certainly have the advantage of providing an expert multidisciplinary approach, which is familiar with the specific problems of that disorder. The team can supply information and counseling support and can act as a focus for self-help groups.

Community Rehabilitation Teams

Follow-up from the acute hospital-based rehabilitation team is essential for many people with significant disabilities to provide continuity of support and access to appropriate health resources after discharge. A community team can still work in a multi- or an interdisciplinary manner in the same way as the acute rehabilitation team but tends to concentrate on changing abilities in activities and participation rather than on the relationship between impairments and abilities. A team is effective for a population of about 120,000. Teams may be peripatetic, based in health/community centers or in community hospitals. Their essential aims are to ensure the well-being of disabled people in the community by organizing therapeutic interventions to ensure optimal outcomes following hospital stays and prevent hospital admissions.

Case Management

Disabled people, particularly those with severe and wide-ranging disabilities, will need a complex array of health and social services. The concept of case management has been developed as a way of assisting disabled people with the coordination of the necessary professional staff. Case management can include the following:

simple coordination within a single agency;

coordination across agency boundaries;

service brokerage, in which the case manager negotiates with the key agencies on the client's behalf;

budget-holding responsibility, where services can be purchased on behalf of the client from statutory bodies or other voluntary or private agencies.

There have been very few controlled studies of the efficacy of case management, which is widely practiced within the United States, Canada, and Scandinavia. It may provide a better and more coherent service, particularly for those who have a degree of cognitive impairment who are unable to find their own way through the maze of services.

Links with Other Agencies

Health-based rehabilitation goes hand in hand with social and vocational rehabilitation, and services need both formal and informal means to break down the artificial barriers between the participating agencies. Cross-representation is necessary at both the strategic and operational levels, and disabled people not only need to be involved but also should lead when and where it is appropriate. There is no single preferred model to suit every location, and each will depend on the local facilities and assets of the participating individuals. However, all new services should take into account the views and advice of users and disabled people's groups on disabled living (Living Options principles and European Year for Disabled People 2003).

REHABILITATION RESEARCH–ACADEMIC BASE

Rehabilitation research is growing in activity and sophistication. However, randomized controlled trials are, to some extent, difficult to perform in this field, but a recent increase in the publication of such studies can be seen. There are now a lot of data about the effectiveness of rehabilitation, and what is now required are data on the value of rehabilitation through cost-effectiveness studies, some of which are under way. Rehabilitation will also have a more solid theoretical basis as the perspectives of fields such as neurobiology, applied physiology, and biomechanics increasingly provide a background for rehabilitation. There is also an increasing use of modern and relevant methods to treat ordinal scale data from various instruments to assess activity limitation, participation restriction, quality of life, and perception of health—all very useful in rehabilitation research.

—Anthony B. Ward and
Gunnar Grimby

See also Assistive Technology; Case Management; Mobility Aids; Physical Medicine and Rehabilitation; Rehabilitation Engineering.

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REHABILITATION PSYCHOLOGY

Rehabilitation psychology is a specialty area of practice that applies psychological knowledge and understanding on behalf of individuals with disabilities and society through research, clinical practice, teaching, public education, development of social policy, and advocacy. Rehabilitation psychologists participate in a wide range of activities, including clinical care and direct service, program development, research, education, administration, and public policy.

They work in acute care hospitals and medical centers, inpatient and outpatient physical rehabilitation units, nursing homes and assisted living centers, and community agencies serving people with specific types of disability or chronic illness (e.g., vision loss and low vision, cerebral palsy, multiple sclerosis, deafness). Their employers include private facilities and government facilities such as Veterans Administration hospitals and centers, industry, and universities, colleges, and private practice. The focus of rehabilitation psychology covers the lifespan from early childhood through late adulthood. Advocacy is an important activity for rehabilitation psychologists as they seek to improve the life conditions for people with disabilities and chronic illnesses; many have sought to develop and promote legislation such as the Americans with Disabilities Act of 1990.

Clinical and counseling services provided by rehabilitation psychologists assist individuals to cope with and adjust following the onset of chronic, traumatic, or congenital injuries or illnesses. These conditions include spinal cord injury; brain injury; stroke; amputations; neuromuscular disorders; medical conditions with the potential to limit functioning and participation in life activities such as cancer, AIDS, multiple sclerosis, or limb weakness; chronic pain; congenital or chronic developmental disorder such as mental retardation; chronic mental illness; alcohol and other drug abuse; impairments in sensory functioning; burn injury; deafness and hearing loss; and blindness and vision loss. Many of these impairments are compounded by cultural, educational, and/or other disadvantages and social stigma.

Psychological services often have the goal of reducing the consequences of impairment, activity limitations, and societal participation restrictions. Persons served are engaged as active partners in the rehabilitation process by taking into account the person's preferences, needs, and resources. Following the World Health Organization's International Classification of Functioning, Disability, and Health (ICF), rehabilitation psychologists have helped address personal factors affecting the ICF domains of impairments, activities, and participation. They do this by addressing neurocognitive status, mood and emotions, desired level of independence or interdependence, freedom of movement, self-esteem and self-determination, subjective view of capabilities and quality of life, and satisfaction with achievements in specific areas such as work, social relationships, and community access. Rehabilitation psychologists consider the influence of culture, ethnicity, gender, residence and geographic location, visibility and assumption of disability on attitudes, and available services when planning services. Also explored are environmental barriers to participation and activity performance, including accommodations and adaptations in existing structures or materials and the use of assistive technology and personal assistance services.

Families, primary caregivers, and other significant people in the individual's social life and community are valued and engaged in rehabilitation activities so as to assist the individual with disability or chronic illness achieve optimal physical, psychological, and interpersonal functioning.

Rehabilitation psychologists work within a wide variety of health care settings and with a broad range of persons with varying disabilities and illnesses. Some specialize in a particular area of clinical practice, while others' practice is broader. Interdisciplinary teamwork is a hallmark of rehabilitation psychology practice across settings and the area of specialization. Rehabilitation psychologists are respected and provide services within existing networks of biological, psychological, social, environmental, and political environments to assist the persons served in achieving their rehabilitation goals. Consultation regarding disability and health issues is another important professional role of rehabilitation psychologists. Attorneys, courts, government agencies, educational institutions, corporate facilities, and insurance companies are the recipients of these services.

Rehabilitation psychologists complete doctoral degrees in psychology and have had extensive predoctoral and postdoctoral training in health care settings. Rehabilitation psychologists who provide clinical services are usually required to be licensed to provide services in their state of practice and to receive reimbursement for services from health insurance payers. The American Board of Professional Psychology (ABPP) recognizes rehabilitation psychology as a specialty area of practice within psychology; the board's definition of rehabilitation psychology was an important source in the development of this description. Rehabilitation psychologists belong to many professional organizations relevant to their area of practice and specialization. The major organization representing rehabilitation psychology is the American Psychological Association (APA), Division of Rehabilitation Psychology. Division 22 publishes a scholarly journal and newsletter; it also sponsors sessions relevant to rehabilitation psychology research and practice at the annual APA conference held annually in August, a midwinter meeting, and other education venues for psychologists and other health professionals. Several excellent textbooks are available on the general topic of rehabilitation psychology, as well as books on areas of specialization within this field.

—Allen Heinemann

See also Physical Medicine and Rehabilitation; Psychiatry; Psychology.

Note: Information for this entry was drawn from the description written by Marcia Scherer, Kelly Blair, Martha E. Banks, Bernard Brucker, John Corrigan, and Stephen Wegener and appears at http://www.apa.org/divisions/div22/RPdef.html.

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REHABILITATION ROBOTS

There are two main types of rehabilitation robots. The first type is an assistive robot that substitutes for lost limb movements. For example, the MANUS robot arm attaches to a wheelchair. The user controls MANUS using a chin switch or other input device. This process is called "telemanipulation" and is similar to an astronaut controlling the space shuttle's cargo bay robot arm from inside the shuttle's cockpit. Powered wheelchairs are another example of teleoperated, assistive robots.

The second type of rehabilitation robot is a therapy robot, which is sometimes called a "rehabilitator." Neuroscience research over the past 20 years has shown that the brain and spinal cord retain a remarkable ability to adapt, even after injury, through the use of practiced movements. Therapy robots are machines or tools for rehabilitation therapists that allow patients to perform practice movements aided by the robot. The first robot used in this way, MIT-Manus, assisted patients with stroke in reaching across a tabletop if they were unable to perform the task by themselves. Patients who received extra therapy from the robot improved the rate of their arm movement recovery. Another recent therapy robot, the Lokomat, supports the weight of a person and moves the legs in a walking pattern over a moving treadmill, with the goal of retraining walking after a spinal cord injury or stroke.

Assistive robots are not yet widely available because of limited functionality and cost. Teleoperating a robot arm to pick up a bottle of water and bring it to the mouth is time-consuming and requires an expensive robot. Robot arms on wheelchairs will become more common as engineers build more intelligence into them. Making robots understand voice commands, recognize objects, and agilely manipulate them in the "real world" is a cutting-edge research area in robotics. Another promising area of research is at the cutting edge of neuroscience: implanting computer chips directly into the brain so that all a user has to do is "think" a command and the robot will do it. This sounds like science fiction, but researchers have recently shown that monkeys can be trained to move a robotic arm in just this fashion—through thought alone.

The main issue limiting therapy robots is that researchers do not understand what exactly the nervous system needs to adapt. Hard work by the patient is important, but what should the robot do? Researchers are developing therapy robots that assist in movement, resist movement when it is uncoordinated, or even make movements more uncoordinated in an attempt to trick the nervous system into adapting. Therapy robots will become more prevalent as researchers figure out the best training techniques. Therapy robots will also likely play a role in assisting the nervous system to regenerate appropriate neural connections following stem cell and other medical treatments.

Finally, the distinction between assistive and therapy robots may fade in the future. Imagine wearing a robotic exoskeleton that helps you to get tasks done but also teaches you to get better at doing those tasks. Such a rehabilitation robot will help people with disabilities by gradually making itself obsolete.

—David J. Reinkensmeyer

See also Assistive Technology; Rehabilitation Engineering.

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RELIGION

A religion is a system(s) of belief(s) and ritual through which people relate to and express their experience of

God(s), the sacred or divine dimensions of life, and their understandings of the meaning of life. Religion includes the practices whereby people live out their faith, and both historically and today, it is a major force in the lives of cultures and civilizations. Hence, people with disabilities and their families are influenced by those religious traditions and systems. In turn, the experience of impairment, as well as its social expression, disability, affects religious understanding and practice as people with and without disabilities seek to understand the meaning of disability, God's relationship to disability, and the subsequent understandings of practice and relationship to which a belief and tradition calls them.

The intersection of disability and religion has complex historical, practical, scientific, and theological dimensions. Disability is paradoxically often central to religion (such as the brokenness of God in Christianity) yet has, in large part, been overlooked in systemic research and the study of religious systems. A critical understanding assists in understanding the historical treatment of disability and its intersection with culture and faith traditions. Religion can be a force for both good and ill regarding disability.

EXPLORING THE COMPLEX RELATIONSHIP

There is no one generalized definition or explanation of the relationship between religion and religion. While religion is a major force in societies, many other factors influence people. Adherence to, or interpretation of, a faith tradition is also shaped by numerous other forces that influence personal and social understandings of disability.

Religion and faith can endorse and enshrine social attitudes and practice or challenge them. There are many examples of ways that faith and religion have been a support to people with disabilities and their families. Likewise, there are many examples of its use to exclude, dehumanize, or harm people with disabilities.

Certainly, there is no central understanding of how religious tradition or faith relates to disability. Reflecting dominant power relations, in faith traditions, disability is not a major focus. Most religious leaders do not live with disability, and few cite sermons or teachings on disability and religion. There are also many different understandings, doctrines, beliefs, and approaches about many issues within a specific religious tradition, including disability.

Hence, even if there were a central understanding or practice within a given tradition about disability, it does not mean that practice would be uniform. Many different forces and experiences shape attitudes and practice.

EXPLORING RELATIONSHIPS AND EMERGING RESEARCH

Despite this, the relationship between religious beliefs and practice and disability (or disabilities) is an area for rich and powerful exploration and research. Having a disability or close relationships with people with disabilities raises many questions about the meaning of life, the nature of suffering, the role of God and divine purpose, difference and community, and understandings of individual rights and justice. Religion and faith shape personal and communal identity, help people to find meaning and purpose regarding core life questions, express understanding of the sacred/divine, and guide ethical practice. Religious traditions and faiths can sustain people in times of crisis, through belief systems, practice, and a wide variety of supports and services within one's religious community (church, synagogue, mosque, etc.). As already stated, these can effect change, both for good and ill.

Religions can support a wide range of beliefs and practices in societies and cultures. This is an area of emerging research in both religious and secular disciplines—for example, strategies shaping inclusive/accessible faith communities or understandings of how faith and religion affect attitudes and coping skills within families and people with disabilities. There is a growing impact of the disability rights movements on religious understandings and practice. This relationship illustrates how disability may not have played an obvious role in its early development of central beliefs, practices, or sacred texts of most religious communities, yet core beliefs and practices (or first principles) can be used to address these issues. Two further areas of research/study arise. First, scholars and practitioners can reexamine religious texts and traditions via social, cultural, and rights understandings of disability, helping shape new appreciation of disability in tradition. Second, disability stories/experience can shape belief and revised practice within a given religious community, often in the name of inclusion or acceptance.

CORE RELIGIOUS QUESTIONS

A common thread in religions about disability is the human search for meaning in the world. There are also common questions about life in different faith traditions and similar forms of exploration. Comparative religion scholars approach those in numerous ways. Two basic dimensions have already been noted: belief and practice.

Four questions/dimensions identify the ways religions and faith traditions understand and relate to disability:

1. What is the belief about the source of disability (i.e., why it happened) and the role of God or the divine?
2. How does that understanding of source affect the understanding and identity of a person with disability?
3. What, then, is the role and purpose of the person with disability in society? In other words, “what am I called to do?”
4. What is the role of the community of faith—that is, what are others called to do, out of their faith, toward persons with disabilities?

EXPLORING WHY: DIVINE ROLE AND PURPOSE

All religious traditions struggle with asking and answering the question “Why?” regarding suffering, death, and difference/deviation. The answer is usually in terms of divine origin (God caused it or sent it) and/or personal responsibility (my fault or someone else’s). Given that most faith traditions envision the divine in charge of events in life and mostly have understood disability as misfortune, a central thread in many faith traditions is that disability is a sign of punishment, moral deviance, or some kind of fallen state.

Thus, in Christian traditions, a disability such as epilepsy might be seen as demonic, or the control of an evil spirit, as in the story of the Gerasene demoniac in the Gospel of Mark. In Judaism, the exclusion of some forms of disability from religious practice or community has often been quickly interpreted as a sign of divine disfavor or as the result of punishment or sin (“The sins of the parents are visited upon the children. . . .”). In Islam, disability has been interpreted as a misfortune sent by Allah or as a challenge to the individual and his or her faith. In Hinduism and Buddhism, disability has been interpreted as something fearful, a punishment for a misdeed in a former life, or one’s karma. People with disabilities and families across many faith traditions can recount stories of the ways that blame, fault, or sin has been ascribed to them by others, with the added weight of God’s will and punishment.

Disability has also been portrayed as a sign of evil or fallen state, with its absence portrayed as a sign of healing or of paradise. Thus, people with disabilities struggle with common understandings of the healings by Jesus in which their disability is cured, or their capacity for healing is equated with the depth of their faith. In Zoroasterism, there was a core vision of a perfect world in which there was no disability or death, a vision with similarities in heaven in other religions. The contrast of a perfect, disability/disease/suffering-free society is central to the founding story of Buddhism, where the young Buddha, raised in a world free of suffering, encounters it for the first time as he moves out of the castle into the world. His life, and the world’s, is forever changed.

But there are also interpretations within major faith traditions that see disability as more neutral, as a challenge to the individual and his or her soul. Going further, in Judaism, Christianity, and Islam, there is a strong belief in the sacredness of every life, and in Eastern religions, there is more focus on the importance of the connection of the individual to the community and the whole of creation. A famous text in the New Testament (John 9) disconnects the equation of disability with sin when the disciples ask Jesus why a man was born blind. The disciples asked whether it was the fault of the blind man or his parents. Jesus' response was, "Neither . . . he was born blind so that God's works might be revealed in him." That captures an understanding of the role of people with disabilities in wider society, in which religious traditions see the disability as an opportunity to teach lessons to others. In Buddhism, the question is not whether God caused the disability but how one's mindfulness and spiritual discipline might shape one's response.

The importance of historical, exegetical, and theological research in this area is shown by the ways that popular religious understandings equating disability with sin or punishment by God are in fact challenged by a more disciplined exploration of religious texts. Religious credence has often blessed or enshrined social attitudes, even perpetuating rather than challenging them. Yet careful research begins to note, for example, that Jewish understandings of disability did not equate it with deviance. Disabled people continued to be part of the community. The blind Levite could not be a priest because one of the functions of a priest was to examine sacrifices for the lack of blemish. A disability did not keep a person from being a major religious leader (e.g., Moses and his speech defect, Jacob and his limp, and Paul and his "thorn in the flesh"). Religious leaders in many traditions have been blind or had other disabilities that were thought to imbue them with special vision and insight. A careful exploration of the understandings of disability as karma can reframe that understanding of disability as punishment for a sin in a former life to a belief that, in a former life, one might have mistreated a person with a disability or been guilty of pride or arrogance, and thus this current disability is a time for rehabilitation, a necessary corrective stage in the journey of one's soul.

Largely nondisabled accounts of divine purpose regarding suffering led to understandings of disability as punishment or evil when the divine is understood as all powerful or in battle with other gods (demonic) or when disability is interpreted only as misfortune and suffering. In more recent times, as science and other disciplines have shaped new religious understanding, religious leaders such as Rabbi Harold Kushner (also a parent of a child with a disability) have questioned whether God is all-powerful. Disability begins to be understood in terms of physical origins, just like other conditions and differences. Other religious traditions and understandings have claimed the "specialness" of people with disabilities in divine creation. Whether that comes out as "angels unaware" or "inspiring example," it is the opposite end of the spectrum of religious interpretation of misfortune as either evidence of bad/evil or good/blessing. Some theologians have also begun to explore the question of how disability relates to our understanding of the divine (e.g., Eiesland 1994).

DISABILITY AND IDENTITY: RELIGIOUS DIMENSIONS

The spectrum from "evil/demonic" to "good/special" also reflects disability as a major characteristic shaping and defining personal identity. Disability is defect, and thus the person is defective. The individual or family becomes the bearer of whatever religious interpretation is placed on the disability, ranging from demonic, curse, and punishment to special and holy. Disability is the fault of the individual/family, the fault of a former incarnation, or God's will/design. Disability thus controls and is a person's identity, rather than being just one of many characteristics. Thus, people with disabilities were seen within religious traditions as they were within society, as "the blind," "the lame," "the possessed," the "idiot," "the deaf," and so on.

Social and religious identities and roles are thus intertwined. Evil and thus shunned or avoided, people with disabilities were often scapegoats for religious questions and social worries. Social and economic factors combine with negative attitudes to create structural disadvantage. In some societies, that led to the religiously sanctioned practices of killing infants with severe disabilities. In others, identity meant a life as "beggar," with the expected religious custom and behavior of supporting those who were weak, a feature in Judaism, Christianity, Islam, and Eastern religions.

The opposite is also true when identity was seen as "special" or "holy." Those traditions ranged from practices of having people with disabilities as jesters in courts, or collected by royalty for entertainment, to beliefs that a person with a disability may have a special ability and capacity to reveal the divine. As will be noted later, in some Eastern religious and cultural traditions, people with various disabilities were expected to develop particular gifts, such as becoming musicians or storytellers. In the Christian tradition, the "deaf" shall in fact "hear," the "blind" see, and "last" be "first."

In contrast to an either/or spectrum of identity, many religions also affirm the value of each person. In Judaism, all humans are a disclosure of the divine, each created "in the image of God." All life has value. All life is a gift. All life has strengths and weaknesses. Christianity is full of stories of Jesus recognizing and affirming the humanity of each person and using the gift of healing not only to remove a disability but also to overcome projections of sin and punishment and restore a person to the community. In Islam, all creation is to be honored. Allah's measure of worth for a person does not depend on physical attributes or achievement but on spiritual maturity and development. Thus, for example, Islam was one of the first faiths to see deaf sign language as valid social and religious communication.

Hence, in all major faiths, there are affirmations of the worth and value of each person. However, evidence of disablism, as well as an illustration of the way that religious attitudes both shape and are shaped by social attitudes and understanding, is found when the language and terms of disability are used as metaphorical descriptions of defective faith and character. For example, in the Qur'an, people could be deaf to the law of Allah or blind to the true path. Lack of faith could be described in terms of disability, and disability was then seen and interpreted as a lack of faith or evidence of wrongdoing. There are many forms of diminishment found in disability labels, with their negative meanings to describe "nondisabled" people whose faith or practice was considered inadequate, wrong, or defective. Yet the ways that people with disabilities have been treated by religious people, communities, or societies can also be used as examples and metaphors of faith that is righteous and just.

As disability is increasingly seen as one part of a person, with difference an expression of human diversity rather than disease, there are new frameworks from which to explore the religious understandings of the giftedness, value, limitations, vulnerabilities, and call of every person and community.

A CALL? THE ROLE AND PURPOSE OF DISABILITY

The purpose of life is a central theme in all faith traditions, with wide variation. For some, it is to follow an individual call, to be a disciple in the Christian tradition, to continue learning in Jewish circles, to keep seeking truth in Islam, to move toward mindfulness and understanding in Buddhism, and so on. The sense of vocation, or following the purpose of one's life, has been much proscribed for people with disabilities by others. Thus, one might ask, was the role for people with disabilities often that of beggar because of their disabilities—that is, was that the only thing they were allowed to do? Or, conversely, we might wonder how social conditions and poverty contribute to disability over time, as they do today, and thus prescribe roles from another direction. This is one area where the social and contextual understandings of disability need profound study and reflection in faith traditions.

Many faith traditions also have affirmed that people with disabilities face the same obligation to obey the divine and practice their beliefs as anyone else, with considerations taken for their disabilities. In Judaism, the person with a disability was obliged to observe the Sabbath and, if a man, could be counted in the minyan for a worshipping community. People with disabilities could not be priests, but in Leviticus, only Levites could be priests, and Levites with disabilities could still eat the food in the temple. In many faiths, rites of passage could be adapted for people with various forms of disability. A fascinating debate in early Islam was about whether people with intellectual disabilities could inherit family resources. That gave rise to some of the first guardianship provisions, as well as a debate that said to take away a right to inherit and the right to make a mistake like anyone else was worse than losing a family fortune.

In Islam, if one could not make a living because of a disability, then one could appeal to Allah and the community for justice, not necessarily charity, because if Allah deprived one of the ability to earn, then it was the duty of everyone to give that person his or her due. People with disabilities were exempt from military service but could serve if they wanted. There was no blame for the lame or blind if they could not participate in other duties, but everyone should still respond to the call of God as much as they can. A Christian understanding of people with intellectual disabilities as "holy innocents" often exempted them from any responsibility and thus denied them a capacity to learn.

In Far Eastern traditions, such as Daoism, there are parallel understandings of the potential "special" role of people with disabilities but also philosophical and religious understandings that "uselessness" could have its own merits. The useless could outsmart the "useful," who tend to get used up (e.g., by being killed in wars). There are parallels here in Christian theology that reflect on the power of the "powerless." There are also Japanese traditions of guilds of professional musicians and storytellers who are all blind.

In every major faith tradition, there are stories of religious leaders with disabilities. We can legitimately ask whether that "holiness" is ascribed to them because of their "difference," such as how they learned how to deal with their situation and/or whether it was a function of living on the boundary between ordinary, divine, and/or demonic worlds. There are also stories, with many different interpretations, about key religious leaders being challenged by a person with a disability, including the famous story of Muhammad being rebuffed for turning away a blind man, Jesus being called to task by people with disabilities, the young Buddha being profoundly changed by death and disease, and more. Yet in most traditions, disability is an impediment to pursuing religious vocation (e.g., admission to a monastic order, seminary, or Holy Orders). This, again, is an area of great change, as people with disabilities seek to break out of confining expectations and disabling environments. As religions seek more valued social roles and callings for everyone, perhaps we also will recover traditions from the past in which every person was expected or had to work simply because families and communities could not afford for anyone to be idle. Religions may now help individuals and societies to reevaluate the vocation or calling of a person with disability.

DISABILITY AND COMMUNITY RESPONSIBILITY

All of the major faith traditions call for people to practice faith in relationship with others, calling for people to be compassionate to others in pain, suffering, or want. In Christianity and Judaism, it is called the Golden Rule. In Islam, charitable acts were not to be done out of pity but as a gesture of seeking good will from Allah and, as noted, establishing justice by giving people their due. Like Judaism, most faith traditions have equivalent injunctions to the commands that others should not put stumbling blocks in the way of the blind, make gestures at them that they cannot see, or curse the deaf. One was not to mock or obstruct people with disabilities. Even if they did not know, God saw. These acts of charity, many of which formed the basis for social support agencies of all kinds throughout the centuries and certainly in modern times, are just as much a part of religious traditions as are the stories and examples of religious shunning of people with various forms of disability because of assumptions about sinfulness and punishment.

At another level, religious faiths have often used the treatment of people with disabilities, along with the treatment of the "weak," "poor," and "widows and orphans," as a measure of the righteousness and character of the society. Jewish prophets, Islamic scholars and leaders, and Christian ministers and leaders have all suggested that society is to be judged by, or will succeed only through, the ways it treats the "least of these." This has led in the past century to new forms of religious advocacy, service, and explorations of the ways that faith and religious communities have a responsibility not just to care for but to include people with disabilities and their families.

In many places in the world, the religious call to charity or service is the major foundation for social services and supports for people with disabilities. In others (sometimes the same places), modern understandings of the abilities and rights of people with disabilities are at odds with confining religious/social attitudes. And in others, people with disabilities and their families are challenging a system of services and supports based on a charity model, whether it comes from a "religious" or "secular" source. A major challenge exists in many Western countries, where governments may use charities auspiced by religious traditions to deliver welfare, sometimes requiring service practices that can marginalize clients.

A BRIEF HISTORICAL OVERVIEW

The examples cited in this discussion of four dimensions of religions and disability emerge from recent research into the historical intersections between religion and disability. Yet the narration and findings of that history depend in measure on what one looks for, in terms of both positive and negative outcomes for people with disabilities and their families. Researchers are beginning to uncover and reexamine old stories and long-held assumptions, and they are finding ways to overcome the fact that disability is not often a major theme in any religious creed, system, or scripture.

Recent scholarship points to ancient rulers in Eastern traditions whose religion and faith led them to develop disability supports and service. Early Islam was one of the first traditions to recognize the rights of people with disabilities, such as the deaf, and develop services for people with mental illness. Christian hostels formed early community services for people with disabilities and were often connected in medieval Europe to the village or town cathedral. Jewish scholars and traditions explored “functional” definitions of disability long before it became a modern practice.

In the past century and a half, in North America and Europe and elsewhere, religious communities have often been the impetus for new services and supports, even if they were gradually taken over by public or secular professions and services. Since the 1950s, there has been growing attention to the intersection of religion and disability, as religions developed special religious education programs for children with disabilities, formed “deaf ministries” networks, and began to work on making religious buildings more accessible and religious communities more inclusive. Leaders such as Helen Keller in the area of blindness, Dorothea Dix in mental illness, and Harold Wilke in physical disabilities, along with Jean Vanier and L’Arche communities in mental retardation and intellectual disabilities, have changed both religious understandings of disability and spawned countless new practices and services. Since the International Year of Disabled People in 1981, most major faith traditions have developed and disseminated position papers and statements on faith and disability, such as the Roman Catholics Bishop’s Pastoral of 1979 or the World Council of Churches statement of 2003.

In more recent developments, there have been partnerships such as the Accessible Congregations Campaign in the United States, coordinated between secular and religious support organizations. Christian and Jewish groups have developed strategies for accommodating religious education, worship practices, and rites of passage to include children and adults with any form of disability. There has been an explosion of written resources for Christian and Jewish networks, as well as the beginnings of scientific research into the power and impact of spirituality and spiritual supports for people with disabilities and their families. One example is the national *Space to Listen* research project by the Foundation for Learning Disabilities in the United Kingdom, which explores the role of spirituality in the lives of people with intellectual disabilities. The *Journal of Religion in Disability and Rehabilitation* has developed into the *Journal of Religion, Disability, and Health.* Theologians and practitioners are exploring ways to include disability in theological education and to affirm the right of people with disabilities to be in training for religious roles.

While admittedly Western in focus, this brief overview points to the huge need for further cross-cultural understanding and research. Some positive developments highlighted are not meant to hide the ways in which faith traditions and practice still often oppress people with disabilities and their families. There are huge questions, such as why religious traditions and communities have often been at the forefront of leadership in civil and human rights in North America but not so connected to the disability rights movement.

It is clear that the intersection of religion and disability:

occurs at many different levels and dimensions, from scholar through the intense believer to the public stereotypes of both religion and disability;

includes many voices, backgrounds, and perspectives—disabled and nondisabled—and a huge diversity of religious understandings; and

affects many areas of "religious" life, such as worship, theology, ritual, ethics, understandings of tradition and history, and reexamination of sacred text, all with implications for individual and community responsibility and practice.

This complexity and diversity has vast room for research and dialogue, the potential for all kinds of misunderstanding and oversimplification, and the possibility of building new bridges of understanding between people with and without disabilities, theoreticians and practitioners from many disciplines, and followers of many different faiths.

—Bill Gaventa and
Christopher Newell

See also Developing World; Judaism; Middle East and the Rise of Islam; Representations of Disability, History of.

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REPETITIVE STRAIN INJURIES

Repetitive strain injuries (*RSIs*), *cumulative trauma disorders, repetitive motion injuries,* and *work-related musculoskeletal disorders* are synonymous terms describing a broad range of injuries resulting from excessive use of the spine, arm, hand, leg, or foot. In 1999, these injuries constituted 9 percent of the injuries in U.S. private industry that resulted in lost workdays. Wrist and hand problems accounted for the majority of the injuries and were the most costly and the most disabling. Some health care systems no longer accept a categorical diagnosis of RSI and insist on more specific diagnoses (e.g., tendonitis, neuritis, fascitis, myositis, carpal tunnel syndrome, thoracic outlet syndrome, cubital tunnel syndrome, degenerative arthritis, tendinosis, fibromyalgia, herniated disk, focal hand dystonia, neuropathic pain).

Healthy tissues constantly turn over, repair, and remodel, a maintenance function that requires good hydration, nutrition, and balanced loading and rest. Normally, structural tissue damage postinjury activates a cellular cascade to mediate the inflammation and initiate repair. However, in patients with chronic repetitive strain injuries, cumulative loading can lead to reduced perfusion (blood supply), poor axonal transport of peripheral nerves and excessive tissue inflammation, scarring, cell compression, matrix degeneration, muscle fiber loss, and cell death. This can lead to tissue discontinuity, biomechanical irritation, pain, and change in the type and organization of the collagen in tendons and ligaments that alters strength, compliance, and flexibility. Thus, some individuals with RSIs can develop severe pain (with or without inflammation), others lose strength and endurance, and still others experience excessive fatigue, poor sensorimotor feedback, and painless loss of fine motor control, specifically at the work task (focal hand dystonia).

Repetitive microtrauma is usually classified by stage:

Stage 1 = injury, probably inflammatory without pathological alterations

Stage 2 = injury associated with pathological alterations

Stage 3 = injury associated with structural failure (rupture)

Stage 4 = injury meets criteria for stages 2 and 3 plus other changes, such as osseous calcification

This classification system focuses on the soft tissue response to injury without consideration of secondary, aberrant central nervous system degradation. Risk factors for RSI include occupation (e.g., heavy, stressful schedules of repetitive hand use that demand high levels of accuracy and progressive task difficulty), biomechanics (e.g., end range, forceful movements), patterns of use (e.g., rapid, stereotypical, near simultaneous, alternating movements), personal health (e.g., prior injury, disease status, hydration, fitness), psychosocial issues (e.g., emotional state, personality, perfectionism, anxiety, family support), and administrative factors (health care coverage, disability benefits, legal issues). These factors can affect the incidence of injury, the extent of the impairment, the potential for recovery, and the magnitude of disability.

Treatment initially includes rest from work, rest of the part, and anti-inflammatory medications. Ideally, intervention should also address prevention, including ergonomic modifications, decreased forceful repetition, aerobic and postural exercises, good hydration, and nutrition. If disabling signs and symptoms persist, intervention must factor in the stage of tissue pathology, the extent of tissue damage, the status of change in cortical function, and whether surgery, medications, therapeutic modalities, assistive devices, and/or therapeutic exercises, including learning-based sensorimotor training, are essential to recovery.

—Nancy Byl

See also Fibromyalgia; Spinal Cord Injury.

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MouseKeyDo, http://mousekeydo.com

REPRESENTATIONS OF DISABILITY, HISTORY OF

Patterns of the historical representation of disability in literary, artistic, and visual media cannot be generalized. This is due to the fact that while all cultures have wrestled with the meaning and nature of disability, social responses themselves vary greatly across time, region, cultures, and situations. Nevertheless, a survey of disability representations demonstrates the degree to which human differences pose substantial conflicts for all communities. Thus, representational art has always grappled with such conflicts, and these documented efforts create a significant historical discourse about disabled people.

Here, we define representation as the efforts of cultural workers to speak on behalf of an individual or group in artistic arenas. While one may argue that images of disability in any textual or visual arena are equally imaginative, we are primarily interested in the specific productions of disability in genres identified as "creative." Representation suggests an effort to imagine perspectives difficult to come by in our everyday lives. In part, this places an ethical demand on art to conjure the lives of those significantly distant from a reader's own experience. The historical sequestration of disabled persons makes them a common representational objective in that artists employ the uniqueness of such perspectives as an impetus for generating audience interest. For instance, in the Greek play *Philoctetes,* the abandonment of the disabled title character on an island because he is inconvenient and "un-useful" ultimately makes it necessary for his fellow warriers to return to retrieve him. Besides recognizing that Philoctetes holds Heracles's bow as a weapon, which could ensure victory in war, his literal absence also causes significant interest as to how he has lived and what wreckage on his psyche the impairment (a painful, festering wound) has caused. His abandonment results in the necessity of a return to the society that originally rejected his body, as if his removal ultimately comes full circle back to our interest in what has become of him. Since representation produces one thing that stands for another, the drama of Philoctetes's rejection ultimately becomes an opportunity to contemplate social tolerance toward difference. Therefore, disability's common ouster from social contexts ironically results in ritualistic returns in imaginative texts. One is tempted to draw a mathematical formula of inverse relations: the degree to which an experience appears absent from social life determines the degree of interest lavished on that object in artistic discourses.

Consequently, while many minority groups have argued that social marginalization occurs, in part, as a result of the absence of their images in artistic discourses, images of disabled people suggest a different representational fate. Their social marginality has occurred despite widespread circulation. In fact, the presence of disability, as allegory, motif, and social cause, can be said to serve as a critical component of a further silencing by representation that disabled persons may experience. In contemporary life, this circulation may be due to the mysteries that attend to bodies that have been hidden away for their lack of propriety. Whether for the sake of charitable act, freak show shock, indication of mysteries, evidence of suffering, or body difficulty that requires social attention to research and prevent it, representations of disability have remained central to acts of cultural production. Until recently, with the generation of a collective discourse concerning disability representation, this circulation of disability imagery has been little discussed by critics, historians, and cultural commentators. Recently, open interpretation of the disability implications of artistic discourses has occurred as an educational and research priority that accompanies deinstitutionalization and human rights initiatives on behalf of disabled persons. Still, representational critique refers us back to a lack of social consensus as to whether access and inclusion, as opposed to cure or sequestration, are the best goals to be held out for disabled persons.

Disability persists as a perpetual topic of commentary (particularly in representational mediums) due to a variety of historical developments:

1. Disability has largely been consigned to the domain of medicine as a matter of individual dysfunction or insufficiency.
2. Stories about disability often conclude with solutions that result in the erasure of impairments either through death or cure.
3. The alleviation of disability in our cultural narratives ultimately asks nothing of the wider society in terms of accommodation, political action, or social recognition.
4. Stories about disability have often featured a single individual existing without reference to a larger population of like-minded/embodied individuals.

While exceptions to these four general patterns of plot certainly exist, as narrative winds its way toward surprise, suspense, and satisfactions for the recipient, the list helps to explain the reasons why disability may be overlooked as a significant mode of characterization or metaphor in literary critical history.

Throughout the scant written records of ancient civilizations such as those from the regions of ancient Mesopotamia and Greece, one encounters the mark of disability as commonly relating to a metaphysical predicament. This fact alone suggests that the appearance of characteristics deemed highly distinctive, while presumed largely detrimental by other social residents, occurs with some frequency. Within the texts of these ancient societies, disability is often treated either as a punishment visited upon individuals and communities for the sins of the past or, at least, in a purely symbolic way as a message from the gods that must be interpreted. In either situation, disability references the mysterious ways of divinities and their unpredictable plans for human communities. At the epistemological level, ancient civilizations often treated disability as if it represented an encoded missive from a vaguely discernible extraterrestrial order—one that demands recognition of its symbolic significance and an appropriate response from the community at large.

Thus, we witness the existence of early prophetic texts, such as cuneiform tablets or oracles that predict future outcomes as encoded by the bodies of aborted fetuses and babies with birth disabilities. For instance, ancient Mesopotamian texts interpret human and animal "deviancies," disabled fetuses and demarcations in sacrificial herd animals, as a sign that something serious is in store for the recipient culture. These references by anatomical difference do not necessarily predict negative events—in some cases, predications about organic differences remark on lengthy regimes for a ruler or a favorable harvest. Yet, more often than not, metaphysical readings prompt visions of cultural catastrophe. Characteristics considered deviations from societal norms rarely refer to individual fates in these early texts. Instead, an entire community or society will be implicated by the meaning derived from a single anatomy. Thus, the arrival of visibly disabled offspring must have precipitated significant anxieties among leaders and citizens alike. Reported practices of the infanticide of "deformed" or "unhearty" children help to solidify this interpretation.

In classical Greek literature, perhaps the first extensive repertoire of disability texts available for scrutiny, we meet up with well-known characters such as the blind and hermaphroditic prophet Tiresias, the ensnared and cane-walking hero Oedipus, the untimely wounded Philoctetes, and the one-eyed gigantic Cyclops representing wholly other physical castes of tribes—among many others—whose bodily differences signify the need for their location on the periphery of various communities. Yet, whereas prophetic texts contended a direct correspondence between disability and social fate, these texts offer up reflexive contemplations of the question. While many narratives eventually justify exclusion based on human differences or presume a naturalized segregation of communities, there are numerous instances where social exile is shown up as an insufficient solution.

In much Greek literature, disabilities function as a sign of a character's "tragic flaw" or "compensatory insight." Tiresias's blindness provides him with an uncanny ability to predict the future and provide sagely commentary on a range of social conflicts; Oedipus's limp (a result of his father, Laius's, efforts to pin his ankles and leave him to die of exposure on a hillside) allows him to draw from his experiences of disability to solve the riddle of the sphinx (an anomalous hybrid figure in her own right); as discussed earlier, Philoctetes's agony from an untreatable wound prompts his fellow soldiers to abandon him on an island; and Cyclops's monstrosity is emphasized by physical characteristics that mark him both as racially foreign and less intellectually agile than his wily captives. Each of these stories turns on revelations drawn directly from the specific disability of each character. Thus, it can be said that Greek literature helps to initiate the long-standing historical reliance of literary characterizations upon disability as a means to differentiate heroes or villains from their less distinguishable (and thus often less storied) literary peers. For instance, the cycle of plays about Oedipus (translated from the Greek as "swollen foot") seems to hurdle toward the revelation that his limp marks him as an ill-fated agent. In other words, the meaning-laden significance of disability must be recognized for its social layering, its predictive consequences, and its psychological, albeit angst-ridden, complexity.

Whereas one finds key literary characters accompanied by disabilities in ancient literature, early Christian and Islamic sources adopt disability as either a strict marker of exclusion or as a generic characteristic of denigrated populations. The Hebrew Bible, for instance, tells the story of Jacob's struggle with his faith (represented as a "stranger" at the river) that results in a permanent disability from severe hip dislocation; Leviticus defines priestly purity primarily through the absence of disability as a source of potential contamination; Tobit's blindness allows him to be duped and then is "cured" by God as a reward for his daughter's loyalty; and Mephiboseth's childhood accident leaves him with a mobility impairment that both disqualifies him from his rightful claim to the kingship and provides him with an all-purpose excuse for his various shortcomings. There is little questioning or interrogation in the Old Testament regarding the way disabled persons should be addressed. Commentators struggle over translations that only continue to certify a naturalized derogatory meaning such as that King David is said to hate the blind and lame and therefore desired their eradication en route to conquering Jerusalem.

In contrast to this narrative tradition, the New Testament seems to offer a more rewarding series of scenarios. Cripples, deaf-mutes, the blind, and epileptic individuals show up with some regularity in these stories—particularly at key moments when the prophetic powers of Christ or his disciples prove in need of exhibition. Still a largely mass phenomenon, disabilities arrive as the characteristics of hordes of unfortunates, as if human vulnerability equates with the imperfection of an earth-bound existence. One finds some of the first lineups of disabled people as supplicants in these stories as an opportunity to demonstrate divine capacities exercised upon human imperfections. This foregrounding of misery through suffering embodiment situates early religious texts at the origins of a lengthy tradition of disability representation. Many biblical scholars have championed the cure of cripples in the New Testament as a historical transition of acceptance toward destitute populations. Furthermore, some scholars have argued that the flayed and broken body of Christ indicates an early form of social integration toward imperfection and suffering on Earth.

However, a paradox of the cure scenario, so often repeated in New Testament writings, turns upon the erasure of disabilities. An alternative tradition of argumentation has begun to take shape around interpretations of miracle cures as the obliteration of human differences rather than as justification for integration or social acceptance. At the very least, the parallel of divinity with the remedy of dysfunction, incapacity, or aesthetic deviation makes little demand on action at the level of wider social networks. Short of existing in a moment populated by a magical healer (the figure of Jesus Christ as one of the first rehabilitation specialists), disabled people (one might suppose) whose differences cannot be erased would find their integration hardpressed at best. Later Christian works, such as those contained in St. Augustine's *City of God* or the stories of St. Francis of Assisi kissing a leper, provide examples of piety demonstrated by the efforts of religious figures to eschew their worldly possessions and live among the downtrodden. A conspicuously promulgated morality exists in decisions to take up an intimacy with those excluded on the basis of fears of contagion, aberrancy, and social transgression.

Meaningful alternatives to these Western traditions of disability representation can be identified among traditions in the Middle East, Asia, and Africa, where disabled people can be found performing important social functions. Such productive representations of disabled people's contributions can be found in works such as "The Meadows of Gold" by Al-Ma'sudi (c. 896–956 CE), which tells a tale of a deaf person thought most worthy to represent the inhabitants of Kufa to the Caliph and also includes discussions about Abu al-Ayna, a blind person of great wit. In addition, the biographies of several prominent deaf, blind, and physically disabled people are detailed by the thirteenth-century Muslim writer Ibn Khallikhan in his biographical dictionary. Such biographies of exceptional persons include a learned blind man in Basra named Katada Ibn Di`ama As-Sadusi (679–735/6); Abu'l-Aswad ad-Duwali, who limped in public and experienced seizures from "palsy" (d. 688/9); renowned deaf teacher Abu'l-Abbas Muhammad Ibn Yakub al-Asamm (d. 957); Muhammed Ibn Sirin (653/4–729), the deaf law lecturer who also wrote one of the early translations of the life of the prophet Muhammed; poet Dibil Ibn Ali-l-Khuzai, who was reportedly deaf and hunchbacked from a "scrofulous swelling on the back"; and Abu 'l-Abbas Ahmad Ibn Yahya Ibn Zaid Ibn Saiyar (also known as Thalab the Grammarian), who became deaf but continued as an influential scholar in Baghdad. In addition, we might also look to the *Semimaru* (Plays of the No Theater) in Japan, written by Zeami during the twelfth century. These plays feature the exploits of a blind *biwa* player who lived on Mt. Osaka and was sentenced to death because of his visual impairment by his father, Emperor Daigo. Zeami's renown as a musician caused the son of prince Minamoto Hakuga to make a long, difficult trip just to hear him play.

In various Asian locales, there exists a long tradition of cultivating the talents of people with sensory disabilities in one particular skill such as music or massage. Far fewer examples of similar investments in those with cognitive or physical disabilities exist. However, a few examples of recuperated meanings around historical individuals with physical disabilities may be found. If we research back to ancient Egypt, King Amenemope, the fourth ruler of the twenty-first dynasty who ruled a substantial kingdom from 993 to 984 BCE, is reported to have had a series of visible physical differences identified in the many statues of him left behind such as an elongated head, large ears, distended stomach, and wide hips. Similarly, we might also reference the later example of the African Oba of Benin (1500–1597), who, upon experiencing lower limb paralysis, claimed that his legs had been transformed into the sacred mudfish. Since mudfish can navigate land on their legs and swim in water, they served as a symbol of the king's capacity to move between earthly and spiritual realms. Such an inversion of the meaning of disability saved this oba from the fate of his predecessors, who were often executed after falling ill. While such examples suggest individuals with disabilities of exceptional talents, they may also gesture toward the possibility of a more inclusive cultural moment in which disability did not automatically disqualify one from participation.

Of course, as in any tradition, one can also find evidence of more dehumanizing treatments toward people with disabilities. For instance, in eleventh-century Persia, instructional manuals for princes published by Kai Kaus ibn Iskander ibn Quabus (1082/3) inaccurately argued the following: "all dumb (i.e., mute) people are deaf" because they lack access to oral speech. In the wake of such beliefs, reports exist that Emperor Akbar undertook some early experimentation on disability by raising groups of children with deaf-mute nurses in a locked house. In addition, there exist many reports from European travel writers that the Ottoman court employed dozens of deaf-mute individuals as reliable servants to various rulers. Their valued capacities included beliefs that the impairments of these individuals rendered them incapable of hearing or bearing witness to the behind-the-scenes escapades of those in power. In these instances, incapacity becomes an ironic "value" while also overlooking the fact that sign languages served as an equally powerful means of communication among presumably incommunicative subjects.

Other than these brief references to the role of disabled people in various rulers' dominions, disability in the Middle Ages becomes increasingly sidelined as an expression of human difference. One finds some early treatment texts on devastating plagues such as those on leprosy and compound fractures of the skull. The sudden diminishment of disability as a common representational device (if this can be said to be the case) may be interpreted in a number of ways. This noticeable dearth of representations signals a new and perhaps even more pronounced disregard of disabled people. One gets the feeling that late Christian texts in this period, such as St. Francis's devotion to communities of people with leprosy as well as the practice of other religious figures renouncing material goods while taking up residence with the poor and incapacitated, play out efforts to combat this widespread neglect. Likewise, we could look to *The Book of Margery Kempe* (1430) for an example of a medieval woman's guild of the Holy Trinity that devotes itself to the care of convalescing disabled women. Such examples, as some scholars have argued, may represent shifting values about human embodiment and a new devotion to those most vulnerable to the violence of social rejection. Disabled and poor people become enshrined during this period as a population that some refuse to reject as deviant or unworthy of human care.

Yet, we might also consider the degree to which devotions paid to socially marginalized peoples provide a moral opportunity in this period to ensure one's own right to salvation in an afterlife. In other words, devotion to the "less fortunate" becomes a powerful system of exchange in this period, wherein one commits oneself to support of these communities as a way of guaranteeing outward signs of divine "election." We could celebrate these examples of religiously derived support to those who are often violently excluded during this period, without having to relinquish analyses of the social benefits that accrue to those who practice benevolent devotions.

Another possibility is that we might comprehend the fading significance of representations of disability during this period as a product of rampant social crises in the transmission of diseases. If much of Europe, for instance, found itself exposed to the ravages of various plagues, then a deepening sense of human vulnerability might have developed. Disabled people have often held down the terms of a radical frailty that others find threatening. Efforts to distance ourselves from disability often expose the degree to which we fail to acknowledge our own potential exposure to various human-made and natural forces. Perhaps one could locate this period as an example of a time when many people felt as if their mortality and/or functionality could be easily compromised, and thus the ability to distance oneself from the vagaries of human embodiment undermined a more explicit division across bodies. Perhaps the degree to which one could afford to recognize disability as a chasm between ourselves and others collapsed during the period, resulting in a failure of common othering strategies determined by investments in bodies and minds as a reliable partition between the vulnerable and invulnerable. We might also look to later texts such as St. Augustine's *City of God* (1467) for its efforts to challenge common beliefs in "monstrosity" as somehow outside of a divine plan of the universe of human embodiment.

However, somewhere between the fourteenth and sixteenth centuries, one starts to witness a desacralization of disability. While various religious systems continued to recognize disabled bodies as an object of charitable investments (massive charity networks developed just prior to this period), a corresponding secularization of disability begins to develop. Although earlier examples of state- and community-sponsored supports exist—such as the monetary provisions to disabled persons identified in the Athenian Constitution of ancient Greece—European legislation of various kinds becomes increasingly numerous. Most of these policies served as early "diagnostic" efforts to divide the "deserving" from the "undeserving" poor. This division would prove key in most Western locations, in that productive capacity to labor became increasingly critical to the definitions of citizenship in the modern nation. Accompanying the rise of urban trading centers and the decline of feudalism as a dominant economic system, cities and towns passed numerous ordinances to punish idleness and the practice of alms seeking. In the English Statute of Laborers, approved in 1349, imprisonment was used as an incentive to compel most citizens into "labor[ing] for their necessary living." While this early legislation identifies a vague group of social misfits based on unwillingness to labor, later legislation deepens this division based on the status of "cripples" as a material inability to work. In addition, such legislation suggests at least the suspicion of an outbreak of crippled pretenders—those who would feign disability to pursue begging as a viable career option to other socially recognized forms of labor. Later, around the year 1697, these English laws were further amended to require that those who were legitimately "on relief" had to wear a badge or mark (such as a large "Roman P") visible to all on their clothing. Such badging efforts were portrayed in the pinning of fox tails on disabled beggars, as seen in Pieter Brueghel the Elder's famous painting of "The Cripples" (1568), now hanging in the Louvre in Paris. Similar badging practices were resuscitated in National Socialist Germany during the 1940s toward those targeted on the basis of disability, sexuality, ethnicity, and race. These two systems—charity and labor capacity—continue to compete for interpretive authority for several hundred years; in fact, we could say that they continue to struggle for cultural capital as two primary modes of modern disability response.

From 1500 to 1800, we witness an explosion of works about "fools" and "court jesters" that represent social struggles over the presumably decreased capacities of individuals with cognitive disabilities and deafmutes, as well as the power often bequeathed to these individuals by rulers and other prominent members of ruling regimes. The court fool was ridiculed and scoffed at for these idiosyncrasies and served as a source of entertainment for gatherings at various royal assemblies. Yet, in addition to these prurient practices of human exhibition, celebrated fools also managed to garner a significant degree of power for their roles. Some individuals with cognitive and physical disabilities were thought to communicate in more metaphysical realms such that their "babblings" proved alarmingly insightful. While most participants in a leader's entourage were expected to comply with and support the dictums of their ruler, fools often found some room for maneuver in these circles. They could openly critique and satirize the doings of those in power as if fools provided a mirror to the rulers under whom they served. Such characters proved relatively singular in these instances, but their mockery provided an effective antidote to the arrogance that often developed in ruling circles. The Spanish painter Velasquez captured the function of fools as agents of critique among hierarchies of power when he positioned his jester figure as the lone individual whose stare breaks the plane of the painting and meets the gaze of viewers directly. The figure poses as both amused and knowing—as if he holds secrets that might easily undermine the "pretense" of the aristocratic family in which he serves.

Texts by European travelers to modern-day territories such as Turkey, the Middle East, and northern Africa during the period between 1500 and 1800 all describe the multitudes of disabled populations in attendance at various ruling class ceremonies. Hordes of deaf-mutes, dwarves, dumb men, eunuchs and women of seraglios, and others provide evidence of the degree to which human differences did not exclude one from participation at the highest levels of culture (no matter how hierarchical and diminished such inclusion might prove). One inventory from 1594 of the royal court in Constantinople by the English traveler, John Sanderson, lists the employ of 300 "falconers, dwarfs, and dome [dumb] men" in a workforce of more than 1 million for Sultan Murad III. As in the earlier discussion of deaf-mutes employed as guards who would not expose secrets or private affairs at court, such figures also played a key role in the seraglios. If rulers and other top officials were allowed to practice their sexuality across populations of women, disabled individuals—particularly those rendered sexually impotent as eunuchs—were thought to be ideal sentries who could not fall prey to the enticements of the harem. At the same time, narratives from the 1550s about the reign of Suleiman in Istanbul suggest that a disabled son in line for the throne could be contested on the basis of his physical differences. In addition, the British historian Richard Knolles reported that a group of seven mutes participated in the brutal assassination of the heir-apparent Mustapha during 1553. All of these stories help to establish the expansive roles of disabled people in various court intrigues. Their differences are invested with various meanings in which their distinct capacities—and, most important, incapacities—situate them within unique proximity to antics of power. Yet, it is not until the sixteenth century that we witness the publication of texts that foreground disabled individuals' own designs on power within such settings.

Perhaps, ironically, the first truly "modern" protagonist, William Shakespeare's rendition of Richard III (1591–1592), develops out of the revelation that disabled people inevitably participate in the seductions of power. In what is widely recognized as the beginning of modern literature, Shakespeare's disabled usurper of the throne delves theatergoers into his conscious musings on his status as a disabled person. For instance, his much-performed opening monologue points out the fact that while his "deformities" allow him full participation in wartime scenarios—where, presumably, the ugliness of military clashes eclipse Richard's own physical "distastefulness"—the peacetime that follows provides no viable role for such a figure. Throughout the drama, Richard mobilizes his disability status to his advantage by simultaneously playing on perceptions of his incapacity while also pursuing a violent scheme of retribution toward those he believes have wronged him on the basis of his disabilities. Thus, Richard III inaugurates a cultivated depth of characterization by hosting a character that appears one way but unveils his interior musings as existing in contradiction to his cultivated public demeanor. Disability could be said to have inaugurated a split between public and personal presentation that would continue to characterize representational strategies from this point onward as an inaugural moment in modern literatures.

One also witnesses the rise of the empirical method during this period as the European Enlightenment gets under way. Sir Francis Bacon and others craft a relationship to natural and social worlds that promises to expose the logical underpinning of the universe without reference to an omnipotent consciousness. The system of analysis depends heavily on what Barbara Maria Stafford (1993) refers to as "technologies of the visible." New instruments and "reading" strategies allow investigators to get below the surface and arrive at the essence of an object made newly available for scrutiny. Various taxonomic systems get under way in this period, such as Carl Linnaeus's *Systema Naturae* (1735) cataloguing of plants and animal life into various classifications of belonging—genus and species, flora and fauna. Likewise, human forms came under similar efforts to sort kinds of humanity into their appropriate columns. For instance, Linnaeus also put his efforts to sorting racial types—Americanus, Europeus, Asiaticus, and Afer—into a hierarchy of values based on his own privileging of northern European civilizations as superior to the denizens of more tropical locales. Disabled people's differences prove particularly critical to this venture in that an increasing premium was placed on the meaning of visible differences as a referencing system for otherwise intangible traits of character. In his essay "Of Deformity" (1601), Bacon—perhaps using Shakespeare's Richard III as his universal model—wrote about the unacknowledged "advantage" of deformity among participants in royal courts. Whereas previous literature had largely emptied out the subjectivity of disabled people from designs of power, Bacon invests "deformed persons" with aspirations of their own. As in the Shakespearian drama, Bacon cultivates an early psychological model of disabled subjectivity by arguing that deformity is a spur to individuals who seek to remove themselves from social ridicule. Rather than divest deformed persons of awareness, Bacon turns the tables and argues that their conditions give them an even greater degree of motivation for climbing the royal hierarchy.

By deploying deformity as an external sign of internal (albeit largely malignant) motivation, Bacon help to set off an entire tradition of sciences of the surface—those fields of investigation that rely on surface phenomena (such as facial countenance or bumps on the skull or visible deformities) to interpret otherwise difficult to detect moral qualities. While this practice was not new—some researchers trace the practice of interpreting questions of moral character in facial expressions back to ancient Greece—physiognomic systems came to be increasingly legitimated as "scientific." For instance, in 1778–1779, Johann Kasper Lavater published a highly influential system for reading the truth of one's character in the slope of the forehead, shape of the ears, line of the nose, and lips. Disabled people faired rather poorly in these interpretive systems, in that their "insufficient" bodies were immediately suspect—as if there existed an automatic shorthand available to locating deficiencies of personal integrity in the "obvious" deficiencies of the body, mind, or senses. Such efforts provide us the opportunity to trace out a history of the rise of normalcy, where the identification of the "deviant" body becomes the grounding for an imaginary normative body—one that is symmetrical, fully functional, independent, racialized, gendered, and economically mobile. Significantly, this idealized normal body came to be increasingly identified as a representative of the "healthy" nation.

Ironically, the rise of literary Romanticism positioned itself in contrast to this burgeoning bodily ideal. Rather than tout the efforts of empiricists and states to analyze, govern, and control the unwieldy nature of the body, Romantic writers took scientific efforts at dominion over nature as their antagonists. Wordsworth's "idiot boy" (1798), Coleridge's chronically depressed mariner (1798), Shelley's Frankenstein monster (1818), Hawthorne's blemished femininity (1843), Poe's obsessive narrators and claustrophobic interiors such as "The Fall of the House of Usher" (1839), Byron's hunchbacked protagonist, and Arnold, in his unfinished drama "The Deformed Transformed" (1824), all point to an era of literary production where disability came to be more synonymous with—rather than divergent from—conditions indicative of human vulnerability. Within these works—perhaps one of the richest in Euro-American representational traditions of disability—the nonidealized body becomes a vehicle of resistance and social critique. Thus, we follow Wordsworth's and Coleridge's entrance into sublime experiences of Nature with disabled characters as our guides; the Frankenstein monster's interrogation of his creator's rejection on the basis of his nonnormative appearance and functionality; the exposure of the alchemist, Aylmer, whose efforts to achieve perfection in his spouse through pursuit of a cure erases a birthmark on her face while also killing her; Poe's shifting mental states as undermining investments in static rationality; and Byron's social critique of disability as engendering violent responses from family and neighbors on the basis of solidifying normative expectation to which he cannot conform. All of these texts establish Romanticism as a key critic of normalcy's violent social scheme—that which the African American writer, Toni Morrison (1970:97), calls the most destructive concept in Western traditions—against which literature must resist. It also inaugurates a period where literature imagines science as a primary opposition in its promotion of schemes that often prove socially inflexible.

In fact, in many ways, we might read the alarm registered in Romantic literature toward empirically backed efforts of dominion over Nature as quite prescient. As the eighteenth century gives way to the nineteenth, one finds disability increasingly targeted by various efforts at "training" and institutionalization. In European locales such as France, Britain, the Netherlands, and Germany, as well as in Canada and the United States, the science of eugenics takes shape. Coined by the British statistician, Sir Francis Galton, in 1889 from the Greek word for "good seed," eugenics recognized certain cognitive, physical, and sensory disabilities as a threat to the progress of the nation. Eugenicists argued that, as in the sciences of horticulture and animal husbandry, human communities had the responsibility to oversee and protect their "hereditary stock" through active breeding practices. Such arguments began to establish a lethal cultural atmosphere toward "inferior" peoples of maligned ethnicities, races, sexualities, and particularly people with disabilities who cross all these identity groups. British social commentator Anna Laeticia Barbauld (1825), for instance, would apply rising sentiments of intolerance when she excoriated writers of her day to avoid defacing their work by populating plots with unsavory characters "suffering" from various bodily ailments. Others, such as entrepreneur Phineas Taylor Barnum (1810–1891), sought to capitalize on the prurience of public sentiments of the time through the exhibition of human "oddities" as a form of specular entertainment. His exhibits explicitly sought to exploit people with disabilities in their marketing as extraordinary anomalies, such as individuals of short stature (e.g., Tom Thumb and Lavinia Warren), those of exceptional height or congenitally truncated limbs, and people of color showcased as evidence of Darwin's evolutionary "missing links." In all cases, individuals with and without bodily anomalies performed for viewers through enhancements that emphasized their differences so as to achieve the desired effect—exceptions so extraordinary that they could command large audiences in the context of the freak show.

Freak shows played upon a fascination with human anomalies as their state-sponsored suppression increased. With the advent and later adoption of theories developed by researchers such as the Dutch botanist, Gregor Mendel, regarding the workings of regressive and dominant genes, eugenics sought to apply forms of reproductive control on human communities as well. Edouard Séguin in France, Samuel Howe in the United States, and Arthur Tredgold in Britain all worked to segregate those diagnosed as "idiots" in the mid-nineteenth century. In many respects, these figures participated as social reformers who identified familial and community neglect of people with disabilities as their primary nemesis. Yet, their arguments increasingly culminated in the proliferation of rabid fears in North American and European nations (as well as among various colonial outposts) that the wealth of the country was directly tied to its ability to promote the reproductive participation of those with good heredity while restricting such liberties for individuals recognized as "defective." Thus, as the nineteenth century draws to a close and the twentieth century begins, we find the proliferation of laws intended to actively police bodies. Marriage restriction laws for those who have experience bouts of "insanity," coerced institutional policies that could imprison "feebleminded" individuals against their will, sterilization laws that required those seeking to avoid institutionalization to exchange reproductive rights for their liberty, and, ultimately, Nazi extermination practices developed on the bodies of disabled people in psychiatric institutions all serve to expose the degree to which Romanticism proved accurate in its association of scientifically backed intolerance toward human variation with an upsurge in violent social practices.

Often in contradistinction to eugenic ideologies, leftist literature of the period sometimes held a close identification with disabled people in that their bodies could provide the material proof of inhumane work conditions as industrialization sped on and capitalist-based economic orders proliferated. In *Uncle Tom's Cabin* (1857), Harriet Beecher Stowe would use disability to metaphorize the wreckage of slave labor on the bodies of her African American characters; Karl Marx (1867) would argue that capitalism sought to make bodies expendable through the creation of surplus labor pools, thus exhausting the capacities of those who labored and then discarding "used up" bodies in favor of fresh, able ones; and in the novella, *Life in the Iron Mills* (1872), Rebecca Harding Davis would present her female hunchbacked narrator as evidence of an industry that mangles its employees with regular frequency. In a parallel spirit, many women writers such as Elisabeth Stuart Phelps (1877), Mary Wilkins Freeman (1890), Charlotte Perkins Gilman (1899), and others provided a "mute" or "hysterical" female body as evidence that patriarchal institutions sought to stifle women's ability to participate meaningfully in public domains gendered as exclusively masculine. Furthermore, one might turn to influential African American sociologist W. E. B. Du Bois (1903), who theorized racial feeblemindedness as a product of inadequate access to education and insufficient diet due to impoverished conditions that prevailed after the Civil War.

Disability allows one the opportunity to reconstruct a rich cultural fabric that weaves all identities into a shared project largely imposed from without. The rise in pathologizing designations during this period oversaw a proliferation of ways in which one could become "inferior." During the European and American nineteenth and early twentieth centuries, one can find racial, sexual, economic, ethnic, and gendered classifications of human deviance all dovetailing beneath the banner of defect—one that depended on a biologically encoded idea of embedded inferiority that could not be transcended to any significant degree by acculturation, training, or rehabilitation. Developments such as Native American reservations, segregated systems of racial apartheid, and widespread institutionalization efforts all shared an interest in sequestration practices as a response to reproductive fears of contamination. Each marginalized group was believed to share a similar capacity in the midst of multiple incapacities: an unnaturally high fertility rate. For instance, eugenicists claimed that those diagnosed as feebleminded of all races reproduced at 6 to 10 times the rate of "normals." As the famed Supreme Court justice Oliver Wendell Holmes stated in *Buck v. Bell* (1927), "Three generations of imbeciles are enough."

This period also witnessed a further tightening of immigration requirements, such as the passage of the Chinese Immigration Act (1885) and an increasingly expanding definition of which disability categories could be barred from entry. Eugenicists who had been instrumental in obtaining restrictive legislation against an array of conditions believed abnormal—feeblemindedness, epilepsy, homosexuality, a variety of psychiatric conditions, and various congenital physical disabilities—played a key role in associating various ethnicities with a greater prevalence of such variations. In fact, in 1913, noted U.S. eugenicist Henry Goddard was invited by the U.S. government to bring his staff from the institution at Vineland, New Jersey, to immigration headquarters at Ellis Island; the purpose was to demonstrate their greater proficiency at "spotting" feebleminded and other defective individuals as immigrant hordes passed by the surveillance station. Eugenics ideology deepened an already growing suspicion of difference across Europe and the United States based on biological rather than cultural principles of inferiority. Entire populations could be placed under suspicion as a result.

The impact of such a sanctioned national ideology would inevitably surface in representational works of the era. Many modernist writers, for instance, would use disabled characters to signify varieties of cultural collapse. If the "rough beast" of Yeats's celebrated poem came "slouching towards Bethlehem" (1919), then that monster often proved disabled in some manner. William Carlos Williams would represent the pure products of America in the figure of a "broken-brained" maid named Elsie (1923); T. S. Eliot would resuscitate the blind prophet, Tiresias, from ancient Greek mythology as a hermaphroditic figure who exposes the cultural wasteland that rolled out before dulled modern sensibilities (1922); Virginia Woolf would explore the promise of incapacitating illness for a woman writer while also espousing eugenic-like scorn for her own mentally disabled sister (1930); Sherwood Anderson would use physically and mentally "grotesque" figures to symbolize the stultifying lives of rural, midwestern existence (1919); the lethal German medical and legal team, Binding and Hoche, would forward an idea of "useless eaters" and "lives unworthy of life" as the central thesis of their tracts on euthanasia (1920); D. H. Lawrence would metaphorize a war-torn, beleaguered masculinity as the impotent, wheelchair-using Clifford Chatterley (1928); and William Faulkner would emblematize the era's chaos as a tale told by a 33-year-old "idiot" named Benjy in his experimental novel *The Sound and the Fury* (1929). All of these literary portraits deploy disability as an indicator of the extent to which nineteenth-century ideals had come crashing down around the moderns.

One can find a similar sensibility extant in graphic arts of the period. German expressionist painter Otto Dix's (1891–1969) paintings teem with disabled figures, as if the imperiled body saturated social landscapes indifferent to their losses. His experience with multiple wounds as a German soldier in World War I fueled his allegorical visions of an amputated civilization going about its business as if nothing had changed. Picasso and other cubist experiments with multiple perspectives sought to destabilize investments in singular, integrated vantage points on well-worn artistic subjects such the female nude, still lifes, and socially marginal individuals, such as his portrait titled *Blind Man's Meal* (1903). Paul Strand's photograph of a blind woman wearing a sign announcing her diagnosis (1916) and Giorgio de Chirico's abstract painting of disabled female muses (1918) also signal artistic efforts to use disability as a device to upstage long-naturalized sites of male investment in feminine "beauty." Whereas Francisco de Goya (Spanish, 1746–1828), Vincent Van Gogh (Dutch, 1853–1890), and Frida Kahlo (Mexican, 1907–1957) explored the rich territory of their own experiences with disability, most artists sought out disability as a metaphorical path to more paranoid visions. Whereas Romanticism would premise a desirable, yet vulnerable and even tragic, humanity through various human incarnations of imperfection, most modernist artists refused this stance as overtly sentimental—thus, disability came to be transformed in this period as evidence of one's willingness to peer, unwaveringly, into the cultural wreckage. In fact, one might be tempted to analyze much of modernist art as a reactionary movement to the artistic efforts about disability that preceded it by approximately one hundred years.

One can worry over the dehumanizing tendencies that so often crop up in the art of this period or marvel at the centrality of disability (even as it references other social conditions beyond itself) to this cultural moment's concerns. With the flood of disabled veterans in the aftermath of two world wars, disability must have been on the minds of many—particularly after effective treatments for bladder infections decreased the mortality of wheelchair users significantly. The rise of key institutions such as vocational rehabilitation, special education, and the various therapies (physical, occupational, speech) that all began—to one degree or another—in eugenics-based training programs of socially segregated populations began to compete with many of the institutions in which they originally appeared. At least in the United States, eugenics began to fracture amid a sea of institutions all vying for the management of disabled populations; rather than full-time segregation in institutions, for instance, special educators argued that a significant cost-saving measure could be achieved by educating handicapped and subnormal students in ungraded classrooms while sending them home each night to receive care in their homes. In Canada, vocational rehabilitation facilities and disabled veterans organizations would press for the provision of technologies—such as hand controls in automobiles or white cane travel training—to reintegrate institutionally static populations into their local communities. This call for disability-specific technologies proved necessary not only on behalf of the restoration of dysfunctional bodies but also largely on the basis of the inaccessibility of mass public transit systems in urbanizing economies. This "reintroduction" of a narrow array of technologized, cyborgian disabled citizens—particularly paraplegic, visually impaired, and postpolio populations—required a historical realignment on the part of societies that had avoided the necessity of more meaningful contact. Thus, just as the female protagonist Scout in Harper Lee's novel, *To Kill a Mockingbird* (1962), has to recognize the humanity of her cognitively disabled neighbor, Boo Radley, so did many Western countries start the difficult process of reintroducing disability perspectives—along with other minority constituencies—to their representational repertoires.

To the extent that early twentieth-century representational arts recognized disability as an encounter with cultural disintegration, many late twentieth-century artists recognized opportunities for unheard stories in the experiences of disabled persons. Andrew Wyeth's celebrated painting, *Christina's World* (1948), appears as a typical pastoral landscape on a farm until one realizes that her vantage point on the ground is that of a woman with a neuromuscular disorder. In photography, American documentary artist Dorothea Lange used her perspective as a woman with post–polio syndrome to identify with and create stirring images of people in the grips of rampant poverty during the U.S. Depression era. In the late 1950s, she also took a series of photos of her atrophied right foot as an object of contemplation and personal difference. In literature of the African diaspora, one witnesses a counterrepresentational effort to distance portrayals of racialized disability from earlier efforts, such as W. E. B. Du Bois's eugenics-era formulation of the "talented tenth" (1903). Rather than adopt this hierarchical model of exceptional racial genius created to combat associations of race with biological models of inferiority, contemporary writers of color began to explore disability as a meaningful part of the mosaic within their own communities. Mrs. Hedges's corpulent and scarred figure in Ann Petry's *The Street* (1946), Ralph Ellison's analyses of social invisibility in *The Invisible Man* (1952), Toni Morrison's multiple examples of disabled characters (Polly and Pecola Breedlove in *The Bluest Eye* [1970], Shadrack and Eva Peace in *Sula* [1973], Sethe in *Beloved* [1987], etc.), Alice Walker's Meridian and Wild Child (1976), Maxine Hong Kingston's "wild man of the Green Swamp" in *China Men* (1980) and Whitman Ah Sing in *Tripmaster Monkey: His Fake Book* (1989), and Louise Erdrich's (1984) and Leslie Marmon Silko's (1977) disabled Native American veterans provide a glimpse into new artistic efforts to revivify disability as part of—rather than a slander upon—racialized communities of color. In the United States alone, such influential minority authors precipitated a representational renaissance of minority viewpoints that often included disability as integral to the burgeoning of nonmainstream narratives.

As literary and cultural critic Leslie Fiedler ([1962] 1996:386) would announce, disability functioned as a "final frontier" of representational exploration. Whether this proclamation would prove true, developed disability perspectives helped to fuel social commitments to the portrayal of devalued lives during the final half of the twentieth century. As civil rights and women's movements gathered steam as vectors of political revision and social renewal, the disability rights movement galvanized its own successes for meaningful integration of bodies deemed formerly unproductive. Rather than late-nineteenth-century emphases on human difference as pathology, disability played a key role in representational efforts to reclaim rejected bodies and lives. Along with the passage of key disability legislation in a variety of global outposts, the stories of disabled people—particularly those produced by contemporary disabled visual, textual, and performance artists and their close allies—became one critical site for reimagining representational domains as critical sites of struggle over meaning. Given the debilitating depictions often associated with disability—those that largely overwhelmed various efforts to appropriate disability as a meaningful aspect of human diversity—media have become increasingly recognized as key to political interventions. Such efforts have not eclipsed the role of art in presenting less nuanced representations, but they have, at the least, charged the field of representation as one that is crucial to contemporary disability politics. Efforts to reimagine disabled people's critical relationship to a variety of social contexts often take place in representational domains—those imaginative landscapes that can provide meaningful blueprints for worlds where disability is treated as integral to human endeavor that have not yet been realized.

—David T. Mitchell and
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See also History of Disability: Ancient West; History of Disability: Early Modern West; History of Disability: Korea; History of Disability: Medical Care in Renaissance Europe; History of Disability: Medieval West; History of Disability: Pleistocene Period.

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REPRESENTATIONS OF DISABILITY, SOCIAL

A phrase such as "representing disability" or "representing disabled people" bears many meanings. The most common refers to the act of (re)presenting disabled people in literature, the arts, and the media. An analysis of the evolution of these forms of representation through history, in particular in literature and the pictorial arts (including cartoons, cinema, and other media), informs us about the place that societies make for impairment in a given era. A second, more conceptual, meaning of representation, which encompasses the first, refers to a theory derived from social psychology. The concept of social representation takes into account the formation of bodies of knowledge originating from common sense and has been widely used in various disciplines of the social sciences.

A third meaning for the term *representation,* more distant and not discussed in this entry, refers to action in the name of another person or a group, that is, becoming a spokesperson or advocate on the political level. Disabled people thus have "representatives" and "representers" in a variety of instances.

REPRESENTATIONS OF DISABILITY IN ARTS AND MEDIA

Since the close of the 1970s and with the emergence of disability studies as an academic discipline, there has been a sharp increase in critical and historical works that address the ways in which disabled people are portrayed in culture, in particular in literature, cinema, and the media. Recurring stereotypes are associated with impairments: "There was the passively suffering angel of the house, the overcompensating supercrip, the tragically innocent disabled child, the malignant disabled avenger and the angry war veteran" (Mitchell and Snyder 2001:202). Some impairments are frequently depicted—epilepsy, restricted growth, the blind, the cripple, the leper—while others are ignored (Shakespeare 1994).

A Dominant Feature: The "Psychologization" of Disability

A first characteristic of works that bring disabled people onto the scene is a general tendency to pass over social conditions in the experience of disability, such as the inadaptation of the physical environment, in favor of individual factors. Thus, social isolation will not be attributed to the staircase that makes the outdoors inaccessible but to the paralysis that prevents walking. The process of "psychologization" that follows associates certain personality features with disabilities. Isolation is made into a tendency toward introversion, the presumed consequence of a necessarily tragic life experience.

Images Creating Ambivalence

A second characteristic of these representations is their bipolarity, which inspires such paradoxical feelings as fear, pity, and guilt but also admiration. The vulnerability and passivity of the innocent afflicted child are contrasted, now with the demonical and vengeful personality of the frustrated cripple, now with the heroism that permits another to "overcome" his or her disability. "In Victorian children's books, crippled young people teach messages of courage, forgiveness and generosity; witches are always ugly, and villains generally have had an impairment—Captain Hook, Long John Silver and all" (Shakespeare 1994:284).

The recurrence of such images and the plots into which they are introduced contribute to reinforcing cultural prejudice toward disabled people. As Barnes (1992:39) emphasized, "They form the bedrock on which the attitudes toward, assumptions about, and expectations of disabled people are based."

Disability as Metaphor

However, the simple distinction between negative and positive images of disability, acceptable or not, does not suffice to explain the metaphorical role that disability plays in culture. In addition, the criteria for what constitutes a negative or positive representation are not easy to define and vary according to the time and the culture.

A historical approach to this artistic reproduction points up the great complexity and richness of representations of disability and illuminates their symbolic and social functions in different periods. By representing the human body in all its diversity, its deficiencies, and its malformations, the artist goes beyond the visible that is apparent to everyone else "to reveal the hitherto concealed visible, to free our gaze from conventions and stereotypes, to imagine, fantasize, to open onto new scenes of human reality that are still unknown or ill known" (Blanc and Stiker 2003:10).

First, an observation: In all of this, the motif of disability is central in all eras, which leads to its recognition as a fundamental category of human experience, the rule rather than the exception (Mitchell and Snyder 2001). Another noteworthy fact is the use of disability as metaphor. By making reference to disability, the author most often seeks to represent, in figurative fashion, misery and depravity as one facet of the human condition. Thus, Clifford Chatterley, the impotent industrialist created by D. H. Lawrence, symbolizes "the decline of privilege and power in the British aristocracy" (Mitchell and Snyder 2001).

Stainton (2003) showed how the Renaissance marked a historical turning point in the ways in which madness and other forms of disability were represented. Until the close of the Middle Ages, representations of madness were purely allegorical. The famous painting *The Ship of Fools,* in which Hieronymus Bosch points up the folly of humans, is one illustration. Bosch stages a group of characters representing the whole of mankind, voyaging through the seas of time on a small ship gone adrift, eating, flirting, playing witless games, and pursuing unattainable objectives. With the exception of one "madman," recognizable by his cloak and hood, who is situated in the background and thus serves as a kind of cipher, none of the characters represented is stigmatized in one way or another. The *Ship of Fools* is not about other people; it is about "common individuals and common institutions, serving as the features of everyman"

(Stainton 2003:235). It is the group as a whole and its context, and not any one person in particular, that represents madness and folly.

Some years later, Brueghel, in *The Cripples,* portrays people voluntarily stigmatized with the help of prostheses. As in Bosch, their representation is metaphorical. The ridiculous headdresses worn by the characters symbolize organized social groups (the Church, peasantry, middle class, aristocracy). Given to our gaze is an inverted social space, "the disorder to be found in order, the mirror of a society that is always ill-formed" (Stiker 2003:128). However, where the rupture occurs, according to Stainton, is that starting with this period, representations of disability begin to be primarily representations of individual people. They are "increasingly associated with moral defects, and the study of physiognomic features as indicators of character was a pseudo-science popular in the sixteenth century" (Stainton 2003:237).

This observation may be juxtaposed with a more general evolution that characterizes the Renaissance: awareness of the existence of an internal self that determines conduct. Philosophers and poets became more and more interested in the workings of the mind. The idea that appearances are deceptive occurs frequently in the works of the period, in particular in the theater of Shakespeare. This cultural context favors the emergence of a belief in an association between physical appearance and character. Shakespeare's *Richard III* is doubtless one of the first illustrations of a natural correspondence between physical imperfection and villainy (Mitchell and Snyder 1997).

In their capacity as metaphors, representations of disability have a symbolic function. They are often hardly realistic and are remote from the experience of the people in question because they have another goal than to inform the public objectively. In a general way, they suggest significations, decoded with the help of the cultural tools available in every age (e.g., mythology, religion, psychology, biology, . . .), of what appears strange, unfamiliar, or even exceptional. These cultural interpretations make it possible to familiarize and domesticate what causes fear. Thus, medieval stories of fantastical children, such as changelings, attribute supernatural powers to children with congenital defects, which were inexplicable at the time. But at the same time as they supply meaning, representations of disability propose new categories of human variations and define, in ways that vary with the culture and the era, the characteristics that will make up the norm and those that will be excluded from it. "Disabilities exemplify that the ideal of the norm cannot exist without its 'deviant' contrast" (Mitchell and Snyder 2001). Here we have all the ambiguity of these representations, which, in a single interpretive act, seek both to domesticate the alien and keep it at a distance.

SOCIAL REPRESENTATIONS OF DISABILITY

The concept of social representations proposed by Mocovici (1984) provides a theoretical framework that allows the linking of representations of disability to the overall culture from which they emerge, and a better understanding of their dynamics, their functions and evolution.

Constructed at the juncture between the individual and the collective, between the subjective and the objective, agency and reproduction, social representations constitute a body of knowledge of common sense particular to a culture. They bring a sense of commonality and they organize social life. "Social representations live and die through the media, conversations, narratives, rituals, myths, patterns of work and art, among many other forms of social mediation" (Jovchelovitch 1996:127). Emerging into the public sphere, the space where intersubjective reality is constructed, they are at one and the same time descriptive, evaluative, and prescriptive. By determining both causes and consequences, they give sense to events, situations, and actions at the same time as they are the vehicle of a judgment, of an evaluation concerning them. These interpretations, socially connoted and shared by the members of a same group, orient future actions, at times serving as their justification. It should also be noted that this common knowledge, to which the dynamics of social representations contribute, is above all practical. It is elaborated at the very heart of daily actions and interactions, in a close relationship with current praxis.

Disability and Representations of the Person

Representations of disability in our cultures can be understood only in the context of the most general representation of the person. The increasingly central place that the rational individual is assuming in the modern age requires the formation of a common understanding—or "common knowledge"—of how the functioning of this individual, along with the reasons and meaning of his or her actions, is to be comprehended. The emergence, in the mid-eighteenth century, of physiognomy and phrenology, which sought to identify character on the basis of facial features or the shape of the skull, was a first manifestation of this need to understand.

Today it is "popular" as distinct from academic psychology that most often fills this same function. The modern individual is free and responsible for personal actions. Even if the individual is subject to the influences of the immediate environment, she or he has the power to control emotions in order to act rationally. The origin of behavior is, then, to be sought in the individual as defined by character or personality, which, once formed, displays a certain stability over time and through situations.

In this new cultural context, the metaphor of disability is transformed. It no longer evokes the human condition in general but an individual situation that nonetheless has a universal character. It becomes the symbol of personal tragedy, of brutal experience with unforeseen and irreversible consequences, experience that any person may encounter but that has victimized the disabled person. It is then the lived dimension of this experience, perceived as terrifying, and its consequences for the individual that social representations seek to articulate through artistic and media-related expressions. Reflective of the ambivalence generated by strangeness, the psychology of the disabled person oscillates between two poles: one marked by dependence, passivity, and frustration (general characteristics of social maladjustment) and the other by its heroic antithesis, driven by will power, coping, and perseverance. In both cases, to be carefree, spontaneous, and "comfortable in one's skin" are characteristics foreign to the dominant representations of disabled people.

Representations Inscribed in Social Practice

The psychological types associated with disability have their roots in a specific historical context. They correspond to the ideology of normalization through rehabilitation that dominated the introduction of medical and social care in the 1950s. The objective was to return people who had been wounded in war or injured in accidents to the multiple interactions of ordinary life, in particular, to the labor market, by acting as if there were no disability and one could become "normal" by trying harder. This pressure toward normalization has been costly in terms of energy and commitment on the part of those involved. The individualism that ignores social causes in favor of individual responsibility produces an effective reversal: Will power and self-control, consequences of great efforts to live up to social expectations, are considered causes of successful rehabilitation (Ville et al. 1994). Viewing as natural what is in fact a social response results in a reinforcement of representations and a legitimization of rehabilitation practices. In fact, such representation makes it possible to impute the failure of normalization to a weakness of character.

Social representations, in their capacity as cultural products rooted in praxis, also participate in the structuring of identities, which are in one sense self-representations. Thus, persons who contracted poliomyelitis (polio) in the 1950s and who responded to the demands of rehabilitation, in particular by assuming "normal" professional activities, exemplify a uniform representation of self, marked by the qualities of self-control, sense of duty, and meticulousness. "This post-polio identity overshadows all other social categories such as age and sex," unlike persons with paraplegia who acquired their impairments on average 25 years later (Ville et al. 1994:314).

New Representations and the Experience of Living with Disability

There has, in fact, been some evolution over the past three decades that offers alternative representations of the experience of disability. Through their collective mobilization and the emergence of disability studies as a discipline, disabled people refute these representations of themselves that are remote from their own experience. Instead, by means of their own production (artistic, scientific, media related), they propose realistic representations in which, neither victims nor heroes and heroines, they are seen above all as people confronting certain difficulties, difficulties most often related to the attitudes of others.

Beyond the variety of these representations, two great trends have today come to the fore, each playing on a different register. The first states its opposition to the individualist conception outlined above by shifting responsibility for the disability from the individual to the social environment. It is the social treatment of people who function differently from the norm that produces disability, that is, all the barriers to social participation (inaccessibility, exclusion, prejudice, and discrimination). The second would reverse the stigma by valorizing the experience of disability, the recognition of a specific culture, and the sense of achievement in contributing to it—disability pride.

While the first approach proposes new causes, located in the environment, the second assigns value to the positive consequences of experience of life with impairments. Although not mutually exclusive, each, by the specific sense that it conveys, seeks to initiate a certain kind of behavior. In the first case, the agenda is clearly political. It is a matter of engagement in actions whose aim is the overthrow of the physical and social barriers present in the environment. The second, on the other hand, stimulates cultural exchanges and cultural production. But they have the common feature of offering the opportunity for positive identifications for disabled people as political or cultural agents, and this can only contribute to anchoring these new representations in both the larger public and in themselves.

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See also Disability Pride; Disability Studies; Film; Journalism; Novel, The.

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REPRODUCTIVE RIGHTS

Reproductive rights and disability issues intersect in two broad areas: whether people with disabilities can become parents and whether all prospective parents should be expected to use prenatal testing and abortion or embryo diagnosis to reduce the births of children who would have impairments.

PEOPLE WITH DISABILITIES AS PARENTS

Most disability does not prevent women and men from participating in creating or raising children, but many developed nations have placed informal and formal barriers to parenthood for people with a range of disabling conditions. A few impairments include female infertility and male sterility (Turner's syndrome and cystic fibrosis for women and men, respectively). Sometimes, women with certain impairments will be advised that a pregnancy will endanger their physical health and significantly increase the physical difficulties occasioned by such conditions as diabetes or multiple sclerosis. This entry concerns the nonmedical factors that influence the reproductive freedom of people with disabilities.

Opposition to parenthood for people with disabilities is especially surprising when it is remembered that most people whose disabling conditions occur after the births of their children simply carry on their parenting responsibilities. Yet for those who acquire impairments before the ages of typical family formation, parenthood is often discouraged. Regardless of impairment, people with disabilities have been assumed incompetent to keep their children safe or to give them the emotional and social guidance necessary for functioning successfully in society. It is believed that children of disabled parents would consequently need financial and social resources from the larger society to ensure their survival and growth. Yet another source of opposition links to social goals of reducing the numbers of people with disabilities in the population because it is feared that people with disabilities would transmit genetic conditions to future children. As a result of these views, many developed nations have encouraged the sterilization of people with a wide range of impairments late into the twentieth century, and prospective disabled parents report hostility from medical professionals, adoption agencies, and social welfare agencies, which have been known to remove children from their rearing parents simply because of a parent's disability. Notwithstanding these professional practices, people with disabilities are becoming parents through ordinary sexual relations, adoption, and assisted reproduction; at least one major national organization exists to provide services and assistance to parents with disabilities (Through the Looking Glass). Adult children of disabled parents have started to publish their reflections of being raised by people with disabilities, and a small body of research has started documenting the strategies that people use to raise their children successfully.

PRENATAL TESTING AND SELECTIVE ABORTION

Worldwide, disability organizations, disability rights activists, and theorists have taken up the question of how the increasing use of prenatal testing and selective abortion affects the place of people with disabilities in the world. Bioethicists, civil libertarians, health professionals, and the public generally argue that prenatal testing, followed by pregnancy termination if an impairment is detected, promotes family well-being and the public health. Testing and termination is simply one more legitimate method of averting disability in the world.

Although sometimes prenatal testing occurs outside of a plan to abort based on results of the test, most people who seek testing plan to abort the fetus if they learn of a disability. Standard justifications include the following.

Attitudes toward congenital disability per se have not changed markedly. Both premodern as well as contemporary societies have regarded disability as undesirable and to be avoided. Not only have parents recognized the birth of a disabled child as a potentially divisive, destructive force in the family unit, but also the larger society has seen disability as unfortunate.

In the absence of adequate justification, a child is morally wronged when he or she is knowingly, deliberately, or negligently brought into being with a health status likely to result in significantly greater disability or suffering or significantly reduced life options relative to the other children with whom he or she will grow up.

The parent's/parents' harms include emotional pain and suffering, loss of opportunities, loss of freedom, isolation, loneliness, fear, guilt, stigmatization, and financial expenses.

Parents of a child with unwanted disability have their interests impinged on by the efforts, time, emotional burdens, and expenses added by the disability that they would not have otherwise experienced with the birth of a healthy child.

Parens and Asch (1999) describe the disability rights critique of prenatal testing as follows.

Rather than improving the medical or social situation of today's or tomorrow's disabled citizens, prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved. In rejecting an otherwise desired child because they believe that the child's disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child's characteristics might occasion.

When prospective parents select against a fetus because of predicted disability, they are making an unfortunate, often misinformed decision that a disabled child will not fulfill what most people seek in child rearing.

The disability critique argues that the practice and the rationales for it are misinformed about the nature of disability and morally problematic in the attitudes they connote about both disability and parenthood. The rationales for the practice are of three types. First, people with disabilities are more costly to society than others, and society should use its resources for children and adults who will not have impairments. Second, either the lives of disabled children are so miserable that they are not worth living at all, or they are more miserable than the lives of nondisabled children are expected to be. Third, the lives of parents and family members will be harmed by the psychological, social, and economic burdens of caring for the child, and these burdens will not be offset by the expected psychic and social rewards of raising a child without a disability.

Disability rights criticism of prenatal testing stems neither from general opposition to abortion nor from misgivings about technology. It is aimed at professional support for testing and abortion for some particular group of characteristics but not other characteristics, suggesting that health professionals, bioethicists, insurers, and policy makers believe that the births of people with some set of characteristics should be prevented. Pro-choice opposition to prenatal testing for disability shares much with those who oppose using the technology to avert the births of children of a particular sex. Suggesting that prospective parents select against an otherwise-wanted child because of its gender or disability implies that people who exist with these characteristics might be less desirable to others and less happy themselves than people with different characteristics. The critique is aimed at changing the way that testing technology is described to prospective parents, as well as at persuading professionals and parents that they have inaccurate ideas about disability and are using testing out of myth and stereotype rather than current information about how disability affects a child's or family's life.

Critics contend that this practice differs from other actions that prevent disability and should not be compared with prenatal care for women, vaccinations for children, or health promotion for everyone. Selective abortion and preimplantation embryo diagnosis both prevent disability not in an existing human being, or in a fetus likely to come to term, but rather prevent disability by preventing the embryo or fetus from becoming a person with a disability. The practices connote that if people do not meet a certain health standard, they should not be welcomed into the family or the world. Critics do not seek to ban the practice, but they believe that aborting a particular fetus differs from aborting any fetus because a woman does not want a child. They respond to each of the claims offered for prenatal testing by arguing the following.

Even if every disability diagnosed prenatally were followed by abortion, it would not materially reduce the prevalence of disability in the world or the need for society to change to better include those with impairments. As contrasted with the claims of Green (1997), who perceives a disability as an unacceptable infringement on a child's future, people with disabilities frequently enjoy their lives and do not generally perceive them as blighted by tragedy, even if their impairments impose some constraints on them. Furthermore, such constraints may be diminished or eliminated by societal changes to better include all citizens.

Most families raising children with disabilities are not ruined by the experience, and, on average, families including disabled children fare as well as other families on measures of well-being and family functioning.

Marsha Saxton (1998) expresses well the sense of offense experienced by many disability rights critics when she says,

> The message at the heart of widespread selective abortion on the basis of prenatal diagnosis is the greatest insult: some of us are "too flawed" in our very DNA to exist; we are unworthy of being born . . . fighting for this issue, our right and worthiness to be born, is the fundamental challenge to disability oppression; it underpins our most basic claim to justice and

> equality—we are indeed worthy of being born, worth the help and expense, and we know it! (p. 391)

Most disability rights opponents of prenatal testing and selective abortion would not claim that the practice is "eugenic" because few governments compel it. However, the very offer of testing for some characteristics, but not all potentially diagnosable ones, connotes that only some characteristics are worth the expense and trouble to avoid. Thus, using embryo diagnosis and prenatal testing is a social decision, expressing societal views, and a direct challenge to the societal claims to include people with disabilities as full citizens and participants in the moral and human community.

The disability critique includes the idea that the sentiments behind offering and using embryo diagnosis and prenatal testing and abortion to avoid bringing children with impairments into the family and the world will ultimately undermine parental appreciation of any children they raise. Pro-choice disability critics agree that if a prospective parent makes a considered decision that the family or the child will have an unacceptable life based on parental hopes and values, embryo rejection or abortion should be available. They caution that such assessments may be misguided about both the nature of disability and the nature of parent-child relationships. Every life, every family, and every parent-child relationship contain disappointment as well as delight. Prospective parents may be misguided and misinformed about parenthood and may thus shortchange themselves and any children they raise by adopting a selective approach to parenthood.

—Adrienne Asch

See also Children of Disabled Parents; Citizenship and Civil Rights; Eugenics; Prenatal Testing; Sterilization; Values.

Further Readings

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RESEARCH

In industrial societies, demographic trends and advances in health care are swelling the ranks of individuals with disabilities. Plunging birthrates are increasing the numbers of elderly populations. Many individuals with catastrophic injuries and illness who previously might have died now survive and become candidates for rehabilitation. As a result, the incidence of chronic disease has accelerated. From both a personal and societal perspective, the incentive to find better solutions for the problems of disability is very high.

Scientific inquiry is a systematic way to solve problems and to have some assurance that the solutions are trustworthy. Disability research is a broad subject, encompassing a wide range of populations and research topics. This entry examines the way in which disability research is conducted, some of the major problems involved and their solutions, and what the future holds for the field.

How disability is defined determines the direction of inquiry. The book *Disability in America,* edited by Andrew M. Pope and Alvin R. Tarlov (1991), provides a traditional view. “A disability refers to limitations in physical or mental function, caused by one or more health conditions, in carrying out socially defined tasks and roles that individuals generally are expected to be able to do” (p. 35). Deficits are a characteristic of the individual in relation to societal expectations, and remediation comes from treatment by health professionals. Although there is recognition that there is an interaction between the individual and the social environment, there is no mention of changing that environment.

A second view of disability is that it is not an attribute of the individual but a social construction that is the product of society and attitudes about disability. Both the built environment and customs and attitudes limit opportunities. It is society’s responsibility to make the necessary modifications so that individuals with disabilities can be integrated into society. Under the second perspective, disability becomes a political issue. These two views are not mutually exclusive; indeed, the World Health Organization’s (WHO’s) International Classification of Functioning, Disability, and Health incorporates both.

The headings that follow organize studies roughly on the basis of the numbers involved and the level of inquiry, which determine the goals of research and the methods by which to attain them. There are overlaps between sections. The classification is a rough scheme by which to organize a very large body of work.

THE SPECTRUM OF RESEARCH STUDIES

Population Studies

For governments to make informed decisions about allocating money, initiating new programs, or determining the effects of existing ones, it is necessary to have an estimate of the numbers of individuals with various disabilities and their status. The aim of epidemiology is to determine the incidence (the number of new cases per year), the prevalence (the number of existing cases at a particular time), or the health status of individuals with a particular condition. Population surveys devoted exclusively to disability are rare; most information comes from those that have other purposes. Census data, which attempt to reach the entire population, provide an estimate of the number of individuals with a disabling condition but have little detailed information. In the United States, the National Center for Health Statistics conducts an annual National Health Interview Survey on 48,000 households that includes questions on impairment or health problems that limit activity. The estimate is that more than 33 million individuals have some degree of activity limitation.

Mental illness is one of the most prevalent disabilities. It has also been one of the most difficult to identify because of changing definitions and methods of diagnosis. In the most recent research, individuals are identified as mentally ill if they have a cluster of signs and symptoms that result in impaired functioning. Most population surveys rely on telephone interviews in which strict sampling methods are used to ensure that the group contacted is representative of the population at large. Also, elaborate systems of questioning have been devised that maximize the potential for receiving truthful answers regarding various symptoms.

The 1999 report of the U.S. Surgeon General estimates that about 20 percent of the U.S. population is affected by mental disorders during a given year, the societal costs of which are enormous. The report found that direct costs of mental health services in 1996 were $69 billion. Indirect costs, estimated for 1990 at $78.6 billion, come from lost productivity at the workplace, school, and home. Additional estimates from surveys are also needed to determine the proportion of those identified with mental illness who need treatment. Most studies find large gaps between the numbers needing treatment and the facilities available.

Community Studies

Community-based studies focus on a sample of people living in one identified area, such as a city or region, with the assumption that the community is reasonably representative of other larger populations. A sample is drawn from the community, so it is possible to study individuals in considerable detail. The research can be a one-time study or repeated surveys that may extend over many years. Longitudinal studies are fairly rare because of the expense involved, but the information derived may be invaluable.

The Framingham Study is a well-known example of work that began in one city in Massachusetts in 1948 and has followed the fate of the study population ever since. The project, aimed at the effects of cardiovascular disease, selected 5,184 men and women between the ages of 28 and 62 at entry and followed them biannually with physical examinations, laboratory testing, and health history evaluation. It has been the source of some of the most important information available on risk factors for coronary heart disease. Because of the long time over which data have been collected, the Framingham Study has also been able to document the natural history of aging and what chronic diseases resulted in illness and functional limitations. Better information is needed on the major determinants of disability among those with chronic diseases to find ways to reduce and prevent physical disability in an aging population. During the 1983–1985 set of examinations, when the population had an average age of 72 years, more than 92 percent reported having no disabilities or functional limitations.

Another example of a community-based study, one that used a single time frame, is the Copenhagen Stroke Study. The question under investigation was whether a dedicated stroke unit resulted in better outcomes than other forms of traditional care. There has been considerable research devoted to this topic, but small numbers and selection bias made it difficult to draw definitive conclusions regarding the effectiveness of special stroke care. When one community in Greater Copenhagen set up a stroke unit that handled all the individuals in that area with strokes, it was possible to compare the results with a neighboring community without a special unit. The key to the research design was that a high proportion of all strokes in the two communities (88 percent) went either to the stroke unit or to medical or neurological units. Treatment on the stroke unit reduced the relative risk of death by 50 percent, reduced the relative risk of discharge to a nursing home by 40 percent, and almost doubled the chance of discharge home. The length of hospital stay was reduced by 30 percent. This was the first study to report on the effect of stroke unit treatment in unselected patients and demonstrated the effectiveness of stroke special units.

Community studies, either short term or longitudinal, are costly and require the mobilization of a team of investigators that may include clinicians, survey research specialists, biostatisticians, and interviewers. If done carefully, however, the yield can provide information that may not come from any other source.

Clinical and Educational Interventions

The largest proportion of disability research comes from a broad spectrum of work involving clinical or educational populations. Studies can range from large, multisite projects to much more modest research aimed at providing insights for the particular facility involved. Unfortunately, a high proportion of published work is not executed with enough attention to research design and methodology to provide useful answers. For several years, large-scale searches of the medical literature to determine the best treatments have found many studies wanting. The implication is that standards for both the execution and publication of research must be improved to ensure that the time and resources will be well spent.

Clinical Research

There are success stories in disability research, however. The example below illustrates several important principles of research. First, it investigates an important problem. Second, it has theoretical foundations that have evolved from several fields of investigation. And last, it took several years of work to develop the insights that were eventually established.

Edward Taub, a neuropsychologist at the University of Alabama at Birmingham, spent several years studying the behavior of monkeys with limb paralysis. He pursued this line of investigation because clinical work with humans with paralysis as a result of strokes or traumatic brain injury had shown limited success in improving functional recovery of upper extremities. Because patients valued the ability to use both limbs, they were frustrated at the lack of improvement.

When affected monkeys had their intact limb strapped down and went through graduated shaping procedures using the paretic limb, Taub found that there was considerable improvement in performance. When the animals had been free to use whatever limb they wanted, they naturally chose the intact one, resulting in a condition he called "learned disuse." Turning to individuals with hemiplegia as the result of stroke, Taub and his associates applied the techniques they had developed with monkeys. They found that immobilization of the good arm and an intense course of physical therapy resulted in impressive gains in ability (see Taub, Crago, and Uswatte 1998). Other research groups have begun to apply these techniques, termed *constraint-induced movement therapy,* and a body of evidence is accumulating regarding their effectiveness.

Educational Research

An essential tool of the research investigator is the ability to review past work. It not only provides a means for determining what has been done in a field of study but also identifies gaps in knowledge and the direction of future research. Easy access to electronic databases also makes the search much easier than in past times. There are large-scale collaborations among nations in the medical and educational literature to establish research evidence. The study below provides an example of a review in an area of study in which there are literately hundreds of pieces of work.

One of the most vexing issues in special education is the appropriate placement for children with disabilities. There is widespread agreement that, whenever possible, such children should be "mainstreamed," that is, included in classes of nondisabled children. The argument has been made on philosophical and legal grounds that children with special problems benefit educationally, socially, and in other ways from such exposure. The issue is a highly complex one, requiring different perspectives depending on age level, classroom objectives, and broader policy considerations.

Virginia Buysse and Donald B. Bailey Jr. of the Frank Porter Graham Child Development Center at the University of North Carolina at Chapel Hill were interested in comparing the outcomes of preschool children with disabilities in integrated and segregated settings. There are many benefits advanced for the integration of such young children, but there have been no reviews that compared these two settings. The authors set up a series of criteria by which to judge studies, particularly those related to the quality of research designs and methodology (Buysse and Bailey 1993). It is obviously important to identify those with strong designs and eliminate those for which conclusions cannot be drawn. Out of the dozens of studies examined, the authors found only 22 that matched the strict criteria they had set up.

The mean level of developmental outcomes, as assessed by standardized measures, did not vary in integrated as opposed to segregated placement. Integrated environments did provide a context that facilitated peer-related behavior; that is, children with disabilities had more social interactions in such settings. But there were questions about whether this led to more sophisticated levels of play and thus would have permanent effects. Integrated settings did show that children had more complex levels of play, with the opportunity to develop play-related skills. All in all, the review showed that there did seem to be some benefits for social-behavioral skills, although there were no advantages developmentally. Their work shows the complexities of trying to answer what seems on the surface a fairly simple question.

A second example of an educational intervention concerns the management of chronic disease. Medical care is limited in the ability to reverse disease processes or relieve symptoms. Individuals with chronic diseases then must learn to live with the disease and to manage their condition. There is a widespread need for health education methods that can assist with chronic disease management. A particularly promising effort is the Chronic Disease Self-Management Program, devised by Kate Lorig and colleagues (1996) at the Stanford University School of Medicine. This group had 12 years of experience with community-based educational programs for people with arthritis. In addition, the group conducted a series of focus groups of both well elderly and those with various chronic diseases. In these groups, they tape-recorded sessions in which the participants described their conditions, expressed their feelings about dealing with illness and disability, described the impact of the disease on the lives of the individuals and their families, and explained how they coped with such events. The records were then systematically analyzed. Finally, they incorporated a social psychology theory called self-efficacy into the program after finding that individuals with arthritis experienced pain reduction and enhanced capabilities when they felt they were in control of their symptoms. In the program that resulted from all this work, trained lay leaders conducted classes in community settings such as senior centers, libraries, hospitals, and recreation centers, teaching individuals how to develop exercise programs, problem solve, use communication skills, use medications, deal with emotion, and improve cognitive strategies for dealing with pain and disability. After training, individuals were better able to cope with chronic disease, experienced less pain, reported a better quality of life, and reduced their use of health care.

OUTCOMES RESEARCH AND QUALITY OF LIFE

The body of work reviewed above illustrates that disability research has many aims. A particularly prominent aim in an era of cost containment has to do with establishing the worth of program interventions. The usual objective of research is to test a hypothesis or establish some relationship, but outcomes research is management oriented. The applied research techniques that are employed still follow the tenets of scientific investigation, but there is relatively little control over what is studied. The goal is to monitor the effectiveness of interventions and to improve their quality.

Clinicians, counselors, and social service workers—all those who provide services—have always had an enduring interest in the success of their efforts. And, of course, clients have had similar concerns. It has only been in the era of accountability, rising costs, and the search for cost-effective care that the results of service have come to be called *outcomes.* The implication of the term is that results will meet some standard of acceptability and that the level of costs will also be acceptable. Programs of all types, from medical to educational, are charged with demonstrating that their outcomes meet expectations. Managers are to "manage" outcomes by improving services and by "risk adjustment," which simply means trying to select those who will benefit most. Unfortunately, this also has the effect of marginalizing many disabled people who are in greatest need.

Outcomes research must identify the principal results of programs and how to measure them. The usual list of outcomes includes improvement of physical and cognitive capabilities, greater independence, decreased need for assistance, decreased use of medical and personal care services, greater life satisfaction, and greater feelings of well-being. When programs are concerned with influencing physical and social environments and increasing opportunities for participation by those with disabilities, measurement of outcomes becomes more complicated. Indexes here include employment, financial support, access to transportation, access to health care, and other such evidence.

A view of service outcomes that is gaining greater acceptance is that the ultimate aim is to improve the day-to-day life of clients and patients. In health care, treatment populations increasingly are those with chronic disease for which there is no cure, but pain and discomfort can be relieved, the patient's functional ability may be improved, and outlook on life can be enhanced. *Quality of life* has been used as an umbrella term to include all the various aspects of health status, daily activities, economic circumstance, and perspective on life. A number of generic health status measures have been advanced as measures of quality of life related to health, but their applicability to disability is in doubt.

A major problem with health-related quality-of-life measures is in what constitutes health. In response to the question, "Does your health result in any limitations to activities?" a person with spinal cord injury might answer no. Likewise, someone with a severe disability that limited the ability to travel outside the house might still regard his or her quality of life as good, a perspective that might be puzzling to an outside observer. Quality-of-life conceptions, even though still not clearly defined or measured, will continue to be used. Whether funding agencies will pay for treatment aimed at improving quality of life could be a problem, although many such organizations recognize that individuals whose health, functional capacity, and life satisfaction improve may use health care services less.

DISABILITY RESEARCH AND EMPOWERMENT

Several forces have converged to force an examination of the role of those with disabilities in the research that affects them. In the 1960s, the civil rights movement resulted in social legislation aimed at improving the way society treated minorities. Although the movement initially concerned individuals of color, it soon spread to include anyone who was disadvantaged, including women and the disabled. A parallel phenomenon, although hardly distinctive enough to be called a movement, was the increasing attention given to the views of consumers. Initially concerned with commercial transactions, the consumer's perspective began to play an increasing role in various services, particularly health care and education. As health care became more competitive, the views of patients on the services they received and the results of services were solicited by means of satisfaction questionnaires. Other types of services have also begun to look at satisfaction. Because a high proportion of respondents indicate they are happy with what happened, satisfaction measurement is a blunt instrument that needs research on the underlying factors that determine satisfaction.

In the 1970s, a coalition of individuals with permanent disabilities began the independent living movement. It was a rebellion against what they saw as a paternalistic system that attempted to dictate how they should live and what services they should receive. This group has vigorously pursued the concept that those with disabilities should, wherever feasible, direct their own care and have a role in whatever studies are done about them. Funding agencies are increasingly requiring that whatever advisory groups grants create, there should be representation from those with disabilities.

To some extent, research investigators are caught between the two models of disability already mentioned. There has been far more research under the medical model, with the search for more effective treatment methods and other ways to improve performance deficiencies. For the most part, this body of work has been planned and executed by professionals with only occasional consultations with those whom it affects. The second model, which has been termed the *socioecological model,* involving the social and physical environments in which individuals with disabilities live, has been given increased standing by inclusion in the WHO International Classification of Functioning, Disability, and Health. In addition, the National Institute on Disability and Rehabilitation Research, the principal source of government-sponsored research funding in the United States, has made its "new paradigm" the centerpiece of planning. In this point of view, the aim is to reduce barriers, create access, and promote wellness and health. The individual with disability is regarded as a research participant and collaborator; decisions regarding research directions are to be made jointly with professionals.

This avenue of investigation produces considerable challenges, however. Ways to characterize and measure either social or physical environments are in early stages. It is not easy to do research in this area, particularly when a high proportion of such work is carried on by those trained in medical aspects of disability rather than in the social sciences. Greater interdisciplinary collaboration is obviously in order. Still another problem in research under the socioecological framework is that the ultimate aim of this work is to make social reforms of some kind. Researchers are not always comfortable in the role of social activist, however.

THE FUTURE

Although there have been impressive gains in the past 25 years in the status of individuals with disabilities and in the services they receive, there is still much to accomplish. Research is hardly the sole instrument in bringing improvements, but it contributes heavily to the development of new methods of treatment and education and in evaluating the effectiveness of those in use. Unfortunately, the priorities for research have come more from legislation and funding sources than from serious attempts at an integrated body of work founded on theory. With research spanning such a variety of problems, it is not surprising that findings are scattered without much organization. Several issues need to be addressed if disability research is to have an impact.

A Common Language. The lack of uniform concepts and a common language has plagued the field from its beginning. There is no consensus for even basic terms such as *disability* and *functional limitations,* which makes it difficult to compare measures and results. The addition of concepts such as *health status* and *quality of life,* even though they have important implications for outcomes, has brought additional confusion. Most studies do not define terms very well, so investigators often simply use an instrument and label it as measuring whatever they want. As a consequence, it is difficult to compare studies, and new knowledge accumulates slowly. In the end, however, it is up to researchers to better define terms and explain the procedures they use.

The Consumer Point of View. Although the views of the consumers of services for disability are sometimes sought, there has been little systematic effort to solicit priorities and preferences. Quite often, what an individual with a disability values as a contribution to his or her lifestyle is very different from the preoccupations of research professionals. The usual program outcomes that are measured are often the result of what can be measured rather than what is of special interest to the subjects studied. There needs to be a systematic method for determining client and patient goals at the beginning of a program and integrating such views into treatment plans and outcomes.

Outcome Measures for Disability. Many of the measures in use in social and medical programs are either of a utilitarian nature, reflecting a decreased burden to society or to caregivers, or enhancement of personal skills. Newer measures such as health status, quality of life, and health-related quality of life were developed without regard for applications with populations with disabilities. Although they are often used anyway or some modifications are made, their utility is less than if they were tailored to the needs and priorities of individuals with disabilities. Development of such measures may be costly, but the number of individuals with chronic diseases and injuries is easily sufficient to justify the effort. The shift in program goals to a socioecological perspective, in which better integration into society is important, will also require as yet undeveloped methods of determining outcomes.

The Subjective Experience of Disability. In the 1940s and 1950s, there were a number of observational studies of the mental hospital, some of which involved researchers being admitted as patients. They were then able to experience the often needless restrictions, the bureaucratic rules invoked primarily for the convenience of the staff, the lack of dignity with which patients were treated, the occasional physical abuse, and the pervasive boredom of routines with nothing to do. Such studies contributed to widespread questioning of the benefits of institutionalization and, ultimately, to the discharge of hundreds of patients from what was viewed as a noxious environment. Unfortunately, such patients were often turned out without adequate provisions of aftercare, and many drifted as homeless people.

Over the years, there have been occasional accounts of what life is like after a stroke, spinal cord injury, or other catastrophic condition. A few individuals have sufficiently recovered from autism to chronicle their experience. Unfortunately, most of these descriptions have been treated as idiosyncratic accounts that do not provide insights of general interest. All of this is in spite of the professed interest in the client/patient point of view. An array of qualitative research methods could provide a rich source of information about the disability experience.

The Challenge of Technology. There are accelerating advances in the miniaturization of circuits, new materials, and computerization of devices useful to those with disabilities. It is necessary, however, to determine the utility of such equipment for everyday life. The history of the use of lower leg braces, for example, has many accounts in which individuals have discarded braces, even though they provided physiological benefit, because they required great effort to use or were cosmetically unacceptable. The integration of special technology into routine life requires more than ever the collaboration of those for whom it is intended if use is to be successful.

Assessment procedures in which patients or clients must respond by computers are destined to become a much more frequent occurrence, even if these individuals have had no experience with this equipment. Touch screens or light pens can be used for multiple-choice answers and do not require keyboard use. Some aspects of personal and health history can be obtained this way, as can responses to a variety of health status questionnaires. Less staff time is required, and the responses can be instantly entered into a database, but respondents may need to be trained in the use of such devices.

Disability research holds great promise for improving the lives of those with disability, but such research is a product of the social and political context in which it occurs. The extent to which it is valued and understandable dictates whether it will be used. There are no shortcuts for creditable work. It must follow scientific principles, the individuals involved must be partners, and society must provide the resources.

—Robert Allen Keith

See also Disability Studies; Epidemiology; Models; Outcome Measures; Translating Theory and Research into Practice.

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See Rehabilitation Engineering Society of Japan (RESJA)

RESNA

See Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)

RETT SYNDROME

Rett syndrome is a progressive developmental disorder associated with intellectual disability, growth retardation, loss of speech and motor skills, and emergence of stereotyped hand mannerisms. The condition is named after Andreas Rett, an Austrian pediatrician, who first described the disorder in 1966. His initial description of 22 patients remained largely unknown until 1983, when Bengt Hagberg of Sweden and his colleagues published an English-language account of an additional 35 cases. In 1999, mutations in the $MCEP_2$ gene were identified in almost one-third of a sample of 21 individuals with Rett syndrome. Further analyses suggest that mutations within this region may account for 50 to 75 percent of all cases of Rett syndrome.

The severity of Rett syndrome varies from mild to profound. Children with Rett syndrome appear to develop normally during the first 6 to 18 months of life, although subtle problems in muscle tone, posture, and movement may be evident from birth. The major clinical signs of Rett syndrome are usually pronounced by 2 years of age, and by 5 to 7 years of age, most children will have progressed to the fourth and final stage of the disorder. Clinical features that emerge over this period include loss of muscle tone, deceleration of head growth, seizure disorder, loss of acquired speech, and deterioration of motor skills, with mobility and functional hand use being significantly impaired. One of the more distinctive features of Rett syndrome is the nearly constant stereotyped hand mannerisms, which typically involve rubbing, wringing, and washing-like movements.

The condition primarily affects females, but similar symptoms have been described in males. Overall prevalence is estimated at 1 in 10,000 to 1 in 15,000 female births, making it the single most common cause of severe developmental and physical disability in females. As the identification of Rett syndrome improves through refined laboratory tests, estimates of prevalence are likely to change and become more accurate.

There is no cure for Rett syndrome, and the prognosis for significant improvement in the cognitive, social, and motor domains is poor. Still, quality of life can be improved by providing opportunities for participation in meaningful and preferred activities. A multidisciplinary treatment approach is recommended, with treatment focused on maintaining health and including provision of physical, occupational, music, and speech therapy. Communication is a major area of need. Even when some speech is preserved, individuals with Rett syndrome generally rely on informal body movements and facial expressions to communicate. Some can be taught to use augmentative communication devices to indicate basic wants and needs. There has been some success in reducing stereotyped hand movements through behavior modification. Individuals with Rett syndrome are often aware of and responsive to others and will therefore benefit from integration experiences in typical classroom and community settings. With regular and sound multidisciplinary management, many individuals with Rett syndrome can be expected to survive into adulthood, although death from malnourishment is not uncommon, and some otherwise healthy individuals may die suddenly from cardiorespiratory problems.

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See also Developmental Disabilities.

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RIGHT TO WORK

At the beginning of the twenty-first century, for the first time in history, international social, economic, and political forces are acting in concert to promote widespread labor force participation of people with disabilities. The United Nations (UN) has acknowledged the right of individuals with disabilities to work, in order to promote equal opportunity and protection from poverty. The economic contributions of workers with disabilities can no longer be ignored in a constantly changing global economy, interlinking notions of work and citizenship. At the same time, an international movement of political activism among people with disabilities promotes a social theory of disability in which employment is seen as one route to community inclusion and protection of civil rights, albeit not the only route.

INTERNATIONAL AFFIRMATION OF THE RIGHT TO WORK

The UN Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities has proposed a series of fundamental principles for member nations. Article 22 of the convention is titled "Right to Work" and affirms that the opportunity to make a living doing work that is "freely chosen" in the "open labour market" is a basic human right. The need to protect workers with disabilities against discrimination in hiring, working conditions, pay, and advancement is affirmed in the article. Perhaps most important, recognizing that people with disabilities are "the poorest of the poor," an explicit connection is made between employment and "protection from poverty."

THE INTERNATIONAL EMPLOYMENT STATUS OF PEOPLE WITH DISABILITIES

Around the globe, people with disabilities live on lower incomes, receive less education, and have fewer job opportunities than their nondisabled counterparts, as revealed by international research statistics, as well as discussions among participants at the UN convention. In Latin America, for example, 75 percent of people with disabilities are not employed. More than two-thirds of British citizens with disabilities are out of the labor force or underemployed. Legislation in many countries forbids citizens with disabilities from entering certain professions. In countries with high unemployment, the labor market exploitation of disabled workers is often greater, so that when they do have access to jobs, these positions are often poorly paid and concentrated in a limited number of stereotypical occupations. Women with disabilities face particularly severe consequences of unemployment and associated poverty. In countries with publicly funded disability income support programs, large numbers of individuals with disabilities are trapped in poverty by income support policies that act as disincentives to employment.

POLITICAL ACTIVISM IN THE DISABILITY COMMUNITY

At the same time, a new conceptualization of disability has emerged that emphasizes community inclusion, accommodation, and protection of civil rights over the traditional focus on assessing impairment and remediation of functional deficits through professional services. Called the new paradigm, the social model, or the sociopolitical model, this new way of thinking about disability has its roots in the many political movements that grew out of the social protest and civil rights era of the 1960s. For example, the international disabled people's movement in the 1960s and the independent living movement of the 1970s sought a better quality of life for people with physical disabilities through equal opportunity and dignified treatment.

By the 1980s, disability rights advocates endorsed shifting the definition of disability from a focus on functional impairments and limitations to a sociopolitical perspective by means of a civil rights–based, "minority group model" of disability. This new paradigm views disability as an interaction between characteristics of an individual and features of his or her cultural, social, natural, and built environments. In this framework, disability does not lie within individuals but in the interface between their characteristics (such as their functional status or personal or social qualities) and the nature of the environments in which they operate. Put simply, the old paradigm views a person with a disability as someone who cannot function because of an impairment, whereas the new paradigm views this person as someone who needs an accommodation to function.

Use of this new model shifts the focus away from being solely on the individual to one that equally encompasses the environment. It highlights how the environments of people with disabilities often are socially isolating, economically constraining, legally exclusionary, and emotionally unsupportive. It also directs the search for solutions and remedies away from the sole concentration on "fixing" individuals by correcting their deficits to removing barriers and creating access through accommodation and reorganization of "disabling environments." It acknowledges that the "employment problem" for people with disabilities is due to faults in national and global economies and not deficiencies of individual workers. Concomitantly, the source of potential interventions expands beyond health professionals and clinical/rehabilitation service providers to include peers, mainstream providers, and consumer advocacy and information services. Most important in the new paradigm, the role of the person with a disability shifts away from being an object of intervention or a patient toward one of a customer, empowered peer, decision maker, and agent of social and political change.

Because these new paradigms have not been universally embraced, both national and international disability policy continues to lack coherence and direction. Much disability policy around the world has remained rooted in economic paradigms that pit benefits for individuals with disabilities against costs to the rest of society, thus reinforcing the medical rehabilitation model. In other countries, no formal disability policies exist, or a laissez-faire, de facto policy of benign neglect characterizes the approach that is taken.

LABOR FORCE DYNAMICS VIEWED THROUGH THE NEW PARADIGM OF DISABILITY

Use of the new paradigm allows for a more comprehensive understanding of the place of people with disabilities in the labor market and, especially, labor force dynamics for people with disabilities. This involves acknowledging that people with disabilities are both similar to and different from those without disabilities in their labor force attachment, experiences, and decision making. In the United States, for example, studies have shown that, while people with disabilities experience proportionally larger gains in employment during periods of market expansion, they also evidence greater losses during times of market contraction than people without disabilities.

The vulnerability of those who return to work while on the public disability insurance rolls in the United States is evident from studies showing that most reenter the labor force because of financial need rather than medical improvement. Those who do return to work tend to be younger and better educated than those who do not. Their initial jobs after reentry are lower paying and for fewer hours than the job held prior to disability onset, and they tend not to return to their previous employers. Finally, while workplace accommodations may extend the average duration of employment, there is evidence that injured workers who receive job accommodations "pay" for these accommodations in the form of lower wages.

These findings support the notion that return to work following onset of disability is a complex phenomenon encompassing more than the individual's level of impairment and functional limitations. Other factors, such as employers' attitudes, labor market conditions, availability of workplace accommodations, and prior employment, all are part of the environmental context that is critical to understand.

Most recently, disability scholars have questioned the notion that workforce participation can be the sole or even the most important route to social inclusion and emancipation. They argue that oppression of people with disabilities reflects a devaluing of impaired modes of being, which can never be fully corrected by inclusion in productive activity. Since the very nature of disability is defined by the ways in which a society organizes its productive activity, significant advances in employment for people with disabilities can only occur through a "radical reformulation" of the meaning and organization of work. This requires changes in the fact that productive activity in much of the Western world reflects values such as profit maximization, competition among organizations and their workers, and waged labor. It is these values, as well as the practices that stem from them, that limit or "disable" people with perceived impairments, rather than the functional limitations themselves. As long as work is organized around these principles, the inclusion of people with disabilities in productive activity is unlikely to bring about large-scale improvement in their economic circumstances. Such skepticism regarding the role of employment in the emancipation of individuals with disabilities is tied to the call for governments to adopt more interventionist labor market policies to encourage full integration. Disability advocates remind us of the long tradition in Western government of labor market restructuring through tax breaks and funding for business and industry to stimulate economies and enhance national security. In line with this thinking, members of the UN committee discussed encouraging member nations to pursue active labor market policies as part of promoting employment opportunities.

TRENDS IN GLOBAL WORKFORCE GROWTH AND LABOR DEMAND

Current trends in the worldwide labor market indicate the occupational context within which job training and employment placement will be occurring over the coming decades. Increasing economic globalization and technological advances have shifted the economy from a focus on "primary production" to one of "postprimary production," in which human services are the primary source of employment and information technology has replaced material production. For example, U.S. labor market projections indicate that the occupations with the largest job growth are expected to be retail trade, business services (including computer-related jobs), health services, and public and private education (including health care providers, teacher aides, teachers, and professors). Also, self-employment is expected to increase by almost 15 percent.

Some have argued that these new forms of production and technological advances offer unprecedented employment opportunities for people with disabilities. Environmental changes in workplace technology, telecommunications, and transportation systems have made the workplace more accessible to people with all kinds of disabilities through expanded transportation options and Internet technology. For example, mobility-impaired individuals can have enhanced access to job opportunities through the World Wide Web, a setting that already has been the focus of rehabilitation efforts.

On the other hand, new technologies must be accessible to people with disabilities if these alterations in the organization of work are to be advantageous. Increased funding to enhance innovation and affordability of assistive technology and universal design are essential. Accessibility to advanced telecommunications and transportation systems remains a major advocacy issue, with primary influence on an individual's likelihood of employment. In developing countries, access to advanced technology is limited among both nondisabled and disabled populations, pointing to the need to bridge the international digital divide.

THE NEED FOR REHABILITATION

In its statement of Right to Work, the UN committee called for increased access to technical and vocational guidance programs, placement services, and employment training, along with vocational and professional rehabilitation and return-to-work programs. The latter point highlights the importance of carefully integrating people with disabilities into mainstream government-sponsored employment programs to eliminate poverty. Special mention was made of "self-employment and starting one's own business," acknowledging the importance of building entrepreneurial skills as part of the rehabilitation process. In public discussions, some UN participants felt that this model applied especially for women with disabilities. Others noted that entrepreneurship provides people with greater freedom to participate in the economic sector of their own countries since they can act as their own employers and provide their own accommodations. A trend toward services and supports delivered by peers with disabilities is growing in many countries. However, in many others, access to vocational rehabilitation is severely limited or nonexistent.

NEW ROLES FOR EMPLOYERS

With expansion of the global economy, businesses have changed through downsizing and outsourcing, resulting in such phenomena as the flattening of workplace hierarchies and the erosion of job security. These trends suggest the need to incorporate employers and their organizations into the vocational rehabilitation process. Employers have been characterized as the "forgotten partners" in vocational rehabilitation efforts. Especially relevant to the new paradigm of disability are models of collaboration with business communities, which view the employment of people with disabilities as a socioenvironmental issue that can be addressed by a "trilateral" approach involving employers, consumers, and service providers. The UN committee recognized the need to encourage employers to hire workers with disabilities through affirmative action programs, incentives, and quotas. Also acknowledged was the need to educate employers about disability-related job discrimination and reasonable accommodations in the workplace.

THE INTERACTION OF DISABILITY AND POVERTY

Poverty co-occurs with disability around the world. In Western countries, this persists despite a series of public disability benefits and entitlements, including cash payments, vouchers, and other income support mechanisms. In countries without nationalized health care, such as the United States, disability beneficiary status provides the only access to medical and mental health treatment, and the need to protect this benefit leads many citizens with disabilities to forgo or limit their labor force participation. Yet even in countries with universal health care access, individuals risk their economic safety net when they work.

Providers of vocational rehabilitation services must be cognizant of service consumers' individual situations regarding eligibility for disability income and how they are affected by employment. Financial planning involving the sharing of accurate information is required so that consumers can consider the relative advantages and disadvantages of different work options. This means that the alleviation of poverty is explicitly addressed as part of the vocational rehabilitation process.

SUMMARY AND CONCLUSIONS

In conclusion, guaranteeing the right to work of people with disabilities might best be characterized as necessary but not sufficient to promote social integration and full participation. Without a reorganization of the values underlying the concept and organization of social production, labor force participation alone will not combat oppression. In the meantime, however, as stated in the UN article on "Social Security and an Adequate Standard of Living," in today's economy, "the best guarantee for independence and social security is employment."

It is hoped that tomorrow's global economy can be restructured through international policies so that employment is only one of the tools of emancipation from oppression available to people with disabilities.

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See also Citizenship and Civil Rights; Employability; Employment; Employment, International; Human Rights; Worksite Modification.

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RISK AND RISK SELECTION RELATED TO INSURANCE

In this entry, the concepts of risk and risk selection in the insurance industry are discussed in the context of the disabled community in the United States. Risk in the insurance industry is a condition in which there is a possibility of an adverse deviation from a desired outcome that is expected or hoped for. The undesirable event is the adverse deviation, and insurance coverage is an attempt to provide protection from the undesirable event. Illness and injury would be undesirable health insurance events.

Adverse selection is the tendency of persons with a higher than average probability of loss to seek or continue insurance to a greater extent than do persons with an average or below-average probability of loss.

While an insurer will provide health insurance coverage to policyholders, the company must protect itself from excessive financial losses and examine its spread of risk by line of business, thereby avoiding a concentration of risk. Health insurance coverage to the disabled community presents the insurer with a business challenge in providing coverage, and the insurer will consequently do so in a manner that limits its risk.

INSURANCE ACCESS

The initiatives to guarantee health care access have been incremental since the introduction of Medicare and Medicaid in 1965. While new delivery models were introduced to promote patient access to providers, the ability to pay for services ultimately guarantees access to providers. The number of people without health insurance increased by 2.4 million, the largest increase in a decade, raising the total to 43.6 million. The increase brought the proportion of people who were uninsured to 15.2 percent, from 14.6 percent in 2001 and 13.6 percent in 2000.

Estimating health insurance demand is difficult to do because of the way health insurance is purchased in the United States. Almost 90 percent of insured individuals younger than 65 years of age obtain coverage from their employer or as dependents of a family member with group-sponsored health insurance. Insurance for medical expenses and for loss of income due to disability is provided by three basic sources: individual insurance policies, employee benefit plans (including fully insured, partially insured, and self-insured programs), and social insurance, including the Old Age, Survivors, and Disability Insurance (OASDI); Medicaid; and Workers Compensation programs.

THE INSURANCE PERSPECTIVE ON RISK

Competing with the public's demand for insurance is the business interest of the insurance company itself. An insurance company is an enterprise in the business to make a profit through the sale of policies to prospective policyholders. Business profiles are developed on an insurance company by various rating services that drive current and future operating performance and can affect long-term financial strength and the company's ability to meet its obligations to policyholders. In analyzing a private insurance company's financial strength, a company's book of business is assessed by line in terms of its geographic, product, and distribution diversification.

Large companies usually write conservative lines of business and avoid a concentration of risk. It would follow that insurance companies will avoid writing insurance policies, be it life or health, to policyholders who presented an untoward risk of injury or death. A companion issue with that of insurance risk in writing a policy is the issue of adverse selection. Adverse selection occurs if those who elect to participate in the program are sicker than average, and program costs may exceed expectations and/or premiums to participants may have to increase.

Adverse selection may cause the insurer to include waiting periods for preexisting conditions and limited benefits (such as exclusion of mental health coverage) in an effort to control selection. In addition, insurance deductibles are used in property, liability, and health insurance. The purpose of the deductible mechanism is generally to reduce problems with moral hazard by requiring that the insured take some responsibility for loss payments. Coinsurance and maximum limits also arise as a result of adverse selection in a competitive insurance market. This is the rationale for the insurance questionnaire prior to a policy being written that requests information of a policyholder's education and drinking and driving habits, as well as access to medical records to verify various medical conditions that may or may not be covered in the policy. The company is prospectively attempting to determine the potential risk of writing a policy to the insured.

From the perspective of an insurance company, the key consideration is whether it can charge a premium rate that reflects the expected cost of a potential enrollment group. The primary purpose of insurance is a controlled spreading of risk across the entire insured population. For example, with experience rating, the insurer estimates the premium based on the past cost experience of the group and then offers a self-supporting premium rate to that group that covers expected medical costs, administrative expenses, other loadings, and a profit. Therefore, obtaining insurance coverage is not precluded just because a group is higher than average cost, but there must be an insurance market for persons/groups of that type, and insurance companies must be willing to offer coverage to those groups. If an insurer can make a reasonable profit (and accurately estimate the cost of the group), then it is likely that insurance is feasible. Risk adjustment methods are another way of estimating costs for groups that have varying levels of risk (in addition to experience rating).

Managed care is another relevant concept in the insurance market. For example, for mental health and substance abuse services, a managed care organization can provide care at a cost that is under a fee-for-service and unmanaged arrangement. In addition to cost containment, managed care organizations (MCOs) usually provide greater access to care (a higher percentage of users), although more care is outpatient, and inpatient care is substantially reduced (in the MCO). The same group of disabled persons may receive a number of different premium rates from different insurers (assuming there is a market), and at least part of the cost difference is a result of the level of cost containment that the insurer can achieve.

DISABILITY

There is no consensus definition of disability that suits all purposes. While the U.S. Social Security Administration defines disability in terms of functional limitations as they affect employability, the Americans with Disabilities Act (ADA) defines disability as a physical or mental impairment that limits one or more major life activities. The point to be made here is that disability includes a number of physical, psychological, and medical conditions from arthritis, congenital anomalies, depression, HIV, hearing and vision impairment, multiple sclerosis, and impairment following an accident or medical episode, among others.

The context of the disability condition and its corresponding disability time period, be it short or of a lengthy duration, will determine the type of insurance that is warranted. Ultimately, disabled people will have to be their own advocates to gain access to insurance and to monitor claims payment to the provider by their insurance.

DISABILITY INSURANCE SOURCES

Risk and adverse risk selection are managed differently based on insurance source. The Social Security Act established Medicare and Medicaid in 1965. Medicare extended health coverage to Americans age 65 or older, disabled persons receiving cash benefits for 24 months under the Social Security program, and persons suffering from end-stage renal disease. Medicare provides health benefits to 41 million elderly and disabled Americans. Medicaid is a program that pays for medical assistance for certain individuals and families with low incomes and resources. The program is jointly funded by federal and state governments. Medicaid covers 47 million low-income people, including 24 million children, 11 million adults, and more than 13 million elderly and disabled people.

Workers' Compensation is insurance coverage, purchased by the employer, that covers occupational accidents and illnesses. Musculoskeletal disorders (MSDs) are the most prevalent and expensive work-related injuries in the United States. These MSDs are injuries and disorders of the muscles, tendons, ligaments, nerves, joints, cartilage, and supporting structures, such as spinal disks, which account for at least one-third of all work-related injuries. Around 1.8 million workers report work-related MSDs, and about 600,000 miss work due to MSDs each year. The final source for insurance is the individual nongovernmental market, developed to fill the gaps left by the employer market, including self-employed persons, graduate students, short-term and part-time workers, unemployed or soon-to-be displaced workers (pending layoff), the smallest of small business that cannot obtain group coverage, and persons before they are eligible for Medicare. The individual nongovernmental market served an estimated 16 million Americans in 2001.

THE DISABLED AND THEIR HEALTH NEEDS

Twenty-eight percent of insured people with disabilities reported that they needed particular therapies, equipment, or medications that were not covered by their health plans, compared to 7 percent of those without disabilities. Nineteen percent of disabled persons reported that they needed medical care within the previous year but did not get it, compared to 6 percent of nondisabled persons. Persons with disabilities attributed these failures to a variety of factors, including lack of insurance coverage (35 percent), high costs (31 percent), difficulties or disagreements with doctors (8 percent), problems getting to doctor offices or clinics (7 percent), and inadequate transportation (4 percent) (Reis et al. 2004). Reis et al. (2004) report that people with disabilities typically have a "thinner margin of health" due to their impairments and functional limitations, fewer opportunities for health maintenance and preventive health care, earlier onset of chronic health conditions, susceptibility to secondary functional losses, and, not uncommonly, a need for complicated and prolonged treatments.

The insurance needs of the disabled community are varied and diverse. Clearly, one insurance source will not satisfy all needs. A person who becomes disabled for a temporary or protracted time period will have to investigate his or her insurance needs and act as an advocate to make sure his or her needs are met.

CONCLUSION

Insurance risk examines the probability of illness, disease, and injury along with the duration of each. Adverse selection is the prospect that an insurer will enroll those who are sicker than average, thereby increasing their medical and administrative costs. Market forces in the private health insurance market dictate that an insurer enroll those who are healthy and who will make limited demand of the insurer. A prospective insured with an excessive need for health care services would not be a financially viable group for a private insurer. Workers' Compensation, Medicare, and Medicaid have provisions for those who become incapacitated for short and permanent time periods.

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See also Health Management Systems; Political Economy.

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ROARTY, JOHN JOSEPH (1921–1996)

Author and disability rights activist

John Roarty was born on February 10, 1921, in Merewether, New South Wales, the youngest of three boys, to Cyril and Margaret Roarty. He was born with cerebral palsy and, as a result, was severely disabled. As well as severe spasticity in all limbs, he had a speech impediment. Roarty never had the advantage of a formal education. His father abandoned the family when John was very young, and his mother got a job as a housekeeper on a property so she could keep the children with her. He eventually became too heavy for his mother to lift and carry around.

On July 11, 1937, at the age of 16, he moved to Weemala Nursing Home, where he resided until his death. In 1971, he was instrumental in forming the Residents' Committee. The lack of access to electric wheelchairs and the curfew on residents were the driving issues of the day. This was one of the first pieces of direct action by residents in an institution for disabled people in Australia.

Roarty's dream of writing his life story was realized when he published *Captives of Care* in 1981, during the International Year of Disabled People (IYDP). He wrote, "That is what this story is about: domination and the power of authority, and our struggles to curb that power and assert our independence and our rights as human beings" (p. 12).

A video of the same title was produced and aired on the ABC in 1982 and went on to win 11 International Awards. This led to a stage production produced by John L. Simpson, a long-time friend of Roarty.

Roarty, who was baptized Roman Catholic, had great commitment and dedication to his Christian spiritual beliefs.

The ultimate accolade to Roarty's commitment to the disability sector came in the form of the Order of Australia in 1988.

—Jan Daisley

See also Activism.

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ROBERTS, ED (1939–1995)

Founder of the independent living movement

Ed Roberts, a John D. and Catherine T. MacArthur Fellow in 1984, was one of the most recognized and admired leaders of the independent living movement of persons with disabilities, which began in the late 1960s. He was a founder of the independent living center concept, served as executive director of the Center for Independent Living (CIL) in 1972–1975 and director of the California Department of Rehabilitation from 1975–1983, and was cofounder and president of the World Institute on Disability (WID) from 1983 until his death in 1995. Roberts contracted polio at age 14. It left him paralyzed from the neck down. Relying on an iron lung or a respirator, Ed became the first severely disabled student at the University of California, Berkeley. While there, he worked with the university to develop a program run by and for disabled students to provide wheelchair repair, attendant referral, peer counseling, and other services that would enable them to live in the community. Due to coverage by *60 Minutes* (CBS News) and other media, Roberts's work to promote the concept of independent living became known throughout the world. In 1996, disability and community leaders created the Ed Roberts Campus, an international center and a service facility in Berkeley, California, in his memory.

—Joan Leon

See also Independent Living; Polio.

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ROOSEVELT, FRANKLIN DELANO (1882–1945)

32nd president of the United States

The central human characteristic that marked Franklin D. Roosevelt (FDR) the person—his severe physical disability—was concealed during his lifetime. From August 21, 1921, to April 12, 1945, every day had to be planned and structured to adapt to his disability. At first, he was confined to his bed at Campobello Island in New Brunswick, Canada, while his wife ministered to his physical and emotional needs. After he was transported back to his home in New York City, he learned to adapt to his disability by working with a nurse therapist who came to his home. After two years, he could stand and ambulate with minimal assistance by means of braces and crutches. After seven years, he was ready to plunge back into the rough-and-tumble world of politics. In his day, many men and women who held high responsibility would have broken under such intense strain. Not one in a thousand returned to combative political life. None except Roosevelt became a world figure.

THE POLIO ATTACK

In July 1921, FDR testified before a congressional committee investigating homosexual acts at a Newport, Rhode Island, naval training station. He had been the assistant secretary of the Navy in the administration of President Woodrow Wilson. On the way back to his summer home in Campobello, he stopped briefly at a Boy Scout camp in New York. Whether he contracted poliomyelitis in Washington or in New York is not known. The incubation period ranges from 3 to 35 days, with the average period lasting between 4 and 10 days. On August 10, he spent a strenuous day with his family swimming and fighting a forest fire. The next morning, he awoke with weakness in his left leg and pain in his back and both legs; by nightfall, he registered a temperature of 102° Fahrenheit. His illness was misdiagnosed by a local physician and by a Philadelphia surgeon, Dr. W. Keen, who was vacationing nearby. Keen's diagnosis was a spinal cord infarct resulting from bladder congestion. FDR's uncle, Fred Delano, contacted the Harvard Infantile Paralysis Commission, whose specialist, Dr. Robert Lovett, was called to Campobello, and he confirmed the diagnosis of infantile paralysis, the term for poliomyelitis used in the early decades of the twentieth century.

Legend has clothed FDR's recovery from the acute phase and his rehabilitation in myth and half-truth. In reality, he was by all accounts deeply depressed during the initial period of the fall of 1921 and the winter of 1922. After a brief stay at Presbyterian Hospital in New York under the care of Dr. George Draper, he was sent home to work with his nurse therapists, Kathleen Lake and Edna Rockey, who observed him daily in his struggle to sit and regain muscle strength. In an effort to spare him the knowledge that his back muscles were impaired, Draper devised a back support. Gradually, the paralysis in his upper extremities receded and was left in his legs. By October 15, he had worked through a severe reactive depression, carefully masked by a facade of cheerfulness. His nurse therapists and his physician observed an extraordinary sensitivity to the psychological aspects of his illness and maintained constant emotional support. His knees were contracted and very painful; although he regained power in his hip muscles, he could not walk. Despite considerable stress, his therapists observed that he was a compliant patient.

FDR's illness placed an enormous burden on his family. His wife, Eleanor, and their five children adapted to a husband and father who had previously been active in state and national politics and who now was confined to home and a limited existence. His mother, Sara Delano Roosevelt, wanted him to return to their country estate at Hyde Park, New York, and assume the role of a country gentleman. His political adviser, Louis Howe, kept up a constant stream of political correspondence to feign an active political life. FDR became the center of a titanic struggle for his soul and his future career, as was observed in the correspondence from Draper to Lovett: “I was able to see with a better perspective the intense and devastating influence of the interplay of these high voltage personalities one upon another.” In June 1922, he went to Phillips House at the Massachusetts General Hospital in Boston to be fitted for a new set of braces. His departure for Boston broke the tension in the Roosevelt household. As long as he remained in New York, he assumed the sick role. When he returned, he had made his adjustment, and in the words of Albert Brewster, a young doctor who knew him in Boston, he was always smiling and seemed to have a charming personality undisturbed by all of the attention around him.

Two years after the poliomyelitis attack, Roosevelt had learned to manage with braces and crutches, but there was no restoration of permanently atrophied muscles. His last visit to Lovett showed only a trace of motion in the quadriceps on the right side and none on the left side, hip flexion was poor bilaterally, and bowel, bladder, and sexual functions were left undiminished. Although he vowed to walk independently, he never walked again without the assistance of a strong person holding his weak left side.

POLITICAL IMPACT OF HIS DISABILITY

Prior to 1921, FDR was perceived as a highly ambitious, rather supercilious young man whose social contacts were composed entirely of people in the higher political and diplomatic circles in Washington. Although he had successfully run for the New York state senate in 1910 and was familiar with the conditions of city slums at the turn of the twentieth century, he had little contact with the working classes and no contact with the problems of rural poverty in the Deep South. Those who knew him at Groton, a private preparatory school, and Harvard College remembered him as extremely ambitious to be popular but also as a snob who seemed ill at ease with people outside of his social group. One Harvard classmate who worked with him on the college newspaper said he did not have the common touch at all and that all of his humanitarianism came much later after he had had the polio attack. Frances Perkins, FDR’s secretary of labor, who knew him before and after the polio, said he changed enormously, that he broadened his sympathies for the underdog and the underprivileged. During his long rehabilitation, he came into contact with ordinary citizens who had suffered polio, and he maintained correspondence with people disabled from polio throughout the United States and Canada.

Polio taught him to be patient and to bide his time for an appropriate reentry into politics. He was moving toward progressive positions in state and national politics before the polio, but he was no flaming liberal. The 1920s was a period of conservatism and isolation from foreign affairs. Although he nominated Al Smith for the presidency in 1924, he did not take an active role in politics until 1928, when he ran for governor of New York. When the stock market crashed in 1929, leading to the Great Depression, he was ready to assume the leadership of the Democratic Party. Polio gave him the chance to gain greater knowledge of the problems of poverty, to enlarge and broaden his circle of friends, and to concentrate on his political goals. In 1932, the nation and the world needed a leader who was as strong and clever as the European dictators. The nation was paralyzed by fear and economic depression. Roosevelt’s triumph over his personal disability became a metaphor for national regeneration. During his 12-year presidency, there was increased attention paid to people with disabilities, through congressional legislation and through periodic charitable drives for people with polio, most significantly the March of Dimes. Perhaps the greatest contribution to the awareness of disability was Roosevelt himself, transferring from a chair to a standing position with the help of an aide, ambulating awkwardly to the podium, and gripping the lectern while deflecting the crowd’s attention with his magnificent smile.

POST-POLIO SYNDROME

Since FDR’s death, new information has been discovered about the late effects of poliomyelitis. Whereas polio was considered in his era to be a viral illness that had marked effects on breathing, movement, and sensation up to 2 years following the initial attack, it was not expected to progress or cause weakening of muscles that had not been initially affected. Patients often regained strength in some muscles and learned to sit, stand, and ambulate by a regimen of exercises and physiotherapy, such as FDR had undertaken. Studies in rehabilitation over the past 20 years, reviewed by Halstead (2004), have demonstrated a wide variety of symptoms experienced by former polio patients, ranging from 20 to 70 years after the polio infection. These symptoms are summarized as fatigue, decreased muscle endurance, muscle pain, joint pain, weakness in previously affected muscles and in unaffected muscles due to disuse, and atrophy. The problem of differential diagnosis is especially difficult with patients who are aging and have complex medical disorders that may simulate symptoms caused by polio. For example, many neurological and orthopedic disorders have similar symptoms of joint pain, muscle weakness, and fatigue. Therefore, a comprehensive medical examination, including an electromyogram, is necessary to confirm the existence of changes in muscle strength and sensation.

Did Roosevelt have post–polio syndrome? The medical evidence is limited by the absence of any continuous medical history from 1928 to 1944. These 16 years witnessed FDR in the governorship and the presidency. Apart from intermittent examinations to document his health for the electorate and to treat chronic sinusitis by his White House physician, Ross McIntyre, there is no record of his various illnesses. The laboratory reports during his presidency were stored under a pseudonym at the U.S. Naval Hospital in Bethesda, Maryland, and could not be found after his death. The most comprehensive and authoritative report was made by Howard Bruenn, a young cardiologist who treated him from March 27, 1944, to April 12, 1945. Bruenn diagnosed him with hypertension, hypertensive heart disease, left ventricular cardiac failure, and acute bronchitis. He recommended bed rest, limited work up to four hours per day, digitalis, a light and easily digestible diet, restricted salt, codeine for cough, sedation at night for sleep, and gradual weight reduction. The gaunt, haggard facial appearance of his last days was due to the loss of weight. Bruenn treated him for 12 months with no significant reduction in blood pressures, which fluctuated widely, from 170/88 to 240/130. Despite occasional chest pain, with one notable episode of substernal pain, FDR avoided an acute myocardial infarct or stroke until April 12, when he died from a massive cerebral hemorrhage. He was 63.

The confirmation of post–polio syndrome (PPS) cannot be made from Bruenn's clinical notes. The only evidence we have is completely anecdotal. Members of his family and of his inner circle of White House aides reported that he had lost muscle strength and endurance as early as 1941. The evidence is consistent with current criteria for diagnosing PPS after 15 years of neurological and functional stability. Moreover, he had less time for aerobic exercise such as swimming and for periodic rest such as frequent vacations due to the unprecedented stress of the world war. He was intolerant to cold, requiring extra warm blankets at home and while traveling to distant lands. After April 1944, Bruenn stopped his swimming in the White House pool because of hypertension. Although some of these symptoms may be caused by vascular disease, they are also indicative of PPS.

Did the late effects of polio contribute to his hypertension and hypertensive heart disease? In my conversations with Bruenn, he said that FDR's blood pressures were essentially normal during his first two terms. He was very active, swimming almost daily in the White House pool, traveling to Warm Springs, and going on frequent fishing trips for relaxation. The muscles in his legs were atrophied, so he used only his arms for moving his wheelchair and for swimming. During the war years, polio prevented him from managing muscle weakness and getting proper rest. Other causes of hypertension, such as renal disease, were absent. Hypertension and arteriosclerosis developed in an aging man, and polio did not have a specific effect on the elevation of blood pressure.

IMPACT ON THE DISABLED COMMUNITY

FDR's impact on people with disabilities came from many contributions: first, he established in 1926 a center for the treatment of polio patients at Warm Springs, Georgia. He spent four years there in an attempt to restore his atrophied muscles. Although he did not learn to walk unassisted, he did learn to use canes and benefited from the psychological support of other patients. He invested two-thirds of his inherited wealth, $201,667, to acquire the property of an old resort, including cottages, springs, and 1,200 acres of land, and established a modern hospital for the treatment of the aftereffects of polio. Some of the methods used to exercise weakened muscles, including physiotherapy, were adopted in a therapeutic environment shared by patients, nursing assistants, and "push boys" who maintained a spirit of equality and teamwork. Second, he established the Warm Springs Foundation, which hired medical specialists from Atlanta to direct orthopedics, build new pools, and expand the facilities. Third, in 1937, he became the prime mover behind the National Foundation for Infantile Paralysis Research, which raised funds for basic research to isolate the polio virus and develop a vaccine. The National Foundation's efforts led to the cultivation of the polio virus in a laboratory by John Enders, Thomas Weller, and Frederick Robbins, as well as the development of the Salk and Sabin vaccines. The announcement of the Salk vaccine was made on the 10th anniversary of FDR's death.

The voluntary campaign for the treatment of polio was the first widespread attempt to raise funds for a major disability. In an era when people with disabilities were either hidden or kept at home, pretty poster children with polio became models for acceptance. Roosevelt was used as a model who overcame his handicaps. It was thought that FDR had learned to stand, walk, and grasp the lectern as he made his political speeches. When a visitor entered his White House office or the State dining room, he was already seated. On the campaign trail, he held the railing of the rear train car while he flashed his magnificent smile and waved to the crowd. "If Roosevelt can do it, I can do it." In his era, he concealed the full extent of his disability in public, where his paralysis was shielded from the eyes of onlookers. Photographers had an unwritten agreement to avoid showing his atrophied legs. He was never seen in public in a wheelchair until March 1945, when he addressed Congress after making a strenuous trip overseas to Yalta in the Crimea.

Fifty-two years later, when the Roosevelt Memorial was opening in Washington, D.C., some disabled citizens criticized FDR for being a poor model since he concealed his disability during his lifetime. After public debate and controversy, a sculpture of him in a wheelchair now graces the memorial. The symbolism of Roosevelt triumphant over disability does not depend on the visible signs of braces and wheelchair but on the inspiration he provided for millions of disabled and able-bodied individuals throughout the world.

—Richard Thayer Goldberg

See also Depression; Polio; Representations of Disability, Social; Stigma.

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ROUSSEAU, JEAN-JACQUES

(1712–1778)

Philosopher and writer

Jean-Jacques Rousseau was one of the most influential thinkers of the eighteenth century, and his work continues to inform debates on education, the state, social welfare and morals. Rousseau spent most of his life residing in his native Switzerland and in Paris. In the novel, *Emile* (1762), he addressed critical issues in education, proposing a pragmatic approach to learning that focused on developing the natural proclivities of the individual and on learning through experience. He thought that teachers should not invest much energy in trying to educate "weak and sick" children because they would essentially end up being caretakers and guardians. He advocated that teachers ought to devote most of their efforts to the more "promising" students. In *The Social Contract* (1762), he argued that individuals could be more successful in facing threats in their lives by belonging to a society, a state, rather than by acting as individuals. The resulting "compact" between individuals about rules of behavior and sanctions for unwanted behavior sets the conditions for membership in society, including both rights and responsibilities. This work laid the foundations for discussions of the state, welfare, and care systems for the aged and disabled. Rousseau made a further contribution to disability discourse in his work on politics and morality. He stated that politics and morality cannot be separated and that the state is obligated to act in moral fashion or it will cease to exercise authority over its citizens. He also argued that the state is created to provide freedom for individuals. Thus, on individual and societal levels, Rousseau provoked discussion and took positions on issues critical to the place of disabled people in society.

—Henri-Jacques Stiker

See also Citizenship and Civil Rights; Education, International; Ethics.

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RUSH, BENJAMIN (1745–1813)

Physician and father of American psychiatry

Rush is known equally for his political and medical activities during the early years of the United States. He was a signer of the Declaration of Independence and served during the subsequent war as the physician general of the Medical Department of the Army. After the Revolutionary War, he actively pursued the still-new medical specialty of mental health and, in 1787, became supervisor of the section of the Pennsylvania Hospital devoted to those with psychiatric or intellectual disabilities (or "madness" and "fatuity," as Rush referred to these conditions in the writings). His textbook, *Medical Inquiries and Observations upon the Diseases of the Mind,* published near the end of Rush's life in 1812, served for many years as an influential summary of the knowledge base in the emerging field of psychology. In 1965, the American Psychiatric Association officially designated Rush as the "father of American psychiatry."

Rush wrote on occasion of the importance of humane treatment in terms that seem to foreshadow the "moral treatment" promoted by psychiatrists in the decades following Rush's death, describing how patients should "taste the blessings of air, and light, and motion, in pleasant and shaded walks in summer." However, many of his ideas and most of his practices were very traditional, punitive, and outdated even for their time, often relying on bloodletting, restraints, rapid spinning, and confinement to straw-covered cells in the basement of the hospital.

—Philip M. Ferguson

See also Psychiatry.

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RUSK, HOWARD (1901–1989)

Physiatrist

Conventionally considered the "father" of organized rehabilitation medicine in the United States, Rusk took his MD at the University of Pennsylvania, trained as an internist in St. Louis, and entered the Army Air Force's Medical Corps as a major during

World War II. Stationed near St. Louis, Rusk was exposed to the military's bimodal system of "rehabilitation." A patient was either "convalescent" and given few functional activities or deemed ready for duty and subjected to 10-mile hikes in full gear.

He designed a convalescent training program, incorporating psychological, physical, and vocational training to increase the functional state of the soldiers. The U.S. Army embraced this model and expanded it to military care facilities throughout its network. At the end of the war, Rusk took this model into civilian life. The military took the model into founding the Veteran's Administration hospital system.

Rusk's methodology invoked holism when reductionism in the medical model was particularly popular. An experimental demonstration while he was in the army, in which one barrack of disabled soldiers received intensive, holistic rehabilitation and another the standard "convalescent" care, dramatically showed the functional value of Rusk's methods to the military bureaucracy and to civilian observers. His genial style garnered him the nickname "Dr. Live-Again," also representing the prominence of the medical model in his early work.

In Manhattan, he founded the Institute of Rehabilitation Medicine at New York University, later named for him. He began a residency training program linking physical medicine with rehabilitation (a reason for his "father" status of the field). His public fund-raising efforts included privately lobbying the powerful, publicly persuading congressional budgeteers, and editing a column in the *New York Times.* Central to his unifying role was membership on the 1943–1952 Baruch Committee on Physical Medicine. He was preceded by figures such as John Coulter, George Albee, Henry Kessler, and Frank Krusen, who also played significant roles in establishing the twain fields of rehabilitation and physical medicine.

—Walton O. Schalick III

See also Physical Medicine and Rehabilitation; Veterans.

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RUSSELL, HAROLD (1914–2002)

Veteran and actor

A disabled veteran from World War II who, after 1945, briefly became a movie star and then a longtime advocate, in a variety of roles, for war veterans and people with disabilities, Harold Russell symbolized American disabled war veterans of the World War II era. Born in Nova Scotia, Canada, Russell immigrated to Boston with his family in 1933 and then worked as a butcher. He enlisted in the U.S. Army the day after the attack on Pearl Harbor. He trained as a paratrooper and then became a demolitions instructor, but he never saw action outside the United States. While working in the latter capacity, a defective fuse exploded a charge of TNT while he was holding it and led to the amputation of both his hands. Boyish charm and a positive attitude toward rehabilitation recommended him to the Army documentary makers, who sought a typical American soldier-amputee for a short training film intended to encourage amputees to achieve normalized lives. Though Russell had no speaking part in *Diary of a Sergeant* (1945), his natural grace before the camera recommended him to director William Wyler, who cast him as Homer Parrish in the Hollywood classic, *The Best Years of Our Lives* (1946). Russell won two Academy Awards: a Best Supporting Actor award for his performance and a humanitarian award for inspiring disabled veterans. Though he made brief appearances in other films and on television thereafter, his principal activities were as an advocate for both veterans and people with disabilities. He helped organize the World Veterans Foundation and served as vice president of the World Veterans Fund. He served three terms as national commander of the American Veterans of World War II (AMVETS). He maintained a consulting firm, which specialized in expanding job opportunities for the disabled. Following an appointment by President Lyndon Johnson in 1964, he served as chairman of the President's Committee on Employment of People with Disabilities, in which capacity he served until 1989. For many years, he also spoke widely on advances in the field of prosthetics. The Harold Russell Foundation continues his work through its

International Veterans Amputee Project, which assists disabled veterans to find and learn to use prosthetic limbs.

—David A. Gerber

See also Veterans.

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CHRONOLOGY

1500 BCE Egypt: The Ebers Papyrus, a medical textbook, devotes an entire chapter to eye diseases. It also shows that deafness is well understood and that clinical knowledge has developed.

400 BCE Graeco-Anatolian Hippocratic writings coin the word e*pilepsy* for a convulsive condition they view as a disease rather than a possession or punishment. Today, it is estimated that more than 80 percent of the 40 million people who currently have epilepsy throughout the world have little access or no access to contemporary treatments.

300 BCE China: *The Yellow Emperor's Internal Classic* is the first text to outline acupuncture. Ordinances on emergency relief for the disabled date to the Han Dynasty, 206 BCE–AD 220. Fiscal and administrative disability classification date at least to the Tang Dynasty, 618–907.

1250–1350 High point of medieval medicalization during which theoretical explanations for conditions gain currency in Western Europe. Prior to this time, in the most general of terms, lay explanations held more sway, ranging from the superstitious to the spiritual to the vindictive. With the founding of the universities, medical theory, typified by the four humors, became more influential in governmental, legal, and elite social circles. Disabling conditions like epilepsy, strokes, and paralyses, as well as psychiatric conditions, increasingly fell under the social control of doctors.

1400 Turkey: Deaf people work in the Ottoman Court from the 15th to the 20th centuries. Sign language becomes a recognized means of communication among both hearing and deaf courtiers.

1593 England: The origins of disability as a social and political category emerge with the first state disability benefits being enacted by Parliament for those disabled in war.

1593 Europe and the United States: English Parliament initiates Europe's first national system of benefits for rank-and-file disabled veterans. The first veterans' homes—France's Hôtel des Invalides, Britain's Chelsea Hospital, and Frederick the Great's Invalidenhaus in Berlin—are established in 1633, 1685, and 1748, respectively. Following the American Civil War, the U.S. government responds with a system of homes, preferences in government hiring, land grants, free prosthetics, and pensions for disabled veterans (however, southern veterans were limited to usually scanty state pensions).

1601 England: The Poor Law is passed to provide family and community support for those unable to make a living for themselves.

1604 Laws on witchcraft in the colonies all evolve from a 1604 English Statute that makes "being a witch" punishable by death. During outbreaks of witch-hunting, the "different" body itself is targeted as a sign and symptom of one's confederation with demonic forces.

1697 England: The first English workhouse for people with mental and physical disabilities is established in Bristol in 1697.

1704 Bethlem Hospital in the United States has 130 residents housing the "furiously mad."

1714 Canada: The Bishop of Quebec opens the first building in Canada exclusively for the confinement of mentally disturbed individuals. It is adjacent to Quebec General Hospital.

1749 France and England: Denis Diderot pens one of the most influential treatises on the blind and education in his *Letter on the Blind* in which he argues that the blind can be educated. In 1784, Valentin Haüy opens the first school for the blind in Paris. He perfects a system of raised *letters* to enable the blind to read. In 1828, Louis Braille modifies a raised *dot* system invented by Charles Barbier, which is used today by blind persons to read and communicate. In 1847, William Moon, an Englishman, develops an embossed script based on Roman capitals that blind adults can learn to read in a few days. It is the first reading system for the blind to be widely adopted across the world, but because it is costly to print, the Braille system, which can be produced by blind individuals for themselves, overtakes Moon's system.

1755 France, the United States, and Germany: The Abbé Charles-Michel de l'Épée establishes the first state-supported school for the training of young deaf children, where he teaches sign language. The school serves as an inspiration for the establishment of other European schools and has a dramatic impact on social attitudes toward the deaf. In 1817, Thomas Gallaudet and Laurent Clerc establish the Asylum for the Deaf (now American School for the Deaf) in Hartford, Connecticut. Clerc imports the French sign system, which influences the makeup of contemporary American Sign Language (ASL). In 1778, Samuel Heinicke establishes a school in Leipzig, Germany, where the "oral method" is used.

1800 France: Victor of Aveyron, a "feral child" found in southern France, is brought to Paris. Jean Marc Gaspard Itard, a French physician, develops a systematic training program for the boy and works intensively with him for five years. Itard considered his attempt at educating Victor to be a failure because the boy did not learn to use a language. Nevertheless, Itard's disciples, including Edouard Séguin, Maria Montessori, and Alfred Binet, continue his work by establishing classes for children considered to be "mentally retarded."

1802 France: The world's first pediatric hospital, L'Hôpital des Enfants Malades, is founded.

1817 The American School for the Deaf is founded in Hartford, Connecticut. It is the first school for disabled children in the Western Hemisphere.

1817 James Parkinson, a London physician, describes what is to become known as Parkinson's disease.

1817 Thomas Gallaudet and Laurent Clerc open the American Asylum for the Education of the Deaf and Dumb in Hartford, Connecticut.

1828 Frenchman Louis Braille, blind from childhood, modifies a raised-dot system of code, one of the most important advances in blind education. It not only allows the blind to read at a much faster rate but also makes it possible for the blind to be teachers of the blind. UNESCO creates the World Braille Council in 1952.

1829 France: Louis Braille publishes an explanation of his embossed dot code.

1832 Samuel Gridley Howe is chosen to direct what is later to be called the Perkins School for the Blind in Boston. It becomes the model for schools around the nation. Laura Bridgman and Helen Keller attend Perkins. In 1837, Ohio establishes the first state-sponsored school for the blind.

1834 England: The English Poor Law Amendment stipulates five categories of those unable to work: children, the sick, the insane, defectives, and the aged and infirm. This sets the stage for the development of specialty institutions that isolate the disabled from the community.

1841 P. T. Barnum purchases Scudder's American Museum in New York City. This moment is considered to be the beginning of the "Golden Age" of freaks, which persists until the 1940s. The tension

between freaks and disability rights comes to a head in 1984, when disability rights activist Barbara Baskin successfully lobbies the New York State Fair to remove Sutton's Incredible Wonders of the World Sideshow, featuring a limbless man who performs as the "Frog Boy," from the midway.

1843 Due to the influence of Dorothea Dix, an American social reformer, the Massachusetts legislature allocates funds to greatly expand the State Mental Hospital at Worcester. Dix also plays an instrumental role in the creation of 32 mental hospitals and becomes nationally known for her reform efforts. By the late 1840s, Dix focuses on developing a national plan that addresses the treatment of people with mental illness.

1846 William Thomas Green Morton discovers anesthesia and in 1867 Joseph Lister provides a model for antisepsis. These new technologies play a central role in the future of aesthetic surgery as well as surgical intervention for every type of disability that calls for it. Penicillin is discovered in 1929, cutting mortality rates in hospitals dramatically.

1848 The North Carolina School for the Deaf begins the first publication for Deaf persons with its school newspaper, *The Deaf Mute.* First published in 1907, the *Matilda Ziegler Magazine for the Blind* is an ongoing Braille publication.

1848 Samuel Gridley Howe founds the first residential institution for people with mental retardation at the Perkins Institution in Boston.

1851 In the United States there are 77 residential institutions for children, 1,151 by 1910, and 1,613 by 1933. By the 1950s and 1960s, family members and politicians throughout Western Europe, Canada, and the United States push for the deinstitutionalization of people with disabilities.

1851 The first International Sanitary Conference is held in Paris, France, with 12 countries participating. It leads to the World Health Organization, the WHO, which formally comes into existence in 1948.

1857 Edward Miner Gallaudet, youngest son of Thomas Hopkins Gallaudet, establishes the Columbian Institution for the Instruction of the Deaf, Dumb, and Blind, located in Washington D.C. Its college division, eventually known as the National Deaf-Mute College, is the world's first institution of higher education for deaf people. Abraham Lincoln signs its charter on April 8, 1864; today it is known as Gallaudet University.

1857 English philosopher Herbert Spencer is first to use the expression "survival of the fittest." The application of his idea in combination with Charles Darwin's theories in his 1859 book, *The Origin of the Species,* is called Social Darwinism. It is widely accepted and promoted in Germany in the 1920s and leads Adolf Hitler to express prejudice against the weak, sick, and disabled.

1863 Louis Agassiz, a significant American naturalist, advocates the permanence of different races and worries about the "tenacious influences of physical disability" if races were mixed.

1864 Germany: Karl Ferdinand Klein, teacher for deaf-mutes, and Heinrich Ernst Stotzner are considered the founding fathers of the *training school,* which calls for schools to be created for less-capable children with the goal of improving their lot. Training schools remain in effect today, but critics maintain that there is an over-representation of socially and economically underprivileged students in this type of setting experiencing little academic success.

1868 Sweden: The Stockholm Deaf Club is the first recorded organization of people with disabilities.

1870 England and Wales: Education for children with disabilities begins when universal elementary education is first introduced around this time. From 1895 onward, schools for "defective" children spring up. In 1899, Alfred Eichholz, an inspector of special education, draws up key recommendations, which leave their mark on the historic 1994 Education Act legislation. In 1978, the Warnock report

introduces the term *special needs education,* which soon gains acceptance worldwide. With the 1994 UNESCO Salamanca Statement and Framework for Action on Special Needs Education, a major shift in organizing educational services for children with disabilities is confirmed internationally.

1876 ◆ Isaac Newton Kerlin, Edouard Séguin, and others establish the Association of Medical Officers of American Institutions for the Idiotic and Feeble-Minded Persons. Today, it is known as the American Association on Mental Retardation. Séguin, who staunchly believes in the educability of those with significant cognitive disabilities, is styled as "apostle to the idiots," by Pope Pius X, reflecting the attitude of the time.

1880 ◆ The United States National Association of the Deaf (NAD), the first organization of deaf or disabled people in the Western Hemisphere, is established. In 1964, the Registry of Interpreters for the Deaf (RID) is formed to establish a national body of professionals who are trained and certified to enable communication between deaf, signing persons and nondeaf, speaking persons.

1880 ◆ Helen Keller is born in Tuscumbia, Alabama. An illness at the age of 19 months leaves her totally deaf and blind. In 1887, Anne Sullivan, recently graduated from Perkins Institution for the Blind, joins the Keller household as Helen's teacher and remains Keller's companion for nearly 50 years. For many, Keller's story is the quintessential overcoming narrative.

1881 ◆ The Chicago City Council enacts the first American "ugly law" forbidding "any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself to public view."

1882 ◆ The first major federal immigration law in the United States, the Immigration Act of 1882, prohibits entry to "lunatics," "idiots," and persons likely to become unable to take care of themselves. Most of the restrictions that apply specifically to disability are removed from U.S. law in 1990. Today, disabled immigrants are still denied an entry visa if they are deemed "likely to become a public charge."

1887 ◆ Walter Fernald serves as superintendent of the Massachusetts School for the Feeble-Minded (now known as the Fernald Center) from 1887 to 1924. Unlike most of his colleagues, Fernald moderates some of his earlier extreme views and eventually develops one of the country's largest "parole" systems for moving institutional residents back into smaller, community-based residences.

1887 ◆ The American Orthopaedic Association is founded. German and British counterparts are founded in 1901 and 1918, respectively.

1895 ◆ The chiropractic profession is founded. This type of care is used to relieve musculoskeletal pain, one of the most common causes of disability.

1899 ◆ Maria Montessori and a colleague open the Scuola Magistrale Ortofrenica in Rome, an educational institute for disabled children and a training institute for instructors. Her method relies on the concept of sensory-based instruction as a means for developing intellectual competence. Her methods allow the child the greatest possible independence in order to foster his or her own development (the child's own inner "building plan").

1904 ◆ Sir Francis Galton, half first cousin of Charles Darwin, defines the term e*ugenics* (which he coined in 1883) in a paper he presents to the Sociological Society on May 16. He argues for planned breeding among the "best stock" of the human population, along with various methods to discourage or prevent breeding among the "worst stock." Galton also develops the idea for intelligence tests. The term *feeblemindedness* is defined as broadly as possible and is widely used by eugenic social reformers to conflate myriad social problems. Further naming, classification, and labeling provides eugenicists with a troubling rationale for treating people with coercion, disrespect, and profound inhumanity. Persons within the various categories of sub-normality become particularly vulnerable

to state-sanctioned segregation, institutional confinement, and enforced sterilization. Eugenics is widely practiced in Europe, the United States, and Canada, culminating in the systemic murder of more than 260,000 disabled people by the Nazis between 1939 and 1945. Today, the so-called new eugenics, known as "human genetics," appeals to the needs of the individual. Critics (some of the first in Germany), however, criticize individualistic eugenic approaches and disclose the connections between human genetics, national socialist racial hygiene, and eugenics.

1905 Alfred Binet and Theodore Simon publish the first intelligence scale, known as the Binet-Simon Test.

1908 The publication of Clifford Beers's *A Mind That Found Itself* initiates the mental health hygiene movement in the United States. Speaking out against mistreatment and neglect within the system, Beers establishes the Connecticut Committee of Mental Hygiene, which expands in 1909, becoming the National Committee for Mental Hygiene and is now known as the National Mental Health Association. In 1940 there are 419,000 patients in 181 state hospitals. In 1943, the patient-doctor ratio is 277:1, and by the mid-1950s in New York state alone, there are 93,000 inpatients. The Bazelon Center for Mental Health Law, founded in 1972 by a group of committed lawyers and professionals in mental health and mental retardation, attempt to improve mental health service provision through individual and class action suits. In 1980, a group of these lawyers form the National Association of Rights Protection and Advocacy (NARPA). One-third of its board of directors must identify themselves as current or former recipients of mental health care. The association is committed to the abolishment of all forced treatment.

1908 Pastor Ernst Jakob Christoffel establishes a home in Turkey for blind and otherwise disabled and orphaned children. This grows into Christoffel-Blindenmission (CBM), an independent aid organization of Christians of various denominations united to help disabled people in third world countries. Today, it supports more than 1,000 development projects in 108 countries. In 1999, CBM, other agencies, and the World Health Organization initiate VISION 2020: The Right to Sight, a global initiative for the elimination of avoidable blindness by the year 2020.

1909 Germany: The German Organization for the Care of Cripples is created as an umbrella organization for the care of the physically disabled. The Prussian Cripples' Care Law of 1920 for the first time provides a right to medical care and scholarly and occupational education for this group.

1912 Henry H. Goddard publishes *The Kadikak Family,* supports the beliefs of the eugenics movements, and helps create a climate of hysteria in which human rights abuse of the disabled, including institutionalization and forced sterilization, increases. In 1927, the U.S. Supreme Court, in *Buck v. Bell,* rules in favor of forced sterilization of people with disabilities, further fueling eugenics movements—the number of sterilizations increases.

1914 By this date, Sigmund Freud develops his most enduring influence on the study of disability, namely, the theory of psychosomatic illness in which a psychopathological flaw is given corporeal form as a symptom, thereby establishing the notion that people succumb to disease or disability because they feel guilty about past or present repressed desires.

1918 The Smith-Sears Veterans Rehabilitation Act passes, authorizing VR services for World War I veterans. In 1916, the National Defense Act marks the beginning of the U.S. government's supportive attitude toward rehabilitation. In 1920, the Smith-Fess Act marks the beginnings of the civilian VR program. The Social Security Act of 1935 establishes state-federal VR as a permanent program that can be discontinued only by an act of Congress.

1919 Edgar "Daddy" Allen establishes what becomes known as the National Society for Crippled Children. In the spring of 1934, the organizational launches its first Easter "seals" money-making campaign. Donors place seals on envelopes containing their contributions. The seal is so well-known that it

becomes part of the organization's official name. Today, Easter Seals assists more than one million children and adults with disabilities and their families annually through a nationwide network of more than 500 service sites. During the 1920s, Franklin D. Roosevelt inspires the March of Dimes.

1920 ◆ At about this time, the Shriners open hospitals for the care of crippled children. President Herbert Hoover establishes a "Children's Charter" in 1928 highlighting the need to attend to the needs of crippled children.

1921 ◆ Franklin D. Roosevelt contracts poliomyelitis. Despite damage to his legs (which makes him a wheelchair user) and deep depression, through enormous rehabilitative effort, he eventually re-enters politics and becomes president of the United States. His triumph over personal disability becomes legendary. Critics, however, fault him for choosing to minimize his disability in what is called his "splendid deception." He establishes a center for the treatment of polio patients in Warm Springs, Georgia, called the Georgia Warm Springs Foundation (1927), which hires medical specialists from Atlanta to direct orthopedics. In 1937, President Roosevelt becomes the prime mover behind the National Foundation for Infantile Paralysis Research.

1921 ◆ Mary L. McMillan (Molly) establishes the American Women's Physical Therapeutic Association, which is known today as the American Physical Therapy Association (APTA).

1921 ◆ The American Foundation for the Blind is established.

1921 ◆ Canada: Researchers isolate the hormone insulin. In 1922, Frederick Banting, Charles Best, J. B. Collip, and J.R.R. Macleod produce and test the pancreatic extract on people with diabetes, for which they are awarded a Nobel Prize. Insulin becomes a wonderful treatment for diabetes, but not a cure.

1921 ◆ France: Three historical waves of advocacy movements can be identified beginning with the National Federation of Injured Workers (FNAT) in 1921 and other organizations that focus essentially on the protection of rights. Another factor that stimulates advocacy groups in the first wave is the wounded veterans of World Wars I and II. A second wave dates from the period after World War II. Many advocacy groups form between 1950 and 1970, such as the Union of Associations of Parents of Maladjusted Children (UNAPEI) in 1960. A third wave finds a gradual emergence of three types of associations: those that run specialized facilities (for example, Living Upright, which, in 1970, leads to the creation of the first group living facility); those interested in trade unions; and those represented by user-advocate associations. Financing comes in large part from public funds, thereby creating a government-association partnership.

1922 ◆ The founding of Rehabilitation International sets the stage for the establishment of other international organizations of and for people with disabilities that link together throughout the world. Later international organizations include, among numerous others, the World Federation of the Deaf (1951), Inclusion International (1962), the International Association for the Scientific Study of Intellectual Disability (1964), Disabled Peoples' International (1981), and the International Disability Alliance (1999).

1925 ◆ The American Speech-Language-Hearing Association, today the American Academy of Speech Correction, is established to provide high-quality services for professionals in speech-language pathology, audiology, and speech and hearing science, and to advocate for people with communication disabilities.

1928 ◆ Charles Nicolle is the first deaf person to be awarded a Nobel Prize.

1929 ◆ Seeing Eye establishes the first dog guide school in the United States.

1930 ◆ The Veterans Administration is created to administer benefits, promote vocational rehabilitation, and return disabled veterans to civil employment. There is a record of provision for disabled veterans in the United States since the Revolutionary War and the Civil War. After World War I, three agencies administer veteran's benefits.

1932 Herbert A. Everest, a mining engineer with a disability, and Harry C. Jennings collaborate to design and patent the cross-frame wheelchair, which becomes the standard for the wheelchair industry that exists today. Developed during World War I, the first powered wheelchair appears, but doesn't gain popularity for another 30 years.

1935 President Franklin D. Roosevelt signs the Social Security Act of 1935 on August 14. Beginning in 1956, SSA amendments provide disability benefits.

1935 By 1935, in the United States more than 30 states pass laws allowing for the compulsory sterilization of those deemed genetically unfit in state and federal institutions. By 1970, more than 60,000 people are sterilized under these laws.

1935 As a result of being denied participation in the Works Progress Administration (WPA), six young people with disabilities hold a sit-in at the offices of New York City's Emergency Relief Bureau, demanding jobs in non-segregated environments and explicitly rejecting charity. The League of the Physically Handicapped is born out of this activism and operates in New York from 1935 to 1938. The League identifies social problems that remain issues today.

1935 Peer support in the United States is traced to the establishment of Alcoholics Anonymous in this year. Interest in peer support increases in the 1960s and is adopted by the disabled community. Movements, such as the Center for Independent Living, and groups, such as the National Spinal Cord Injury Association, make peer support one of their major activities.

1936 The American Academy of Physical Medicine & Rehabilitation is founded, leading to the approval of the American Board of Physical Medicine & Rehabilitation by the American Medical Association in 1947.

1937 The Fair Housing Act of 1937 passes with a mandate to assist the poor, a group that includes people with disabilities, by creating public housing. However, it is not until the Rehabilitation Act of 1973 that housing law specifically deals with discrimination faced by individuals with disabilities in housing programs that receive federal funding. The 1988 amendment to the Fair Housing Act of 1968 extends protection for people with disabilities beyond those of Section 504 of the Rehabilitation Act to include private housing.

1939 The Nazi regime institutes the Aktion T4 program in Germany. Children and, later, adults with disabilities are selectively killed both in hospitals and in special centers. The program was officially terminated by Adolf Hitler in August 1941, but practitioners "informally" continued it through a phase historians have called "wild euthanasia."

1940 State activists for the blind, including Jacobus Broek, come together in Wilkes-Barre, Pennsylvania, to charter the National Federation of the Blind (NFB). In 1957, the NFB publishes the first edition of the *Braille Monitor,* which is still in print today. In 1960, dissatisfied NFB members form the American Council of the Blind (ACB).

1940 Paul Strachan establishes the American Federation of the Physically Handicapped, the nation's first cross-disability, national political organization.

1942 The American Psychiatric Association develops a position statement in favor of the euthanasia of children classified as *idiots* and *imbeciles.*

1943 The LaFollette-Barden Act, also known as the Vocational Rehabilitation Amendments, adds physical rehabilitation to federally funded vocational rehabilitation programs.

1943 The United Nations is established on October 24 by 51 countries. The global Programme on the Disability is the lead program concerning disability. Many other types of programs, activities, and instruments include the 1975 Declaration on the Rights of Disabled Persons, the 1981 International Year of

Disabled Persons, the 1982 World Programme of Action Concerning Disabled Persons, the 1983–1992 UN Decade of Disabled Persons, and the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In 1988, the first UN Disability Database (DISTAT) publishes statistics from 63 national studies covering 55 countries and the 2001 publication presents 111 national studies from 78 countries, indicating a growing interest worldwide for the collection of usable data. In 2005, a UN Ad Hoc Committee continues to consider a Convention on the Rights of Disabled Persons that is a legally binding human rights instrument. Today the UN membership totals 191 countries.

1943 Sweden: In possibly the first reference to the concept of normalization, the most significant driving force in the ongoing closure of state-run or state-funded institutions for people with a disability is made by the Committee for the Partially Able-Bodied, established by the Swedish Government. Through the advocacy of people such as Niels Erik Bank-Mikkelsen, normalization, with its profound positive effect on the lives of people who were once removed and segregated from society, remains relevant today.

1944 Richard Hoover invents long white canes known as Hoover canes that are used by many blind people.

1944 The word *genocide* first appears in a book by a Polish lawyer Raphael Lemkin titled *Axis Rule in Occupied Europe* in which he describes Nazi Germany's practices but also seeks the adoption of legal restrictions so that genocide will not occur. In 1948, the United Nations adopts a declaration and then a convention on genocide that describe both against whom genocide might be directed and acts constituting genocide. Article 6 of the Rome Statute of the International Criminal Court (ICC), established in 2002, uses language identical to that in the UN convention to define genocide. More than 90 countries are parties to the ICC, but not the United States.

1945 President Harry Truman signs into law an annual National Employ the Handicapped Week. In 1952, it becomes the Presidents' Committee on Employment of the Physically Handicapped, a permanent organization, which reports to the President and Congress.

1945 Canada: Lyndhurst Lodge, the first specialized rehabilitation center for spinal cord injury (SCI) in the world, and the Canadian Paraplegic Association, the first association in the world administered by individuals with SCI, are established.

1946 The first chapter of what will become the United Cerebral Palsy Association, Inc. is established in New York City. It is chartered in 1949, and along with the Association for Retarded Children, it becomes a major force in the parents' movement of the 1950s.

1946 The National Mental Health Foundation is founded by attendants at state mental institutions who aim to expose abusive conditions. Their work is an early step toward deinstitutionalization.

1946 The National Institutes of Mental Health (NIMH) are founded in the United States.

1946 Europe: The European Union is founded on September 17 in Paris. It consistently shows its commitment to eliminating discrimination on many fronts through joint declarations, resolutions, directives, and action programs. With regard to disability, the European Union supports actions in favor of people with disabilities, principally in the form of European Social Fund interventions. Action programs aim at facilitating the exchange of information between member states and nongovernmental organizations with a view to identifying good practices, integrating people with disabilities into society, and raising awareness of related issues. The EU Council of Ministers Recommendation on the Employment of Disabled People (1986) calls on member states to "eliminate negative discrimination by reviewing laws, regulations and administrative provisions to ensure that they are not contrary to the principle of fair opportunity for disabled people." Further

steps are taken in 1996 when a communication on equality of opportunities for disabled people sets out a new European disability strategy that promotes a rights-based approach, rather than a welfare-type approach. This is strengthened in 1997 when the heads of state act to strengthen Article 13 of the European Community Charter of Fundamental Social Rights of Workers (1989), giving the European Community specific powers to take action to combat a broad spectrum of discrimination that includes disability.

1948 ◆ The National Paraplegia Foundation is established as the civilian branch of the Paralyzed Veterans of America.

1948 ◆ The World Health Organization is established. The WHO actively promotes human rights and the principle of equity in health among all people of the world, including persons with disabilities. Today it consists of 191 member states, but strives for universal membership. In 1980, the WHO publishes the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and issues a revised version in 2001, the International Classification of Functioning, Disability, and Health (ICF).

1948 ◆ The United Nations General Assembly adopts the "Universal Declaration of Human Rights," which promotes and affirms the fundamental rights to life, liberty, and security; to medical care and social services; and to the benefit from scientific progress and its uses.

1948 ◆ Sir Ludwig Guttmann organizes the first Stoke Mandeville (England) Games for the Paralysed, thus launching the Paralympic movement. The Games become international in 1952. In 1960, the first Paralympic Summer games are held in Rome and the first Paralympic Winter Games follow in 1976. The Paralympic Games are multi-disability, multi-sport competitions and have become the second-largest sporting event in the world, only after the Olympic Games.

1948 ◆ World War II bomber pilot and war hero Leonard Cheshire establishes what is to become the largest charitable supplier of services for disabled people in the United Kingdom. In the 1960s, the resistance of disabled people who live in one Leonard Cheshire home, Le Court, plays a major role in establishing the British disabled people's movement. In the late 1990s, the Leonard Cheshire organization establishes the Disabled People's Forum, which is run by disabled people and supports disabled people's involvement and empowerment.

1949 ◆ Timothy Nugent founds the National Wheelchair Basketball Association, and the first Annual Wheelchair Basketball Tournament takes place.

1949 ◆ Europe: The Council of Europe, an intergovernmental organization, is founded. Its activities cover all major issues facing European society other than defense. Human dignity, equal opportunities, independent living, and active participation in the life of the community form the heart of the Council of Europe's activities in relation to people with disabilities. The European Social Charter of 1961 and its revision in 1996 include specific wording and expand the rights of individuals with disabilities.

1950 ◆ The Social Security Amendments of 1950 provide federal-state aid to the permanently and totally disabled (APTD), which serves as a limited prototype for future Social Security assistance programs for disabled people.

1950 ◆ The National Mental Health Association is formed with the mission to continue 1908-advocate Clifford W. Beers's goals of "spreading tolerance and awareness, improving mental health services, preventing mental illness, and promoting mental health."

1950 ◆ The National Association for Retarded Children (NARC) is established by families in Minneapolis. It is the first and most powerful parent-driven human-services lobby in the nation to emerge in the 1950s.

1950 Amniocentesis is developed by a Uruguayan obstetrician. Later, advanced prenatal testing provides a battery of powerful medical tools to predict risk of disability and provide information to parents about their pregnancies.

1951 With the founding of the World Federation of the Deaf, the deaf community becomes international.

1953 Francis Crick and James Watson propose a three-dimensional structure for the DNA molecule. The paper they publish also gives clues to genetic mechanisms. Today, more than 6,000 monogenic disorders have been identified, and these affect approximately 1 in 200 live births.

1955 The polio vaccine, developed by Dr. Jonas Salk, becomes available, thus ending polio epidemics in the Western world. A new oral vaccine, developed by Dr. Albert B. Sabin, is approved for use in 1961.

1956 Social Security Disability Insurance (SSDI) becomes available through amendments to the Social Security Act of 1935 (SSA) for those aged 50–64. Other important amendments to SSA include the following: 1958: provides for dependents of disabled workers; 1960: removes age limit; 1965: Medicare and Medicaid provide benefits within the framework of the SSA (until 1977); 1967: provides benefits to widows and widowers over the age of 50; 1972: Supplemental Security Income (SSI) establishes a needs-based program for the aged, blind, and disabled; 1984: the Social Security Disability Reform Act responds to the complaints of hundreds of thousands of people whose disability benefits have been terminated; 1996: President Clinton signs the Personal Responsibility and Work Opportunity Reconciliation Act, making it more difficult for children to qualify as disabled for SSI purposes.

1959 The UN Declaration of the Rights of the Child is adopted; the UN Convention on the Rights of the Child is adopted in 1989. A central principle of both documents is access to education for all children including those with disabilities. In 1993, a related UN document, the Standard Rules for the Equalization of Opportunity, extends this to preschool children, and in 1994, UNESCO's Salamanca Statement and Framework for Action specifies the provision of special education for children with disabilities or learning difficulties. These documents constitute a universal bill of rights that can serve as a framework in the development of national policies worldwide.

1961 The American Council of the Blind is established.

1961 Europe: The European Social Charter (ESC) protects "the right of physically and mentally disabled persons to vocational training, rehabilitation and social resettlement." In 1996, it is revised, updated, and expanded to take account of social changes.

1961 Michel Foucault's work *The History of Madness in the Classical Age* becomes obligatory reading for those concerned with the archaeology of madness and its treatments. It continues to be an academic *rite de passage.*

1962 Battered child syndrome is defined. Researchers estimate that the incidence of maltreatment of children with disabilities is between 1.7 and 3.4 times greater than of children without disabilities.

1962 Russia: The Moscow Theater of Mime and Gesture is the first professional deaf theater in the world. It has been in continuous operation for more than 40 years and has staged more than 100 classic and modern plays.

1963 Congress enacts new legislation to ensure funding for a comprehensive program of research on mental retardation through the National Institute on Child Health & Human Development. In 1965, the Office of Economic Opportunity launches the Elementary and Secondary Education Act (ESEA), commonly known as Project Head Start. The goal is to prevent developmental disability by providing increased opportunities for disadvantaged children in the preschool years.

1963 The Developmentally Disabled Assistance and Bill of Rights Act (DD ACT) is authorized, with its last reauthorization in 1996. It focuses on individuals with developmental disabilities such as intellectual disability, autism, cerebral palsy, epilepsy, and hearing and visual impairments, among others.

1964 The Civil Rights Act is passed. It becomes the model for future disability rights legislation.

1964 France: L'Arche is established. By the beginning of the twentieth-first century, it includes more than 113 communities in 30 countries. "The Ark" is a distinctive style of community living, based on "core members" and "assistants," who view their commitment as sharing life *with* people with disabilities, rather than as caregivers.

1965 Newly enacted Medicare and Medicaid provide national health insurance for both elderly (over 65) and disabled persons.

1965 The Vocational Rehabilitation Amendments of 1965 are passed. They provide federal funds for the construction of rehabilitation centers and create the National Commission on Architectural Barriers to Rehabilitation of the Handicapped.

1965 The Autism Society of America is founded.

1967 Deaf actors establish the National Theatre of the Deaf (NTD). It is the world's first professional deaf theater company and the oldest continually producing touring theater company in the United States. Today, after almost 40 years, the NTD chronicles over 6,000 performances. The National Theatre Workshop for the Handicapped begins in 1977 and the Other Voices Project in 1982. These groups are among the earliest groups formally to place the disability experience at the heart of their creative endeavors.

1967 Heart transplantation is introduced. This technology is preceded by open-heart surgery developed in the 1950s and coronary bypass and internal pacemakers in the1960s. The Framingham Heart Study begins in 1948. It collects data over the next decades that help identify major risk factors contributors to heart disease.

1967 Paul Lemoine in France in 1967 and Kenneth Jones and David Smith in the United States in 1973 independently describe the condition fetal alcohol syndrome (FAS), which comprises a recognizable pattern of birth defects attributable to the adverse effects of maternal alcohol abuse during pregnancy.

1967 England: St. Christopher's Hospice in South London opens. It is the first attempt to develop a modern approach to hospice and palliative care.

1968 Congress enacts the Architectural Barriers Act. The ABA requires access to facilities designed, built, altered, or leased with federal funds.

1968 The Fair Housing Amendments to the Civil Rights Act of 1968 guarantees civil rights of people with disabilities in the residential setting. The amendments extend coverage of the fair housing laws to people with disabilities and establish accessible design and construction standards for all new multifamily housing built for first occupancy on or after March 13, 1991.

1968 Sweden: The origins of People First® go back to a meeting of parents of children with intellectual disabilities whose motto is "we speak for them." However, the people with disabilities in attendance wish to speak for themselves and start their own self-advocacy group. Similar groups quickly spread to England and Canada. The name People First is chosen at a conference held in Salem, Oregon, in 1974. People First is an international self-advocacy organization run by and for people with intellectual disabilities to work on civil and human rights issues.

1970 Landmark legal cases such as *Diana v. State Board of Education* (1970; Latino students) and *Larry P. v. Riles* (1971–1979; minority students) challenge biases inherent in standardized testing procedures used to identify students as eligible for special education. Both cases call into question the widespread use of "scientifically" objective measures to gauge intellectual ability. Today, despite reforms, a disproportionate number of students from racial, ethnic, and linguistic minorities continue to be placed in special education classes.

1970 Japan: The Disabled Persons' Fundamental Law (DPFL) becomes one of the 27 fundamental laws that stipulate basic principles in each policy area. Major revision takes place in 1993 reflecting a progress of guiding principles in disability policy that are deeply influenced by international movements such as the International Year of Disabled Persons (1981) and the UN Decade of Disabled Persons (1983–1992). Disability Studies as well as modern disability movements are born this same year, when members of Aoi Shiba, a group of people with cerebral palsy, protest publicly for the first time against sympathetic views toward the killing of disabled children by their parents. Aoi Shiba and other disability movements join in the establishment of Disabled Peoples' International in 1981. In 1986, the Rehabilitation Engineering Society of Japan (RESJA) is established. In 1992, disability movements in Japan initiate the Asian and Pacific Decade of Disabled Persons 1993 to 2002. The Japan Society for Disability Studies is established in 2003 and a unified national organization, Japan Disability Forum (JDF), is established in 2004.

1970 United Kingdom: The Chronically Sick and Disabled Persons Act (CSDPA) strengthens the provisions in the 1948 National Assistance Act (NAA). Later, the Disability Discrimination Acts of 1995 and 2005, together with the Disability Rights Commission Act of 1999, constitute the primary source of antidiscrimination legislation for disabled people.

1971 A U.S. District Court decision in *Wyatt v. Stickney* is the first important victory in the fight for deinstitutionalization.

1971 WGBH Public Television establishes the Caption Center, which provides captioned programming for deaf viewers.

1971 Gerontologist M. Powell Lawton defines *functional assessment* as any systematic attempt to objectively measure the level at which a person is functioning in a variety of domains. Over 30 years later, functional assessment, in combination with *outcomes analysis,* is considered one of the "basic sciences" of rehabilitation. In 1980, the World Health Organization proposes a series of definitions, which have a profound impact on the assessment of functional status and outcomes in rehabilitation. It is modified and revised in 1993 and 2001.

1971 The Declaration on the Rights of Mentally Retarded Persons (UN 1971), the Declaration on the Rights of Disabled Persons (UN 1975), and the World Programme of Action Concerning Disabled Persons (UN 1982) indicate the emergence of a global discourse of rights for disability.

1972 A group of people with disabilities (including Ed Roberts, John Hessler, and Hale Zukas), known as the Rolling Quads, living together in Berkeley, California, formally incorporate as the Center for Independent Living (CIL). This first CIL in the country becomes the model for Title VII of the Rehabilitation Act of 1973. In the late 1980s and early 1990s the group's advocacy efforts help pass the Americans with Disabilities Act (ADA). CILs are always controlled by disabled people. Accepted by most people as the birth of the modern independent living movement, the Berkeley concept migrates to other countries. In 1999, a global summit on independent living is held in Washington D.C. The summit brings together more than 70 countries. The Washington Declaration that comes out of the conference establishes a set of basic principles. In 1996, the Ed Roberts Campus, an international center and a service facility, is created in Berkeley, California, in memory of Edward V. Roberts, founder of the independent living concept.

1972 ◆ A young television reporter for the ABC network, Geraldo Rivera, is given a key to one of the wards at Willowbrook State School on Staten Island, New York. Established in the late 1930s as a state-of-the-art facility for the "mentally deficient," by 1972, Willowbrook becomes a warehouse for the "socially undesirable" of New York City, with a substantial minority having no disability at all. The inhumane conditions deteriorate to the extent that a visitor remarks, "In Denmark we don't let our cattle live this way." Rivera's exposé leads to a lawsuit that results in the Willowbrook Consent Decree of 1975, which creates a detailed system of monitoring and oversight of all residents living there at that time, to be met until the last of the "class clients," as they are sometimes referred to, pass on. The property has since been sold to a college.

1972 ◆ Paul Hunt's call for a consumer group to promote the views of actual and potential residents of institutional homes for the disabled in the United Kingdom results in the establishment of the Union of the Physically Impaired against Segregation (UPIAS). The group's aim is to formulate and publicize plans for alternative forms of support in the community. Hunt is regarded by many disability activists as the founder of the modern disabled people's movement.

1972 ◆ New Zealand: Three key pieces of legislation pass have long-term effects on the disabled community: the 1972 no-fault Accident Compensation Act that provides monetary compensation to victims based on level of impairment suffered; the 1975 Disabled Persons Community Welfare Act, giving assistance to disabled people, parents, and guardians, as well as voluntary associations; and the Human Rights Act of 1977, which does not include disability as a recognized grounds for discrimination. Today, disabled populations in New Zealand continue to fight to establish an identity as disabled people rather than a group needing "welfare." One task is to promote legislation that includes disability as a group against whom discrimination is outlawed.

1973 ◆ The Rehabilitation Act of 1973 lays the foundation for the disability rights movement. Its Section 504 asserts that people with disabilities have equal rights that prevent discrimination based on their disability in programs or activities that receive federal funding. This is the first major nationwide antidiscriminatory legislation designed to protect disabled Americans. These rights are further protected with the landmark Americans with Disabilities Act (ADA) of 1990.

Section 501 of the Act requires affirmative action and nondiscrimination in employment by federal agencies of the executive branch. Section 502 creates the Access Board, which grows out of the 1965 National Commission on Architectural Barriers to Rehabilitation of the Handicapped. As a result of the commission's June 1968 report, Congress enacts the Architectural Barriers Act (ABA). Section 503 requires that to receive certain government contracts, entities must demonstrate that they are taking affirmative action to employ people with disabilities. The enduring hallmark of the act, Section 504, provides that no otherwise qualified individual with a disability shall, solely by reason of his or her disability, be excluded from the participation in, denied the benefits of, or subjected to discrimination under any program or activity receiving federal funds. However, it would take five years of lobbying and protesting before the American Coalition of Citizens with Disabilities (ACCD) wins the release of regulations that allow Section 504 to be implemented.

The Act is in many ways the direct predecessor to the ADA. However, the primary focus is vocational training and rehabilitation, and over the next half-century, disability law and advocacy move from the medical (medical issues) and vocational (often a justification for welfare and benefits) models to a civil rights model, which seeks to remove the barriers that impede the full integration of people with disabilities into society.

1973 ◆ The term *mainstreaming* emerges within the educational jargon associated with the Education for All Handicapped Children Act (EHA), the early U.S. legislation subsequently reauthorized as the Individuals with Disabilities Act (IDEA) in 1990.

1973 ◆ Ronald Mace is the driving force behind the creation of the first accessible state building code in the United States (North Carolina, 1974) and in the drafting of national accessibility codes and

standards. He coins the term *universal design* to capture and promote his expanded philosophy of "design for all ages and abilities"—curb cuts being his favorite example.

1973 Washington D.C. introduces the first handicap parking stickers. The Federal-Aid Highway Act funds curb cuts.

1974 First Lady Betty Ford and investigative reporter Rose Kushner are diagnosed with breast cancer. They help break the public silence on this topic. In 1954, Terese Lasser begins Reach to Recovery, a program of volunteers who have previously undergone radical mastectomies who provide emotional support to hospitalized women who have just had the operation. Today, one in eight women is diagnosed with breast cancer during her lifetime.

1975 The Education for All Handicapped Children Act, the first separate federal legislation authorizing special education for children and youth, passes, due, in part, to the advocacy efforts of a group of parents. In 1990, it becomes known as the Individuals with Disabilities Education Act, or IDEA.

1975 The Developmentally Disabled Assistance and Bill of Rights Act, providing federal funds for programs that provide services for people with developmental disabilities, passes.

1975 The Association of Persons with Severe Handicaps (TASH) is founded. It calls for the end of aversive behavior modification and deinstitutionalization of people with disabilities.

1975 The UN General Assembly adopts the Declaration on the Rights of Disabled Persons, which states that all persons with disabilities have the same rights as other people. This document is not legally binding and can be attributed in part to a UN Ad Hoc Committee set up in 2001 to consider a Convention on the Rights of Disabled Persons that is legally binding.

1975 United Kindom: The Union of the Physically Impaired against Segregation (UPIAS) publishes a paper that redefines the term *disability,* which becomes known as the social model of disability as it radically transforms the way disabled people see themselves and their place in society.

1976 The Higher Education Act of 1965, which establishes grants for student support services aimed at fostering an institutional climate supportive of low-income and first-generation college students, is amended to include individuals with disabilities. In March 1978, the Association on Handicapped Student Service Programs in Post-Secondary Education is founded. It later becomes the Association on Higher Education and Disability (AHEAD).

1976 Sponsored by Ralph Nader's Center for the Study of Responsive Law, the Disability Rights Center is founded in Washington D.C.

1977 Protesting the federal government's delayed enactment of the rules and regulations for the implementation of the Rehabilitation Act of 1973, disabled activists on April 1 organize protests at the federal offices of the Department of Health and Human Services in various cities across the United States. In San Francisco, protesters hold the regional offices hostage for 28 days, gaining national attention and resulting in an agreement with federal officials for the rapid establishment of the rules and regulations to implement Section 504 of the Act.

1977 Max Cleland is appointed to head the U.S. Veterans Administration. He is the first severely disabled person to hold this post.

1977 S. Z. Nagi defines *disability* as an individual's performance of tasks and activities related to achievement of social roles—a distinct concept, different from *impairment*. It is further formalized with the introduction of the World Health Organization's International Classification of Impairments, Disabilities, and Handicaps in 1980 and further refined in 2001 in its International

Classification of Functioning, Disability, and Health. Nagi's model is used as the basis for the Americans with Disabilities Act, for almost all disability social policy in the United States, and for statistics at the United Nations and in Europe.

1978 ◆ The Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 and the Adoption Assistance and Child Welfare Act of 1980 promote the adoption of children with special needs, including disabilities.

1978 ◆ The Atlantis Community, the second independent living center in the country after Berkeley, is established in Denver, Colorado, in 1975. On July 5–6, 1978, twenty disabled activists from the Atlantis Community block buses with their wheelchairs and bodies and bring traffic to a standstill at a busy downtown intersection. This act of civil disobedience results in the American Disabled for Accessible Public Transit, the original name for the American Disabled for Attendant Programs Today, or ADAPT.

1978 ◆ Legislation creates the National Institute on Handicapped Research. In 1986, it is renamed the U.S. National Institute on Disability and Rehabilitation Research (NIDRR). Its mission is to contribute to the independence of persons of all ages who have disabilities. It is located in the Department of Education under the Office of Special Education and Rehabilitation Services.

1978 ◆ The World Health Organization starts to promote the concept of community-based rehabilitation (CBR) as a means of helping people with disabilities in the developing world. It emerges, in part, from the WHO primary health care campaign Health for All by the Year 2000. Around the same time, in Western countries, home-visiting programs in which a trained worker regularly visits the family to advise on ways of promoting child development become one of the success stories of modern disability services. Among the best-known programs are those based on a model originating in Portage, Wisconsin, and now used in many countries.

1978 ◆ England: The Warnock report introduces the term *special needs education.* It marks a major shift in organizing educational services for children with disabilities and results in the new conceptualization of special needs education. This change is confirmed internationally by the Salamanca Statement and Framework for Action on Special Needs Education at the UNESCO's Conference held in Salamanca in 1994. This theoretical shift is marked with the change of the term *integration* to *inclusion* or *inclusive education.*

1978 ◆ USSR: The Action Group to Defend the Rights of the Disabled is established to advocate for legal rights for Soviets with disabilities.

1979 ◆ The Disability Rights Education and Defense Fund (DREDF) establishes itself as a leading cross-disability civil rights law and policy center. It is founded by people with disabilities and parents of children with disabilities. Because its philosophy is closely aligned with other civil rights struggles, in 1981, DREDF is invited to join the executive committee of the national's largest coalition of civil rights groups, the Leadership Conference on Civil Rights. In 1987, DREDF establishes the Disability Rights Clinical Legal Education Program and begins teaching disability rights law at the University of California's Boalt Hall School of Law.

1979 ◆ The National Alliance for the Mentally Ill (NAMI) is founded. NAMI is an advocacy and education organization.

1979 ◆ Germany: The first Cripples' Group is founded as a cross-disability group with emancipatory aims. In an attempt to reinterpret disability in positive terms, the cofounders choose the term *Krüppel* over handicapped or disabled.

1979 ◆ Nicaragua: The Organization of the Revolutionary Disabled is set up in the wake of the Sandinista victory.

1980 ◆ The California Governor's Committee on Employment of People with Disabilities and entertainment and media industry professionals establish the Media Access Office (MAO).

1980 ◆ About the time Congress is considering passage of the ADA (1990), marketers begin to acknowledge the economic potential of the disabled community; consequently, the appearance of disabled characters in consumer goods advertising mushroom and ability-integrated advertising becomes much more commonplace. Organizations such as MAO and NOD (National Organization on Disability) provide advertising strategies and guidance.

1980 ◆ The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), an interdisciplinary association composed of individuals interested in technology and disability, is founded.

1980 ◆ The World Health Organization's International Classification of Impairments, Disabilities, and Handicaps (ICIDH), a groundbreaking, but controversial, classification system is tentatively released for trial purposes with the goal of uniform information collection worldwide. It has a negligible impact on disability statistics or data collection; however, researchers argue that it is a vast improvement over available tools. It is renamed and vastly revised in 2001.

1980 ◆ England: Graeae Theatre Group, composed of disabled actors, directors, and other theater professionals, is founded in London by Nabil Shaban and Richard Tomlinson. It takes its name from the the Graeae of Greek mythology, three gray-haired sisters who shared one eye and one tooth. Graeae's first production is *Sideshow*.

1980 ◆ Netherlands: The Liliane Foundation starts by assisting 14 children. In 2002, it helps 31,982 children spread over 80 countries. The Foundation's efforts are directed primarily toward children with disabilities living at home. Its aim is to have direct contact with the child within the home situation and to assist the personal growth and happiness of the child, thus providing "tailor-made" assistance.

1980 ◆ Taiwan: The Physically and Mentally Disabled Citizens Protection Law is promulgated. It guarantees legal rights for the disabled and creates a significant improvement in their welfare. Although most of the disabled people in Taiwan still struggle to earn their due respect, today, public awareness of this group is emerging gradually and significantly.

1980 ◆ United Kingdom and Europe: The Black Report (*Report of the Working Group on Inequalities in Health)* is published. Among other groups it targets disabled people for better conditions that lead to better health. The report does not find favor with the Conservative government, but begins to be implemented under the Labour government in 1997. With its central theme of equity, the report plays a central role in the shaping of the World Health Organization's Common Health Strategy of the European Region.

1981 ◆ The Reagan Administration begins to amend and revoke disability benefits, a policy that continues throughout his administration and leads several disabled people who are in despair over the loss of their benefits to commit suicide.

1981 ◆ Justin Dart, recognized as the founder of the Americans with Disabilities Act (ADA, 1990), is appointed to be vice-chair of the National Council on Disability. The council drafts a national policy on equal rights for disabled people; the document becomes the foundation of the ADA.

1981 The Committee on Personal Computers and the Handicapped is established in Illinois, an indicator of the disabled community's interest in information technology (IT) accessibility, but in order to stimulate the development of suitable products, activists lobby for legislative protections, which are included in the Americans with Disabilities Act of 1990. In 2000, a suit brought by the National Federation of the Blind against AOL is suspended when AOL agrees to make its software accessible by April 2001. The World Wide Web Accessibility Initiative (WAI) launches in 1997. It raises the level of awareness of disability accessibility issues within the Internet community, especially among those who design and implement web pages.

1981 The first reported cases of AIDS in the United States appear in June. Today, the World Health Organization estimates that worldwide, approximately 40 million people are living with HIV/AIDS; 22 million men, women, and children have died; and 14,000 new infections are contracted every day. Around the world, in the year 2003, the AIDS epidemic claims an estimated 3 million lives, and almost 5 million people acquire HIV, 700,000 of them children. Currently, 6 million people infected with HIV in the developing world are estimated to need access to antiretroviral therapy to survive, but only 400,000 have this access.

1981 Disabled Peoples' International (DPI) is officially founded at a meeting in Singapore. The establishment of such international organizations around this time represents the disability movement becoming a global social movement instead of a national one. DPI is directed by persons with disabilities working in human rights advocacy. It sponsors World Assemblies, which are held every four years to develop a multiyear action plan. The most recent one is held in 2002 in Sapporo, Japan, where delegates from more than 100 countries come together. A leading slogan for DPI and other disability groups, coined in the early 1990s, is "nothing about us without us."

1981 The International Year of Disabled Persons encourages governments to sponsor programs that assimilate people with disabilities into mainstream society. Despite the positive worldwide effects it has, the UN program also creates some angry activists with disabilities who protest against the charity approach officially adopted for the event. Consequently, the activists build their own infrastructure consisting of counseling and advocacy facilities as well as job creation programs.

1981 Australia: Australia's modern disability policy takes shape after the 1981 International Year of Disabled Persons. Examples: The 1980s see a shift away from institutional care; the Commonwealth Disability Service Act provides a framework for the provision of disability services; and in 1991, the federal Disability Reform Package maximizes the employment of disabled. In 1995, a legal decision represents a watershed in telecommunications policy for people with disabilities when a commission's inquiry finds the national carrier, Telstra, guilty of discrimination against people with severe hearing or speech impairments. The success of the action results in the Telecommunications Act of 1997, which includes new provisions for the deaf community.

1981 Mexico: The Program of Rehabilitation Organized by Disabled Youth of Western Mexico begins as a rural community-based rehabilitation program.

1981 Soweto: The Self Help Association of Paraplegics begins as an economic development project.

1981 United Kingdom: Disabled people set up the British Council of Disabled Persons (BCOPD), the United Kingdom's national organization of disabled people, to promote their full equality and participation in UK society.

1981 Zimbabwe: The National Council of Disabled Persons, initially registered as a welfare organization, becomes a national disability rights group.

1982 Disability Studies originates with the formation of the Society for the Study of Chronic Illness, Impairment, and Disability. In 1986, it officially changes its name to the Society for Disability Studies (SDS). Disability Studies is a critical field of study based in human and social science.

1982 *In re Infant Doe* (commonly known as the Baby Doe case) launches the debate as to whether parents or medical authorities should choose to let a disabled infant die rather than provide the necessary medical treatment and nourishment essential to sustain life. In response to this and other cases, the U.S. Department of Health and Human Services creates a rule maintaining it unlawful for any federally funded hospital to withhold medical treatment from disabled infants. In 1984, the U.S. Congress enacts the Child Abuse Amendments, which calls for the medical treatment of newborns with disabilities unless the child would die even with medical intervention. The issue makes it to the U.S. Supreme Court in 1986 with the *Bowen v. American Hospital Association* case. The Court holds that denying treatment to disabled infants does not constitute legally protected discrimination under Section 504 of the Rehabilitation Act and that hospitals and physicians are to implement the decision of the parents. The decision results in the passage of the Child Abuse Prevention and Treatment Act Amendments of 1984. In the year 2000, a scholar argues that the Amendments, presidential commission writings, and disability advocates "have all combined to ensure that most babies who can benefit from medical interventions do receive them."

1982 Disability Awareness in Action (DAA) and other groups such as the Disabled Peoples' International (DPI) and International Disability Alliance (IDA) are the driving force behind the globalization of disability issues through the World Program of Action (1982), the United Nations Standard Rules of Equalization of Opportunities for People with Disabilities (1993), the World Summit for Social Development (1995), and the Education for All Framework for Action (2000), as well as the current campaign to secure a UN convention on the rights of disabled people.

1982 The National Council on Independent Living (NCIL) is formed in the United States. It provides an excellent example of leadership for people with disabilities by people with disabilities.

1982 Canada: The Charter of Rights and Freedoms section of the Constitution provides protection to persons with disabilities.

1982 France: Handicap International is founded in Lyon. It is active in various areas associated with all the causes of handicaps, both traumatological (land mines, road accidents) and infectious (polio, leprosy). In the 1990s it begins working on mental disability issues as a result of experience with Romanian orphanages and the war in the Balkans. In 1992, Handicap International creates its first two mine clearance programs and in 1997 it is the joint winner of the Nobel Peace Prize for its leading role in the fight against landmines.

1983 Rights-based approaches to disability rapidly gain currency in many developing countries since the UN Decade of Disabled Persons, 1983–1992. UNESCAP's Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-Based Society for People with Disabilities in Asia and the Pacific sets the priorities for the extended Decade of Disabled Persons, 2003–2012.

1983 Access and accessibility are concepts discussed throughout the World Programme of Action Concerning Disabled Persons passed by the UN General Assembly. The General Assembly in 1993 passes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

1983 England: The first Covent Garden Day of Disabled Artists is held in London.

1983 Thailand: DPI-Thailand is established.

1984 The Access Board issues the "Minimum Guidelines and Requirements for Accessible Design," which today serves as the basis for enforceable design standards. The 1990 Americans with

Disabilities Act (ADA) expands the board's mandate to include developing the accessibility guidelines for facilities and transit vehicles. The Rehabilitation Act Amendments of 1998 give the Access Board additional responsibility for developing accessibility standards for electronic and information technology. In 2001, Section 508 of federal law establishes design standards for federal websites, making them accessible to individuals with disabilities.

1985 The U.S. Department of Health and Human Services issues the first comprehensive national minority health study, which shows racial disparity in health and concludes that the difference in mortality is not acceptable. In 1998, studies indicate that racial disparity has not improved as much as hoped; consequently, President Bill Clinton launches an initiative that sets a national goal of eliminating disparities in six key areas by the year 2010. Some of these areas include diseases and conditions considered to be disabling as well as life threatening.

1986 The Air Carrier Access Act (ACAA) passes. It requires the U.S. Department of Transportation to develop new regulations that ensure that disabled people are treated without discrimination in a way consistent with the safe carriage of all passengers. The relevant regulations, Air Carrier Access rules, are published in March 1990.

1986 The National Council on the Handicapped publishes its report *Toward Independence.* It recommends that "Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities" and suggests that the law be called "the Americans with Disabilities Act." In its 1988 follow-up report, *On the Threshold of Independence,* the council takes the somewhat unusual step of publishing its own draft of the ADA bill.

1986 The Equal Opportunities for Disabled Americans Act allows recipients of federal disability benefits to retain them even after they obtain work, thus removing a disincentive that keeps disabled people unemployed.

1986 Australia: The Disability Services Act provides that a person with disability has the right to achieve his or her individual capacity for physical, social, emotional, and intellectual development. In 1992, the Disability Discrimination Act supports nondiscrimination in education and training. It also makes it unlawful to discriminate in relation to access to premises, including public transportation.

1986 Canada: The Employment Equity Act mandates the institution of positive policies and practices to ensure that persons in designated groups, including persons with disabilities, achieve at least proportionate employment opportunities.

1986 England: The first issue of the magazine *Disability Arts in London* (DAIL) is produced in London.

1986 Southern Africa: The Southern Africa Federation of the Disabled is formed as a federation of nongovernmental organizations of disabled persons.

1988 The Technology Act (Technology-Related Assistance for Individuals with Disabilities Act of 1988 and its 1994 amendments), and, in 1998, the Assistive Technology Act (AT) provide financial assistance to states to support programs of technology-related assistance for individuals with disabilities of all ages. The1988 act defines *assistive technology* (AT). The Americans with Disabilities Act of 1990 prohibits discrimination against people with disabilities in employment, public institutions, commercial facilities, transportation, and telecommunications, which includes accessibility to all entrances, bathrooms, program areas, and parking spaces as well as interpreters for the deaf and Braille and large-print materials for the blind. The Telecommunications Act of 1996 requires the telecommunication industry to make equipment that will support transmission of information in forms accessible to people with disabilities including broadband and television program captioning. By 2000, approximately 10 percent of the U.S. population uses AT devices and/or modifications to their home, work, or school that allow them to participate in major life activities.

1988 ◆ Congress introduces a series of amendments to the Civil Rights Act of 1968, including a prohibition of housing discrimination against people with disabilities. These amendments are known as the Fair Housing Act Amendments of 1988.

1988 ◆ China: Deng Pufang, a wheelchair user and son of the late Chinese leader Deng Xiaoping, is the driving force behind a series of laws and programs initiated to improve life for the disabled. In 1984, he sets up the China Welfare Fund for Disabled Persons and, in 1988, the China Disabled Persons' Federation, which endeavors to improve public images of disabled people. Today, there are 60 million disabled people in China.

1989 ◆ The European Network on Independent Living (ENIL) is set up. It focuses on personal assistance as a key component of independent living.

1990 ◆ ADAPT, the American Disabled for Attendant Programs Today, originally called the American Disabled for Accessible Public Transit, continues to gain public awareness through tactics of civil disobedience until regulations are finally issued with the passage of the Americans with Disabilities Act (ADA).

The ADA passes, after ADAPT uses tactics of civil disobedience, in the tradition of other civil rights movements, in one of the largest disability rights protests to date (600 demonstrators), the "Wheels of Justice March," during which dozens of protesters throw themselves out of their wheelchairs and begin crawling up the 83 marble steps to the Capitol to deliver a scroll of the Declaration of Independence. The following day 150 ADAPT protesters lock wheelchairs together in the Capitol rotunda and engage in a sit-in until police carry them away one by one.

George H.W. Bush signs the ADA on July 26. It provides employment protections for qualifying persons with disability. It is the most prominent and comprehensive law prohibiting discrimination on the basis of disability in the United States, expanding the mandate of Section 504 of the Rehabilitation Act of 1973 to eliminate discrimination by prohibiting discrimination in employment, housing, public accommodations, education, and public services.

In June 2000, the National Council on Disability issues a report, *Promises to Keep: A decade of Federal Enforcement of the Americans with Disabilities Act,* which includes 104 specific recommendations for improvements to the ADA enforcement effort. On December 1, 2004, the council issues a final summary report, *Righting the ADA,* in order to address "a series of negative court decisions [that] is returning [Americans with disabilities] to 'second-class citizen' status that the Americans with Disabilities Act was supposed to remedy forever."

1990 ◆ The ADA requires public entities and businesses to provide effective communication to individuals with disabilities. Title IV of the ADA mandates that nationwide telecommunication systems be accessible to persons with speech or hearing disabilities. The Federal Communications Commission (FCC) requires relay services to be in place by July 26, 1993. The Telecommunications Act of 1996 adds provisions to the Communications Act of 1934 that requires manufactures and providers of telecommunications equipment and services to ensure accessibility to persons with disabilities. In 2000, President Bill Clinton establishes regulations governing the accessibility to people with disabilities of the electronic and information technology used within the federal government.

1990 ◆ The Individuals with Disabilities Education Act (IDEA) is enacted. It guarantees the right to free and appropriate education for children and youth with disabilities and focuses on higher expectations, mainstreaming students where possible, and an increased federal rule in ensuring equal educational opportunity for all students. IDEA requires schools to provide a free and appropriate public education to eligible children with disabilities. It also requires schools to develop an individualized education plan (IEP) for each child and placement in the least restrictive environment (LRE) for their education. IDEA is amended in 1997 and reauthorized again in 2004 as the Individuals with Disabilities Education Improvement Act.

1990 Legislation establishes the National Center for Medical Rehabilitation Research (NCMRR), whose mission is to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of persons with disabilities. It has primary responsibility for the U.S. Government's medical rehabilitation research that is supported by the National Institutes of Health (NIH).

1990 The World Declaration on Education for All (EFA) is adopted in Jomtien, Thailand, by more than 1,500 persons representing the international community. Article 23 of the UN Convention on the Rights of the Child states that disabled children have the right to a "full and decent life" and that member nations provide free education and training to disabled children whenever possible in order to provide the "fullest possible social integration and individual development." UNESCO is the lead UN organization for special needs education.

1990 Korea: The disability movement celebrates the passage of the Employment Promotion Act for People with Disabilities. The government imposes control over the disabled population in the 1960s and 1970s by forwarding institutionalization under the banner of "protection," promoting sterilization, and violating the rights of disabled people in general. The 1981 International Year of Disabled Persons influences the government, and new laws, such as the Welfare Law for Mentally and Physically Handicapped, are enacted, and the human rights of disabled people becomes the dominant rhetoric of the disability movement.

1990 United Kingdom: The National Disability Arts Forum is launched at the UK-OK Conference at Beaumont College in Lancashire, UK.

1991 The Resolution on Personal Assistance Services is passed at the International Personal Assistance Symposium. Personal assistance services are the most critical services for individuals. Critical aspects of these services are that they must be available up to 24 hours a day, 7 days a week, to people of all ages, and with access to governmental payments. In the United States alone, personal assistance services affect the lives of more than 9.6 million citizens with disabilities.

1991 Australia: The federal Disability Reform Package is introduced; the Disability Discrimination Act, which covers issues of discrimination in education, is enacted in 1992; and the Commonwealth Disability Strategy, designed to provide equal access to government services for people with disabilities, is first introduced in 1994 and then revised in 2000. During the 1990s similar discrimination legislation emerges in other countries, such as New Zealand's Human Rights Act, the U.K.'s Disability Discrimination Act, Israel's Disabled Persons Act, Canada's Human Rights Act, and India's Disabled Person's Act.

1991 China: The most important laws and initiatives reside in the 1991 Law on Protection of Disabled Persons and a series of National Work Programs for Disabled Persons (1988, 1991, 1996, 2001), which integrate disability into the government's Five-Year Plans. China participates heavily in the United Nations Decade of Disabled Persons, 1983–1992, and initiates the Asia Pacific Decade of the Disabled Persons, 1993–2002. China continues to collaborate with UN projects involving the disabled and will host the 2007 International Special Olympics in Shanghai.

1991 Serbia and Montenegro: From the 1960s to the 1980s, post–World War II Yugoslavia is lauded for being a socially advanced nonaligned nation, but the contemporary wars that decimate Yugoslavia begin in 1991, and today there are more than one million disabled citizens, refugees, and casualties due to the wars. Disabled people in Serbia and Montenegro (formally named the Federal Republic of Yugoslavia—FRY) are left with shattered pieces of the spent past with little hope for the near future. Although the FRY constitution prescribes special protection of disabled persons in accordance with legal provisions and Serbia is party to numerous UN documents and acts, a disabled expert in 2004 admits that discrimination against persons with disability in Serbia and Montenegro is a

long-term problem that people without disability tend to ignore. Two of the most effective advocacy groups making in-roads today are the Association of Students with Disabilities and the Center for Independent Living in Belgrade.

1992 ◆ The UN Economic and Social Commission of Asia and the Pacific (ESCAP) proclaims a 10-year program known as the Asian and Pacific Decade of Disabled Persons 1993–2002 with goals of full participation and equality for persons with disabilities.

1993 ◆ The United Nations publishes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which becomes the international legal standards for disability programs, laws, and policies. Although not legally enforceable this instrument sets an inclusive and antidiscriminatory standard that is used when national policies are developed. It marks a clear shift from the rehabilitation and prevention paradigm to the human rights perspective on disability.

1993 ◆ Slovak Republic: The Czech and Slovak Republics separate into two independent countries. They both join the European Union in 2004. In Slovakia, a large number of highly innovative and resourceful grassroots nongovernmental organizations emerge to address the human rights, quality-of-life, and independent living priorities of citizens with disabilities. They pursue this mission, however, with extremely limited resources and with varying degrees of support from a multiparty parliament.

1993 ◆ Sweden: The Independent Living Institute (ILI) is founded.

1994 ◆ Two networks, one for elderly persons and the other for persons with disabilities, join together to form the U.S. National Coalition on Aging and Disability. In following years, policy makers and advocates begin to see the benefits of merging some services.

1994 ◆ Germany: The disability rights movement is successful in using for its own aims the reform of the German constitution, which is made necessary by the reunification process. An amendment to the constitution forbids discrimination on the grounds of disability. Other such laws as the Rehabilitation of Participation Law (2001) and the Federal Equal Rights Law (2002) are formulated with the active contribution of disability rights activists, and in 2003, the official German program of the European Year of People with Disabilities is organized by a prominent activist.

1994 ◆ Sweden: The Swedish Disability Act (LSS) comes into force. It expands the 1985 Special Services Act. The LSS is also more ambitious than its predecessor, calling for “good living conditions” rather than just an “acceptable standard of living.”

1995 ◆ The National Council on Disability, a federal agency, makes recommendations to the president and Congress on disability issues. Among other issues, it calls for the end to the use of aversives (techniques of behavior control such as restraints, isolation, and electric shocks) because they are abusive, dehumanizing, and psychologically and physically dangerous. Other organizations follow, such as the Autism National Committee in 1999, TASH in 2004, and the International Association for the Right to Effective Treatment in 2003.

1995 ◆ The Commission for Case Management Certification (CCMC) incorporates. Case management is a process of care planning and coordination of the services and resources used by people with disabilities and their families.

1995 ◆ Europe: The Association for the Advancement of Assistive Technology in Europe (AAATE) is founded as an interdisciplinary association devoted to increasing awareness, promoting research and development, and facilitating the exchange of information. AAATE is composed of more than 250 members from 19 countries. It interacts with sister organizations in North America, Japan, and Australia to advance assistive technology worldwide. The Tokushima Agreement, signed in 2000 by AAATE, the Rehabilitation Engineering and Assistive Technology Society of North America

(RESNA), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation and Assistive Technology Association (ARATA), promotes exchange of information and collaboration.

1995 United Kingdom: The campaign for antidiscrimination legislation begins in earnest with the emergence of the disability movement in the late 1970s. The Disability Discrimination Act of 1995 (DDA) together with the Disability Rights Commission Act of 1999 constitute the primary source of antidiscrimination legislation for disabled people in the United Kingdom. The Disability Discrimination Act 2005 extends the protection.

1996 There are 1.4 million fewer disabled older persons in the United States than would have been expected if the health status of older people had not improved since the early 1980s.

1996 Advocates for mental health parity such as the National Alliance for the Mentally Ill (NAMI; 1979) believe that mental illnesses are real illnesses and that health insurance and health plan coverage for treatment should be equal with coverage of treatment for all other illnesses. Due in part to advocacy, the Mental Health Parity Act becomes law in 1996. In 1999, mental illness ranks first in causing disabilities among many industrialized nations, including the United States, which experiences a loss of productivity in this year of $63 billion. In the United States, 5 to 7 percent of adults suffer from serious mental disorders and 5 to 9 percent of children suffer from serious emotional disturbances that severely disrupt their social, academic, and emotional functioning.

1996 Costa Rica: Approval of a law called Equal Opportunities for People with Disabilities is a turning point for the population with disabilities, which is among the most excluded sectors of society. The law is inspired in part by the United Nations Standard Rules on the Equalization of Opportunities for Disabled People (1993). Disability experience in Costa Rica is definitely transformed as a result of the mandates of this generic law, as people with disabilities and their families start to use this legal instrument as a strategy to empower themselves.

1996 Europe: Created in 1996, the European Disability Forum (EDF) is today the largest independent, trans-European organization that exists to represent disabled people in dialogue with the European Union (EU) and other European authorities. Its mission is to promote equal opportunities for disabled people and to ensure disabled citizens full access to fundamental and human rights through its active involvement in policy development and implementation in the EU. The EDF has national councils in 17 European countries and has 127 member organizations. The European Year of People with Disabilities 2003 is one of the EDF's most important campaigns.

1996 India: The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, becomes law. It is the first legislation for equal opportunities for disabled people. Prior to this, disabled persons receive services but not legal protection. Improvements in conditions begin in 1981 with the International Year of Disabled Persons. India is a signatory to the UN resolution of 1976 establishing it and is thereby committed to improving the lot of the disabled. The Lunacy Act of 1912 is repealed and the National Mental Health Act is passed in 1987. Nonetheless, with approximately 70 million disabled people residing in India (in a population of over a billion), the government does not include the domain of disability in the 2001 census, which reflects the attitudinal barriers in acknowledging the disabled identity.

1997 Government expenditures on behalf of persons with disabilities may total as much as $217.3 billion (taking into account the costs that would be expected among persons with disabilities in the absence of the disability), the equivalent of 2.6 percent of the gross domestic product in the United States for 1997.

1997 The landmark 1997 UNESCO Universal Declaration on the Human Genome and Human Rights frames the actual application of the new scientific developments raised by genetics. As a policy

statement, it provides the first signs that genetics will be applied in ways that maintain human rights. In 2003, the Council of Europe and the council's Steering Committee in Bioethics issue policy statements in a working document titled Application of Genetics for Health Purposes. In the case of gene therapy, in 1994, the Group of Advisors on the Ethical Implications of Biotechnology of the European Commission voices concern regarding equity, maintaining that all genetic services that are available for the entire population should be equally available for persons of disability. Today, UNESCO's Human Genome Organization's Ethics Committee, the World Health Organization, the Council of Europe, and consumer organizations such as Inclusion International, Rehabilitation International, and Disabled Peoples' International play major roles in translating genetic innovations into health service and public health fields, helping develop policies that focus on the general recognition, respect, and protection of the rights to which all people, whether disabled or nondisabled, are entitled. Concerns related to the possible undermining of human rights are expressed in 2003 when Disabled People's International demands a prohibition on compulsory genetic testing.

1997 ◆ Colombia: The General Act for People with Disabilities, also known as the Disability Act: Law for Opportunity, passes. The 2003–2006 National Plan of Attention to Persons with Disabilities estimates that 18 percent of the general population has some type of disability. Despite the existence of at least 37 disability-related legal policies (2001), the government provides limited spending on programs that protect the rights of people with disabilities, and the lack of enforcement of rights remains a major concern. Today's awareness efforts include marathons with the participation of the general population to raise money for educational programs for children with special needs, Special Olympics, new organizations such as the Colombian Association for the Development of People with Disabilities, and media awareness campaigns.

1998 ◆ President Bill Clinton issues an executive order ensuring that the federal government assumes the role of a model employer of adults with disabilities.

1998 ◆ President Clinton signs into law the Rehabilitation Act of 1973 Amendments. Section 508 requires that electronic and information technology (EIT), such as federal websites, telecommunications, software, and information kiosks, must be usable by persons with disabilities.

1998 ◆ Ireland: The Irish Employment Equality Act entitles all individuals, including disabled persons, equal treatment in training and employment opportunities. The Education Act of 1998 requires schools to provide education to students that is appropriate to their abilities and needs. The Education for Persons with Disabilities Bill passes in 2003. A Disability Bill published in 2001 fails to underpin a rights-based approach and is withdrawn amid a storm of protest in 2002; a redrafting of a new Disability Bill is suffering from continuing delays. Traditionally, Irish voluntary organizations play a reactionary role in the development of services for people with disabilities and a key role as pressure groups trying to keep disability issues on the political agenda.

1999 ◆ The National Center on Physical Activity and Disability (NCPAD) is established as an information and resource center that offers people with disabilities, caregivers, and professionals the latest information on fitness, recreation, and sports programs for people with disabilities.

1999 ◆ Established by a panel of experts brought together to evaluate the UN Standard Rules on the Equalization of Opportunities for Persons with Disability, the International Disability Alliance (IDA) encourages cross-disability collaboration and supports the participation of international disability organizations in the elaboration of a proposed UN convention on disability.

1999 ◆ England: The first disability film festival, Lifting the Lid, is held at the Lux Cinema in London.

2000 The National Telability Media Center collects documentation of 3,000+ newsletters, 200 magazines, 50 newspapers, 40 radio programs, and 40 television programs dedicated to disability in the United States alone. *The Ragged Edge, Mainstream* (Internet-based), and *Mouth* are examples of disability rights-focused publications.

2000 *Healthy People 2000,* the second edition of the Surgeon General's report on health promotion and disease prevention (the first edition published in 1979), includes some reference to the health and well-being of people with disabilities, but few data are available. In the mid-1990s, the U.S. Department of Health and Human Services begins a dialogue with the Centers for Disease Control and Prevention to include people with disabilities in the third edition, *Healthy People 2010.* The resulting report includes more than 100 objectives that include "people with disabilities" as a subpopulation for data gathering.

2000 The World Bank, increasingly concerned with how to include disabled persons in the economies and societies of developing nations, establishes an online clearinghouse to make documents concerning the disabled readily available to member nations and the general public and holds its first course on disability issues in 2004 in Guatemala.

2000 Africa: The African Decade of Persons with Disabilities, 2000–2009, is adopted by the Declaration of the Organization of African Unity. The African Network of Women with Disabilities (2001) and the community-based rehabilitation organization CBR Africa Network (CAN) are examples of the many activities that result from the African Decade.

2000 Brazil is one of the few countries to include an entire section on disability in its 2000 census. Results show that 14.5 percent of the population, roughly 24 million people, report having some form of disability, the poorest region, the northeast, reporting the highest percentage and the richest, in the south, the lowest. People with disabilities in the first half of the twentieth century have no voice or representation. In 1932, the first Pestalozzi Society, a community-based school for children with intellectual disabilities, is founded. By the end of the twentieth century, there are 146 Pestalozzi Societies and more than 1,700 chapters of the Association of Parents and Friends of the Exceptional. The first center for independent living is established in 1988 (CVI-RIO). In 1992 and 1995, CVI-RIO organizes two international conferences on disability issues called DefRio, out of which comes "Goals of the ILM," a document that delineates the basis for the independent living movement in Brazil; however, financial support is not provided by the government, creating a struggle for sustainability. Brazil has progressive policies toward disability. The constitution includes sections on the rights of people with disabilities, and laws have been passed with regard to accessibility, education, and employment.

2000 Europe: A European Community directive requires all member states to have introduced antidiscrimination laws in the fields of employment and training by the end of 2006. It seeks to establish a general framework for equal treatment in employment and occupation and to render unlawful discrimination based on, among other categories, disability. The European Union Charter of Fundamental Rights sets out in a single text, for the first time in the EU's history, the whole range of civil, political, economic, and social rights of European citizens. Disability is included in the general nondiscrimination clause (Article 21), but Article 26 specifically states that the Union recognizes and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community.

2000 The Human Genome Project (HGP), an international effort to specify the 3 billion pairs of genes that make up the DNA sequence of the entire human genome, produces its first draft in June 2000. Formally begun in October 1990, it is completed in 2003.

2001 President Clinton declares in Executive Order No. 13217 the commitment of the United States to community-based alternatives for individuals with disabilities. This ensures that the *Olmstead v. L.C.* decision (1999), which mandates the right for persons with disability to live in the least-restrictive setting with reasonable accommodations, is implemented in a timely manner. The executive order directs federal agencies to work together to tear down the barriers to community living.

2001 In the United States, census data indicate that only 48 percent of citizens 25 to 64 years old with severe disabilities have health insurance compared with 80 percent of individuals with nonservere disabilities and 82 percent of nondisabled Americans. Women with disabilities in general are more likely to live in poverty than men. Minorities with disabilities are more likely to live in poverty than nonminorities with disabilities. In 2003, in the United States, about 28 percent of children with disabilities live in poor families compared with 16 percent of all children.

2001 A UN Ad Hoc Committee begins discussions for a legally binding convention under the draft title Comprehensive and Integral Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Its fifth session is held in early 2005.

2001 A new World Health Organization classification of people with disabilities, the International Classification of Functioning, Disability, and Health (ICF), replaces the old International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The ICF definition shifts the focus from disability as an innate deficit ("medical model") to disability as constructed through the interaction between the individual and the environment ("social model"). This shift encourages a focus on the kinds and levels of interventions appropriate to the needs of individuals.

2001 UNESCO launches pilot education projects for disabled children in Cameroon, the Dominican Republic, Egypt, Ghana, India, Madagascar, Mauritius, Nicaragua, Paraguay, South Africa, Vietnam, and Yemen. The global initiative Education for All 2000 has as its primary millennium development goal universal education by the year 2015.

2002 The U.S. Supreme Court rules that executing persons with mental retardation is unconstitutional.

2002 Disabled Peoples' International's 2002 Sapporo Platform, developed by 3,000 delegates from more than 90 countries, urges members to take every opportunity to seek publicity and awareness in order to change negative images of disabled people.

2002 Canada: The Canadian International Development Bank announces the approval of the Canada-Russia Disability Program, a four-year $4 million project, focusing on education, disability studies, social work practice, social policy, and information dissemination.

2003 A national survey that updates the Disability Supplement to the 10-year-old National Health Interview Survey highlights barriers to care among the uninsured. The uninsured are four times as likely to postpone care and three times as likely to go without needed supplies.

2003 The National Association of Social Workers (NASW) issues a policy statement that discusses their core values with respect to working with people with disabilities, including self-determination, social justice, and dignity and worth of the person. The statement emphasizes that social workers are responsible to take action with people who have disabilities in advocating for their rights to fully participate in society.

2003 The Disability Awareness in Action (DAA) database contains a total of 1,910 reports of known abuse affecting nearly 2.5 million disabled people. In the area of education alone, it documents

118 cases affecting 768,205 people in 67 countries. Responding to this documentation and other reports, the United Nations Commission on Human Rights creates the Global Rights campaign to address human rights abuses. Disability rights organizations use this information to insist on a UN convention on the rights of disabled people that would be legally binding on nation-states.

2003 ◆ The International Association for the Study of Pain has more than 6,700 members, representing more than 100 countries and 60 disciplinary fields. Chronic pain is one of the leading causes of recurrent and permanent disability in the developed world today, yet less than 1 percent of the U.S. National Institutes of Health's budget supports research into mechanisms and management of pain. The U.S. Congress declares 2000–2010 the Decade of Pain Control and Research.

2004 ◆ The *Journal of Gene Medicine* (January) reports that 636 gene therapy clinical trials are completed or ongoing, involving 3,496 patients. The first gene therapy clinical trials begin in the early 1990s.

Today ◆ Seventy to eighty percent—approximately 400 million—of the world's disabled people (600 million, or 10 percent of the world's population) live in the developing world, and of the world's poorest of the poor, 20 to 25 percent are disabled. In most countries, 1 out of 10 persons has a disability. Many international efforts are under way to address poverty and disability, such as those of the Action on Disability Development and the Chronic Poverty Research Centre.

Today ◆ E-health is the use of emerging interactive telecommunications technologies such as the Internet, interactive TV, kiosks, personal digital assistants, CD-ROMs, and DVD-ROMs to facilitate health improvement and health care services, including those with disabilities. E-health relies on environments that use a variety of technologies that can compensate for the lack of sensory ability. Telerehabilitation is an example of services delivered information technology and telecommunication networks.

Today ◆ Celebrating difference is the mantra and visible manifestation of disability culture in all regions of the world.

SEARCHING FOR AND EVALUATING WEBSITES

Anne Armstrong

The Internet, or Web, provides a vast number of channels through which researchers can find information on virtually any subject. The expansiveness of the Web can be daunting to new researchers. On the other hand, researchers often assume that they have mastered the Web in its entirety when indeed they have merely scratched the surface in terms of the numbers of resources they have consulted and searches they have performed.

Because the field of disability studies is continually evolving and inherently multidisciplinary, Web searchers can draw on previously conducted research from disciplines within the humanities, social sciences, and health sciences. This guide aims to expose beginning researchers to a mixture of general and subject-specialized Web-based search tools, as well as strategies for performing sophisticated Web searches and criteria for evaluating websites. In addition to its broad subject coverage, the field of disability studies differs from most fields in that many researchers may themselves have disabilities affecting their ability to perform research on the Web. For this reason, this description concludes with an overview of accessibility issues on the Web and suggestions for further reading.

OVERVIEW OF WEB-BASED RESEARCH TOOLS

When approaching Web searching, researchers should be aware of the multitude of search tools available to them, in addition to the varying purposes of these tools. Many users approach Web searching with the assumption that "everything is in Google," but this is a limiting misconception. No single search engine contains everything on the Web. Furthermore, all search engines function differently and rank results differently. Therefore, sampling various search tools increases the comprehensiveness of results on any topic. This discussion outlines multiple types of search tools available on the Web and offers potential starting points for Internet research on issues related to disability studies, whether from a health sciences, social sciences, or humanities perspective.

The Web-based search tools outlined in this chapter include general search engines, subject-specialized search engines, directories, indexes, catalogs, and Listservs. It is important to note that different types of search tools cover different parts of the Web. The Web is composed of layers. The top layer is detectible by general search engines, while a deeper layer termed "the invisible Web" can be penetrated only by specialized search engines, indexes, and catalogs. Readers should be aware that because the Web is in a constant state of flux, currently available resources may become obsolete over time, and newer, more sophisticated search tools will undoubtedly evolve.

General Search Engines

Most people who have searched the Web are familiar with sites such as Google, HotBot, or Lycos, which allow them to enter a string of keywords into a search box to retrieve a list of relevant websites (see Table 1). These sites, referred to as search engines, search the Web by means of a program called a *spider* (also

Table 1 Selected General Search Engines

Name	*URL*
AltaVista	www.altavista.com
Excite	www.excite.com
GO	www.go.com
Google	www.google.com
HotBot	www.hotbot.com
Lycos	www.lycos.com
Yahoo!	www.yahoo.com

called a *robot* or *crawler*). Since search engines tend to index millions of websites, they are most useful for entering specific search terms rather than broad concepts such as disability studies.

While Web searchers tend to pick a favorite search engine and return to it repeatedly, it is important to note that different search engines produce varying results, and that a truly comprehensive Web searcher should compare the results of multiple search engines. The variation between search engines can be attributed to differences between the spiders fueling the search engines as well as differences in the level of indexing and the order in which results are ranked. While some search engines index the full text of documents, others may index only the first page, or merely the *meta-tags*, which are lines of code containing keywords. Web searchers should be aware that developers of websites may intentionally increase their usage of certain words or meta-tags to increase the prominence of their website among search results. This practice has been referred to as *spamdexing* and is most prevalent among the developers of commercial websites advertising products and services. Due to the constant fluctuation of the Web, no search engine is entirely up-to-date; results produced by identical searches can vary greatly from one day to the next, even when one is using the same search engine.

Subject-Specialized Search Engines

Subject-specialized search engines (also referred to as subject portals) developed by educational institutions, associations, government agencies, and corporate entities narrow the broad scope of the Web, providing a focused channel by which researchers can search for information when they have determined the discipline from which their topic stems. Examples of such search engines are listed in Table 2. While subject-specialized search engines index considerably fewer websites and documents than general search engines, the information contained within them has been preselected, ideally by experts within a given field. Many subject-specialized search engines expose searchers to parts of the "invisible Web" not indexed by general search engines. Subject-specialized search engines can ease the research process by whittling down the Web to a more manageable size. However, researchers who use them should take the time to view the criteria for selection of

Table 2 Examples of Subject-Specialized Search Engines

Name	*URL*	*Subject Coverage*
Center for International Rehabilitation Research Information and Exchange (CIRRIE)	http://cirrie.buffalo.edu	Rehabilitation research
FamilyDoctor.org	http://familydoctor.org	Health sciences
FirstGov	www.firstgov.gov	Government
Google's Uncle Sam	www.google.com/unclesam	Government
Health*Web*	www.healthweb.org	Health sciences
Mayo Clinic	www.mayoclinic.com	Health sciences
MedlinePlus	http://medlineplus.gov	Health sciences
National Center for the Dissemination of Disability Research (NCDDR)	www.ncddr.org	Disability studies
Social Science Information Gateway (SOSIG)	www.sosig.ac.uk	Social sciences
Thomas	http://thomas.loc.gov/	Legislative information
Voice of the Shuttle	http://vos.ucsb.edu	Humanities
*Web*MD	www.webmd.com	Health Sciences

information contained within them. This information is usually posted within online "help" or "about" pages on the home page.

Table 3 contains search tools that have been developed distinctly for the purpose of locating specialized search engines by subject.

Table 3 Resources for Finding Subject-Specialized Search Engines

Name	*URL*
CompletePlanet	www.completeplanet.com
Direct Search	www.freepint.com/gary/direct.htm
InfoMine	www.infomine.com
Invisible Web Directory	www.invisible-web.net
Librarians' Index to the Internet	www.lii.org
Search Engine Colossus	www.searchenginecolossus.com

Directories

Directories are hierarchically arranged subject guides composed of websites chosen by or recommended to editors of the directory (Table 4). Usually, directories follow a template in which major subject categories such as health, sciences, social sciences, or humanities are posted on the top-level page. Each of these links leads to lists of narrower subcategories. The links on the second level lead to narrower subcategories, and so on. A sample hierarchy from the directory created by Google (available at http://directory.google.com) lists the following subject breakdown: Society → Disabled → Disability studies.

Directories provide Web searchers with the ability to browse recommended resources in various subject areas without having to enter specific search terms. Other useful attributes of directories are that they often contain summaries and evaluations of websites.

Table 4 Selected Directories

Name	*URL*
eBlast	www.eblast.com
Google Directory[a]	http://directory.google.com
Internet Public Library	www.ipl.org
LookSmart	www.looksmart.com
Yahoo! Directory[a]	www.yahoo.com

a. These sites contain both directories and general search engines.

Article Indexes

Article indexes allow researchers to search by topic for published articles in magazines and scholarly journals. Researchers could certainly locate journal and magazine articles using a freely available search engine such as Google, but they would merely be skimming the surface of what has been published. While the Web provides access to *more* content, it does not provide comprehensive access to research published in journal articles. Article indexes are for the expressed purpose of finding journal articles. With a few exceptions (such as PubMed, an article index of health sciences journals developed and maintained by the National Library of Medicine), article indexes are not freely available on the Web. Libraries purchase subscriptions to multiple article indexes covering a wide spectrum of disciplines. The indexes available through a given library are often dictated by the curriculum of the college or university that the library serves. Thus, large research institutions offer a greater number of specialized article indexes than smaller institutions and public libraries. Due to licensing agreements between article index providers and libraries, off-site access to indexes is usually limited to faculty and students of a college or university. However, there are many libraries that allow members of the public to use their article indexes from within the library. A local public library would be a good starting place for those not connected with academic or commercial organizations.

Since article indexes are proprietary products developed by companies for sale to libraries, they tend to offer specialized search features that are not always available on freely available search engines. These features include subject headings, thesauri, abstracts (summaries of articles), and frequently the full text of articles. Researchers should familiarize themselves with online tutorials, "help" screens, and "about" pages to increase the effectiveness of their searching.

Freely available article indexes relevant to disability studies include the following:

- PubMed: A product of the National Library of Medicine, which includes more than 14 million citations for biomedical articles dating back to the 1950s. URL: http://www.ncbi.nlm.nih.gov/entrez

- CIRRIE: Center for International Rehabilitation Research Information and Exchange, a database containing more than 24,000 citations of international research published from 1990 to the present. URL: http://cirrie.buffalo.edu

Catalogs

While researchers can search indexes to find articles on specific topics, they can search online catalogs to find books. Some catalogs list the books available at individual libraries, while others contain the holdings of multiple libraries and institutions. The individual catalogs of public libraries and universities are usually freely available on the Web. The most comprehensive catalog is called WorldCat, developed by an organization called OCLC (Online Computer Library Center). WorldCat lists books available at public and academic libraries throughout the world. Like most article indexes, WorldCat is not freely available on the Web and must be accessed through a library.

Listservs

Listservs are mailing lists on the Internet that facilitate online discussions on various subjects. They allow researchers within a given field to communicate about scholarly issues via email. People customarily sign up for Listservs by sending an e-mail to the Listserv address stating that they wish to subscribe. Several Listservs related to disability studies are listed in Table 5. In addition, Web searchers can perform a search on a database called tile.net to search for Listservs by topic.

SEARCH STRATEGIES

Since search capabilities vary from site to site, Web searchers should use online "help" screens and tutorials to learn search tips and strategies for improving their search results. Some search techniques common to several Web-based search tools are summarized below.

Quotation Marks

When entering a search, users should enter phrases in quotation marks to stipulate that they would like the results to contain a specific word combination and order. For instance, multiword concepts such as "disability studies," "adaptive technology," and "section 508" should be entered within quotation marks. Proper names can also be entered within quotation marks.

Table 5 Disability Studies Listservs

Name	*URL*
ADA-LAW	http://listserv.nodak.edu/archives/ada-law.html
Disability-Research Discussion List	http://www.leeds.ac.uk/disability-studies/discuss.htm
Disability Studies at Yahoo.com	http://www.groups.yahoo.com/group/disabilitystudies
Disabled Student Services in Higher Education (DSSHE-L)	http://listserv.acsu.buffalo.edu/archives/dsshe-l.html
Women's International Linkage on Disability (D-WILD)	http://groups.yahoo.com/group/d-wild

Truncation

Truncation symbols allow Web searchers to simultaneously search for multiple endings of a given word. For instance, assuming that the asterisk is the designated truncation symbol in a search engine, entering the word "impair*" would produce results including all forms of the word after the root, including "impair," "impaired," "impairment" and "impairments." In addition to adding truncation symbols to the end of words, users may also insert internal truncation symbols if there are potential variations for the spelling of the middle of a word. For instance, entering the word "colo*r" would simultaneously search for the words "color" and "colour." "Help" screens or "search tips" usually list the designated truncation symbol for a given database.

Boolean Logic

Developed by the English mathematician George Boole, Boolean logic is a mathematical framework that Web searchers can apply to broaden or refine their searches. There are three words, or *operators*, that Web searchers can use to combine their keywords to perform more complex searches: AND, OR, and NOT. The three Boolean operators are summarized below, along with potential applications. It is important to read the online "help" section of a database before performing a Boolean search, as Boolean searching does not work in all databases.

Using the Boolean Operator "AND"

Combining words with "AND" narrows a search, as the database retrieves only items that contain *all* the words entered. The second search example below will produce fewer results than the first, since there are three keywords that must appear within the content of each result.

"disability studies" AND theory
"disability studies" AND theory AND history

Using the Boolean Operator "OR"

Entering the term "OR" between keywords stipulates that any, but not all, of the words entered must appear within the search results. Using "OR" is a way of searching for synonyms or related terms when there are multiple words for the same concept. The example below shows how you could broaden your search if you wanted to search for multiple adaptive technology applications in a search engine. The second search example will potentially produce more results than the first, since there is an additional keyword that the results could include.

JAWS OR "Ruby OpenBook"
JAWS OR "Ruby OpenBook" or "window eyes"

Using the Boolean Operator "NOT"

Entering the Boolean operator "NOT" after a word stipulates that the word should not appear within the results. Using "NOT" in a search can be particularly useful if a word is frequently used in multiple contexts and you wish to eliminate results dealing with a particular topic. In the example below, the second search will ideally eliminate items relating to the state of New Mexico, given that the researcher is looking for information on legislation related to disabilities in the country of Mexico. The use of NOT can be too limiting. The second search would eliminate results that discussed both Mexico and New Mexico.

Disabilities AND legislation AND Mexico
Disabilities AND legislation AND Mexico NOT "new mexico"

Nesting

Nesting allows Web searchers to simultaneously search for multiple search terms relating to the same topic. The grouping of synonymous terms within parenthesis is referred to as nesting, as multiple terms relating to the same idea are clustered together as a single concept. When using nesting, the words within the parenthesis are connected by the Boolean operator "OR."

To find information about software for people who are visually impaired, search results are increased by using nesting to group multiple words for each facet of the topic:

(software or "adaptive technology") AND ("visually impaired" or blind)

Plus and Minus Signs

Most general search engines allow users to enter plus or minus signs before a particular word. Entering a plus sign before a word (e.g., +ADA) stipulates that the word must appear within the search results. A minus sign before a word (e.g.,–mobility) stipulates that the word should not appear within the results. Since some search engines also use plus and minus signs as substitutes for Boolean operators, it is important to view online "help" or "search tips."

Search Limits

Most search engines allow users to limit their results by date, language, or document type. Limiting capabilities vary from site to site and are customarily outlined in online "help" screens. In general, article indexes have more sophisticated limiting capabilities than search engines that are freely available on the Web.

EVALUATING WEBSITES

A researcher weighing the quality of a journal article faces a lesser challenge than a researcher considering a website as a potential resource. The publishing industry applies labels to periodicals of varying type: Scholarly journals, popular magazines, trade publications, and newspapers comprise the major categories. Articles submitted to scholarly journals undergo a peer review process by experts in a given field. If in doubt as to the suitability of journal for scholarly purposes, a researcher can consult a directory of periodicals such as *Ulrich's Periodicals Directory,* which indicates whether or not a journal is peer reviewed.

The fact that the Web has no comparable methods of control complicates the task of determining whether a website is appropriate for research purposes. While websites produced by certain types of agencies and organizations certainly undergo a form of *internal*

review, the Web is a free forum; people can post anything they want, and no one has the right to force to take it down if it fails to meet certain standards of quality or accuracy. To complicate the matter, inaccurate or inexpert information can hide like a wolf in the sheep's clothing of sophisticated graphics, layout, and design. The Web has no peer review process to ensure quality. While none of the evaluation criteria outlined below can provide the final word as to the suitability of a website for scholarly use, a researcher who searches the Web with multiple evaluation criteria in mind expedites the process of finding quality information.

Authorship

When determining the credibility of a website, researchers should use multiple techniques to determine the credentials of the author as well as the character of the organization hosting, or sponsoring, the site. If individuals are listed as authors, researchers should take steps to determine their credentials and reputation in the field by performing a search in a general search engine to find biographical information or other documents written about the author. This will also produce references to the author on the sites of other authors within a field. Researchers can also consult a number of biographical sources available at libraries, such as *Who's Who in the America* or sources tailored to particular fields of study, such as *Who's Who in Science and Engineering.*

Website addresses, or URLs (Uniform Resource Locators) can also provide hints as to author affiliations and potential bias. Personal websites are often hosted on commercial ISP (Internet Service Provider) Web servers such as aol.com, or geocites.com. URLs of personal websites often contain first or last names, as well as percent (%) or tilde (~) signs. While personal websites may contain authoritative information, researchers should question why the same content does not appear on a site sponsored by an educational or research organization.. Was the site created as a pastime or to serve as a forum for airing personal views? Or does the site reflect serious scholarship backed up by other credentials and research published in scholarly publications?

Every website URL ends with a *domain name*, usually a series of three letters preceded by a period. The domain name denotes the type of institution that hosts the website and can often provide clues as to the purpose or potential bias of a site. Common domain names include the following:

Educational sites: .edu
Government sites: .gov, .mil, or country codes (e.g., .uk = United Kingdom, .au = Australia, .do = Dominican Republic)
Nonprofit organization sites: .org
Commercial sites: .com

Most URLs contain multiple levels separated by slashes (e.g., http://www.nod.org/stats/). To learn more about the sponsor or publisher of a particular site, you can remove levels of the URL one by one to see where the site is hosted and determine the character of the sponsoring entity. For instance, if a site is hosted on the site of an association, viewing the mission statement on the home page of the association can provide clues as to the bias or purpose of the content. When judging the credentials of the publishing entity, researchers should look for contact information and institutional logos. In general, sites devoid of identifying information or contact numbers and addresses should raise suspicion.

Audience

When evaluating a site, researchers should determine whether the content succeeds in addressing the stated audience through tone and presentation. Sites for adults should not have a childlike appearance or tone. Likewise, sites may be deliberately overrun by technical language or jargon to confuse or mislead a particular audience. High-quality sites clearly define their intended purpose.

Currency

Medical research findings or population statistics may become obsolete at a faster rate than research in the humanities. Web researchers should check sites for copyright dates and the date of the last update. Broken links are a sign of neglect, as they may indicate that URLs have changed or become obsolete since the last update of the site. To verify the currency of information on a site, researchers should check for several sites covering the same subject matter.

Accuracy

Determining accuracy involves further research to ensure that the claims or findings on a site are substantiated by other sources. If a site presents original research, the methods of the research and instruments used should be clearly explained, as well as potential limitations of the research. If authors make claims or conclusions, they should cite their

sources, and these sources should be tracked down to ensure their existence and authenticity. Websites should contain a list of works cited or footnotes on par with any print book or article. Since websites sometimes include fabricated resources, and erroneous or incomplete citations, sources should be verified using library tools such as indexes and catalogs. Lists of works cited with multiple errors reflect irresponsible research. If a website contains links, the links should be checked. Researchers should be wary of websites populated by broken links or links to defunct websites.

Quality

In general, sites that are poorly organized or sloppy should be approached with caution. Shoddy design may point to further weaknesses. Poor grammar and spelling errors are also red flags.

Bias

While bias is not always a negative attribute, Web searchers should be cognizant of bias as the search for information. The bias of a website can be partially discerned by the domain name (as discussed above under "Authorship"). Commercial websites may be motivated by the goal to market a product or service. Nonprofit organizations may promote a political agenda. While bias may be clearly stated in mission statements and "about" pages, many websites deliberately shroud their bias. Thorough research involves consulting additional sources to determine the history and activities of a particular organization. If a site contains links to other sites, those links should be checked to discern the character and activities of the other organizations listed. If a site is sponsored by other organizations, researchers should consider the relationship between the sponsors and the creators of the site.

Special Considerations for Evaluating Health Information on the Web

The American Medical Association (AMA) has published "Guidelines for Medical and Health Information Sites on the Internet" outlining evaluation criteria for websites publishing health information, whether for consumers or health professionals. While these guidelines are technically enforced only on sites sponsored by the AMA or affiliated organizations, they could be applied to all sites containing health information. Many of these guidelines mirror the previously outlined criteria for evaluating all websites, but there are certain factors that are heavily emphasized in the AMA guidelines, including the importance of peer review by experts in the field, the importance of clearly identifying sources of funding, an explanation of the relationship between individual researchers and the institutions sponsoring the research, the importance of clearly stating the purpose and intended audience of a site, and the need to address the stated audience in a consistent and effective tone. Seven criteria for assessing the quality of health information on the Internet have been developed by the Health Summit Working Group (Health Information Technology Institute 1999).

Information on health-related websites should be verified by checking sources such as journal articles, books, and other websites. These measures are needed as health information on the Web frequently includes unsubstantiated claims.

OVERVIEW OF ACCESSIBILITY ISSUES ON THE WEB

Disability studies research is unique in that many scholars in the field have disabilities that may impact their ability to effectively search the Web. While in many ways the Web "evens the playing field" by making a vast number of resources available electronically, inaccessible design frequently places barriers on Web searchers with disabilities.

Principles of Web accessibility have been developed by the World Wide Web Consortium's (W3C) Web Accessibility Initiative (WAI). The WAI establishes guidelines for creating accessible websites, browsers, and authoring tools to increase the ease of use of the Web for users with disabilities. Multiple scenarios outlining potential challenges to Web searchers with disabilities are summarized in a W3C working draft titled "How People with Disabilities Use the Web" (2001). Among other scenarios, the document emphasizes that many Web searchers with cognitive or visual disabilities use OCR (optical character recognition) software, which reads Web page text and transmits the information to a speech synthesizer and/or refreshable Braille display. Many users with visual disabilities use text-based Internet browsers instead of standard graphical browsers. The successful use of these tools requires that images on websites be accompanied by descriptive text and *ALT tags*. ALT tags are textual labels that appear on the computer screen when a mouse moves over an image. Since visually impaired

Web searchers often enlarge Web-based text using screen magnification programs, Web designers must create pages with nonfixed font sizes that can be altered as necessary. These are only a few of the issues facing Web searchers with disabilities. Other population groups with disabilities discussed in the guidelines include individuals with cognitive disabilities, hearing impairment, and mobility-related disabilities. Readers should consult the WAI website for the complete guidelines (http://www.w3.org/WAI/).

To support the goals of WAI, an online tool called Bobby™ helps website developers test the accessibility of their sites and adhere to accessibility guidelines. By entering a URL into the Bobby website, a Web developer can generate a report outlining which features of the site need to be adjusted to make it "Bobby compliant" and adhere to both W3C accessibility guidelines and guidelines established by the U.S. government's Section 508, a 1998 amendment to the Rehabilitation Act requiring that all federal agencies make their electronic and information technology accessible to people with disabilities. Complete information about these guidelines can be found on the Section 508 website (www.section508.gov).

CONCLUSION

While "one-stop shopping" in Google may be tempting, there is no single search engine leading to everything on the Web. Comprehensive and effective research in disability studies involves consulting multiple search tools, including but not limited to general search engines, subject-specialized search engines, directories, and indexes. In addition to using multiple search tools, Web searchers should experiment with multiple search strategies to maximize the effectiveness of their searching. As there are no standards of quality on the Web, researchers should apply multiple evaluation criteria to every website, verifying that research findings posted on sites are supported by other sources. Web accessibility is a crucial component to disability studies, as the Web has the potential to deliver equal content to all users but frequently presents barriers to people with disabilities by failing to adhere to standards of accessible design. Researchers can develop an awareness of accessibility issues on the Web by familiarizing themselves with the standards outlined by W3C's Web Accessibility Initiative and Section 508.

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Disabled Peoples' International
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International Disability Organizations
League of the Physically Handicapped
Leonard Cheshire
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National Center for Medical Rehabilitation Research (United States)
National Institute on Disability and Rehabilitation Research (NIDRR) (United States)
People First
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S

SAINT VITUS' DANCE

St. Vitus, the patron saint of dancers and performers, grew up in Sicily and became a matyr during the reign of Emperor Diocletian (ca. 243–316). Sometime during the sixteenth century in Germany, his name began to be invoked to ward off diseases and conditions such as epilepsy, nervous disorders, and, most notably, Sydenham chorea minor and major. Sydenham chorea, referred to as St. Vitus' dance throughout the seventeenth century, caused involuntary movements of the muscles associated with the onset of rheumatic fever. These movements were thought to be stress-induced responses of "wild dancing." Multitudes of people were recorded as experiencing this condition across the continent of Europe, particularly during the fourteenth century. The condition could last from days to weeks and has been traditionally associated with women. The spasticity of movement was often believed to be a sign of insanity. As Burton's *Medical Encyclopedia* explained in 1621, "They that are taken with it can do nothing but dance till they be dead, or cured." The U.S. television show, *Buffy the Vampire Slayer,* spoofed this condition as a demon-induced plague in the musical episode "Once More with Feeling."

—David T. Mitchell

See also Disease.

SANGER, MARGARET (1879–1966)

Birth control activist

"Margaret Higgins" was the sixth of 11 children born live to her Irish American working-class parents, Anne and Michael Higgins. When her mother, who suffered from tuberculosis and became progressively weaker with each pregnancy, died at age 49, Margaret attributed her death to her numerous pregnancies. Margaret herself acquired tuberculosis, and during her nursing training at White Plains Hospital in New York state, she was afforded an early example of a disability accommodation when her work/study day was shortened by several hours so that she could take walks and get fresh air, the treatment then for tuberculosis. Her only daughter, Peggy, contracted polio at age three and died of pneumonia two years later. When her second husband, millionaire Noah Slee, suffered a stroke in 1943 and began using a wheelchair, Sanger installed a bell on the wheelchair by which he could summon her. She devoted herself to his care until he died a few months later.

Like early feminists before her, Sanger linked birth control with freedom of sexual expression and reproductive rights. Over time, Sanger's arguments evolved to portray birth control as a women's health issue as well as a method of social control. Sanger explicitly linked birth control to eugenics, and one of the goals of International Planned Parenthood, which Sanger founded, included establishing scientific research into the "elimination of harmful dysgenic births in the nation." She also supported research for hormonal anovulants, and by the time of her death, an oral contraceptive had been developed and was being used by women worldwide.

In addition to tuberculosis, Sanger experienced a number of disabling conditions during her adult years, including a nervous disorder, depression, heart condition, alcohol and drug dependency, and leukemia. She spent her last five years in a nursing home, where she died at age 86.

—Sharon Lamp

See also Feminism; Reproductive Rights.

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SARASWATI, VIRJANANDA

(1779–1868)

Vedic scholar

Swami Virjananda Saraswati was blinded by smallpox when he was about five years old and orphaned six years later. At 15, he left his brother's unwelcoming home, found refuge among the scholars and saints at Hardwar on the Ganges, and became an assiduous student of Vedic literature, orally taught. Virjananda eventually became a teacher of Sanskrit grammar among religious students at several of northern India's holy cities. He denounced the vast range and shallowness of superstitions bound up in popular Hindu belief and campaigned for a return to the austere fundamentals of Vedic teaching. In later life, Virjananda had a profound influence on Dayananda Saraswati (1824–1883) and thus on the founding and direction of the powerful Hindu reform movement, the Arya Samaj, with effects continuing into the twenty-first century. Dayananda sat at Virjananda's feet in Mathura from 1861 to 1863, showing more perseverance than most, for the blind guru was famously volcanic. Centuries of the downmarket end of Hindu belief and practice received condign punishment from the elderly scholar, whose cane fell on the nearest proxies, the hapless students sitting before him.

—Kumur B. Selim

See also Disability in Contemporary India; Experience of Disability: India.

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SAUNDERSON, NICHOLAS

(1682–1739)

English mathematician, linguist, and teacher

Nicholas Saunderson, blinded by smallpox in infancy, became a proficient mathematician, linguist, and teacher. In childhood, his education was mostly informal, but the teenage boy's intelligence attracted teachers, and his mathematical ability was assisted by two tactile learning boards that he devised for arithmetic and geometry. The first enabled him to calculate rapidly, using his own code of larger and smaller pins in a grid of holes. On the second board, he made and altered shapes with thread attached to pins. Saunderson continued his education from various tutors, and in 1707, he went to Cambridge, where his talents as a teacher were exercised. In 1711, he received an M.A. and was elected Lucasian Professor, against stiff competition. He was highly regarded as a teacher of mathematics and science, both by his students and colleagues, although some of the former found his standards too exacting and tried his patience, while some of the latter suffered from his frankly aired opinions. A modern mathematician notes that Saunderson hardly contributed to mathematical research but produced useful textbooks and guides to his subjects. He married in 1723 and had children. With some adjustments, Saunderson apparently lived the typical life of an able and gregarious professor of his times.

—Kumur B. Selim

See also Blindness and Visual Impairment.

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SAVELJEV, PAVEL ALEKSEEVICH (1890–1975)

First chairman of the All-Russian Federation of the Deaf

Pavel Alekseevich Saveljev lost his hearing at the age of nine. In 1924, he started publishing the newspaper *Life of Deaf-Mutes.* In 1926, he set up the All-Russian Federation of the Deaf and was its chairman from 1926 to 1949. He also organized evening schools, workshops, factories, and vocational training for the deaf. In 1957, he organized a drama school that attracted many amateur deaf actors. In 1960, the school became a part of the Schukin Professional Drama College in Moscow. Seventeen deaf students were trained there and, in four years, received certificates as professional drama actors. Three more groups of deaf actors graduated from the drama school.

—Anna Komarova and
Victor Palenny

See also Deaf, History of the.

SCHIZOAFFECTIVE DISORDERS

The term *schizoaffective disorder* was originally coined by Kasanin (1933) to define a subgroup of psychoses in which affective and schizophrenic symptoms are prominent simultaneously, or within a few days of each other, within the same episode of illness. Historically, other concepts, such as *intermediate psychoses* or *mixed psychoses,* have been also used to describe the psychoses between affective and schizophrenic disorders. The current definition in the diagnostic manuals of mental disorders states that this co-occurrence of affective and schizophrenic syndromes is required for diagnosis. Two types of schizoaffective disorders have been established according to the affective symptoms: *manic or bipolar type* if the mood disturbance includes a manic or a mixed episode and *depressive type* if the mood disturbance includes only major depressive episodes. About 1 in every 200 people (0.5 percent of population) develops a schizoaffective disorder at some time during her or his life. Although it is well established that this is a biological disorder, the specific cause or causes are unknown. The studies of sociodemographic, clinical, biological, and outcome characteristics have demonstrated that schizoaffective disorders lie midway between the two major psychoses, schizophrenia and pure affective disorders. Although patients with schizoaffective disorders suffer from recurrent episodes and thus need preventive treatment, they usually make a full recovery, and only a small percentage of cases end in chronicity or a defect state.

—Benedicto Crespo-Facorro

See also Mental Illness; Psychosis; Schizophrenia.

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SCHIZOPHRENIA

Schizophrenia is a serious mental illness that begins early in life and leads to substantial morbidity, increased mortality, and significant disability. Recent World Health Organization (WHO) estimates suggest that schizophrenia is among the top 10 causes of disability worldwide. Characteristic symptoms include hallucinations, delusions, unusual behavior, and disorganized thinking (positive symptoms); decreased motivation, decreased energy, and social withdrawal (negative symptoms); and cognitive impairments leading to functional disability. Basic social skills, including the capacity to read and respond to facial expressions, are often lacking, making social communication difficult. The illness runs a protracted course in many patients and frequently leads to chronic institutionalization or multiple hospitalizations, homelessness, unemployment, and social isolation. There is evidence that in less industrialized countries, individuals with schizophrenia have a more favorable outcome and less disability as they are better able to manage the social skills needed for survival in less complex societies.

While conventional antipsychotic medications effectively control positive symptoms, they have little impact on cognitive impairment and functional disability. Recent research suggests that atypical or "second-generation" antipsychotics compared with conventional antipsychotics may have superiority in rectifying functional impairments in schizophrenia. However, atypical antipsychotics produce only limited improvements in overall disability; a comprehensive approach to overall management, including individual-, group-, and community-based psychosocial treatments, is therefore critical. There have been recent major advances in such treatments.

MODELS OF COMMUNITY CARE

A good deal of research has been conducted on two approaches to community care: the assertive community treatment (ACT) and intensive case management (ICM) models. ACT provides a continuum of medical, psychiatric, and social services to patients in the community via mobile outreach teams of clinicians providing services needed to keep patients out of the hospitals. Such services include case management, social service entitlements, housing, vocational rehabilitation, crisis intervention, financial support, and advocacy. Specifically, case managers help in discharge planning, establishing linkages with community programs, and networking to confirm that quality community care is provided. These models reduce time in the hospital and improve housing stability, especially among patients who are high service users. ACT and ICM also have moderate effects on improving symptomatology and quality of life. However, most studies suggest relatively less effect of ACT and ICM on disabilities in social functioning, arrests, time spent in jail, or vocational functioning. Some British studies have failed to replicate American observations of improved outcomes in ACT. However, these differences might reflect variable implementation of differences in available resources for ACT in the United Kingdom versus the United States.

SUPPORTED EMPLOYMENT

Most patients with severe mental illness live in the community, but many are socially isolated and few have jobs. In recent years, supported employment, an approach that uses the "place and train" as opposed to the "train and place" method, has been increasingly gaining acceptance as the preferred method for vocational rehabilitation. Such supportive employment, coordinated with clinical care, increases the rate of competitive employment, lower hospital admission, and better treatment compliance. The addition of social skills training, combined with supported employment, may enhance the individual's ability to meet the interpersonal demands of the workplace.

SUPPORTED HOUSING

The gradual deinstitutionalization in the past several decades has necessitated the need for developing a variety of housing alternatives, ranging from transitional housing, 24-hour highly staffed residential care or board, and home care through staffed group homes to less supervised and more normalized community settings. Too frequently, states have allowed the "warehousing" of chronic schizophrenic patients in nursing homes, which have little or no treatment or rehabilitation interest. Recent years have witnessed a move from facilities in which to "place" patients toward partnership between the mental health service provider and providers of ordinary housing. A range of mobile case management, crisis intervention, and continuous treatment services allows patients to be managed in the housing of their choice. Patients and treatment providers often prefer this approach; quality of life is usually increased, and length of hospitalizations may also be reduced.

SOCIAL SKILLS TRAINING

Social skills training is a widely used psychosocial intervention in the management of schizophrenia. Complex social skills are broken down into simpler and smaller steps and then taught using a variety of techniques, including didactic and Socratic instruction, modeling, corrective feedback, and homework exercises. Several randomized controlled trials have shown that social skills training produces improvement on specific behavioral measures, although changes in symptoms and community functioning are less pronounced.

The Schizophrenia Patient Outcomes Research Team (PORT) pointed to the underutilization of these approaches and recommended their inclusion in the treatment package. Social skills training was also included in the practice guidelines for treating patients with schizophrenia published by the American Psychiatric Association.

FAMILY INTERVENTIONS

It has been known for some decades that patients who return to families with high expressed emotion (EE) (e.g., criticism) have a higher likelihood of relapse than those whose families are low in EE. Family interventions (i.e., family psychoeducation and behavioral family therapy) are highly effective for reducing families' EE and improving patients' relapse rates and outcomes. Furthermore, family interventions are also associated with reduced family burden. Several studies have demonstrated the efficacy of family psychoeducation leading to reduced relapse rates, improved recovery of patients, and improved family well-being among participants. Effective approaches in family psychoeducation programs include empathic engagement, education, ongoing support, and clinical resources during periods of crisis; social network enhancement; and problem-solving and communication skills. Coordination among patient and family advocacy organizations, clinician training, and ongoing technical consultation and supervision can help in implementing psychoeducational approaches in routine clinical settings. Family psychoeducation for a particular patient and family should be tailored to the extent and quality of family and patient interest and involvement.

COGNITIVE REMEDIATION

In the past few decades, cognitive dysfunction has been recognized as a fundamental disability feature of schizophrenia. Domains of cognition that are impaired in schizophrenia include attention, working memory (e.g., capacity to keep things in mind long enough for immediate use, such as directions or a phone number), and learning and general memory. Other deficits include impairments in forward planning, concept formation, initiation, and self-monitoring. These impairments are noticeable against a background of generalized cognitive deficits and may affect between 40 and 95 percent of individuals with schizophrenia. Specific executive deficits appear to be related to specific symptom clusters and are linked to structural and functional brain abnormalities. Recent research has convincingly demonstrated a relationship between cognitive deficits and functional outcome in schizophrenia.

Cognitive remediation involves repeated practice and acquisition of compensatory strategies on cognitive exercises designed to engage underfunctioning brain systems. Researchers in Pittsburgh have recently developed a novel approach to the cognitive remediation in schizophrenia, called cognitive enhancement therapy (CET). This approach capitalizes on observations that deficits related to social cognition—the ability to act wisely in social interactions—may be of particular importance in impeding social and vocational recovery. Social cognition is acquired during adolescence and early adulthood and may be at least partly independent of formal IQ and neuropsychological problems. CET draws on a contemporary neurodevelopmental model of schizophrenia whereby social cognition deficits are thought to serve as intermediary links between impairments in executive cognitive functions and the emergence of characteristic symptoms of schizophrenia. CET is designed to facilitate the individual's transition from prepubertal to young adult style of social cognition and emphasizes developmental learning experiences during the remediation of social cognitive deficits. The treatment involves helping the individual to develop a "gistful" appraisal of interpersonal behavior and novel social contexts. Cognitive remediation strategies vary widely along dimensions of duration, intensity, method, target of behavioral intervention, and clinical status of participants. Using these approaches, improvements have been observed on measures of working memory, emotion perception, and executive function. Functional magnetic resonance imaging studies have begun to suggest changes in task-evoked brain activation in several functionally relevant neural systems.

COGNITIVE ADAPTATION

U.S. researchers in Texas have developed cognitive adaptation training. This involves modification of the patients' environment to allow patients to bypass their deficits. Following a detailed behavioral assessment and analysis of the home environment, behaviors are modified by increased structure, signs and labels, and electronic devices—such as tape recorders—for providing cues and instructions. Cognitive adaptation interventions have also been found, in a controlled trial, to produce improvements in symptoms, psychosocial status, and relapse rates.

CONCLUSIONS

More research is needed to establish cost-effective approaches to psychosocial rehabilitation in schizophrenia. The best evidence suggests that if rehabilitation interventions can begin in early adolescence or young adulthood, schizophrenia can be far less disabling than it has been historically. Characteristics of successful psychiatric rehabilitation programs include interventions that (1) are direct and behavioral; (2) have specific effects on related outcomes, with generalization to other domains; (3) are long-term; (4) are delivered close to patients' natural environments; and (5) combine skills training and environmental support. However, despite improved knowledge about approaches to psychosocial rehabilitation, a wide discrepancy persists between efficacy in trials and effectiveness (what is actually implemented in naturalistic settings). Administrative, financial, and organizational barriers need to be broken down by obtaining evidence-based new information and disseminating such knowledge to the relevant professional groups, advocacy groups, and policy makers.

—Matcheri Keshavan

See also Case Management; Mental Illness; Psychiatric Disorders; Schizoaffective Disorders.

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SCOLIOSIS

A condition of the lateral deviation of the spine, scoliosis has been documented in skeletons dating from at least 26,000 years ago. One of the first medical descriptions of scoliosis occurs in the *Hippocratic Corpus* from the fourth century BCE. Historically, there are many examples of figures, both prominent and less so, who reputedly had scoliosis, ranging from Tutankhamun to Richard III.

As a clinical condition affecting between 3 and 30 percent of the U.S. population, scoliosis can exist at birth or be acquired from trauma, infection (e.g., tuberculosis), or disease of the nerves and muscles; the most common cause is from unknown causes (idiopathic). Scoliosis is categorized as congenital, infantile, juvenile, adolescent, or adult (degenerative) in onset. Either static or progressive, scoliosis can lead to pain, weakness, impaired breathing, or death from a compromise of lung function. "Discosmetic" effects are suggested by the term *hunchback.* Kyphosis, a condition in which there is forward deviation of the spine, is frequently associated with osteoporosis (e.g., "dowager's hump"). Contemporary Western medicine characterizes scoliosis by the anatomical location of the curvature, the severity of the curvature, and progression. Intervention varies from observation (the most common therapy) to bracing and casting (usually until growth of the bones has stopped) to surgical correction, including fusing vertebrae together or the introduction of stainless steel rods to maintain the straight position of the spine.

Scoliosis as an object of focused medical intervention started in the late eighteenth century and had an early peak in the 1830s in France with the rise of a bourgeoisie concerned about their posture and its implications for employment and marriage. Putative correction through exercise, bracing, regimental programs, and proprietary devices was the means through which a variety of kinds of medical practitioners competed for clientele. Orthopedists, early therapists, nonsurgical physicians, and nonprofessional healers all offered therapies. With the advent of anesthesia and antiseptic/aseptic surgery in the mid- to late nineteenth century, orthopedists increasingly "won" this competition. The invention of the X-ray examination of the spine gave investigators a tool to make numerical studies of scolioses and gradually allowed them to gather enough epidemiologic knowledge to create decision rules about when to intervene. By the early twentieth century, pediatricians began to include examination for scoliosis in their emerging "routine" physical examination of schoolchildren. The other significant interventional tool has been pulmonary and cardiovascular evaluation. The first artificial disk was cleared by the Food and Drug Administration in June 2004. While the physical effects of scoliosis can be significant, inspiring the above medical developments, the physically and psychologically damaging effects of medical interventions over the centuries have been equally profound. That history has yet to be written.

In literature and art, scoliosis has often been a trope for indicating the outcast or menacing character, such as Shakespeare's Richard III. This theme has led some to argue that people with severe scolioses were burdened with unfortunate fates in premodern cultures. Nevertheless, figures such as the hunchback, Quasimodo (meaning "partially formed"), in Victor Hugo's *Notre-Dame de Paris* show that individuals with scoliosis were also employable and could evoke respect as well as pity.

—Walton O. Schalick III

See also Orthopedics; Pain; Spinal Cord Injury.

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SCOTT AND DISABLED PEOPLES INTERNATIONAL (AUSTRALIA) v. TELSTRA (1995)

The decision in *Scott and Disabled Peoples International (Australia) v. Telstra,* handed down following a four-day Human Rights and Equal Opportunity Commission (HREOC) inquiry in 1995, represents a watershed in telecommunications policy for people with disabilities. The commission found Australia's national carrier, Telstra, guilty of discrimination against the class of people with severe hearing or speech impairments. In particular, a joint complaint from Geoff Scott and Disabled Peoples International (Australia) (DPI(A)) claimed the carrier exercised indirect discrimination for not providing them with access to teletypewriters (TTYs) on the same basis as others obtained standard telephone handsets (T200s) to access the telecommunications network. The findings of the committee were as follows:

> In my opinion, the services provided by the respondent are the provision of access to a telecommunications service. It is unreal for the respondent to say that the services are the provision of products (that is the network, telephone line and T200 [standard handset]) it supplies, rather than the purpose for which the products are supplied, that is, communication over the network. The emphasis in the objects of the Telecommunications Act (s.3(a)(ii)) on the telephone service being "reasonably accessible to all people in Australia" must be taken to include people with a profound hearing disability. (Human Rights and Equal Opportunity Commission 1995:12)

At the time, Australians requiring TTYs paid approximately $600 for the equipment.

The case tested the application of the Disability Discrimination Act of 1992 and the inclusiveness of the definition of universal service obligation (USO) in the Telecommunications Act of 1991.

The Telstra lawyers claimed that the carrier was not discriminating against anyone because people had a right to use its services or not. Primarily, the counsel acting for the carrier claimed that it was not in the business of supplying specialized equipment but a standard service that gave access to the telecommunications network. Furthermore, Telstra revealed that it had supplied millions of dollars of free and heavily subsidized services to Australians with disabilities.

The complainants argued that the carrier exercised discrimination against hearing- or speech-impaired consumers by placing unreasonable conditions for network access, which are not required of most in the wider community. Furthermore, Scott and DPI(A) argued that Telstra's corporate generosity was irrelevant to the issue before the commission.

The commissioner, Sir Ron Wilson, accepted Telstra's claim that it had no obligation to provide a new service as stated in section 24 of the Disability Discrimination Act. However, Wilson also accepted the complainants' argument that they were not seeking a new service but access to the existing service that formed Telstra's social obligation under the USO.

Wilson's statement at the beginning of this entry identifies the telephone service primarily as a social phenomenon and not a technological system or even a market commodity. Once a social context is used as the defining environment in which the standard telephone service operates, it is difficult to dispute the claim that *all* does not include people with disabilities. Part of the service includes the point of access in the same way that a retail shop front door is a point of access for a customer to a shop. Consequently, the disputed provision is not a new or changed service but another mode of access to the existing service. Furthermore, the commissioner ruled that Telstra exercised illegal discrimination by refusing to accommodate those affected with modified access to the network in the form of affordable access to TTYs, which would not place unjustifiable financial hardship on the national carrier.

The HREOC inquiry represents a tension among discourses of disability. Arguably, the respondent framed disability within charity and market models of policy, which emphasize corporate philanthropy, dependency, and profit maximization. In contrast, the complainants framed disability within a rights model that emphasized the legislated entitlement of citizen-consumers as active political subjects. The success of the action resulted in new provisions for the Deaf community and people with severe speech impairments in the Telecommunications Act of 1997, which provided affordable equitable access to TTYs and associated services.

—Michael Bourk

See also Disability in Contemporary Australia; Disability Studies: Australia; Worksite Modification.

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SEATING AND POSITIONING

The term *seating* refers to all components (seat cushion, back support, external body supports) that assist a person in achieving and maintaining a sitting position. This includes items that individuals use daily such as dining room chairs, desk chairs, couches and seats in automobiles as well as specialized supports designed for individuals with disabilities.

The term *positioning* means placing and maintaining a person in a specific postural alignment such as sitting, side lying, standing, supine, or prone. Some examples of positioning devices include seats, back supports, and standing devices. For all individuals, the primary goals of positioning are to maximize an individual's comfort, support, and function to allow participation in a given task. For individuals with disabilities, additional positioning goals include improving postural alignment and stability, improving motor control, preventing or minimizing contractures and deformities, and improving sensory and bodily functions.

Typically, an individual's seating and positioning needs are assessed with relation to wheelchair mobility (either manual or electric powered). The purpose of the assessment process is to determine the postural needs of an individual and relate those needs to appropriate positioning components and methods of mobility. An individual or a team of individuals with specialized experience and training in the field of seating, positioning, and wheeled mobility devices performs the evaluation. These individuals can be (but are not limited to) physical therapists, occupational therapists, and rehabilitation engineers.

An individual's seated posture is assessed in parts and as a whole. The alignment of the pelvis is typically assessed first because this is the base of support in a seated posture. Once a functional pelvic position is established, the alignment of the lower extremities, the spine, and ultimately the head and neck position is assessed and established. Emphasis is placed on the individual's ability to perform functional tasks from this position.

Typical cushion materials used in manufacturing specialized seating include foams, air, and viscous fluids. The materials can be used alone or in combination with each other to create a support surface that matches an individual's postural and pressure management needs. Material properties such as density, stiffness, and envelopment are critical to the decision-making process when selecting a material for a specific application.

There are three main categories of specialized seating systems for use by individuals with disabilities. They are linear/planar, generically contoured, and custom contoured/custom molded.

Linear/planar cushions. These cushions (seat or back) are typically made of foam and covered with fabric upholstery (e.g., Lycra, Cordura, vinyl). They are typically flat and provide a firm base of support.

Generically contoured. Nearly all seat cushions and back supports available commercially today fall into the generically contoured category because they have a generic, preestablished shape. The shapes, typically, cannot be easily altered but offer general curves and contours to provide a functional base of support for some individuals. They can be made of foam, air, viscous fluids, or combinations of them.

Custom contoured/custom molded. These seat cushions and back supports represent the highest end of options. These supports are custom made for an individual to conform to body parts to provide increased pressure distribution and increased postural control. They are typically made of specialized foams.

—Brenda A. Sposato

See also Mobility Aids; Rehabilitation Engineering; Wheelchair; Wheelchair, Electric.

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SÉGUIN, EDOUARD ONESIMUS (1812–1880)

French physician

Styled the "apostle to the idiots" by Pope Pius X, Edouard Séguin studied at the *lycées* of Auxerre and St. Louis in Paris prior to learning medicine with Jean Itard and Jean-Etienne Esquirol. Following Itard's halting methods to help the "Wild Boy of Aveyron," Séguin convinced Esquirol of the possibility of teaching "idiots"; Esquirol obtained a post for him at the Bicêtre. Upon the death of his mentors, Séguin also took a post at the Salpêtrière and continued a long string of publications. His meteoric rise in Parisian medical circles was halted after a shadowy falling out with the Bicêtre medical staff and his dismissal in

1843. Despite relative disgrace, Séguin continued a private practice and his writing, including his most influential book, *Moral Treatment, Hygiene and Education of Idiots* (1846). In 1850, he emigrated to the United States, where he helped found a large number of institutions for children with disabilities, finally obtained a medical degree (University Medical College of New York), and died in New York City.

Séguin's influence came from his staunch belief in the heretofore unthinkable educability of those with significant cognitive disabilities, regarded by contemporaries as "idiots" or "backward." His "physiological method" employed exercise and the senses as a lever to stimulate the will, ideas, and thence education; these techniques were influenced by Philippe Pinel's (1745–1826) "moral treatment" of the insane, Rousseauvian ideas of the senses, and Christian socialism, then popular among Parisian mental health reformers. Séguin also absorbed the contemporary Parisian emphasis on comparison with "the normal," and after his MD, his writings increasingly evoked the medical model. Séguin's influence was particularly strong in the United States, especially among those working in institutions for "idiots" and reforming them, helping to remove "the mark of the beast," as a eulogist noted.

—*Walton O. Schalick III*

See also Medicine; Mental Health.

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SELF-SUFFICIENCY

Self-sufficiency is a goal that the disability rights movement has promoted, challenged, and redefined in its quest to increase options available to people with disabilities. Some advocates view self-sufficiency as an impossible standard that should be rejected in favor of recognition of universal interdependency. Others claim self-sufficiency as a right to which all are entitled, including those who may need support to exercise it.

Historically, Western culture has put a high value on self-sufficiency, defined as the ability to provide for one's own needs with minimal assistance or support from other people. In this light, the goal of self-sufficiency assumes and requires that all individuals are equally capable of functioning within the existing environment. By this definition, which many disabled people were unable to fulfill, disability was seen as inadequacy and as a reason to exclude people with disabilities from social roles and benefits. Without the capacity to be completely self-sufficient—for instance, because of a need for physical assistance, extra learning support, or other help—people with disabilities were judged unfit to compete and thus undeserving of equal resources, rights, and responsibilities. Dependency, neediness, and failure were therefore deemed to be the inevitable consequences of disability.

Because of this bias, disabled people who could not be entirely self-sufficient (i.e., those who need assistance or support) have often had to forfeit some of the basic choices and opportunities that other citizens take for granted. For example, people needing help with dressing, eating, and other activities of daily living are often forced by public policy to enter a facility, the only setting in which an adequate level of support is available. People who need publicly subsidized health care coverage and/or in-home support services may have to forego employment because poverty is a precondition for eligibility. These forfeited choices and opportunities, mandated by social conditions and political decisions, tend to undermine disabled people's self-sufficiency much more than the disabilities themselves.

Beginning in the 1970s, the U.S. independent living movement has put forward a new view of disabled people as being capable of independent choice and responsibility, even if not capable of fully independent functioning. Independence, these advocates insisted, is not a matter of doing everything unassisted but of making one's own decisions without penalty or coercion. Some explicitly rejected the concept of self-sufficiency, arguing instead for self-determination. Others have used the terms *self-sufficiency, self-determination,* and *independence* more or less interchangeably.

Currently, the term *self-sufficiency* is most often used in the context of employment and the ability to support oneself financially. For example, in the preamble to the 1990 Americans with Disabilities Act (ADA), Congress found that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency" (ADA 1990, sec. 2(a)8).

—Laura Hershey

See also Americans with Disabilities Act of 1990 (United States); Independent Living.

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SEQUOYAH (1770?–1843)

Cherokee warrior who devised the Cherokee alphabet

Disabled due to a swelling on his knee, Sequoyah (1770?–1843) was made lame by the shortening of his diseased leg. While his lameness prevented him from becoming a foot warrior, he participated as a horse-mounted combatant, serving in the Cherokee regiment under Colonel Gideon Morgan against the 1813 Alabama Red Stick Creeks in the Battle of Horseshoe in General Andrew Jackson's campaign. Though lame, Sequoyah led his people, the Cherokees, to heights untenable to other Native American Indians: the path to literacy. He analyzed and reduced a complex inflected multidialect language to 85 (originally 86) minimal sound units, to each of which he attached a particular symbol. A daughter assisted him during the arduous process. Completed by 1819 and spread by 1821, this writing system allowed Cherokees to become literate almost overnight and culturally revitalized. Sequoyah's discovery of the concept of the phonemic structure predated academic linguists one hundred years. Fascinated with European American writing styles that he named "talking leaves," he worked tirelessly to bring all Cherokees together through his unique writing convention. Correspondence between east and west Cherokees could easily be facilitated because the efficiency of the syllabary permitted Cherokees to become proficient writers with a few days' study.

Born in the prehistoric capital, Echota, on the Little Tennessee River in what is now Monroe County (Tennessee) between 1760 and 1770, Sequoyah left his ancient village among the Overhill Cherokees and migrated south as far as his territory would take him, then to Willstown, in what is now DeKalb County (Alabama). He followed other Cherokees who had been moving south for decades to escape border ruffianism.

After introducing his writing style to Cherokees in the East in 1821, he migrated to the Arkansas Territory in 1822 to join fellow Cherokees, who had left the East for the West. There he continued to teach his syllabary. After the infamous Trail of Tears (1838–1839), whereby eastern and western Cherokees reunified their nation in Indian Territory, Sequoyah's syllabary was the nucleus of unification for both traditional and acculturated Cherokees. Cherokee shamans recorded sacred formulas for ceremonial purposes in the syllabary. The power of his writing convention facilitated his teaching of the syllabary to Cherokees in the Indian Territory and those living beyond its borders.

Seeking to usher in literacy among as many Cherokees as possible, in 1842, Sequoyah left the Cherokee capital Tahlequah (Oklahoma) in an oxcart for Mexico, where he hoped to create literacy among Mexican Cherokees. In 1843, Sequoyah died in northern Mexico before his companions, once alerted to his grave condition, were able to get him assistance.

—Rowena McClinton

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SERBIA

See Experience of Disability: Serbia

SEX INDUSTRY, INTERNATIONAL

The term *international sex industry* includes prostitution and prostitution-related activities; the pornography industry; the sex-related entertainment industry, including phone sex and Internet sex services; syndicates involved in the trafficking business in persons and drugs; travel agencies that promote sex tourism; and other related activities. Commercial sexual services also include paramedical areas such as sexual surrogate therapy. The relationship between disability and the sex industry has become increasingly visible globally as the sexuality of people with disabilities has emerged as an important issue.

Due to the heavily gendered aspect of sex commerce—typically involving men as buyers and women as sellers—any discussion of the sex industry requires attention to the issue of gender as well as disability and other categories of inequality. The gender dynamic involved in the operation of the sex industry complicates the position of disabled women and men but also highlights the limitations of considering “disabled people” as a unified category. Another important factor is the global dynamic associated with commercialized sex, which exploits disabled and nondisabled women from the non-Western world for the benefit of men from wealthier countries.

DEFINITIONS AND SCOPE OF THE INTERNATIONAL SEX INDUSTRY

The international sex industry is a multi-billion-dollar concern operating all around the world. Income from the sex industry supports a massive underground economy of pimps, procurers, and organized criminals, as well as multinational conglomerates operating hotels, airlines, and tourist industries. Definitions of the sex industry from feminist perspectives have emphasized its financial aspects and its power differentials. Brock and Thistlethwaite (1996) define sex industries as the institutionalized sexual use by more powerful members of male-dominant societies of the less powerful. One of the most important elements of the international sex industry is trafficking in human beings, which usually targets vulnerable sections of the population, including disabled people. Human trafficking has been defined in the “UN Protocol to Prevent, Suppress and Punish Trafficking in Persons, Especially Women and Children” in the following manner:

> Trafficking in persons’ shall mean the recruitment, transportation, transfer, harboring or receipt of persons, by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability or of the giving or receiving of payments or benefits to achieve the consent of a person having control over another person, for the purpose of exploitation. Exploitation shall include, at a minimum, the exploitation of the prostitution of others or other forms of sexual exploitation, forced labour or services, slavery or practices similar to slavery, servitude or the removal of organs. (see http://www.state.gov/g/tip/rls/fs/2005/43630.htm)

The United Nations reports estimate that 4 million women have been trafficked, both within countries and from one country to another. U.S. reports estimate that between 700,000 and 2 million women and children are internationally trafficked each year for the sex industry and for labor (Richard 1999). Most of the victims of human trafficking are women and children, and they are often moved to other countries where they are isolated and essentially enslaved. The sale of mail-order brides and sex tours are important dimensions of human trafficking. Mail-order brides are typically from Asia and Eastern Europe and are often promoted as conforming to more traditional, “feminine” notions of womanhood than their Euro-American counterparts. In 1998, the International

Labour Organization (ILO) estimates of the number of prostitutes in Indonesia ranged from 140,000 to 230,000; in Malaysia, from 43,000 to more than 142,000; in the Philippines, from 100,000 to 600,000 (and the ILO suggests that 500,000 is a more reliable figure); and in Thailand, the estimated number of prostitutes in 1997 was between 200,000 and 300,000. Such figures are not unique to Asian countries—an article in the *New York Times* by Michael Specter in 1998 estimated that approximately half a million women are also trafficked into Western Europe every year. The European Conference on Trafficking in Women in June 1996 claimed that women from Africa (Ghana, Nigeria, Morocco), Latin America (Brazil, Colombia, the Dominican Republic), South East Asia (the Philippines, Thailand), and Central and Eastern Europe (Czech Republic, Hungary, Poland, Romania, Russia, Ukraine) were being trafficked into the European Union in large numbers.

The key issues regarding disability and the sex industry can be identified as follows: (1) disabled people's entrance to the sex industry in various forms as workers, (2) disabled men's access rights to prostitution or pornographic material as consumers, (3) seeking destigmatized or legalized prostitution by relying on a rationale that it is necessary for disabled men, and (4) advocating for medically prescribed sexual services (not involving prostitution) such as sexual surrogacy for disabled people, with an emphasis on the psychological benefits of sex for self-esteem.

DISABLED PEOPLE'S ENTRANCE TO THE SEX INDUSTRY

Disabled people are employed as sex workers in a number of fields. Some customers specifically look for certain attributes in prostitutes—such as disability—as a form of sexual fetish. It is becoming increasingly common for a "disability fetish" to be advertised on commercial Internet sex sites. There are niche markets for videos of disabled women having sex, pictures of naked amputees, and pictures of naked little people. For instance, recent videos include *Gimp Lovin, Roped Gimp, Gimp Pain,* and *The Gimp Sees a Doctor.* Websites such as "criptease.com" or "disabilitypayperview.com" sell photos and videos of fantasies involving disabled people who use wheelchairs and braces, who are amputees, who use strong glasses and other ocular devices, or who have leg casts. Often, these sites involve disabled women from Asia or Eastern Europe—such as Romania and the former Soviet Union. Similarly, there are devotees whose fetish involves other impairments, such as blood clotting. Calendars showing naked disabled people are also available and are advertised under such titles as "Gimps Gone Wild." A related fetish is the "medical fetish," which is also served by the commercial sex industry, through the production of videos of people receiving medical examinations, enemas, and so on. This industry also sells medical equipment such as neck braces, straitjackets, electrostimulators, catheters, mouth spreaders, and speculum (http:// www.medicaltoys.com/enemas.htm).

It has also been noted that the technological involvement in the sex industry, including Internet and phone connections, has resulted in an increase in both the number and the nature of sexual workers. In particular, there has been an increase in sex work outside of the sphere of genital contact. Many disabled women have been recruited into the industry in this way. For instance, increasing numbers of women with physical disabilities have been employed in the phone sex industry. In South Korea, it is reported that women with cognitive or physical disabilities have been procured and forced to prostitution. Disabled women often enter into traditional prostitution as the lowest and cheapest commodity due to their extremely marginalized status (commonly lacking resources and education and having a history of sexual abuse). *The Women's News* reported in 2003 that the Coalition for Eradicating Sex Trade of Women with Disabilities and the Rescue Hotline have been recently installed to deal with this problem in South Korea. In Zimbabwe, forced marriages and prostitution put women and girls, including the disabled, in danger of contracting sexually transmitted diseases or HIV/AIDS. This seems to be more serious for women and girls with disabilities as they are being sexually abused and raped by people who believe that HIV/AIDS can be cured by having sex with someone with a disability.

While Indian women and girls are trafficked into Kuwait and other Middle Eastern countries for purposes of prostitution, disabled Muslim children, primarily girls, are trafficked to Saudi Arabia for the purposes of begging or being sold into brothels. Hwang and Bedford (2003) reported that mentally disabled girls and other aboriginal girls were forced into indentured prostitution and kept in control with violence, deception, indebtedness, and affection in Taiwan. In China, the most common traditional image of the blind woman is a prostitute. Traditionally, blindness became an advantage in a prostitute, presumably because the client's own identity and defects were thereby spared any scrutiny.

DISABLED MEN'S RIGHT TO COMMERCIAL SEX AS AN ACCESS ISSUE

Some Western disability rights movements have made a connection between disabled people's sexual rights and the need to use commercialized sex. Sexual liberalism arose among disability activists to challenge discriminatory attitudes prohibiting and controlling disabled people's sexuality. Sexual liberalism suggests that disabled people should have equal access to prostitution and to other kinds of paid sexual services that are available to able-bodied citizens. This argument sometimes asserts that the cost of such commercial sexual services should be covered by a state welfare fund. It is proposed that prostitution is often the only way disabled people can have sex or even close physical contact with another person. This approach emphasizes the private and personal nature of purchasing a sex service. It is based on an individual's personal choice, and the fact that disabled customers can enjoy themselves away from their families and personal assistants is a sign of independence, which is thought to be a key element in their pleasure as sex industry consumers.

In addition to being positioned as an access issue, within sexual liberalism, disabled people's right to hire prostitutes often falls within a discourse of consumerism. There was a disabled Dutch man who fought a seven-year battle to win a 1997 court ruling giving him a monthly allowance for using the sex industry, paid by his council (Ananova 2005). Following the lead of a Dutch town that implemented a similar program, Ivo Konings, a city councilor with a disability in Hasselt, Belgium, proposed to give disabled men money to visit prostitutes. Konings, a former adviser to the Belgian government, consulted an organization of prostitutes in Hasselt about providing discounted rates for disabled customers and education for prostitutes. However, conservative arguments promote the abstinence of disabled people by emphasizing the potential danger of sexual activities to physical and mental health. Religious ethics forbid disabled men from seeking an "alternative" way of having sexual lives as well. Responding to such conservatism, the liberal approach is often paralleled by moves for the legalization of prostitution, with the prostitutes' rights movement asserting the necessity of their work in terms of disabled people's needs. In this way, disabled people's campaigns for practical solutions that will enable them to have access to sexual relationships converge with the efforts of the sex industry to promote access for "special" customers. For example, the Netherlands Prostitution Information Center provides tips for disabled customers on its website.

The Pink Palace in Melbourne also gained favorable media attention by carrying out building modifications that made their premises more accessible. Its new features included enlarged doors to accommodate wheelchairs and the installation of a sit-down shower. George Taleporos (2001), a researcher in the area of sexuality and disability, said in a BBC interview that many disabled people used prostitutes and brothels because it is difficult to date in the "usual" way. In Australia, the Accsex Network aims to provide disabled people with "therapeutic help" and access to sex services. The name *Accsex* stems from a combination of the words *access* and *sexuality.* Two of the major achievements of Accsex were establishing a fund by the Eros Foundation (Australia's sex industry trade union) to financially assist people with physical disabilities on low incomes to access the sex industry and raising awareness with attendant care providers about the need for "sex attendants" or attendant carers who are prepared and trained to assist their clients in sexually related activities. These activities, according to Taleporos, may include, among other things, "visiting a brothel, having sex with a partner, being assisted to purchase or use erotica or sex toys or providing assistance with masturbation."

The issue of access to pornography in alternative formats and assistance to purchase pornography has been controversial. A Braille copy of *Playboy* was provided by the National Library Service for the Blind and Handicapped in the United States, but Congress banned later funds for its production. Many people in the disability rights movement saw this as the violation of the First Amendment of the U.S. Constitution. Of course, disabled people are not only consumers of pornography but also may be its objects. For instance, the June 1987 *Playboy* employed disabled female Ellen Stohl. Ellen Stohl sought to express her sexuality by being included in the sex industry. The position of nondisabled caregiving women complicates the arguments regarding the right of disabled people to access the sex industry. A number of specialty brothels are provided for disabled men, and state-employed caretakers, who are mostly women, must take these men to the brothels if they wish to go. The competing rights of these women to be free from an environment that they may find objectionable and objectifying complicates the argument that disabled men, as their employers, have an unfettered right to access the sex industry.

USING DISABILITY TO DESTIGMATIZE PROSTITUTION

In contrast to the movement to end prostitution entirely, sex workers and some feminist movements have advocated decriminalization of all prostitution between consenting adults and have promoted the destigmatization of prostitutes. The need to sexually serve disabled people is often employed as a rationale for justifying prostitution in this context. Some sex workers find pride and identity in their roles, particularly when they define themselves as sex experts helping people with disabilities. In this paradigm, sexual exchange between a disabled man and a prostitute is perceived as friendly, mutual, supportive, and therapeutic. The asexual or emasculated image of disabled men can position disabled men as naive and in need of care, and prostitutes become seemingly authoritative in terms of sexual experience and knowledge. The power domination and violence prevalent in some feminist criticisms of prostitution are often assumed to be absent in prostitution relationships involving someone with a disability. In 2003, when New Zealand passed the Prostitution Reform Bill that decriminalized prostitution, it was argued that access to prostitution improves the lives of disabled people. The Green Party argued that prostitution was often the only way people with disabilities could have sex or even close physical contact with another person.

The call for respect for prostitutes, improvements in their conditions of work, and acknowledgment of prostitution as a profession has been addressed in a number of concrete schemes. For instance, as Shrage (1994) points out, as a result of the growing AIDS risk in the international sex industry, there have been some attempts to promote the medicalization of sex services and the licensing of prostitutes as "sex providers" with college-level education to assign social authority. The 1997 International Conference on Prostitution included the workshop on "Sex Work, Sex, and the Disabled." Sex surrogates working with a variety of disabled people called on fellow sex workers to deal with disabled clients with particular care and sensitivity. In this context, the label *sex surrogates* refers to prostitutes who specialize in dealing with disabled clients.

Tuppy Owen, organizer of Britain's annual Sex Maniac's Balls, which raise funds to "help handicapped people find love," has gone so far as to describe neighbors, friends, and hospital staff who masturbate people who are unable to masturbate themselves as "sex angels" (Steinberg 1997). Another argument that is used to justify prostitution is that it provides sex for persons who would otherwise be deprived of sex, for example, male migrant workers without their wives, disabled or old men, or men in the military. However, in responding to these arguments, feminists who are against prostitution argue that this argument is underpinned by an assumption that men, in any and every circumstance, must be able to have sex. Feminist organizations have made a strong stance against the exploitation of women, including disabled women, by the commercial sex industry.

In the words of Australian activists Mary Sullivan and Sheila Jeffreys (2001), from the Coalition Against Trafficking in Women,

> So normalized has brothel become that the sex industry markets itself as promoting the "rights" of people with disabilities by specifically catering to men and disability charities. Disabled men are seen as a good

> market opportunity by the legalized sex industry, and carers are expected to help these men engage in the abuse of women in brothels, or at least deliver them and wait in the lounge. It is the "rights" of men that are being catered to here. Disabled women are not mentioned.

MEDICALLY PRESCRIBED SEX SERVICES FOR DISABLED PEOPLE

Medicalized practices around disabled sexuality are another axis in the discussion of disabled men's participation in the sex industry. The sexological invention of sex therapy (more specifically, sexual surrogate partner therapy) has been employed for disabled men from the early 1980s in the United States. In this approach, sexuality is considered as a psychological and biological necessity for life and has to be promoted in a certain way. Disabled people's access to such sexual experiences and commercial sexual service first emerged in clinical settings. Promoters of sexual surrogacy for disabled people tend to distinguish sexual surrogacy from prostitution by arguing that sexual surrogates provide more than sexual service to the clients with whom they work. They attempt to meet the special psychological needs of clients and emphasize the therapeutic effects of their work. The term *partner surrogate,* suggested by Masters and Johnson (1970), refers to the partner provided for an unmarried man referred for treatment, who has no one to provide psychological and physiological support during the acute phase of his therapy. In the 2002 volume of *Disability Studies Quarterly,* it was suggested that disabled people should have the cost of hiring sexual surrogates incorporated into Ontario's government-sponsored personalized funding program presumably because sexual surrogacy functions as a real and meaningful form of erotic communication and self-realization and is practiced widely in the United States.

However, as Noonan (2000) points out, sexual surrogate therapy tends not to address heterosexual disabled women since heterosexual male surrogates remain the most rare of sex surrogates. Despite the fact that the concept of sexual surrogacy came from medical sex therapy discourse and was associated with professional discourse through the involvement of the team therapist, a licensed and/or certified professional with an advanced degree, sex surrogacy is actually more likely to exist within a continuum of sex industry practices. European advocates of sexual surrogacy are closely related to prostitute/sex worker organizations. The employment of sex therapy for disabled people's sexual experience or "fulfillment" in the rehabilitation paradigm is a relatively recent combination. Sex therapy has been mostly dedicated to the problems of able-bodied males who experience general anxiety over fulfilling cultural standards of masculine sexuality. Many sex therapists are not members of the medical profession. However, as researchers such as E. J. Haeberle (1983) suggest, there are tendencies on the part of many therapists and promoters to borrow respectability and authority from the medical establishment.

Even though sexual surrogates are supposed to be paid to aid people to express and develop their sexuality and not to give sexual gratification, there have been criticisms that sexual surrogates are simply providing medicalized and institutionalized sex. There have also been suggestions that surrogacy places disabled people's sexuality in the medical area alongside many other therapies; Shakespeare, Gillespie-Sells, and Davis (1996) and O'Brien (1990) both argue that suggesting sex workers require "special" training to engage in sexual activity with a disabled person can be seen as reinforcing the medical model of disability and ignoring institutional oppression and societal barriers, which are some of the causes of imposed celibacy.

A Swiss organization, Pro Infirmis, launched the "touchers project" in Zurich in June 2003 and publicized this project internationally. The pilot scheme involved training 12 professional "touchers" under the guidance of Dutch disabled sex pioneer Nina de Vries. Service would range from massage, body contact, stroking, holding, and bringing people to organism. "The successful applicants were then expected to offer sexual and emotional relief to the Zurich disabled community." However, after this project was announced, the organization suffered a significant reduction in donations. Pro Infirmis decided to end its direct involvement in the project and announced that it was looking for an independent association to take over. Similar programs were known to be running for years in Germany, Denmark, and the Netherlands, where it was called *Stichting Alternatieve Relatiebemiddeling*. The expansion of "therapeutic sexual services" for disabled people has therefore opened up new occupations for sex workers, sexual counselors, and surrogates.

The concept of sexual surrogacy came from a medical sex therapy discourse and seems to evoke a sense of professionalism because it involves a team therapist who is a licensed and/or certified professional with an advanced degree. However, sex surrogacy should still be understood in the context of a massive worldwide effort to make profits out of the sex industry. Often, sexual surrogates simply refer disabled people to sex workers who are prepared to have sex with them. In effect, *sex surrogacy* is interchangeable with *prostitution* in its implementation.

CONCLUSION

The international sex industry is a large-scale industry that includes prostitution, pornography, sex-related entertainment such as phone sex and Internet sex services, sex tourism, and other related activities. Representatives of the international sex industry often use disability to justify their existence by suggesting that commercial sex is the only way of helping disabled people meet their sexual needs. Commercial sex activities are also commonly discussed in a medicalized discourse, such as when they are euphemistically referred to as "therapy." At the same time, sex therapy in medical settings provides programs for disabled people who presumably have problems in sexual relationships. Sexual surrogate therapy emphasizes its psychological benefit to disabled people. However, the fact that the sex industry largely involves women from the non-Western world and many disabled women performing sexual activities for the benefit of men from wealthier countries makes it difficult to sustain the arguments that access to the commercial sex industry is an issue of "equal rights for all." Instead, this argument seems to involve an extension of male privilege to include disabled men, with little regard for the women who work in the industry, including the disabled women who work in prostitution, phone sex, pornography, and other related fields. It has been noted that the expansion of sexual services, facilitated by technological developments, has increased the number and nature of sexual workers, especially outside the sphere of genital contact. Expansion of the therapeutic sexual service area has also opened up new occupations for sexual counselors and surrogates. Such specialized sexual services are often used to justify the existence of sexual labor in general.

—Eunjung Kim and Mark Sherry

See also Accessible Internet; Gender; Sexual Access; Sexuality.

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SEX THERAPY

Sex therapy offers treatment for problems of sexual function and expression. A professional therapist will use specialized clinical skills to help individuals and couples to overcome sexual problems. The types of issues that clients present with include loss of desire, erectile dysfunction, premature ejaculation, pain on intercourse, and communication or other relationship problems. Many individuals are uninformed or unconfident about sexual issues. Many people experience sexual problems at some point in their lives.

Sex therapy is of particular relevance to disabled people. Some impairments may lead to loss of feeling or to difficulty in achieving sexual positions or performing sexual acts. Others may affect body image and lead to the individual feeling abnormal or unattractive. Those who are born with impairment may have been treated as asexual. They may not have received sex education or support in developing their sexuality. Some individuals may also not have been able to express feelings of same-sex attraction due to dependence on family and carers. Those who become impaired may believe that their sexual lives are over. They may experience this reaction from family, friends, and medical professionals. These attitudes may undermine self-esteem, self-confidence, and sexual expression. Disabled people's sexual problems are social and cultural as well as medical and physical: experience of social exclusion and disempowerment may be as important as particular functional issues.

Sex therapists should be trained in sexual anatomy and physiology, have counseling or therapeutic training, have the experience of relationship counseling, and adhere to a professional code of ethics. A series of sex therapy sessions will start by identifying problems and then finding solutions. A program of exercises and activities may be devised for the client(s) to do at home.

Sexual surrogacy is a separate and more controversial form of sex therapy in which an individual with sexual problems is referred by a sex therapist to a sexual surrogate, who will engage in sexual activity with that individual. Whereas sex therapy may work on emotional problems and may offer advice and exercises, sexual surrogacy works with bodies and offers practical sexual activity to resolve difficulties. The dividing line between sexual surrogacy, facilitated sex, and sex work or prostitution may be blurred and may not be recognized by law in some jurisdictions. Disabled people, who may have had difficulties forming relationships and may have issues with sexual activities or with body image and confidence, are commonly cited as potential beneficiaries of sexual surrogacy services.

Sexuality is an important part of self-identity; therefore, sexual problems may be experienced as undermining and distressing in general. Sexual rights have been neglected within both traditional rehabilitation services and the disability movement's campaigning and advocacy work. Disabled people have the same needs as nondisabled people, and sex therapy and sex education should be regarded as priorities alongside more obvious goals such as independent living, employment, and education.

See also Identity; Sexuality.

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British Association for Sexual and Relationship Therapy, http://www.basrt.org.uk

Relate (U.K. agency offering relationship counseling), http://www.relate.org.uk/sexproblems/sextherapy

Sexual Health (advice and support website founded by a disabled man, with a particular attention to disabled sexuality), http://www.sexualhealth.com

SEXUAL ACCESS

Despite an increase in critical approaches to disability, gender, and sexuality (Shuttleworth 2000b, 2003; Shuttleworth and Mona 2002), researchers need to develop conceptual frames that can be applied to a wide range of relevant issues and also assist in politicizing these issues. The concept of sexual access has recently been proposed to fit the bill for elucidating both the impediments and avenues to sexual well-being for disabled people (Shuttleworth and Mona 2002; Shuttleworth 2003, forthcoming; Grossman, Shuttleworth, and Prinz 2004). Application of the cornerstone disability studies concept of access has traditionally been limited to easily demarcated contexts such as schools, workplaces, and the built environment. A legalistic and technical understanding of the term has held sway that does not appreciably alter even when programmatic access becomes the analytical target (see, e.g., Burgstahler 1994). Embodied feelings, communicative processes, and the symbolic aspects of disability are usually not taken into account. Yet in terms of disabled people's sexual issues, these aspects are often the most crucial to interrogate.

Conceptualization of sexual access as it is developing in disability studies must be clearly differentiated from a similar term used by bioevolutionary scholars to refer to the degree to which males of a species have access to sex with females (e.g., Buss 1994). Instead, sexual access as theorized by the above disability studies researchers encompasses several related meanings. First and foremost, interpersonal sexual negotiations are viewed as situated within a cultural and sociostructural framework of inclusion-exclusion. It is important to interrogate not only sexual negotiations themselves but also multiple aspects of this framework to discern the degree to which these aspects work toward access to sexual expression and sexual relationships for disabled people. Depending on a disabled person's particular situation, relevant aspects of this framework may include physical access to environments and social contexts in which sexually relevant interpersonal encounters may occur, monetary access, programmatic access to personal assistance services, access to transportation, communication access, and many others. Perhaps the most powerful impingement on disabled people's interpersonal sexual negotiations, which presents formidable difficulties for systematic investigation, is the adverse context of cultural images and meanings of disability and sexual desirability.

Sexual well-being is reliant on psychological, social, and cultural supports that sustain a positive sense of one's sexual self. The availability of these supports for disabled people is another sense by which sexual access or exclusion may be gauged. Disabled people, whether it is in their families of origin, institutional contexts, or in the society at large, often experience a lack of support for their sexuality. For instance, people with early onset impairments often report that family members do not expect them to experience a sex life and marriage (Shuttleworth 2000a, 2000b; Mona and Gardos 2000; Shakespeare, Gillespie-Sells, and Davies 1996; Rousso 1993). One example of the way psychological, social, and cultural supports might reinforce each other to promote disabled people's sexual access and sexual well-being is if disabled people were represented in more sexually positive ways in the media. For some disabled people, this more positive sexual representation might result in a more positive sexual self-identification and heightened sexual self-esteem, which might also result in many nondisabled people perceiving them in a more sexual light.

A final sense in which the concept of sexual access might be fruitfully used is in interrogating the formation of gender and sexual identities for disabled people. For significantly disabled people, especially those who live in more structured living environments such as nursing homes and group homes, access to opportunities for sexual and gender expression may be limited given the multiple social restrictions operating and minimal sociocultural support within these institutions (Shuttleworth and Mona 2002; Hamilton 2002; Wade 2002). The question that needs to be asked is to what degree can one form a sexual or gender identity (normative or not) and a sense of one's self as a sexual agent in these kind of living environments.

The concept of sexual access can thus be used to critically frame many of disabled people's sexual issues. Use of an access frame importantly situates disabled people's sexuality squarely within a political context on par with other issues on the disability rights agenda (Shuttleworth 2003, forthcoming).

—Russell P. Shuttleworth

See also Sex Therapy; Sexuality.

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SEXUALITY

Historically, people with disabilities have either been regarded as asexual or sometimes as sexually deviant and threatening. The sexuality of people with disabilities has often been ignored by health and social services. If the sexuality of people with disabilities were considered, it was mostly in relation to physiological functioning. The psychosocial influences on the sexual lives of people with disabilities were generally overlooked in favor of purely medically focused models. After the Vietnam War, there was a significant increase in U.S. attention toward physical impairment and sexual functioning in men but sparse recognition of the wider issues.

Today, there is widespread awareness that sexuality is equally important to men and women with disabilities and that sexuality is an integral part of the development and experience of all people. Disability activists have played a strong role in this, campaigning for the sexual rights of people with disabilities to be recognized, including the right to have sexual relationships, the right to be parents, and the right to access sexual services.

Recognizing the physiological, psychological, and social aspects of sexuality is essential to obtaining an understanding of the issues related to the sexuality of people with disabilities. While hormones, the nervous system, and the human body in general play a significant role in regulating sexuality, sexuality is also influenced by psychological characteristics, culture, and society.

PHYSIOLOGICAL ISSUES AND SEXUAL FUNCTION

Different impairments affect sexual response in different ways, and most disabilities do not affect sexual functioning. However, impairments that affect the sensory pathways, such as spinal cord injuries and multiple sclerosis, are often associated with challenges for people in sexual function. Men can find it difficult to achieve and maintain an erection and ejaculation, and vaginal sensation and lubrication and orgasm can be problematic for women. Some developmental disabilities are also associated with impaired sexual functioning.

PHYSICAL DISABILITY AND SEXUAL FUNCTIONING

For men with spinal cord injury (SCI), sexual response is likely to be permanently affected in some way. This will vary according to the level and completeness of the lesion and whether a sphincterectomy, which commonly abolishes erectile function, has been performed. Many men with SCI are capable of erections. Erections have been reported to occur in most men within one year following their injury. Those with incomplete upper motor neuron lesions are more likely to have erectile capabilities. The type of erection experienced may be either psychogenic, caused by a psychological stimulus, or reflexogenic, caused by a physical stimulus. Psychogenic erections are more likely in men with incomplete lower motor neuron lesions, and reflexogenic erections are more likely in men with complete upper motor neuron lesions. Ejaculation is less likely than erection because of the common experience of retrograde ejaculation, where the semen is ejected into the bladder rather than the urethral meatus. The frequency of self-reported orgasm is approximately 45 percent.

Vaginal lubrication may remain in women with incomplete injuries at all spinal levels. For women with complete injuries between the T10 and T12 level, there is typically an absence of either psychogenic or reflexogenic lubrication. The act of sexual intercourse may be made difficult as a result of spasticity of the adductor muscles and pelvic floor. It has been reported that 53 percent of women experience orgasm after SCI.

Difficulties with erections may eventually be experienced by nearly half of men with multiple sclerosis (MS), and this is likely to be caused by lesions of the thoracic spine and autonomic nerves. Sexual difficulties, ranging from premature ejaculation to lack of sexual interest and reduced frequency of masturbation, are also common. Women also experience sexual difficulties as a result of MS, including loss of libido and lack of vaginal lubrication. Women with MS also report difficulty achieving orgasm and a decrease in their frequency of having intercourse since diagnosis. Women with MS also commonly report numbness, spasms, fatigue, and painful intercourse.

An inability for people with disabilities to perform sexual acts may be associated with depression and low sexual esteem for the person with the impaired sexual response, particularly when social and cultural values are considered. For example, some may feel like they are not suitable as sexual partners because of their impaired sexual functioning, particularly in Western society, where there is a strong emphasis on sexual performance.

INTELLECTUAL DISABILITY AND SEXUAL FUNCTIONING

People with intellectual disabilities generally do not experience difficulties in sexual function as a direct result of their impairment. There are a few exceptions of note where the genetic etiology affects sexual development and function of the individual's reproductive capacity. Men with Down syndrome have been observed to have a very low fertility rate and may require reproductive assistance to become a parent. Men with Down syndrome can also experience cryptorchidism (undescended testes). Almost all men with fragile X syndrome experience macrorchidism (enlarged testes), and this is frequently not observed until puberty. Men who have Prader-Willi syndrome can experience cryptorchidism and hypogonadism (smaller testes and penis) and may not develop secondary sexual characteristics (voice breaking, body hair, etc.) due to lower testosterone production.

People who have psychiatric disabilities and are prescribed psychotropic medications sometimes report the medications having an impact on sexual function and libido. This impact may be caused by the impairment itself, a result of side effects from their prescribed medication, or a combined effect.

Women with intellectual disabilities have commonly experienced sterilization, often without their knowledge and consent. Women who have had a hysterectomy at a young age have reported difficulties sexually. Some of these women have experienced menopause at a young age and have difficulties with vaginal lubrication and report sex to be painful.

Many women with intellectual disabilities have described sex as painful. When discussing sex, very few talk about it as a source of pleasure or mention that they have orgasms when they have intercourse. Sex is something that they describe being done to them rather than them having an active role. Much of their experience of sex is from sexual assault. When women with intellectual disabilities describe the consenting sex they have, it is frequently void of foreplay and can often be very hurried, resulting in a painful experience due to poor vaginal lubrication.

Men with intellectual disabilities can also be subject to medical control of their sexuality. The negative perceptions of others toward these men's sexual expression (including masturbation) can result in chemical intervention through the prescription of antiandrogenic drugs that reduce testosterone levels or various forms of confinement or control.

SOCIAL AND PRACTICAL BARRIERS TO SEXUAL EXPRESSION

While sexual dysfunction relates to specific impairments, other barriers to sexual expression are likely to exist across the range of impairments. These barriers are associated with societal attitudes as well as the physical impediments that are associated with decreased mobility, speech impairment, and a dependence on others for care.

Societal Attitudes

It is widely accepted that the problems people with disabilities face in sexuality more often reflect attitudinal barriers set up by our culture and accepted by both disabled and nondisabled persons rather than actual physical limitations. Furthermore, it is claimed that sexual problems experienced by people with disabilities are more often related to culturally established attitudinal barriers rather than physical limitations.

A common social attitude is that people with physical disabilities are dependent and helpless. This attitude may lead to other assumptions that prevent an able-bodied person from accepting a person with a disability as a sexual partner. For example, the person with the disability may be perceived as very "needy," and a relationship with this person could be viewed as extremely demanding and never equal. This attitude may be internalized by people with disabilities as they come to believe that they will always rely on their families and that their dependency makes them undesirable life partners.

Dominant beliefs held about the sexualities of people with disabilities come from mythologies. People with intellectual disabilities, in particular, are either believed to be oversexed and dangerous because of an innate inability to know what they want and control themselves in a socially acceptable way or they are perceived to be asexual, eternally childlike, and not in possession of adult sexual desires. Other pervasive myths about people with disabilities are that they are unable to parent, conceive, or adequately raise children.

The myth that people with disabilities are asexual or that sex is not relevant to them is also commonly blamed for the exclusion of people with disabilities from sexual activities. This has been highlighted by an increasingly vocal constituency of people with disabilities who have expressed frustration at the social barriers to full participation in life, particularly in the taboo area of sexuality.

According to Tom Shakespeare (2000), a prolific author in this field, where disabled people are seen as sexual, it is in terms of deviant sexuality, for example, inappropriate sexual display or masturbation. Therefore, the sexuality of people with disabilities is more likely to be considered when it is a problem. Shakespeare also argues that there is an unspoken taboo about sexuality and disability, pointing out that disabled people's sexual and emotional needs are rarely included in any discussion or representation in popular culture such as movies, music, and magazines. This reinforces the public's attitudes and expectations toward disabled people as seeing them as "sick and sexless" rather than participating in full sexual and family relationships.

Much of what we know about the social barriers that people with disabilities face in relation to their sexuality comes from the reports of people with disabilities themselves. Robert Murphy (1995) drew on his personal experience living with quadriplegia to reflect on the position of physical disability in American society. He argued that the disabled, individually and as a group, contravene all the values of youth, virility, activity, and physical beauty that Americans cherish. He believed that disabled people are resented by the able-bodied and are seen by them as ugly and repulsive—they are perceived as subverters of social values and ideals. According to Murphy, these values and ideals include strength, independence, virility, and health, and they are promoted and affirmed constantly in the media, while the disabled body is hidden or presented as something to be avoided, corrected, and pitied.

The sexualities of people with disabilities have been and continue to be affected by the ideology of eugenics. Historically, there has been a fear that people with disabilities will produce offspring with disabilities, as well as a belief that this is something that should be avoided. This stems from a fear of disability and a belief that people with disabilities are of less value and a threat to the genetic good or survival of the human species. Sometimes the message is implicit and at other times explicit. Explicitly, the continuing practice of sterilization as a reproductive control of people with disabilities (particularly women with intellectual disabilities) and the institutionalization of people with disabilities (particularly people with intellectual, cognitive, or psychiatric disabilities) show the continuing influence of the eugenic ideology and have a serious impact on sexuality.

There is also evidence that people with disabilities (particularly women) experience sexual abuse at a higher rate than in the general population. This may be because people with disabilities are more likely to live in institutions or to have contact with a wide range of caregivers; it may be because communication barriers mean that people with disabilities are less likely to be heard or believed if they report abuse; it may also be because of physical vulnerability or availability. Awareness of the dangers of abuse may be lacking and protection absent. Conversely, focus on abuse may lead to overprotectiveness of people with disabilities and an unwillingness to provide information about their bodies and sexual behavior. It may be thought that raising awareness of sexuality increases vulnerability, whereas appropriate education may instead reduce the likelihood of an assault and increase the possibility of individuals reporting inappropriate attention or actions.

People with disabilities are vulnerable to sexually transmitted infections like any other member of society. People are placed at increased risk of exposure if they do not receive education on the risks and protective measures that people can take. Particular groups of people may be more vulnerable due to their sexual practice and where they live (e.g., men who have sex with other men where there is a high prevalence of HIV among homosexual men). Sex education and HIV/AIDS education need to take into account information barriers: for example, making health information available in simple text, via sign language and in different formats for people with visual impairments.

General societal attitudes toward sexuality are also likely to affect people with disabilities. Society places a great deal of emphasis on sexual intercourse, and other kinds of sexual behavior, such as kissing, cuddling, and mutual masturbation, are viewed as less significant and labeled "foreplay." The achievement of orgasm is also emphasized, and sensation and movement are equated with sexual eligibility. For some people with physical disabilities, these attitudes could hinder their sexual esteem, as they may be physically unable to engage in the sex acts that are socially valued. Likewise, they are discouraged from participating in the acts that they are capable of because they are socially devalued. A more open approach to sexuality may value nonheterosexual forms of sexuality, may foster a more imaginative and experimental approach to sexual expression and activity, and may enable people with disabilities to achieve pleasure and intimacy in diverse and individual ways.

Practical Barriers

Reduced mobility may interfere with sexual expression in all physical impairments, but the exact nature of the practical difficulty is likely to be disability specific. For example, people with an impaired urinary system, such as those with MS and SCI, may need to contend with removing an indwelling or external catheter or bending and taping the catheter when preparing for sexual intercourse. They also risk spontaneous bladder and bowel emptying. People with impairments that cause physical weakness, such as neuromuscular conditions, may not have sufficient motor strength to masturbate to orgasm or to sufficiently pleasure a sexual partner. Mobility problems involving inaccessible public transport, clubs, and housing are also likely to affect opportunities to socialize and meet potential sexual partners.

Speech impairment can also be a significant barrier to establishing sexual relationships. The use of augmentative communication devices requires skill and patience, and consequently, the speech-impaired person's opportunities to express his or her personality and attract a partner through two-way communication are affected.

Dependence on others for care can also seriously restrict an individual's opportunities to freely express his or her sexuality because of a lack of privacy and overprotective parents or caregivers. For people who live with their parents, the establishment of sexual relationships is likely to relate to the degree of independence from parental figures. However, the person with a disability often remains dependent on parents much longer than the able-bodied individual. The parents of a person with a disability may have difficulty acknowledging the sexuality of their child and struggle accepting that their son or daughter could have a life independent of them. These overprotective parents may be especially concerned about their child being "hurt" or "exploited," and they may communicate, either directly or indirectly to their child, that a sexual relationship and marriage are not a realistic possibility. Overprotective parents and a dependence on others for care can be a contributing factor to social isolation, which limits the social and sexual opportunities of a person with a disability.

For people with disabilities who reside in supported accommodation, social isolation and barriers to sexual relationships can be even more serious as a result of cramped conditions, a lack of privacy, and the intrusion of support staff. These people are often more segregated from able-bodied people, and in some institutions, sexual contact between residents is prohibited. In cases where sexual contact is allowed, it is still unlikely to be possible if both residents have mobility problems, and often the only able-bodied people they associate with are professionals who are forbidden to engage in sexual relationships with a resident or to provide the assistance needed for two residents to have sex.

People with disabilities may experience enormous external pressures that impinge on their sexualities. This control can come from family members, carers, service providers, and support agencies that provide accommodation, recreation, or medical services. To self-advocate and assert their choices and express sexual desires in such a negative climate takes huge courage and determination. The places where people with disabilities live (institutions, nursing homes, boarding houses, hospitals, prisons, group homes, and, particularly for people with cognitive and psychiatric disabilities, on the street) all have an impact of the sexuality of people with disabilities and affects the way they see themselves and their opportunities for forming a positive sexual identity. People with intellectual disabilities who have experienced living in institutions and group homes in the community have sadly reported fewer opportunities in group homes to have sexual relationships due to the increased level of supervision (those staff see it as their job to prevent sexual contact rather than enable people's relationships) than when people resided in institutions. Many aspects of people's lives have seen conscious planning and support for people to gain independent skills or have their needs met by services in the areas of managing finances, learning housekeeping skills, and having educational and vocational opportunities, but the area of sexuality has largely been ignored, reinforcing the belief that people with disabilities are not whole and that emotional and sexual connections with others should not be encouraged.

Wider discrimination against people with disabilities also affects the capacity to achieve intimacy and express sexuality. For example, people with disabilities may be isolated and lonely. Many people make friends or meet partners at college or in the workplace: if people with disabilities are excluded from both those domains, their social life may suffer. To participate in leisure activities, they need money to buy clothes, pay for admission to venues, and buy drinks and meals, but because many people with disabilities are poor, this may be impossible for them. Above all, meeting people and making friends and becoming lovers all depends on individual self-esteem and confidence: if people with disabilities are socialized into dependency, feel bad about their bodies, or lack self-worth, then they may find it difficult to overcome barriers to interaction and may be seen as unattractive or undesirable.

SEXUAL MINORITIES WITH DISABILITIES

While most are probably heterosexual, some people with disabilities are gay, lesbian, bisexual, intersex, and transgender. These sexual minorities face unique challenges when they are coupled with disability. For example, a dependence on others for care makes the exploration of a person's sexuality and the gay, lesbian, bisexual, and transgender community more difficult. This early exploration is usually achieved privately and independently, at a time when the person feels a sense of apprehension and cautiousness. The nondisabled person can do this with minimal risk and with little fear of his or her family and friends knowing. However, a person with a disability may need support to attend a gay or lesbian venue, such as assistance with transport, communication, or personal care. This often requires negotiation and disclosure and the need to "come out" at a time when the person may not feel prepared or confident. Furthermore, physical access to the venue also needs to be considered. For transgendered people who require assistance to dress, there may be a fear of asking to wear clothing of their choice. If they do ask, their requests may be refused, and they may be subjected to abuse and ridicule.

The sexualities of people with disabilities are also affected by common assumptions that people should only have monogamous relationships and that the sex they have cannot involve experimentation, sexual role-play, cross-dressing, or an expression of fetishism. Engaging in any of these activities is often perceived as being sexually deviant if one or more partners have a disability, whereas it is seen to be within the spectrum of sexual behavior for those without disability.

SEXUAL RIGHTS OF PEOPLE WITH DISABILITIES

In the face of the many barriers, it is important to consider the sexual rights of people with disabilities. Ann Craft (1994) identified the following rights. First, they have the right to be treated as adults and not perceived by others as eternally childlike and sexless and to be treated with the dignity and respect accorded to adults. Second, they have the right to be provided with accurate knowledge about sex and sexuality in ways that they can understand. Third, they have the right to be sexual and to make and break relationships. People with disabilities need to be able to exercise risk taking in order to learn and should not be overprotected for fear they may suffer some emotional or physical harm. A lack of experience will place the person at greater risk. Fourth, they have the right not to be at the mercy of the individual sexual attitudes of different caregivers. Those supporting people with disabilities need to promote self-realization in the individuals, not compliance, enabling them to make their own choices and be able to express their own sexual identity without a prescribed notion of what constitutes a norm. Finally, they have the right to live in humane and dignified environments, free from sexual abuse. To foster a positive and healthy sexuality, people require a safe space that affords privacy, personal control, and choice.

While traditional service providers have neglected the sexual rights of people with disabilities, for reasons discussed above, it is perhaps more surprising that the disability movements have been slow to take up the campaign for sexual rights. American disabled feminist Ann Finger (1992) argues that the disability rights movement has not put sexual rights at the forefront of its agenda:

> Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about—and formulate strategies for changing—discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction. (p. 9)

Perhaps because other disability rights have been prioritized, perhaps because acknowledging the exclusion from intimacy is painful, or perhaps because of wider taboos about sexuality, effective work to achieve the sexual rights of disabled people has been neglected in many countries. However, promising developments include better campaigns around HIV/AIDS and sexual health, often based on peer education; better training for professionals, carers, and personal assistants; provision of nightclubs and other social activities for people with learning difficulties; respect for privacy and the right to have control over your own body; and new positive images of disabled people's bodies, sexuality, and relationships, such as the Australian Intimate Encounters project.

Despite the history of exclusion and the reality of isolation and abuse for many people with disabilities, it is important to note that for other people with disabilities, their sexual rights are being achieved, and they are leading satisfying sexual lives. People with disabilities are having relationships of all kinds, heterosexual, homosexual, monogamous, and polyamorous. People with disabilities are having children. Many are marrying other disabled people and people who do not have disabilities. People with disabilities are dating, loving, touching, kissing, hugging, sucking, fingering, and fucking. Some are accessing the sex industry, visiting sex workers, working as sex workers, consuming pornography, and, in some instances, making pornography. People with disabilities are learning and teaching about sex, as sex educators, counselors, and researchers. They are finding and sharing useful ways to enjoy sexuality and increase sexual pleasure and sexual esteem. Prioritizing the sexual rights of people with disabilities, as well as breaking down taboos and silences, will ensure that these successful stories become the norm for most people with disabilities in years to come.

—George Taleporos and Matthew Bowden

See also Children of Disabled Parents; Gender; Identity; Sexual Access.

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Websites

Bent, http://www.bentvoices.org

Disabled Sex, http://www.disabledsex.org

Intimate Encounters, http://www.intimate-encounters.com.au

Sexual Health Network, http://www.sexualhealth.com

SHELTERED EMPLOYMENT

Sheltered employment provides paid work opportunities for people with disabilities for whom a job in the community-based labor force is believed to be unlikely. These work activities are typically offered in protected environments or sheltered workshops, where the demands of competitive employment are minimized. For example, the sheltered working environment can be constructed to reduce levels of responsibility, hours of employment, pace of work, and the number of work demands placed on an employee. It is organized to provide assistance from human services support personnel so that individuals engaged in sheltered employment can reach their maximum level of performance and productivity.

In recent years, sheltered employment has been the focus of much critical debate because the underlying beliefs about work and disability, as well as the structure and practices of this employment model, have serious implications for the community inclusion and citizenship of people with disabilities.

THE STRUCTURE AND FUNCTIONS OF SHELTERED EMPLOYMENT

Sheltered employment is offered in small- to medium-sized organizations, typically employing fewer then 100 persons. It is administered by private, nonprofit, or voluntary organizations. The jobs offered by sheltered employment are varied, but they may include commercial ventures (e.g., a car wash, catering, or woodworking business serving the public), subcontracts negotiated through other industries (such as packaging or assembly), activities to serve the administrative organization (such as mailing and filing), or simulated work activities. In most cases, sheltered employment receives government funding or subsidy for costs such as human resources, equipment, space, and employee payment. Control of the income realized through the sales of goods and services depends on the relationship to the funding source. The extent to which organizations offering sheltered employment retain control of their income will have significant implications on their ability to purchase equipment, offer compensation to workers, upgrade facilities, and other activities that are common in workplaces in the regular community labor market.

Sheltered employment has been developed to fulfill several functions. The first is to provide people with disabilities the opportunity to participate in work for pay. From this perspective, the person is considered an employee, and sheltered work can be conceptualized as the person's job or occupational status.

A second function of sheltered employment is to create a context for improvements in health and well-being. Through participation in work activities, individuals with disabilities have the opportunity to experience psychosocial benefits, including the development of self-esteem and worker identity, promoting a sense of personal competence, which contributes to the community and establishes social relationships. Work is thought to have therapeutic functions, and sheltered work improves physical, mental, and emotional impairments. From this perspective, individuals working in sheltered employment are clients of a health service that is an integral part of their treatment.

Finally, sheltered employment provides training to develop skills essential in the regular, community-based labor force. These include skills needed to successfully perform work activities (such as concentrating on the task, consistently producing high-quality products, working at speeds that are considered standard in regular employment settings), work-related skills (such as good grooming and personal hygiene, traveling to work, punctuality and attendance), and social skills at work (including getting along with coworkers, following instructions, and respecting authority). Sometimes, sheltered employment is organized to include work enclaves, direct job placement, and follow-up support to assist in the move to regular employment settings. From this perspective, the individual involved in sheltered employment is a trainee, learning skills that can lead to employment in the regular community labor market.

HISTORICAL PERSPECTIVES

Contemporary applications of sheltered employment for persons with disabilities can trace their origins back to the sixteenth and seventeenth centuries. The development of workhouses for the poor, as well as asylums for the indigent and people with disabilities, established work settings segregated from the public, which provided relief from poverty and the spiritual deterioration associated with idleness and loss of employment. In the nineteenth century, sheltered employment was developed on the grounds of institutions that provided long-term care with a view to promoting the therapeutic benefits of work participation and a daily routine, including a balance of work and rest. The rehabilitation functions of sheltered employment likely originated from efforts by schools for the blind in the late nineteenth century to facilitate the vocational training of students. Sheltered employment was actively promoted as a viable option in vocational rehabilitation until the late 1970s, when the model was criticized by activists promoting the civil rights of persons with disabilities. The model also came in conflict with legislation designed to combat worker exploitation. It was also shown that sheltered employment did not lead to full and integrated employment. New models of employment in the 1970s and 1980s demonstrated how individuals with disabilities could be supported directly in regular employment settings, encouraging a trend toward vocational rehabilitation efforts that supported, rather than sheltered, people in their employment.

PROBLEMS WITH SHELTERED EMPLOYMENT

Sheltered employment has been criticized because its tenets and assumptions are inconsistent with contemporary perspectives on disability that highlight the basic rights of all persons to participation in the life of the community, including full integration in regular occupational settings, and on the social and economic costs incurred when the potential of all citizens is underused. Sheltered employment designs the work situation with the aim of promoting workers' health and well-being, as well as their potential for regular employment. Traditionally, though, sheltered employment has not incorporated practices consistent with the social perspective of disability, such as working directly with employers to secure an integrated employment situation, one that incorporates accommodations and other supports that help workers function in integrated work settings.

The sheltered employment model has been criticized precisely because it "shelters" workers from the demands of regular work and segregates them from larger society. While workers in sheltered employment may contribute to society through the goods and services they produce, the model is structured to regulate the extent to which workers have direct contact with people in their communities, with nondisabled workers, or even with other community businesses to acquire needed supplies or services.

Sheltered employment has generally been unable to prepare people for employment in the open labor market. The nature of the work that can be done in segregated settings is limited, and generally it has not been able to provide jobs that are consistent with the knowledge, innovation, and technological demands of the current economy. It has been argued that the model cannot adequately prepare people if they are not exposed to the actual production and social context of mainstream employment. Similarly, individuals with disabilities are deprived of experiencing all of the personal benefits of work, including elements of work that might contribute to their own motivation to seek and maintain employment. For example, holding a job in the regular labor force may provide an individual with a social status that is personally valued and encourages staying at the job.

Critics also point out that the many functions of sheltered employment are incompatible, which hinders efforts to achieve mainstream employment. For example, the therapeutic functions of the model mean that it is likely to depend heavily on government funding, while the employment functions of the model support a more heavily production-oriented organization that is oriented to decreasing government assistance. This has significant implications for people with disabilities who may be held back in the sheltered setting because of their capacity to contribute to production demands. It can also affect those who are denied access to sheltered employment because they are perceived as less able to meet production standards.

The working conditions of sheltered employment have also been the object of some concern. The physical plant, work tasks, and the social segregation of sheltered work environments give the impression of an asylum and contribute to negative social attitudes. In addition, the nature of the work offered tends to be repetitive, requiring a low skill level, and without opportunities for advancement. This undermines efforts to present sheltered work as a credible place to acquire work skills and possibly contributes to discrimination toward persons with disabilities in the regular workforce. Furthermore, workers in sheltered employment may not have access to basic rights of employment enjoyed in the open labor market, such as compensation for unemployment and vacations, the protection of minimum wage standards, or the ability to organize themselves as a collective to negotiate their conditions of employment.

INTERNATIONAL PERSPECTIVES

Sheltered employment is an international phenomenon, and it is on the increase, despite efforts to develop alternate models that favor mainstream employment through the provision of supports and accommodations directly in regular community work settings.

There is considerable variation in the way sheltered employment is organized and structured around the world, so it is difficult to generalize about sheltered work. For example, sheltered employment will be affected by the employment rates of a country. Where the unemployment rate is rising, the numbers of individuals in sheltered employment can be expected to rise. There is also considerable variation between countries with respect to the nature of the disabilities experienced by workers in sheltered employment. Countries take different approaches to sheltered employment. European countries, for example, tend to focus on production functions and so are more likely to have people without disabilities working alongside disabled people, which is less common in North America.

Legislation will influence the prevalence of sheltered work. In countries with strong legislation to promote inclusion in the workforce, sheltered employment is likely to be a less prominent employment model. Where standard labor laws are applied to sheltered employment, employees can benefit from the standards and rights enjoyed by all workers. National policies may categorize some workers in sheltered employment as trainees or as employees, each with distinct policies governing their employment. Some countries recognize workers in sheltered employment only as clients of a service, and no formal employee relationship is established. While most countries provide some form of income support for persons with disabilities who are not economically self-sufficient, national policies will differ on the status granted sheltered employment with respect to minimum wage provisions and the remuneration for labor.

THE FUTURE OF SHELTERED EMPLOYMENT

The future of sheltered employment is uncertain. There are powerful arguments for the termination of sheltered employment as a vocational support program. Yet, the model persists internationally, probably because it is so difficult to change established social structures. The pressure to close sheltered work will be resisted by the support staff. Workers with disabilities may also resist, especially if they are long-time employees in sheltered settings. There are also concerns that, although more consistent with the ideals of mainstream employment, new employment models will not secure work opportunities for all people with disabilities, both because of constraints within the open labor markets (e.g., variable employment rates) and because it will be hard to support those with the most severe disabilities. Some worry that supported models may lead to bad working conditions and segregation within the workplace, without the benefits of the camaraderie available in the sheltered employment setting.

In response to criticisms directed at the model, modification can be expected. For example, sheltered employment may be modified to incorporate supported employment services or to develop a broader variety of work options and opportunities for advancement. Attempts may be made to enhance worker ownership and control, as well as develop training measures that are more likely to lead to the development of skills associated with success in mainstream employment. Whether true "sheltered" employment remains after these changes is not entirely clear.

—Terry Krupa

See also Employability; Employment; Job Analysis and Placement; Job Training; Supported Services; Vocational Rehabilitation.

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SIBLINGS OF PEOPLE WITH DISABILITIES

Unlike their parents, who remember a time "before," the nondisabled siblings of people with disabilities often possess an intimate familiarity with disability from their first memories. Psychological literature identifies many common themes in the lives of such siblings: gradual awareness of the disabled sibling's difference, competition for the parents' resources, fear that the sibling's disability will reflect on their own competence or health, increased sensitivity and acceptance of diverse abilities, and rebellion against, or acquiescence to, the expectation that they will take on advocate or guardian roles for their disabled sibling into adulthood. These assumptions are generalized mainly from recent, Western, family studies; whether they apply across cultures and eras remains to be seen. While past decades saw an emphasis on warning about the problems siblings would experience, current thinking holds that most siblings in otherwise "functional" families gain useful adaptive skills through their relationships to disabled brothers or sisters.

Many historical figures have been the siblings of people with disabilities. In the American context, at least two U.S. presidents (Thomas Jefferson and John F. Kennedy) had sisters with mental retardation. Ralph Waldo Emerson was responsible for the supervision of more than one institutionalized brother; his friend Margaret Fuller held a similar role in her family.

As siblings are seen as potential lifelong supports to individuals with disabilities, public programs have begun to concentrate some effort on addressing their concerns and educating them for this role. For example, "Sibshops" are offered by many community agencies serving people with disabilities; usually, but not always, developmental disabilities are the focus. Directed at school-age brothers and sisters of children with disabilities, they enable peer interaction through discussion, recreation, and activities designed to increase disability awareness in age-appropriate ways.

Beyond juvenile literature, support group curricula, and advice books for parents, reflective memoirs (and other literary nonfiction) by adult siblings have been published in increasing numbers in recent years. Rachel Simon's (2002) *Riding the Bus with My Sister* is perhaps the most lauded of these. This genre is still far less developed than the parental narrative but shows promise as a useful alternative glimpse at family life and disability.

—Penny L. Richards

See also Family; Family, International.

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SICK ROLE

Sick roles are the culturally established expectations for how a person should act when he or she is ill or is perceived as ill/abnormal in a particular group. Each person learns these sick roles through a process known as socialization, in which people are subtly educated in the norms of a particular group.

While the term *socialization* can be used to refer to modest processes such as introducing a new employee to the norms of a business or institution, here we are interested in the broader and more fundamental socialization that teaches a person how to become a member of society. This process starts neonatally and occurs at each moment of interaction with others. Over time, by living and interacting with others within a given society, each person internalizes the norms and expectations of others, sometimes to such an extent that they seem essential and natural—the only way the world could possibly be and the only way people could possibly behave within it. When this occurs, those "essential" norms and expectations become tinged with morality so that people refer to them with "shoulds" and "ought tos" and look disapprovingly at any ideas, behaviors, or realities that flaunt them. This process embeds within each person more or less a similar sense of appropriate behavior, for example, that murder and theft are bad and following traffic rules is good. Socialization makes society possible in a very fundamental way. And yet, the socialization of the sick role, the assumption that people with any illness or disability are morally obligated to behave in a particular way, has become deeply problematic in American society. But before exploring this, let us review the scholarly history of the notion of the sick role so that we might understand the recent backlash against it.

The first scholarly work on the subject of sick roles was published in 1929 in German by the medical historian Henry E. Sigerist. Sigerist, examining Western civilization but also drawing on cross-cultural information, defined illness as whatever disturbed the rhythm of a person's life so that the physiological symptoms isolated him or her, making that person suffer in helplessness, pain, and fear. For Sigerist, this sick role of isolation, dependency, and fear was the universal outcome of physiological suffering.

Talcott Parsons, the mid-twentieth-century American sociologist who made the notion of sick roles famous, did not take such a universalistic approach and instead grounded sick roles in the cultural and social dynamics of American medicine in the 1940s and 1950s.

Parsons recognized that for Americans of that era, illness and disability were both a deviation from an idealized norm of health and a deviation from the normal expectations of society. Parsons outlined basic features of the American sick role. First, the person who showed signs of deviating from health is exempted from his or her normal social activities and obligations and is exonerated from normal expectations of self-responsibility; in essence, the person takes on a dependent, childlike social status. Second, and largely because of the first feature, the person is socially isolated. Third, the person must accept that he or she is in this undesirable state, in need of help, and morally obligated to cooperate with others' therapeutic efforts at restoring the person to society's ideal of normal health so that the person can resume or take on normal social activities and obligations. The most appropriate source of therapy was seen as Western biomedicine.

This American model of the sick role developed out of an idealized notion of the body as normatively healthy and in conjunction with a model of biomedicine as a hierarchically structured, active, authoritative, parental institution that was responsible for making grateful, passive, childlike, and cooperative patients into healthy persons who could fulfill society's normal expectations and responsibilities.

There have been numerous scholarly criticisms of Parsons's sketch of the sick role, particularly the problems of applying it to specific physical conditions. Parsons based his sick role on the patterns of behavior that arise in response to those maladies that are temporarily incapacitating. Many conditions do not fit comfortably within his typology, including pregnancy, alcoholism, mental illness, chronic illness, congenital abnormalities, and many physical and mental disabilities. In such cases, the classification of sickness and its corresponding expectations for sick role behavior simply do not fit.

Indeed, the central problem of Parsons's sick role is the idea that perfect health and a perfect body are normal, and any deviation from these idealized norms constitutes sickness and the need for a sick role.

Norms of health vary tremendously cross-culturally, as do the expectations of what a person does when identified as sick. Sick roles, as the expectation for behavior when identified as ill or disabled, also vary significantly cross-culturally based on two variables: (1) who has access to medical information and technology and (2) how health is defined.

In societies where all people consider themselves more or less well, however far from perfect health, as long as they can fulfill some modest responsibilities in a society, illness itself becomes narrowly circumscribed to those instances of acute suffering. In such societies, long-term or chronic conditions are unlikely to be socially labeled as ill, but simply as a personal characteristic of the particular person. Among the Sasak of Indonesia, a place where the people describe themselves as "less than healthy," disabilities stemming from conditions such as skeletal deformities, chronic heart failure, and severe arthritis may physically limit tasks and are evaluated on a case-by-case basis, but they do not carry automatic expectations of changed behavior or responsibilities. The anthropological record, in fact, is full of examples in which people with chronic or debilitating conditions are not isolated or even viewed as sick until contact with the Western biomedical gaze medicalizes conditions, isolating their victims in the process.

The theoretical idea of a sick role has come under fire in the social sciences since the 1980s for various reasons. First, sick roles are an ideal type that may describe patterns of behavior across patients in a given culturally constituted social group but cannot predict or thoroughly describe the behavior of any particular patient. Second, the sick *role* has theatrical implications, suggesting that a person can perform or take on a role without being intricately bound to it; the notion of a sick role does not reflect the ontological reality and suffering of people who are ill or disabled. As a result of these criticisms, social science research has been more person centered, focused on patient narrative, patient experience, and sociolinguistic detailing of physician-patient interactions. The results of this work show a tremendous amount of diversity in the behaviors, attitudes, experiences, and interpretations of people who are ill or disabled.

In addition to this scholarly reaction, significant portions of Western society itself have reacted against the social expectations of patient passivity and isolation that Sigerist and Parsons described. Beginning in the 1970s but taking off in the 1980s, particularly with the AIDS movement, for some members of the population, ideals of passivity have changed gradually into expectations for activity and engagement. For people in America today, there are at least two widely distributed cultural ideas of what someone should do when he or she is sick. First, the passive, isolated behavioral expectation as described by Parsons and Sigerist remains a salient model for behavior. Second, there is an active and engaged model in which patients remain engaged in their lives, keep their social responsibilities, are considered responsible for their own recovery, and are educated and empowered consumers of health care. Recent scholarship suggests that people may choose either role or blend the two as best suits their particular needs and circumstances at the time.

Sick roles, as the cultural expectations of how someone who is ill or otherwise disabled should behave, can and do shift over time within a single society and vary significantly across societies.

—M. Cameron Hay-Rollins

See also Patient-Professional Relations; Patients' Rights; Stigma.

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SIGN LANGUAGE

Sign language is a means of communication through the use of body movements, gestures, and facial expressions. It could be described as plainly as pointing, shrugging, and grimacing or could be as complex as a combination of coded manual signals or signs.

Beyond simply a means of communication, American Sign Language (ASL) is the primary language used by Deaf and hard-of-hearing people in the United States and in parts of Canada. It is the native language of many Deaf men and women, as well as some hearing children born into Deaf families.

ASL is a visual-spatial language based on concepts rather than words. It is a linguistically complete language, gaining recognition and acceptance as a genuine, formal language due in large part to the research done by an English professor named William Stokoe. Stokoe worked to legitimize ASL, proving scientifically and unequivocally that ASL meets the full criteria of linguistics phonology, morphology, syntax, and semantics to be classified as a fully developed language. ASL shares no grammatical similarities to English and should not be considered in any way to be a broken, mimed, or gestural form of English. For example, ASL has a topic-comment syntax, while English uses subject-object-verb.

The history of ASL begins in the mid-eighteenth century in France. In 1755, Abbé Charles Michel de L'Épée (1712–1789) of Paris founded the first free school for deaf people, where the first sign language was developed. In 1815, Thomas Hopkins Gallaudet (1787–1851), an American Episcopal priest, traveled to Europe to study methods of communicating with the Deaf. After several months, Gallaudet returned to the United States with Laurent Clerc, a Deaf instructor from the Paris school for the Deaf. In 1817, Gallaudet established the first American school for the Deaf in Hartford, Connecticut, and Clerc played a primary role instructing Deaf children using sign language. The opening of subsequent residential schools for the Deaf throughout the United States promoted the standardization of ASL. Today, America has one of the most complete and expressive sign language systems of any country in the world, owing much to the French sign system, from which many present-day ASL signs, though modified, have been derived.

ASL is the primary language of Deaf people in the United States. This number of people represents those who view themselves as members of a cultural-linguistic minority group (Deaf), as opposed to those who audiologically are unable to hear (deaf). Estimates for the number of ASL users in the United States range from 300,000 to as high as 900,000. The most recent estimate given by the Gallaudet Research Institute puts that number at 360,000. Precise numbers are hard to come by due to the difficulty of discerning in the population those who are audiologically deaf and those who are culturally Deaf. In addition, it is also difficult to discern and measure the actual sign language used. A spectrum exists between ASL and other manually coded English (MCE) signs. Beginning signers, mainstreamed Deaf children, and late-deafened adults generally comprise the MCE side of the spectrum, while expert signers and Deaf families fall on the ASL side of the spectrum. In between there exist signers with a wide variety of skill.

The Deaf share a common history, language, value system, beliefs, characteristics, and behaviors, with American Sign Language as the common thread that binds them together. ASL is the fourth most commonly used language in the United States.

Deaf communities around the world use native sign languages that are indigenous to Deaf communities within specific countries and geographic locations. Within each signed language, there are regional dialects and variations that represent geographical differences; sign language is not universal. Signers in Great Britain use British Sign Language (BSL), while those in France use French Sign Language (LSF), and those in Switzerland have five distinct sign language dialects. There are international communication systems such as Gestuno and International Signs, which are similar to spoken Esperanto and commonly used in international conferences. These systems are more or less agreements on a vocabulary of signs among the international Deaf community.

—William Ennis

See also Deaf, History of the; Deaf Culture.

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SIGN LANGUAGE INTERPRETATION

Sign language interpreting has been a practice since signers came into contact with speakers. Facilitating communication between these two groups of people constitutes what Stewart, Schein, and Cartwright (1998) call "the art and science" of sign language interpreting, a profession now centered on enabling communication between deaf, signing persons and nondeaf, speaking persons. The interpreting process involves more than just these two (groups of) people, however. Indeed, interpreting is always a triangular act, calling on three—and sometimes even four—groups of people: those who know and use sign or sign languages, those who do not, those who interpret between those two, and sometimes also those who administer and finance interpreting programs.

While the practice of sign language interpreting is nothing new, the development of a profession around it is. The unlicensed predecessors of this profession were (more often than not) anonymous individuals—most likely friends or family—who have interpreted for deaf people in oral/aural-centered communication situations throughout undocumented periods of history. In this preprofessional period, interpreting was usually performed as a favor. The interpreting profession in the United States marks its inception in June 1964, when Ball State Teachers College in Muncie, Indiana, hosted the Workshop on Interpreting for the Deaf, sponsored by the Vocational Rehabilitation Agency, and members of this workshop voted to establish a national body of professional interpreters. This body was originally known as the National Registry of Professional Interpreters and Translators for the Deaf and is now known, more simply, as the Registry of Interpreters for the Deaf (RID). Fifteen years later, in 1979, Canadian interpreters formed the Association of Visual Language Interpreters of Canada (AVLIC); similar associations have also been formed in Great Britain, Australia, and a few other countries. Interpreting, as a recognized and organized profession, still rarely exists throughout the rest of the world.

Immediately after the RID was formed, two institutions developed interpreter training programs (ITPs): California State at Northridge in 1965 and the National Technical Institute for the Deaf (NTID) at Rochester Institute of Technology (RIT) in 1966. In 2003, the RID listed 159 interpreter training programs offering the following degrees: Certificate in Interpreting (43), associate's degree (75), bachelor's degree (30), graduate degree (3), and distance learning programs (8).

KEY LEGISLATION IN THE UNITED STATES

Several important pieces of legislation have helped instigate, effect, and even reinforce the professionalization of sign language in the United States. The Vocational Rehabilitation Act amendments in 1965 (P.L. 89–333) gave state rehabilitation agencies the authorization to employ interpreters for deaf clients, and in 1973, interpreting for deaf people in additional settings was mandated with the Rehabilitation Act amendments. This 1973 act contained Section 504, guaranteeing rights for "the handicapped." Included in those rights, the provision of interpreters—especially trained and qualified ones—in schools and "under any program or activity receiving Federal financial assistance" was no longer seen as a favor or a fairly rare occurrence. The power of this 1973 law was carried forward and even expanded with the passage of the Americans with Disabilities Act (ADA) in 1990. Between those two key pieces of legislation, the Bilingual, Hearing and Speech Impaired Court Interpreter Act was also passed by the U.S. Congress in 1977, stating that a federal court must appoint and pay for interpreting for a deaf person who is the subject of any criminal or civic action initiated by the federal government.

THE REGISTRY OF INTERPRETERS OF THE DEAF (RID)

In July 2002, full RID membership stood at 10,007, with 3,779 of those (about 37 percent) currently fully certified and practicing. These numbers are also supplemented by interpreters who are certified by the National Association of the Deaf (NAD). The RID now follows the definition of the ADA (see above) as its standard for recognizing a "qualified interpreter" as "an interpreter who is able to interpret effectively, accurately and impartially both receptively and expressively, using any necessary specialized vocabulary." As an indicator of the increasing demand for qualified interpreters and the specialization of this evolving profession, the RID currently offers 20 different certificates, including, for example, the following: Certified Deaf Interpreter (CDI), interpreters who are themselves deaf or hard of hearing; the Reverse Skills Certificate (RSC), for interpreting between American Sign Language and other English-based sign language forms; four different certificates for oral transliteration or interpreting; and specialist certificates for legal interpreting or performance arts interpretation (see www.rid.org).

THE INTERPRETING PROCESS

There are three key steps in the interpreting process: the interpreter must first understand the meaning of the message being received, the message must then be encoded into the target language, and the message must then be effectively expressed in that target language. In these steps, the ability to use both short- and long-term memory simultaneously is necessary as the interpreter moves between reception, encoding, and expression across not only two languages but also two modalities (spoken to visual/manual or vice versa). Interpreters must be able to walk (in one language) and chew gum (in another) at the same time.

Several sets of factors can greatly influence the interpreting process: physical, psychological, forms of interpreting, and the settings/scenes for the interpretation. Physical factors are often related to the auditory field, the visual field, personal factors, and the environment itself. In the auditory field, for example, the positioning of the three members of the triangulated situation, the acoustics of the setting, and the ambient noise all matter. The visual field also influences the interpreting process in such dimensions as the positioning of three members (again), the available lighting, the background "visual noise," and even the appearance of the participants. Interpreters tend to dress in dark, single colors and to avoid patterns in their professional clothing to present an uncomplicated and visually effective background for their hands. Personal factors also come into play in the interpreting process: interpreters should have good eyesight and hearing, the ability to focus in potentially distractive settings, and mechanisms for managing the cumulative stress that recent research shows often—carpal tunnel syndrome and repetitive stress tendonitis in their arms and shoulders, for example. Finally, management and manipulation of the communication environment itself must often take place to facilitate the process. For example, while a seating/standing rearrangement of not only the speaker, interpreter, and receiver (or vice versa) often occurs in interpretation, even nonparticipants in the interpreting process must also often resituate themselves—moving out of the line of sight, giving up the front-row seats, and so on.

Psychological factors play as great a role, if not sometimes even greater, as do physical ones. The interpreter's success at becoming either anonymous and seemingly absent in the process—and yet also, if needed, the center of attention—is one dimension of the psychological arena that interpreting often occurs in. Interpreters often find that they must also walk multiple fine lines: moving between their needs and their client's needs, practicing advocacy without oppression or paternalism, negotiating the stress of communication speed and time, dealing with overlapping speech and/or signs, balancing their own ethics (over the discourse they receive) with the accuracy of what they express back, and simultaneously maintaining distance—yet some camaraderie—with their clients. Gender variations in receiving, encoding, and processing language are also likely to influence the interpreting process, although little research has been conducted in this area (the profession is dominated by approximately 75 percent women).

In addition to these psychological factors, as the availability and even quality of interpreters seem to increase, so do the standards of the people who use them. Thus, the interpreting process can be affected by these standards when interpreters are almost always caught in the center of blame for failed communication between the other two stakeholders and when interpreters are sometimes viewed as merely communication conduits (not humans with inherently fallible communication capabilities) or as prostheses (akin, for example, to a hearing aid). Psychological causes and effects have also come to surround the tension created by legislating deaf citizens' "rights" for interpreters and the institution of their existence as a paid professional act. A vacillation between (too much or too little) trust of them and a concern over too much dependency on them commonly defines their contemporary relationship with deaf clients, who have also come to understand that interpreters make a living (and a good one, at that) off of their socially constructed "disability." Interpreters in the post-ADA era are often cursed if they do and cursed if they don't do their jobs.

Beyond physical and psychological factors are variations in discourse/language forms and in the settings that interpretation takes place in. Examples of forms might include interpreting for deaf-blind clients, oral interpretation, transliterations of cued speech, relay interpreting (often used with clients who have minimal language competency) when two or more kinds of interpreters are involved, and the now common use of tag-team interpreting—when paired interpreters alternate turns in timed periods over the course of a longer period. Each of these interpreting formats can change the interpreting process substantially. In addition, the form of the signed language itself matters: whether, for example, American Sign Language (ASL) or a pidgin/contact version that moves toward English is used, such as Signed Exact English (SEE) or Pidgin Signed English (PSE). Code switching and lexical borrowing between these three, as well as across regional "dialects" of signs and levels of formality, are also likely to enter into the interpreting process.

Interpreting now takes place in an endless variety of settings. Even the most common of these settings illustrates the breadth of skills any one interpreter might need to successfully insert specialized discourses into the interpreting process: legal, health/medical, mental health, rehabilitation and workplace, performance or "platform," religious, educational (across all levels and subjects), and emergency situations.

EDUCATIONAL INTERPRETING

Since the Education for All Handicapped Law (P.L. 94–142) and the Individuals with Disabilities Education Act (IDEA) in 1973, educational interpreting has comprised the largest arena of certified interpreting. The "mainstreaming" or "inclusion" of deaf and hard-of-hearing students into "regular" classrooms and public school settings has probably created more questions and issues (and demands) for the interpreting profession than any other dimension. The stakes are so high and the ethical, legislative, and policy implications for placing (typically adult) interpreters alongside (typically children) clients throughout the course of a school day are so varied and immense that research around and general attention to educational interpreting have come to the forefront of the interpreting profession. As one study published in the *American Annals for the Deaf* has shown (Antia and Kreimeyer 2001), interpreters often come to occupy an interesting variety of additional roles in the course of those school days—clarifying teacher directions, facilitating peer interactions, tutoring deaf children, and even informing teachers of the deaf child's progress or difficulties.

ETHICS

As might be expected, the ethical issues around interpreting are thick and thorny. When one group of people (sign language interpreters) represents the communication of another group of people (deaf, signing) and literally even "voices" their expressions and ideas, difficulties are likely to arise. The development of an official code of ethics was one of the first acts the RID undertook at its inception. The first code set forth in 1964, however, was heavily flavored with religious undertones since interpreting in the United States and Canada was grounded in volunteers who interpreted for church services. But by 1965, only a year later, the first official RID Code of Ethics had been substantially revised to include eight major points that interpreters were expected to strive for and maintain: (1) confidentiality about client, assignment, and so forth; (2) accuracy and completeness of message; (3) impartiality; (4) discretion, especially in not working beyond their own competence; (5) compensation commensurate with professional standards and situation; (6) professional standards; (7) professional obligations such as continuing their education and updating skills; and (8) application of sound judgment in all interpreting situations.

—Brenda Jo Brueggemann

See also Ethics; Sign Language.

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SIGN POETRY

Sign poetry, like its written and spoken counterparts, is a literary art form recognized for its heightened use of language. Yet, rather than featuring the acoustic patterns of spoken language, sign poetry manipulates the visual, spatial, and kinetic properties of its embodied medium.

As manual languages have had no written form, the Deaf community has been practicing what could ironically be referred to as an "oral" literary tradition. They have handed down their traditions from generation to generation in Deaf schools, clubs, and social gatherings. As a part of this "oral tradition," the American Deaf community has generated several unique genres that derive from technical and literary play on the "manual constraints" of the language. The most prominent of these are known as "ABC poems," "number poems," and "handshape poems," where the poetic narratives are told with predetermined pattern of handshapes, either those of the manual alphabet or the number system, or other specific handshapes. These predetermined structural forms may be similar to other literary traditions that feature formal constraints such as sonnets, haiku, and acrostic poems. The literary merit of a poem is often determined by the poet's ability to work within the constraints to produce a poem that ultimately transcends them.

While this oral tradition has been a lively part of the Deaf community since the nineteenth century, two events in the last half of the twentieth century have had an impact on sign poetry. First, the validation that American Sign Language (ASL) is a full human language, which began in the 1960s, instigated a desire to exploit this language for its poetic potential in ways analogous to spoken and written poetic language. Several Deaf poets originally composed poems in written English until it became apparent that ASL could just as easily be the primary language of a new body of Deaf literature. Many of these poets emerged as their work was supported through the National Theatre for the Deaf, including Bernard Bragg, Dorothy Miles, Gil Eastman, Ella Mae Lentz, Joseph Castronovo, and Pat Graybill. The National Theatre of the Deaf's landmark performance of *My Third Eye* in 1971 represented a break with previous traditions of sign performance, which still placed the written text as the "script." Instead, *My Third Eye* began to feature sign language for its strong ability to create visual imagery, thereby placing the written text in a secondary role.

This newfound awareness of sign language and a growing sense of a Deaf culture were accompanied by the advent of video technology, which allowed poets to "write" their poems on video. Deaf poets began to create and revise their works according to rough video drafts of a poem. This technology transformed an "oral" tradition into a body of poetry that became published and distributed much like written poetry, only in video format. The first ASL poetry videotapes appeared in 1988, in the *Poetry in Motion* series produced by Sign Media Inc. These featured the works of Patrick Graybill, Debbie Rennie, and Clayton Valli. These tapes still sell widely within the Deaf community, yet as they are not voice interpreted, they are not accessible to nonsigners. In 1995, Ella Mae Lentz produced *The Treasure,* which broke new ground it its use of cinematic effects, including stage sets, costumes, and camera movements. Clayton Valli's *ASL Poetry: Selected Works of Clayton Valli,* which appeared in 1995, features a collection of Valli's poems. The author, however, does not recite the poems; instead, they are performed by a host of different signers, ranging from children younger than age 10 to older members of the Deaf community. After all of the poems have been performed, the text replays each in slow motion, explaining the various poetic techniques employed in the poems. Valli's *Selected Poetry* demonstrates the ways in which the linguistic validation of signed languages, accompanied by the use of video technology, has influenced the ways that critics discuss sign poetry and poetics.

Clayton Valli has identified a wide range of poetic techniques as they appear in signed languages. Rhymes, for example, are based not on sound patterns but on visual patterns of linguistic units. These units, which are equivalent to phonemic elements, consist of

- particular handshapes,
- movement paths of the hands,
- signing location,
- palm orientation, and
- nonmanual signals on the face and body.

A single poem may be threaded together with one or more of these rhyme types. A single handshape may run throughout a poem, a movement path (i.e., circular, diagonal, etc.) may lend a particular symbolic and aesthetic structure to a poem, or a repeated pattern signing location may accentuate contrasts between stanzas and topics.

In Clayton Valli's "Hands," for example, the principle handshape is the open "five" handshape, which Valli then uses to weave images that correspond to the seasons, each of which is placed along a larger circle, representing the full-year cycle. Valli ends the poem with breaking the plane of the circle, foregrounding his hands. In this poem, which takes less than a minute to perform, there is a complex structure of handshape, signing location, and nonmanual signals (facial expressions) that work simultaneously to create a distinct visual and spatial poetic effect.

Clayton Valli's work is highly structured and often lyrical. In fact, he often likens his work to the poetry of Robert Frost, who represents a lyrical, highly symbolic poetic tradition in American poetry. Yet, just as with broader traditions in American poetry, sign poetry also features emerging traditions. On one hand, poets such as Ella Mae Lentz, Clayton Valli, and Patrick Graybill create poems that are densely structured, highly lyrical, and often related to Deaf themes; other poets have created a more experimental, avant-garde tradition that might be likened to the imagist poetry of Ezra Pound and the beat poetry of Allen Ginsberg. These poets emerged from Rochester, New York, the hotbed of ASL poetry in the 1980s, including Debbie Rennie and Flying Words Project—Deaf poet Peter Cook and hearing collaborator, Kenny Lerner. This poetic community, inspired in part by hearing poet Jim Cohn, promoted sign poetry to both Deaf and hearing communities by sponsoring the first national ASL poetry conference and meetings with hearing poets such as Allen Ginsberg. Flying Words Project has now produced two videotapes, titled *The Year of Walking Dog: The Early Poems* and *The Can't Touch Tour: Current Works.*

This poetic tradition emphasizes the cinematic nature of the signed languages, often making deliberate use of the poetic technique named by Bernard Bragg as "visual vernacular." This technique enables the poet to embody characters and images within the poem, giving a distinctly cinematic impression, replete with such signed versions of cinematic techniques as closeup, medium and distant, and cut-away shots. In Debbie Rennie's "Missing Children," for example, Rennie deftly assumes the character of a small Nicaraguan boy and then a member of a government death squad, back and forth, until we witness the murder of the boy, which is told using another cinematic technique, slow motion. In addition, Flying Words Project often features cinematic techniques as a means of producing hard, clear images.

The work of Flying Words Project is unique in its use of spoken English as a part of the text. Most sign poetry has not been translated for hearing audiences. Poets are often very aware of the difficulties in translating a text from the visual, spatial, and kinetic domain of sign to the static written page, or the invisible voice. This is not to suggest, however, that sign poetry is not relevant to the wider practice of poetry. Indeed, poets have been experimenting with the visual and performative aspects of poetry. Sign poetry seems to realize some of the creative experimentations in poetic form, while also contributing to the aesthetic and literary aspects of Deaf culture.

Sign poetry, therefore, is an emerging domain of creative practice that promises to produce works that give a voice to Deaf resistance and affirmation, in addition to furthering the boundaries of conventional poetic practices that have been mostly confined to speech and writing.

—H-Dirksen L. Bauman

See also Deaf Culture; National Theatre of the Deaf; Poetry; Sign Language.

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▣ SLOVAK REPUBLIC

See Experience of Disability: Slovak Republic

▣ SOCIAL CAPITAL

Social capital is becoming an increasingly important and more generally accepted concept within the broad area of inquiry commonly referred to as social determinants of health. Social determinants of health include factors that influence health at multiple levels, including the individual, group, organization, community, system, and global levels. Factors such as risky behavior, social support, organizational culture, environmental stress, and the political system work simultaneously to determine the health of individuals and populations. More recently, the concept of social capital has been demonstrated to be an additional determinant of health and health outcomes (e.g., physical and mental morbidity) at both the person and group levels.

There are numerous definitions of *social capital,* but in general, the term is understood to refer to "resources" available to a population that bind it together as a system of social relations. The World Bank defines social capital as the norms and social relations embedded in the social structures of societies that enable people to coordinate action to achieve desired goals (www.worldbank.org/poverty/scapital/). Some research suggests that the resources that comprise social capital can be broken down into two parts: structural (i.e., how people interact with each other) and cognitive (i.e., how people perceive their interactions with others). Structural aspects of social capital could include the number and strength of social relationships, and cognitive aspects of social capital could include issues such as trust, sharing, and support. A second way to understand social capital is to view the "resources" according to their function. In this view, social capital is understood to have both a "bonding" and a "bridging" function. The bonding perspective suggests that social capital functions to bond similar and like groups to one another (social cohesion) at a horizontal or "within the same context" level. The bridging perspective suggests that social capital functions across contextual levels or vertically and aims to bridge relationships between different societal levels (social integration). An important distinction to keep in mind when defining social capital is that it is essentially an ecologic characteristic that is related to social structure. It is not a characteristic that is related to individual attributes as are the concepts of social support and social network.

The empirical relationship between social capital and health has just recently been demonstrated. In the United States, social capital has been shown to be associated with self-ratings of health, violent crime, heart disease, infant mortality, and life expectancy. In developing countries, social capital has been related to general household status. Several instruments to measure social capital have been developed, and most of them include variables that measure the structural and cognitive aspects of the construct. For example, factors related to connectedness and participation with family, friends, local communities, work, and neighborhoods are used to measure structure while, factors such as feelings of safety, trust, and tolerance of diversity can be used to measure the cognitive aspects of social capital.

The inclusion of social capital concepts, particularly as might be related to disability, provides numerous opportunities for new empirical research. For example, the notions of bonding and bridging functions suggest that the disability community might gain both local and national political power as it builds local community and national-level constituencies. Likewise, increased access to organizations that promote the working status of disabled individuals may increase feelings of self-esteem, thus demonstrating the positive impacts of both the structural and cognitive social capital.

More research is needed on how to incorporate the bonding and bridging concepts into social capital measurement, and there is also a need for combining these quantitative measures with more qualitative measures that might better capture the social capital of communities with diverse cultures, history, and health status.

—*Karen E. Peters*

See also Models; Social Networks; Social Support.

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SOCIAL MODELS

See Models

SOCIAL MODEL: SWEDEN

Before "social model" became an established way of thinking in disability research, a similar but not identical way of conceptualizing disability was developed in Swedish politics and research.

Since the 1970s, Swedish disability policy and disability research have been guided by what has become known in Sweden as "the relative concept of handicap." The basic meaning of such a concept is that handicap is something that arises in the meeting between an individual and his or her environment.

Handicap/disability was defined as a specific area of politics in the mid-1960s. A parliamentary investigation made clear that some groups were lagging behind in the development standard of living. Many of them suffered from chronic illness or different kinds of impairments. To capture their vulnerable situation, these different groups were collectively labeled "handicapped." Of course, several measures had been taken for groups with different impairments before that, but they were usually dealt with and thought of as separate groups—one type of measures for the intellectually disabled, another type for the visually disabled, and so on. What was new was the explicit formulation of a broader group as "handicapped."

Introducing such a general concept created a need to know what groups with different impairments had in common. In official documents, they were described in terms of the substantial difficulties they experienced in their daily living. From that definition, it was but a small step to realize that those difficulties were not in themselves a necessary outcome of having impairment. They were also dependent on the kind of environment in which individuals lived their daily lives. The relative way of defining handicap/disability grew out of that insight. It was especially promoted by the organizations of the disabled. In response to the general definition of handicap, organizations for groups with different impairments/disabilities came together during the 1970s and formed an "umbrella organization" that most energetically argued for a relative definition. If the environment is adjusted to the capabilities of disabled people, there will be no handicap. So, this organization argued, general reforms to change the environment are the most effective way of reducing the problems for people with impairments. The creation of "a society for all" should help eliminate or at least diminish problems of handicap in society. A clear expression of those ambitions was the internationally well-known formulation of the principle of normalization by Bengt Nirje, who was the ombudsman at the organization for persons with intellectual disabilities, which argued for the right of such persons to life patterns and living conditions that were as close to the normal patterns as possible.

In response to those demands, several reforms (such as a law demanding that new buildings be made accessible, the implementation of transport services in the municipalities supported by state grants, and laws that obliged the employer to adapt work environments and only to fire people on "objective grounds") were introduced.

During "the golden age of the welfare state," the social democratic hegemony in politics was well established. The beginning of the postwar period was driven by an ambition to create a material safety net for all citizens, but in the 1960s, those ambitions were raised. This was a decade of fast economic growth and bright forecasts for the future. But the structural changes that created the economic growth also created new social problems. This was pointed out by different interest groups (e.g., organizations of the disabled), and claims for further social reforms were often supported by public opinion.

The shift in ambitions was articulated in the vision of "the strong society": a society that had the means and resources to help "weak" persons and disadvantaged groups should not have social reforms that just aim at caring for or curing manifest problems. The ambition of prevention, of getting to the cause of the problems to solve them, became apparent in many areas. Education is a case in point. Earlier reforms strove to abandon a parallel school system in favor of a comprehensive school that gave equal opportunity to everyone. The school reforms of the 1970s had much broader ambitions. In a comprehensive school, children with such problems should not be segregated, but resources should be allocated to support managing problems within the ordinary school context.

The relative definition of handicap and the ideological arguments as formulated by the organizations of the disabled were thus in accordance with the general welfare ideology of the time.

The relative concept of handicap also influenced research. When the first initiatives to promote social research in the field (which had up until then been dominated by medical/clinical research) were taken in 1980s, it was explicitly stated that disability research should occupy itself with the process by which impairments were transformed into handicap—that is, the interplay between individual and environment that created disadvantages for persons with impairments. The initiative contributed to a wave of research that focused on evaluating reforms, often with the emphasis on how they affected the everyday lives of persons with disabilities, their social relations, and the possibilities to influence that situation.

The extent to which there is a "Swedish social model" grew out of these ambitions to create a "strong society," which were directed toward general environmental reforms, and the perspective on disabilities was a relative one.

But since the "golden era of the welfare state" and the introduction of the relative notion of handicap, Swedish society has changed. The centralized social engineering that characterized the "golden age" has been succeeded by a more decentralized and individualistic system. In the field of disability, this manifests itself in several ways. One is the introduction of "right laws," where a person with a severe disability can apply for specific services to which she or he is entitled to by law. The social engineers and the state are no longer responsible for centrally intervening and producing the services but are, through legislation, trying to strengthen the position of the individual in his or her dealing with local authorities. The general trend of individualization is also mirrored in the way different actors in the field conceptualize influence for persons with disabilities. In the earlier period, influence meant influence for the disability organizations, something that mirrors the collective and cooperative ideas of the time. The "strong society" needed a strong collective counterpart to legitimate the reforms. Nowadays, *influence* always refers to the possibilities that the individual has to influence her or his everyday life. Also, a concept such as "empowerment" is nowadays usually interpreted as empowering individuals, not collectives, with common interests.

This means a substantial change in what might be called "the Swedish social model." Redistribution of resources by collective labels is substituted by legally strengthening the individual's possibilities to steer her or his own life. Material welfare is substituted by identity politics. Formal rights of individuals are emphasized rather than obligations of the state to correct unjust distribution of resources.

This change can also be noticed in social research, although it is not as obvious. Most researchers still try to apply a relative perspective on disability. But the emphasis in research mirrors the political changes by focusing on the political catchwords of today: participation, influence, and empowerment for individuals rather than collectives and organizations, as well as individual identities more than political ideologies.

The basis of the "Swedish model," the relative definition of handicap, is still adhered to in politics as well as research. But the application of that framework is now more individualistic than before.

In international literature, "the social model" referred to is usually the one developed by English disability researchers. That model has a strong materialistic base and emphasizes the oppression that different groups of the disabled share. In that sense, it can be said to be a collective model that also underlines the liberation from oppression to be a collective task.

In that perspective, the "Swedish model" developed in the 1970s and 1980s shares some characteristics of the British model, at least more so than the present individualistic one. But there are also differences, the major one perhaps being that the "Swedish model" was developed in a close interplay between central politicians ("social engineers") and organizations of the disabled and consequently was more reformist than the comparatively militant British one. One way of expressing the difference is to say that both the Swedish model (in both its earlier and its present manifestations) and the British model share a relative notion of disability, emphasizing the role of environment. But the Swedish model is more focused on the interplay between individual and environment at different levels, while the British model focuses on the environmental side of that interplay. Or, to put it another way, the Swedish model is a "weak" example of a social model, while the British model, at least in its earliest formulation, is a "strong" social model.

—Mårten Söder

See also Disability Law: Sweden; Models; Politics of Disability: International.

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SOCIAL NETWORKS

Social networks are basic building blocks of human experience. They map the connections that individuals have to one another. They also map relationships among organizations, for example, examining "cracks" in social service systems. Networks hold the potential to be rich sources of support, care, and information as well as monitoring, control, and hassle.

The idea that "others" are important has become a major focus in epidemiological and health services literatures. Much existing research has focused on the role of social ties, particularly social isolation, on mortality and morbidity. Networks have been demonstrated to be vectors of the incidence and prevalence of infectious disease, from common colds to HIV infection, as well as chronic problems such as heart disease. Networks have also been implicated in the consequence of health and disability, including the recognition of problems as physical or mental health issues, help seeking (e.g., knowledge, advice, access, system barriers), involuntary treatment (e.g., coercion), caregiving, adherence, and outcomes.

THE NATURE OF NETWORKS

The central focus is on relationships between a social actor ("ego" or the "focal" person, organization) and the social actors ("alters") with whom they have a certain kind of relationship. Three overall characteristics are central to mapping social networks: structure, content, and function. Structure targets the overall size of the network, the different types of relationships that people can have (e.g., kin, coworker), the basis of connection (i.e., multiplexity), how tightly knit the social network is (i.e., density), and strength (strong/weak, frequent/infrequent, close/distant). Content taps the kinds of things that flow from or to each individual or organizational actor (e.g., social support, contact-based resources, positive/negative valence, belief structure). Network ties can be helpful or harmful; they can integrate individuals into a community or isolate them from others. Finally, networks serve a variety of functions—emotional support (e.g., care and concern), instrumental aid (e.g., lending money, providing transportation), appraisal (e.g., evaluating a problem or a source of aid), and monitoring (e.g., making sure a person takes his or her medications).

For health- and disability-related concerns, another simple distinction is important—external and internal social networks. *External social networks* are composed of family and friends, which Freidson (1970) referred to as the "lay referral system" and Wellman (1982) called "personal communities of meaning." They map individuals' community-based relationships and represent the more usual notion of "community ties." *Internal social networks* are ties within treatment and rehabilitation organizations and systems. They open up the "black box" of treatment by seeing it, at least in part, as the human provision of care. Internal networks are not "treatment," but any diagnostic, treatment or rehabilitation instrument, or medication or manipulation delivered by human providers in human service organizations. Interventions determine "what" is offered; internal networks shape "how" it is implemented.

Three types of external tie relationships are important: between individuals and providers (client-provider), among providers within organizations (provider-provider), and among providers across organizations (agency-agency). The nature of these provider- and organization-level networks influences client participation and outcomes. Finally, inside and outside networks meet at the interface of community and treatment networks. They can work together or in opposition.

NETWORK THEORY

Social network perspectives aim to understand behavior through social relationships that shape everyday lives and experiences through exposure, consultation, resource sharing, suggestion, support, and nagging. While many epidemiological studies incorporate networks into their analysis of risk and protective factors, the most detailed theoretical frameworks address issues related to service use. For example, the health belief model, which focuses on whether individuals seek out preventive or curative medical services, incorporates social networks into its concept of normative influence. "Others" shape individuals' views of the efficacy and applicability of services.

The only existing network-based theory synthesizes work from a number of relevant traditions. The network episode model (NEM) starts with the idea that dealing with any health problem or disability is a social process managed through the contacts that individuals have in the community, the treatment system, and social service agencies. Interaction in social networks is the underlying mechanism at work, thereby contextualizing the response to disabilities in everyday life. Individuals are seen as pragmatic, having commonsense knowledge and cultural routines that they draw from past experience. People face disabilities by interacting with other people who may recognize (or deny) a problem, send them to (or provide) treatment, and support, cajole, or nag them about appointments, medications, or lifestyle. These day-to-day encounters provide meaning to issues surrounding health or physical impairment.

The "illness or disability career" marks all of an individual's attempts to cope with the onset of an episode of a health or physical impairment or associated acute illness episode, charting what individuals do and when they do it. Careers are embedded in personal lives and changing communities. At any time, network advisers may or may not be consulted, they may or may not be a stable set, or they may or may not be consistent in their advice. Strong ties may provide the greatest support, but weak ties act as a bridge to other resources. Too much oversight, whether positive or negative, can be stifling and repressive.

MEASUREMENT ISSUES

Deciding which kinds of social networks are of interest and how to elicit the ties are critical issues. There is no standard way to chart network relationships—they may be derived from a list on a survey form where individuals are asked to name persons they trust, consult, or dislike. The information may come from observing the behavior of individuals (e.g., who they talk to in their work group) or the behavior of organizations, checking which organizations in the health care system have referral agreements. They may also be different from the perspective of the interacting parties.

In surveys, the selection of the "stem question" or "network generator" can determine, for example, whether a researcher taps into a personal support network, a trail of contacts in a search for information, or a set of formal treatment arrangements. The network generator can elicit ties sent (e.g., On whom do you depend for advice?) or ties received (e.g., Who depends on you for advice?).

Sociodemographic characteristics, such as age, sex, race/ethnicity, and social class, cannot be used as indicators of existing social networks because their role in placing limits around interaction partners is decreasing historically. Sociodemographic characteristics may interact with social networks, for example, making the influence of social networks different for men and women.

FUTURE DIRECTIONS

Network theory contrasts with approaches focusing on individuals' cognitive maps. However, symptoms, identity, cognition, and even biology may shape and be shaped by social bonds. This view requires bringing together the expertise of different, traditional disciplines. Furthermore, networks are dynamic, not static, structures and processes. A consideration of the degree of change inherent in social networks requires that we consider the ebb and flow across time and over the illness career. This also raises the issue of the causal relationship between social networks and health status. The ability to form and maintain social ties may be the result of changes in health status (social consequence), not simply factors implicated in their cause (social causation).

Finally, a social network approach presents challenges in capturing social networks. Can they be measured with reasonable scientific precision and ethical sensitivity? Can we improve the measurement of networks while reducing their current cumbersome approaches? In 1986, Berkman suggested that adequate social network measures had not been developed and that this issue remains. We have only recently begun to discuss the inevitable ethical questions that surround asking people about intimate connections or using them clinically.

In sum, at this point in time, empirical findings mostly document that social networks matter rather than how or why they operate; how and why they change; how they are meshed with psychological, biological, or clinical factors; or how to efficiently and ethically map them.

—Bernice A. Pescosolido

See also Caregiving; Community-Based Rehabilitation; Family; Peer Support; Social Support.

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SOCIAL SUPPORT

Social support has been diversely defined in the human services fields, often as perceived social support in the context of relief of stress (Sarason, Sarason, and Pierce 1990). In its purer sense, social support is a positive aspect of exchange between or among parties, offering benefits for the persons involved, families, neighbors and coworkers, organizations, associations, and even the broader community and society (human ecological roots; Brofenbrenner 1979).

The research contributions in this field concentrate on negative support (Riley and Eckenrode 1986) and the costs of social support (Schumaker and Brownell 1984), in addition to an understanding of its benefits to the well-being of the person. Social support is viewed as buffering critical life events (e.g., Lin, Woelfel, and Light 1985) and provides protection against the difficulties encountered in life (e.g., unemployment, death of spouse, divorce).

Social support has been defined in family support as mediating outcomes for the child, person, and family. In the research sense, it is a "multi-dimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support" (Dunst and Trivette 1986:403). Social support is also a personality characteristic (attachment theory), a sense of acceptance, and highly related to concepts such as intimacy (Sarason et al. 1990).

Social support is viewed as enhancing child rearing in families and as "encompassing a multitude of activities, relationships and subjective appraisals" (Vaux 1988). One of the goals of social support theory and practice is to improve the skills of community resources. Social support has more than 20 years of research and is one of the largest literatures in community and social intervention (Barrera 1999) contributing to the growth in community support.

Social networks is a related concept and research area that introduces the complexity of social ties and their contradictory nature (Cochran 1990). Social network research involves the acquisition of friends, the neighborhoods, the family status, social class and structures, and cultures of the world (e.g., Sweden). Social support intervention is also one of the purposes of social support research and has been the subject of studies on children and families, in work and welfare, in the community and neighborhoods, and in caregiving and service systems.

Today, social support has been described as consisting of formal and informal supports (Bulmer 1987), improving the understanding of the service systems that have proliferated in nations such as the United States and in countries in Europe, Asia, and Africa. In this context, social support has been studied by contrasting the perspectives of service users and workers on support (Racino and O'Connor 1994). Social support theory remains as leaders in many fields worldwide both conceptually and practically merge it with the newer consumer empowerment theories, including in service systems (see Racino 2000).

—Julie Ann Racino

See also Family; Peer Support; Social Networks.

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SOCIAL WORK

Social work is a profession that includes practice with individuals, families, groups, organizations, and communities toward the goal of enhancing human functioning. A key concept in social work practice is simultaneous emphasis on change for both individuals and the environment. According to the Code of Ethics of the National Association of Social Workers (NASW) in the United States, the mission of the social work profession includes helping to meet the basic human needs of all people, with a primary focus on the needs and empowerment of people who are poor, vulnerable, and/or oppressed. People with disabilities have historically been an important group to social workers as part of their professional mission. Core social work values relevant to working with people with disabilities include self-determination, social justice, and dignity and worth of the person.

The NASW issued a policy statement in 2003 that discusses these core values with respect to working with people with disabilities. Self-determination is a key value that emphasizes the importance of working *with* consumers rather than providing services *for* them. The NASW policy statement mandates the promotion of full participation of people with disabilities in decisions regarding housing, community accessibility, education, employment, income, and health care. Consistent with another key value, that of social justice, the NASW statement emphasizes that social workers are responsible to take action with people who have disabilities toward advocating for their rights to fully participate in society. The value of dignity and worth of the person implies that social workers should recognize people with disabilities from a strengths perspective, which requires a focus on abilities rather than limitations. Although these ideals are consistent with the current emphasis in the field of disabilities on choice and empowerment, actual social work practice with people who have disabilities has room for improvement in meeting these ideals.

Throughout the history of services for people with disabilities, social workers have fulfilled many roles. These roles have included a micro focus on working with individuals and families, a midlevel focus on developing and managing programs for people with disabilities, and a macro focus on advocating for changes in policies and attitudes on behalf of and with people with disabilities and their families.

Over the past several decades, the specific roles of social workers working with people with disabilities and their families (micro-level practice) have varied and evolved depending on shifting paradigms and service delivery models. During the 1960s and before, a medical model of service delivery was prevalent, and persons with disabilities were typically characterized as patients who had disorders, illnesses, and impediments. Service delivery settings included large institutions and custodial care. Within this context, social workers were often part of an interdisciplinary team of health professionals. They frequently served as counselors who helped individuals and primarily their families adjust to the diagnosis and disability. During the 1970s and 1980s, a developmental approach was used in service delivery. Deinstutionalization was taking place, and community placement was the focus of intervention. Persons with disabilities were typically considered to be clients. Social workers served as case managers who coordinated individual program plans. These plans were focused along a developmental continuum that assessed skills needed by persons with disabilities to move them into less restrictive vocational and living environments. More recently, a support model of care is being implemented that considers persons with disabilities to be consumers and works to provide a number of individualized supports. The goal in this model is for consumers and their circles of support to direct their own service planning. In this context, social workers are collaborators with persons with disabilities and serve in roles as consultants and brokers.

Some examples of the support model are family support programs and cash and counseling programs. Family support programs are a way of providing flexible services to families who have children with disabilities through the provision of vouchers or cash allotments. Self-determination and empowering families are key components of these programs. Within family support programs, social workers serve as service coordinators, advocates, and brokers. Cash and counseling programs are a relatively new joint initiative of the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services. These programs allocate a monthly allowance to people with disabilities to use for long-term supports. A personal broker, who is often a social worker, is made available to help consumers make decisions about services, locate resources, and monitor the quality of supports and services. Consumers also have the option of managing an individualized budget instead of choosing a broker.

Although the support model of care is most consistent with the ideals and values of the social work profession, its implementation is in varying stages across the United States. Barriers to the expansion of home and community-based services include budgetary constraints and waiting lists. Furthermore, remnants of the medical and developmental models persist in many settings, and social workers continue to fulfill roles within these models.

In addition to support models of care, other domains that social workers are involved in include supportive living, vocational and employment services, health and mental health, transportation and accessibility, leisure and recreation, and social and sexuality issues. Social workers also fulfill roles in programs across the lifespan related to disabilities (e.g., birth to age three programs, school age, transition planning for older teens, adult services, and programs for the growing aging population). In their varying roles on the micro level of practice, social workers are trained to work across systems and on interdisciplinary teams as well. While health professionals address specific medical and treatment needs for people with disabilities, social workers complement these areas by working with people who have disabilities on social and environmental issues in their lives and on helping with the overall coordination of services. This may include advocating with and on behalf of consumers to eliminate barriers to receiving services or other necessities. Social workers are also involved in building bridges and supporting persons with disabilities to use the "generic" human service systems.

Within the field of disabilities, social workers are also involved in midlevel practice such as designing agency programs that serve people with disabilities and serving as managers and administrators of those programs. Social work education provides social workers with skills for community and administrative work, including the ability to see the larger picture of individuals and their interactions in the environment.

At the macro level, social workers are involved in advocating for and developing state and national disability policies. An important part of social work education is the development of skills relating to policy analysis and development as well as specialized skills in advocacy. Social work researchers are frequently involved in analyzing disability policy and programs and investigating the effectiveness of new programs and models of care. An example of social work professionals' involvement in advocacy is the active participation in the self-advocacy movement by the late Gunner Dybwad. Professor Dybwad was a social worker and lawyer by training as well as a professor at the Heller School of Social Welfare Policy at Brandeis University in Waltham, Massachusetts. Professor Dybwad, other social workers, and professionals in other fields have worked side by side with people with disabilities to build national organizations and a national movement to push for empowerment of people with disabilities on a political level.

In summary, the movement in the disability field toward self-determination and empowerment is consistent with the mission and ideals of the social work profession. While social workers are involved in the provision and coordination of services to people with disabilities, their role as collaborators and advocates is essential to their own professional values and to the disability movement. Social workers play valuable roles in service provision and ensuring quality of life for people who have disabilities, and these roles encompass micro, midlevel, and macro levels of practice.

—Sandra Magaña

See also Empowerment and Emancipation; Health Care and Disability; Models.

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SOCIOECONOMIC CLASS

Disability and *social class* are both contested terms, so this entry begins by noting the different ways in which both of these terms have been used by different actors and for diverse purposes. Subsequently, the interaction of disability and social class is examined in a range of key policy arenas (health, employment, income, and benefits and education). Because of difficulties in accessing international statistics in this area, selected Scottish and U.K. statistics are used. A different picture might emerge in different international contexts (e.g., the United States, Nordic countries, developing countries). Overall, it is argued that the relationship between disability and social class has not been widely explored in part because both these terms are conceptually complex. However, in his classic study of poverty in the United Kingdom, undertaken in the 1970s, Peter Townsend (1979) noted, "More of the working, than the middle class, particularly unskilled manual workers and their families, are disabled. Increasing incapacity is correlated with falling cash incomes. . . . At successive ages, greater incapacity was associated with greater risk of being poor." Today, the evidence continues to indicate that poorer people are more likely to be disabled, and disabled people become poorer as a direct result of their impairment and of the discriminatory attitudes and barriers that surround them. There is very little research and writing, however, on the subjective experience of social class and disability and the way these two elements interrelate in the formation of individual identities. Before discussing the available evidence, it is necessary to review briefly current thinking in relation to the conceptualization of both disability and social class.

DISABILITY AND SOCIOECONOMIC CLASS: DEFINING THE CONCEPTS

In the welfare states of industrialized countries, disability has often been defined in terms of administrative categories devised by social security or social services to determine access to benefits and services. For example, Deborah Stone (1984) noted that disability originated as an "administrative category out of a collection of separate conditions understood to be legitimate reasons for not working." Major surveys conducted within the United Kingdom and Scotland have sought to determine how many people are disabled by asking whether individuals have a long-term illness or disability that has an impact on their normal daily activities or ability to work. Surveys conducted in Scotland for a range of purposes have produced similar findings with regard to the proportion of disabled people. For example:

- The Scottish Executive Health Department, based on its own data, estimated that there were 800,000 disabled adults in Scotland in 1999. This is about 20 percent of the adult population.
- The Scottish Household Survey of 2001 found that 20 percent of respondents reported a disability or long-standing illness.
- Labour Force Survey data estimate that there are 636,000 disabled people of working age in Scotland (20 percent of the working-age population).
- The Scottish Household Survey of 2001 found increasing incidence of disability with age. Forty percent of people age 65 or older reported a disability or long-term illness, in contrast to 5 percent of people ages 16 to 24.

The surveys referred to above adopt a categorical approach, assuming a dichotomy between disabled and nondisabled people. The Disability Discrimination Act of 1995 also operates on the assumption that a distinction may be drawn between disabled and nondisabled people. Under the terms of the act, a person is disabled if he or she has a physical or mental impairment that has a significant and long-term adverse effect on that person's ability to perform normal day-to-day activities.

This categorical view of disability has been challenged by the social model of disability, which drew a distinction between disability and impairment and emphasized the social relational nature of disability (see, e.g., the work of Michael Oliver [1990] and Colin Barnes [1991], key players in the development of social model thinking in the United Kingdom). Within the social model, disability is seen as independent of impairment in that it is a product of the social context in which impairment is experienced. Recently, postmodern and poststructuralist writers have taken these arguments further, critiquing the taken-for-granted distinction between disabled and nondisabled people. Writers such as Mairian Corker and Tom Shakespeare (2002) have argued that such dichotomies perpetuate Enlightenment fallacies that social categories and constructions are "real." Recent writing on disability, culture, and identity has draw attention to the diversity of disabled people's cultural experiences, which may be shaped by their age, gender, or ethnic identity as well as the nature of their impairment. There is, therefore, an unresolved tension between those who work on the assumption that the categories of disabled and nondisabled are meaningful, having their basis in material reality, and those who see these categories as social constructs.

Very similar tensions exist in the field of social class, and commentators have noted the problematic nature of social class categories. Many different definitions of social class exist, but they are generally based on the idea that an individual's social class position is determined by his or her access to economic, social, and cultural resources or capital. Social class is often defined in relation to occupation, and a number of classificatory models and scales are still used extensively. The Registrar General's Classification of Occupation, until recently the most commonly used system in the United Kingdom, grouped the population into six classes on the basis of occupation (1, professional; 2, managerial; 3-NM, skilled nonmanual; 3-M, skilled manual; 4, partly skilled; 5, unskilled). A similar social grade system is used by the Market Research Society (A, B, C1, C2, D, E). Such scales are frequently revised. For example, in November 1998, the Office for National Statistics (ONS) announced the U.K. government's new social classification system, the National Statistics Socio-Economic Classification (NS-SEC), which uses seven occupational categories.

There are a number of problems with occupational classification systems. For example, people who are economically inactive are classified as "other," and in certain parts of the United Kingdom, numbers thus classified may be as high as 50 percent of the population. Members of the category may be very diverse since it includes people on long-term incapacity benefits and those who have been out of work for a short period of time but are likely to find work, possibly at a professional level. The categories were defined with men rather than women in mind and do not accommodate easily families in which the mother and father have different occupations. In addition, as the service sector expands, more jobs are likely to be classified as 3-NM, but in terms of substance, pay, and degree of autonomy, these may differ little from jobs in the old manufacturing sectors. Furthermore, the categories do not readily reflect the position of young people such as university students. It is assumed that young people retain the social class of their families until they have independent jobs. However, with the collapse of the youth labor market in the late 1970s, there has increasingly been a delay in young people having occupational locations independent of their parents. Critics of the occupational classificatory system also point out that the category assigned to individuals may bear little relationship to their internal sense of social class. So, for example, those with professional occupations would be defined as middle class, irrespective of their social origins and identity. Even if individuals have professional occupations, their parents may have had unskilled occupations, and their working-class origins may be more significant in their identity than their more recently acquired occupational status. An assigned social class status may therefore have little subjective validity.

As a result of dissatisfaction with defining social class in relation to an individual's occupation, alternative ways of measuring deprivation have focused on assessing multiple indicators of deprivation. Classificatory systems, such as the Carstairs Deprivation Index, characterize geographical areas on the basis of the characteristics of individuals and households in those areas. The Carstairs Deprivation Index is based on measures of overcrowding, male unemployment, low social class (as measured by occupation), and car ownership. In Scotland, the population is normally distributed from 1 (least deprived) to 7 (most deprived), but some areas have far greater concentrations of people in the most or least deprived categories. For example, in the area covered by the Greater Glasgow Health Board, more than half (51 percent) of the population lives in deprivation categories 6 or 7.

Given the spatial distribution of deprivation, there are arguments over whether regeneration strategies should focus on individuals or on areas where there are clusters of deprivation. There are also debates between those who argue that poverty should be the focus of analysis and those who maintain that there should be a wider focus on social exclusion. The concept of social exclusion, which is highly influential within European and U.K. social policy, emphasizes the multidimensionality of marginalization, which may relate to, for example, people's ethnic as well as their social class location. Social exclusion theorists also stress the complex ramifications of exclusionary processes, which go beyond material deprivation to inadequate social participation, lack of social integration, and lack of power.

To summarize, in relation to both disability and social class, the use of categorical data has been criticized for imposing an oversimplified dichotomous worldview (see, e.g., Paul Abberley's [1987] critique of the OPCS [Office of Population, Censuses and Surveys, United Kingdom] categorization of disability, on the grounds that it is based on a medical reductionist view of the world). Alternative approaches have been suggested by cultural theorists such as Raymond Williams, who argues that social class goes much deeper than occupation and should be understood in terms of the structuring of emotions and consciousness. The sociologist Bourdieu (1984) developed the idea of social class habitus, reflecting the idea of social class as a fundamental framework structuring experiences and shaping the lens through which the individual views the world.

While categorical data on social characteristics have been criticized as tools of an increasingly managerialist society, it is important to remember that such information may also be used in pursuit of social justice goals. Monitoring of institutional performance against equality indicators is promoted by the British Equality Commissions and U.K. Government Social Inclusion Units. Some researchers have explicitly tried to work with both categorical and interpretative approaches. For example, Louise Archer's study of widening access to higher education adopted multiple strategies, using fixed categories to analyze statistical patterns of participation while also exploring the way in which particular groups of students negotiate their identities within specific institutional contexts (Archer, Hutchings, and Ross 2003).

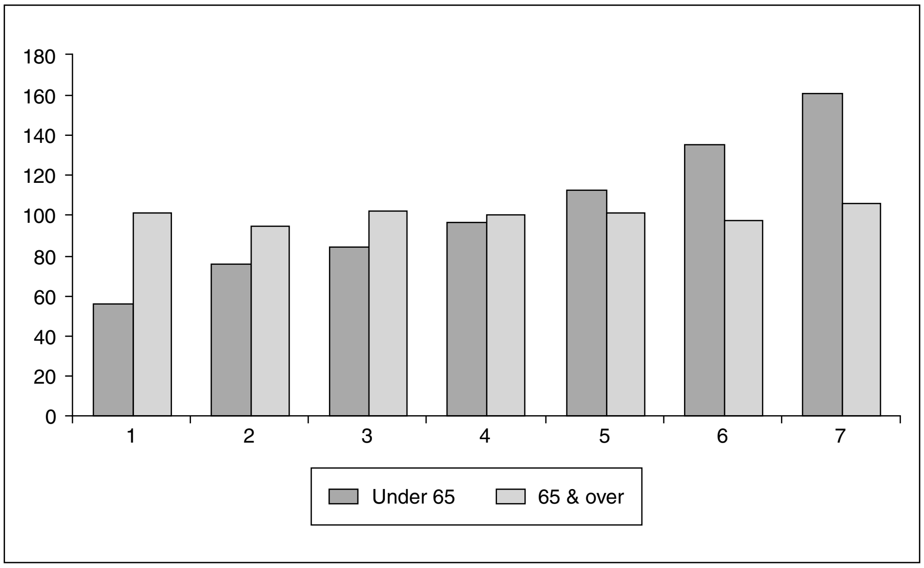

Figure 1 Stroke: Standardized Mortality Ratios (SMR) by Deprivation Category and Age Group (1994–1998)

Source: Scottish Executive Information and Statistics Division, 2001.

Note: Deprivation categories 1–7 are based on the Carstairs Deprivation Index. See text for an explanation.

In the following sections, official statistics are used to explore some of the emerging relationships between social class and disability before considering the types of research that will be needed in the future to investigate the ways in which subjective identities and experiences are shaped simultaneously by a range of factors, including social class and disability.

DISABILITY, SOCIAL CLASS, AND HEALTH

Sickness and *disability* are not synonymous, and many disabled people are perfectly healthy. However, it is important to recognize that people who are seriously ill are likely to be disabled; indeed, stroke is the biggest cause of long-term impairment in Scotland. Within a number of European countries, including Scotland, there are marked and growing inequalities between the health of richer and poorer communities. Abberley (1987) drew attention to the importance of investigating the social creation, as well as the social construction, of disability, pointing out that, particularly in the developing world, much illness and disability arise as a result of war, pollution, and the lack of access to clean drinking water and basic medication. In the developed world, the growing gap between rich and poor has led to greater diversity in life chances and life expectancy. It is extremely important, therefore, to examine the links between major illnesses and social class.

Figure 1 illustrates the relationship between stroke, deprivation category, and age. The incidence of stroke increases with age (in 1997–1998, more than 80 percent of people admitted to the hospital with stroke were age 60+). For people who are age 65 and older, there is no significant relationship between deprivation category and death from stroke. However, for people younger than 65, there is a very strong relationship. In essence, younger people from the most deprived backgrounds in Scotland are about three times as likely to die from stroke as people from the least deprived backgrounds. Among stroke survivors, about half are left with a permanent impairment. A recent study of young stroke survivors in Scotland, led by Pauline Banks of the Strathclyde Centre for Disability Research at the University of Glasgow, found that two thirds of these people did not return to work after experiencing a stroke.

There are also very strong associations between mental health problems and social deprivation. In contrast with the erroneous perception that high-flying business executives experience the greatest levels of stress, Figure 2 demonstrates that people with the highest levels of deprivation are about three times as likely to visit their general practitioner (GP) as a result of a mental health problem compared with those with the lowest levels of deprivation. Figure 2 also reveals an important story in relation to gender, with women in all social groups significantly more likely than men to visit their GPs as a result of a mental health problem.

Poorer people in Scotland are also more likely to be diagnosed with lung and cervical cancer, and among

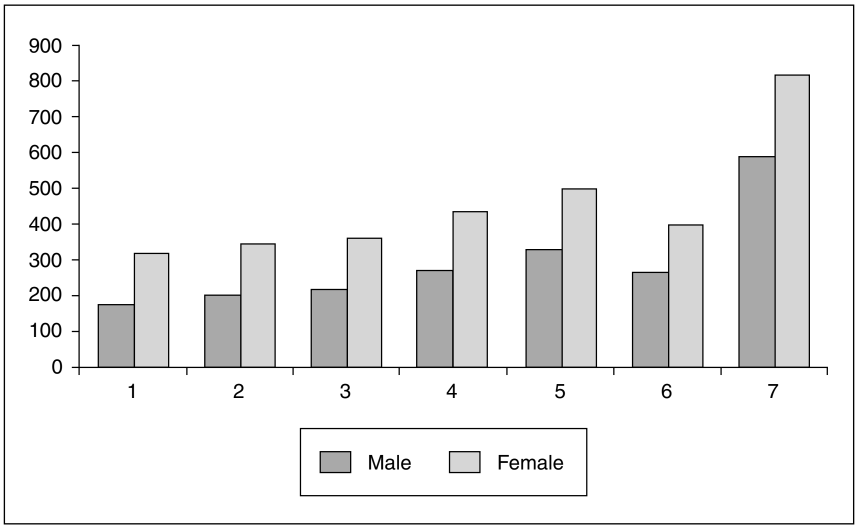

Figure 2 Mental Health: GP Contacts (Rate Per 1,000 Population) by Deprivation Category in Scotland, Year Ending March 2000

Source: Scottish Executive Information and Statistics Division, 2001.

Note: Deprivation categories 1–7 are based on the Carstairs Deprivation Index. See text for an explanation.

the four most common forms of cancer (lung, cervical, breast, and bowel), there is decreased survival with increasing deprivation. Scottish Executive data reviewed by Riddell and Banks (2001) demonstrates that children living in deprived areas are also more likely to be killed or injured in road traffic accidents. These findings all reinforce the arguments made by Carol Thomas that there is a need for a greater rapprochement between disability studies and medical sociology, recognizing that the latter may be one of the "engines for the formulation of an ever more sophisticated sociology of disability." The development of a social model of health in tandem with the social model of disability may help to develop a "materialist theorisation of disability, but one that encompasses questions of culture, difference and impairment."

DISABILITY, SOCIAL CLASS, AND EMPLOYMENT

As noted above in relation to young stroke survivors, there are strong associations between disability, health, and employment, with significant consequences for income, quality of life, and life chances. Using Labour Force Survey data, Figure 3 illustrates the marginalization of disabled people in Scotland in relation to employment. In Scotland, in winter 2001, the Labour Force Survey found the following:

- Disabled people in Scotland account for 20 percent of the working-age population and 11 percent of the workforce.
- Of disabled people, 39 percent had work, in contrast to 81 percent of nondisabled people.
- Fifty percent of disabled people were not working and were on state benefits compared with 6 percent of nondisabled people.
- Of the disabled people of working age in Scotland, 22 percent were not working and were on state benefits but would like to work, compared with 5 percent of nondisabled people.
- Of the disabled people on benefits, 41 percent would like to work. This represents about 136,000 people.

The U.K. New Labour government emphasizes employment as the key to social inclusion, and in a green paper published in 1998, it promised "work for those who can; security for those who cannot." The government's strategy to improve the position of disabled people in employment is three-pronged. First, the Disability Discrimination Act (DDA) of 1995 (as amended) made it unlawful for employers to discriminate against disabled people in relation to employment, access to goods and services, and, since 2001, education. Second, a range of government-funded programs is intended to help disabled people enter and retain employment. Finally, as spelled out in a green paper published in 2003, access to long-term incapacity benefits is to be made more difficult, so that fewer people are certified as permanently incapable of working. Evidence of the success of these measures suggests that employers may not be aware of their new duties under the DDA and that government programs may offer insufficient support to disabled people, particularly those with higher support needs. The extent

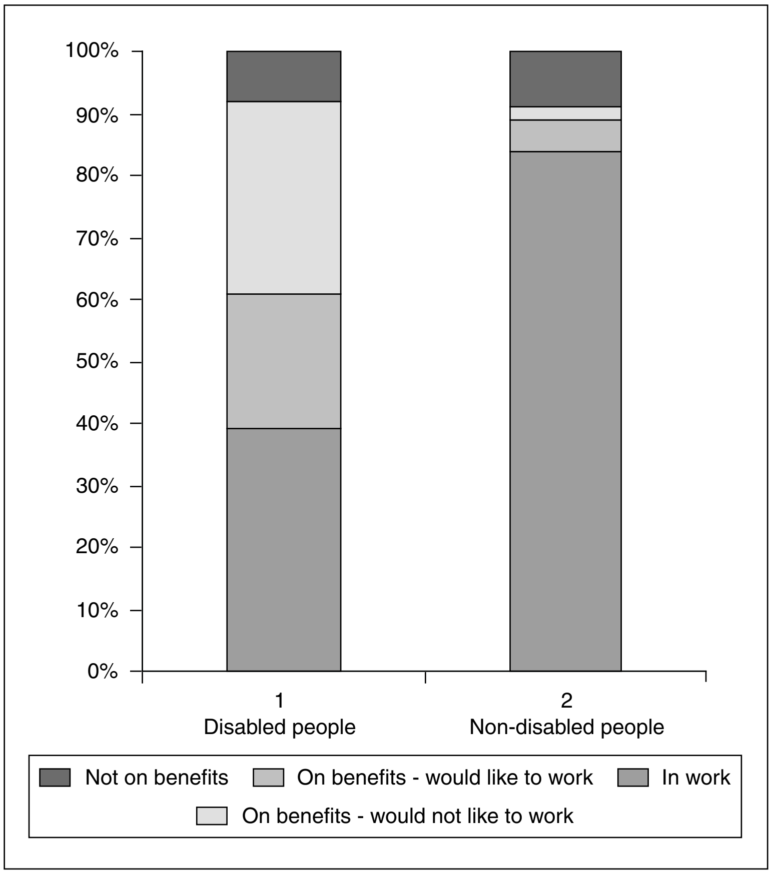

Figure 3 Disabled People in the Labor Market in Scotland

Source: Labour Force Survey, winter 2001.

to which the government will be successful in its goal of reducing the number of people on long-term incapacity benefits remains to be seen.

The complexity of this area is illustrated by analysis of economic inactivity in Glasgow, based on data from the Department for Work and Pensions for 2002. In Glasgow, 111,000 (40 percent of the working-age population) claimed some sort of state unemployment benefit. Claimants fell into the following categories:

18,700 unemployed claiming Job Seekers Allowance

16,800 lone parents

70,800 sick and disabled

4,700 other category

There are thus almost four times as many people on long-term incapacity benefits as there are on unemployment benefits, and the percentage of people who are claiming long-term incapacity benefits accounts for 25 percent of the working-age population (1 in 4). Clearly, these numbers need careful interpretation; during the 1980s, there was a deliberate policy to move people onto incapacity benefits to massage the unemployment figures. For claimants themselves, there are advantages to claiming incapacity benefits because these are slightly higher than unemployment benefits, and at least until recently, there has been no pressure on claimants with incapacity benefits to seek work. However, as we noted in the previous section, Glasgow has very poor health compared with Scotland, the rest of the United Kingdom, and Europe. This results in extremely high levels of impairment, with serious consequences in terms of poverty and social marginalization.

The focus of research in relation to disabled people and employment has tended to be on those who are economically inactive because the level of long-term incapacity benefits claims is construed as a "social problem." Much less is known about the employment experiences of professional or skilled disabled workers, although Alan Roulstone (1998) studied disabled people's experience of new technology in employment and included a wide range of people, including those attempting to break into the labor market, who had little control over the technology, and those working in higher-level occupations, who had much more say over the way in which new technology was used to enhance their working lives.

DISABILITY, SOCIAL CLASS, AND HOUSEHOLD INCOME

As noted above, disabled people are much less likely to be employed than are nondisabled people, and this has major implications for quality of life, power, and autonomy. Overall, 11 percent of the working-age population in Scotland receives incapacity benefits (although the proportion in certain areas, such as Glasgow, is much higher). Scottish Household Survey data in Figure 4 show that 33 percent of households with a disabled person have an income of less than £6,000, compared with 26 percent of households of persons without a disabled person. Only 6 percent of households with a disabled person have an income of more than £20,000, in contrast to 24 percent of households without a disabled person. As we noted earlier, disabled people are more likely to be poor than the rest of the population, and occupational-based measures of social class may fail to capture this concentration of poverty, classifying those who are economically inactive as "other," particularly if they have been out of work for many years or have never worked.

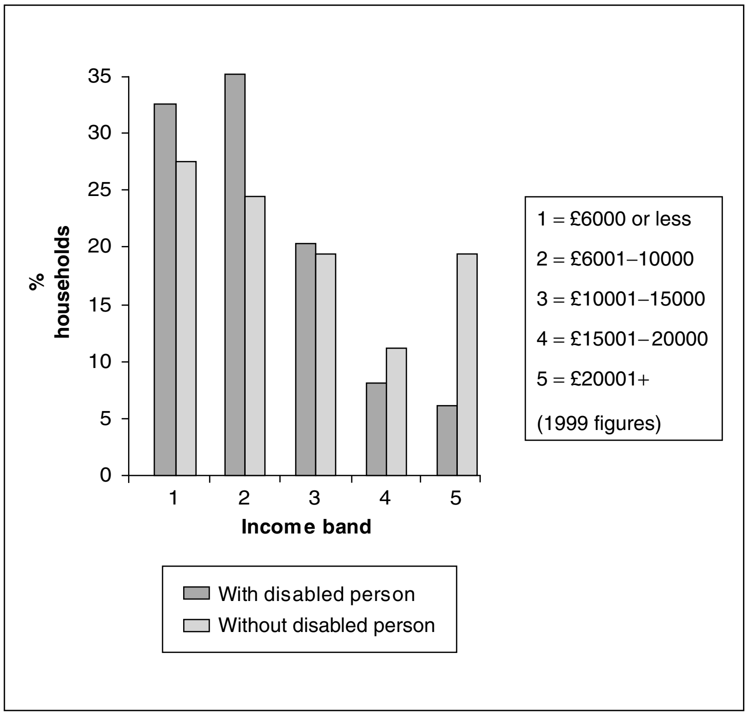

Figure 4 Income for Households with and without a Resident Disabled Person, Scotland 1999

Source: Scottish Household Survey, 1999 (http://www.dataarchive.ac.uk/findingsData/snDescription.asp?sn=435).

DISABILITY AND DECLINING SOCIAL CLASS

For many people, disability is linked to declining access to economic, social, and cultural capital. Research has demonstrated, for example, that the onset of illness or the worsening of a long-term condition is associated with a drop in living standards and the loss of employment. Figure 5, for example, draws on data from a study of people with neuromuscular dystrophies, led by Pauline Banks of the Strathclyde Centre for Disability Research, University of Glasgow. People with neuromuscular dystrophies were asked if they had a job, including self-employment, but were no longer working; how long they worked after first noticing symptoms of their illness; and at what age they had stopped working. Analysis revealed the following:

- More than half of all people with neuromuscular dystrophies (51.4 percent) stopped working prior to age 60. Of these, 33 (26.2 percent) stopped working in their 50s, 31 (24.6 percent) in their 40s, 28 (22.2 percent) in their 30s, 24 (19 percent) in their 20s, and 10 (7.9 percent) during their teens.
- Of people with neuromuscular dystrophies who retired before they were age 60 (n = 126), 54 (42.9 percent) did not work at all following the onset of symptoms, 39 (31 percent) worked for between 1 and 5 years, six (4.8 percent) worked for 6 to 10 years, and 27 (21.4 percent) worked for 11+ years.

Qualitative data from the Strathclyde Centre for Disability Research studies of people with neuromuscular dystrophies and Parkinson's disease indicated that the loss of work was accompanied by a deepening sense of financial anxiety and social marginalization. These findings echo Townsend's (1979) work, which documented the cumulative detrimental effects of lacking the financial resources necessary to participate in normal social events such as having holidays, visiting friends, and giving birthday presents.

It should be noted that there are negative consequences associated with having any member of the household with a disability. For example, living with an older disabled relative or having a disabled child affects the ability of working-age adults, particularly women, to hold down a job and advance in their career. This finding is reinforced by Kirsten Stalker's review of services supporting disabled children and their families in Scotland, funded by the Joseph Rowntree Foundation. A number of studies have also

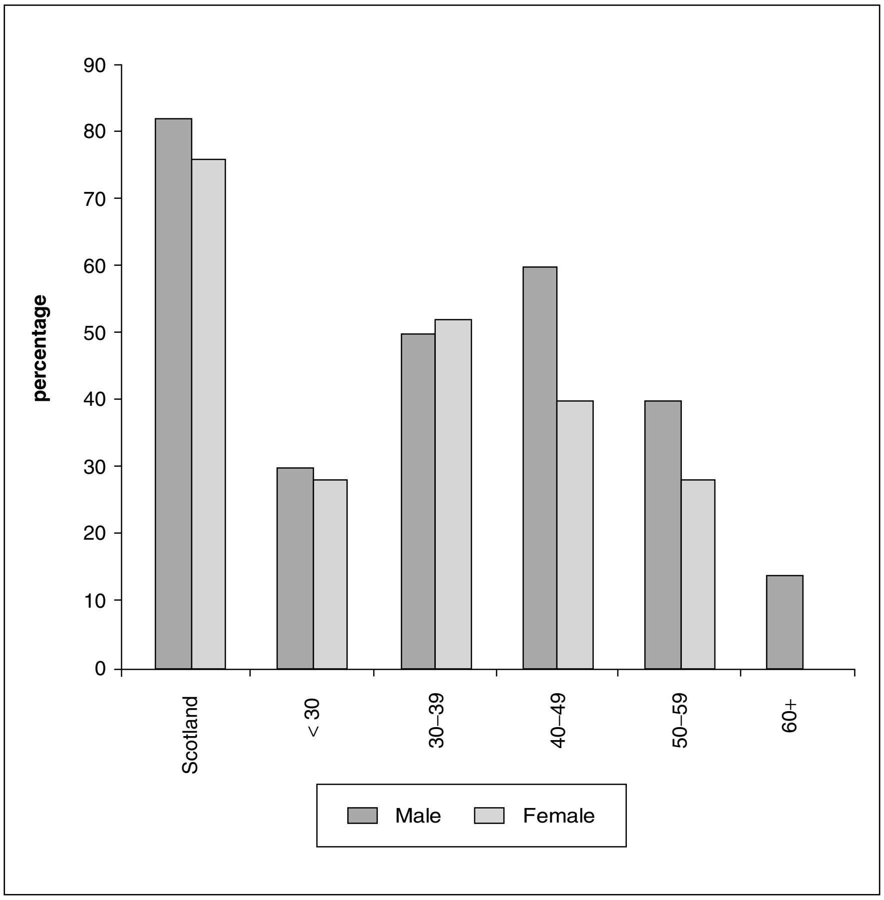

Figure 5 People with Neuromuscular Disorders and Scottish Employment Rate by Gender and Age Group

Source: Edson et al. (2003).

pointed to the inadequacy of benefits that are intended to assist disabled people and parents of disabled children. In the United Kingdom, the Disability Living Allowance (DLA) is intended to help people with the added expense of having a disability. A recent study funded by Disability Agenda Scotland found that 97 percent of respondents had extreme difficulties in claiming the funds available, partly as a result of overcomplicated forms and difficulty communicating with the Benefits Agency.

A number of Scottish studies mentioned above indicate that many of those at risk of experiencing illness or having a disabled child are already leading a marginalized and stressful social existence and often living in poor housing conditions on rundown estates (see the data presented earlier on mental health problems, stroke, and deprivation). Local education, health, and social services may have become residualized, as market-based policies ensure that the more entrepreneurial are able to use services in more advantaged neighborhoods. The onset of illness or the birth of a disabled child may intensify an existing experience of social exclusion. At the same time, it is important to remember that illness or the birth of a disabled child may affect people across the social spectrum, including the relatively comfortable middle class. There is therefore a need for longitudinal research to track the interaction of illness and social class over time.

DISABILITY, SOCIAL CLASS, AND EDUCATION

Within educational sociology, there is a considerable body of research in the "political arithmetic" tradition that has charted working-class pupils' poorer educational attainment on entry to school and their slower rates of progress compared with middle-class pupils during their time in school. More recent work has begun to explore the strategies used by middle-class parents to secure their family's positional advantage within education. While it is known that children of poorer parents, particularly boys, are more likely to be assessed as having moderate learning difficulties and/or social, emotional, and behavioral difficulties, studies of educational outcomes in relation to social class have generally not considered disability as a key variable. There is a body of work, however, that has explored the construction of deficit categories in school over time. It has been noted, for example, that dyslexia is much more likely to be diagnosed among middle-class than working-class pupils.

Within the higher education sector, greater attention has been focused on access to higher education

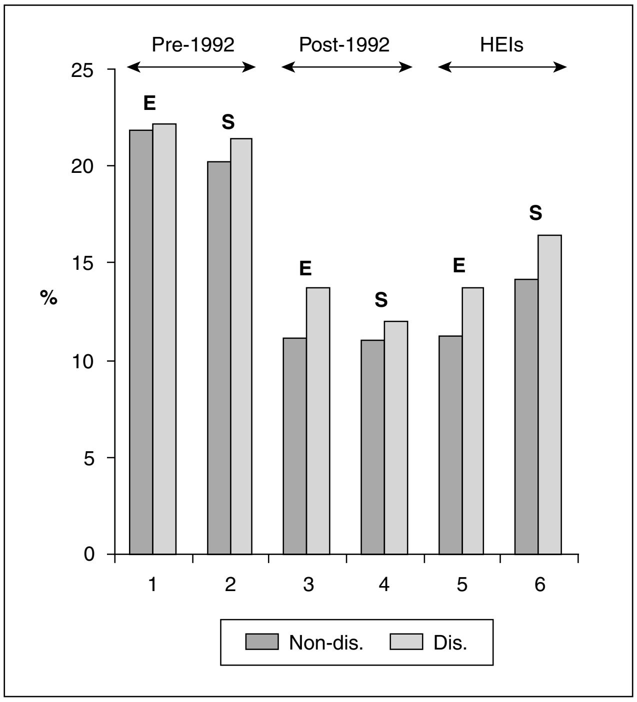

Figure 6 Percentage of Undergraduates from Social Class 1* by Sector, Country, and Disability Status

Source: Higher Education Statistics Agency, 2002.

*As defined by the Office of Population Censuses and Surveys.
E = England; S = Scotland.
HELs: Higher education institutions without university status.

over recent years, given the growing importance of higher-level qualifications in accessing professional and managerial employment. Studies have traditionally compared the relative chances of children from working-class and middle-class families of winning a place in higher education. Government reports on widening access to higher education have picked up on these studies and have often interpreted access to higher education in terms of enhancing the access of children whose parents (usually fathers) have working-class occupations or are from low participating neighborhoods and schools.

Until 2002, data on the disability status of higher education students were not published by the U.K. Higher Education Statistics Agency. Disabled students are now included officially as an "underrepresented group," and the disability indicator is based on the number of students receiving the Disabled Students Allowance on the basis of a needs assessment. The Funding Councils make additional premium payments to institutions based on social class and disability indicators. The benchmarks published in relation to each indicator are based on the performance of other comparable institutions in the sector and are intended to signal to institutions whether they are performing better or worse than expected.

Recent work by Riddell, Wilson, and Tinklin (2002) on access to higher education in the United Kingdom has looked at the interrelationships of a range of variables, including social class, gender, disability, and ethnicity. Higher education institutions fall into three categories: traditional pre-1992 universities, new post-1992 universities, and higher education institutions, which have degree-awarding powers but not university status. The findings, shown in Figure 6, indicate that disabled students in the elite universities share the privileged social class background of the majority of other students in those institutions. This again underlies the point that it is quite wrong to regard disabled people as a homogeneous group. The divisions among disabled people in relation to social class, ethnicity, gender, and nature of impairment need to be investigated to develop a more sophisticated sociology of disability.

DISABLED PEOPLE AND REGENERATION

It was noted earlier that there have been ongoing debates about whether deprivation should be measured on the basis of an individual's social class or in relation to the cumulative measures of deprivation within an area. Traditionally, urban regeneration programs have focused their energies on areas rather than individuals. However, recent reviews of regeneration strategies have indicated a tendency to base their interventions on the assumption of a homogeneous population. Little attention has been paid to the particular situation of disabled people, those from minority ethnic groups, travelers, lone parents, and so on. Regeneration programs have frequently sought to involve community groups, but disabled people have rarely formed pan-impairment groups and, as a result, have not been easily identifiable in consultation processes. Where disabled people have been involved in regeneration strategies, it is often as a result of a particularly targeted initiative, and they have rarely been included in consultations as ordinary members of communities. Given the overrepresentation of disabled people in areas of deprivation, it is important that more effective ways are found of consulting and involving them in local economic development.

CONCLUSION

We began by noting the conceptual problems in trying to work with disability and social class as social variables. Nonetheless, the categories do still have some utility as organizing frameworks connected to the material realities of people's lives. Statistical data were used to demonstrate that people experiencing high levels of deprivation, another way of measuring social class, were much more likely to experience serious health problems than people living in more socially advantaged circumstances. Attention was drawn to the concentration of disabled people among those classified as economically inactive, highlighting the problem with traditional measures of social class, which would assign all those not working to the category of "other." Data on household income revealed the financial consequences of exclusion from the labor market, with many households including a disabled person experiencing a significant degree of poverty. Despite the evidence of the links between social deprivation and disability, as well as the tendency of the onset of illness to trigger further social and economic hardship, urban regeneration programs have tended to bypass disabled people because of their invisibility.

Overall, there appear to be strong arguments for the development of more research that systematically investigates the links between different equality and social justice concerns, so that people are not conceived of as unidimensional subjects. Such studies would also need to track changes in social identity and social status over time. This is in line with the U.K. government's attempts to "mainstream" equality issues, possibly establishing a single commission to deal with all six equality strands covered by Article 13 of the European Union's Employment Directive. However, it should be noted that social class does not feature as an equality issue, being dealt with as a social justice concern under a separate policy stream. Much research on disabled people, including work informed by the social model, has tended to assume that all disabled people have similar social class backgrounds and therefore encounter the same barriers. Research such as the higher education study, referred to above, notes that disabled people from socially advantaged backgrounds may share some of the positional goods of their social class, such as access to elite higher education institutions. Recognizing the diverse social class interests of disabled people may be seen as undermining the unity of the disability movement, but in the long run, a more nuanced analysis is likely to lead to a stronger sociology of disability that is able to feed into the future development of the political movement.

—Sheila Riddell

See also Economic and Social Development; Economic and Social Development, International; Employment; Employment, International; Poverty.

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SOCIOLOGY

The identification and experience of disability takes place on a daily basis within the social context, whether in the home or workplace, a rehabilitation center or a shopping center, a neighborhood or a foreign country. Because of this, sociology, which is a discipline that examines the social structure as well as social relationships and interactions, provides a key perspective to understanding that identification process and the experience of living with a disability. Disability is most commonly examined within the specialization of medical sociology, which is an area that focuses on the structure of the health care system as well as the delivery and receipt of health care within the health care institutions that have been developed in a particular society. These institutions can be hospitals, rehabilitation facilities, and health maintenance organizations in the broader U.S. society or the system of barefoot doctors within the Chinese culture. However, many of the other specialty areas of sociology can also provide insights into how we come to define disability and the ways that disability affects personal experience and relationships.

As a discipline, sociology provides ideas about how things work, at either a macro level or a micro level. Those ideas help to explain outcomes associated with a particular organizational structure or relationships in a particular social setting. For example, at the macro level, understanding how the factors within an organizational structure that are part of the accepted way to do things can either facilitate or inhibit the access of people with disabilities to employment within that organization. Sociologists try to understand these underlying assumptions that guide organizational behavior and thus create the outcomes that are observed. At a more micro level, sociologists try to understand how people interact with each other and what aspects of the cultural norms influence interaction in a variety of settings, both formal, such as a court of law, and informal, such as the family setting.

More than ever before, populations in most societies are experiencing circumstances that lead to disability, and these can also be addressed by sociological perspectives. It makes no difference whether the population varies ethnically, racially, or by age or gender; the increased presence of chronic illness, effects of pollution from environmental toxins, industrial or automobile accidents, and the increase in armed conflicts throughout the world create disabling problems for people everywhere. How, when, or why a society intervenes will influence the number and types of disabilities developed among the population. Medicine has taken on primary responsibility for those who experience disease or injury, but medical institutions, medical knowledge, and medical technology are inadequate to address all the issues that take place in the social context of the person who is born with or acquires a disability during his or her lifetime. Sociology as a discipline has developed a group of theories about how the social structure works or how people interact in social relationships. Any number of these can be applied to the study of disability.

One of the first and most important contributions of sociology to our knowledge about disability is the understanding that what constitutes "disability" itself is socially defined. Saad Nagi, a sociologist, was among the first to observe and write about the importance of the social context in defining and understanding disability. In 1965, he noted that disability can be understood as a pattern of behavior that evolves in a situation where there is long-term impairment associated with functional limitations. He described how these patterns of behavior are influenced, not only by the characteristics of the impairment and subsequent functional limitation but also by very socially defined aspects of life. These social aspects include the individual's definition of the situation and his and her reaction, *as well as* the reactions and expectations of those around the individual with the limitations. In more recent years, theoretical models of the relationship among impairments and functional limitations and social contextual factors have proliferated, with the Institute of Medicine model and the World Health Organization model being widely regarded as the most important. While there are some disagreements between the two models, both rely heavily on sociological concepts about social structure and social role.

SOCIAL DEFINITION

Paul Higgins (1992) has helped to explain how society defines disability by elaborating on the processes that are involved in that construction. Higgins and others have pointed out that we make disability through our beliefs and behaviors, through our interpersonal interaction, and through our organizational and social activities, and it is an active process that is ongoing daily. The beliefs and actions of a particular culture about disability are built through government policy, the media, programs that serve the disabled population, work or school situations, and the family. An important point to recognize in this process is that we produce the variation we recognize in others, whether it is associated with physical or mental capacity or skin color or age or gender. While this approach helps us understand how disability comes to be defined, it also documents how having a disability or being labeled as having a disability is experienced.

Most conceptualizing of disability individualizes the phenomenon; that is, the problem or condition is seen to reside within the individual. This is particularly reinforced in the medical setting, where the disease or impairment is diagnosed, labeled, and, if possible, treated. This is not necessarily inappropriate in that particular setting. However, when that label is attached to the individual, it not only provides a protocol for treatment but, when taken up by other branches of the social structure, also provides a validation for attributing the problem to the individual, thereby reinforcing the differentiation. Other elements of the "defining" process are associated with the socialization process, which is a common concept in sociology. We are all socialized into a variety of roles as we grow and mature. Our family socializes us to the role of son or daughter, sister or brother, while our schools socialize us to be students and to take on roles of independence such as work roles, citizenship roles, and others. Thus, the expectation that a person with an impairment or functional limitation is somehow less independent or less able to do certain tasks or take on certain roles (such as working) becomes a part of the social interactions surrounding and molding the person.

Other useful approaches to understanding the social construction of disability have also been developed. The minority group perspective that was developed by Hahn (1988), Gliedman and Roth (1980), and others does help to develop the conceptualization beyond the individual and forces the recognition of prejudice and discrimination toward the group of individuals with disabilities. A precursor to this approach was the study of attitudes toward persons with disabilities, which demonstrated that some impairments, such as mental retardation, are viewed more negatively than others. While the focus on attitudes was still based on the individualized approach to disability, it documented the widespread and relative uniform prejudice and discrimination toward specific groups. The minority group perspective was a step toward considering individuals as part of a group, regardless of their individual impairments, and subject to experiences because of their group membership rather than their individual characteristics.

SOCIAL MOVEMENTS

Sociological social movement theory has also contributed to understanding the changes in the opportunity structure for persons with disabilities in more recent years. As an outgrowth of the minority group perspective, Barnartt and Scotch (2001), among others, began tracking how persons with disabilities have sought to regain power and self-determination by participating in protests and other actions to improve (and, at times, reclaim since many acquired disability at later ages and at one time had lived as the "standard" of expectations) their status in society. In many ways, the upsurge of the disability movement, which began to be evident in the early 1970s, was not unlike the civil rights movement and the women's movement, although it took quite a while for the movement to gain the widespread support and recognition those earlier movements received.

Social movements are a form of collective behavior that occurs outside of the usual social structural context. Sociological theory provides discussion of the membership and goals of social movements as well as the types of tactics used in social movement activities. Basically, these movements are a reflection of power and politics and are generally focused on change of some sort. What is interesting about a social movement on disability is that the participants need to develop a collective consciousness to see beyond their individualized impairment. With the development of this consciousness on the part of persons with disabilities, the purpose of moving the social structure beyond the individualized perspective is solidified.

Early social movement activity by parents and caregivers for persons with disabilities, particularly mental retardation and mental illness, was aimed at improving conditions for these individuals who were often living in institutions. But those early movement activities did not reflect a collective consciousness on the part of persons with disabilities themselves, which was essential to develop the emotion needed to engage in the risky actions necessary to demonstrate the issues. The development of this collective consciousness across impairment types and the ability of those with disabilities to see themselves as one group with boundaries and also as one group with common experiences of prejudice and isolation was an important step in changing the social structure not only attitudinally but also physically.

As with blacks in the civil rights movement and women in the women's movement, a very important issue for the disability movement was equal opportunity, as represented by equal access to education and employment. However, the demands of the disability movement go further to address the issues of environmental accessibility of the built environment so that the buildings housing the education or work opportunity, as well as the shopping areas and other commercial areas, are useable for the population. Even governmental entities such as motor vehicle offices, public transportation, and the voting place have been areas for the focus of equal access.

MEASUREMENT AND COUNTING

The success of the disability social movement in changing both the social structure to protect the civil rights of persons with disabilities (as represented by the Americans with Disabilities Act) and the environmental access of people with disabilities to the built structure (through the Architectural Barriers Act) has created an imperative to be able to measure and count persons with disabilities to monitor the success of these laws. Sociology methodological studies have made an important contribution to this activities. However, measurement and counting are very tenuous activities. Measurement of a phenomenon is very much influenced by how it is defined, and the definition is associated with the purpose of the counting activity. The policy issues associated with these laws and other programs focused on the disabled population create a need for a fixed and dichotomous way to identify the population similar to a measure of sex or race. However, in fact, disability is more accurately conceived of as fluid and continuous. Irving Zola (1993), whose work made well-known contributions to the sociological study of disability, wrote about this problem with measuring and counting persons with disabilities and identified many of the problem areas.

A well-known analysis about the political aspects of enumeration concludes that "political judgments are implicit in the choice of what to measure, how to measure it, how often to measure it and how to present and interpret the results"(Alonso and Starr 1987:3). How we define disability, often a political decision, can make a great difference in how many we count and who we count. For example, if we define disability in terms of chronic disease conditions, we will undoubtedly find a different number than if we define disability in terms of specific functional limitations experienced by the individual. Not only will the numbers be different, but the people who are counted can also be different, at least partially, since not all persons with chronic conditions have functional limitations, and not all persons with functional limitations have chronic conditions.

Today, several groups, involving sociological methodologists, are seeking to define disability and measure it for a variety of purposes. Concern with the employment rates of persons with disabilities has prompted the Bureau of Labor Statistics to develop a measure of disability to use in its surveys that track employment rates of the working-age population. At the same time, another group associated with the census also seeks to develop a useful measure to identify the population with disabilities for the purpose of distributing resources and developing programs nationwide. This measure is of concern to the Social Security Administration as well since workers who can no longer work because of disability are eligible for benefits. Budgeting for this group requires accurate estimates of the potential numbers who will seek those benefits.

Once again, measurement of disability in large social surveys or in the census focuses on the individual and identifies a person as disabled based on his or her conditions, impairments, level of physical functioning, or ability to participate in major roles such as work roles and family roles. While the social movement activity and the theoretical models that explain disability have introduced the very important element of the environment to understanding that disability is the result of the interaction of the person with his or her environment, we are not yet able to adequately measure environment. Much of the social science research that contributes to our understanding of disability and the circumstances of the person with a disability is based on large national surveys whose methods for measuring disability vary widely. Great care must be taken in developing the measures, using the measures, and interpreting the measures and the results of analyses, be it levels of employment, living arrangements, or the use of assistive devices. Sociology has taken a lead in this important work.

As this brief discussion of the application of sociological theories, methodologies, and perspectives shows, sociology has been a rich source of intellectual ideas to help in understanding disability. Sociology contributes to a clear understanding of how the human variation that is identified as disability has come to be defined, both interpersonally and structurally. It has also contributed to developing measures of this phenomenon and interpreting the measures and the counts of persons with disabilities that result. Sociology also holds the potential for further contributions to the study of disability by providing a greater understanding of the role of the environment and the larger political context as a counterbalance to the interpretation of the individual responsibility for the problem. The important contributions of sociology to understanding the causes and consequences of poverty, the role of gender in the life of an individual, and the structure and functioning of social organizations are indicators of the largely untapped resource that sociology can provide to this field. In addition, the study of disability provides an important challenge to the field of sociology. Disability is a multifaceted construct, with all the complexity of gender or race but with additional dimensions as well. It can provide a test of the theories and methodologies that have been so carefully crafted over the past 100 or more years and will undoubtedly improve and refine those theories and methodologies in the process.

—Barbara M. Altman

See also Disability Studies; Models; Research.

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SOCRATES 469–399 BCE

Greek philosopher

According to his intellectual heirs, Plato and Aristotle, Socrates ceaselessly engaged his fellow citizens in an examination of the right way to live by a method of cross-questioning. Socrates's contemporary, the comic Aristophanes, shows us another side of the Athenian perception of Socrates, in which his interests are esoteric and his methods are annoying. From the perspective of disability studies, Socrates is especially interesting for two reasons. First, he is characterized in literature and in artistic representation as extremely unattractive, a counterpoint to the idea that the Greeks believed that wisdom and beauty were inseparable. Second, Socrates's characteristics, such as his susceptibility to trances and his unkempt appearance, would be categorized today as a medical diagnosis, perhaps schizophrenia or autism. Temple Grandin, in *Thinking in Pictures* (1995), points out that genius is, after all, an abnormality. Grandin describes geniuses such as Albert Einstein, who had little sense of social convention or personal appearance—"he just did not care" (p. 183). At the height of classical Athens, Socrates was tolerated—and venerated by some—for carrying out what he thought was his duty to be a stinging fly biting the horse of Athens so that Athens would not become complacent. After the disastrous Peloponnesian War, when Athens had crumbled and its citizens were nervous, a jury of his peers condemned Socrates to die in 399 BCE.

—*M. Lynn Rose*

See also Aristotle; History of Disability: Ancient West.

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SOKOLOV, SERGEY I. (1888–1945)

Russian organizer of the Moscow Society of the Deaf

Sergey I. Sokolov was one of the organizers of the Moscow Society of the Deaf (1912) as well as chairman of the All-Russian Union of the Deaf (1917–1920). In the 1930s, he organized and was the director of a training course for sign language interpreters.

—*Anna Komarova and Victor Palenny*

See also Deaf, History of the; Sign Language; Sign Language Interpretation.

SOUTH ASIAN ARCHETYPES

In the Indian epics *Mahabharata* and *Ramayana,* characters such as blind King Dhritarashtra and his blindfolded wife, Gandhari; Ashtavakra, the "eight ways disabled" scholar; and the crafty hunchback Manthara (also known as Kubja) may be hard to link with historical people having dates of birth and places of residence. However, over centuries, they have been popular South Asian archetypes of disabled persons, known to hundreds of millions of people through local dramas drawn from the epics and, more recently, on film, video, the Internet, and schoolbooks.

Dhritarashtra, born blind, was thereby disqualified from kingship. He managed, nevertheless, to acquire the kingdom after his half-brother Pandu died. His disability and legitimacy thus became pivotal to the conflict between his own sons and Pandu's sons, providing the frame story for the *Mahabharata.* Dhritarashtra married Princess Gandhari, who immediately began wearing a blindfold to avoid the shameful situation of knowing more than her lord. Later, Dhritarashtra complained to his driver that because he was blind and could not engage actively in the conflict, his eldest son Duryodhana considered him a fool and paid little heed to his words.

Ashtavakra also appeared in the *Mahabharata.* When the learned Kahoda's wife became pregnant, the fetus, who was already well versed in the Vedas, found fault with Kahoda's reading. Kahoda cursed his yet unborn critic to be eight ways crooked. At King Janaka's court, Kahoda was defeated in academic debate by Vandin and forfeited his life. Later, as a young man, Ashtavakra went to King Janaka, but the guards refused him entry. He then asserted his rights as a Brahmin over "the blind, the deaf, the women, carriers of burdens, and the king respectively." He gained admittance and defeated Vandin in debate. Kahoda reappeared and reflected that weak men may have strong sons, stupid men may have clever sons. Ashtavakra later entered the river Samanga, and his limbs were straightened.

Manthara, hunchbacked maid to Queen Kaikeyi, was the hinge on which the *Ramayana* frame story turned. When King Dasaratha, the (earthly) father of Rama, became decrepit and nominated Rama to succeed him, Manthara persuaded the junior Queen Kaikeyi to campaign for enthronement of her own son instead. Manthara's wiles resulted in Rama's exile to the forest with his wife Sita. In Valmiki's *Ramayana,* Queen Kaikeyi thought that women with deformities were usually sinful and perverse, but Manthara's "hunch" contained her knowledge and wisdom. In some versions, Rama later reflected that in his boyhood, he teased Manthara about her disability, and this was why she took revenge on him or was the instrument by which the consequences of his mistaken conduct were visited upon him. (Such reflections do not appear in later versions that emphasize the divinity of Rama.)

—Kumur B. Selim

See also Experience of Disability: India; India, Impact of Gender in; India, Marriage and Disabled Women in.

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SPECIAL EDUCATION

THE HISTORIES

Depending on the perspective taken, special education can be defined as follows: a legally mandated system of services that ensures access to educational provision for disabled students and their families; a mechanism that ensures some, but not all, children will be afforded access to life opportunities as a consequence of historically inequitable educational provision; or as an institutional safeguard to protect students and teachers in the general education system from the problems posed by disability and difference in public schools. Despite recent efforts that call for "inclusion" in public schools through the return of disabled students to the general education classroom and their neighborhood schools, special education continues to predominate within practice. In teacher education programs, inclusive education now forms part of the curriculum, either replacing "special needs" provision or coexisting uneasily with it. According to Slee (2001), inclusive education has been adopted enthusiastically by special educators because it has enabled them to continue their practices from a publicly acceptable base and to convert the student teacher into a "card carrying designator of disability" (p. 171).

Rather than retell the often-told story about special education and its origins in the Western world, what is offered here is an attempt to trouble that which Brantlinger (2003) casts as the "peaceable kingdom" narrative of continuous progress in the field of special education. We draw from primary sources and the analyses of some historians (Foucault 1977; Richardson 1999; Trent 1994) to question the naive interpretation of linear progress that typically frames special education despite its obviously problematic core assumptions. These include the following: (1) disabilities are pathological conditions that students have, (2) differential diagnosis is objective and useful, (3) special education is a rationally conceived and coordinated system of services that benefits diagnosed students, and (4) progress results from rational technological improvements in diagnostic and instructional practices (Skrtic 1991). We also draw on contemporary scholars (Baker 2002; Slee 2001, 2004) to trace some of the key elements in the trajectory of special education and to analyze the nature of its resilience.

THE GENESIS OF SPECIAL EDUCATION

Depending on the perspective taken, special education histories trace back over centuries, with origin stories that generally begin with a recounting of educational provision in special schools for deaf and blind students early in the 1800s and, later, for students with physical, cognitive, and emotional disabilities. The creation of the special school in contexts across the world isolated the disabled individual from the community as such facilities were typically located in rural settings where educational provision was impairment specific and cast in the rhetoric of individual and specialized instruction. Undeniably, contemporary special education is informed by multiple histories, some more nuanced than others and some that remain, as yet, unexcavated. Our analysis aims to inform awareness of the conditions that emerged to establish the need for special education and its unyielding resilience. Our insights fall outside the narrative of rational technical progress in the field of special education "proper" as this remains a naive and unproblematized history of self-congratulation among professionals for the hard-won rights of children. The trajectory we provide considers issues of practice and the resulting effects of special education on children and their families. Likewise, our analysis troubles the critical links between special education and class issues rooted to economic need and the growth of industrial capitalism in both the United States and the United Kingdom.

COMPULSORY SCHOOLING AND SPECIAL EDUCATION

Richardson (1999) provides insight into the effects of compulsory attendance laws that ultimately served as an "essential precondition" for the development of policy and the systematic provision of special education services. The evolution of European-based practices of book learning and apprenticeships in the trades, accompanied by mandatory "enrollments of indenture" that included a range of student abilities, would, no doubt, inform inclusion as it is cast in the present moment. What is pertinent here, however, is that by the mid-nineteenth century, "standardized" education across society was becoming common. At roughly the same time, the "invention" of idiocy signaled the launch of processes to differentiate dependent people throughout society. In the language of contemporary special education discourse, the early nineteenth century signaled the beginning stages of the development of qualification criteria, needs identification, assessment, and the necessary legal authority to act on behalf of children with special needs. Through these established disciplinary mechanisms for social control, as Foucault (1977) has argued, communities were empowered to exercise compassion and benevolence toward the "poor and the infirm." This nascent form of special education turned on securing the legal authority to supersede the traditional rights of parents in favor of arguments for the promotion of a broader welfare. Over time, these disciplinary mechanisms advanced a form of professional zealotry common among many special education professionals who position themselves as advocates driven to act in the "best interests of the child." Despite mounting evidence that long-term placement in special education yields poor academic and social gains for children (National Council on Disabilities), the profession maintains that theirs is a moral calling to act on behalf of children with disabilities (for an insightful critique of the profession, see Skrtic 1991; Slee 2001, 2004; Tomlinson 2004).

SPECIAL EDUCATION PRACTICE

Public school classes for mentally defective children were common throughout Europe in the late 1800s and as early as 1867 in Germany. Although some institutions in the United States imported the European model, others pressed for a community-based response to the education of feebleminded children. Citing decades of limited success among the American institutions to sort successfully the feebleminded from the "merely" backward youth, Walter E. Fernald, superintendent of the Massachusetts School for the Feeble-Minded, called for improved technologies and the creation of special classrooms in urban public schools (Fernald 1904). He was at once sympathetic to families forced to institutionalize their children in their "tender" years and critical of those families who "lacked" the desirable moral and intellectual influences necessary for encouraging proper developmental gain among their offspring. This early campaign to relocate children from institutions to their local community and schools slowly shaped the view of special education as a place rather than a service—an enduring problem inherent in our dual system of service delivery model in the twenty-first century.

SPECIAL EDUCATION AS PLACE

By 1917, compulsory schooling was well under way in the United States, and for students unable to progress through the system of a graded curriculum, the "special class" emerged. Similar in structure to the special school, provision in the special class was disability specific and cast in the rhetoric of individual and specialized instruction. A close examination of the historical record of compulsory education provides insight into the organizational dilemmas posed by enacting schooling for the "backward child"—the then commonly used terminology for students in need of schooling that was "less for the head and more for the hand," as Ware (forthcoming) has observed. Earlier distinctions of difference included terms such as "troublesome, truant, backward, defective, retarded, slow, mentally deficient, those with excessive 'badness' and those with physical and mental markers of imbecility or idiocy" (Ware forthcoming). Buried within these descriptors was reference to the foreign-born and burgeoning immigrant population. Under the auspices of improved social welfare, kindergarten-age students at the Training School at Vineland, New Jersey, were enrolled in a curriculum that emphasized "punctuality, obedience to authority, patience, teamwork, and respect of the rights of others" (Trent 1994:109). Vineland researchers noted this population included "those whose minds have not developed normally" and "American born children of parents who have not succeeded . . . [and who] . . . are deprived from birth of the possibility of even a moderate degree of success" (Irwin 1913:67). Armed with new protocols to medicalize difference, these early researchers contrasted the "familiar" East Side neighborhood populated by first-, second-, and third-generation Americans with their target community—one in which the "foreign-born population swarms the streets and a strange language meets the ear from every hand" (Irwin 1913:67).

It was initially projected that roughly 1 percent of children younger than 14 years of age enrolled in the public schools were "defective mentally," but data collected in 1920 indicated that in New York City, 31 percent of the population labeled "mental defectives" were immigrants. Exploring the intersections between immigration and special education would obviously enrich contemporary analyses of the overrepresentation of minorities in special education; however, in the United States, such excavations are rare compared to the rich analyses undertaken by British sociologists, who have persistently probed these critical connections. Their insights trouble the previously blurred lines between ensuring educational provision for those children who were formerly institutionalized and the creation of the urban special class that served as the mechanism to absorb increasing student diversity in the public schools. Although the threads may appear less evident when attempting to link the parallel development of curriculum for both populations, the section that follows indicates how disenfranchised youth on both sides of the Atlantic, whether disabled or ethnic, were tracked into a skills-based education that targeted vocational ends and minimized exposure to enriched educational experiences. Thus, their life options were circumscribed by institutionally sanctioned limits on learning.

SPECIAL EDUCATION PEDAGOGY

In the example of special education pedagogy and practice, Edouard Séguin, celebrated by Pope Pius X as the "apostle to the idiots," remains a central figure (Trent 1994). Séguin, who was a student of Itard, developed pedagogy that assumed that all idiots shared the twin characteristics of dormant senses and an undeveloped will. His curriculum aimed to awaken the senses through "physiological education" that emphasized the interplay between physical motor activity, sense stimulation to arouse the intellect, and moral intervention to shape the will. Trent (1994) notes that Séguin's approach has been modified very little in the past 150 years and remains "amazingly contemporary." However, the context and aims of his method and the subsequent curriculum shifted as a consequence of divided class interests and increasing pressures for social control. The dramatic decline of state-based provision and the increased availability of private care prompted a reappropriation of his curriculum for common usage as "habit training." In a culture enthralled by eugenic tendencies and the demand for regulating difference, correcting for atypical characteristics emerged as a worthy goal.

Researchers forged agreement on the problem of the feebleminded child as primarily a school problem, and thus the first step was to separate all children into classes best suited to their needs so as to "rid the normal children of this unnecessary burden" (Irwin 1913:68). The Binet test (later, Stanford-Binet) emerged to sort students into categories labeled as follows: the normal (those testing within two years of their chronological age), the backward (those testing between two and three years younger than their chronological age), and the feebleminded (those whose differences exceeded three years). This early research inspired the scientific approach to the diagnosis and treatment of difference, where the lines easily blurred between those with inherited or congenital difference and those whose ethnic difference marked their "strangeness" as troublesome within the same boundaries of feeblemindedness. Subsequently, the curriculum for both populations became one that aimed toward vocational training: the exact opposite direction originally conceived by Séguin. Although a seemingly subtle shift, the effect intensified over time as new emphasis was placed on human worth and one's ability to produce in a capitalist society.

These early influences ensured the development of special education as a technical field, located within a positivist framework, concerned with issues of diagnosis, assessment and causes of disability, and appropriate forms of treatment. New York City took the lead and organized special classes for "pedagogic reasons" into three levels: (1) bright truants, (2) normal children with sensory deficits, and (3) children truly mentally defective. Once the categories existed, school administrators could weed out those children from the normal classes, justified by the rhetoric of "relief." Fernald (1904) espoused the logic of bureaucratic convenience, arguing that relief was overdue for educational systems inundated by the influx of immigrant children who taxed the ordinary capacities of educators. These early arguments influenced the development of special education as an institutional safeguard to protect general education students and teachers from the problems posed by disability and difference in public schools. Although Fernald also claimed that "relief" was due to families who suffered "ceaseless anxiety and sorrow caused by the presence of the blighted child" (p. 34), his claims were issued in the same era as the nascent formation of a factory/machine bureaucracy for school organization—one that privileged bureaucratic convenience over student needs. This vestige of the past, as noted by Skrtic (1991), guarantees the inability of schools to meet the needs of individual learners.

THE SPECIAL EDUCATION LEGACY

The stigmata associated with disability have historically centered on perceptions of deviance; as a consequence, individual conditions have been considered alternately mysterious and deserved, dangerous but exploitable, and alien yet innocent. While interactions with the nondisabled community were infrequent, the public perception of disability was readily shaped by fear, pathos, and scorn so as to fix our gaze on the person labeled mentally retarded. As a consequence, research aimed no further than individual pathology and social problem. That the original interventions of Séguin's system of physiological education have witnessed little fundamental innovation in more than 150 years is both evidence and indictment of special education's enduring legacy—an inability to move beyond pathologizing discourses that unproblematically demand perfecting technologies, as Baker (2002) has noted. Not only does this lesson endure, but we are temperamentally unable to unlearn it and unable to resist the "hunt for disability." Slee (2001, 2004) concurs, arguing that the continuing dominance of special education has had a domesticating and taming effect on inclusive education. Special education continues to be preserved, while inclusive education discourses are silenced, not least of all by professionals in the United States who hold a vested stake in protecting their own interests in segregated education by issuing dire warnings about the "illusion" of full inclusion. In the United Kingdom, the defense of special education is less emphatic but no less effective. Both Baker and Slee contend that the legacy of special education can only be challenged by reframing it as cultural politics and by encouraging professionals to turn the gaze back on themselves and, thus, to better understand their own complicity in preserving special education.

—Linda Ware and Julie Allan

See also Education, International; Education and Disability; Educational Assistive Technology; Edouard Onesimus Séguin.

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National Council on Disability (NCD), http://www.ncd.org

SPECIAL OLYMPICS

See Classification in Paralympic Sport; Paralympics

SPEECH AND LANGUAGE PATHOLOGY

The field of speech-language pathology encompasses both human communication behaviors and disorders, as well as swallowing functions and disorders. Speech-language pathologists are professionals who work with individuals of all ages to provide prevention, screening, assessment and diagnosis, intervention, counseling, and follow-up services for a variety of disorders that affect communication and swallowing. The practice of speech-language pathology also includes elective modification of communication behaviors that may result from cultural and linguistic factors, as well as enhancement of personal or professional communication performance. By affecting measurable and functional changes in the individual's communication or swallowing status, speech-language pathologists help the individual to participate as fully as possible in all aspects of life—social, educational, and vocational—thereby enhancing quality of life for the individuals they serve.

COMMUNICATION DISORDERS

Speech-language pathologists work with individuals who have communication disorders. A communication disorder may be developmental or acquired and may range in severity from mild to profound. A communication disorder may result in a primary disability, or it may be secondary to other disabilities. An estimated 46 million people in the United States, of all ages, races, and gender, have experienced some type of communication disorder. Communication disorders include disorders of speech, language, cognition, and hearing. Individuals may demonstrate one or any combination of these disorders.

A speech disorder refers to difficulty with the articulation of speech sounds, fluency, and/or voice. An articulation disorder, the atypical production of speech sounds, is characterized by substitutions, omissions, additions, or distortions that may interfere with intelligibility. Articulation disorders are among the most prevalent communication disabilities among preschool and school-age children. Children with articulation disorders may be at risk for reading and writing disabilities. The goal of speech therapy is to improve the accuracy and use of speech sounds and to achieve maximum intelligibility in single words and connected speech in all settings in which communication occurs.

When the speech impairment is caused by neurological damage, it is called a dysarthria and is characterized by slow, weak, uncoordinated movements of the speech musculature. Dysarthria can be congenital (e.g., cerebral palsy) or acquired (e.g., Parkinson's disease, stroke). In developing and implementing a treatment plan for speech disorders associated with degenerative diseases such as amyotrophic lateral sclerosis, speech-language pathologists match the intervention to the stage of the disease because such diseases frequently progress through a series of stages from mild speech impairment to loss of speech.

Fluency disorders, or stuttering, are another category of speech disorders. Fluency disorders are characterized by a disruption in the flow of speech and include repetitions of speech sounds, hesitations before and during speaking, and the prolonged emphasis of speech sounds. This may be accompanied by excessive tension, struggle behavior, and secondary mannerisms. Clinical evidence shows that individuals who stutter can benefit from treatment provided by speech-language pathologists at any time in their lifespan. Treatment typically focuses on changing the timing of speech (e.g., slowing down, stretching out sounds) or reducing the physical tension during speaking (e.g., gentle onsets of speech movements). Treatment also focuses on improving the speaker's attitudes toward communication and minimizing the negative impact of stuttering on the speaker's life.

A voice disorder is characterized by abnormal pitch, loudness, or vocal quality resulting from disordered laryngeal function and may cause pain or vocal fatigue. Voice disorders range from mild hoarseness to complete voice loss and limit the effectiveness of oral communication. Voice disorders can be caused by an injury resulting in paralysis of a vocal fold, an improper breathing pattern, or misuse of the voice. Voice disorders can also be due to medical or physical conditions, or they may be neurological in nature. Studies find that voice treatment, including vocal hygiene, can improve voice function and reduce the occurrence of laryngeal pathology.

A language disorder refers to impaired comprehension and/or use of spoken, written, and/or other symbol systems. The disorder may involve the form of the language (phonology, morphology, syntax), the content of the language (semantics), or the use of the language in context (pragmatics). Language disorders may affect individuals across the lifespan. For children who do not use language normally from birth or who acquire an impairment during childhood, language may not be fully developed or acquired. Many adults acquire disorders of language because of stroke, head injury, dementia, or brain tumors. One role of the speech-language pathologist is the establishment of augmentative and alternative communication techniques and strategies, when needed. Augmentative/alternative communication systems attempt to compensate and facilitate, temporarily or permanently, for the impairment and disability patterns of individuals with severe expressive and/or language comprehension disorders. Speech-language pathologists may also coordinate the selection and use of other kinds of assistive technology.

Cognition and language are intrinsically linked and reciprocally related in both development and function. Cognitive-based impairments of communication are referred to as cognitive-communication impairments. Speech-language pathologists work on improving cognitive aspects of communication, including attention, memory, perception, organization, reasoning, problem solving, and executive functions. Speech-language pathologists also may address other areas of function affected by cognitive-communication impairments, including behavioral self-regulation, social interaction, activities of daily living, learning and academic performance, and vocational performance.

Speech-language pathologists may provide services to individuals with hearing loss and their families/caregivers. Services may include auditory training, speech reading, speech and language intervention, and visual inspection and listening checks of amplification devices for the purpose of troubleshooting.

SWALLOWING DISORDERS

Speech-language pathologists identify, assess, and treat individuals of all ages—infants, children, and adults—with dysphagia. Treatment approaches include compensatory strategies designed to have an immediate effect on the swallow (postural changes or diet manipulation), as well as direct muscle-strengthening exercises for improving the swallowing physiology. Treatment approaches improve nutritional status and hydration and reduce morbidity from pneumonia.

SPEECH-LANGUAGE PATHOLOGY SERVICES

Speech-language pathologists deliver services that are consistent with the framework and components of the World Health Organization's International Classification of Functioning, Disability, and Health (2001). Assessment is conducted to identify the strengths and deficits related to underlying structures and functions that affect communication and swallowing performance, as well as the effects of these impairments on the individual's activities (capacity and performance in everyday contexts) and participation. Assessment also identifies the contextual factors that serve as barriers to or facilitators of successful communication/swallowing activities and participation.

Intervention is designed to capitalize on the strengths and address the weaknesses related to underlying structures and functions that affect communication/swallowing. The goal of intervention is to facilitate the individual's activities and participation by facilitating the acquisition of new communication/swallowing skills and strategies. Intervention also includes modifying contextual factors to reduce barriers and enhance facilitators of successful communication/swallowing activities and participation, as well as providing appropriate accommodations and other supports. Since speech-language pathology services are provided to individuals of all ages, intervention strategies reflect changing developmental stages and language needs and proficiencies throughout the lifespan.

At the present time, there are a number of acceptable treatment approaches for each type of communication and swallowing disorder. However, the field of speech-language pathology is dynamic and evolving. Speech-language pathologists keep current with best practices in prevention, assessment, and intervention. Research and outcome data alter assessment and intervention techniques, influence models and theories of practice, and expand the scope of practice of speech-language pathologists.

Speech-language pathologists provide services in a wide variety of settings, which may include the following: public and private schools; health care settings (e.g., hospitals, medical rehabilitation facilities, long-term care facilities, home health agencies, community clinics, behavioral/mental health facilities, neonatal intensive care units); early intervention settings, preschools, and day care centers; group homes and sheltered workshops; community and state agencies and institutions; correctional institutions; private practice settings; universities and university clinics; individuals' homes; corporate and industrial settings; and research facilities. Although speech-language pathologists are autonomous professionals, successful delivery of speech-language pathology services often requires the collaborative involvement of other professionals, as well as the patient, family, and significant others.

The American Speech-Language-Hearing Association (ASHA) is the professional, scientific, and credentialing association for speech-language pathologists, audiologists, and speech, language, and hearing scientists in the United States and internationally. The mission of the American Speech-Language-Hearing Association is to promote the interests of and provide the highest quality services for professionals in speech-language pathology, audiology, and speech and hearing science and to advocate for people with communication disabilities. The association was originally founded in 1925 as the American Academy of Speech Correction. The current name, the American Speech-Language-Hearing Association, was adopted in 1978.

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See also Dysphagia; Hearing Impairment.

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SPINAL CORD INJURY

Injury to the spinal cord can be caused by acute or chronic trauma as well as by medical conditions. Frequent causes of chronic compression injury are herniated intervertebral disks and primary or secondary tumors. Acute deterioration of blood perfusion, as seen in anterior spinal cord syndrome, can also severely compromise spinal cord function. However, probably the most dramatic setting for spinal cord injury (SCI) is acute trauma.

EPIDEMIOLOGY OF ACUTE SPINAL CORD TRAUMA

Estimates of incidence vary, depending on country and mode of reporting, ranging from 15 to 71 per million. According to estimates by the Canadian Paraplegic Association, about 35 new cases per million population are seen each year in Canada. Of the 12,000 new cases of paraplegia and quadriplegia that occur in the United States each year, 4,000 patients die before reaching the hospital. Causes for acute SCI include motor vehicle accidents, work-related accidents, recreational accidents, and violence (shot and stab wounds). Men are afflicted four times as often as women. About 60 percent of the injury victims are 30 years or younger. A long-term outcome study of patients ages 25 to 34 who had suffered acute traumatic SCI while still in the pediatric age group showed that the employment rate was only 54 percent, while the employment rate in the general population for the same age group was 84 percent. Limitation or complete loss of the capability to achieve economic independence following SCI can cause severe economic hardship for the afflicted person and his or her immediate family. Further limitations to participation in social life are caused by architectural barriers (i.e., buildings accessible by stairs only, lack of ramps on boardwalk intersections) and barriers created by negative or overprotective attitudes of healthy, noninjured people toward persons with spinal cord injury. Where reintegration of young SCI victims cannot be achieved, society might suffer a double loss: not only are contributions to society lost, but heavy expenses are incurred to pay for special lifelong care. In 1990, the costs for acute and long-term care of surviving spinal cord injury victims were estimated at $4 billion annually in the United States alone.

THERAPEUTIC APPROACHES AND CHANGING ATTITUDES

The first known description of acute spinal cord trauma and resulting neurological deficits was found in the so-called Edwin Smith papyrus, which is believed to be more than 3,500 years old. In this ancient Egyptian document, typical conditions encountered in medical practice were presented as case descriptions, and advice regarding treatment was offered. According to the papyrus, spinal cord injury was “an ailment not to be treated.” This was possibly an expression of helplessness on the side of the medical profession at the time. A doctor’s value would be measured by the extent of cure achieved. Since no strategies that ensured long-term survival for patients with spinal cord injury existed, the doctor would waste time and efforts and endanger his reputation. This basic attitude toward victims of spinal cord injury lasted well into the twentieth century.

Medical statistics from World War I show up to 95 percent mortality for patients with spinal cord injury, attributed mainly to urinary sepsis and pressure sores. During World War II, the number of both military and civilian casualties, including those with spinal cord injuries, increased dramatically in Europe. The success of specialized hospital units (so-called peripheral nerve centers), developed between the wars in Germany and the United States, had demonstrated the advantages of concentrating special-needs patients under specialized care. Great importance had been attributed to the unique opportunities offered by such specialized units—namely, to gain new insight in the natural course of the disease and to further the development of new therapeutic strategies. Building on those experiences, several specialized spinal cord units were opened throughout England in the 1940s. Pioneered by the team of Dr. Ludwig Guttmann at the Spinal Cord Unit of the Stoke Mandeville Hospital, new treatment approaches included frequent repositioning of paralyzed patients to avoid development of bedsores as potential source of sepsis and intermittent sterile catheterization to prevent urinary sepsis. The success, measured in patient survival, was dramatic enough to require the development of completely new strategies for social reintegration of patients with spinal cord injury. The creation of adapted workplaces and wheelchair-accessible housing, as championed in the 1940s and 1950s by the English Red Cross, has today become an integral component in the framework of social politics in most industrialized countries. While respiratory complications are now perceived as the leading cause of death in patients admitted with SCI, the runners-up are heart disease, septicemia, pulmonary emboli, suicide, and unintentional injuries.

THE PARALYMPIC GAMES

Guttmann and his colleagues viewed physical rehabilitation as the basis of social reintegration, both physically and psychologically. Consequently, they supported the idea of athletic competition in disciplines adequate and adapted to the physical capacity of their patients. Starting with a two-team competition in 1948, paralleling the Olympic Games in England, the idea of competitive sports for the paralyzed developed rapidly. In 1960, the first Paralympic Games were held in Rome. Not only were competitions held in the same year as the Olympic Games for the able-bodied, but both the Olympic and Paralympic games were using the same facilities, a tradition that has been followed ever since. The idea of competitive sports has long since been extended to include people with a multitude of physical handicaps other than spinal cord injury.

INITIATIVES AND PUBLIC AWARENESS

Noticeable is the number of initiatives that have sprung up at communal and national levels in many countries, with the intent to decrease the incidence of spinal cord trauma, to lend support and advice to patients with spinal cord injuries and their families. Some also offer financial support for basic science and clinical research. The prevention-oriented “Think First” initiative, Canadian-based CORD and Wheels in Motion, the Christopher Reeve Paralysis Foundation, the U.K. Spinal Cord Trust, and the Paralyzed Veterans of America, to name but a few, maintain informative sites on the Internet, where further valuable information on the subject of spinal cord injury can be found.

Although the overall incidence of SCI has not yet decreased noticeably, there is an appreciable decrease with regard to the severity of injuries (i.e., fewer complete injuries and an increased survival rate have been reported). This has been attributed to improvements in prehospital care, including widespread instruction in the principles of first aid as well as introduction of the principle of spinal cord immobilization during rescue and transport. Increased public awareness of risk factors leading to head trauma and spinal cord injury, the introduction of the mandatory use of safety belts, and the installation of air bags in cars furthermore are suited to decrease trauma severity.

RESEARCH

Until fairly recently, a dogma underlying the approach to spinal cord injury research postulated that, once spinal cord trauma had occurred, nothing could be done to alter the natural course of developing pathology, that damage to the central nervous system (CNS) was permanent and repair impossible. At the beginning of the twenty-first century, this dogma ceases to exist in the minds of scientists, clinicians, and patients and their families. In laboratories around the world, research is focused on two general approaches: prevention of *secondary injury* and repair of manifest damage. The term secondary injury is used to describe the observation that CNS structures, which have survived the primary, mechanical trauma, die at a later time point due to deterioration of the milieu at the site of injury. The volume of secondary tissue injury can be significantly larger than that caused by the primary injury. Research is focused on the identification of substances and therapeutic methods that help to minimize secondary injury. New methods in the field of cell biology allow the study, isolation, and manipulation of specific cell types. Efforts are being made to induce certain cell types, including stem cells and olfactory ensheathing cells, to help repair damaged CNS structures.

The focus of clinical research is on ameliorating the consequences of spinal cord injury (i.e., stimulators for bladder control, orthopedic correctional procedures) and on physical mobilization. Integration of biomedical research (i.e., pattern generators, mechanics and kinetics of movement) with the latest developments in computer science and engineering has led to the creation of neuronal networks. On this basis, neuroprostheses are being developed, which allow completely paraplegic persons to ambulate.

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See also Accidents; Orthopedics; Paralympics; Paralysis; Wheelchair; Wheelchair, Electric.

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Rick Hansen Man in Motion Foundation, http://www.rickhansen.com

SPORTS AND DISABILITY

Sport plays an important role in the lives of many people, and sports programs have high visibility in many communities around the world. Participation in sports activities is an important goal for many persons with disabilities, and it has been shown to have significant and positive effects on physical function, psychological and emotional status, and general health. People with disabilities who participate in sports have higher self-esteem and quality of life, and their participation in sports activities, limited for many years for the able-bodied, contributes to the elimination of myths and misconceptions surrounding disability and the removal of barriers to integration into society. Among other things, sports participation can be used to (1) maximize the benefits of the rehabilitation process early after injury or disease, (2) facilitate community reintegration efforts after rehabilitation, (3) provide leisure-time recreational opportunities, (4) enhance skill- and health-related fitness and general health, and (5) provide the high-performance competitive experience that many athletes enjoy.

REHABILITATION

The restoration of form and function (i.e., rehabilitation) after injury or illness can be achieved using a wide variety of therapeutic strategies and interventions.

These include occupational and physical therapy, speech therapy, recreation therapy, nutritional counseling, psychological interventions, and pharmacological management. Most people with disabilities have mobility limitations, and it is not surprising that sports programs can be used to provide some of the occupational, physical, and psychological therapy that is needed early in the rehabilitation process. Furthermore, sports participation can also be included in the process of "habilitation" of children with congenital disabilities or impairments acquired very early in life. Recovery or development of muscle strength, cardiorespiratory endurance, balance, and coordination, all fitness-related attributes lost as a result of injury or disease, can be facilitated through the participation in sports activities. Traditionally, gym-based activities have been used for this purpose, but the addition of sports activities (outdoors and indoors) such as windsurfing, horseback riding, and kayaking has brought much-needed diversity to the traditional programs. Patients in a rehabilitation hospital may be more motivated to do their exercises if the activity providing the stimulus is similar or more relevant to their favorite sport. The use of sport during the rehabilitation process was pioneered by Sir Ludwig Guttmann in the United Kingdom.

RECREATION

Leisure-time physical activity is an important component of a healthy lifestyle. People who participate in recreational activities develop confidence in their ability to participate in and contribute to society. Through recreational sports participation, people with disabilities can learn to enjoy life, reduce stress, develop special skills, improve functional capacity, and take control over their lives. Furthermore, many recreational activities can include the family. In fact, participation of husband or wife and their children can enhance compliance with activity programs. Also, leisure time can provide that much-needed opportunity to socialize with friends who share the same recreational interests. By eliminating barriers such as poor self-image and low self-esteem, recreational activities increase the chances of a successful return to community life, including family and occupational obligations.

HEALTH AND FITNESS

With advances in health care, many people with disabilities have a longer life expectancy. The causes of death in some groups of people with disabilities, such as those with spinal cord injuries, are more similar to those in the general population now than 20 years ago. For example, the incidence of chronic diseases, including coronary heart disease and atherosclerosis, is increasing in this population. Therefore, interventions that can reduce risk factors for chronic disease such as high blood pressure, sedentary lifestyle, and high cholesterol levels and enhance cardiovascular and metabolic functions can be of great benefit for persons with disabilities. The benefits of physical activity and exercise in men and women of all ages have been extensively studied and documented in the past 50 years. People with disabilities should receive the same benefits, and participation in several sports is one way of providing the exercise stimulus needed to enhance fitness and health. Sports such as wheelchair racing, swimming, and cycling provide that stimulus necessary to develop cardiovascular fitness and reduce the incidence of risk factors. Furthermore, fitness programs in sports clubs designed to enhance flexibility, strength, and aerobic capacity have become more popular among people with disabilities.

Sports participation can be used to enhance fitness in persons with disabilities due to chronic illnesses. Examples of chronic diseases that could benefit from sports programs include asthma, high blood pressure, obesity, stroke, osteoarthritis, osteoporosis, diabetes, and others. The use of sports programs in this context can be considered a form of secondary prevention. The benefits are many and could include better medical control of the disease, a reduction in the amount of medication needed to treat the disease, a reduction in the rate of complications, and an improvement in the functional capacity and tolerance to regular activities.

COMPETITIVE SPORTS

Competitive sports represent a real option for persons with disabilities who like the challenge of high-level athletic performance. Sir Ludwig Guttmann organized the first international sports competition for people with disabilities at Stoke-Mandeville in the United Kingdom. The Paralympic Games became part of the Olympic program, starting in 1960 with the summer games and in 1976 for the winter sports.

Many people with disabilities can participate in sports using standard equipment, depending on the requirements of the sport and the level of disability. However, an important consideration for persons with disabilities interested in many competitive sports programs is the need for special equipment that could make their participation possible and/or safer. Dramatic improvements in technology and biomaterials have allowed persons with a wide range of disabilities to participate in sports such as wheelchair racing, archery, golf, cycling, quad rugby, goal ball for the blind, horseback riding, boating, weightlifting, basketball, tennis, snow skiing, swimming, ice hockey, and many others. New prosthetic devices for amputees and ice hockey players, lightweight wheelchairs for racers and basketball players, and field event chairs for the javelin throw are some examples of devices that enhance the individual's activity and participation level.

Participation and competition in different sports are facilitated by the use of classification systems to make sure that athletes with disabilities competing against each other have equivalent levels of impairments and disabilities. This is consistent with the Olympic principle of "fair play" and may be consider equivalent to the classification systems based on, for example, body weight used in sports for people without disabilities. Sophisticated classification systems have been designed for use in local, regional, national, and international competitions such as the Paralympic Games. One example is the classification used by the U.S. Cerebral Palsy Association, which divides the competitors into eight groups based on the level of involvement of the limbs and torso, the need for a wheelchair, coordination, and related characteristics. Other examples are the classification system used for people with spinal cord injuries based on eight levels of injury and impairment and the classification of sports for three classes of visual impairment. More recently, the participant's functional capacity and performance in real sports activities has been proposed as the most effective way of classifying athletes. Although sometimes controversial, classification systems must be developed for all sports and understood by those who organize competitions for people with disabilities. These systems, however, may not be useful or necessary in recreational activities or when sports participation is used to enhance fitness and health.

Participation in sports per se can be positive, but persons with disabilities involved in serious sports competitions must follow a training program designed to enhance fitness and sports performance. Many training principles followed by athletes without disabilities also apply to the preparation for events such as the Paralympics. A sound training program must (1) include appropriate training loads that vary according to the dates of the competition, (2) be specific for the sport, (3) include the technical and tactical aspects of the sport, (4) monitor closely the health of the athlete, (5) include adequate nutritional support, and (6) never use doping agents or boosting techniques to artificially enhance performance during competition. Because many sports are practiced using a wheelchair, particular attention must be given to the training of the upper limbs and torso. It is important to keep in mind that athletes with disabilities have the same risk of injury per athletic exposure for an athlete without a disability. Physicians practicing sports medicine must understand the risk factors for overuse and traumatic injuries in this population. In addition, the specific medical needs that may result from the interaction between the medical condition that resulted in a disability (high-level spinal cord injury, diabetes) and the demands of training and competition must be taken into consideration. For example, some athletes with spinal cord injuries may be intolerant to the heat and high humidity typical of many cities during the summer. Also, exercise may alter the metabolism and effects of drugs such as insulin, requiring adjustments in the dose before training sessions or competitions.

—Walter R. Frontera

See also Exercise and Physical Activity; Paralympics; Participation; Recreation.

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STANDARD RULES

See United Nations Standard Rules

STEIFF, MARGARETE (1847–1909)

German toy manufacturer

When the German toy manufacturer, Margarete Steiff, died at the age of 61, she left behind a world-famous enterprise. She was born on July 24, 1847, in Giengen, south Germany. At the age of 1, she contracted polio, which left both legs and her right arm paralyzed. Steiff, along with her three siblings, had a carefree childhood. She took part in the games of the neighborhood children—while sitting in a wooden wagon—and attended the local elementary school. Two long stays in a children's hospital were combined with the hope that she would walk again. This hope proved futile. Also, an operation brought no success. Steiff stated in her memoirs, "The useless search for a cure does not let an individual come to peace."

Economic independence was very important to Steiff for she was dependent on her mother and, later, on her sister-in-law with respect to her caretaking needs. She bought herself a sewing machine and maintained a sewing room at first. Later, she got some assistants and soon produced felt slips and coats, which were very successful. In 1877, she opened a "Filzkonfektionsgeschäft," a ready-made felt business. A little later, she began to produce stuffed animals as children's toys. Her business—which she built with the help of her nephews—flourished. She placed a great amount of worth on the quality of her products. Her success made it possible for Steiff to build a new, ramped residential and business house in 1903.

In the same year, the Steiff firm introduced a new stuffed animal at the toy fair in Leipzig: a bear with a hump. Shortly before the fair closed, an American dealer purchased the entire bear collection, and soon thereafter, the new toy had a catchy name. The bear was named "Teddy" after American President Theodore Roosevelt. Provided with the well-known brand name "Knopf im Ohr" ("button in ear"), it soon became a huge international success. At the 1904 World's Fair in St. Louis, Steiff was awarded the "Grand Prize" for her life's work. She died unexpectedly on May 9, 1909, from pneumonia.

—Anneliese Mayer

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STEREOTYPING

See Stigma

STERILIZATION

The earliest use of sterilization in North America likely occurred in institutions for "feebleminded" people around 1890. The procedure used was *castration,* a term that institutional authorities applied to both sexes. (Besides hysterectomy, female castration included salpingectomy, the removal of the fallopian tubes, and ooephorectomy, the removal of the ovaries.) In 1892, Isaac Kerlin, superintendent of the Pennsylvania Training School for Feeble-Minded Youth, argued for “asexualization” before his colleagues at the annual meeting of the Association of American Institutions for Idiotic and Feeble-Minded Persons. Kerlin told his fellow superintendents that castration controlled “epileptic tendency” and aided in the “removal of inordinate desires which [are] . . . an offense to the community.” He noted that he had allowed the sterilization of one inmate at the Pennsylvania Training School. That case involved the removal of the “procreative organs” of a young woman. When Kerlin referred to “inordinate desires,” he alluded to a problem that he and other superintendents faced in their institutions—inmates who publicly masturbated. Especially troublesome during Sunday visits from church groups or during the visits of relatives, inmates who masturbated were an ongoing embarrassment for the superintendents.

Two years later in March 1894, F. Hoyt Pilcher, the superintendent of the Kansas State Asylum for Idiotic and Imbecile Youth, began castrating older boys and men who masturbated. By 1895, he had castrated 11 inmates. Around 1895, he expanded the castrations to women. His practice drew the attention of several regional medical journals and local papers. Eventually, the publicity became a state scandal, with officials expressing both support and opposition for Pilcher’s surgeries. Nevertheless, he continued his practice, and by 1897, he had castrated 47 additional inmates, 14 women and 33 men.

What began as a curiosity in the 1890s would become, after 1900, an increasingly discussed practice among superintendents of institutions for the so-called feebleminded. By the end of the first decade of the new century, superintendents of insane asylums, penitentiary officials, and social welfare authorities joined their colleagues in feeblemindedness to show their interest in sterilization. Two factors influenced this growing attention. First, eugenics, along with the newly discovered work of Gregor Mendel, opened institutional officials to new ways of linking heredity and mental disability, heredity and crime, and heredity and pauperism. Second, two new surgical procedures, the vasectomy and the tubal ligation, made sterilization a more socially acceptable practice.

In 1899, Harry C. Sharp, a physician at the Indiana State Reformatory, developed the vasectomy. The surgery achieved male sexual sterility without castration. In 1902, he published a paper on the new procedure. In it, he made an explicit connection between sterilization and heredity. Although the first tubal ligation was performed around 1880, the procedure became an involuntary means of sterilization after 1900 in institutions that housed “feebleminded” women. By the first decade of the new century, then, new views about heredity, as well as new and less invasive procedures, would allow institutional officials to expand sterilization from behavioral control to the control of heredity. These same officials would appropriate the term *eugenics,* first coined by Francis Galton, to identify and justify their new interest in hereditary control.

With the support of the State Board of Charities, in 1907, Indiana became the first state to pass a sterilization statute. Focusing on habitual criminals and rapists, the legislation also allowed for the involuntary sterilization of the state’s institutionalized insane, epileptic, and “feebleminded” populations. By 1917, in the name of eugenics, 11 more states had authorized the use of sterilization. After World War I, 15 additional states passed sterilization legislation. In most states, institutional superintendents (at least behind the scenes) led support for the legislation, and usually they did so in the name of eugenics. Joining these institutional officials were academics such as sociologist E. A. Ross and biologist Michael F. Guyer, who advocated for sterilization before the Wisconsin legislature; businessmen such as New Jersey real estate executive Bleeker Van Wagenen and Michigan’s John H. Kellogg of the cereal fortune; and religious leaders such as Ohio’s Washington Gladden, Harry Emerson Fosdick in New York, and Louis Poteat in North Carolina.

Not all of the institutional superintendents supported involuntary sterilization, and some would change their support over the years. Opposition also came from state and national figures. By 1921, of the 15 state statutes, only 10 were still law. The New York Supreme Court declared its sterilization laws unconstitutional in 1918. After that, statutes in New Jersey, Nevada, Michigan, and Indiana were thrown out by their respective state courts. In 1911, the governor of Indiana, where the first law had been signed, declined to release state funds to any institution that performed involuntary sterilizations. In Oregon, Vermont, Nebraska, and Idaho, governors vetoed sterilization legislation.

Although it lost much of its steam by the 1940s, involuntary sterilization continued to find pockets of state-sanctioned support. In New Jersey, North Carolina, and California, state-sanctioned sterilization mechanisms continued even into the 1960s and 1970s. Since the 1970s, various federal and state court rulings along with regulations from the executive branches of the federal and various state governments have reduced, if not eliminated, involuntary sterilization.

—James W. Trent

See also Eugenics; Racial Hygiene (*Rassenhygiene*); Reproductive Rights.

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STEVENSON, ROBERT LOUIS (1850–1894)

Scottish writer

The Scottish-born writer Robert Louis Stevenson suffered from severe lung problems, possibly including tuberculosis, in addition to other chronic ailments. His major works include *Treasure Island* (1883), *Kidnapped* (1886), "The Strange Case of Dr. Jekyll and Mr. Hyde" (1886), and *A Child's Garden of Verses* (1885). Advised to go abroad for relief from his lung problems, Stevenson wrote about his travels in *An Inland Voyage* (1878) and T*ravels with a Donkey in the Cevennes* (1879), both about France; *The Silverado Squatters* (1883), about California; and *In the South Seas* (1896). He found better health during the last five years of his life in Samoa—the backdrop for his late fiction and political writings. Much of his work is concerned with physiological trauma and with spiritual, emotional, or physical compensations. Dr. Jekyll's quest to transcend human limitations through an elixir that produces instead the deformed, malignant Mr. Hyde is the best-known instance, but debilitated, neurasthenic, and melancholic characters proliferate in his work, as do fantasies of unrestrained adventure and magical power. He died of a cerebral hemorrhage.

—John Kucich

See also Novel, The.

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STIGMA

The ancient Greek term *stigma* referred to tattoos or other bodily marks, but in modern times, stigma has come to refer to any signs that expose something unusual or bad about a person. According to Erving Goffman (1963), there are three main types of stigma. These include abominations of the body (physical deformities), blemishes of individual character, and tribal stigma of race, nation, and religion. The bodily signs differentiate a person from what society considers normal. This deviation from societal norms is classified as deviant, and those who fall into this category often face discrimination from other members of society. Attitudes toward individuals with tribal stigmata depend on the ways the tribe or group is viewed.

Although the term *stigma* is still used today, it now refers more to the disgrace itself than to the mark, bodily or otherwise, that reveals it. Today, stigma refers to any persistent quality of an individual or group that evokes negative or punitive responses from others. Individuals are said to be stigmatized when they are singled out from the population for ridicule or maltreatment due to differences in physical, mental, behavioral, or other attributes. When they encounter prejudice or discrimination due to their perceived limitations, persons with disabilities fit this definition of stigma. They are the recipients of unwanted and unfavorable identities. At one time, the problems faced by persons with disabilities were attributed to their impairments and/or medical conditions alone. Recently, however, attitudinal and environmental factors are coming to be seen as important in the definition of disability. Many today believe that it is societal restrictions and social responses rather than functional limitations or personal impairments that constitute the greatest problems faced by individuals with disabilities. This perspective is a core belief of the social model of disability and places the process of stigmatization front and center in the lives of persons with disabilities.

THE ORIGINS OF STIGMA

The process of stigmatization excludes certain individuals from particular types of social interactions due to characteristics they possess or due to their membership in a certain group. Stigmatization occurs when members of a society reject members of a group due to a particular characteristic shared by group members, such as the color of their skin, their inability to see, their age, or some other quality. Persons with disabilities may be stigmatized in social interactions if they do not meet the normative expectations of others. This has often been the case when individuals with disabilities are stigmatized by society. Goffman's (1963) theory of stigma is that it occurs when a mark becomes linked to an attitude that negatively views the bearer of the mark. The negative attitude associated with the mark may at first be associated with one activity or type of social interaction and later be generalized to other areas of life and society. Similarly, once members of a group are marked for exclusion from one activity or type of interaction, they may be excluded or ignored in others as well. Not only may stigma generalize outwardly to apply to multiple social contexts, but it may also generalize inwardly to the individual's own self-concept. For this reason, stigmatized individuals may come to possess negative perceptions of themselves as well as the quality or characteristic that signifies a social identity that is devalued in one or more social contexts. For people with disabilities, the quality or characteristic that leads to stigma may be a physical disability (e.g., paralysis, quadriplegia, etc.), a sensory disability (e.g., blindness, deafness), an emotional disability (e.g., schizophrenia, bulimia), or an intellectual disability.

Why do people participate in stigmatizing others? Three functions have been suggested. People may stigmatize others to (1) enhance their self-esteem, (2) enhance their social identity, or (3) justify a social, political, or economic structure. From an evolutionary perspective, stigma may serve any of several functions for those who are not stigmatized:

Dyadic Cooperation. Stigma may be an adaptation designed to lead an individual to avoid interactions with others who are viewed as poor partners for social exchange, who pose greater costs than potential benefits in social exchange, or who fail to meet any other criteria for being potentially valuable social partners. Individuals with disabilities may be seen as being unable to fully contribute to social roles (e.g., job, family duties, and social relationships) and to require high levels of care. Their strengths and abilities go unrecognized.

Coalitional Exploitation. This refers to adaptations designed to cause the exclusion of individuals from enjoying benefits widely available to members of society and to exploit these excluded individuals. Nondisabled individuals may dissociate themselves from persons with disabilities to prevent them from using scarce resources and exclude them from certain groups (e.g., the educated, the employed, and homeowners) and take advantage of them. For example, the public transit system may require a person who uses a wheelchair to get up at 5:30 a.m. to schedule a ride with the public paratransit service for that day. A sheltered workshop may pay people with intellectual disabilities a dollar an hour to assemble lamps at a time when the customary wage in society is $8 an hour for the same work.

Parasitic Avoidance. This may arise from the belief that persons with disabilities are likely to carry communicable pathogens. These adaptations are designed to prevent contact with individuals who may transmit their condition to others. The belief that persons with disabilities have defective genes and are undesirable sexual partners may also result in parasitic avoidance. Since only some disabilities involve a genetic predisposition and/or can be socially transmitted, the factual basis for this kind of adaptation is quite limited. In sum, this evolutionary approach offers these adaptations as perhaps a partial explanation for why members of groups can agree on who should be stigmatized and why the stigmatization of persons with disabilities is present in most, if not all, cultures.

DIMENSIONS OF STIGMA

The Experience of Stigma

Having a disability not only means limitations to one's physical or mental capabilities but also involves experiencing discrimination, vulnerability, and assaults on one's identity and self-esteem. Stigma is, thus, a form of oppression through social restrictions and disapproval. Many believe that these experiences are a result of the undesired differences that separate people with disabilities from the general population and give way to stigmatization.

Stigma and Expectations

Stigma causes discomfort and stress to persons with and without disabilities. It has been suggested that such tension may be a result of persons with and without disabilities not understanding each group's expectations of the other. Neither knows what the other expects. The tension created by misunderstood and unexpressed expectations may increase the tendency for persons without disabilities to ostracize those with disabilities and for those with disabilities to avoid contact with persons who do not have disabilities.

Cultural Values and Stigma

The expectations of Western culture concerning certain desirable characteristics of persons also may perpetuate the stigmatization of individuals with disabilities. Western culture places a great deal of value on independence, self-reliance, beauty, and health. Because they may differ from traditional expectations concerning these qualities, persons with disabilities may both be stigmatized and feel stigmatized.

Media and Stigma

Media in Western society tend to portray persons with ideal forms of the cultural values noted above, especially beauty, thereby heightening their relevance. Media also frequently present persons with disabilities in stereotypical ways. This is particularly true for persons with mental illness, who are often characterized as more dangerous or threatening to persons without disabilities than they are in fact. Such negative portrayals foster stigma and may justify poor treatment of persons with disabilities in the popular mind.

Stigma and Self-Perception

Stigma affects the self-perceptions of persons with disabilities. Not only does the stigmatization of individuals with disabilities affect the perceptions of others, but the stigma can also have a tremendous effect on the person with the disability as well. A stigmatized person may have some sense of normalcy and of being like other people and may be treated by most others in a manner consistent with such a perception. However, this individual may perceive quite correctly that whatever others profess, they do not really accept him or her and do not meet him or her on equal grounds. Therefore, despite some sense of normalcy, the person with a disability also may accept the premises and values that underlie a discredited social identity. Such a spoiled identity may increase the likelihood of internalized shame, withdrawal from others, and even social rejection and financial insecurity as the individual shies away from opportunities that might provide personal and substantive rewards. Spoiled identity may lead to loss of social status and a sense that one is discounted and discredited. Such internalized shame can focus a person on the label "disabled" as a central and primarily negative focus of the person's identity, engendering greater anxiety, shame, and withdrawal.

CONCEALABLE AND VISIBLE DISABILITIES

Even though there are many types and effects of disability, all disabilities are either concealable (e.g., bulimia) or visible (e.g., physical disability). People with concealable disabilities are often able to hide their disabilities at least temporarily in the attempt to avoid stigmatization. In fact, societal stigma is so substantial that even people with what are commonly considered visible disabilities, such as blindness, report passing as nondisabled, so as not to call attention to their limitations. However, people who conceal their disabilities are often in some important way not accepting themselves. Consequently, they appear to be more likely to demonstrate effects associated with negative self-perceptions such as depression, anxiety, or suicidality than individuals with visible disabilities who do not conceal them. Because their disabilities are concealable, and others with these disabilities are also concealing them, a state called pluralistic ignorance may exist. That is, individuals with concealable disabilities are less likely to be aware that others share their situation. They may even believe that there are few, if any, other people like them. They lack the benefits of similar others, such as meaningful group membership, successful social interactions, and moral support. Contact with similar others can buffer the negative effects of stigmatization on the mental well-being of culturally stigmatized persons.

Persons with concealable disabilities may find it difficult to find people who share their group membership. To do so, they are faced with a dilemma: either risk social rejection in hopes of finding social contact or shun social contact to avoid social rejection. Individuals will be most vulnerable to negative self-perceptions when they are unable to find similar others for support. Research has shown that, compared to participants with conspicuous stigma, individuals with concealable stigma felt worse about themselves and were more anxious and depressed. Only in the presence of similar others did these individuals improve in mood and self-esteem. Similar others may provide positive self-perceptions because they decrease individuals' sense of isolation and feelings of being different. Being with similar others may also result in more positive attitudes about the group. Despite these potential benefits, the fear of negative social evaluation may be more potent than the anticipated benefits of interaction with similar others.

According to a preoccupation view of secrecy, attempts at keeping a concealable disability secret activate a set of cognitive processes, which may lead to an obsessive preoccupation with the disability. The preoccupation results in renewed attempts to keep such thoughts suppressed. Eventually, intrusive thoughts and thought suppression occur cyclically. This cycle yields a continuous preoccupation with the individual's disability that can extend beyond the circumstances that prompted the initial secrecy. This obsessive preoccupation, combined with lack of support from similar others, can be of great harm to individuals with concealable disabilities. They may be overly distracted by the task of impression management and suffer in performance of cognitive tasks.

Individuals with disabilities that cannot be concealed are also subject to internalized negative evaluations and anticipated negative behavior of others. There have been numerous examples in which individuals who believed others were aware of their disabilities also believed that such awareness caused them to be less appreciated or to be judged in a negative manner. Persons with visible and concealable disabilities may have difficulties in social interaction. These may be partially due to how they believe others will react to their disability. Stigma consciousness (i.e., the extent to which individuals focus on their stereotyped/stigmatized status) may have important implications for how the individual experiences being stereotyped. People who are high in stigma consciousness are more negatively affected by the stigmatization of their disability. However, individuals with conspicuous or visible disabilities have an easier time identifying groups of similar others. Constructive connections with similar others often create positive self-perceptions among group members, which may decrease the extent to which stigma consciousness affects their reactions to stigma.

OTHER FACTORS AFFECTING THE DEGREE OF STIGMA

The degree of stigmatization also depends on other factors. These factors include the type of disability, the perceived responsibility of the individual for the disability, the perceived consequences of the disability for others, the outward manifestations of the disability, and the perceived impact of the disability on an individual's level of socially valued competence. Research also shows that the permanence of the disability affects others' perceptions and responses. Those with observable physical impairments have been found to suffer relatively fewer effects of stigmatization, whereas those with mental illness seem to be stigmatized to the greatest degree. Greater stigmatization of persons with mental illness may be due to perceived danger posed by the person to others and perceptions that a person with mental illness is responsible for his or her disability.

WAYS TO REDUCE/DISCREDIT STIGMA

Research offers three strategies to diminish the stigmatization of disabled individuals and groups: protest, education, and positive contact with stigmatized individuals. Protest may increase awareness of and decrease negative attitudes and beliefs about people with disabilities. However, to date, research suggests that it does not promote positive attitudes or increase knowledge about disabilities. Protest may also lead to short-term reactive effects; that is, it may make negative information about the disabled group more salient for a time. However, little research has been done on the effects of repeated protests on attitudes or beliefs. It is possible that reactive effects may be less likely to occur with repeated protests. To date, research has only examined the effects of protest on attitude change. It will be important to examine the effects of protest on behavior toward persons with disabilities.

Education facilitates greater understanding of persons with disabilities by providing accurate information. People who have a better understanding of a stigmatizing condition are less likely to endorse the stigma and discrimination. The type of information received may affect responses toward persons with disabilities. Participants in one study were either told about an individual's symptoms or his or her after-care plan. Those who received information regarding psychological symptoms increased their negative attitudes about the mental illness, while the after-care information reduced negative judgments. Greater knowledge of a disability prior to participating in an education program reduces stigmatizing attitudes after completing the program.

Personal contact with persons who have disabilities also decreases stigma. This decrease may be due to the positive effects of attitudes and beliefs about the common humanity and empowerment of persons with disabilities. Ultimately, greater social inclusion and changed societal attitudes may be the key to addressing the negative effects of all aspects of stigmatization.

The recent developments in the disability rights movement are creating stronger awareness of a positive disability culture. The development of disability culture identifies and affirms the strengths of people with disabilities, their high degree of life satisfaction, and their contributions to others with disabilities and to society at large. For people with disabilities, disability culture can be an effective antidote to stigma and its deleterious effects. For people without disabilities, it can provide important information about the impact of mainstream society, positive and negative, on people with disabilities. It can provide mainstream society with a more complete and ultimately positive perspective concerning people with disabilities. Thereby, disability culture may promote the development of mainstream cultural values that are inclusive of all people, as well as media reports that accurately reflect the challenges and celebrations of living with a disability.

—Robert I.Westerholm, Laura Radak,
Christopher B. Keys, and David B. Henry

See also Attitudes; Inclusion and Exclusion; Representations of Disability, Social; Stigma; Stigma, International.

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STIGMA, INTERNATIONAL

The stigma associated with disabilities can be seen in every culture regardless of religion or ethnicity. In some cultures, people with disabilities are viewed as unclean or dangerous. Individuals with disabilities may be seen as the cause of societal "pollution." People with disabilities may also be viewed as being in a transitional state between sickness and health. Some aspects of the stigma associated with disabilities are quite consistent cross-culturally. For example, mental illness is strongly stigmatized in most cultures, with exceptions including some Native American and Russian societies. Across many cultures, disabilities that manifest themselves in unpredictable or odd behavior are associated with greater stigma (e.g., schizophrenia, addictions) than are other disabilities that do not (e.g., polio).

Despite these similarities, the stigma associated with disability does differ across cultures. Because societal views of disabilities are socially constructed, stigma associated with disabilities varies among cultures in many respects. The lives of persons with disabilities around the world are usually far more limited by prevailing social, cultural, and economic constraints than by specific physical, sensory, psychological, or intellectual impairments. Cultures differ in their popular explanations for why some individuals and not others have disabilities and how persons with disabilities should be treated. Societies differ in what roles are appropriate and inappropriate for persons with disabilities and what rights and responsibilities individuals with disabilities are either entitled to or denied.

Besides differences in the content and rationale for stigma, there is also a difference in the degree to which stigmatization occurs in different countries and cultures. There are differences in which and how many disabilities are viewed negatively and therefore are stigmatized to a greater extent. Popular wisdom and mythology regarding the causes of disabilities vary across cultures and lead to different levels of stigmatization.

The treatment that persons with disabilities receive is based in part on cultural beliefs about how and why they became disabled. Explanations for disabilities may include factors as diverse as divine displeasure, witchcraft, evil spirits, reincarnation, negative parenting, tainted blood, and genetics. More positive mythologies also exist. For example, in northern Mexico and Botswana, the birth of a disabled child may be welcomed as evidence of God's trust in the ability of specific parents to care for a delicate child.

Variations in cultural values may also be, in part, responsible for differences in stigma across cultures. The valued and devalued attributes or qualities admired in a society play a role in influencing which disabilities are more heavily stigmatized. Typically, those with disabilities are socially and culturally devalued and therefore are discriminated against in many forms. For example, in a society where survival is based on the success of hunters and gatherers, physical stamina and strength are of particular importance. Individuals with physical disabilities who cannot contribute to these tasks are likely to be more stigmatized than they would be in a society that relies on a virtual economy in which one can earn a good living working in physically accessible offices and meeting rooms. Moreover, because views of disabilities are socially constructed, the degree to which a particular disability is stigmatized may depend on factors unrelated to the disability itself, such as gender or income. For example, in North American society, bladder control problems are associated with stigma more for men than for women. In some Pacific Island societies, a man's status is determined in part by his ability to speak well in public. Therefore, hearing loss or a speech impediment will be stigmatized more heavily than other disabilities.

Another source of cross-cultural differences in the perceptions of disability is the extent to which collectivism, rather than individualism, is a cultural value in a society. Disabilities are often more heavily stigmatized in collectivist societies than in individualistic societies. Collectivist societies view the individual as an extension of the family or community collective. In a collectivist society, an individual may choose an occupation because it is needed in the community. The individual's achievements and failures may be viewed as sources of pride or disgrace to his or her family more than is the case in more individualistic cultures. Persons with disabilities will be stigmatized based on the extent to which the disability limits their contribution to the collective and the extent to which a disability is a source of shame for the collective.

Collectivist societies emphasize conformity to a greater extent than do individualistic societies, where nonconformity may be valued. The strong emphasis on conformity in collectivist cultures results in stigmatization of those who deviate from the norm in any respect. Persons with disabilities may be unable, because of their disabilities, to conform and thus may be stigmatized more heavily in collectivist societies. Another reason those with disabilities are more apt to be stigmatized in collectivist societies is that those with disabilities are associated with the inability to fulfill contributory roles in society. If they are not able to fulfill their part and contribute meaningfully to society, they are stigmatized.

In 2000, it was estimated that approximately 80 percent of the world's persons with disabilities lived in Third World nations in Asia or Africa. In these countries, malnutrition and unsanitary conditions contribute to low birth weight and birth defects and thus children with disabilities. Disabilities in the adult population are often the result of wars, natural disasters, and traffic accidents as the development of safety regulations lags behind rapid modernization. Stigma can limit the claim of people with disabilities on the scarce resources available. Given the concentration of people with disabilities in Asia and Africa, we will focus our attention on these parts of the planet as we consider stigma of persons with disabilities internationally.

STIGMA AND DISABILITIES IN ASIA

Across the many cultures of Asia, nations tend to emphasize the well-being of the community over that of the individual. In countries as diverse as India and Japan, this collectivist emphasis is closely intertwined with concepts of harmony and duty, and these values strongly influence the lives of individuals and communities. In Asian societies, people with disabilities tend to feel less shame at being dependent on others than would be the case in individualist countries such as the United States. It is common practice for family members to take care of other family members with disabilities. China has more people with disabilities than any other country in the world. A cultural norm among the Han Chinese, the major ethnic group, is to experience significant instinctive embarrassment at having a disability or having persons with disabilities in their midst. This embarrassment may be associated with an array of behaviors related to stigmatization, including discrimination and abandoning or euthanizing newborns with disabilities. In Thailand, families sometimes feel so ashamed of relatives with disabilities that they do not submit the birth certificates of babies born with disabilities to the government. Thai parents may see the disability of a child as a direct consequence of some previous transgression of the parent. In India, persons with leprosy go to great efforts to hide signs of it from view. They seek to avoid the judgment that they have engaged in sexual transgressions for which they are being punished and to avoid the further sanction of being excluded from their community. The Hindu/Buddhist idea of karma as the inevitable consequence of individual actions, even across generations in a family, is deeply entwined with perceptions of disability.

Social embarrassment at disability may also result in excessive protection of persons with disabilities, instead of considering them as having equal rights. It is not unusual for parents of children with disabilities to be unwilling to allow their children to go out by themselves. This same strong tendency to shelter or protect those with disabilities can be seen in the Philippines. Such protection, often done with the best of intent, can have serious long-term consequences. It is likely to limit opportunities for full development, reducing opportunities for people with disabilities in education, employment, marriage, and participation in community life. As is the case with the treatment of persons with disabilities in China and the Philippines, this belief system of shame and embarrassment results in people adopting stigmatizing extremes: overprotectiveness or discrimination, sometimes simultaneously.

In Japanese society, the pattern of stigma has been similar and now is showing some signs of change. The term used to refer to people with disabilities is *shougaisha.* This term conveys perceptions of people with disabilities as people of "obstacles," "illness," and/or "loss." Similar to views in other parts of Asia, the Japanese believe that being sick or having a disability is the result of sin in the past or in a previous life. This belief results in feelings of shame for having someone with disability in one's family. Japanese individuals without disabilities tend to perceive those with disabilities as being like children. In Japan, the distinction between persons with and without disabilities is clearly drawn. An example is the existence of disabled-only bathrooms, which, unlike their counterparts in some other societies, have stigma associated with them. The Japanese tend to have clearer categories and expect others to adhere tightly to the categorization.

Insights into stigma in Japan may come from the concepts of uncertainty avoidance and *Kegare.* People high in uncertainty avoidance perceive people and ideas that deviate from societal norms to be dangerous. Cross-cultural studies suggest that Japan has one of the highest population levels of uncertainty avoidance of any country in the world. *Kegare* is a Japanese term that implies impurity/contamination and encompasses everything that is outside the blessings of the gods. *Kegare* is thought of as contagious in Japanese culture and is associated with individuals with disabilities. *Kegare* also has a kinship connection. The mother of a child with a disability would be considered to be linked to the child's perceived impurity. Historically, children with disabilities were often kept from public view and given fewer opportunities to develop their abilities.

Presently, there are efforts in Japan and nascent efforts elsewhere in Asia, such as China and Korea, to reduce the stigma associated with disability and its negative effects. Programs to reduce the prevalence of abuse of people with disabilities, to increase educational and employment opportunities, and to promote independent community living all can help reduce stigma and its sequelae. Advocacy groups are working to build greater awareness of the positive contributions of people with disabilities to Japanese society. Students planning to enter the human services have positive rather than stigmatizing attitudes toward people with disabilities. As other Asian economies strengthen over time, it is reasonable to anticipate reduced stigma associated with disability.

PEOPLE WITH DISABILITIES IN AFRICA

In many ways, African conditions for persons with disabilities are similar to those in Asia. In African nations such as Botswana, the family rather than the individual is the primary unit of society. Persons with disabilities are involved in families and communities. For this reason, Western concepts such as inclusion, integration, least restrictive environment, and normalization may have little meaning. However, recent studies have shown that the introduction of Western education systems, which encourage greater focus on the individual, has led to segregated classes for pupils with disabilities.

The languages of many African nations and cultures have no term for disability. For example, the language of the Songye culture in Zaire has three categories of "abnormal children": (1) ceremonial, (2) bad, and (3) faulty. The Songye tend to attribute the acquisition of disability to ancestral acts, insufficient payment by the wife's family of dowry upon marriage, sorcery, or God's punishments rather than to any sort of genetic/chromosomal cause. In a similar vein, the Maasai culture in Kenya views illness and disability as signs of cosmic disorder projected on the human body. The Maasai, however, do not make the direct link between physical limitation, on one hand, and stigma and resulting inferior treatment, on the other. Both the Songye and the Maasai include persons with disabilities into their subsistence-oriented community life.

In Uganda, the issue of insider-outsider status is crucial for an individual with a disability. Specifically, an individual with a disability who is part of the community will be integrated, whereas an outsider with a disability may be isolated and avoided by the rest of the community. Part of this outsider avoidance may be due to the perceived contagiousness of disability. Ugandans' initial concern is that the loss of function related to the disability will spread rather than how the persons with disabilities compensate for their impairment. The idea of spread posits that the loss of one function leads to a decrease of capacity in other physical functions. In contrast, the idea of compensation posits that the loss of one function is likely to lead to increased capacity of other functions. As is the case in other countries, the degree of stigmatization may differ by gender. Finally, similar to Asian societies and many others, the power differential between the genders has, in general, been found to lead to more stigmatization for disabled females than males.

In addition, as is true in Asia, African societies see the individual according to his or her ability to contribute to the well-being of the community. Although persons with disabilities may be viewed negatively because of religious or philosophical interpretations in both Asian and African cultures, they usually are included in family and community life, receiving care from family members. Recent years have challenged these traditional structures, however. The HIV/AIDS epidemic has taxed the resources of families and communities, created many more people with chronic illness and disability, and decimated the ranks of potential caregivers.

In sum, cultural, psychological, religious, and economic factors all affect the degree and form of stigma associated with disabilities across cultures. While progress is being made internationally to improve the status and reduce the stigma of people with disabilities, such improvements are subject to changing conditions and attitudes in every human society. If the past is prologue, then the future is likely to see progress that continues to be uncertain, uneven, and reversible.

—Robert I. Westerholm, Laura Radak,
Christopher B. Keys, and David B. Henry

See also Attitudes; Inclusion and Exclusion; Stigma.

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STRESS

Stress is defined as a reaction to external situational pressures, resulting in both physical and psychological changes in the individual. It is most often viewed as negative in the form of anxiety-producing and compromising physical and mental well-being. In some cases, however, stress is seen as positive (eustress)—perhaps pushing an individual toward extra effort or associated with positive changes in the life course, such as marriage. Stress related to disabilities can be examined in terms of physical characteristics (e.g., sight/hearing impairment) as well as mental or cognitive characteristics and impairment (e.g., learning disability/dementia). A concept closely tied to disabilities and stress is stigma, or the real or perceived ostracism, labeling, and “devaluation” of individuals and groups, often resulting in compromised social status, associated with having a disability. Stress associated with disabilities must be examined from social and interactional perspectives. A significant factor in reducing distress and important to the acquisition of legitimacy for people with disabilities is self-esteem—both at the individual and group levels—which allows people to believe they are included as members of society and, therefore, strive for the achievement of integration.

The impact of disabilities on the family has been a particular focus related to stress. Parents of children with developmental disabilities have been shown to have greater stress, depression, and health problems than parents of children without disabilities. Of interest, while children with disabilities can have a negative impact on parents' marriage, it has been reported that children with disabilities can also bring parents closer together and that a strong marital relationship is one of the most important factors mediating parental stress. Coping resources that have been shown to minimize familial stress related to disabilities include social support from friends and individual personality and beliefs (e.g., religious faith). Literature on the coping responses of adolescent siblings of children with disabilities indicates the need for professional support and the establishment of strong support networks to facilitate coping.

Research on disability and job stress indicates that people with work disabilities often experience increased risk for physical and psychological complications of job stress. Disability management programs implementing stress management interventions—targeting such disorders as back pain, multiple sclerosis, HIV, chronic fatigue syndrome, arthritis, high blood pressure, headache, and general psychological distress—have been shown to improve physical and mental health, reduce costs to employers, and facilitate the reintegration of injured individuals into the work environment. Interventions include use of cognitive behavioral stress management and a team approach, including physicians, nurses, psychologists, occupational therapists, social workers, and physical therapists.

Understanding and addressing quality of life, including stress, in people with disabilities requires modifications in social and societal attitudes and behaviors. In medical encounters, people with disabilities, while generally satisfied with their medical care, report lack of satisfaction with doctors' understanding of their conditions, thorough discussions of health problems, and being hurried during medical visits. The concept of the "disability paradox" looks at the inconsistency between general perceptions of the undesirable daily existence of people with disabilities compared to their own views of good or excellent quality of life. In examining and addressing stress in people with disabilities, quality of life needs to be understood in the context of the individual's balance between mind, body, and self and relationships with the social and environmental context.

—Michael L. Glasser and Karen E. Peters

See also Siblings of People with Disabilities.

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STROKE

Stroke is one of the most common causes of acquired disability in adults throughout the world. The World Health Organization estimates that 15 million individuals worldwide sustain a stroke each year, with 5 million deaths. Of the survivors, approximately 5 million are left with significant disability.

The existence of stroke as a distinct condition has been known since antiquity. Psalm 137 appears to describe the symptoms of stroke. "If I forget thee, O Jerusalem, let my right hand forget her cunning. If I do not remember thee, let my tongue cleave to the roof of my mouth." Ancient Greek physicians, including Hippocrates and Galen, recognized the essential symptoms of "apoplexy," though they debated the causes and location of the disease. Characterization of the anatomical basis of stroke syndromes, such as Broca's aphasia, occurred during the nineteenth century. A clear understanding of the mechanisms and major risk factors for stroke occurred during the twentieth century.

Because of its prevalence and ability to cause substantial disability, stroke has affected numerous world figures and altered the course of history. A prominent example from the twentieth century is the severely disabling stroke sustained by Woodrow Wilson during his second term as U.S. president. This stroke prevented him from exercising his duties as chief executive. The extent of his disability was hidden from the public and even from most of his cabinet; a small inner circle, including his wife and personal physician, controlled all access to the president during the remainder of his term. Subsequent recognition of the inadequate provisions in the U.S. Constitution for the disability of the president ultimately contributed to the adoption of the 25th Amendment in 1967. Other contemporary examples of the impact of stroke on world history include Franklin Roosevelt's death while in office from a cerebral hemorrhage in 1944 and Joseph Stalin's death from a stroke in 1953.

Strokes are broadly divided into two categories based on the cause of damage to the brain. Approximately 88 percent of strokes are ischemic and result from the loss of the supply of blood to an area of the brain that occurs when a blood vessel becomes blocked. The remaining 12 percent of strokes result from bleeding either within the brain (hemorrhagic stroke) or adjacent to the brain from the blood vessels that supply it (subarachnoid hemorrhage). The destruction of brain tissue that results from these various etiologies results in neurologic deficits that are the hallmark of stroke.

Risk factors for ischemic stroke are well established, and many are amenable to behavioral or medical preventive measures. Age and race are important nonmodifiable risk factors, with men having a higher risk than women (approximately 1.25 times the risk) and African Americans having a higher risk than Caucasian Americans (nearly twice the risk). Hypertension, smoking, inactivity, and obesity are all important modifiable risk factors that may be addressed in part through behavioral changes and in part through medical treatments. Behavioral modifications include smoking cessation, regular exercise, limiting caloric intake, and reducing intake of saturated fats. Preventative medical treatments include the use of platelet-inhibiting medications such as aspirin and clopidogrel; in selected circumstances (such as atrial fibrillation), anticoagulants (primarily warfarin) are indicated. In individuals with a severely narrowed carotid artery (one of the major blood vessels supplying the brain), surgery to remove the blockage within the artery can reduce the risk of stroke significantly.

Stroke can cause disability by affecting one or more of a multitude of neurologic functions. Loss of muscle strength and coordination (hemiplegia) is the most common cause of physical disability after stroke. Aphasia (loss of the ability to comprehend and/or produce speech or other linguistic communication) is another major cause of disability. Cognitive impairments, including reduced attentiveness, memory loss, and loss of insight, are frequent sequelae of stroke and contribute to the burden of disability. Swallowing difficulties (dysphagia) can cause malnutrition, dehydration, and predisposition to pneumonia. The location of a stroke is the major determining factor in the resulting neurological impairments; a small stroke in a critical area can cause more profound symptoms than a larger stroke in a less critical region. Some strokes are "silent" inasmuch as they do not result in any noticeable symptoms. Prior silent strokes are commonly discovered incidentally when brain imaging is performed for a new (symptomatic) stroke.

Improved acute treatment of stroke remains a priority area of medical research. As recently as the early 1990s, acute stroke care largely consisted of supportive measures to prevent medical complications, and no interventions were available to limit damage from an ongoing stroke. Intravenous medications (such as alteplase) are used to dissolve blood clots depriving brain tissue of blood flow and are now an important part of the management of acute stroke. Unfortunately, relatively few individuals with stroke are eligible for thrombolytic (clot-dissolving) treatments due to the narrow time window for their use (typically within three hours of symptom onset). The use of catheters threaded through the blood vessels to instill these medications directly to the vicinity of the blood clot is under study, as are other interventional approaches to opening blocked arteries. A variety of medications have been studied as potential neuroprotectants to reduce the damage induced by a stroke, but none has yet reached routine clinical use.

Due to the limitations in stroke prevention and acute treatment, residual disability is a common result of stroke. Stroke rehabilitation has its roots in antiquity, and references to the use of a crutch after stroke are found in Babylonian texts from the second millennium BCE. Modern rehabilitation has increasingly emphasized the use of active participation by the stroke survivor to achieve maximal recovery, rather than the use of passive treatments provided by medical providers. Stroke rehabilitation in developed countries typically includes physical, occupational, and speech therapy for a period of weeks to months. Efforts to reduce hospital or other institutional stays are ongoing, with increasing emphasis on rehabilitation in the home environment. Rehabilitation hospital stays after stroke now average two or three weeks in the United States; they remain longer in other countries, such as Japan.

Rehabilitation in less developed countries varies widely. Some rely more on family members and informal rehabilitation than on medically directed rehabilitation. Little data are available to compare functional outcomes between the various rehabilitation systems in different countries.

Recent research has found considerable plasticity in the adult human brain. Both changes in brain function, as demonstrated with the use of functional magnetic resonance imaging and other techniques, as well as changes in motor abilities have resulted from therapeutic exercise programs. This plasticity can be harnessed by structured exercise programs to improve motor outcomes after hemiplegic stroke. Intensive exercise programs appear to provide greater benefit than lower dose exercise programs and are being actively studied. Some centers are also exploring the use of technological aids such as robotic exercise devices to facilitate the delivery of exercise after stroke. The use of medications, growth factors, and stem cells to expand the capability of the brain to recover from stroke is being studied and is likely to be combined with rehabilitation programs in the future.

Plasticity clearly affects other impairments resulting from stroke, such as aphasia and cognitive deficits, and therapeutic interventions directed at these impairments appear to facilitate recovery. The optimal program of therapeutic interventions to stimulate brain plasticity and maximize functional recovery remains to be elucidated.

Functional outcome after stroke can be measured using a variety of tools, including the Functional Independence Measure, the Barthel Index, and others. Among ischemic stroke survivors in the United States who are at least 65 years old, 26 percent are institutionalized in a nursing home six months after a stroke. Depression is a common consequence of stroke, and as many as 40 percent of stroke survivors experience significant depression within the months following a stroke.

—*Joel Stein*

See also Aphasia; Dysphagia; Physical Medicine and Rehabilitation; Traumatic Brain Injury.

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SUB-SAHARAN AFRICA

See Experience of Disability: Sub-Sahara Africa

SUBSTANCE ABUSE

EPIDEMIOLOGY

Substance abuse is one major source of health problems afflicting individuals worldwide. It is estimated that one fourth of Americans experience a lifetime substance use disorder. Substance-related disorders are covered under the Americans with Disabilities Act of 1990. Therefore, problems derived from substance abuse can be viewed as disabilities.

Even excluding substance abuse as the primary disability diagnosis, persons with cognitive and physical disabilities are more likely to have a substance use disorder than the general population, yet they are less likely to obtain and complete treatment for it. Treatment barriers include not only those related to physical accessibility but also poor professional training to deal with the particular needs of individuals with concurrent substance abuse and disabilities.

It is estimated that 20 to 40 percent of persons in treatment for substance use disorders have some sort of mental or physical disability (mostly a comorbid psychiatric condition, followed by mobility, developmental handicaps, and sensory—vision and hearing—impairments). Often undetected, the presence of a disability, even subtle, may affect treatment effectiveness. A high prevalence of comorbid disability and substance use is also observed in other settings such as prison and court populations, where approximately 50 percent of offenders with an intellectual disability also have an alcohol problem.

ETIOLOGY

Substance abuse is often a factor in trauma-related physical injuries. Driving under the influence of alcohol contributes to traffic accidents and related disability. Despite the fact that legal blood alcohol concentrations (BACs) vary widely across countries, evidence shows increased risk of car crashes with BACs above 0.02 percent (that translates to approximately one bottle of beer, but factors such as sex and body weight may interfere with this estimate).

A relationship between unfavorable childhood conditions, early deviant behavior, and later alcohol abuse and related disability has been demonstrated. Drunken driving and criminal behavior in young males were related with more disability pensions and sick leaves on a 20-year follow-up. Thus, monitoring of such behaviors may help identify at-risk populations for disabilities. The relationship between substance abuse and disability seems more complex than just one of cause and consequence, with substance abuse working both as a risk factor and a maladjusted response augmenting disability after injury. For instance, substance abuse that develops after an injury can be a hindrance to rehabilitation.

Aside from physical disability, substance abuse is also implicated in psychological maladjustment, particularly among young people, demonstrated by increased rates of conduct and personality disorders (mainly those characterized by intense impulsiveness, such as antisocial and borderline). A number of psychiatric conditions are also overrepresented in substance-abusing populations, including affective, anxiety, and psychotic disorders. The risk of other addictive disorders is increased (polydrug abuse and eating disorders, particularly bulimia nervosa, for instance). Adding to the physical sequels of addiction, pathological gambling is another concern, with its associated impulsiveness (with greater likelihood of suicide attempts and criminal offenses), risk of bankruptcy, discredit, and deeper social disruption. Rates of attention deficit disorder are increased among substance-abusing individuals. Women are at higher risk for psychiatric comorbidity and to develop iatrogenic substance abuse/dependence as they are more likely to be prescribed medications such as benzodiazepines. Worries about body image also put them at risk of abusing amphetamines and other diet pills. Theories to explain these increased associations include (1) self-medication of a primary mental disorder, (2) substance abuse leading to the development of secondary psychopathology, (3) coexistence of substance abuse and psychiatric morbidity independently, and (4) a common etiologic factor leading to both substance abuse and psychiatric morbidity.

Substance abuse is also etiologically related to development of a disability during pregnancy. For instance, fetal alcohol syndrome (FAS) represents the third most common cause of mental retardation (the leading cause if genetic causes are excluded), with increasing risk in association with binge drinking. It produces long-term consequences, particularly social maladjustment and communication deficits. The full syndrome is present in about 30 percent of the offspring of women who consume 10 standard drinks daily. Fetal alcohol effects (FAE) are often underdetected. Symptoms may include central nervous system abnormalities, with mental retardation in about half the cases of full syndrome, facial dysmorphism (characterized by short palpebral fissures, epicanthic folds, and maxillary hypoplasia), and other birth defects (microencephaly, altered palmar creases, and heart abnormalities). Diagnosis after puberty is even more difficult, as the facial dysmorphism is usually not as pronounced. FAS and FAE are often associated with increased psychiatric comorbidity, substance use disorders, antisocial behavior, and multiple pregnancies in adolescence and adulthood. Early detection and appropriate referral may prevent further morbidity. Because safe levels of alcohol consumption during pregnancy are not defined, it is best to recommend complete abstinence to prevent FAS and FAE.

Tobacco use during pregnancy is also associated with perinatal problems (e.g., fetal growth retardation, obstetric complications, premature delivery, low birth weight and height, neonatal mortality, sudden infant death syndrome, and hypertension), with some long-term physical and behavioral consequences to the offspring (such as reduced lung function, substance abuse, criminality, and antisocial behavior), independent of other factors. Both alcohol and tobacco (by far the substances that cause the most problems if consumed during pregnancy) have addictive effects in combination with other substances. Besides the effects of substances themselves, the lifestyle often associated with substance abuse, including poor nutrition, lack of resources, and appropriate medical care, further contributes to these long-lasting disabilities in offspring.

Environmental circumstances faced by persons with disabilities may contribute to substance use and abuse, such as job problems and unemployment, lack of leisure opportunities, social isolation, poverty, homelessness, and various forms of abuse (emotional, physical, and sexual, both from domestic and external sources).

To improve detection of coexisting disabilities among persons entering treatment for substance use disorders, it is strongly recommended that every person should be specifically screened for disabilities, not only those obviously affected. More important than diagnosing a potential disability—a task that most professionals in addiction treatment centers are not prepared for—the levels of functionality need to be assessed since adjustments in the treatment protocol will be based on these aspects. This is important because even people with similar disabilities may have very different abilities and limitations. Assessment should be tailored to the nature of the disability (e.g., finding alternatives to self-report questionnaires for the mentally handicapped or to visual-analogical scales for the vision impaired).

In addition, the assessment team needs to be sensitive to the fact that some people have more difficulties accepting an eventual disability than others (depending on issues such as severity, age, marital status, income, and sociability). Likewise, a confidential climate needs to be ensured (particularly important when the disability implies that family members and friends will accompany the client) to enable the collection of relevant and accurate information. Clients should be referred for additional assessment by a qualified professional if initial screening indicates that a disability diagnosis might be present. Screening can be part of the usual assessment process for potential clients and can incorporate indirect questioning (such as questions about environmental factors that may be related to disabilities; prior medical history, including medications and hospitalizations; and accidents) and direct questioning (such as questions about history of any disability or health benefits and learning, hearing, reading, communicating, writing, decision-making, or mobility difficulties). Besides work absences, effort to function should be considered. Recently, the 36-item short form health survey of psychosocial functioning has been proposed as a tool for screening and measuring disability due to psychiatric conditions.

Attitudes toward persons with coexisting disabilities in addiction treatment should emphasize accommodation of any special needs and requirements.

In addition to avoiding rigid rules and deadlines that may make treatment participation virtually impossible, professionals must attempt not to enable clients' negative attitudes (such as accepting a client's refusal to attend mutual-help meetings for fear of not being accepted by peers) that could erode treatment efforts. Arranging for alternative groups and schedules is a more desirable option. Many clients with coexisting disabilities may be under a medication regimen. Some addiction treatment programs demand that potential clients discontinue any medications before entering treatment, which is obviously not feasible in many circumstances.

Finally, getting acquainted and networking with disability-related resources in the community, by ensuring referral to properly equipped services, may save time and effort that can be best directed to treatment itself.

—Monica L. Zilberman and Hermano Tavares

See also Fetal Alcohol Syndrome.

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SUBSTITUTE DECISION MAKING

Substitute decision making occurs when a person lacks mental competence to make a decision, and the situation requires that a decision be made. Substitute decision making ordinarily becomes controversial when the decisions concern very serious financial or health matters. The controversies tend to center on two main issues. The first issue is the choice of who should be the substitute decision maker. The second issue is concerned with how the decision should be made.

DECISION MAKERS

There are numerous ways that a person can be chosen to be a substitute decision maker, and the legalities of the process vary across jurisdictions. Generally speaking, there are three types of decision makers: a decision maker appointed by the incapacitated person prior to incompetence, a decision maker appointed by the state, and a decision maker in an emergency.

A Decision Maker Appointed by the Incapacitated Person

Many jurisdictions allow individuals to appoint someone to take care of their property and health matters in the event that they become unable to make decisions for themselves. For example, in parts of the United States, Britain, Australia, New Zealand, and Canada, it is possible to create an *enduring* or *durable power of attorney,* which grants a substitute decision maker the power to act on behalf of a person who has become mentally incompetent. These powers of attorney are described as "durable" because, unlike ordinary powers of attorney, they continue to be effective after the grantor of the power has become incompetent.

In addition to choosing a decision maker, powers of attorney will normally define the role of the decision maker and contain instructions on the types of decisions that can be made and the preferences of the person subject to the power. It should be noted that these documents are different from advance directives or living wills because they allow the substitute decision maker to make the ultimate choice. In an advance directive, the patient is the decision maker.

One limitation exists with this method of choosing a substitute decision maker. These documents cannot be created by a person who has always lacked mental competence.

A Decision Maker Appointed by the State

The state has a role in protecting people who are unable to make decisions for themselves. In the common-law tradition, this is evidenced by the *parens patriae* jurisdiction, an eleventh-century English concept, which granted to the sovereign the power and responsibility to care for infants, "lunatics," and "natural fools and idiots." The parens patriae jurisdiction has survived into modern times and is still relied on by courts in Australia, Canada, New Zealand, and the United States as the source of power to make substitute decisions for mentally incompetent adults and children. It is also used to appoint other decision makers. Strangely, England no longer has a parens patriae jurisdiction over adults because of an administrative error in 1969, which removed it from the list of prerogative powers enjoyed by the sovereign.

Most jurisdictions provide for state-based appointment of substitute decision makers, ordinarily when the person has not exercised a choice via a power of attorney, either using the parens patriae power or legislative powers. Most commonly, state-appointed substitute decision makers are referred to as *guardians,* but the terms *conservator, custodian,* and *curator* are also employed in parts of the United States. Courts or specialist guardianship tribunals are ordinarily given the task of appointing guardians. Ordinarily, a relative or close friend is chosen because they are best equipped to look after the person under guardianship.

If no suitable candidate is available to be appointed as a guardian, a public body or official (such as a court, guardianship tribunal, adult guardian, or public guardian) may be appointed in the role.

A Decision Maker in an Emergency

It may be necessary in an emergency for someone to make a substitute decision for another because that other person is mentally incapable and has never appointed a substitute decision maker. The most common example of this occurs in medical emergencies, when a person is unconscious or seriously injured and unable to make a decision about treatment.

In parts of the United States, it has been assumed that relatives automatically have the power to consent in such situations, and in emergencies, doctors will ordinarily seek the consent of a relative unless the situation demands immediate treatment. In countries in the British Commonwealth (such as Australia, Canada, New Zealand, United Kingdom), relatives only have power to consent to treatment when the patient is a child. Relatives cannot consent to emergency treatment for incompetent adults. This gap in consent has led some legislatures to grant powers to relatives so that they can consent to emergency medical treatment, without the need for a power of attorney or an order by the courts. For example, in the Australian states of New South Wales, South Australia, Tasmania, Victoria, Queensland, and in the Australian Capital Territory, legislation allows relatives to consent to treatment when the patient is not competent. If no relative is available, a doctor may continue to treat the patient according to the patient's best interests. There are moves to adopt such laws in England and Wales.

What if a person's relatives cannot be contacted? In such emergencies, the common law empowers health professionals to treat an incompetent person, even in situations when the treatment is quite invasive. Such situations are seen as an exception to the general rule against touching another person without his or her consent. Health professionals can raise the defense of emergency (sometimes called the defense of necessity) to any claims of battery or wrongful interference. To properly mount such a defense, the health professional must be able to show that the patient was incompetent, that there was no substitute decision maker to seek consent from, and that the treatment was a necessary and proportionate response to the illness or injury of the patient.

Some jurisdictions (e.g., parts of Australia, Scotland, and the United States) have enshrined these rights of emergency medical treatment in legislation.

HOW SHOULD DECISIONS BE MADE?

Generally speaking, two approaches can be employed in substitute decision making.

The Best-Interests Approach

The best-interests approach requires the decision maker to choose the course of action that can be considered on objective grounds to best serve the interests of the incompetent person.

For example, in the United Kingdom case of *Airedale NHS Trust v. Bland* (1993), the House of Lords had to decide whether it was in the best interests of a young man in a permanent vegetative state to continue to be treated with artificial feeding and hydration. The House examined the issues of the probability of success of treatment, the likelihood of recovery, and issues concerning the man's lack of quality of life. The House took evidence from doctors and other health professionals to assess these factors and decided that it was no longer in best interests to receive such treatment.

The best-interests test is the standard of substitute decision making most commonly employed in the United Kingdom, Australia, New Zealand, and Canada. It is also employed in some states in the United States.

The problem with the best-interests approach is that it can be vague, and best-interests assessment can often be disputed. It is difficult to pinpoint exactly what objective factors should be considered in different types of decision, and the approach says nothing about how those factors should be weighed against each other. There is also the possibility that the decision maker's own prejudices will be disguised as "objective assessment." The best-interests test also runs the risk of reducing the autonomy of the incompetent person because of its focus on objective factors rather than the subjective desires of the incompetent person.

Substituted Judgment

The substituted judgment approach requires the decision maker to take into account the subjective beliefs, feelings, and desires of the incompetent person. A person exercising substituted judgment must choose the course of action that (according to the decision maker) would be the course of action chosen by the incompetent person.

The substituted judgment approach originated in English equity courts in their supervision of an incompetent person's property. It was primarily used to justify gifts from the estate of the "lunatic" to the lunatic's family or friends on the basis that such gifts would have been what the incompetent person would have wanted. In modern times, it is widely employed in the United States as the method of substitute decision making.

We can compare the best-interests approach used in *Bland* above with the substituted judgment approach used in a similar case, *Matter of Quinlan* (1976). In this case, the father of a severely disabled patient sought to be appointed her guardian, so that he could authorize the cessation of her respiratory support. The court appointed the father as guardian and said that he should exercise his best judgment as to whether the patient would have refused treatment in the circumstances that arose. Later, in *Superintendent of Belchertown State School v. Saikewicz* (1977), a case concerning a never-competent man with cancer, it was said that the substitute decision maker dons the mental mantle of the incompetent and substitutes herself or himself as nearly as possible for the individual in the decision-making process.

Several criticisms have been made of substituted judgment. The first is that it is a fiction to presume that another person knows what would have been decided by the mentally incompetent person. To counter this critique, some jurisdictions require clear and convincing evidence of what the incompetent person would have decided, such as statements made by the incompetent person or evidence of similar decisions made by the person previously. Others have said that this raises the standard so high that the evidence required is the same evidence that would be required to substantiate advance directives.

Problems also occur when the incompetent person never expressed an opinion or desire or never had the ability to express a desire or opinion. In Canada, the substituted judgment test has undergone judicial criticism for this reason. In *Re Eve* (1986), Justice La Forest denied that the test had any bearing on the issue of the sterilization of a mentally handicapped woman who had suffered from the disability since birth. Justice La Forest saw the substituted judgment test as "sophistry" and "speculation."

Combined Approaches

To counter the difficulties with both approaches, some jurisdictions (such as New Jersey) have adopted a combined approach, whereby substituted judgment is attempted first, and if it is not determinative, best-interest factors can be considered. Alternatively, an expanded best-interests test is employed in some jurisdictions, which contains elements of substituted judgment (see, e.g., cases from Minnesota and New Zealand).

—Cameron Stewart

See also Caregiving; Decision Making; Family; Social Support.

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New Zealand Ministry of Justice, http://www.courts.govt.nz/family/pppr.html

Public Guardianship Office, http://www.guardianship.gov.uk

SUGIYAMA, WA'ICHI (1610–1694)

Acupuncturist

Sugiyama Wa'ichi lost his sight in childhood. As a young man, he went to Edo (Tokyo) and studied acupuncture under the teacher Kengyō Yamase. However, "because he was too slow to learn he was expelled by his master." Later, Sugiyama overcame his difficulties, developed an innovative technique for guiding the insertion of needles, and eventually became a famous practitioner and official acupuncturist to the Shogun Tsunayoshi. Kengyō Sugiyama Wa'ichi founded his own school, wrote books on the field, and at the end of his life achieved the highest position in the powerful Guild of the Blind. He is credited with "establishing acupuncture as a common occupation for the blind" and organizing them into a cohesive group during the seventeenth century.

—Kumur B. Selim

See also Acupuncture; Complementary and Alternative Medicine.

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SUICIDE

The relationship between disability and suicide hinges simultaneously on scientific, political, and moral questions. The scientific question is whether disability represents a significant risk factor to suicide and why. The political question is whether people with disabilities who threaten suicide should receive the same response from health professionals as nondisabled people. The moral question involves the question of "quality of life" and whether disabilities make "life not worth living." Underlying all three of these questions is our cultural attitude toward self-sufficiency and interdependency.

THE SCIENTIFIC QUESTION

Very little data have been gathered with regard to suicide risk factors for people with disabilities, but there is no reason to assume that they differ from risk factors for nondisabled people. Warning signs for suicide for both groups can be found in (1) disruptive family history factors such as abuse or neglect in childhood, enmeshment, separation, loss, and suicide itself; (2) toxic personal history factors such as depression, schizophrenia, substance abuse, low self-esteem and frustration tolerance, demoralization/hopelessness, and rigid/constricted thinking; and (3) personal stressors such as relationship loss or abuse, loss or control over life, social isolation, and problems in work, housing and finances. People with disabilities may face social discrimination that heightens some of the above triggers for suicide.

For example, people with disabilities may face difficulties with the legal and medical system, difficulties of obtaining personal assistance, social devaluation, and threatened loss of independence. These factors may be especially overwhelming for people with newly acquired disabilities. Physically disabled people are no different in this regard from many people with mental disorders such as schizophrenia. The risk for suicide, for example, is much higher in the first few years after a diagnosis of schizophrenia and diminishes after that as schizophrenia turns into a more chronic condition, suggesting some adjustment to illness. However, individuals with schizophrenia are again at increased risk when psychotic symptoms such as auditory hallucinations return, suggesting that adjustment to illness and symptoms themselves may independently be suicide risk factors. People may adjust to physical disability in the same way.

There is concern and debate around the issue of physician-assisted suicide for patients with terminal illness and/or disabilities. Data suggest that disability is a risk factor in people seeking physician-assisted suicide and/or perhaps in being selected by medical personnel for this "treatment." However, the data also suggest that it may not be disability per se that leads people to seek suicide but psychological factors associated with suicide that would also push nondisabled people to attempt to end their lives.

For example, there is a case on record of a woman with cerebral palsy who expressed the wish for physician-assisted suicide after a series of severe losses, including a miscarriage and a marital separation that left her essentially homeless and impoverished. A videotape of another patient revealed a highly accomplished patient with the beginning of Alzheimer's who found that much of her activities and abilities were now discounted and belittled. For example, although she could still play tennis, she could no longer keep score on her own. Even though she could still play piano, she could no longer sight-read.

THE POLITICAL QUESTION

The political question stems directly from these examples. Are disabled people who threaten suicide treated the same or differently than nondisabled people who threaten suicide?

When a person comes to a health professional with suicidal desires, such desires are typically interpreted as the product of a temporarily self-destructive and tumultuous state of upheaval leading the person to be temporarily tunnel-visioned and to temporarily see suicide as the solution to problems. The person may be hospitalized, friends and family will be notified, and the suicidal wishes will be interpreted as profoundly irrational—indeed, a permanent solution to a temporary problem. The health professional will attempt to keep the person safe until the temporary madness has passed.

For example, a young woman may have just ended a destructive romantic relationship and feels that nothing in her life has any value. The woman's feelings are interpreted by the professional as only temporary. The professional may emphasize that when one is in a depression, he or she always views the future through a negative lens. Likewise, a man whose spouse has died may be devastated and, in his bereavement, may become highly suicidal. Similar examples can be found in many life crises, including loss of a job, infidelity of one's spouse, and death of a loved one. Before a person is able to gather social support networks and can cope sufficiently to envision a future after the loss, he or she may be very drawn to suicide as an alternative to the pain of living. The mental health professional will work to minimize the effects of the loss to prevent collateral damage. The therapist must emphasize to the patient that although he may have failed, he is not a failure. He will get another, perhaps a better, job. The therapist must play for time with the patient, until the person's coping mechanisms activate and he or she is able to reassert a drive for life. Consider these examples if the person is disabled.

Here the temptation is to see the person's suicidal desires as not irrational at all but rational, stemming from the disability, rather than from the actual psychosocial stressors underlying the suicidal wishes. The desire to die may not be interpreted as suicidal but as an attempt to free oneself from suffering. This may be especially true if the person depends on medical intervention to remain alive. A desire for suicide may be euphemized as "refusing treatment."

The person's suicidal desires may be interpreted as rational, rather than irrational, even though the triggering factors are the same as for a nondisabled person. This fixation on disability represents what the disability community labels a "deadly compassion," which may emerge because of one's own fear of becoming disabled. The professional in such a situation may not try very hard to prevent the person's suicide and, if not actively assisting him or her in it, may well give implicit approval that the suicide is quite understandable. Indeed, in the physician-assisted suicide case discussed above, the husband of the patient suffering from the beginning of Alzheimer's opined that he would take his own life if such a calamity befell him. Such a double-tiered approach to suicidal wishes is profoundly troubling to the disability community. Suicidal wishes in a nondisabled person will be labeled as irrational and evoke suicide prevention responses on the part of health professionals. The same wishes on the part of a disabled person might be labeled as rational and evoke silence or even calls to assist the person to carry out his or her suicidal wishes.

THE MORAL QUESTION

The moral question is whether life is of unconditional worth or whether it is only worthwhile if it has a certain "quality." This debate goes back to biblical Israel and Greece of classical antiquity. The Greek and Roman stoics advocated suicide if life no longer conformed to a person's expectations or desires. Disability, as well as simply boredom, could well represent a rational reason for suicide. Suicides were abundant in ancient Greece and Rome, and Greek tragedy is filled with such instances. The Judeo-Christian biblical world, in contrast, does not view suicide as rational and indeed equates it with homicide. Strikingly, no such concept as "quality of life" exists in biblical thought. Life is not seen as divisible but as having an intrinsic and infinite worth. Suicides are rare in the Bible and not associated with disability. There are data also to show that people living in countries where religion imposes strict taboos against suicide have lower rates, but again, these data have not been separated for disabled people only.

One major concern to address when considering the suicide-disability relationship is how society views dependency and independence. There are cultures that highly value or arguably overvalue independence, and in such societies, a disabled person may feel unvalued and even a burden, making suicide a natural action to consider. Other societies highly value connectedness on interdependency within the context of extended family or cultural group. In such societies, being dependent might not have the same pejorative connotation and therefore not as likely to lead to suicidal thoughts.

—Kalman J. Kaplan and
Martin Harrow

See also Infanticide; Physician-Assisted Suicide; Refusal of Life-Sustaining Treatment; Values.

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SULLIVAN, ANNE (1866–1936)

Special educator

Anne Sullivan was born in 1866 near Springfield, Massachusetts. At the age of 4, she became totally blind due to trachoma, an eye disease associated with poor sanitation. Her mother died when she was 10, and she and her younger brother were sent to the almshouse, at Tewksbury. Shortly after their arrival, her brother died from tuberculosis, but Annie lived there for another four years and then was sent as a charity student to the Perkins Institution for the Blind in Boston. Her sight was partially restored through a series of experimental surgeries, though her vision remained impaired, and eventually she became blind again at the end of her life.

In 1887, Sullivan was chosen to travel to Tuscumbia, Alabama, to serve as the teacher of a young deaf-blind girl named Helen Keller. Using methods develop by Perkins founder Samuel Gridley Howe, in his work with the deaf-blind girl, Laura Bridgman (1829–1889), she trained Keller to communicate with the manual alphabet for the Deaf. Sullivan's innovation was to simulate the way a hearing child learns to speak by being constantly surrounded by spoken language. She did not restrict her instruction to scheduled lessons but spelled constantly into Keller's hand. She remained Keller's companion for nearly 50 years, helping her to pursue her education and acting as her interpreter at lectures and as an editor of her numerous publications. In 1905, she married John Macy, Harvard professor and editor of Keller's first book, *The Story of My Life.* The couple separated a decade later, though they were never divorced.

Sullivan and Keller never felt that Sullivan's work as an educator received the recognition it deserved. She was alternately lauded as a miracle worker and critiqued as a self-promoting charlatan who exaggerated the accomplishments of her pupil. Both views reflect a general belief that Keller's accomplishments were exceptional, far in excess of what should be expected from a deaf-blind child.

—Georgina Kleege

See also Helen Keller; Special Education.

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SUMMARY MEASURES OF POPULATION HEALTH

The generic label *summary measures of population health* (SMPH) refers to a class of statistics that describe and quantify different elements of population health. The relatively large number of SMPHs is attributable to the variety of uses for SMPHs and the fact that each use might, in principle, require a somewhat different SMPH. The resulting set of SMPHs reflects the various and evolving approaches to measurement that have been used over time by different researchers and health-related organizations.

Table 1 Purposes of SMPHs

1. Intrinsic interest: Indicating how long and in what state of health different individuals are likely to live
2. Cross-national comparisons and benchmarking
3. System planning: Indicating the likely future health profile population for social and economic planning
4. Planning time: Time-series data to monitor health and plan health services and health workforce
5. "Micro" planning: Disease-specific population measures
6. Comparison of subpopulations within a country
7. Measuring the *burden* of different diseases in health sector planning
8. Measuring health benefits from medical or other interventions
9. Epidemiological and health services research
10. Prioritizing medical research

Table 1 lists 10 possible uses for SMPHs. Broadly, these include the intrinsic interest, benchmarking, social and health sector planning, and the evaluation of performance at both national and program levels. The resulting SMPHs vary along a number of dimensions, some of which are summarized in Table 2. While some of the differences in SMPHs are attributable to different technical approaches to measurement, most differences in Table 2 arise because of differences in the concept being measured—for example, life versus the value of life and prevalence or incidence of a disease.

Different concepts, in turn, arise because of the different purposes for which they were created. For example, the measurement of the current burden of disease uses a prevalence-based metric, whereas measuring the total impact of new health policies often uses an incidence-based concept. These decisions tend to be pragmatic and arbitrary, depending on ease of access to appropriate data.

Depending on the purpose, the construction of an SMPH can involve up to seven stages:

1. defining the objectives of the measure;
2. defining the populations to be described, such as a whole country or a randomized controlled trial study group;
3. defining the time span of the measure, such as a human lifetime or a five-year period;
4. defining the range of health states and illnesses to be included in the measurement process;
5. measuring the numbers of people in the different health states and illness in the population;
6. estimating the severity of the health states of the people in the population by a process of valuation;
7. defining the health target or goal to be achieved in the population.

HEALTH EXPECTANCIES AND HEALTH GAPS

The most basic distinction in Table 2 is between the measurement of health expectancy and health gaps, and this is used to classify the SMPHs in Table 3, which summarizes the different measures. Health expectancies are based on the actual health experience of a population. Health gaps estimate the difference between actual health and some theoretical norm or goal of population health.

Health Expectancies. Health expectancies (HEs) estimate the expectation of years of life lived in various health states, expressed as average survivorship from fixed ages (e.g., life expectancy from birth). This includes expectations for specific health states (e.g., disability-free life expectancy) and for value equivalents of different health states (e.g., disability-adjusted life expectancy).

Table 2 Characteristics of SMPHs

Quantity Measured
Health expectancy versus gap
Lives versus life years
Incidence versus prevalence
Unadjusted data (mortality/1,000) versus adjusted data (life expectancy)
Life versus value of life
Technical issues
Cohort versus period measures
Mean versus median
Dichotomous versus continuous

Health-Adjusted Life Expectancies. Health-adjusted life expectancies (HALEs) are those HEs that estimate the expectation of equivalent years of good health, calculated for health states defined in terms of valuation of disability severity. HALEs give a weight of 1.00 to years of good health and weights between 0.00 and 1.00 to other states of less than good health. Healthy life expectancy is now used as a synonym for HALE, rather than its previous usage for a health state expectancy for perceived (self-reported) good health. Disability-adjusted life expectancy (DALE) is a synonym for HALE but uses a different valuation methodology. HEs are of two main classes: those that use dichotomous health state weights (including disability-free life, disabled, demented, or dead) and those that use health state valuations for an exhaustive set of health states (based on specific valuations of measured ICD disease prevalence and the measured distribution of different disability states within the diseased populations).

QALYs. Quality-adjusted life years (QALYs) are generally used for measuring the outcomes of health services or programs but could be interchanged with disability-adjusted life years (DALYs) as an SMPH. Years of full health are assigned an index (index) value of 1.00. Morbid years are weighted by an index of utility (strength of preference), as measured by the time trade-off, standard gamble, or rating scale techniques. DALYs are a form of QALY estimated with a particular methodology, which includes age weights and the use of the person trade-off technique of preference elicitation.

Health Gaps. Various health gaps have been defined that vary according to (1) the selected normative target used to measure the difference (health gap) from the current health conditions in a population, (2) the method used to value time spent in health states

Table 3 Table of Terms

Measure	*Date*	*Description*	*Reference*
Health Expectancy (HE)		Generic term for summary measures of population health, which estimate the expectation of years of life lived in various health states.	Chiang, C. L. 1965. *An Index of Health: Mathematical Models*. Vital and Health Statistics Series 2, No 5. Washington, DC: National Center for Health Statistics.
Life expectancy (proposed)	1964	A weighted average time to death from different ages (e.g., birth, 21, 50, 75): usually based on the current mortality rates extrapolated into the future.	Sanders, B. S. 1964. "Measuring Community Health Levels." *American Journal of Public Health* 54(7): 1063–1070.
Life expectancy (developed)	1972		Sullivan, D. F. 1971. "A Single Index of Mortality and Morbidity." *HSMHA Health Reports* 86(4): 347–354.
Quality-adjusted life expectancy (QALE)	1970	A form of health-adjusted life expectancy (HALE) that is based on a question on activity restriction in the Canada Health Survey.	Fanshel, S., and J. W. Bush. 1970. "A Health-Status Index and Its Application to Health Services Outcomes." *Operations Research* 18(6): 1021–1065.
Active life expectancy (ALE)	1983	A form of disability-free life expectancy (DFLE) based on survey questions on limitations in activities of daily living (ADL).	Katz, S., L. G. Branch, and M. H. Branson. 1983. "Active Life Expectancy." *New England Journal of Medicine* 309:1218–1224.
Disability-free life expectancy (DFLE)	1980s	A weighted average time to onset of disability from different ages.	Mathers, C. D. and J. M. Robine. 1993. "Health Expectancy Indicators: A Review of the Work of REVES to Date." In *Calculation of Health Expectancies, Harmonization, Consensus Achieved and Future Perspectives* (Proceedings of the 6th meeting of the International Network on Health Expectancy and the Disability Process REVES, October 1992, Montpellier), edited by J. M. Robine, C. D. Mathers, M. R. Bone, and I. Romieu. Paris: John Libbey Eurotext.
Health-adjusted life expectancy (HALE or DALE)	2000	A weighted average time to death from different ages, with the value of the time between onset of disability and death reduced by standard fractions for different diseases based on some community judgment of the impact of those disabilities.	World Health Organization (WHO). 2000. *The World Health Report 2000. Health Systems: Improving Performance*. Geneva, Switzerland: World Health Organization.

(Continued)

Table 3 (Continued)

Measure	*Date*	*Description*	*Reference*
Quality-adjusted life year (QALY)	1978	QALYs for full health and death are assigned scores of 1.00 and 0.00, respectively. Marked years are weighted generally by the standard gamble, time trade-off, or rating scale techniques by the strength of preference (utility) for the state. Various SMPHs are derived from the use of different techniques for conceptualizing and quantifying the numerical value of years of ill health.	Torrance, G. W. 1986. "Measurement of Health State Utilities for Economic Appraisal." *Journal of Health Economics* 5:1-30.
Health gaps (HG)		A generic term for summary measures of population health; estimates the gap between the current population health and a normative goal for population health.	
Years of life lost (YLL)	1947	The component of the DALY (q.v.) that measures the years lost through premature mortality, with morbid years weighted by the extent of the disability.	Dempsey, M. 1947. "Decline in Tuberculosis: The Death Rate Fails to Tell the Entire Story." *American Review of Tuberculosis* 56:157-164.
Disability-adjusted life years (DALYs)		The health gap attributable to a disease, with marked years weighted by a person trade-off (PTO)-based assessment of the severity. Conceptually similar to the QALY.	Murray, C. J. L. and A. D. Lopez. 1996. World Health *Organization Global Burden of Disease*. Geneva, Switzerland: WHO.
Years of healthy life (YHL)	1995	A form of DFLE (q.v.) based on two questions collected in the U.S. National Health Interview Survey, which are concerned with activity limitations and perceived general health.	Erickson, P., R. Wilson, and I. Shannon. 1995. *Years of Healthy Life*. CDC/NCHS, Healthy People, Statistical Notes No. 7. Hyattsville, MD: U.S. Department of Health and Human Services, National Center for Health Statistics.
Healthy life years (HeaLYs)	1998	A health gap (q.v.) measure calculated on the basis of the incidence of pathological processes and the future nonfatal health outcomes and mortality from those processes.	Hyder, A. A., G. Rotllant, and R. Morrow. 1998. "Measuring the Burden of Disease: Healthy Life-Years." *American Journal of Public Health* 88(2): 196-202.

less than ideal health, and (3) the inclusion of other social values, such as age weights, time preference, and equity weights.

The normative targets may be a fixed age (e.g., years of life lost to age 75), the expectancy of the healthiest known populations within countries, or a mathematical projection of the expected optimum life expectancy based on the mortality and morbidity experience of the whole world (e.g., the HALE of the World Health Organization's [WHO's] World Health Report 2000). Fixed-age health gaps are simple to calculate but place no value on life beyond the age threshold. Normative targets based on national or international comparisons are more complex to calculate but do not contain implicit age biases.

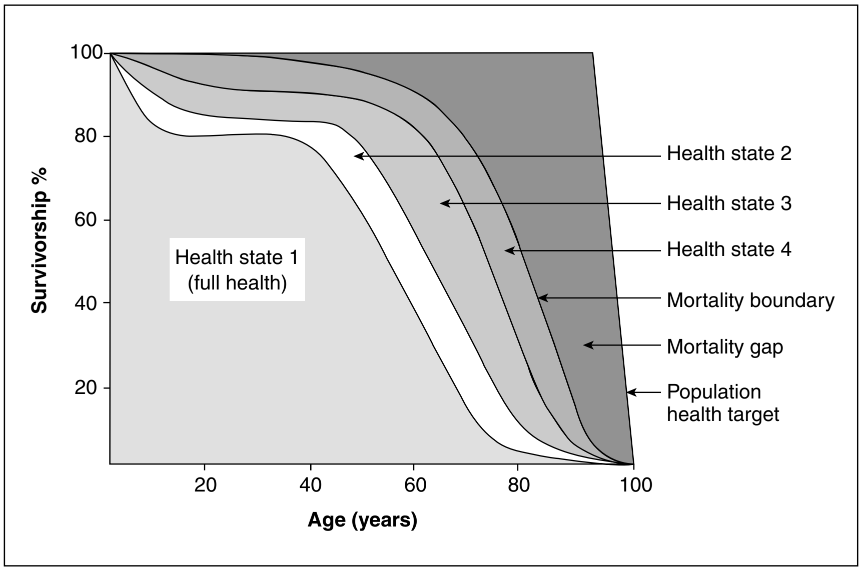

Figure 1 Survivorship Curves Used to Calculate Health Expectancies and Health Gaps

Health gap estimation is most useful when it identifies the constituent populations and causes of the loss of health and allows planning for the elimination of the gaps. The WHO Global Burden of Disease studies estimate the mortality and morbidity incidence and prevalence based on reported national mortality statistics and other estimates of disease prevalence. This approach assumes that all causes of loss of health are understood and can be identified by the disease classification systems. Its measurement is not always independent of the activity of health services.

Measurement of Health Expectancies and Health Gaps. Health expectancies are estimated for populations using routine mortality statistics, supplemented by measurement of morbidity rates using a variety of routine health service activity measures and health surveys. Period HEs are used to predict the future by assuming that the age-specific mortality and disease prevalence rates today will be the same as those that will be achieved by the corresponding age-specific cohorts in the future. These are constructed mathematically by applying the observed mortality and morbidity rates to a theoretical population existing only in a computer. Cohort HEs are the actual measure of the survival and health experience of a real age cohort observed over decades, but these can only be known in retrospect and so are not available for service planning.

Figure 1 schematically represents a limited number of survivorship curves constructed from the measured mortality and morbidity rates in a population. HALEs measure the area under the survivorship curve, taking into account different weighting for years lived in different health states. The position of the population health target is an entirely "political" construct.

SMPHs are calculated using the following formulas:

Life expectancy = $\text{HS1}_{\text{area}} + \text{HS2}_{\text{area}} + \text{HS3}_{\text{area}} + \text{HS4}_{\text{area}} + \text{HS}i_{\text{area}}$

Health-adjusted life expectancy = $\text{HS1}_{\text{area}} + \text{value}_2 \times \text{HS2}_{\text{area}} + \text{value}_3 \times \text{HS3}_{\text{area}} + \text{value}_4 \times \text{HS4}_{\text{area}} + \text{value}_i \times \text{HSi}_{\text{area}}$ population

Mortality gap = $\text{PHT}_{\text{area–}}$Life expectancy

Health gap = $\text{PHT}_{\text{area–}}$Health-adjusted life expectancy

where $\text{HS}i_{\text{area}}$ is the average years in health state i (measured by area under the curve), value_i is the weighting assigned to health state i, and TPH_{area} is the total number of years if the entire population achieves the population health target.

While population sizes and mortality rates may be fairly accurately known, morbidity rates are more problematical. If the purpose of the SMPH is to judge the effectiveness of health services, it may be inappropriate to use health service activity alone as a measure of morbidity. Unmet needs will be unmeasured, and service activity data may not include sufficient information to determine the disease severity levels in a way that can be translated by valuation into life-year equivalents in reliably comparable forms. This issue is important for common, high-impact conditions that are underdiagnosed, such as depression and chronic pain syndromes. Health surveys may measure symptoms of illness, whether or not the illness is being managed, but may not be able to accurately diagnose the cause of the symptoms.

DISCUSSION

SMPHs are often composite measures that combine the quality and quantity of life according to some algorithm. Some have argued that the resulting composite is conceptually confused—that it is not possible to add apples and oranges. The appropriate response to this is that apples and oranges are not combined. Rather, it is the *value* of the different attributes that is combined. It is legitimate to criticize the combination rule (algorithm), but this is a separate issue from the conceptual validity of combining dissimilar attributes, something done routinely in what is probably the most useful construct in the social sciences—namely, the gross domestic product (GDP), which compares the *value* of a vast array of goods and services.

A second methodological issue concerns the way in which SMPHs are selected. One approach is to presuppose that a single broad concept exists that is the correct measure in any health-related context—namely, the concept of "health" per se. This approach has elsewhere in the physical and social sciences resulted in a search for the "essence" of the concept associated with general terms and an attempt to codify the essence in a precise definition that can then be used in deductive argument or for the guidance of measurement. The approach has been historically associated with intellectual stagnation. Karl Popper's (1974) summation of the impact of "essentialism" is as follows:

> The development of thoughts since Aristotle could, I think, be summed up by saying that every discipline which still uses the Aristotelian method of definition has remained arrested in a state of empty verbiage and barren scholasticism, and the degree to which the various sciences have been able to make any progress depends upon the degree to which they have been able to get rid of this essentialist method. (This is why so much of our "social sciences" still belong to the middle ages.) (p. 9)

The alternate preferred approach is to commence with the problem of interest, to determine, conceptually, the likely solution and then to select or create the definitions that help to describe and summarize the relevant concepts and operationalize the solutions ("nominalism"). SMPHs have arisen not as a result of differing attempts to capture the essence of a healthy population but (generally) as a result of the differing "problems" involving population health, the differing solutions, and the concepts, definitions, and metrics implied by these solutions. A life insurance company may be interested in its future financial obligations. For this purpose, life expectancy is the most useful metric. Health authorities may be interested in "that which society wishes to maximize." This might lead to the concept of a QALY or DALY, possibly with importance weights for equity and probably with preference weights for the timing of the benefits (i.e., discounting).

Finally, the field of SMPHs is evolving. This commonly involves disagreement, and in the SMPH literature, there have been and remain contentious issues. These include the choice between period- and cohort-based life expectancy, the theoretical life expectancy used in gap measurement, the measurement of quality or "disability," the use of incidence- and prevalence-based measurement, and the inclusion of age or other social weights.

Ongoing debate over both technical issues of measurement and social objectives makes it highly likely that the field of SMPH will continue to evolve.

—Jeff Richardson and
Iain Robertson

See also International Classification of Functioning, Disability, and Health (ICF/ICIDH); Epidemiology; Quality of Life; Research; World Health Organization.

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SUPPORTED EMPLOYMENT

Supported employment is an approach to helping people with disabilities find and keep jobs in the community. It is defined as competitive work in integrated settings, with ongoing support for individuals who have traditionally been excluded from the workforce. Although it emerged as an approach for people with developmental disabilities in the United States, supported employment is currently being practiced in many countries around the globe for individuals with various disabilities, including psychiatric, physical, intellectual, and cognitive disorders. The emergence of supported employment has dramatically changed the lives of many individuals with significant disabilities who were previously denied access to employment opportunities outside segregated settings.

VALUES AND GOALS OF SUPPORTED EMPLOYMENT

Supported employment is based on the fundamental belief that all citizens should have opportunities to participate in the workforce and earn a competitive wage. The underlying assumptions are as follows: every individual can be gainfully employed if provided with the proper supports, each person has something unique to offer, and people with disabilities can be dedicated, hardworking employees. Supported employment entails principles of choice, empowerment, and equality. Accordingly, no person should be denied access to such services due to limitations caused by their impairment. Supported employment is about finding the right support to enable persons with disabilities to reach their full potential as workers.

The main goal of supported employment is to promote active social inclusion and community participation of people with disabilities through the workplace, by providing opportunities to find permanent competitive employment and to receive the individualized support required for successful job performance. It is through workplace participation that supported employment strives to increase the capacity of local businesses and communities to provide the support their citizens need to realize their full potential as contributing members of society. The success of supported employment is measured in terms of its capacity to build meaningful relationships among community members and to increase the quality of life of citizens with disabilities.

Several factors strengthen the rationale for supported employment from the perspective of people with disabilities, employers, and community members. First, it addresses the inadequacies of the traditional approach to vocational services for people with disabilities by helping people maximize their potential within competitive work opportunities. At the same time, there is a growing recognition of the importance of meaningful work experiences in building relationships with others, formulating a self-identity beyond the disability, and developing increased self-esteem and self-worth. The underlying philosophy and goals of supported employment represent an important progression toward equality and empowerment of people with disabilities in society.

COMPONENTS OF SUPPORTED EMPLOYMENT

Supported employment contains three basic components: competitive work, integrated settings, and the provision of ongoing, individualized support. Competitive work refers to a job that may be available to all citizens, regardless of their ability, in which the worker is paid the labor market wage for the position. Integrated work settings are workplaces where persons with disabilities work alongside those without disabilities. This component reflects an emphasis on social inclusion and involvement of persons with disabilities in the workforce, a critical aspect of community life. Placing individuals with disabilities in the workplace with nondisabled peers is a vital aspect of supported employment and a shift from previous models of vocational services.

The provision of ongoing, individualized support is the most distinctive characteristic of the supported employment approach. While traditional vocational programs provide only time-limited support, supported employment calls for support that is ongoing and individualized. That is, support by an employment specialist (or job coach) is made available to workers with disabilities for as long as each individual wants and needs it. The frequency and intensity of the support are flexible and designed to meet the ongoing and dynamic needs of the worker on the job.

Traditional sheltered workshops and vocational programs typically provide lengthy employment readiness assessments and preemployment training. Once placed, support is often reduced or terminated. Thus, the traditional approach has been referred to as the “train-place” model. Supported employment, by contrast, uses the “place-train” approach, where the preemployment phase is relatively short and the focus is on rapid placement and time-unlimited support on the job in the actual work setting.

HISTORICAL OVERVIEW

The concept of supported employment evolved with shifts in social values and beliefs, especially dissatisfaction with the inability of traditional sheltered workshops and vocational programs to move beyond segregated or “practice” settings. Transition from traditional vocational programs into competitive employment was extremely slow, if not impossible. Most individuals did not progress to competitive employment and experienced few opportunities for advancement. As awareness of these limitations and shortcomings increased, people began to search for alternative ways of providing employment opportunities and choices to people with disabilities. Some revolutionary programs emerged that transformed the perceived employment potential of people with disabilities. For example, the clubhouse model, which was developed in 1948 by former psychiatric patients at Fountain House in the United States, is considered an early precursor to supported employment.

In the early 1970s, the growth of the disability rights movement and the emergence of the principles of social inclusion and “normalization” emphasized the need to provide all persons with opportunities to participate in valued social roles in the community. Implementing these ideas into employment practices meant a move toward real work in the community, rather than “make-work” in segregated facilities. In this way, employment programs using the principles of supported employment were developed.

The success of supported employment spread from the United States to other countries. In Canada, the Metropolitan Toronto Association for Community Living and the Sioux Lookout-Hudson received government funding in the mid-1970s to provide long-term support in the workplace to people with disabilities. Supported employment services also emerged in Asia and Europe. For example, supported employment has existed in Hong Kong since the late 1980s and in Finland since the mid-1990s. Although local modifications to the supported employment approach may alter the target population and the level of success achieved, the basic premise and components remain the same internationally.

MODELS OF SUPPORTED EMPLOYMENT

A number of different models of supported employment are being practiced, including some that focus on individuals in supported work settings, others on groups of individuals with disabilities who are placed in supported work settings. The individual placement model (IPM) offers intensive and individualized training and support for individuals with disabilities. It is the most common approach to supported employment and the most effective, with employment outcomes surpassing those of group models. The IPM is also less stigmatizing, as there are no special groupings at work, and the person with a disability is generally hired as a regular employee, earning the same wages as other workers.

The IPM incorporates job development (finding or creating appropriate jobs), job placement (carefully matching the person to the job), on-the-job training (skill training by a specific staff member who is aligned with the worker), ongoing assessment of work performance, and job maintenance strategies (including problem solving, job modifications, and advocacy for job retention). An employment specialist is usually responsible for these functions and remains involved as a formal support on a long-term basis. The expectation, however, is that the intensity of support will fade over time. The individual approach is more challenging to maintain for clients whose job skills, rate of work, and work behaviors do not match job requirements.

A modified version of the IPM can be found within the psychiatric literature and service delivery system. The individual placement and support (IPS) model incorporates rapid job search, integration of rehabilitation and mental health services, attention to consumer preferences, continuous and comprehensive assessment, time-unlimited support, and competitive employment as the goal.

The enclave model involves groups of individuals with disabilities working with ongoing support within a business or industry. It is the second most common form of supported employment and is frequently found in the developmental disability literature and service delivery system. Full-time support, training, and supervision are provided by an employment specialist or enclave supervisor, who may be employed by an outside supported employment agency or by the business itself. The supervisor locates and develops jobs from the company, trains the workers, and supports them through their integration into the workplace. Most often, the outside agency employs the workers and is subcontracted by the business to provide the labor force. Workers may also be hired directly by the business. Examples of enclave models vary in their documented rate of pay: some are at minimum wage; others are lower and based on production. Enclave models have been criticized for low pay and the potential for isolation from the general workforce. Accordingly, work in an enclave is recommended as a stepping stone to individual placements for those workers who meet job demands and become acclimatized to the workplace.

An adapted form of the enclave model is the cluster model, where workers are dispersed throughout a work area and integrated with nondisabled coworkers. Often, these cluster placements evolve as workers are added to a job site. These placements can look like individual placements, but an enclave supervisor is available on an ongoing basis within the business.

Work crews or mobile work crews are small businesses with small groups of persons with disabilities, which perform work for an employer on a contract basis at the employer's work site. An employment specialist secures the work, supervises and trains the workers, supports them in adjusting to the workplace, and ensures that quality work standards are met. Ideally, the work crew is established as a small business and manages the quantity and type of work according to the changing needs of its employees. Staff responsibilities include not only employment support services but also tasks of managing and marketing a small business. Most commonly, the work performed by work crews consists of housekeeping, janitorial, or groundskeeping services. Workers are usually paid by the supported employment program from contract revenue.

EFFECTIVENESS

Literature comparing the effectiveness of supported employment models as they cross disability groups is very limited. Most outcome research on supported employment deals with the effectiveness of a single model for a defined population. The few studies that do cross models and disabilities reveal that everyone, regardless of disability, benefits from supported employment and that individual placement models generate employment outcomes superior to those from group models. Differences in employment outcomes across groups have been found in the areas of wages, type of employment, and job retention, but the paucity of research on this issue prohibits firm conclusions. The most common populations discussed are psychiatric and developmental disability groups.

In the psychiatric disability literature, randomized controlled trials that compare supported employment with prevocational training reveal that clients in supported employment earn more and work more hours per month than those in prevocational training. Other studies reveal that although placement rates for people in supported employment programs are strikingly higher than those generally cited for this group, employment outcomes such as wages, job satisfaction, and long-term job maintenance are questionable. Characteristics of exemplary supported employment programs for this group include use of multiple funding sources, integration of mental health and vocational services within the same programs, early entry into competitive employment with intensive support, a high degree of involvement of the employment specialist in the interview process, and an interest in evaluating supported employment services.

Outcomes in the developmental disability literature have been very positive: rates of people entering the workforce through supported employment opportunities have grown over the past decade, and integration and wage benefits are strong when compared with sheltered work and segregated settings. Components of service delivery associated with successful outcomes within this group include an emphasis on collateral behavior (social and communicative interaction), client advocacy, a focus on job analysis and job matching, follow-up support, and the use of advisory councils or local businesspeople to assist with marketing. Supported employment with persons with developmental disabilities is often criticized because those most often placed in supported employment settings are only mildly or moderately disabled, thus excluding individuals with more severe disabilities. Others have raised concerns regarding funding disincentives, that is, the way the system reduces or cuts levels of social assistance as people earn wages. Therefore, supported employment is sometimes used as an additional service option rather than the standard course of action.

COST EFFECTIVENESS

Some evidence is available to show that supported employment programs approach or achieve cost efficiency. However, many studies of cost-benefit draw on such small samples that the results need to be interpreted with caution. A few studies suggest that while costs may initially exceed benefits, the reverse is true several years after the establishment of a supported employment program. Savings to public income support vary across funding systems. Studies in the United States suggest that savings are generally low, possibly due to low salaries of employees and the resulting need to draw on social assistance even while working. Canadian research reports substantial reduction in individuals' need for social assistance. Furthermore, every individual in supported employment programs pays and contributes to pension and employment insurance plans. Reports documenting the conversion of existing programs to supported employment programs demonstrate improved vocational outcomes without increasing costs.

Supported employment offers hope and work opportunities to people with disabilities within mainstream employment. Businesses and communities at large are recognizing the multiple benefits possible through supported employment opportunities.

—Bonnie Kirsh and Rebecca Gewurtz

See also Employability; Employment; Employment, International; Inclusion and Exclusion; Worksite Modification.

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SUPPORTED SERVICES

In the past, people with disabilities had little choice about what kind of services, if any, were open to them. Institutions smothered individual differences, while an absence of any form of help meant that many individuals were simply left adrift in an unforgiving environment. By contrast, *supported services* refers to an array of supports that are available when and where individuals require them. What unifies these personal, social, instrumental, and tangible interventions is the notion that, whether or not they have disabilities, people live their lives connected to their environments and the people with whom they live and work.

A human story unearthed from sites where humankind’s remote ancestors lived shows that they must have cared for their young and also for others who were evidently vulnerable. From the current vantage some thousands of years later, one can only infer their motives—whether affective or whether calculated to ensure that more people in a group would thrive and thus be strong enough to protect each other. All humans need support in infancy and childhood. And most will do so into their old age, an ever more certain horizon in the future for people in both developed and still developing countries. Even in the prime of life, people look for help to prosper, to keep healthy, and to fulfill obligations to families and employers.

In every society and every age, there are individuals who need much more support than others. Those with disabilities, for instance, may have particular needs for support that punctuate the course of their adult lives. The place that people with diverse needs should hold in a modern democratic society is but one issue fuelling today’s debates in political philosophy. The debate is whether to embed social contracts on the premise that some individuals are more vulnerable than others, not merely as infants or older, dependent people. Given that *disability* is a construct whose boundaries are fuzzy across time, cultures, and contexts, it follows that the nature of optimal support made available to individuals in a society will vary as well. In addition, individuals identified as having the same disabling condition may manifest distinctive patterns of living, and thus uniform solutions to meet their support needs are not useful. Typically, individuals draw on support from family members and friends. In societies where formal systems of health and social services have been organized, they may also depend, at least in part, on these sources of support. Private and public domains intersect at the point where an individual with disability encounters support—perhaps personal intimacy, friendship, instrumental assistance in carrying out daily tasks, income, or other benefits in kind.

In the past, people with disabilities were often numbered among the deserving poor, albeit a drain on society’s purse if alms were not forthcoming. Separate but unequal systems of providing support for people with disabilities became widespread. The industrialized countries built structures to classify and sustain people with disabilities within health and social systems shored up by public funds. An administrative solution might take the form of a segregated facility housing people with intellectual and other disabilities and associated conditions—mental illness or epilepsy, for example. Remnants of large-scale institutional care persist today, not only in former Eastern bloc countries of Europe but more widely. In many less prosperous countries, whether through tradition or simply through lack of means, large-scale institutions were never built.

Yet it is striking to reflect that worldwide, most people with disabilities live with their families and rely on them for care and support. Today, adults in societies where independence is valued may chafe at what they perceive as intrusive services and aspire to live in their own homes. As people with disabilities grow older, it is more likely for them to move away from the family home if alternatives are available. While some developed countries have embraced community living for their citizens with disabilities as the standard for adults, others have been slow to give up large residential centers.

As institutions have declined in prominence in many industrialized countries, supported residential services aim to help people with disabilities find a good place to live by themselves or with the people they choose. Since the last decades of the twentieth century, many thousands of people with disabilities began to leave old-style institutions, moving to ordinary homes and workplaces. In their stead, *supported services* have come about to meet the needs of individuals with disabilities in their pursuit of satisfying life outcomes. The ultimate aim of such services is to support individuals so that they can live and work as they wish. The springs of this sea change flowed in part from radical rethinking about the injustice of segregation for any marginal social group and the primacy of self-determination expressed in fresh policies and laws. In the United States, for example, disability advocacy groups, federal legislation, and judicial decisions converged in policies promoting individualized supports to achieve the person's own preferred goals. *Person-centered planning* is a programmatic tool developed to identify and attain these goals with the support of the individual's named allies, including family members, human service staff, and others. A focus on the person as director of his or her life plan turns the tables on previous practices, which tried to shape individuals so that they would fit into preexisting forms of social support devised for groups. Today, many people with disabilities live satisfying lives of their choosing in their own homes, perhaps with coresidents of their choice. Service agencies are charged not with herding people under a single roof for ease of administration but rather with tempering supports to suit particular needs in the individual's own home.

Typically, adults with disabilities experience very high rates of unemployment. Many thousands of these individuals have no jobs at all or work only in sheltered settings where prospects are modest and where there are no employees who do not have disabilities. For those who wish to do so, supported employment services help them to find, get, and keep preferred jobs. Many individuals with disabilities will in time outgrow the support needed at the outset as they enter the ordinary workplace, such as through in-service job training. Others will require coaching throughout their careers from a mix of specialist and natural sources such as coworkers. Supported services have made it possible for thousands of men and women with disabilities to enter the ordinary workplace and earn an income for the first time. However, supported employment—offering an ordinary job, full- or part-time—is not as widely available as may be indicated by policies favoring social and vocational integration in Europe and other regions of the world.

The widespread transfer from block services to individualized supports for people with disabilities yields dilemmas. Individuals and their family members may reasonably be anxious if the balance between autonomy and risk shifts to their disadvantage. They have concerns regarding the adequacy of support for people with complex, significant disabilities and those with physical disabilities of such scope that they need others to help with every aspect of their personal care to aspire to anything like independent living.

The abandonment of large institutions can potentially leave a vacuum in the lives of some people with disabilities if sufficient supports are not in place.

Those who believe that vulnerable people thrust into a complex world may lose out in terms of stability and companionship argue that some individuals will always need the special supports available in professionally run, separate residences or workshops. Others argue that society, in time, will simply care less about people inserted into the mainstream without the trappings of special status. Furthermore, many people with disabilities living in very poor circumstances—sharing conditions of deprivation, with little opportunity for a comfortable, secure life—need additional supports. There is an ongoing debate about whether independence in the community is the only legitimate goal for these people.

Independence was a foremost goal as people with disabilities moved away from the confines of institutions and separate forms of care. Sometimes social isolation resulted, fomenting pleas for a return to old ways of gathering together people with disabilities. More recently, interdependence has emerged as a crosscutting principle in all aspects of society. On the world stage, globalization is founded on the premise that the political and economic fortunes of all countries are linked. At the personal level, interdependence is expressed in transactional models of human development: individuals interact with family members, friends, and the socioeconomic and physical contexts in which they grow and develop. From infancy through old age, individuals are both influenced by their environments but also shape these environments actively. People with disabilities may seek supports to help negotiate these reciprocal relationships.

No injection of funds and no political decision can confidently produce an ideal form of support for each person in every circumstance: some argue forcibly that it is not society's business to try to do so. Rather, questions about how society values people who are dependent or especially vulnerable and responds to their distinctive needs for support reflect dilemmas springing from the human condition. For as the American philosopher Martha Nussbaum (2001:34) reminds us, "The way we think about the needs of children and adults with disabilities is not a special department of life." Supported services are a tangible sign that society recognizes that individuals have needs that are worth meeting and that to do so is for everyone's sake.

—Patricia Noonan Walsh

See also Independent Living; Peer Support; Social Support; Social Networks.

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SUR DAS (1480s?–1580s?)

Indian musician and poet

For four centuries, Sur Das has been the most famous blind musician and poet of North India, with the result that "Sur Das" as a nickname could get attached to any (male) blind Hindu or Sikh who sang or played music. The "original" Sur Das has become elusive, and no detail can be fixed with certainty. The theory that the celebrated poet and musician was identical with a documented Sur Das, son of Ram Das, who lived at Braj, was blind, and performed at the court of Akbar (regn. 1560–1605), is unquestioned by many Indian scholars and supported by some Westerners (Lehmann 1982; Vaudeville 1971). Most people concede that the legend originated with a real-life artist and poet, who composed most or all of the thousands of poems in the *Sur Sagar* (*Ocean of Song*).

Traditional assertions about Sur Das continue to be questioned—especially by those who dismiss Indian oral history, argue about the mentions of blindness in Sur's literary work, and are surprised that, "if Sūr was blind, he did not make a great point of it before the world" (Hawley 1984).

—Kumur B. Selim

See also Experience of Disability: India.

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SURGERY AND DISABILITY

A number of surgical procedures produce postoperative disabilities. Although these procedures may alleviate discomfort, save or prolong life, or provide a cure because the diseased tissue or organ is excised, they nevertheless leave a significant postoperative residue or set of new disabling problems with which the patient and their carers have to cope. In other words, because of the surgical rearrangement of the human body, impairment is created in the form of a loss, reduction, or change in function, which actually or potentially limits the full engagement of the individual in the social world.

The types of surgery that fall into this category include amputations; radical surgery to the head, face, and neck; mastectomies, colostomies, ileostomies, and urostomies; surgery of the prostate and the penis; and some gynecological operations. Not infrequently, these procedures are conducted to deal with life-threatening diseases, especially cancer, or with long-term chronic illnesses such as diabetes, colitis, and Crohn's disease. While the patient's life may be saved, the disease held in check for a further period of time, or a total cure effected, the postoperative period brings with it a new series of problems. These problems may temporarily or permanently make the patient's quality of life worse rather than better. From the patient's point of view, surgery may seem especially undesirable preoperatively. The surgical outcome may seem to be worse than the disease itself.

LOSS OF FUNCTION

This is the most obvious type of postsurgical disability and the one most easily linked to the traditional literature on disability. Loss of the ability to walk or significant reduction in mobility following limb amputation would be good illustrations. Amputations of hands or arms or lower limb extremities have differing degrees of functional loss consequent on them. The extent of the loss of mobility will be determined by a range of factors. These are the extent of the amputation, the effectiveness of and ability to use prostheses, the age of the individual, the presence of other comorbidities, the home environment, and the degree of support provided by carers in the family or though health and social services.

Other types of surgical procedures involving loss of function have different, more attenuated functional consequences but are nonetheless very serious. Surgery of the mouth, tongue, face, and neck has potentially very significant functional implications for eating, drinking, and phonation. Surgery of the throat, voice, and larynx has impacts on the ability to speak and eat. Surgeries of the prostate, vagina, penis, anal sphincter, bladder, and gut all have a significant impact on the functions of urination, defecation, nutrition, and sex. Operations on the uterus may affect fertility, and a range of procedures may affect male fertility and potency. Bodily functions that the normal healthy human routinely takes for granted are undermined. In the postoperative state, patients have to relearn skills they originally acquired in childhood. So when surgery affects the ability to speak, eat, and control feces and the bladder, it is striking at some of the most fundamental aspects of our humanity.

What is at issue here is not that individuals cannot do what they used to do or that, with the aid of prostheses and appliances, they can find a functional alternative. It is rather that the skills and competencies that define what it is to be a competent adult member of society—to walk, manipulate objects in the environment, talk, eat, and control the anal sphincter—are changed.

One need not subscribe to a psychoanalytic view of the world to see that destroying the basic skills acquired in childhood of walking, manipulation, eating, drinking, talking, and emptying the bowel and bladder is to assault the human psyche, as well as the human body, in potentially profound ways.

RESPONSE TO LOSS

It has been observed in many types of surgical procedures—especially but not exclusively coronary artery bypass grafts, mastectomies, and ileostomies—that the consequent emotional response is very powerful indeed. It is sometimes suggested that the destruction of body image is the problem. Among the responses noted are phantom limb experiences by people who have had amputations, denial, clinical depression, and something that mimics the well-described pathways of grief.

These responses can be severe, potentially disabling, and, in some cases, psychologically morbid. Helping patients work though their feelings about loss is very important. It is just as important as helping them to acquire new skills in using their appliances or their new prostheses. Arguably, the importance of allowing patients undergoing such procedures the space and time to grieve for the loss or express and ventilate other emotions is a critical way of beginning the psychological as well as the physical healing process.

SOCIAL AND PSYCHOLOGICAL RESPONSES

A very useful way to conceptualize the overall social and psychological processes involved is to distinguish between the concepts of self and identity. The concept of self captures the idea that each and every human being carries a notion of what he or she is like as a human being. Some of these things will be attributes such as being friendly, vivacious, good looking, and hardworking. Other elements will refer to social roles and group membership. Some individuals may think of themselves as a man, father, husband, lover, writer, black, and middle-aged. Still other parts of the concept of self will refer to skills the individual thinks he or she possesses: "I can play basketball, I can drive a car, I can paint, I can play the piano," and so on. Some of the elements relate to more fundamental human skills and competencies: "I am an able bodied adult in control of my body and of my life."

Many of the procedures focused on here critically change the core aspects of self and very frighteningly result not only in the loss of control of some aspect of the body and its functions but also the ability to be in control of one's own destiny. Given that in Western society, control and self-control are highly valued, their loss is of considerable import. Not only that, their loss affects primal understandings of who or what we think we are. The assaults on basic activities such as eating, drinking, evacuation, walking, and talking are attacks on the very definition of what the able-bodied world takes to be human. This is because these skills and competencies spill over into and define other aspects of our sense of what we are and our place in the world.

It is not just the obstacles that arise because of the loss of function that are important. Physical barriers are significant because they prevent the postoperative patient doing things and participating in social activities. But also important is the meaning that not doing these things has for the personal biography. So no longer being able to have an erection and to have sexual relations, for example, is not just about not being able to father children or enjoy sexual relations—it is about what that means for the individual's sense of being a man, a husband, a father, and lover. Not being able to talk is not simply about learning new ways of communicating—it is about conversation, chatter, social intimacy, friendship, and being a member of the human community.

Consequently, because of the changes, postoperative patients have to develop a new or altered sense of self, a new sense of who and what they are, a new sense of their place in the world, and a new way of making sense of the world and of their lives. This is not an inconsiderable undertaking. We are basically setting the expectation that the patient will become, in effect, a different person. Not surprisingly, patients often resist and doggedly cling to their earlier sense of self, very reluctantly give it up, mourn its loss, and take a considerable time to embrace new aspects of their new self.

Another useful concept to help articulate the mechanisms involved is identity. The term *identity* is used to mean that public aspect of the person as it is known to others. Identity refers to the elements of role, social position, group membership, and personality as they are known to others. The labels that others apply to us are the key points of reference that we also use to categorize and organize the myriad of others with whom we come into contact. For ordinary able-bodied adults, the key aspects of public identity are usually things such as gender, age, appearance, ethnicity, style of dress, occupation, and all the well-known social signifiers that surround us most of the time. The important point about the kinds of surgery of interest here is that in certain circumstances, the sequelae of surgery are plainly visible to others and constitute a significant aspect of public identity. Amputation and radical face and neck surgery, for example, are immediately visible social signifiers to others. Some authors have talked about stigma in this context, arguing that certain external bodily markers are so significant that they constitute both ways of organizing perceptions (in the same way that things such as age and gender do) and also organizing public identity in very negative ways. In effect, the discrimination to which many disabled people are subject can be understood as a consequence, at the personal level, of the negative labeling and stereotyping and the stigmatizing response of others toward the functional impairment. This is distinct from the social level of discrimination that exists in legal codes and environmental and physical barriers to integration and full involvement in social matters. It is, generally speaking, a much more straightforward matter to change legal arrangements, to outlaw discrimination in the workplace, and to modify the physical environment than it is to change underlying stigmatizing attitudes and stigmatized public identities.

Some of the surgical conditions referred to in this section are invisible when someone is fully clothed. Someone who has had a mastectomy or a colostomy is like this. For them, the problem of public identity is slightly different. They of course have to manage their bodies, their functions, their appliances, and their prostheses. However, others who are not intimate and knowledgeable about the condition—strangers, fellow travelers on public transport, and fellow customers in a shop—would not be aware of the functional difference in their bodies. The question for those with these postoperative states is the extent to which they wish to tell others about their condition, their operation, or indeed the extent they might be compelled to reveal their situation. At these points, they face the possibility of their true identity being found out and their being labeled negatively.

COPING

A number of types of coping are at the heart of learning to live with a disability that arises as a consequence of surgery. The first of these is technical. Technical coping relates to the specific management of the way the body now functions and to managing any associated prostheses, appliances, and drugs. It relates to the skills that are required to keep functioning despite the consequences of surgery.

The second type of coping skill is *intrasubjective,* meaning within the individual. This is the thinking, feeling, and emotional response to the situation. Having a chronic condition such as cancer, in which the patient has to deal with a sudden diagnosis, surgery, radiation, chemotherapy, rehabilitation, and perhaps reconstructive surgery, is a disruptive and emotionally charged experience. The patient has a lot to deal with, and for many, there will be varying degrees of intense emotional response. Dealing with these feelings and working them through is an important process the patient has to go through and cope with.

The third type of process relates to interpersonal relations. Because of changes to self and identity, interpersonal relations are inevitably disrupted and renegotiated with intimates and with a broader circle of friends and acquaintances. Just as the body is not the same after surgery as it was before, so too are relationships shifted. The size of the shift may well depend on the surgery; patients may also only experience a shift in their patterns of social contacts in the short run, but shifts in interpersonal relations are part of the process.

Finally, there is a process that is called *intersubjective,* which is about rendering the experience meaningful. All of us, to a greater or lesser extent, seek to make sense of our circumstances, our life, and our place in the scheme of things. When people experience life events that arise from these operations, not only will they find that their previous sense of what they thought and what the future holds will need to significantly reappraised, but new meanings for the new circumstances in which they now find themselves will also have to be found.

Some people find hope and great comfort in what they learn about themselves in such experiences; for others, it an experience devoid of anything positive, and they see the whole thing in personally tragic terms. Of course, it may matter a great deal if someone takes a very positive attitude versus someone who does not, not least because of the impact on quality of life and return to ordinary everyday things. But just being positive is not the whole answer by a long way.

The experience of the surgery, which alters the way a human body functions and looks and creates a disability, is physically and emotionally painful. Human suffering on a grand, albeit personal, level is involved. People going through these procedures do sometimes feel despair before they can experience and see things positively. This makes it all the more important to allow time and space for those emotions to be ventilated and the opportunity for the person to do his or her grieving. Even then, of course, if the harsh external world assigns these individuals a stigmatized and negative label and identity, the task is hard indeed. We should not seek to find out from a psychological point of view which personality types cope best, nor should we blindly encourage a positive attitude. We should instead recognize that there are stages in the process of coming through this type of surgery, and the various coping processes have to come into play at different times.

—Michael P. Kelly

See also Amputation; Cancer; Identity; Phantom Limb Pain; Stigma.

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▣ SWEDEN

See Disability Law: Sweden; Social Model: Sweden

▣ SWITZER, MARY ELIZABETH (1900–1971)

Developer of U.S. disability and rehabilitation policy

Mary Elizabeth Switzer, distinguished public administrator and developer of U.S. disability and rehabilitation policy, was born in Newton, Massachusetts, on February 16, 1900. In 1921, as Radcliffe College’s first graduate in International Relations, Switzer began a lifetime of increasing public service responsibility in Washington. Her career paralleled the development of social programs in the United States, stretching through the tenures of Presidents Harding to Nixon. Mary Switzer believed that bureaucracy existed to serve people and directed the forces of government to include persons with disabilities in the work and play of the nation.

Public Law 565 is the capstone of Mary Switzer’s career. Switzer’s effect on the quality of life for millions of persons with disabilities and their families is memorialized in bricks and mortar (the Switzer building in Washington and Switzer buildings at the Helen Keller Center, Assumption College, and the Woodrow Wilson Rehabilitation Center), in scholarships, by annual lectures and seminars, in 17 honorary degrees, and in dozens of awards she received during her lifetime.

—Martha L. Walker

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▣ SYDNEY PARALYMPICS

Some 20 years after the 1981 International Year of Disabled Persons, Sydney hosted an exceptional Olympic and Paralympic Games, in which people with disabilities were competitors, spectators, volunteers, media, or employees. At the Sydney 2000 Paralympic Games, some 4,000 athletes from 125 countries competed in 18 sports. Of these sports, 14 are common to the Olympic Games, with the sports of wheelchair rugby, boccia, goal ball, and power lifting being specific to the Paralympics. People competing were from the following disability categories: Amputee, Cerebral Palsy, Intellectual Disability, Vision Impaired, Wheelchair, and Les autres (literally, the "others"). The Sydney Paralympics claimed a number of records, including the following:

- the most number of spectators to witness a Paralympic Games,
- the most number of tickets sold, and
- the Paralympic Opening Ceremony being the most watched television program in the history of the Australian Broadcasting Commission.

Why was this so? The Paralympics followed the undoubted success of the Olympic Games and the party atmosphere created. People enjoyed themselves tremendously and wanted to continue enjoying themselves. The Sydney Paralympic Organising Committee (SPOC) had also undertaken a very successful Reaching the Community Program that targeted schoolchildren and seniors. The program was regarded as important to raise awareness of disability in the community and was essential to weekday crowd numbers because, unlike the Olympics, the Paralympics were not held during school holidays.

There was no research carried out in Sydney investigating the effect of the Paralympics on attitudes to disability. However, the positive images of athletes with disabilities competing in sport were empowering and challenged the stereotypes of disability portrayed in the media and film. Yet, the representations of athletes with disabilities by the SPOC and the athletes themselves were diametrically opposed. The Australian Paralympians identified themselves as highly trained elite athletes, whereas SPOC marketing sought to evoke the sympathy of the nondisabled public to support the "poor cripple." This image was based on the public finding inspiration in "the disabled" overcoming their "deficits" through sporting participation.

This polemic was epitomized by the words of the mayor of the Paralympic Village, who referred to the athletes as "Bravehearts." This term was viewed by the Australian Paralympians as patronizing and led to a debate in the Sydney media about the perceptions of the Paralympics. The debate discussed the merits of Paralympians as elite athletes and not "disabled people," the merit of the Paralympics as a "true" sporting spectacle, and the language of disability. Yet, it was the inspirational message that the majority of media focused on.

The Paralympics provided athletes and spectators with disabilities with an unprecedented accessible experience. However, while the games were heralded for their inclusive planning practices, there were documented discriminatory practices. These involved

spectator and volunteer services,

general mobility and sensory access issues,

equality of transport provision,

the ticketing program not providing people with disabilities with appropriate seating, and

information, ticketing, and online resources not provided in accessible formats.

Most recognize that the major legacy of the games was the provision of accessible infrastructure that was developed in a relatively short timeframe. The professionals involved in the planning of the venues, the common domain, and transport now understand the principles and practices required for an inclusive planning process. One tangible outcome of the Paralympics was the development of an online access resource for planning accessible environments and events. The resource has incorporated the games' planning, development, construction, and operations experiences for disability and access. However, what was overlooked was that most of the inclusive practices could not have been delivered without a human rights framework and the blood, sweat, and tears of the Australian disability community. The Paralympics were made better by the social changes instigated by people with disabilities and disability advocacy organizations in consultations, lobbying, and advocacy that occurred in the lead-up to the games.

—Simon Darcy

See also Paralympics; Sports and Disability.

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SYLE, EDWARD W. (1817–1890)

Missionary and scholar

The learned and genial English clergyman, Dr. Edward Syle, was a missionary, scholar, and founder of formal vocational work with blind people in China, at the Shanghai Asylum for the Blind. He worked with the American Episcopal Mission at Shanghai from 1845 to 1860 and kept a detailed journal, incidentally noting many aspects of disability. The journal gave much thoughtful description of Chinese life and customs and was serialized in the Episcopalian serial *The Spirit of Missions.* Syle studied the occupations of blind Chinese people and, in 1856, noticed an old woman "twisting some long sedgy grass into strings, such as are used for holding together, by hundreds, the copper 'cash' which are in such constant use." Syle asked her to teach his blind pensioners this craft, and "thinking, perhaps, that I was slightly deranged," she agreed. The craftwork soon expanded, as did the idea of elderly blind people being active contributors in the community. Syle later worked for seven years in Yokohama and Tokyo. His son, Henry Winter Syle (1846–1890), who lost his hearing at the age of six, became a deaf activist in Pennsylvania and was also ordained as a priest.

—Kumur B. Selim

See also Religion.

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SYPHILIS

For half a millennium, syphilis was a feared and stigmatized disease. Known as "the great imitator" for its ability to mimic the symptoms of other illnesses, left untreated, it can damage any organ of the body. Beginning as a small genital chancre or sore, syphilis can lay seemingly dormant for weeks to decades. Then its reappearance could bring a range of ills from rashes and gummas across the body, deafness, blindness, perforated palates, madness, mania, excruciating joint pains and deteriorating bones, damage to the aorta of the heart, and death. Its visual components were frightening to see and its debilitating effects devastating.

Secrets and silences often accompanied the disease as its transmission through sexual intercourse or congenitally from mother to fetus trailed moral judgments and state intervention in their wake. Seen as the grand disease of the "other," its appearance often reached epidemic levels after wars and invasions and was usually blamed on someone else. Explanations for its existence, from heavenly wrath to promiscuity to betrayed innocence, underlay its power to evince interventions by priests, doctors, scientists, and healers alike. Both experimentation on patients, willing and unwilling, and self-experimentation by doctors in search of understanding and cures has characterized its long history.

Syphilis is caused by a microscopic spirochete called *Treponema pallidum.* Its modern name comes from a character in a poem by physician Girolama Fracastoro that was written in 1530 in Verona, in what is now Italy. Having offended the gods, Syphilius the shepherd was sent the disease as punishment for his sins and his name given to all who suffered as he did. The disease's common appellation often changed as it moved, labeled as the great pox, *lues venerea,* the French sickness, the Spanish disease, the Italian disease, Chinese ulcers, plum-tree poison, or sometimes bad blood.

The origins of syphilis are still being debated. Arguments have ranged for centuries on whether it was a disease of the Old World brought to the island of Hispaniola by Columbus's men in 1492 or a New World disease sent back in European bodies as revenge by the peoples who had been plundered. In 1495, the disease appeared in epidemic form during an invasion of the Kingdom of Naples by a French army with Spanish soldiers and sailors. Over sea and trade routes and following invading armies, the disease spread rapidly throughout the Mediterranean world to India, China, and Japan. Even before the spirochete was identified at the end of the nineteenth century, the various stages of the disease began to be mapped.

The primary infection appears usually on the genitals as a chancre that disappears, but not so the infection. In the secondary stage, rashes and sores, hair loss, swellings, and growths are common. In various parts of the latency stage, the disease's progress is often invisible, but chancres and rashes are possible. In the late stage, when the disease is not transmissible, the damage to major organs and death can occur. Pregnant women can pass the disease on to their fetuses with the risk of stillbirth, early death of a newborn, or serious medical problems. Reinfection can also occur.

By the sixteenth century, syphilis was widespread in the European population, counting as its victims both princes and paupers. The use of mercury, known to Arabic physicians for centuries as a cure for skin diseases, began to make its European debut. Those in the aristocracy could afford the ministrations of the learned doctors and were treated to a range of cures that usually involved purges, sweats, and rubs made from the bark of the gaiac tree as well as mercury. For those whose sexual conquests were a badge of honor, syphilis was more of an expected consequence than a sign of debauchery.

For the commoners, however, the stigma of the disease was much greater and shaming more widespread. Kept from the great physicians, such sufferers often found themselves locked in the back wards of institutions. They were treated by barber-surgeons and pox doctors who provided a wide variety of eclectic and often violent remedies, especially preparations of the frequently toxic mercury in the form of blue pills, rubs, and vapors. Historian Kevin Siena argues that in London between 1600 and 1800, a "gendered geography" was created, with men given admittance to the hospitals, women to the workhouses, while inventive efforts were made by all to hide their ills.

The adage that "a night with Venus might mean a lifetime with Mercury" reflected the connection that linked sex, syphilis, and the heavy metal "cure." With the rise of a more bourgeois sense of morality, as historian Owsei Temkin (1977) noted, by the seventeenth century, "acquisition of lues is proof of offence against morality, of an alliance with vice."

By the nineteenth century, syphilology was becoming a crucial branch of Western medicine. In search of understanding and cures, various kinds of experiments were carried out, often involving injecting both humans and animals with pus or blood. By the end of the century, syphilis and gonorrhea were shown to be separate diseases and the links between syphilis and a wide variety of other ills documented. In 1909, after a series of experiments in Berlin, Paul Ehrlich and Sahachiro Hata found that arsephenamine (an arsenical compound) would kill the treponema. By the early 1920s, mercury, neo-arsephenamine, and bismuth were used as cures (often taking more than a year to evince relief), and malaria was induced to create fevers for those with neurological complications.

In the United States, the twentieth century brought more research, the emphasis on statistical accounting for the disease, the opening of specialty clinics in major urban hospitals, and the beginnings of more open discussion of the disease in theatrical productions. In 1913, the American Social Hygiene

Association was formed to combat venereal diseases and the silences surrounding them. Posters, motion pictures, and educational campaigns began as Americans were warned to find marriage partners with "good blood." Blood tests required before marriages are a result of these efforts.

Syphilis became the focus of intense research. Under the leadership of the U.S. Public Health Service (PHS), a Cooperative Group Study in major hospitals was organized in the late 1920s to understand the disease. In the 1930s, Surgeon General Thomas Parran, having been kept off the radio for attempting to use the word *syphilis,* wrote extensively about the disease and encouraged public education campaigns to make the warnings about venereal diseases more widely known and to open discussions. The PHS's Venereal Disease division lent doctors to local and state public health departments and provided clinics for indigent patients.

In both World Wars I and II, emphasis was placed on prophylaxis for soldiers and the rounding up and incarcerating of assumed to be diseased prostitutes and "khaki-wackies," young women who followed the soldiers around. After experiments done by the PHS in the mid-1940s, penicillin proved to be a drug capable of curing syphilis in its early stages extremely quickly, and its widespread use followed.

Perhaps syphilis's most enduring legacy, however, was research done by the PHS in the counties in and around Tuskegee, Alabama. The PHS thought it had a situation that would allow for a study of the "natural history" of the disease, especially in African Americans who were assumed to have higher incidences and perhaps even a different disease than whites. What was supposed to be a short study stretched on for 40 years (1932 to 1972) as approximately 399 African American men who were in the late latent stage of the disease and 201 controls were followed as their symptoms worsened and deaths began to occur. But the men were never told they were in an experiment or that the rubs, tonics, and aspirins they were being given were not treatment for their disease. Even when penicillin became widely available, efforts that were not completely successful continued to keep most men from treatment.

Public outcry against the research in Tuskegee rose in 1972, when a newspaper story spread knowledge about its existence outside the confines of the medical and public health communities. What followed was a federal investigation, Senate hearings, a lawsuit, histories, plays, poems, music, and, finally in 1997, an apology from President Bill Clinton. Rumors persist that the PHS infected the men, although there is absolutely no evidence for this. Tuskegee's legacy has continued, however, as a metaphor for the fears in the black community over research, and Tuskegee's story is told over and over again as a warning to scientists about the ethics of research.

With the rise of HIV and AIDS, concern with syphilis has reappeared and coinfections not uncommon. Syphilis may no longer be the scourge it was half a millennium ago. But it remains a stigmatized, debilitating if untreated, and dangerous systemic illness that should be either prevented or cured.

—Susan M. Reverby

See also HIV/AIDS; Sex Industry, International; Stigma.

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T

▣ T4 PROGRAM

The T4 Program (also called "T4 Action" or "euthanasia") was the camouflage name for the mass murdering of thousands of mentally ill and disabled people during World War II in Germany. The name stemmed from the postal address of the central executive agency, the Tötungsbehörde (literally: "killing office"), at 4 Tiergarten Street in Berlin. The T4 Program was not officially legalized, but Adolf Hitler, the leader of the Third Reich, issued an authorization that was originally written in October 1939 but was dated back to September 1, 1939, the very day when World War II started. Hitler wanted to indicate that the beginning war was aimed not only against external but also against internal enemies.

The T4 Program was bureaucratically organized. It started with the registration of patients using specially designed forms. Every psychiatric hospital, medical institution, and charitable home in Germany had to fill out these forms about each of their patients, inmates, and clients. About 60 physicians recruited by the T4 agency served as experts. They reviewed the documents and decided who would live and who would be killed. After this step, the T4 agency sifted through the forms once more and made the final decision about life or death. Finally, the T4 bureaucrats compiled patient lists for each institution involved. The T4 agency also set up a special transport unit whose personnel were recruited from the SS, the notorious Nazi organization. This transport unit used seemingly neutral grey buses and was responsible for the victims' deportation to the six sites selected as the places where the killing of the victims in gas chambers occurred. At these institutions, special registration offices were also set up; they had the task of issuing official declarations of death and sending the urns with the ashes of the cremated to their families. T4 locations existed in Brandenburg, Brandenburg; Bernburg, Saxony-Anhalt; Sonnenstein, Saxony; Hartheim, Austria; Grafeneck, Württemberg; and Hadamar, Hesse.

The T4 Program started in the autumn of 1939 and officially stopped on August 24, 1941. The reasons for this sudden stop were manifold. One important reason was that although the Nazis originally intended for the measures to be kept secret, the spread of rumors in the villages surrounding the extermination sites could not be prevented. People living near the buildings observed that a continuous stream of patients entered the institutions, but nobody ever came back. Neighbors saw the smoke that arose when the dead were cremated. Families also became suspicious when a family member had been physically healthy before he or she came to one of the "euthanasia" institutions. Often, "weakening" or "debilitation" was indicated in the death certificates issued by the registration offices. The Nazi propaganda machinery could not prevent the T4 Program from being debated in public, when Clemens August von Galen, a Catholic bishop of Munster in Westphalia, took up the issue in a prayer in his church. He openly condemned the measures. After this event, the national socialist government decided to reduce the mass murder program.

However, the official ending did not mean that "euthanasia" measures stopped. The extermination sites in Bernburg, Sonnenstein, and Hartheim stayed open and continued the killing. Furthermore, after August 1941, the so-called "wild euthanasia" started. One main target group was prisoners who had become ill in the concentration camps. On one hand, the centralized murdering in special institutions lost its importance; on the other hand, ordinary physicians in various psychiatric hospitals and medical institutions all over the country participated in the murdering. They killed their patients mostly with drugs or poison, often in combination with strategically aimed underfeeding of inmates. A further "euthanasia" measure was directed at children with inborn impairments; it had been put into operation before the official start of the T4 Program and was continued after that.

In summary, more than 70,000 disabled persons were killed prior to August 1941. When World War II ended in May 1945, about 120,000 "euthanasia" victims had lost their lives at the extermination sites and through the various measures carried out by the T4 agency in Berlin.

—Volker van der Locht

See also Eugenics; Eugenics: Germany; Euthanasia; Nazism.

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TAIWAN

See Experience of Disability: Taiwan.

TELEREHABILITATION

Telerehabilitation is the delivery of rehabilitation services via information technology and telecommunication networks. It is related to the more general field of telemedicine. During a real-time consultation, clinicians can see and talk with the client by means of a remote video camera and can record still images and measurements from sensors.

Interest in delivering care remotely has been driven by demographic changes due to increased numbers of people living with chronic diseases and disability and high costs of hospital and clinic visits. Furthermore, rural areas may lack local specialists, and extended travel wastes time and increases costs even more.

Typical applications include post-discharge follow-up of newly disabled people by physiatrists and therapists, seating and mobility services (wheelchair adjustments, assistive technology prescription), monitoring and prevention of pressure sores, wound assessment, evaluation of home modifications, and training in the use of augmentative communication devices. Virtual reality simulations can be used to create an engaging environment for exercise, using games to alleviate boredom.

Initially, POTS (plain old telephone systems) were used, but their bandwidth (amount of data able to be transmitted in bits per second) is low, resulting in small picture size, low resolution, slow frame rates, and poor audio quality. These problems have been eliminated with fiber-optic cable networks, using integrated services digital networks (ISDNs) or digital subscriber lines (DSLs). A mathematical technique called compression also enables the available bandwidth to be used more effectively.

Wireless devices are now widespread, allowing caregivers and clients to stay in touch while moving throughout the community. Cell phones, pagers, and personal digital assistants (PDAs) support voice, text, and image communication. Wireless Ethernet (WiFi, IEEE802.11b), Bluetooth, and ZigBee transceivers facilitate transmission of data (telemetry) from wearable sensors for recording vital signs, movement, and other variables. Mobile wireless devices can also help caregivers to locate people who are at risk of wandering. Health management and rehabilitation information resources are also available through the wireless application protocol (WAP). Virtual reality may be used to provide a range of simulated environments for therapy.

Some limitations and challenges have become evident. Access to high-bandwidth networks is growing rapidly but is still not universal, and service coverage may be patchy, especially in rural areas. Display and interface design need more attention. Since the technology is new, there are often problems with interoperability, reliability, and lack of standardization. Training of clinicians as teletherapists will need to be instituted. Although prices continue to fall, cost is still a major consideration, and reimbursement is problematic because, currently, it is usually contingent on attendance by a caregiver. Security, patient rights, and privacy issues must be addressed, using encryption where appropriate. Theoretically, there may be a risk with medical equipment such as pacemakers and powered wheelchairs, although in practice this is rare. There is a need for more quantitative tools that can measure joint motion, pressure, and force (haptic) feedback. Finally, there may be a "fear factor" associated with the use of technology.

While telerehabilitation is unlikely to replace traditional therapy, it is likely to provide services to an increasing number of people in the future.

—Chris Kirtley

See also E-Health Care/Telemedicine; Rehabilitation Medicine, International.

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TELETHONS

The roots of telethons in the United States as a means to raise money to "cure" or "help" people with a variety of disabilities arose from charity efforts in the pretelevision era. According to the Disability History Project, the most direct precursors were the posters, speeches, radio spots, and movie star–studded events used by friends and associates of polio survivor President Franklin D. Roosevelt to raise funds for treatment and services for people with polio at Warm Springs, Georgia.

When television evolved as a mass medium in the late 1950s and early 1960s, it became the mechanism by which charities made their appeals for money. In their efforts to draw the sympathy of the TV audience, these telethons turned to those previously successful print charity campaigns by employing "poster children." Along with the other techniques employed by the pretelevision charity events, featuring disabled children became a mainstay of telethons as an effective strategy to inspire donations.

However, when these poster children grew into adults, some began to question the techniques of telethons that used pity appeals to gather money. By the late 1970s, disability rights advocates joined together in a cohesive civil rights movement, and the Rehabilitation Act made U.S. society more accessible to people with disabilities. With these efforts came an understanding that the images of people with disabilities in the media had a powerful impact on society's acceptance of disability issues and on the self-concept of people with disabilities. Telethon images further stigmatized people with disabilities in society, according to disability rights activists. Disability historian Paul Longmore explained in a 1993 *Vanity Fair* article, "The message of telethons is whatever condition people with disabilities have, that condition has essentially spoiled their lives, and the only way to correct that is to cure them. The message of the disability rights movement is that it's possible to be a whole person with a disability" (p. 92).

However, the most famous telethon host, Jerry Lewis of the Muscular Dystrophy Association (MDA), told *Esquire* magazine in 1991 that disabled people needed help because "God goofed, and it's up to us to correct his mistakes" (p. 100). This statement from the 1973 MDA telethon, according to *Esquire,* caused some outrage about his insensitivity. However, according to Mary Johnson of the *Disability Rag,* the first big wave of protests against telethons began in 1981, when the American Coalition of Citizens with Disabilities, which represented 126 disability organizations, and the Disability Rights Center in Washington, DC, put an ad in the entertainment trade magazine *Variety,* criticizing the MDA telethon. The director of the Disability

Rights Center, Evan Kemp (who later became head of the U.S. Equal Employment Opportunities Commission), wrote opinion columns for the *New York Times* and the *Washington Post* explaining that the telethon was a "pity-a-thon" that left an impression that people with disabilities are not capable or employable. Lewis, who began hosting the telethon in 1966, was angered by the criticism and debated Kemp on the Phil Donahue TV show. This event in 1981 kicked off more than 20 years of clashes between Jerry Lewis and disability rights activists.

Jerry Lewis and the MDA telethon became the focus of most antitelethon activists because they made few changes in their pity approach tactics, whereas other disability-related charities began retooling their telethon efforts as a result of criticism, financial resources, and changes in TV. For example, by 1984, no TV station in New York City would air the Easter Seals Society telethon. TV station directors said that even though the charitable organizations paid to use a station's studio and crew, the station lost money because those fees did not cover all expenses, and the station lost ad revenue it would have received during the telethon hours. The charitable organizations also began to see how costly telethons could be. A March of Dimes executive said in 1987 that the organization stopped its national telethon because it was spending 50 cents to make one dollar, so the cost became too high. In addition, by the late 1980s, cable TV had grown in popularity. With many more choices, TV viewers no longer had to watch a telethon.

By 1990, many national telethons went away. The efforts of disability rights activists paid off in other ways as well. Some disability charities understood their criticism and changed their fundraising tactics completely. For example, Easter Seals said in 1992 that it wanted to focus on public awareness and advocacy. It brought more people with disabilities into its decision-making processes. An executive from United Cerebral Palsy explained that the media-savvy general public did not want sappy, inspirational pitches any longer; they wanted to know what disability organizations were doing to make people's lives better.

However, the national MDA Jerry Lewis Labor Day telethon remained virtually unchanged, so disability rights advocates redoubled efforts to get it off the air. In 1990, Lewis himself solidified the efforts against him when he wrote a first-person *Parade Magazine* article titled, "What If I Had Muscular Dystrophy?" A 1992 *Newsweek* story on the controversy reported that after using a wheelchair, he called it a "steel imprisonment" and referred to "the courage it takes to get on the court with other cripples and play wheelchair basketball" (p. 29). He then reflected on what he believed life using a wheelchair was all about: "I realize my life is half, so I must learn to do things halfway. I just have to learn to try to be good at being half a person" (reprinted in the August 1992 *Mainstream* magazine, p. 12).

His offensive references reenergized efforts among disability rights activists to stop his involvement with the MDA telethon. Two disability activists in particular used Lewis's words to launch an antitelethon group called Jerry's Orphans. Mike Ervin and Cris Matthews, a brother and sister who had muscular dystrophy, had been MDA poster children in 1961 and organized Jerry's Orphans to lobby the MDA to change its fundraising methods and, most importantly, to drop Jerry Lewis from the telethon. In a September/October 1992 *Disability Rag* article, Matthews said the MDA was "expert in exploiting the worst side of disability and, with the eager assistance of Lewis, has made us out to be nothing more than pathetic burdens to society, whose only desire is to walk" (p. 5). The brother-sister team said they had no problem with research efforts or anyone's desire to seek a cure, but they disliked the patronizing methods used to raise money for those tasks. Jerry's Orphans organized antitelethon protests in seven cities. Other disability activists also began their own protests of the MDA telethon. Laura Hershey, another former MDA poster child in Denver, organized a "Tune Jerry Out" protest of the 1991 telethon.

Another issue regarding telethons was financial. Many activists and others were concerned by the small percentage of the funds raised that were actually used for medical research or disability services. The *Disability Rag* reported that the executive director of MDA was one the highest paid charity executives in the United States. Telethon protesters also targeted corporate contributors to telethons. They asked them to give their donations through some other venue. They never asked contributors to give less money to the MDA, just not to make donations via the telethon. Jerry's Orphans and the disability rights group ADAPT (American Disabled for Attendant Programs Today, also called American Disabled for Accessible Public Transit) spoke with many of the MDA's corporate sponsors and requested that they not appear on the telethon; however, most corporate sponsors did not honor the request.

The other major event that helped society at large to understand the stigma of telethons was the Americans with Disabilities Act (ADA) of 1990, which mandated equal rights for people with disabilities in most aspects of society from transportation to employment to building access. However, Jerry Lewis refused to change his language or behavior on post-1990 telethons and would not take the concerns of disability activists into consideration, according a *Vanity Fair* article. The article also cited some praise for Lewis from his "kids." Stephen Mikita, an assistant attorney general in Utah and one of "Jerry's kids," said that he was proud to be called one of "Jerry's kids." He said the term shows that Lewis cares about people with muscular dystrophy as if they are his own family. Mikita added that Lewis was one of the first people to bring disabled people out into the open. "Lewis spoke about persons with disabilities, and embraced persons with disabilities, long before it was politically correct or in vogue to do so," Mikita said in the 1993 *Vanity Fair* article (p. 92).

Although Jerry Lewis did not change his rhetoric, the MDA telethon began making some changes after 1990 to reflect a society that now had the ADA. For example, the 1992 telethon featured more empowering video profiles of adults with muscular dystrophy working and making their way in the world. One video profile featured Matt Schuman, a former poster child, working at his job as a sports reporter for the *Greeley Tribune* in Colorado. The MDA telethon also changed in length by the late 1990s. Depending on the TV station, the telethon shrunk to just a few hours, rather than a day and a night of programming.

However, controversies involving Jerry Lewis's comments continued. In 2001, while being interviewed by the CBS *Morning Show,* Lewis defended the pity approach to getting telethon donations. "I'm telling you about a child in trouble. If it's pity, we'll get some money. I'm giving you the facts. Pity. You don't want to be pitied because you are a cripple in a wheelchair, stay in your house," Lewis said on the May 20, 2001, CBS *Morning Show,* as reported in *The Washington Post* (p. C1). After these comments, he issued an apology, saying he did not mean what he said. The MDA issued a statement distancing itself from Lewis and his comments, explaining that they did not reflect the views of the organization or its leaders.

—Beth A. Haller

See also ADAPT; Americans with Disabilities Act of 1990 (United States); Charity; Easter Seals; Poster Child; Franklin Delano Roosevelt; Television.

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▣ TELEVISION

The portrayal of disability on television shares traits with that of literature, drama, and film. Most typically, a disabled character appears on the small screen as a background figure, to provide comic relief, or to increase a sense of crisis. Although a number of made-for-television movies feature disability as a predictably melodramatic central concern, requiring cure and mourning while representing loss or enhancing the seeming mental fitness of other characters, more widely watched television shows rarely have disability as a regular central theme. Interestingly, disability has more prominence within the science fiction genre on television, indicating that a higher degree of fantasy allows for a higher degree of disability representation. Exaggerating this feature, the wave of offbeat comedies, often animated, in the late 1990s and early 2000s, such as *South Park, Malcolm in the Middle,* and *Family Guy,* frequently represent disability in an openly aggressive, perhaps satiric way that depends highly on the genre's clear distance from realism.

There are a number of stock plots that incorporate disability on television. The most frequent involves cure, in part because so many television shows are set in medical environments (e.g., *St. Elsewhere, ER, Scrubs*). Another common plot involves disability fraud. This shows up both in situation comedies (such as *Seinfeld*) and in dramas, especially those that feature the legal professions, both police and law, prominently (e.g., *Hill Street Blues, LA Law, Law and Order, CSI*). Disability arising from tragic accident or illness surfaces throughout television shows to create new, compelling interest on the part of viewers (e.g., *ER, The West Wing, Diff'rent Strokes*). Though not quite as laughable as the dramatic jumping of the shark tank on *Happy Days,* now widely recognized as a moment of television desperation, this spectacular turn to disability plots reinforces a popular misconception of disability as outside the bounds of everyday life.

DISABILITY AND DRAMATIC TELEVISION

Although predictably rare as central figures, characters with disabilities make periodic appearances in dramatic television productions, usually in minor roles. In their study of a six-week period in which they viewed 1,286 dramatic prime-time British television shows, Cumberbatch and Negrine found that 1.4 percent of the shows portrayed a disabled character with a speaking part. A recent greater social awareness of the prevalence of disability, enhanced by the advocacy of such actors as Michael J. Fox, has increased the prominence of disability in television. However, as is the case in most narrative forms, disability is often present on dramatic television but is rarely adequately explored. Most often, disability invites humor, moves along a tired plot, or helps to provide insight into able-bodied characters.

Television dramas that do have a continuing character with a disability often turn to that trope to signify human fallibility. Wheelchair-using Robert T. Ironside's relationship with black caregiver Mark Sanger presents disability prominently as dependency. *Wiseguy*'s Daniel Burroughs, a mentor who is an apparent paraplegic and wheelchair user, plays on the stereotype of the intellect with the frail body. (Interestingly, on *Highlander,* the same actor also portrays a wheelchair user, in this case a Vietnam war veteran.) In *LA Law,* Benny's developmental disability allows other characters to seem helpful and sympathetic.

Television drama also takes the opportunity to turn to disabled characters to make a political point. For example, the 1992–1996 David Kelley vehicle, *Picket Fences,* Zelda Rubenstein portrayed short-statured receptionist Ginny Weeden (the show also included Marlee Matlin as a deaf character and Robert Cornthwaite as an elderly character with Alzheimer's disease). NBC's popular prime-time drama *The West Wing* debuted with a daring representation of the injured president predicting the physical fallibility encapsulated in a vague bad back the show continues to feature. Later, the president's controversial choice not to disclose his diagnosis of multiple sclerosis foregrounds the politics of disability identity along with the public signification of disability as a marker of fallibility. *Law and Order*'s repeated featuring of assisted suicide plots raises questions of disability rights, if not always constructively.

The depiction of cure, or desired cure, of disabling conditions dominates prime-time drama. Despite the subtle portrayal of Dr. Carrie Weaver as physically disabled, a remarkable instance since her disability is never a central issue on the show, *ER* focuses most of its attention on cure. This becomes clearest when Dr. Romano has an arm amputated by a helicopter and angrily seeks all surgical means to normalize himself. The intriguing subplot that had Grissom becoming deaf, as his mother had been, and put sign language onto the *CSI* screen was cut short by his surgery that has now cured the otosclerosis. As in *ER,* this cured disability is balanced by the presence of a continuing character with a chronic disability (in this case the chief pathologist with an amputated leg). Similarly, *Joan of Arcadia,* invested as it is in the miraculous presence of God, still portrays medical science as the only hope (though a dim one) for Joan's wheelchair-using brother.

SCIENCE FICTION

Science fiction, with its frequent investment in mutant body forms, provides a sometimes restrictive and sometimes liberating view of disability. The familiar themes of cure and pity recur, but they are accompanied by some creative interrogations into the social (and sometime literal) construction of the body.

Star Trek continuously considers questions of differing bodily form and repeatedly returns to the idea that disability is contextual. The original captain of the Enterprise appears as a paraplegic in an episode that tries Kirk for misconduct. Though nonverbal, he communicates through a red and green light implanted in his chest. The original *Star Trek* series also features the famous episode "Plato's Stepchildren," better known for offering television's first interracial kiss than for the portrayal by Michael Dunn of Alexander, the dwarf jester. Levar Burton's depiction of Geordie La Forge on *Star Trek: The Next Generation* continues a relationship between racialized and ableist representation on this science fiction drama. La Forge "overcomes" his birth blindness by means of a VISOR that painfully requires such great focus that it also lends him incredible skill with warp engineering. This depiction is innovative in that he is at times less able and at times more able than characters without the VISOR, thereby contributing to a social constructionist or at least contingent model of disability.

Most often, science fiction television shows take familiar disability plots and add larger questions about the mutability of bodily form to their typical opportunistic forms. *Dark Angel* features the disabled avenger plot line, with a paraplegic mastermind, but he is one among mutants—with super and animal powers—so that he is rendered less powerful by comparison. The *X-Files* "Humbug" episode develops the freak-show plot and plays on Tod Browning's well-known "one of us" scene by having the small-statured ring master look at the always-dapper Mulder and say, "Ugh, can you imagine having to live your life like that?" Similarly, *Buffy the Vampire Slayer* satirizes disability stereotypes when Spike uses a wheelchair and when Xander has an eye poked out, so that disability is again the site of humor, but without being objectified.

DISABILITY AND SITUATION COMEDY

Cumberbatch and Negrine found that only 9 percent of British sitcoms in 1980 featured characters portrayed as having a disability, and they did so usually to make the character the object of humor. This has also largely been the case in American sitcoms, where a disabled character, very frequently in a wheelchair, appears for an episode or two and is either the butt of many jokes, the means by which other characters learn about themselves and get to feel at first embarrassed and then altruistic or at least enlightened, or both. For example, on *Happy Days,* Fonzie, who had experienced temporary disability himself after tearing the ligaments in his leg during a TV motorcycle stunt, and temporary blindness after being hit over the head, hires a disabled mechanic with a stereotypical chip on his shoulder. A wheelchair user, Don Konig has worked as a mechanic before being hit by a drunk driver, and he now needs Fonzie's help both in giving him work and in signing a social security form. The family's straightforwardness cures Don of his bitterness, and the episode ends in a friendly family meal. On *Diff'rent Strokes,* Arnold's wheelchair-using friend shows up in episodes focused on Arnold's unhappiness with his short stature. He learns the hard way, by trying to support his friend, that disabled people are stigmatized, and the whole Drummond family becomes more smug as a result.

Also a sitcom but crossing over into drama, *M*A*S*H,* running for 11 years, from 1972 to 1983, follows and influences a big-screen pattern of depicting war veterans coming to terms with their disabilities. Not only do countless young soldiers come through the 4077th in the hopes of surviving their frequently mortal wounds, but this long-standing drama/comedy includes one of the most memorable cases of disability fraud on television. In the first season, Hawkeye fakes a mental illness to obtain a leave but fails to get a diagnosis. Later, Klinger joins the 4077th and cross-dresses in an attempt to convince psychiatrists that he is unfit for service.

These patterns continue through sitcom production, where disability is rarely an ongoing concern but shows up to move the plot along or just create a new site of humor. Almost every popular sitcom has an episode about a disabled guest character. *Becker* is unique in that it features a continuous character who is blind (played by a sighted actor).

ANIMATION

Disability plays an at times troubling role in a series of late 1990s and early 2000s adult animation television programs that are not only removed from the conventions of realism but also deliberately created in bad taste. *Family Guy* offers an easily duped ex-cop who is in a wheelchair. *South Park*'s Timmy, a young boy with cerebral palsy, is the butt of jokes because of his tendency to say his own name repeatedly. He propels plots that present disability themes, including a satire on Christopher Reeve as "fake disabled," but mostly he is even more ridiculous than other *South Park* characters because of his cerebral palsy. *Quads* focuses entirely on disability but does not forward any particular critique or expression of disability identity in doing so.

DISABLED ACTORS

The most well-known disabled television actors are Marlee Matlin, who has been on 19 television shows, including *ER, Seinfeld, Spin City, Gideon's Crossing, Law and Order,* and *The West Wing;* Jim Byrnes, who has been on more than 20 television shows, including *Sliders, The Outer Limits, Highlander,* and *X-Men: Evolution;* and the late Christopher Reeve, who started his career on a small-screen soap opera, played a disabled war veteran on stage, and then returned to television after he became disabled himself.

Chris Burke, an actor with Down syndrome, played Corky Thatcher on *Life Goes On,* a 1980s family drama that features Corky being mainstreamed and fighting his own battles at school. Burke has also appeared on *ER, Touched by an Angel, Promised Land,* and *The Commish.*

While their status as actors may remain in question, a number of people with disabilities have appeared on reality television shows. One show, *The Littlest Groom,* made disability its central device by having a short-statured groom choose among average-sized and little women as his future bride. *The Amazing Race* included a short-statured competitor whose size was a distinct advantage in competition. *Survivor* has included one deaf competitor, who received some negative publicity from her friends at Gallaudet University for not signing during the show, and one character with a partially amputated leg. As with most television formats, reality television reflects both an increasing representativeness by including these characters with disabilities and also an exploitative thirst for the spectacle they produce.

ADVERTISING

As Ganahl and Arbuckle together with Haller and Ralph demonstrate, people with disabilities do not have adequate representation in television advertisements, though it is increasing. The rise in prominence is not resulting in more positive images, however. The most troubling examples include Christopher Reeve, in the prime Super Bowl advertising spot, depicted as cured and able to walk again. Similarly, Mothers Against Drunk Driving sponsored an ad with a young walking man purchasing a wheelchair. The implication is that he plans to drink and drive, and this will have the apparently horrifying effect of landing him in a wheelchair. These advertisements together signal the white, male physically disabled figure as the disability representative most likely to appear in advertisements that play on the general public's desire not to become disabled. The lack of televised coverage of the Paralympics as compared with the inordinate attention to athletic achievements of Olympians reinforces this imbalance.

—Sally Chivers and
Tiffany Potter

See also Advertising; Drama and Performance; Paralympics; Telethon.

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TEMPORAL LOBE EPILEPSIES

See Epilepsies, Temporal Lobe.

TENBROEK, JACOBUS

(1911–1968)

American Advocate for the Blind

Dr. Jacobus tenBroek, called "Chick" by friends and family, blinded at the age of seven in a hunting accident, was a charter member and the first president of the National Federation of the Blind (NFB), founded in 1940 in Wilkes-Barre, Pennsylvania. The NFB grew to become the largest advocacy group of blind people in the United States. TenBroek was a constitutional scholar who wrote academic monographs on the 14th Amendment, public policy (particularly as it pertained to welfare programs), and the nascent Social Security Administration and its impact on the blind. TenBroek waged a relentless war of words against publicly financed programs that purported to assist the blind but that were in fact, he asserted, institutions rife with paternalistic attitudes and designed to perpetuate the inferior status and indigency of the blind. TenBroek argued in favor of a pension for the blind that would not require means testing as did social security. After earning a law degree and a doctorate in public policy, tenBroek taught speech and political science at the University of California at Berkeley for 25 years.

As a boy, tenBroek studied with Newell Perry at the California School for the Blind in Oakland, California. Perry mentored a generation of leaders that would found the California Council for the Blind in the 1930s, along with a handful of other state advocacy groups that would coalesce into a nationwide movement of blind activists. TenBroek would galvanize this generation of activists and draw them into the NFB under his leadership.

TenBroek served as president of the NFB from 1940 to 1961, when he resigned at the NFB national convention in Kansas City amidst a firestorm of dissension among a number of NFB state affiliates. By resigning, tenBroek managed to quell this dissent and put in place the next generation of leaders who he felt best represented his vision for the organization and the broader movement.

—Brian R. Miller

See also Advocacy; Blind, History of the; Blindness and Visual Impairment.

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TERATOLOGY

In the twenty-first century, freak shows are more about performance than somatic oddity. Suspension of disbelief must accompany the exhibit that purports to be a cross between species, and even the most naïve person knows that unusual physical features such as extra limbs or variant statures do not result from supernatural forces. In the ancient world, people were not equipped to understand physical configurations as we do in the modern world, and ancient scientific thought provided no reason to disbelieve the combination of a horse and a man or the existence of a human with a hundred hands. Monstrous beings—*terata,* in Greek—usually inhabited lands around the edge of the earth and the mythological past. Monstrous beings also inhabited the Roman imagination: Historians of the Roman world frequently reported monstrous births as portents.

A distinction must be drawn between people with disabilities and monsters. People with disabilities comprised a significant proportion of the ancient landscape, and an ordinary community member who had some sort of disfigurement would not have been considered to be a monster; indeed, the unknown characterizes the monster. In the ancient world as today, physical configuration alone does not make a monster; rather, a confluence of social forces defines what lies within the bounds of human normality and what lies outside it. Plutarch, the first century AD biographer, refers to a Roman "monster market," where one could buy human oddities such as people with three eyes. This may have been a market in which people with variant bodies were sold and may have doubled as a sort of freak show; it must have had as much to do with salesmanship and showmanship as with somatic variation.

Monsters lend order to the world by defining the boundary of normal human parameters. The ancient world was not guided by the statistical bell curve of the eighteenth century; instead, the monster delineated physical normalcy by reflecting its antithesis. In the fourth century BC, in *Generation of Animals,* Aristotle described *monstrosity* as the failure to resemble a human being at all. Monstrosities, in Aristotle's view, included aberrations such as animal heads on human bodies or humans with extra heads.

In addition to defining physical normalcy, monsters also reflect social and moral bounds of their culture. Robert Garland (1995), in *The Eye of the Beholder,* argues that the Roman emperors, often reported to have people with physical anomalies amongst their courtiers, were themselves in the category of the monstrous. Sexual ambivalence, too, was seen as a monstrosity, as argued by Luc Brisson (2002).

A collection of essays on monstrosity in the Graeco-Roman world (the majority on the Greek world) can be found in Catherine Atherton's (2002) *Monsters and Monstrosity in Greek and Roman Culture.*

—M. Lynn Rose

See also Monsters.

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THALAB THE GRAMMARIAN

(ca. 845–904)

Iraqi grammarian and philologist

Abu 'l-Abbas Ahmad ibn Yahya ibn Zaid ibn Saiyar, more briefly known as Thalab, became the foremost grammarian and philologist at Kufa in Iraq. Even in his youth, reference was made to him as a reliable source of accurate knowledge. In his later years, he lost most of his hearing. One Friday afternoon, he left the mosque and was walking along the street while reading a book "when a horse knocked against him and threw him into a deep pit, out of which he was taken nearly senseless." He died in Baghdad the next day.

—Kumur B. Selim

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TIMUR THE LAME (1336–1405)

Tatar Warrior

From 1369 until his death, the Tatar warrior Timur Lang (the Lame) led his army through north India and central and west Asia, enlarging his dominion from Aleppo through Baghdad, Shiraz, and Hormuz in the south, bounded eastward by the Indus, and stretching north to the Aral Sea and much of the Caspian coast. He died while marching on China. Contemporaries mention his lame right leg and arm, from battle wounds or a youthful sheep-stealing incident. Examination of his skeleton in the 1940s confirmed the lameness. Memoirs attributed to Timur include a description of leading troops through snowbound mountains and being lowered down a precipice in a wicker basket attached with long ropes. He experienced rheumatic pain during such campaigns but drove himself on. A story has Timur laughing at Sultan Bayazid, who he had captured. Bayazid reminded Timur that the rise and fall of kingdoms was in God's hands. Timur replied that he was laughing at their mutual ugliness, because God gave kingdoms indifferently to "such ugly Fellows as we are, you a squinting clown, and I a lame Wretch."

—*Kumur B. Selim*

See also The Lame.

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TOKENISM

In modern industrial societies, people with disabilities have been widely underrepresented publicly and in the workforce, especially within white-collar professional jobs and other high-status positions in the media, government, and business. Within labor markets based on segmentation and hierarchy, very few people with disabilities have been able to break through what feminist discourse has labeled the "glass ceiling," into the upper echelons of leadership and power. Indeed, in most developed societies, a large majority of people with disabilities are denied employment altogether, curtailing their cultural participation as effective and self-determined individuals.

Unfortunately, the underrepresentation of large numbers of people with disabilities inevitably puts tremendous pressure on those in the public eye to embody a type of disability overcoming. From a historical perspective, famous high-achieving individuals with disabilities, such as reformer and writer Helen Keller and U.S. President Franklin Roosevelt, have been represented as inspirational examples of success against great personal obstacles. Similarly, figures such as Vincent van Gogh and Virginia Woolf are appreciated for their tremendous genius, while their experience of mental illness is separated out as a tragic fate. In such cases, disability is understood as an impediment to be overcome, rather than as an intrinsic component of one's individual work, art, or social perspective. Of course, while overcoming narratives are misleading and destructive in their own right, social interpretations of the vast majority of people with disabilities revolve around discourses of dependency, tragedy, and victimization.

Within this framework, contemporary public figures with recognized disabilities tend to be positioned within a binary construct—as either an extraordinary role model or an embodiment of the tragic nature of disability. Stephen Hawking's scientific genius seems to "transcend" his disability. On the other hand, Jerry Lewis's telethons, which feature the tragic stories of "poster children" with muscular dystrophy, perpetuate a belief system that invalidates the agency of people with disabilities. These reductive perspectives are indicative of the way disability tokenism functions. Out of this socially manufactured binary, individuals with disabilities who do gain power and influence are represented within public discourse as the "truth" of disability. Within this framework, they are living in a problematic double bind: If they succeed, the media may broadcast false expectations of other people with similar or dissimilar impairments; if they fail, they can be used as a rationalization for further broad-based discrimination.

Feminist scholars have described gender tokenism as a process of granting power and privilege to a few while withholding it from the vast majority of women. In this way, it appears that if one is truly qualified, that person can achieve any position she desires. The tokenized person is used by the establishment as (faulty) evidence that a system of justice based on personal merit is intact. The visible success of very few people is used to displace the social reality that the vast majority of people with disabilities lack the resources, opportunities, and support to experience the kind of success promised by this gesture of tokenism.

In effect, without support from a community of allies and other people with disabilities, people who are put in positions and expected to represent disability are set up to fail themselves and their community, because either outcome distorts any real relationship to the diverse and complex heterogeneity that disability represents.

—*Michelle Jarman*

See also Employment; Feminism; Helen Keller; Franklin Delano Roosevelt; Vincent van Gogh; Virginia Woolf.

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TRAINING SCHOOLS

In the United States, training schools were institutions erected to house some of the children designated as feebleminded. They appeared mainly during the later part of the nineteenth century and the early decades of the twentieth century. Historically, they emerged as in-between sites, formalizing generally after the earlier East Coast asylums and religious-based charity institutions and before the special education classes funded under the auspices of public school authorities. By the early 1900s, scholars such as Henry Goddard of the Vineland Institute of New Jersey on the East Coast and Lewis Terman of Stanford University on the West Coast were arguing that 2–3 percent of the U.S. population were classifiable as feebleminded.

Training schools were initially institutions to which parents, for the most part, had to be persuaded to send their children. For most social groups in the United States at that point, voluntary segregation of the young from immediate family was generally not a preferred cultural experience. As such, welfare experts, religious workers, and concerned donors established rigorous programs of persuasion to segregate feebleminded children and place them in the new institutions.

The overt nature of this effort indicated a refiguration of the relationships that constituted the state. The shift in relationship structures, especially within families, was often commented on in two key sites where the successes and failures of training schools were reported. Two national conferences held annually in the United States documented these efforts across states and are important to note (published proceedings are available): the National Conference of Charities and Corrections and the National Conference on the Education of Backward, Truant, Delinquent, Dependent, and Defective Children. In addition, journals focused specifically on feeblemindedness, such as the *Training School Journal* and the *Journal of Psycho-aesthenics,* stood alongside more broadly conceived journals concerned with education in general, such as G. Stanley Hall's *Journal of Genetic Psychology* and *Pedagogical Seminary,* both of which frequently contained articles on feeblemindedness and degeneracy. (G. Stanley Hall was a founder of the *American Psychological Association* and a leading exponent of the child study movement.)

The new relationship of children to statehood was borne out in such documentary sites. These sites of information exchange are particularly significant for understanding how feebleminded children were constructed and imagined in relation to training schools and, in turn, nationhood. Under discourses of scientifically managed citizenship and a competitive eugenic philosophy, the routes through which human bonding could proceed and the methods for getting things done had changed. The child-adult binary had been refigured through the establishment of a variety of institutions that separated the young from each other and their elders, such as children's hospitals, schools of different kinds, and youth clubs, all of which were often further segregated by race in their establishment or operation. While all the young were now to be thought of as vulnerable, ignorant, segregable, and delayed from responsibility, children designated as feebleminded were made to embody the perpetuity of these features symbolically and to represent an apparent threat to the strength of the nation.

The variety of training schools that existed indicated an uncertainty over the minutiae of this logic but reflected a common dedication to segregation. Different schools had different functions. In a 40-year period around the turn of the twentieth century, training schools were one of several sites to which children labeled feebleminded could be allocated, depending on local laws and availability. For example, children could be assigned to (1) publicly funded training schools, some of which taught manual labor tasks; (2) privately endowed training schools; (3) philanthropic institutions more overtly concerned with segregation and medicalization; (4) state-care medical institutions that did not assume themselves to have pedagogical functions, including asylums; or (5) special classes either attached to a public school or centralized in a separate building within a given school district. In regard to training schools specifically, some had more of a "warehousing" function, while others placed an emphasis on manual training designed to "mitigate" the effects of feebleminded children on the larger group of citizens. Training schools were thus also "in-between" institutions, not only in terms of when they emerged, but insofar as the children sent to them were sometimes considered to be liminal—trainable but not educable, with manual or vocational labor being the only kind offered, if at all.

Because training schools emerged as part of a proliferation of formal segregating institutions, their role has been viewed in ways that go beyond their specific or intended internal functions. Earlier forms of segregation, such as reservation systems and slavery, were followed by other forms, such as asylums, prisons, orphanages, schools for Deaf and Blind, industrial schools, centers for juvenile delinquents, and training schools. Historians of education such as John Richardson (1999) have suggested that compulsory attendance legislation would not have been possible without this prior experience of confinement. By 1918, all existing U.S. states had compulsory attendance legislation, which was less about a commitment to elementary public schooling and more about who was *not* allowed to attend. In sum, training schools, alongside other prior institutions, had several kinds of purification purposes: (1) reforming state relations: they were believed to purify the child of familial influence by removing them and opening them to expert governance; (2) production and reproduction: to purify the wider population from "having to see" feebleminded children, with the hope of ending the reproduction of feebleminded people while simultaneously molding cheap, productive laborers; and (3) defining the citizen and the public: to purify state-funded "regular" or mainstream schooling by offering segregated spaces that made possible a more narrow definition of who the public was in public schooling.

—Bernadette Baker

See also Education and Disability; *Feeblemindedness*; Henry Herbert Goddard; Special Education.

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TRANSGRESSION

Transgression is a form of resistance involving the crossing of limits or boundaries. It is not antagonistic or aggressive, nor does it involve a contest in which there is a victor; rather, transgression is playful and creative. Among disabled people, transgression has been a significant means of challenging limits and disabling barriers. Disability activists have been involved in a long campaign of direct action against disabling barriers, whereas transgression has been a more indirect and subtle form of challenge by disabled people.

The concept of transgression has been elaborated extensively by Michel Foucault, who was interested in Kant's critique of limits but wished to pursue more practical (and political) forms of engagement. Foucault saw transgression as distinctively different from transcendence or transformation: He did not envisage individuals as gaining absolute freedom from limits, as transcending, or as finding a new self. Instead, he suggested that individuals, in crossing limits or boundaries, might find moments of freedom or of otherness. Foucault's account of where transgression takes place is somewhat complex. In his "Preface to Transgression" (1963), written as an introduction to the work of Georges Bataille, he argues that "it is likely that transgression has its entire space in the line it crosses" (Foucault, 1963/1984, p. 73). This implies a boundary that can only exist if it is crossed. The limit and transgression depend on each other, but the relationship is not a simple one; rather, Foucault explains the relationship as being like a spiral, with moments of crossing of the limit appearing as flashes of lightning in the night that give a darkening intensity to the night they obscure. He also describes the interplay of limits and transgression as being regulated by a simple obstinacy. The act of crossing the limit does not violate it, but simultaneously affirms and weakens it. Foucault regards this as a form of nonpositive affirmation, which has to be constantly repeated, and likens it to Blanchôt's notion of contestation, which does not imply a generalized negation, but an affirmation that affirms nothing. A more positive version of transgression was developed by Foucault in the shape of practices of the self, whereby individuals set about changing their own selves.

Derrida sees transgression as being achieved in deconstructive readings of texts, which cross the protective limit given by traditional readings. It involves going beyond the first reading of a text and examining its ambivalences, contradictions, and slippages. Deconstruction transgresses against the protection that a traditional reading affords, by reading against the grain, exploring alternative meanings, and considering how the text itself *performs.* The playful nature of deconstruction and the transgressive forms of writing that are often adopted has provoked some criticism about its acceptability as a form of scholarship and has even led to the publication in *Social Theory* of a hoax article by Alan Sokal entitled "Transgressing the Boundaries: Toward a Transformative Hermeneutic of Quantum Gravity." However, those practicing deconstruction maintain that the transgressive strategies may be playful, but their intent—to challenge assumptions, orthodoxy, and dogma—is deadly serious.

Foucault uses sexuality to illustrate transgression, arguing that since the writings of Sade and, more recently, Bataille, sexuality has been a fissure that marks the limit within us and designates us as a limit. Foucault has been criticized extensively for failing to provide empirical examples of his concepts, and indeed, his discussion of sexuality provides little guidance into the practical pursuit of transgression. It has been suggested by one of Foucault's biographers, however, that sexuality is one area in which he did in fact experiment, and his own testing of the limits of homosexuality involved promiscuous behavior that led to his premature death from an AIDS-related illness.

Nevertheless, transgression has been viewed as an attractive construct in relation to marginalized and oppressed groups, as Foucault points out, not least of all because "it serves as a glorification of what it excludes" and forces recognition of exclusion. For those who transgress, according to Boyne (1990), "otherness lies ahead" (p. 82), and this allows individuals to shape their own identities by subverting the norms that compel them to perform repeatedly as gendered or disabled subjects. They are not required to—and indeed could not—reject these identities entirely, but they can vary the way in which they have to repeat these performances. Researchers studying transgression have uncovered strategies in which new mothers have avoided both breast feeding and the wrath of the health visitors checking on them. Within disability, it has been suggested that self-help groups for "ME sufferers" (those with myalgic encephalomyelitis/chronic fatigue syndrome) enable them to transgress against the regulatory norms that inscribe their bodies differently. Research with disabled students by Allan in 1999 documented the ways in which they transgressed both in and out of disability. Transgressive strategies that moved the students away from a disabled identity included using humor to put peers at ease, pretending to be "blind drunk" rather than drunk, or avoiding going to the toilet; acts of transgression toward disability included claiming a more disabled label and requiring peers to provide help. Teachers were generally unsympathetic to, and critical of, the students' transgressive practices, tending to read these as evidence of students' failure to accept the "fact" that they were disabled. There appeared to be a clash of discourses within the school, between, on one hand, the students' discourse of desire, within which they practiced transgression, and, on the other hand, the teachers' discourse of special educational needs, within which they provided support.

Disability arts represent a particularly creative and innovative form of transgression. They celebrate difference but also seek to subvert the normality genre by using the body as a weapon to subvert and undermine disabling barriers. Disability arts deploy difference strategically and involve individuals portraying themselves as aesthetic objects, through dance, photography, art, and other cultural forms. One powerful example comes from Cheryl Marie Wade, who, in her poem "I Am Not One of the," reverses beauty and ugliness, portrays herself both as a sexual object, with lace panties, and as deformed, with a stub, and demands a presence that has hitherto been denied. In "Crip Pride," Jessie Aaron presents herself and her "family" of disabled people as subjects with sexualities. She offers solidarity and difference as a response to the rejection she and others have experienced. Both writers assert their sexual and gendered identities in playful ways that challenge the desexing discourses of disability. Their transgression, therefore, has an impact on their own identities, but also on those who read the poems and who are forced to examine their own normalizing and disabling knowledge and actions.

Foucault acknowledges a "difficulty with words" that hampers philosophy and sees the absence of a language with which to talk about transgression as inhibiting its practice. Nevertheless, he expresses his hope that one day transgression will be as much a part of our culture as contradiction was for dialectical thought. Bataille also looks forward to the normalization of transgression whereby silent contemplation would be substituted with language (Foucault 1984). It could be said that transgression is indeed part of everyday culture, albeit denoting some marginal activities: A web search suggests that transgression has become synonymous with forms of eroticism and "deviant" sex. Transgression is also prevalent in the arts: Anton Chekhov's short story, Kate Jordan's play, and a film written and directed by Michael diPaulo all have the title *Transgression,* and Joyce Carol Oates's collection of short stories is entitled *Faithless: Tales of Transgression.*

Transgression appears to provide an important way for disabled people to engage playfully with limits imposed on them by a disabling society. It seems to provide scope for challenging the very existence of some of these limits and for self-transformation. Transgression operates within a discourse of desire, and this discourse has to be extremely powerful to speak against the needs-based discourses that dominate disability services.

—Julie Allan

See also Dance; Disability Arts; Drama and Performance; Film; Michel Foucault; Poetry.

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TRANSITIONS IN EDUCATION AND EMPLOYMENT

Transition generally refers to any process that characterizes an evolution resulting in something new or different from that which was before. It may express the process of change in form, as in the shape or structure of the human body as it grows or ages, or it may refer to the process of changing emotional states, as in the swing from a normal to a depressed emotional state. In any case, *transition* is the term we use to label the process of change, reflecting the movement from one set of identifiable characteristics of something or someone to a new set of identifiable characteristics.

In the past two decades, *transition* has been the term used in education, particularly vocational education, to refer to the process of helping secondary education students become "work ready." In this context, transition includes all of the efforts of schools to modify and improve their vocationally oriented practices that more directly and effectively prepare students for the world of work. It refers to system-level efforts, including curriculum reform, changes or additions to course offerings, and enhanced work experiences. It quite literally refers to any effort by schools to influence and improve the potential for their students to achieve positive vocational outcomes. Transition from school to work, as it is often called, is the application of those practices referring to the transformation process of being school oriented to being work oriented.

The term *transition* has a more specific and formal meaning in special education. In this context, transition not only refers to the general school-based process of preparing students for the world of work, but also denotes a component of the individualized education plan (IEP) of students aged 14 and older. Thus, transition refers to improvements in "system" practices as well as to the application of those practices to individual students. Students with disabilities (who have an IEP) are required to have a formal transition plan as part of their education plan. The purpose and focus of the transition plan are to ensure that appropriate steps are in place that will lead to successful integration of students with disabilities into adult living environments, with special emphasis on work and post–secondary education settings.

TRANSITION AND STUDENTS WITH DISABILITIES

The concept of transition in special education has its roots in the early 1980s, when parents and advocates of students with disabilities began to voice concerns about the employment prospects for their children. The U.S. Education for All Handicapped Children Act (P.L. 94–142), which called for a free and appropriate education for students with disabilities, had been in place for nearly a decade. Evaluation data regarding its lack of effectiveness in stimulating the schools to adequately prepare students with disabilities for adult living and the world of work were beginning to mount and raised serious concerns among parents and advocacy groups. The facts that schools were now required to provide appropriate education to students with disabilities together with the accumulating data revealing the apparent lack of preparation for work and adult living led to sustained advocacy efforts to get the schools to include school-to-work transition planning as part of the educational plan for every secondary-age student. That advocacy effort culminated in the Individuals with Disabilities Education Act (IDEA) of 1990, which also mandated schools to incorporate into each student's IEP an outcome-oriented statement about transition services.

IDEA describes a transition plan as an outcome-oriented process that leads the student to successful linkages with the adult community. Successful linkages include postsecondary education; vocational training, integrated employment, or continuing adult education; adult services; or independent living and community participation. The entire emphasis of transition planning is to ensure that when the student exits the school setting—thus absolving the school of any further IEP responsibility—he or she has a direction and is effectively engaged in the adult environment. Practically, given individual interests and abilities, that could mean the student is working (has a job), is engaged in vocational rehabilitation services, is enrolled at a college or university, or is doing all three. Equally important, transition planning is intended to convey that students are linked with the community and community services in such a way that they have as much control over their lives and daily living as possible or are moving toward self-directed independence and independent living.

THE FOCUS OF TRANSITION PLANS

Transition plans embody a comprehensive and often complex strategy for bringing about the successful movement of students with disabilities from school to work and adult living. Comprehensive plans consider the wide range of programs in the workforce development system (including the school) that should play a role in bringing individual student success. In doing so, successful transition plans are characterized by four common elements: They are student centered, incorporate input from and identify critical stakeholders in the transition process, reflect interagency collaboration in meeting student needs, and address the broad range of student needs that will lead to successful transition.

The foundation of a successful transition plan is a genuine student-centered planning process. Successful transition plans reflect a clear and strong commitment to the goals, interests, and dreams of the student. Schools are obliged to work with the student through testing and assessment to determine his or her strengths and interests in order to articulate the intent, focus, and chief outcomes of the plan. The more closely the plan is tied to the goals of the student, the more likely its success will be. As plans are developed and modified over time, the student's goals and interests remain the centerpiece in the planning process. Successful transition plans take on appropriate detail depending on the interests, abilities, and needs of the student. No two plans are alike.

Stakeholder input and participation in plan execution are key characteristics of successful transition plans. Stakeholders can include the student, family members, teachers and other relevant educators, adult service providers, and relevant community members (e.g., advocacy groups) as appropriate and needed. The challenging aspects of stakeholder involvement are identifying the individuals who can play a key role in the development and execution of the plan and the timing of their involvement.

The third characteristic of successful transition plans is interagency collaboration. Involving the schools alone in the transition planning process is considered to be shortsighted and ineffective when adult service providers can supply key insight and services that can offer the student real-world experiences. Thus, it is imperative that schools involve agency representatives in planning both content and timing. In addition, plans should describe the details of how students will be linked to adult and community service agencies. At a minimum, the plan should include representatives from vocational rehabilitation services and the local workforce development system. In the United States, these are now called the "one-stop" employment development agencies. Other agencies that may play a role in transition planning and execution include mental health services, developmental disabilities, local centers for independent living, and the myriad of community-based services.

The fourth characteristic of successful transition plans is the focus on the broad range of student development needs. All students, whether bound for college or sheltered employment, will need assistance to meet the broad range of adult living requirements. Thus, transition plans should reflect the activities that are needed to meet those requirements, including consideration of life skills instruction, career and vocational exploration, structured work experiences, and support services.

THE TRANSITION PLANNING PROCESS

Transition planning typically begins when the student reaches high school age. IDEA mandates the development of a transition plan at age 14. The general idea is that the plan is first articulated early in the student's high school experience and is refined over time to reflect new information, changing demands, and refined interests. Successful plans result from planning activities that are open and participatory, ongoing, and centered on the goals and interests of the student. The process is open in that it involves individuals who have and feel a stake in the success of the resulting plan. The planning process is controlled by interested stakeholders, including the student for whom the plan is designed. All stakeholders provide input to the plan and share in the responsibilities for carrying out the plan.

Successful transition plans are dynamic and undergo periodic review to assess progress. They rarely remain static from initiation to completion, as opportunities and environments change over time. To take advantage of new opportunities, stakeholders should periodically assess progress of the plan toward the intended goals, review activities and supports, and revise as appropriate.

—William D. Frey

See also Education, College and University; Education, Primary and Secondary; Education and Disability; Employment; Individualized Education Plan; Individuals with Disabilities Education Act of 1990 (United States); Sheltered Employment; Special Education.

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TRANSLATING THEORY AND RESEARCH INTO PRACTICE

The issue of translating theory and research into practice is ultimately one of disseminating and utilizing research findings. Through the dissemination and utilization of theories, practical programs implement and test new theories on varieties of populations and situations. The iterative nature of this process requires a constant dialogue between researchers and practitioners. While so-called pure research may be valued in the quest for knowledge in and of itself, applied research on disability, for example, presumes that individuals with disabilities, their family members, researchers, policy makers, and activists will be able to utilize those theories and findings in their own lives or professional work. To those ends, translating theory into practice is an important issue for many applied fields that work with and serve members of disability communities.

This entry has three objectives. First, five dimensions of dissemination that influence the utilization of new knowledge will be explored to suggest factors that should be considered during the dissemination process. Second, two models of information integration will be detailed to explore how practitioners incorporate new knowledge and processes. Finally, the implications of these components for integrating research findings into practice will be briefly discussed.

DIMENSIONS OF DISSEMINATION

Based on a literature review, the National Center for the Dissemination of Disability Research (NCDDR) identified four key dimensions that affect the acceptance of new theories and knowledge. The first dimension is the source of new knowledge: Where is the information coming from? This dimension speaks to the information source's credibility. If the information is from a reputable institution or researcher, the findings may be more readily accepted and integrated into the daily activities of an individual or agency. However, if the information originates from unknown or dubious sources, the information consumer may quickly disregard the findings. Indeed, the source of information is often more important than the actual information presented.

Second, the content of the disseminated message impacts whether it is incorporated into practice. While the previous dimension focuses on the quality of the information provider, this dimension focuses specifically on the message. To gauge the quality of the information, an individual must weigh the content against existing knowledge to see whether their experience confirms the theory. As consumers of information, people are constantly weighing new theories and messages against preexisting knowledge. As these messages cohere with previous knowledge and experience, the information will be accepted and implemented.

Third, the medium through which the theory is conveyed can affect its utilization. This dimension concerns how the material is disseminated. Perhaps the largest breakdown in theory implementation occurs in this dimension. For researchers based at colleges and universities, their positions often require them to present research findings at academic conferences or in scholarly journals. These venues may not be appropriate locations or formats for members of disability communities, practitioners, or agency staff. Research findings must be presented and conveyed in accessible formats and locations to assist in broader practice implementation. During the past several years, the Internet has made knowledge dissemination much faster and more accessible through web pages and an increasing number of online journals. However, with so much information coming from so many sources, people are forced to critically evaluate the credibility of information now more than ever.

Fourth, the users receiving the knowledge affect how the theories are translated into practice. As the

NCDDR suggests, facilitating a user's utilization of knowledge can be accomplished in two primary ways. First, the materials need to be relevant to the user's daily life. Second, the user must be ready to accept the information. Thus, from the information receiver's point of view, knowledge is more likely to be implemented as its utility increases. Within some academic fields, researchers have addressed issues of utility through participatory action research that incorporates the potential users of the information not only in selecting research questions, but also in developing theories and methods to answer those questions. Research suggests that through this collaboration, users and agencies are more likely to utilize the research findings.

A fifth dimension to the implementation of information that the NCDDR did not mention is the speed at which the information arrives to practitioners. The time lag between the research project and the dissemination of research findings can make the information out-of-date by the time practitioners and agencies receive it. This time lag occurs at numerous stages of the research and dissemination process. For example, when looking at possible racial and ethnic discrimination in vocational rehabilitation (VR) services in the United States, many of the articles that were published in 2002 and 2003 relied on information from the 1996 and 1997 Rehabilitation Services Administration's database, RSA-911. This lag of approximately six years could make the findings useless to VR practitioners and agencies as policies and administrations remain in flux.

MODELS OF INFORMATION INTEGRATION

The literature suggests two primary models to explain how theory is adopted into practice. First, the agricultural extension model suggests that people adopt new models for pragmatic reasons. If the theory produces a more efficient and efficacious means of getting outcomes, then it should be utilized. Second, the constructivist model indicates that people will adapt new methods only when their old methods fail and the new method reflects their experiences. Therefore, the first model can be seen as more of an objective approach and the second model as more of a subjective approach.

Agricultural Extension Model

The agricultural extension model developed as a model of translating theory into practice following patterns established in agriculture. This model focuses primarily on spreading the word of successful interventions. For example, in pharmacology, Viagra initially began as a treatment for high blood pressure and was used on young, male medical students. While the drug was successful at reducing high blood pressure, it also had an adverse side effect of an erection. Now the drug not only is used generally for men with impotence but also is used for men with spinal cord injuries to enhance their sexual functioning. Through that process, the use of Viagra spread from people with high blood pressure to older men with erectile dysfunction to men with paraplegia and tetraplegia.

This agricultural extension model also establishes "best practices" paradigms in fields such as public health and medicine. However, this model presents a narrow notion of knowledge dissemination. For example, the agricultural extension model assumes that the environmental and individual factors will be the same despite any differences that may exist between the initial study site and future sites where the knowledge may be applied. For this reason, some researchers in the literature have called for "best practices" to be considered "best processes" so that environmental and individual variables can be better considered in utilization. Indeed, this transition contextualizes the processes within the specific situations and reminds users to consider that context when adapting those processes.

Constructivist Model

The constructivist model is primarily concerned with how dissemination fits into the process of learning. This model considers how individuals and groups assimilate knowledge based on how well it blends with previous experience. Essentially, learners accept knowledge if it meshes with their personal experience and reject knowledge if it does not mesh with their experience. As a consequence of this model, people are likely to maintain the status quo unless faced with a problem. This stagnancy further detracts from possible innovations that may develop during process improvements. A possible way to counteract this stagnancy and push for innovations is to maintain cross-disciplinary teams to introduce theories from different fields when considering new practices.

CONCLUSIONS AND SUGGESTIONS

This entry has examined important factors in the research dissemination process and models to explain why practitioners and agencies may utilize research findings. At least three suggestions can be made based on the dissemination literature. First, researchers need to make new information accessible to all levels of users (e.g., researchers, individuals with disabilities, families, activists, policy makers). Accessibility may mean publishing and presenting the materials differently to different groups. This implication follows one of the primary rules of writing: Always consider your audience.

Second, researchers need to ground their research in communities that may implement their findings. This activity accomplishes several goals. Not only does the researcher gain credibility in the community, but also the community will be more likely to utilize the research findings. Participatory action research has provided a useful model to assist with this process. By incorporating community members in all phases of research and maintaining this connection throughout the project, researchers may be able to disseminate their findings more quickly to the people who are most likely to utilize them.

Finally, researchers need to understand models that lead people to utilize research findings so their dissemination efforts can target those models. For example, if individuals only accept new theories when old theories fail them, then researchers disseminating new findings need to show why old theories no longer apply. This concentration on dissemination packaging is vital to increase the likelihood of translating theory into practice.

—*R. Noam Ostrander*

See also Research; Vocational Rehabilitation.

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TRAUMATIC BRAIN INJURY

Traumatic brain injury (TBI) is defined as any damage to the brain from an applied force. The forces involved can be from direct contact, as in blunt or penetrating head injury, from a gravitational source such as fierce shaking, or from rotational energy, as in shaken baby syndrome. Often, a combination of these forces is involved (a motor vehicle collision can cause both direct blunt trauma and rotational and rapid velocity changes). These events cause a deformation of the brain tissue that results in several types of pathology. In addition to the *primary injury* (caused at the moment the force is applied), a series of events is set in motion that continue to cause cellular damage over the next days to weeks, or even longer. These *secondary injury* events include a complex set of biochemical reactions and molecular changes that extend cellular damage, brain edema, and inflammation in a self-perpetuating cycle that rapidly increases the extent of the brain damage.

PRIMARY INJURY

Direct contact with the skull or brain is classified as *blunt trauma* (caused by, for example, a baseball bat or windshield) or *penetrating trauma* (from gunshot wounds, shrapnel, and knives). Blunt contact causes injury directly below the contact point. The impact can also cause the brain to move or shift back and forth inside the skull, damaging the opposite side of the brain, in a "contracoup" injury. The base of the skull is bony and rough and can cause tearing and bruising to brain tissue when it bounces back and forth. The extent of the damage varies depending on the intensity of force applied. The primary injuries that result are contusions (bruising of the brain tissue), tearing of the tissue and blood vessels, bleeding, tissue shearing, and disruption of neuronal networks. There are multiple types of contusions. Blunt head injury may be *open,* if the skull has been compromised to the point that brain tissue is open to the environment, or *closed.*

In addition to the direct blow, blunt trauma to the head causes the transmission of forces throughout the brain tissue. If strong enough, they can cause shearing and disruption of tissue and neural networks deep within the brain. This type of damage tends to be diffuse and can result in axonal damage (*diffuse axonal injury* [DAI]), diffuse edema, and extensive neuronal death and can extend the toxic secondary injury throughout the brain to areas far from the point of original contact. The same acceleration forces that cause DAI can also cause stretching and tearing of blood vessels leading to subcortical hemorrhages, additional neuronal damage, and disrupted functional activity in otherwise intact neurons.

Penetrating injury results in different injury patterns from blunt injury. The biggest factors in the degree of damage from a penetrating injury are the velocity and mass of the projectile. Shells from high-powered rifles and other high-velocity projectiles can cause an enormous pressure wave that damages the brain tissue in predictable patterns and can be massive and devastating. Lower-velocity projectiles cause less pressure-wave damage and less direct shrapnel path damage. As with blunt TBI, penetrating injury sets off a secondary injury cascade.

SECONDARY INJURY

The initial trauma to the brain that kills or damages nerve cells is only the first step in a drawn-out and complex cascade of events that cause further cell death. Immediately after a TBI, some cells are mortally wounded, while others farther away from the injury insult receive lesser wounds. However, within hours to days after the injury, if the metabolic and cellular machinery in the nerves (*homeostasis*) is too perturbed, these cells swell and die (*necrosis*). Necrosis can be caused by inflammatory factors produced in the brain, by free radicals entering into the brain, or by the excessive release of excitatory neurotransmitters such as glutamate. Some cells that survive the initial injury may die days, weeks, or months later, when mechanisms inside the nucleus of the cell trigger a breakdown of its DNA. This process is known as *apoptosis,* or programmed cell death, because it is triggered by genes within the cell nucleus responding to external signals caused by the TBI.

Components of the secondary injury cascade include *anoxia* (absence of oxygen), *hypoxemia* (low oxygen content in the blood), *hypotension* (low blood pressure) and *anemia* (low blood count), *hemorrhages* (bleeding in the brain), *edema* (swelling), and increased intracranial pressure. Edema is a common component of TBI that occurs when disruption of the blood-brain barrier allows fluid to leak into the brain, or cellular swelling follows cell membrane damage and ion transport dysfunction. Edema increases intracranial pressure and can result in further damage to brain tissue. If intracranial pressure continues to increase, it leads to compression of the brain tissue and eventual herniation of tissue through the brain stem, resulting in death. In addition to edema any new lesion or mass that occupies space causes increased intracranial pressure after TBI, and if these masses continue to grow, permanent brain damage ensues.

OUTCOMES

Traumatic brain injury is broadly defined in terms of three categories of severity: mild, moderate, and severe, based on the Glasgow Coma Scale, a 15-point scale designed to measure the patient's ability to respond to environmental stimulus (visual, verbal, motor) after TBI. The degree of impairment depends on the extent of damage to critical brain areas. In the United States, approximately 80 percent of TBIs are mild, 10 percent are moderate, and 10 percent are severe. Outcome after TBI can vary widely depending on the locus and extent of damage, age and sex of the patient, prior medical conditions, socioeconomic and educational status, early treatment interventions, and subsequent extent of rehabilitation and medical therapy. An equally broad range of symptoms—loss of consciousness and coma, persistent vegetative state, seizures, disrupted motor functions, visual defects, dizziness, disordered language, executive functions and communication skills, lack of emotional control, diminished (or enhanced) sex drive, depression, changes in personality, inability to focus and loss of attention, and impaired memory, especially short-term processing of information—can occur in the successive stages after TBI.

There are currently no clinically effective treatments than can directly repair the damaged brain. Basic research in this area focuses either on developing drugs that can prevent swelling, necrosis, and apoptosis (neuroprotection), or on agents or physiological techniques that encourage intact nerve cells to grow new branches, or to increase or even change their activity to replace the neurons that have been lost (enhancing neuroplasticity). A third category of research, using stem cells or other genetically modified cells (glial cells) that are transplanted into the zone of injury, seeks to replace damaged cells with substitute neurons or other cells that can restore function.

In the current absence of treatments, symptoms can persist indefinitely, although there may be gradual amelioration that can sometimes be improved with rehabilitation therapy. Many patients diagnosed with mild TBI develop behavioral problems and symptoms that prevent them from returning fully to their preinjury lifestyles or work, and in about 30 percent of cases, they are accused of malingering, although this condition is not easy to verify. There is now accumulating evidence that even mild but repeated head injuries (e.g., those associated with sports such as boxing or football) occurring over time can result in cumulative impairments that can be very disabling or even fatal.

According to the Centers for Disease Control, each year in the United States, 1.5 million people sustain some form of TBI—8 times the number of people diagnosed with breast cancer and 34 times the number of new cases of HIV/AIDS. TBI is the leading cause of death in males aged younger than 35 years. Fifty thousand people die from TBI each year, and these account for one-third of all injury-related deaths. Eighty to ninety thousand people each year "will experience the onset of long-term or lifelong disability associated with TBI" (Thurman et al. 1999:612). TBI is a leading cause of death and disability in people aged older than 75 years, mostly from falls and related accidents.

—Donald Stein

See also Medicine.

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TRAVEL

Travel can narrow or widen gaps among people with disabilities (PWDs) and gaps between disabled and nondisabled people. As with the political, economic, and social development that often fosters it, travel can (but sometimes does not) create an egalitarian civil society. For many of the world's PWDs, economic, social, and political factors compound structural barriers to travel. PWDs are tourists traveling for leisure, "hosts" for the tourist industry, migrant laborers, students in educational exchange, and travelers in search of refuge.

Travel has several definitions, with different implications for disabled people. A basic definition is in the *Cambridge English Dictionary:* "to make a journey, usually over a long distance." Especially in Commonwealth countries, reference to travelers is often to migrants who are excluded from many social services.

Many authors looking at globalization, disability, and travel examine the dualisms (e.g., rich and poor, urban and rural) affected by globalization. But for the most part, these analyses have looked at disability only tangentially. Since disability, travel, and globalization are inextricably linked, this is a shame.

LEISURE AND BUSINESS TRAVEL

On the upper side of the gap between the "haves" and "have-nots" among PWDs are most leisure and business travelers. Travel for leisure or business is most frequent and easiest in the United States, followed by Canada and Western Europe, and most infrequent and difficult in most of Asia and Africa.

Many books and organizations have emphasized the gains that disabled people receive from travel. In the United States, Jillian Magalaner's publication of a travel guide geared toward travelers with disabilities in 1994 (revised in a new edition by Fodor in 1996) was a landmark. The publications acknowledged the importance of legislation, especially the Americans with Disabilities Act (ADA) of 1990, in bringing about change, and acknowledged that laws worked most effectively when people held businesses accountable. In 2002, the American Automobile Association (AAA) published *Guides to Barrier-Free Travel* for New York City, Washington, DC, and other destinations.

Such publications indicate progress, but the need for them reflects the limited access for travelers. They also reflect extensive cooperation between individuals and groups designed to promote accessible travel by PWDs. The AAA publications, for instance, drew on "accessibility appraisers" that included for-profit and nonprofit entities such as Access-Able Travel Source in Colorado, Accessible San Diego, and a Canadian company, Beyond Ability International.

Travel for disabled people has had an impact in the travel industry. This is reflected in growth and development of organizations such as the Society for Accessible Tourism and Hospitality (SATH) and estimates such as one from a 1999 publication of the European Commission: "an unserved potential of 35 million overnight travelers and 630 million nights could be generated (p. 4). Globally, that potential is much greater.

The global travel industry may have negative effects on tourist destinations. High disability expectancy characterizes some parts of the tourist industry. Deborah McLaren (2003) observed that "the general health of people in tourist destinations is declining, and locals are the least likely to be able to afford treatment" (p. 82). She offers specifics, such as the rise of HIV/AIDS in Thailand. Global travel and urbanization affects both the scope and the nature of disability.

TRANSPORTATION

Air, rail, cruise ship, and highway travel are all impacted by disability. In each, there have been many standards and aspirations for disability access but fewer enforceable rules.

In the United States, air carriers are regulated under the Air Carriers Access Act (ACAA). The ACAA's adoption in 1986 was unevenly implemented, however, and was aided by Department of Transportation's rule-making regarding matters such as service animals, boarding, and seating. That major problems remained was evident in a 1999 report of the U.S. National Council on Disability. In 2000, the ACAA's provisions were extended to foreign carriers landing in the United States. Writing in 2002, Curtis Edmonds suggested the need for a private right of action, allowing for individual lawsuits to bring about the promise of the ACAA.

Cruise lines attract many PWDs. Plaintiffs hoping that a U.S. court would order imposition of ADA standards on foreign-flagged cruise ships were ultimately successful. In *Spector v. Norwegian Cruise Lines,* the appellate court reversed a district court ruling where people faced barriers making access to services and evacuation equipment difficult or impossible. The ship flew the Bahamian flag, so the cruise line argued that it was not bound to comply with the ADA. Then, on June 6, 2005, the U.S. Supreme Court reversed the appellate court's decision and sided with the plaintiffs in their argument that the ADA's guarantees of access were applicable.

The concept of universal design has been applied to transportation systems, with the design of bus, rail, and air facilities intended to accommodate everyone.

Accessible transportation solutions exist but often are not adopted by industries and public authorities alleging budgetary restraints.

LODGING

Bathrooms, signage, elevators, telephones, transportation, staff training, parking, and other factors may determine how accommodating a hotel or motel will be for travelers with disabilities.

In the United States, lodgings are "public accommodations" covered under Title III of the ADA. Through the Access Board, there are specific requirements that lodgings should meet. Some adaptations have been made voluntarily, and some of the requirements have been enforced through the courts and through settlement agreements. However, requirements such as choice of rooms (e.g., twin, double double, or suite) and access to public areas (e.g., breakfast room, patio) continue to be violated. So do simple and widely known requirements for service dog access and placement of furniture to accommodate travelers with mobility impairments. As evidenced by numerous guides, though, accessible lodging exists, and some establishments have made major improvements.

ACCESS TO RECREATION

As with lodging, many recreational sites are "public accommodations" and are covered by legislation such as the ADA. Technological developments, such as all-terrain wheelchairs, can make accessible recreational attractions that were not accessible before.

Travelers' access to recreation may be purchased at the expense of high rates of disability in the host community, which becomes a basis for discrimination. In Pakistan, Kenneth MacDonald found that local porters had increasingly short careers aiding outside mountaineers, often because of chronic disability.

TRAVEL FOR EDUCATION, CIVIC ENGAGEMENT, AND MEDICAL SERVICES

People may travel for study in boarding schools, educational exchanges, study trips, Elderhostels, or other programs. Travel may be within a country or to another country.

Protections for U.S. citizens studying abroad were litigated in *Bird v. Lewis and Clark College,* where the court held that the guarantees of the ADA did not extend to overseas travel programs of U.S. universities.

Travel may catalyze civic engagement. In Zimbabwe, Rosangela Berman Bieler (one of Jim Charlton's [2000] respondents) said that she got involved at her rehabilitation center because she "wanted to travel, do sports, and other social things" (p. 13). Often, travel and involvement are mutually reinforcing. Many travel programs deliberately promote foreign study as equal exchange, rather than as a reflection of global inequalities. They involve PWDs as participating students and in host countries.

People may travel in search of medical services. Differing laws and economic, social, and cultural factors mean that different drugs, services, and barriers to access to care exist in different places. "Suicide tourism" was reported in accounts of physician-assisted suicide—actual in Switzerland and the Netherlands, hypothetical in Oregon. In India, the lure of tourism induced several poor people to sell kidneys. Medicinal marijuana and pharmaceuticals are more available in some jurisdictions than in others. More travel by PWDs is the likely result.

REFUGEES, ASYLUM, MIGRATION, DISABLED PEOPLE, AND TRAVEL

Millions of people, many of them PWDs, travel because of political, social, or economic conditions that push them away from their homes and pull them voluntarily or involuntarily to new homes. Some of these people are disabled when they leave their old homes; more will become disabled because of conditions during and after their travel.

Refugees and Asylum

Disability may affect an individual's getting asylum or extended departure. To claim refugee status, a person needs to show "well founded fear of persecution" on account of group membership (Convention Relating to the Status of Refugees 1954). Membership in a racial or religious group is more often useful in claiming refugee status than membership in an "other social group" (Convention Relating to the Status of Refugees

1954), which Arlene Kanter and others have persuasively argued should be read as including PWDs. Immigration officials often disagree, however. Disability also influences claims to asylum, which governments often deny on economic grounds.

Nongovernmental organizations (NGOs) and governments distinguish “refugees” from “internally displaced people” according to whether their travel was across national boundaries. In each case, many previously nondisabled people become disabled through travel, and disabled people are disproportionately likely to bear the consequences of unequal access. In Cambodia, Danilo Delfin (another Charlton [2000] respondent) observed that “if you are disabled, you automatically have people after you” (p. 102). The government and Khmer Rouge would each assume that a PWD was the enemy.

Migration

Millions of people each year migrate, often for employment or to follow tradition. The Commission for Racial Equality (2004) in the United Kingdom recently bemoaned that the “last ‘respectable’ form of racism” (para. 4) was against Gypsies (Rom) and travelers. Consequences include a life expectancy of 11 years less than average, diminished access to education, and poorer access to health care, all issues that disproportionately impact PWDs.

Several observers have noted a significant connection between the classification of mental disability and the immigration or refugee experience. In addition to the impairments that accompany migration, professionals may attach the “disability” label to the range of reasons why immigrants might not “fit in.”

REGULATION OF TRAVEL

Many changes easing PWD travel result from pressure exerted by PWDs and allies in the disability rights movement. Kanter (2003a) described encouraging legislative developments as the “globalization of disability rights law.” A common focus is access to buildings and transportation, which sometimes (not always) includes explicit mention of PWDs’ right to travel.

National Governments

National governmental laws, such as the ADA in the United States, are mentioned above. Many countries have legislation acknowledging disability rights; in most cases, travel is indirectly implicated in provisions on transportation and access to public and, in some cases, private facilities.

The United Nations

Within the United Nations (UN), PWDs have participated in the development of rules, hoping to move them from aspiration to binding law. The 1982 World Programme of Action Concerning Disabled Persons included a section on recreation. It linked PWDs’ having equal opportunities for recreation to use of hotels, beaches, restaurants, travel agencies, holiday resorts, and other facilities.

In 1993, the UN General Assembly adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The Rules are not compulsory but provide goals, including Rule 11 on Recreation and Sports. This Rule mandates that travel services and hotels should offer their services and opportunities to all.

Despite the lofty objectives agreed to by national governments, achievements do not match aspirations. Arlene Kanter (2003a) noted that “disability remains invisible and marginalized as a human rights issue, even among human rights organizations and NGO’s” (p. 266). With a Convention (treaty), parties would be legally bound to comply, and the public would be in a stronger position to pressure nonparties.

The Convention was the subject of a Mexican United Nations General Assembly resolution and ad hoc conferences on a “Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities.” Adoption of a Convention with provisions related to (although not necessarily explicitly mentioning) travel is probable; as with other human rights conventions, implementation will be uneven.

Regional Organizations

Regional organizations, especially the European Union and the Organization of American States (OAS), also are arenas where disability and travel are discussed. The first intergovernmental disability rights convention was a regional one, the Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities, adopted by the OAS in 1999. Parties agree to promote integration "by public authorities and/or private entities" and eliminate discrimination "gradually" in transportation, recreation, services, and other areas (Inter-American Convention 1999). Mexico and Costa Rica are among the countries bound by this treaty; Canada and the United States are not.

NONGOVERNMENTAL ORGANIZATIONS AND TRAVEL

Prominent NGOs include organizations devoted to the travel industry, seeking to entice PWD travelers; organizations promoting the well-being of displaced people, many of whom are PWDs; and organizations devoted to participation by disabled people in all sectors of life, including travel.

Society for Accessible Tourism and Hospitality

SATH was founded in 1976 as the Society for Advancement of Travel for the Handicapped. Its mission is "to raise awareness of the needs of all travelers with disabilities, remove physical and attitudinal barriers to free access and expand travel opportunities in the United States and abroad" (Society for Accessible Tourism and Hospitality n.d., para. 1). SATH members include PWD consumers, but the organization's primary appeal is to travel professionals.

Independent Living Institute

The Independent Living Institute (ILI) was founded in Sweden in 1993 as the Institute on Independent Living. Since its inception, the ILI has worked across borders in Europe and disseminated information worldwide. It deals with a full range of independent living issues. Some, such as personal assistance, are unrelated to travel. The ILI website has a useful Recreation & Travel heading in its online library, recently added a section on Study and Work Abroad for All, and has long had an international Vacation Home Exchange.

Mobility International USA

Mobility International USA (MIUSA) was cofounded in 1981 by Susan Sygall (currently the executive director) and Barbara Williams. Its programs and services include the National Clearinghouse on Disability and Exchange (NCDE); International Development and Disability; International Exchange and Leadership Development; and Loud, Proud and Passionate!—International Women with Disabilities Leadership and Networking Projects. It promotes travel as empowering, particularly for disabled women facing sexism and ableism. MIUSA promotes a central role for PWDs in the development process. Travel is both an effect of and part of that process.

Other Nongovernmental Organizations

Travel and PWDs are touched upon by many NGOs, including the International Organization for Migration and Disabled Peoples' International. Travel is central to the mission of other NGOs, such as Access Exchange International. Together they influence perceptions of the connection between disability and travel. As NGOs become stronger, more PWDs should be participating in travel for leisure or business and fewer because of the "push" and "pull" factors generated by economic inequality.

—*Arthur Blaser*

See also Air Carrier Access; Americans with Disabilities Act of 1990 (United States); Public Transportation; United Nations; United Nations Standard Rules.

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TREDGOLD, ALFRED F.

(1870–1952)

British physician and eugenicist

Alfred F. Tredgold was an influential writer and medical expert in the early decades of the twentieth century, both in Great Britain and—through his influential textbook—throughout the English-speaking world. His book, *Mental Deficiency (Amentia),* first published in 1908, went through some eight editions before Tredgold’s death in 1952, continuing to be revised by new editors through 1979.

In the Edwardian era in England, Tredgold was also a prominent eugenicist, writing and testifying on the social importance of dealing with the “problem of the feeble-minded” (Tredgold 1911) and arguing that “morbid heredity . . . is present in 80 percent of cases [of amentia]” (Tredgold 1908:38). During this period, Tredgold testified for the Royal Commission on the Care and Control of the Feeble-Minded and served as consulting physician to the Littleton Home for Defective Children and the National Association for Promoting the Welfare of the Feeble-Minded. Along with other British eugenicists of the era, Tredgold warned the government to act aggressively to counter the burgeoning birth rates of intellectually disabled mothers. Only through segregation and sterilization, Tredgold argued, could Britain successfully arrest the “manner in which feeble-mindedness is permeating the country and swamping the mental and moral vigour of the community” (Jackson 2000:140).

—Philip M. Ferguson

See also Eugenics; *Feeblemindedness;* Sterilization.

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TROPICAL DISEASES

The nosological category of tropical diseases grew out of the colonial expansion of European nations and the United States at the end of the nineteenth century. In less than a hundred years, *tropical medicine* became a term increasingly devoid of meaning, as scientific research, deteriorating public health infrastructures, and rapid, large-scale human displacement (among other reasons) produced the identification of new vector-borne infections in temperate climates and the reemergence of others long gone. In addition, the largest proportion of diseases found today in tropical countries are not due to parasites or vector-borne agents but to globally distributed causes such as tuberculosis, HIV, and smoking, whose prevalence and severity are increased by the conjunction of poverty, hunger, and lack of medical care.

The list of infections with a primary locus of transmission in tropical areas is vast, so this entry will comment only on the most important causes of disability (short- or long-term incapacitation on a mass scale). Those selected by Murray and Lopez in their analysis of the global burden of disease include four diseases transmitted by the bite of a mosquito (malaria, dengue hemorrhagic fever, Japanese encephalitis, and lymphatic filariasis); four transmitted by other arthropods (onchocerciasis, trypanosomiasis, Chagas disease, and leishmaniasis); two acquired by contact with a contaminated environment—soil (intestinal nematode infections) or water with infected snails (schistosomiasis); one acquired through contact with contaminated secretions or by flies (trachoma); and leprosy, for which close, prolonged personal contact is the suspected mode of transmission. A succinct exposition of the natural history, preventive measures, and drug therapy for these diseases can be found elsewhere. In all of these diseases, treatment (if available) to cure the infection will partially or not at all reverse the long-term disability produced by the disease. In almost all of these diseases, the initial infection usually produces a short, undifferentiated febrile illness or may be asymptomatic. Only malaria, dengue, and Japanese encephalitis are likely to produce life-threatening syndromes on first infection, and the resulting long-term disability (other than the incapacitation due to malarial relapses) mostly depends on the severity of the initial episode and sequelae from shock or respiratory compromise. Among all these diseases, the major producers of days of illness and early death according to Murray and Lopez are malaria (by far the most common), filariasis, leishmaniasis, and intestinal nematodes, so they are considered in the short space allowed by this entry. It must be emphasized, though, that the true illness burden is underestimated because of the lack of local resources, even for data collection.

Malaria is caused by any of four protozoan *Plasmodium* species (*falciparum, malariae, ovale,* and *vivax*) and produces fever, chills, sweats, and headache for a week to a month or longer, with relapses at irregular intervals for years thereafter, unless the proper antibiotic is provided. Falciparum malaria may progress to jaundice, shock, renal and liver failure, encephalopathy, and coma, with case-fatality ratios of 10–40 percent if untreated. Cases of cerebral malaria may recover with significant neuromotor deficits.

In contrast, the severe manifestations of lymphatic filariasis are usually the result of repeated infections that are active for years. *Wuchereria bancrofti, Brugia malayi,* and *Brugia timori* larvae, transmitted by mosquitoes, lodge in the lymph tissue and the lungs and may produce paroxysmal nocturnal asthma, chronic lung disease, renal disease, arthritis, adenitis, lymphangitis, chyluria, and elephantiasis of the genitalia or limbs. Drug treatment clears most microfilariae from the blood but may not destroy all adult worms, so it must usually be repeated at yearly intervals. The principal goal in the treatment of these patients is to prevent secondary bacterial infections in areas swollen with lymph, which can be accomplished through good hygiene, prevention and cure of skin lesions, exercise, elevation of affected limbs, and wearing of appropriate shoes. Hydrocele (collection of fluid inside the scrotal sac) can be treated with surgery. A very useful guide for management of areas with lymph swelling (lymphedema) has been recently published (Dreyer et al. 2002).

Onchocerciasis (river blindness) is also produced by filarial worms (*Onchocerca volvulus*) but transmitted by the bite of infected *Simulium* (black) flies. The microfilariae migrate through the skin and produce a chronic systemic illness with skin edema and atrophy, subcutaneous or periosteal fibrous nodules, and, if they reach the eye, visual disturbances or blindness. The introduction of ivermectin for onchocerciasis in 1987 was a milestone of disease treatment in less developed countries because of the efficacy and safety of the drug and because the manufacturer (Merck) decided to donate it without charge. This gift provided the incentive for establishing community-based distribution networks in affected areas (even if they had no established public health systems), stimulated similar donations by other pharmaceutical companies, and is seen as an example of what could potentially be accomplished for AIDS therapy.

Leishmaniasis, caused by a number of species of the protozoan genus *Leishmania,* is transmitted by the bite of sandflies and produces cutaneous and mucosal lesions that may last weeks or months and then heal spontaneously, only to recur even years later with dissemination and nasopharyngeal tissue destruction. Visceral leishmaniasis (kala-azar), characterized by fever, diarrhea, abdominal pain, hepatosplenomegaly, pancytopenia, and progressive emaciation, is usually fatal within 3–20 months if untreated.

The principal intestinal nematode infections are hookworm disease (uncinariasis, by *Ancylostoma duodenale, Ancylostoma ceylanicum,* and *Necator americanus*), roundworm disease (*Ascaris lumbricoides*), and trichuriasis (*Trichuris trichiura*). Hookworm eggs passed with feces hatch in the ground. Larvae penetrate human skin (usually the bare feet) and migrate through lymphatics and blood to the lungs, up the trachea, and then down the esophagus to the small intestine, where they attach to the wall, feed off the patient's blood, and produce thousands of eggs each day. This process may result in pulmonary infiltrates, cough, and tracheitis, but the major cause of disability in heavy infections is iron deficiency, with hypochromic microcytic anemia, hypoproteinemia, and retarded mental and physical development of children. *Ascaris* and *Trichuris* are acquired by the ingestion of eggs through pica or contaminated vegetables. The larvae attach to the mucosa of the intestine, and heavy infections may produce bowel obstruction, bloody stools, diarrhea, nutritional deficiency, and growth retardation in children.

The principal specialized medical care required by the long-term sequelae of these "tropical" infections can be grouped as follows: neurological and physical rehabilitation for cerebral malaria, encephalitis due to dengue or Japanese encephalitis virus, lymphatic filariasis, and leprosy; skin care and reconstructive surgery for lymphatic filariasis, leprosy, leishmaniasis, and onchocerciasis; ophthalmologic treatment for onchocerciasis, trachoma, and leprosy; gastroenterological expertise in hepatic schistosomiasis and Chagasic megacolon; and cardiological, urological, and pulmonary care for Chagasic cardiomyopathy, urinary schistosomiasis, and filarial interstitial lung disease, respectively. Unfortunately, these services are required by populations with other highly endemic severe diseases, such as HIV, that have little access to education and medical attention and are also burdened by poverty and malnutrition.

—José G. Rigau

See also Disease; HIV/AIDS; Infectious Diseases; Leprosy; Medicine.

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TUBERCULOSIS

Tuberculosis is a communicable disease caused by a mycobacterium. Its most common form is pulmonary tuberculosis, what used to be called *consumption.* A chronic disease, tuberculosis was endemic in Western countries until the post–World War II period. It is now endemic in developing countries, with the World Health Organization declaring a global emergency in 1992. Without antibiotic treatment, in the past in the West, and currently elsewhere, individuals have been disabled for many years by this long-term illness. In countries such as Germany, the United Kingdom, and Australia, the massive problem of tuberculosis prompted some of the earliest experiments in government welfare in the late nineteenth and early twentieth centuries. These early disability allowances, insurance programs, and pensions were often the basis on which later sickness, welfare, and disability support programs developed.

Tuberculosis has not always been understood as a communicable disease. In the nineteenth century and earlier, it was sometimes thought to be hereditary and at other times thought to be an effect of environment or constitutional weakness or a combination of these factors. Indeed, although the tuberculosis pathogen was identified by Robert Koch in 1882, the question "Is consumption contagious?" continued to be asked well into the twentieth century. In Victorian literature and visual culture, the aestheticized, chronically weak and bed-ridden consumptive was a stock figure. Partly but not wholly as a response to the identification of the causative organism, comprehension of the disease shifted from this individualized understanding to being an issue of public health. It became a disease associated with poverty and urbanization, disproportionately affecting minority groups, especially in cities.

Toward the end of the nineteenth century, a therapeutic regimen known as "open-air treatment" was developed. Typically, this involved several months' stay in an isolated institutional environment. The first British institutions opened in Edinburgh in 1889, modelled on German private institutions for open-air treatment. In the United States, similar institutions began about 1884. There was a phenomenal proliferation of tuberculosis sanatoria over the next few decades and well into the interwar period. Still understood within climatic theories of health and ill health, sanatoria for open-air treatment of tuberculosis were often built in carefully selected rural, mountain, or seaside locations. Following the basic principle that fresh air was itself curative, people were enjoined to undertake as much of their daily activity as possible outside: school, rest, sleep, exercise. At the height of its popularity, sanatorium treatment involved a radical, sometimes coerced and tightly controlled regimen of rest and incremental exercise. A person might be brought to the sanatorium and forced into total bedrest and, in some systems, total silence. Gradually, and sometimes over a period of six months, the patient was permitted to sit, move, and exercise in controlled ways, from small walks, to inclines, to long walks. Progress was measured by the person's temperature at specified times during the day, by appetite, and by capacity for exercise.

The idea of open-air treatment was to control rather than to cure the disease, but in doing so, the therapy temporarily "disabled" patients sometimes more than the disease itself. The major twentieth-century sociologist Erving Goffman's classic study on segregation and institutionalization, *Asylum,* was based on his time and observations in a tuberculosis sanatorium. The nature of these sanatoria ranged from versions of health resorts to versions of government workhouses, according to the social position of patients, usually depending on their class or race. The correlation of tuberculosis with urbanization and poverty meant that many indigent people were disabled by the disease and were institutionalized in sanatoria. In these instances, the tuberculosis sanatorium was also a place of detention, of unwilling institutionalization and segregation. In the United States, there is a particular history of the institutionalization of indigent African Americans on the grounds of their infection with tuberculosis.

Tuberculosis is arguably the most significant illness in the history of the development of welfare and health insurance programs over the twentieth century. At a population level, tuberculosis mattered greatly, because it typically disabled men and women in the middle years of life; it was not usually a disease of old age. Thus, as was noted over and over again until the antibiotic era, tuberculosis struck men and women in their "prime" productive and reproductive years. These people were usually, though not always, chronically disabled. This made the disease an economically significant one and prompted major new experiments in welfare, insurance, and disability allowance programs.

Because tuberculosis was so endemic in Western countries, the idea and sometimes the legal concept of disability itself were constructed specifically in relation to it. In Germany, novel programs for work-related insurance were developed in the late nineteenth century. In the United Kingdom in the early twentieth century, governments took financial responsibility for treatment of this disease in an unprecedented way. Often, "disability," and therefore eligibility for a pension, free treatment, or insurance payment, was determined by a person's capacity or incapacity to work. To qualify for the invalid pension in Australia, for example, an individual had to be deemed "totally and permanently incapacitated": disabled and, as it was then seen, unfit for work. These employment-oriented systems of insurance and welfare were problematically devised around the idea of a male breadwinner and a female dependent.

Over the twentieth century, the treatment for tuberculosis changed dramatically. Following the principle of rest to arrest the disease, physicians in the 1930s and 1940s sometimes surgically collapsed one lung for long periods. From late 1940s, chemotherapy began to replace previous therapies, dramatically changing the incidence of the disease in countries where the drugs were available: streptomycin in the 1940s, isoniazid and para-aminosalicylic acid (PAS) in the early 1950s, and rifampicin from the late 1960s. Once considered powerful enough to eradicate tuberculosis, chemotherapies have proven effective for populations with access to them. However, for nations and subpopulations without access to antibiotics, the tuberculosis problem escalates. This has been compounded by the emergence of multidrug-resistant strains. In countries such as Russia, the problem of coinfection with HIV and multidrug-resistant tuberculosis is an extremely serious one. Elsewhere, the issue of tuberculosis and global migration have become intertwined: For many nations, a central aspect of global movement and border control has been the strict screening of migrants, asylum seekers, and travelers for tuberculosis.

—Alison Bashford

See also Disease; HIV/AIDS; Infectious Diseases; Institutionalization and Segregation; Medicine.

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TUBMAN, ARAMINTA ROSS (HARRIET) (1820–1913)

American abolitionist

Born into slavery in Dorchester County, Maryland, Harriet was said to be of purely African ancestry. Raised under harsh conditions, she was subjected to whippings and heavy labor at an early age. At the age of 12, a blow to the head by her master resulted in constant blackouts and periods of narcolepsy throughout her lifetime. At the age of 25, she married John Tubman, a free black man, but when her master's slaves were put up for sale five years later, she escaped, and, with the help of white antislavery sympathizers, Harriet made her way to Philadelphia. There, she became acquainted with William Still, founder and Philadelphia stationmaster of the Underground Railroad. With the assistance of Still and other members of the Philadelphia Anti-Slavery Society, she learned about the workings of the Underground Railroad. She remained in Philadelphia for two years, working and saving money to return to Maryland for her husband, but when she reached him, she found that he had taken another wife and had no interest in returning north. At this juncture, Harriet dedicated herself to a life as a "conductor" on the Underground Railroad.

As the "Black Moses," Tubman "delivered" 300 slaves safely to the Free States or to Canada. Every time she traveled south, the dangers increased. This was partially due to her habit of falling into deep sleep-like states during the journey. Throughout her life, Tubman was subject to periods of seizures and periods of falling into a deep sleep. The slaves (and later soldiers) who traveled with her to freedom came to understand and expect that behavior. It was even rumored that during those sleeplike periods, she was receiving messages from God as to which route was the safest to lead her charges. In 1860, being too well-known and constantly hunted by slave catchers, she went into the South for the last time to bring back slaves.

During the Civil War, Tubman was a soldier, a spy, and a nurse, serving for a time at Fortress Monroe, which would later become the prison of Jefferson Davis. She slipped through enemy lines to bring back valuable information to the Union Army. She led soldiers through the Southern lines, bringing them back as safely as the slaves she had once led to freedom. While guiding a group of black soldiers through South Carolina, Tubman met Nelson Davis, who she would marry after the Civil War. The couple moved to Auburn, New York, where Tubman stayed active in support of the women's rights movement.

In 1908, Harriet Tubman built a house for the aged. It was there that she worked and was cared for in the years before her death in 1913. After her death, she was buried in Fort Hill Cemetery in Auburn, with military honors. She has since received many honors. On June 14, 1914, a large bronze plaque was placed at the Cayuga County Courthouse, and a civic holiday was declared in her honor. Freedom Park, a tribute to the memory of Harriet Tubman, opened in the summer of 1994 at 17 North Street in Auburn, and in 1995, the U.S. Post Office honored Harriet Tubman with a commemorative stamp. Tubman is widely remembered as a trusted spy, "conductor," and activist in the abolition and woman's rights movements.

—Carlos Clarke Drazen

See also Feminism; Race and Ethnicity; Racism.

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▣ "UGLY LAWS"

In May 1881, the Chicago City Council enacted the first American "ugly law" forbidding "any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself to public view." National networks of ministers, charity organizers, city planners, and municipal officials followed Chicago's ordinance with efforts to enact similar laws elsewhere: in Denver and Lincoln in 1889, in Columbus in 1894, in New York (unsuccessfully) in 1895, and in the entire state of Pennsylvania in 1891. The ordinance, wrote one Chicago reporter, would stamp its author, Alderman Peevey, as a public benefactor: "He proposes to abolish . . . the woman with two sick children who was drawn through the carding-machine in a woolen mill and who grinds 'Mollie Darling' incessantly on a hurdy-gurdy on a street corner." Remembering the woman who played "Mollie Darling," contemporary disability activists cite the extremity of "ugly law" as a signal reminder of the sometimes less obvious but still persistent forms of disability oppression today.

Most of these citations derive from a single and partly misleading paragraph in a landmark work of legal scholarship, Marcia Pearce Burgdorf and Robert Burgdorf Jr.'s "A History of Unequal Treatment: The Qualifications of Handicapped Persons as a 'Suspect Class' under the Equal Protection Clause," published in 1975. The Burgdorfs coined the phrase "ugly law" and placed it in "Chicago 1911," the date and place most commonly used when people quote it now. "Ugly," it should be noted, appears nowhere in the wording of the actual ordinances. "Unsightly beggar" ordinance is more accurate historically, since some of these laws, though not all, appear under that heading in the code books. Inventing "ugly" law, the Burgdorfs performed an act of advocacy probably inspired by the title of a newspaper article they footnoted concerning the last known arrest (in Omaha in 1974), "Begging Law Punishes Only the Ugly."

Unsightly beggar laws were enforced unevenly and perhaps rarely, as historian Brad Byrom has argued. Nonetheless, they had both concrete and chilling effects. A 1916 report by the "Committee on Cripples of the Welfare Federation of Cleveland" records the story of an unnamed man who sold newspapers until "the enforcement of a statute which prevented cripples from exposing their deformity by selling on street corners abolished [his] job. . . . Although it seemed rather hard," the Cleveland Cripple Survey reports, "he appreciated the meaning of it, but considered it ill-advised unless some step went with it for providing other opportunity for work for cripples." Understanding the meaning that this man, in his guarded, strategic protest, is said to appreciate requires placing the "ugly laws" within a complex set of vectors. These include the "tramp scare" and fears of vagrancy; the influence of the charity organization movement; new conditions of visibility in modern urbanity; labor unrest; social Darwinist theories and the rise of eugenics; and, not least, the concurrent development of institutions for the blind, deaf, feebleminded, and generally "dependent and defective classes."

—Susan Schweik

See also Begging; Deformity; Normality.

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UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION (UPIAS)

The initiative to form the Union of the Physically Impaired against Segregation (UPIAS) was taken by Paul Hunt in 1972 when he called for a consumer group to promote the views of actual and potential residents of institutional homes for disabled people in the United Kingdom. The aim was to formulate and publicize plans for alternative forms of support in the community.

Exploring what support was needed to enable the most severely impaired people to live in the community encouraged UPIAS to completely rethink the prevailing interpretation of *disability*. In 1974, UPIAS published its detailed policies. This proposed the examination of "ways of *changing our conditions of life*, and thus *overcoming* the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us."

This interpretation of *disability* was taken a step further in 1975 when it published "Fundamental Principles of Disability" and set out its radical definitions:

> *Impairment*—lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body.
>
> *Disability*—the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

This interpretation of *disability* came to be known as the social model of disability. It radically transformed the way disabled people came to see themselves and their place in society.

—Vic Finkelstein

See also Disability Studies; Paul Hunt; Models.

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UNITED NATIONS

The United Nations was established on October 24, 1945, by 51 countries. Today, UN membership totals 191 countries. The United Nations has four purposes: to maintain international peace and security; to develop friendly relations among nations; to cooperate in solving international problems and in promoting respect for human rights; and to be a center for harmonizing the actions of nations for peace and development based on the fundamental principles of human rights for justice, human dignity, and well-being of all people. The United Nations affords the opportunity for countries to balance global interdependence and national interests when addressing international problems to pursue these goals. The current 191 members of the United Nations meet in the General Assembly, the highest decision-making organ within the UN system, in which each country, large or small, rich or poor, has a vote and voice in this process; however, the decisions taken by the assembly are not legally binding. There are six main organs of the United Nations: the General Assembly, the Security Council, the Economic and Social Council, the Trusteeship Council, the Secretariat, and the International Court of Justice (The Hague in the Netherlands). Six official languages are used at the United Nations: Arabic, Chinese, English, French, Russian, and Spanish.

The UN global Programme on Disability is the lead program concerning disability—the focal point within the UN system. It is housed in the Division for Social Policy and Development at the Department of Economic and Social Affairs of the UN Secretariat. The mandate of the UN global Programme on Disability emanates from the 1982 World Programme of Action Concerning Disabled Persons and the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities as well as other relevant international instruments, such as the UN Charter, the Universal Declaration of Human Rights (UDHR), the International Covenant on Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights.

The major objectives of the World Programme are (1) to support the full and effective participation of persons with disabilities in social life and development, (2) to advance the rights and protect the dignity of persons with disabilities, and (3) to promote equal access to employment, education, information, goods, and services. Since 2001, the UN global Programme on Disability also serves as the substantive secretariat for the General Assembly Ad Hoc Committee on a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities.

In its early period, the United Nations focused on improvement of the well-being of persons with disabilities to meet their needs in the social context.

In the 1960s, initiatives within the disability community and adoption by the United Nations of the international human rights conventions both in civil and political and economic, social, and cultural realms resulted in a fundamental reevaluation of the rights of persons with disabilities within the context of development. In the 1970s, the evolution of thinking on disability issues at the United Nations resulted in a number of initiatives embracing the growing international concept of human rights of persons with disabilities and equalization of opportunities for them. These include the 1971 Declaration on the Rights of Mentally Retarded Persons and the 1975 Declaration on the Rights of Disabled Persons.

These efforts were intensified within the framework of the UN Decade of Disabled Persons (1983–1992). A major outcome of the International Year of Disabled Persons, which preceded the Decade of Disabled Persons, was the World Programme of Action Concerning Disabled Persons, the most comprehensive global strategy, which took "equalization of opportunities" as its guiding principle. The Standard Rules, a major outcome of the Decade of Disabled Persons, provide an instrument for policy making and a basis for technical and economic cooperation. The international frameworks to promote the rights of persons with disabilities were further advanced by a series of 1990s UN development conferences and their respective five-year reviews, such as the 1993 Vienna Declaration and Programme of Action for human rights, the 1995 Copenhagen Declaration and Programme of Action for social development, the 1995 Beijing Declaration and Platform for Action, the Millennium Development Goals, and other relevant international commitments.

To implement the World Programme and the Standard Rules, the United Nations' global comparative studies suggest that disability is a quintessential cross-cutting development issue. The international community is witnessing a significant expansion of constituencies concerned with disability and the situation of persons with disabilities. In part, this can be attributed to the aging of the world's populations and the increased number of persons surviving diseases or conflicts with a disability. Disability issues and the situation of persons with disabilities within the context of overall national development need to be addressed. Examining these issues contributes to a growing awareness of universal design concepts globally and to recognition of the importance of incorporating universal design principles in international policies and programs for social infrastructure, social services, and promotion and development of accessible environments and institutions. While universal approaches to policy design and program planning represent a somewhat new trend, they reflect the concern of the United Nations not only with social and economic development but also with fundamental human rights.

While the means chosen to promote full realization of economic, social, and cultural rights of persons with disabilities will differ from one country to another, there is no country in which a major policy or program effort is not required. The commitment of member states to realization of the fundamental human rights of all persons would require governments to take all possible measures to make further progress in protection and promotion of the rights of persons with disabilities.

More recently, the initiative on a comprehensive and integral convention to promote and protect the rights of disabled persons resulted from a proposal made by Mexico during the 56th session of the UN General Assembly, which called on the international community to combat poverty and social exclusion. The importance was highlighted to involve all citizens as stakeholders and that a just world must be inclusive of all groups. For that reason, Mexico proposed the establishment of a special committee to study the elaboration of an international convention on promoting the rights and dignity of persons with disabilities, which was endorsed by General Assembly resolution 56/168.

The Ad Hoc Committee of the General Assembly on a comprehensive and integral convention on the rights of persons with disabilities was established in 2001 by assembly resolution 56/168. It was established in the context of addressing poverty and promoting social integration so as to create just and equitable societies based on participation of all citizens as stakeholders. The elaboration of a convention and its future adoption and implementation are expected to provide for a normative basis not only for implementation of the rights of persons with disabilities within the existing legal frameworks but also for formulating strategic options for policies and programs and evaluating measures to promote full and equal participation of persons with disabilities in society and development. National, regional, and international consultations concerning the potential convention are resulting in the emergence of new disability- sensitive networks of policy makers, program specialists, academics, and advocates.

—Akiko Ito

See also Developing World; Economic and Social Development; United Nations Declaration on the Rights of Disabled Persons; United Nations Disability Convention; United Nations Disability Statistics; United Nations Standard Rules.

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UNITED NATIONS DECLARATION ON THE RIGHTS OF DISABLED PERSONS

In December 1975, the United Nations (UN) General Assembly adopted the Declaration on the Rights of Disabled Persons, which states that all persons with disabilities have the same rights as other persons. Provisions of the declaration include (1) defining a “disabled person” as anyone who cannot ensure the necessities of a normal individual and/or social life, as a result of a deficiency in physical or mental capabilities; (2) a nondiscrimination clause applying the rights to all disabled persons regardless of race, color, sex, language, religion, political or other opinions, national or social origin, state of wealth, or birth situation; (3) a right to respect for human dignity; (4) civil and political rights; (5) the right to measures to enable self-reliance; (6) the right to medical, psychological, and functional treatment; (7) the right to economic and social security and to a decent level of living and, according to capability, to employment; (8) the right to have their special needs taken into consideration at all stages of economic and social planning; (9) the right to live with family and to participate in all social, creative, or recreational activities; (10) the right to be protected against all exploitation/discrimination/abuse/degradation; (11) the right to qualified legal aid; (12) a clause stipulating that organizations of disabled persons may be consulted regarding the rights; and (13) a clause urging that persons with disabilities, their families, and communities be fully informed of the rights contained in the declaration. This act culminated the beginning of a new conceptual approach to disability issues as human rights issues.

Prior to 1970, the United Nations approached disability issues from a social welfare perspective. Little attention was paid to obstacles created by social institutions and society in general. The late 1960s became a time for reevaluation. In 1969, the General Assembly adopted the Declaration on Social Progress and Development, which, in Article 19, advocated the provision of health, social security, and social welfare services for all persons, including the provision of measures to rehabilitate the mentally and physically disabled to facilitate their integration into society. Education, vocational/social guidance, and job training and placement provisions were included. On December 20, 1971, the General Assembly proclaimed the Declaration on the Rights of Mentally Retarded Persons, which stated that the mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings, a right to proper medical care and education, to economic security, to a qualified guardian if required, to protection from exploitation, and to legal procedures. The declaration stressed that mentally retarded persons should live with their families and participate in the community. These declarations led up to the movement to create the Declaration on the Rights of Disabled Persons, which, in some sense, represents an attempt to delineate that the 1948 UN Declaration of Human Rights clearly applies to persons with disabilities.

Though nonbinding, the declaration led to several subsequent UN initiatives, such as the UN Year of Disabled Persons, the World Programme of Action Concerning Disabled Persons, the UN Decade on Disability, and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. These initiatives have comprised policies specifically to address the situation of persons with disabilities.

A parallel movement has occurred related to the incorporation of disability issues in UN policy initiatives designed to address the needs of all persons. For instance, in 1993, the World Conference on Human Rights in Vienna reconsidered universally recognized human rights issues and produced the Vienna Declaration and Programme of Action to guide human rights efforts. The conference declared that all human rights and fundamental freedoms are universal, and, hence, people with disabilities have these rights. Thus, any discrimination, intentional or unintentional against persons with disabilities, is viewed per se as a violation of human rights.

Since this declaration, the UN system has monitored the incorporation of disability issues into broader human rights initiatives. In 1998, the UN Commission on Human Rights adopted resolution 1998/31, which clearly recognizes that any violation of the fundamental principle of equality or any other discrimination or other negative differential treatment of persons with disabilities inconsistent with the United Nations Standard Rules is an infringement of the human rights of persons with disabilities. It encouraged all human rights treaty- monitoring bodies to monitor the compliance of nation-states with their commitments under human rights instruments to ensure the rights of persons with disabilities. Though expectations from this resolution were high, concerns were present when the commission met two years later. As a result, the commission adopted another resolution asking the UN High Commissioner for Human Rights to examine measures to strengthen the protection and monitoring of the human rights of persons with disabilities.

The incorporation of disability-specific policies within broader human rights instruments, combined with instruments specifically targeting persons with disabilities, has led to the creation of the UN Ad Hoc Committee to consider a Convention on the Rights of Disabled Persons. This represents a movement toward a legally binding human rights instrument for states that ratify it, as opposed to the Declaration on the Rights of Disabled Persons, which was not legally binding.

Nevertheless, the movement toward such a convention can be attributed in part to the original declaration.

—Scott Brown

See also United Nations; United Nations Disability Convention; United Nations Standard Rules.

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UNITED NATIONS DISABILITY CONVENTION

Human rights are basic rights to which every human being is entitled irrespective of age, merit, sex, race, disability, or any other status. Human rights cannot be given or taken away by governments or other entities. They cannot be gained through status or merit nor can they be lost through "inhuman," "deviant," or criminal behavior. Human rights contain the moral values on which modern societies that believe in peace are founded. This is why we often find them in the constitution or some other fundamental legal source of a country. While the history of human rights is much longer, the most affluent period of human rights policy and law began after World War II with the establishment of the United Nations (UN). Human rights are one of the core values mentioned in the Charter of the United Nations and are the topic of one of the first legal instruments adopted by the United Nations, the Universal Declaration of Human Rights of 1948.

The development of UN human rights policy and law is a direct answer to the atrocities of German national socialism during World War II. Since disabled persons were one of the groups victimized by Nazi elimination programs, human rights are an important subject to disability for historical reasons. However, during the first three decades of international human rights law and policy disabled persons were invisible citizens. None of the core UN human rights instruments that were adopted during this time address the situation of disabled persons. Despite the fact that more than 600 million people, or approximately 10 percent of the world's population, have a disability, UN human rights discourse neglected and ignored persons with disabilities. Vice versa, in disability policy human rights were not an issue for a long time. Disability was treated as an issue of medical rehabilitation and welfare policy, issues that also were not regarded as human rights issues during the first decades. Similarly, it was ignored that two-thirds of disabled persons live in developing countries and that the link between poverty and disability is direct and strong. And while many disabled persons live in institutions under conditions that are overt examples of cruel, inhuman, and degrading treatment, they were not seen as victims of human rights violations but as victims of their own personal tragedy caused by their impairments. Neither was the situation of disabled women, who are at a much higher risk of sexual violence and exploitation, dealt with in a human rights context.

A dramatic shift in perspective has taken place over the past two decades from an approach motivated by charity toward the disabled to one based on rights. This shift can be described as a paradigm shift from the medical/individual model of disability to a human rights model. Thus, the issue of human rights has become important to the subject of disability rather recently as a milestone of perspective change. In essence, it means viewing disabled persons not as objects but as subjects. It entails moving away from seeing disabled persons as problems to viewing them as right holders. Importantly, it means locating problems outside the disabled person and looking at the manner in which economic, social, civil, and political processes are structured and whether they accommodate differences, such as disability. With the paradigm shift, a whole set of values that have not yet been applied to disability policy and law become available. Those are the values that underpin human rights: the inestimable dignity of each and every human being, the concept of autonomy and self-determination that demands that the person be placed at the center of all decisions affecting him or her, the inherent equality of all regardless of difference, and the concept of solidarity that requires society to sustain freedom of the person with appropriate social supports.

The shift from a medical/individual model of disability to a human rights perspective is a slow process, but it takes place at every level of modern society. The human rights model of disability has been authoritatively endorsed at the level of the United Nations over the past two decades. The process has led to the current drafting process of a UN treaty on human rights of persons with disabilities. Governments are clearly moving in the direction of the human rights perspective on disability. Recent research shows that more than 40 nation-states in all regions of the world have adopted nondiscrimination or equal opportunity legislation for their disabled citizens. National institutions for the promotion and protection of human rights in many countries take an active interest in disability issues. This helps to bridge the international human rights debate on disability to domestic discourses on disability law and policy reform. Finally, civil society is taking part in the change process. Disability organizations at international and national levels have come to characterize themselves as human rights organizations and have started to use human rights law and human rights mechanisms to foster their cause. Within a short time, disability organizations have become experts in the field, presenting hard facts on human rights violations against disabled persons all over the world, monitoring projects, and becoming actively involved in the drafting process. Disability organizations also have started to involve nongovernmental organizations (NGOs), which are mainstream human rights organizations that have in the past neglected disabled persons.

New human rights laws for disabled persons have emerged at the national as well as at the supranational and international levels. Today, we have binding and nonbinding instruments of international human rights explicitly for disabled persons that have been adopted by the General Assembly of the United Nations as well as by some of the specialized UN organizations, notable among them the International Labour Organization. At the regional level, the Organization of American States (OAS) and the European Union (EU) have passed strong equality legislation on disability. The OAS is the first intergovernmental organization that has a binding human rights treaty on disability. In 1999, the Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities (IACPWD) was adopted.

Most of these human rights laws on disability have been adopted during the past two decades. Developments within the main bodies of the United Nations had a strong impact. These started with two resolutions adopted by the General Assembly in the 1970s. These were the 1971 Declaration on the Rights of Mentally Retarded Persons and the 1975 Declaration on the Rights of Disabled Persons. They are the first signs of a shift from a “caring” to a “rights-based” approach. The International Year of Disabled Persons (1981) was followed by the Decade of Disabled Persons (1983–1992), and the guiding policy instrument was the landmark World Programme of Action Concerning Disabled Persons (WPA), adopted in 1982 by the General Assembly. While the first two aims of the WPA reflect a more traditional approach to disability in that they focus on rehabilitation and prevention, the third aim—“equalization of opportunities”—is sign of a slow but sure shift to a human rights–based approach. The WPA has been prolonged and is still the guiding policy instrument on disability within the United Nations today. It is reviewed every five years (1987, 1992, 1997, 2002). The next review is due in 2007. During the Decade of Disabled Persons, two significant studies on human rights and disability were carried out under the auspice of the UN Commission on Human Rights and its subcommission. The first was a report prepared by Erica-Irene A. Daes, who was appointed special rapporteur by the Sub-Commission on Prevention of Discrimination and Protection of Minorities. It was titled *Principles, Guidelines and Guarantees for the Protection of Persons Detained on Grounds of Mental Ill-Health or Suffering from Mental Disorder* (1986). The report led to a 1991 resolution titled *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*. These principles have been hailed as a new departure in the perception of the role of law in this area. In recent years, however, this instrument has been criticized by some NGOs.

The second report was prepared by Leandro Despouy, who was also appointed a special rapporteur by the subcommission in 1984. His thoughtful and comprehensive report was titled *Human Rights and Disabled Persons* (1993). The Despouy report chronicles widespread human rights abuses in the area of disability and cites a number of such abuses as causes of disability.

The UN Disability Decade also led to the first efforts to adopt a human rights convention on disability. Such a recommendation was made by a global experts meeting in Stockholm in 1987, which had the mandate to review the WPA. Similarly, the Despouy report emphasized the need for a convention in order to put disabled persons on an equal footing with women, children, or migrant workers. Unlike these groups, who have their own thematic convention, disabled persons were left with what is called soft law. Unlike conventions, which are binding treaties to those member states that have signed and ratified them, declarations and resolutions adopted by the General Assembly have no binding legal effect.

Following these recommendations, Italy in 1987 and Sweden in 1989 proposed the drafting of a convention to the General Assembly, but did not succeed. As an alternative, a different kind of instrument was adopted by the General Assembly. The 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities (StRE) are unbinding soft law, but they have become the guiding principles for disability policy within the United Nations and its member states. They mark a clear shift from the rehabilitation and prevention paradigm to the human rights perspective on disability. Unlike the aforementioned instruments, the StRE have their own monitoring mechanism. A special rapporteur who is supported by a panel of experts, composed of representatives of the main international disability organizations, is assigned the task of monitoring implementation of the StRE. The special rapporteur reports to the Commission on Social Development. The first special rapporteur of the StRE was a disabled person. Bengt Lindqvist of Sweden held office from 1994 to 2002. In 2003, Sheika Hissa K.A. Al-Thani from Qatar was appointed second special rapporteur.

With respect to hard human rights law, disability has been an issue to some extent during the past decade. There are currently seven human rights treaties, which also apply to disabled persons. The two core treaties are the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR), both of which were adopted in 1966. Another treaty, adopted in 1984, deals with torture, the Convention against Torture and Other Forms of Cruel, Inhuman or Degrading Treatment and Punishment, whereas the other four treaties deal with specific groups: the 1965 Convention on the Elimination of All Forms of Racial Discrimination (CERD), the 1979 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the 1989 Convention on the Rights of the Child (CRC), and the 1990 International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (CMW). While only the CRC addresses disabled children in the text of the treaty, some of these treaties have been officially interpreted with respect to disabled persons. Such an official interpretation takes place when "General Comments" or "General Recommendations" to these treaties are adopted by their monitoring bodies. Thus, the Committee on CESCR adopted in 1994 General Comment No. 5 on disabled persons. Similarly, the CEDAW Committee mentioned disabled women in two of its general recommendations.

Despite these efforts to include disability into the monitoring process of hard human rights law, disabled persons have remained marginalized. The study *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (Degener and

Quinn 2002a) has shown that treaty-monitoring bodies do not have the resources or the expertise to deal with disability comprehensively and on a general basis. The study, which was commissioned by the High Commissioner for Human Rights, entails a number of recommendations on how to improve the current human rights system with respect to disability. In addition, the need for a new disability rights convention is emphasized.

The idea of a thematic convention has been taken up by many NGOs in recent years again. On the initiative of Mexico, the issue was put on the General Assembly agenda again in 2001. GA Resolution 56/168 of December 19, 2001, established an Ad Hoc Committee

> to consider proposals for a comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, based on the holistic approach in the work done in the fields of social development, human rights and non-discrimination.

The Ad Hoc Committee, which is open to all UN member states and observers, met twice (2002 and 2003) before it established a working group with the aim of preparing a draft text of a convention, which would be the basis for negotiation by the Ad Hoc Committee. The working group would take into account all previous contributions submitted to the Ad Hoc Committee by states; observers; regional meetings; relevant UN bodies, entities, and agencies; regional commissions and intergovernmental organizations; and civil society including NGOs, national disability and human rights institutions, and independent experts. The working group met in January 2004 for 10 working days and was composed of representatives of 27 member states, 12 NGOs, and 1 National Institute on Human Rights. For the first time in the history of UN law, NGOs had an equal status to member states in the drafting process of a treaty.

The drafting process revealed many yet unresolved issues that have to be negotiated by the member states in future Ad Hoc Committee meetings. How to define disability and disability-based discrimination are examples of these issues. Today, there is no universal definition of disability. The debate about the medical versus social model of disability has raised concern about medically oriented definitions. The well-known World Health Organization (WHO) definition of disability, the ICF (formerly ICIDH), is not seen as appropriate for a legal text by many experts.

The question on how to define disability-based discrimination is closely linked to the equality concept at stake. A more formal equality concept does not tackle all forms of discrimination, that is, not those caused by structural barriers. A more material equality concept would, however, include that governments need to actively take steps to build an inclusive society that accommodates differences. The key words are "reasonable accommodation" (or "effective adjustment").

Other controversial issues are whether the treaty should include third-generation rights (i.e., the right to development and the duty of international cooperation) or new human rights that are not enumerated in the two core human rights treaties (ICCPR and ICESCR) or others. An example for a new right would be the right to be different. Since disability is closely linked to poverty and two-thirds of all disabled persons live in developing countries, the right to development is endorsed by many member states from developing regions as well as by NGOs. Not surprisingly, member states from richer regions are reluctant to include such a right in a human rights treaty that is not supposed to protect governments but people. Similarly, "new" human rights will not easily find consensus among member states, in times when international politics are in turmoil.

Finally, the implementation and monitoring mechanism of the treaty will cause much debate in the Ad Hoc Committee. The current UN treaty-monitoring system is in the process of reform for various reasons, such as overload of state reporting obligations and lack of resources. Some member states are reluctant to accept yet another treaty-monitoring body. Others prefer the StRE monitoring mechanism with a special rapporteur and a panel of experts. Another, related question is which role national human rights institutions shall play. These institutions are a rather modern development of human rights promotion and implementation, and there are vast differences between countries regarding mandate, independence, and competency of these institutes. There is some likelihood that the issue of monitoring and implementation will be postponed to a later drafting stage, to await the outcome of the reform process.

While many controversial issues remain to be resolved, the fact that a human rights convention for disabled persons is now finally being drafted is a tremendous progress in human rights and disability policy.

—Theresia Degener and
Gerard Quinn

See also United Nations; United Nations Declaration on the Rights of Disabled Persons; United Nations Standard Rules.

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UNITED NATIONS DISABILITY STATISTICS

The collection and dissemination of disability statistics, by the United Nations Statistics Division (UNSD), started in the early 1980s in response to an increasing international interest in issues pertaining to disability. For example, 1981 was declared the International Year of Disabled Persons and the period 1983 to 1992 the Decade of Disabled Persons. The World Programme of Action Concerning Disabled Persons was adopted as an international guide for use in monitoring the situation of persons with disabilities. This Programme of Action called on the United Nations to develop, on a continuous basis, suitable systems for the collection and dissemination of information on disability necessary for program evaluation at all levels. UNSD therefore has been collecting and disseminating national disability statistics based on censuses and sample survey results, including administrative records. This has involved a worldwide review of published reports and direct communication with national statistics offices and relevant government ministries.

FRAMEWORK FOR DATA COLLECTION AND CLASSIFICATION

The United Nations encourages countries to use the conceptual framework of the International Classification of Functioning, Disability, and Health (ICF) for collection and classification of data on disability. The use of the common framework will facilitate the comparability of data at both the national and international levels, which is currently lacking within and among many countries.

In view of the problems of comparability of disability statistics, the international community is currently working to standardize and harmonize concepts and measures, for use in collecting and reporting disability data based on the ICF conceptual framework. The ICF provides a framework that describes health and health-related domains as body functions and structures, activities, and participation. The domains are classified from body, individual, and societal perspectives. The use of the ICF would result in better measures of disability compared to the use of strictly a severe impairment model. The ICF is multidimensional and has multiple domains and as such presents a framework to collect and present data on impairments, activity limitations, and participation restrictions as well as on the role of the environment. It places disability on a continuum of health with established thresholds for defining decrements of health that constitute disability. It also recognizes the impact of the environment on levels of functioning.

In the "Guidelines and Principles for the Development of Disability Statistics" (United Nations 2001), it is recommended that the ICF be the basis for defining the population with disabilities, developing questions, and classifying the data resulting from such measurements. Before the ICF was developed, the framework and terminology of the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) were recommended so as to harmonize concepts used in disability measurement and classification.

THE UNITED NATIONS DISABILITY DATABASE

The United Nations Disability Database (DISTAT) is meant to promote wider dissemination and use of disability statistics. This database apart from providing statistical data and prevalence rates gives textual information or metadata from surveys and censuses conducted in a number of countries, such as questions used in studies, coverage, and sources of data. Metadata are particularly important in the area of disability statistics because currently different studies use different definitions and concepts of disability as well as conceptually different questions to identify the population with disabilities.

DISTAT-1, which was published in 1988, presents statistics from 63 national studies covering 55 countries. This information is published in the "Disability Statistics Compendium." The database contains national statistics on disability status of the population as well as socioeconomic characteristics of the population with and without disability such as marital status, education, and economic status.

DISTAT-2 shows a relative increase in the number of countries collecting and disseminating data on disability. The 2001 publication has 111 national studies from 78 countries worldwide. Common sources of disability data are censuses and surveys. The majority of countries in Africa and Asia collected disability data through censuses. Only a few countries in the database have statistics on disability that were compiled from administrative records.

ISSUES OF COMPARABILITY

The major problems in comparing disability prevalence rates among countries and within countries, over time, are the absence of internationally standardized definitions, concepts, classifications, and measures of disability. For example, some countries, which collected disability statistics through surveys, have included relatively detailed questions in the survey instruments that focus on activity limitations and participation restrictions. On the other hand, most countries, which collected data on disability through censuses, focused on persons with severe impairments, such as blindness, deafness, and mental retardation. Prevalence rates calculated on the basis of the two different approaches result in wide variation. Countries using questions based on the latter approach have relatively lower rates compared to countries using the former approach.

This wide disparity among prevalence rates has initiated a debate in the field of disability statistics where some people argue that there is no point in maintaining a database with seemingly incomparable prevalence rates. Others argue that the data serve their purpose by showing how prevalence rates are affected by concepts used and questions asked in various studies. The metadata included in the database therefore help readers to discern the inherent conceptual differences underlying the prevalence rates.

Statistics in DISTAT show wide variations among estimates of the prevalence of disability based on various studies and for different countries because of the use of different concepts and definitions among countries and studies. For example, the disability prevalence rate for Zambia based on the 1990 census was 0.9 compared to 20 percent for the 1996 survey in New Zealand. Methodological differences in the measurement of disability therefore constrain the straightforward comparisons of disability prevalence rates among studies and countries.

DEVELOPING STANDARD MEASURES OF DISABILITY

Efforts are under way to identify minimum common questions that can be used, by countries, in censuses and sample surveys. In June 2001, the United Nations hosted an international seminar on disability measurement. The purpose of this seminar was to review and assess methods used in data collection activities related to the measurement of disability in national statistical systems and to develop recommendations and priorities. The seminar recommended establishment of a forum called the Washington Group on disability measurement. The objectives of the group are (1) to guide the development of a small set of general disability measures suitable for censuses, national sample surveys, or any other source that will provide basic necessary information on disability worldwide; (2) to recommend one or more extended sets of survey items to measure disability or principles for their design, to be used as components of population censuses or as modules to specialized surveys; and (3) to address the methodological issues associated with the measurement of disability as identified by the group.

The first meeting of the group covered various methodological issues related to disability measurement including purposes of measurement. The group also reviewed the ICF model, disability tables in the United Nations census recommendations, global measures of disability, relationship of global measures to the ICF, the confounding function of assistive device use, cultural practices that influence the nature of the environment or proscribe participation, cultural issues that act as barriers to collecting data, and cross-national comparability of information.

The second meeting discussed a matrix that linked the characteristics of questions on disability to purposes for collecting the data and results of methodological testing of general measures of disability. At the third meeting, it was agreed that disability was multidimensional, therefore it was not possible to ascertain the single "true" disabled person, and therefore different purposes were related to different dimensions of disability. The fourth meeting agreed on a draft set of questions on disability for use in population censuses.

TRAINING WORKSHOPS

To encourage countries to use the ICF and improve data collection methodologies, UNSD has conducted regional/subregional workshops on disability statistics, one in Africa and the other for the countries in the Economic and Social Council for Western Asia (ESCWA). Apart from covering the sources and uses of disability statistics, the workshops covered the elements and concepts of the ICF as a basis for statistical measurement of disability. This approach encourages the use of common definitions and concepts, which would eventually generate internationally comparable data. In the Economic and Social Commission for Asia and the Pacific (ESCAP) region, they conducted a similar workshop on improving disability data for policy use. The next workshop, on improving disability statistics and measurement, was held in Bangkok, September 2004.

REGULARIZING INTERNATIONAL DATA COLLECTION

In October 2005, the UNSD will initiate a systematic and regular national collection of basic disability statistics as part of the Demographic Yearbook data collection system.

—Jeremiah Banda

See also Epidemiology; International Classification of Functioning, Disability, and Health (ICF/ICIDH); United Nations.

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UNITED NATIONS STANDARD RULES

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities have their origin in the passage by the United Nations General Assembly of the World Programme of Action Concerning Disabled Persons on December 3, 1982. The World Programme outlined three goals: the prevention of disability, rehabilitation for persons with disabilities, and the equalization of opportunities for disabled persons. While not abandoning the more traditional efforts regarding disability, its inclusion in the World Programme placed equalization of opportunities on a par with the more traditional concerns. Care was taken to define equality as a parity of opportunities with those of the whole population. This parity was viewed not as a static phenomenon but one that would be fostered and maintained as countries engaged in economic and social development. Thus, the concepts would apply equally to both developing and developed countries.

In December 1992, the General Assembly wanted to continue implementing the World Programme and passed a resolution urging expedited elaboration of standard rules on the equalization of opportunity for persons with disabilities. The Standard Rules were adopted on December 20, 1993. Their purpose was “to ensure that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others” (United Nations General Assembly 1993, Resolution 48/96, paragraph 15, p. 8). The Standard Rules, although not compulsory, offered an instrument for policy making and action to persons with disabilities and their organizations, while providing a basis for technical and economic cooperation.

The Standard Rules delineated UN member states’ responsibilities in three areas. The first area, preconditions for equal participation, included member state responsibilities to (1) raise awareness, (2) provide effective medical care to persons with disabilities, (3) provide rehabilitation services, and (4) ensure the development and supply of support services, including assistive devices. The next area, target areas for equal participation, comprised the following rules: (5) accessibility, (6) education, (7) employment, (8) income maintenance and social security, (9) family life and personal integrity, (10) culture, (11) recreation and sports, and (12) religion. Rule 7 for employment, for example, stipulated that persons with disabilities must have equal opportunities for productive and gainful employment in the labor market in both rural and urban areas. The final group provided implementation measures for member states on (13) information and research, (14) policy making and planning, (15) legislation, (16) economic policies, (17) coordination of work, (18) organizations of persons with disabilities, (19) personnel training, (20) national monitoring and evaluation of disability programmers in the implementation of the Standard Rules, (21) technical and economic cooperation, and (22) international cooperation.

Member states were urged to establish national coordinating committees to monitor the Standard Rules and to coordinate implementation efforts with organizations of people with disabilities. The rules recommended the establishment of a special rapporteur to monitor the rules at the international level and this feature was implemented. A panel of experts established by nongovernmental organizations (NGOs) consults with the special rapporteur to monitor implementation of the rules.

—Scott Brown

See also Developing World; Economic and Social Development; United Nations.

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UNITED WAY OF AMERICA

The United Way of America (UWA) traces its beginnings back to 1887, when the Charity Organization Society began in Denver, Colorado. While this organization did not provide any direct human service provisions, it did conduct regular fund-raising campaigns for 22 local social service agencies and served as an intermediary between philanthropists and human service agencies. This sort of fund-raising role became the hallmark of what would become the UWA as it continued to develop throughout the twentieth century. By 1974, the UWA raised more than $1 billion in the United States and Canada, becoming the first charity to raise that much money.

In recent years, UWA has sought to evolve from strictly a fund-raising organization to a community empowerment organization. Three factors may have contributed to this evolution. First, widely publicized embezzlement scandals in not-for-profit organizations, including the UWA, have led contributors to demand greater transparency from these organizations. The UWA, however, provides no aggregate information about how much of the total money raised by United Way organizations across the United States goes to programs versus overhead costs. Second, following the terrorist attacks of September 11, 2001, on New York City, individuals and foundations donated large amounts of money to relief organizations such as Red Cross International and the Salvation Army. These contributions were targeted specifically for the victims of September 11 and left little money for other human services and other not-for-profit organizations in America. Finally, as a consequence of the first two factors, new philanthropists wanted to be more involved with agencies and wanted see how these agencies spent their donations.

To this day, as UWA transitions into a community empowerment agency, it maintains its identity as a fund-raising organization. For example, in 2002–2003, the United Way organizations across the United States raised $4.44 billion to target broad-impact areas such as strengthening families, building safe communities, supporting self-sufficiency, supporting vulnerable populations (e.g., people with disabilities and the elderly), and helping youths succeed. During its current transition period, UWA began referring to "member agencies" (i.e., agencies receiving money from the UWA) as "partner agencies." UWA's change in nomenclature from "member agencies" to "partner agencies" hints at the initial actualization of the organization's community empowerment vision.

This vision emerged further through UWA's greater emphasis on program evaluation among partner agencies. Now agencies must demonstrate both a need for program funding through a needs assessment and the program's effectiveness through formative and summative evaluations. To assist with these increased reporting requirements, the agency has created an innovative and informational web page, as well as developed numerous trainings concentrating on empowering social service agencies with greater program evaluation skills. These evaluation skills and the requirements the UWA developed necessitate greater transparency among agencies. Furthermore, once agencies develop the capacity for formal evaluation, they can use those skills to find grants outside the UWA. Indeed, UWA has shown that social service agencies now not only need to do good work, but they must also prove they do good work to remain viable.

—R. Noam Ostrander

See also Charity.

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United Way of America, http://national.unitedway.org/

UNIVERSAL DESIGN

See Accessibility; Aids for Activities of Daily Living; Assistive Technology; Visitability

UNIVERSALISM

The word *universalism* is sometimes not found in dictionaries, yet it is in current use. In the sphere of disability, it stands in opposition to an overly specialized perspective that would leave some people as exceptions and in marginalized status. But the term also has a more general meaning, derived from the word *universal*. Here it refers to the totality of reality, to that which extends to the entire collectivity.

The term is employed in the domain of disability to focus attention on the fact that we must above all make social spaces accessible—physical space, educational space, and mental space. As a consequence, it is a matter of reforming society so that it is receptive to the greatest possible number of disabled persons. The phrase "universal design" sums up this vision. The term is then in opposition to a particularist conception that would authorize intervention in social spaces only in the event of this or that specific deficiency. For example, instead of planning for maximum accessibility in the construction of an apartment building—for the entire building (universalism)—provision is made for one or two apartments outfitted for people in wheelchairs (particularism). It is quite clear that it will never be possible to foresee everyone's needs in every case and circumstance. But the very fact of setting accessibility as a goal for the majority of cases lowers the level of difficulty for a very great number of people and precludes handicap, or at least surplus handicap. This is one of the meanings of the word universal, as a synonym for general: what extends to the greatest number. Striving for universalism dictates working on and with the common everyday environment to avoid detours through specialist institutions or social stigmatization. Everything that enables disabled citizens to participate without obstacle in the life of the community must be attempted.

The limitation that has been recognized, that total accessibility cannot be achieved, will assist us in better understanding what *universal* and the doctrine of *universalism* really mean. Universal designates that which extends to the entire universe, to the total reality of the world or of the human collectivity. Apart from the laws of physics (an apple falls in the same way in Beijing as in New York), we may ask whether there are rules that are valid for humanity in its entirety. One could doubtless assert, for example, that some fundamental proscriptions seem common to all societies (the ban against killing, in particular one's kin; the ban against incest; the ban against generalized lying). But we must immediately add that the modalities, boundaries, and sanctions affecting these forbidden areas are extremely diverse. We more often encounter resistant particularisms, deeply anchored in culture, than common norms, customs, and conceptions. This is why it is perhaps better to view universalism in the narrow sense of logicians. They speak of a "universal term," that is, a term understood in its fullest extension, encompassing all the individuals in the category of individuals under consideration. The universal deals with a human group—a set—but not with the whole of humanity.

Philosophy has not always understood the universal in this sense. We should recall the celebrated "Dispute over Universals" that raged in the Middle Ages. Behind the diversity of beings, is there something that can be called "being"? Behind our ideas and the varied forms of what we call beauty, goodness, truth, is there a heaven where ideas of the beautiful, the good, the truthful exist? More recent is the question whether behind the diversity of languages there are laws that apply without exception to the totality of languages. This was the debate between linguists such as Sapir, on the one hand, and Chomsky, on the other, to cite but these two names. The universal, be it ontological, formal, or linguistic, is still being debated. Perhaps the most telling "last word" in the medieval debate was that of the fourteenth-century philosopher William of Ockham, who said, "The universal is an intention of the mind, susceptible of being attributed to a great number of subjects" (*Ordinatio sive scriptum in librum primum Sententiarum*, distinction II, question 6).

In this quick review of meanings of the words *universal* and *universalism*, we should also note the religious signification, Christian in particular, that makes universalism the doctrine of those who believe that all human beings are saved, whatever their religious views and thus without the mediation of Jesus Christ, while mainstream theology affirms that no one is saved without that mediation. Here universalism has a pejorative shading, even though the Christian religion lays claim to a universal calling, addressing all people of all times, to teach them of the promise of universal salvation through Christ. This, it may be noted in passing, is a neat reconciliation between the universal and the particular: Salvation is available to everyone but is mediated by the singular person of Christ.

Last, a more sociological signification for the word *universalism* should be noted. Social or cosmic reality is a whole on which individuals are dependent. In this context, the word emphasizes the social totality that precedes and determines individuals. The universal is primary with respect to the particular; it proceeds as a deduction and is not the result of a kind of induction from particulars toward a general level. Societies that have been called holistic operate on the basis of this primacy of the totality, of what dominates individuals and constitutes the common law to which they must submit. This sense of the word does not characterize modern societies, in which the point of departure is always individuals, their rights and their claims. Yet, on the other hand, our contemporary societies are borne along by the movement called globalization. Here we cannot analyze the different meanings and different levels of globalization. It will suffice to note that one of its aspects is the forcible application, often initiated by the countries most powerful in terms of demography and economy, of canons, standards, styles, technologies, which tend to be imposed on everyone, everywhere. The English language, to take a single example, is progressively becoming the universal language, the one in which the inhabitants of the culturally most remote countries will communicate, the one that will serve as the medium of exchange in all four corners of the world. This globalization is realized, by the very coercive nature of things, to the detriment, greater or lesser, of distinctive collective identities and ancestral traditions.

To summarize, the word *universalism* can have many meanings (religion claiming to address all humans; a doctrine that views reality as a totality, preceding all individuals; a philosophy in search of universals; a science that seeks laws without exception; a culture that imposes itself on other, earlier cultures), but it always comes back to the question of knowing whether we should focus on singularities in order to move to a higher level or posit a universal that subsumes these singularities. The problem of the universal will always be that of the relationship between the particular, always certifiable, and a superior level that transcends it, one established by the mind but not empirical.

In this general, abstract question, it is important to distinguish among a multitude of concepts. What is constant is not fully universal, because a constant is not susceptible, at a given time, to exceptions, although it does not rule out surprises. The general is not a synonym for the universal, because generality is the product of a statistical, probabilistic perspective and cannot claim to be valid for the whole of reality or society. Nor is global a synonym for universal, since globalization refers to the international without our being able to predict its universality.

This discursive tour of semantics, in the context of an encyclopedia devoted to disability, is not intended to make a full exposition of the problems of the universal. What stands out is that the universal has never been realized and never will. Its role is to establish, as some philosophers put it, a “horizon,” that is, a kind of ideal in front of us that we must not drop from sight, one with which we must constantly concern ourselves without getting lost in the restrictive, sequestering detail of particularist views and special interests. The status of the universal, and consequently that which must sustain universalism, stems from a double necessity: to refuse to believe that the universal is something that has already been achieved, and to refuse to renounce attaining it. This only appears to be paradoxical. In fact, anyone who claimed to have realized the universal would only have imposed his or her particularism on others. We have seen this in colonialism; we see it now in the standards of various technologies. It was seen in the Marxist ideology that sought to subject the world; it is seen now in the pretentions of the cultures of developed countries to regulate, and thus to reduce, other cultures (under the cover of universal human rights, nonetheless indispensable, or under the cover of democracy on the American, French, or British model). On the other hand, anyone who renounces the universal as goal opens the way to all kinds of excess, all kinds of cowardly tolerance and imprisonment in archaism. This is evident when no one speaks to the exploitation of women by certain religions, or when one accords this or that fanaticism the same respect and rights as the defense of human dignity, or when one fails to affirm that there are rights to be recognized for all humans, in their simple capacity as human beings.

To return, in conclusion, to the specific problem of disabled people, it seems important to claim that all of society be open to them and that the same real rights and responsibilities be recognized for them. At the same time, it is equally important not to neglect to insist that certain specific measures be taken, in particular for certain onerous or rare deficiencies, for instance. Aiming for universality in these measures and arrangements prevents us from siding with any one category of disadvantaged citizens, but believing that generalized accessibility is in itself sufficient would leave us the victims of illusion, since this would also entail abandoning certain people. Universalism remains a horizon, a perspective, a stimulating goal. The worst that could happen to it would be to believe that it is no longer worth pursuing.

—Henri-Jacques Stiker

See also Globalization; Inclusion and Exclusion; Values.

UNIVERSITY AND COLLEGE EDUCATION

See Education, College and University

UPIAS

See Union of the Physically Impaired against Segregation

URBANIZATION

Most people in the Western world live in cities, and increasingly people living in developing countries are moving to urban areas. In this urbanizing world, the majority of job opportunities, access to goods and services, entertainment, and other functions are found in cities. Since the late nineteenth century, the city has been viewed as a source of social alienation and anomie, characterized by fragmentation and the dissolution of traditional (often rural) social networks. Urbanization over the course of the twentieth century has witnessed, some commentators suggest, the emergence of unsustainable cities and modes of living. In this view, the city is conceived of as dystopia, increasingly plagued by environmental pollution, poor health for its inhabitants, social polarization between rich and poor neighborhoods, land degradation, and crime.

Such observations resonate with many disabled people whose experiences of urban environments are far from positive and are conditioned, in part, by their difficulties in moving about and getting access to places in the city. From sidewalks cluttered with street furniture such as benches and other physical obstacles to the absence of clear signage, urban areas are constructed in ways that do not contribute to the mobility of disabled people. In this respect, urban areas may be regarded as reproducing inequalities between disabled and nondisabled people (see Allen, Milner, and Price 2002; Imrie 1996, 2005; Imrie and Hall 2001). For some, urbanization is characterized by a design "apartheid" in which the design of the built environment actively disables disabled people, which, in turn, prevents them from accessing facilities such as shops, parks, transport, and dwellings without help.

For instance, common experiences of the effects of urbanization for disabled people who use wheelchairs include the following: ramps that are installed but prove to be too steep to be used safely, dropped curbs that are present but are badly placed; a government office on the second floor of a building but with no elevator; a shopping center without a disabled person's toilet; streets without clear signage or tactile walkways or means of way finding; a "wheelchair friendly" restaurant that has two steps at the entrance; a museum that has ramps and a disabled person's toilet but no elevator, so that wheelchair users can visit only the ground floor; and a municipal building with a ramp that is so steep that most wheelchair users prefer to go down it backwards. Such features are commonplace, so much so that they are broadly accepted by the population as a whole as normal and inevitable parts of everyday life.

An important theme in the study of the city and disability is that the disabling nature of the urban built environment is, in part, related to the purposive plans and policies of urban planners who have the responsibility for the production of cities. Urbanization, as product and process, takes shape through the context of the values of and actions by professionals, who, in Western societies, have rarely acknowledged disabled people and their needs. Rather, the urban subject—those whom planners seek to plan for—is conceived of as an abstract generalization and is rarely thought of in terms of differences in relation to the body, ethnicity, gender, or sexuality. Disability, as a descriptor or category of social reality, has rarely figured in architectural or planning education, and, as Greed (1999:270) suggested, the subcultures of design, property, and construction professionals are resistant to change in not permitting "much space for wider strategic and holistic approaches to . . . social factors."

While building regulators and officials have some scope to influence the form of the urban environment, the physical shape of urbanization is largely determined by the values and practices of property developers and builders. The values of property professionals are usually impervious to disability, and they tend to perpetuate problematical, and erroneous, assumptions about disabled people in relation to the design of their buildings. Professionals in the building industry continue to argue that there is insufficient demand by disabled people for an accessible built environment and that the provision of accessible buildings is prohibitively expensive. While both assumptions have been shown to be false, they persist as blocks to a progressive urbanism characterized by barrier-free environments.

Disabled people's experiences of urbanization are not just related to the form of the physical environment but are also determined, in part, by what Ellin (1996:252) referred to as the city with "a confluence of meanings rather than functions." Thus, many of the symbols and images of the city do not provide disabled people with the means for self-expression or autonomous behavior, but rather encourage a retreat into private spaces (or out of sight and off the streets). For instance, steps into shops or nightclubs not only prevent a wheelchair user ease of access to the facility but also create a context of dependence on others for assistance while transmitting a sense that those without "able" limbs, or independent use of body parts, are unwelcome. Likewise, for many wheelchair users, "back door treatment" is the norm, in which the entrance to a building is often through side doors, back doors, or everywhere but the front. In this sense, the built environment is marked out by spatial signifiers or symbols of difference that serve, potentially, to separate disabled people from their "normal" counterparts (see Hawkesworth 2001).

What are the possibilities for an urbanization that will facilitate livable places for disabled people? Most forms of urban renewal are characterized by a property-based approach to development, in which people-based issues are sidelined. However, recent debates about the "good city" revolve around principles of new urbanism, in which it is suggested that cities should be constructed as compact spaces with an emphasis on accessible, safe, and inclusive spaces. Its emphasis on small-scale, localized forms of urbanization, based on diverse neighborhoods and human scales of interaction, provides potential for crafting urban spaces based on human need rather than profit. In this respect, the people-centered design philosophy of new urbanism, while not a panacea, gives some hope that urban renewal will be attentive to some of the needs of disabled people (see Talen 1999).

Its translation into the lived realities of urbanization will depend, in part, on shifts in social attitudes and practices in relation to disability and a greater willingness of building professionals and others to recognize and respond to disabled people's intrinsic rights to access and mobility and movement in cities. In the United States and the United Kingdom, legislation is an important part of requiring much more provision of accessibility features than was hitherto the case, and city governments are adopting diversity agendas that require urban renewal policies and plans to incorporate the needs of disabled people. For instance, in the United Kingdom, all new dwellings have to be constructed to minimum levels of accessibility, while in the United States, many state and local governments have adopted ordinances that require developers to provide access in single-family dwellings. While legal measures, in and of themselves, cannot guarantee barrier-free environments, they provide the possibilities for a new era of urbanization characterized by the breakup of social and physical barriers in cities.

—Rob Imrie

See also Accessibility; Accessibility Codes and Standards; Fair Housing Act Amendments of 1988 (United States); Health Care and Disability.

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URINARY TRACT INFECTION IN SPINAL CORD–DISABLED PATIENTS

Urinary tract infection (UTI) refers to infectious diseases of the kidneys (pyelonephritis), ureters, bladder (cystitis), and urethra (urethritis). The most common way for bacteria to enter the urinary tract is through an ascending route from the genitourinary region through the urethra, counter to the usual flow of urine. Thus, the typical causes are bacteria from the gastrointestinal tract and vagina given their close proximity to the urethra.

Patients with disabilities are particularly at risk for UTI. The most notable group includes individuals with spinal cord dysfunction (SCD) including spinal cord injury and multiple sclerosis. Important complications of the urinary tract include kidney failure and infection. They have traditionally been ranked as leading causes of death in those affected with SCD. Prior to the early 1990s, diseases of the urinary tract accounted for two-thirds of deaths in this group of people. While medical care of patients with SCD has dramatically improved over the past one to two decades, UTI still ranks as the second most common medical complication. Increasing disability in patients with SCD increases the risk of UTI whereby 75 percent of patients with paraplegia and over 85 percent with quadriplegia experience UTI. As a result of recurrent UTI among patients with SCD, the medical costs are substantial; rehospitalization for complications can cost in excess of $12,000.

The basis for increased rates of UTI among patients with SCD is principally two-fold: (1) the decreased ability to completely empty urine from the bladder, producing static urine where even small numbers of contaminating bacteria can replicate, and (2) the requirement for either intermittent or indwelling catheterization for drainage of the urine, each of which can provide direct access for bacteria to the urinary tract. The use of catheters has dramatically improved the care of patients with SCD; however, catheters also substantially increase the risk of UTI especially when indwelling catheters are employed. Undoubtedly, antibiotics have had a major impact on treatment of serious UTI in patients with SCD, decreasing morbidity and mortality. Unfortunately, the diagnosis and the appropriate treatment for UTI in people with SCD are exceptionally difficult because individuals can have bacteria persist in their bladders without disease and can have dramatic cases of infection without fever or pain (as a result of their spinal cord injury). Antibiotics given prophylactically decrease the persistence of bacteria in the urine and delay the time until the development of a UTI; however, patients on prophylaxis still experience the same number of bona fide infections. The constant use of antibiotics also increases the occurrence of infections with antibiotic-resistant bacteria, a public health challenge.

In the future, medical advances may produce tests that differentiate true UTI from persistent bacteria in the urine. Examples of preventive therapies include colonization of the bladder with benign bacteria that block the disease-causing agents from gaining a foothold and vaccination against the most important causes of UTI. Improvements in rehabilitation may improve patients' sensation and thus their ability to appreciate pain and other symptoms of urinary infection while improving bladder function, decreasing their dependence on catheterization.

—Patrick C. Seed

See also Bladder Control; Multiple Sclerosis; Spinal Cord Injury.

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V

VALLATHOL (1878–1958)

Indian poet, essayist, and cultural architect

Vallathol Narayan Menon was a South Indian poet, essayist, and major contributor to the renaissance of the Malayalam language and culture. He lost much of his hearing as a young man. In his early 30s, he wrote *Badhira Vilapam* (*Lament of a Deaf Person*) expressing a sense of loss and deprivation as he became deaf. Vallathol had earlier translated Valmiki's *Ramayana* into Malayalam, and in his 70s he completed a translation of the *Rig Veda*. His eight-volume "Bouquet of Books" appeared successively from 1917 to 1970, after his death.

The dream of his mature years was to initiate the revival of Kathakali dance drama. He opened the Kerala *Kalamandalam* in 1930 to teach all the classical arts of Kerala, and his cultural crusade was recognized and honored after India's independence. The American danseuse La Meri (1941:27) studied gestural communication in Kerala in the 1930s and noted that "Vallathol, the great poet who has revived the Kathakali form in Malabar, is deaf and so converses entirely by means of the beautiful gesture-language of India."

—Kumur B. Selim

See also Dance; Experience of Disability: India; Poetry; Sign Poetry.

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VALUES

Any discussion of disability as a social phenomenon must also include the issue of values. Values are a set of principles or standards concerning the relative worth, utility, or importance of things and experiences. Often values appear in everyday life as judgments or points of view on behaviors and social problems. Disability as a category or a label is not value neutral. The term itself—*dis*-ability—implies a value judgment. All individuals vary in the skills and abilities they possess. Yet for a whole class of individuals, society considers their physical limitations to be a defining characteristic. Therefore, discussions of disability must be mindful of how values shape our attitudes and actions toward those with disability in society.

Social values are significant for how we, as a society, interact with, think of, and provide services for individuals with disabilities. However, the experience of disability is highly variable. The ways that individuals value (or devalue) their experience of disability is dependent on a wide range of factors. These factors include the age at onset of disability, the cause of their limitation, its visibility to others, and the degree to which it poses functional challenges or impediments in their daily lives. Each factor influences the value one places on his or her own life as well as the value of his or her life to others. Beyond individual values, society also values (or devalues) disability. Society's values are reflected in public policy initiatives and in the physical and social environments. This entry highlights the importance of values, as they influence behaviors and actions at both an individual and social level.

A person may experience disability at any point in life. The point of onset of disability may have a profound effect on how individuals think about and value their lives and their disability. Individuals who experience the onset of disability later in life must address their loss of physical function. Even more, they may perceive a loss of self. People who experience the onset of disability during adulthood often grapple with the loss of physical function and reconcile their current abilities with their ideas about who they were and the role they served. The ability to perform social roles such as wife, father, or employee might be limited by the physical experience of disability. This inability to fulfill their familiar roles may lead people not only to resent their disability but also to regard themselves as less valuable members of society.

Those who experience the onset of disability at an early age are faced with another set of social and personal challenges. Children may be unaware of their disability and how others perceive them. Many children without disability are not taught how to talk about disability. Rather than acknowledging children's curiosity, many parents hush them when they inquire about another child's disability in public, furthering the stigma that disability is something to be devalued. Furthermore, because children do not know what/how to talk about disability and difference, it makes social interactions all the more awkward for children with disabilities. As children age, they may realize that they do some things differently from their peers or cannot participate in some activities. As a result, they may see themselves as less socially valued. Alternatively, children may be able to incorporate their disability into their self-concept or identity from the start, thus avoiding the difficult transition experienced by many adults.

The visibility of one's disability could also play a role in how individuals think about and value their disability. Those with more visible disabilities—paralysis, amputeeism, severe forms of mental retardation—may experience more prejudice than do those whose disabilities are hidden, such as chronic pain. Alternatively, those with hidden disabilities may experience insensitive treatment from individuals who, unaware of their disability, do not anticipate the need for accommodation. More visible disabling conditions create an opportunity for the general public to pass judgment on and label those who experience disability. These judgments and associated labels indicate how society values disability.

Our discussion here focuses on the American experience of disability; however, how disability is valued is context dependent. The experience of disability depends on the social, cultural, economic, and political context in which a person lives, as well as the norms and beliefs associated with these dimensions. For example, some Middle-Eastern Muslim societies view those with mental retardation as "saints." Likewise, the economic circumstances of an area can influence social perceptions of disability. In a hunter-gatherer society, physical disabilities may be seen as exceptionally detrimental to the well-being of the tribe. Overall, there are very different cultural reactions toward those with disability. These cultural reactions shape the values of a society and thus influence the way those with disability are labeled and cared for in society.

The words that we use to talk about a phenomenon not only describe it but also shape the nature of the phenomenon itself. Language reflects the social values of the times. Today, many use *disability* and *impairment* interchangeably, yet they have profoundly different indications for how we are to think about the very nature of the state itself. The World Health Organization (WHO) has tried to reconcile these definitions in its International Classification of Impairments, Disabilities, and Handicaps (1980) and more recently in its International Classification of Functioning (2001). *Impairment* refers to problems in physical function, loss, or abnormality. *Disability* occurs when there is a mismatch between the physical capabilities of a person and the demands of the environment. In other words, the environment does not accommodate the limitation or inability of the person to perform such tasks as boarding a public bus or entering some buildings, creating "disability." Therefore, the WHO definition suggests that disability should not be viewed as a problem located solely within the individual, but rather as a problem in how society and the physical environment are structured.

Disability rights activists have long argued this point. They suggest that disability is a condition created by society and how it is arranged. They reject that disability is a personal inability to perform tasks because of a physical or mental deviation from "normal." These activists see disability as the result of an environment that is not accepting or accessible to people with abilities that stray from "normal." The concept of universal design taps into this notion. Universal design refers to an architectural approach that is accepting of all variants of physical ability. Stairs are replaced by gradual inclines; floors are neither so smooth to make it difficult to walk nor so coarse that it impedes mobility in a wheelchair. Disability activists' social model of disability favors environmental change rather than personal change. That is, environments should be accessible to all people, regardless of their physical and mental levels of function. This principle views disability as value neutral or even value added. Overall, this type of environment would better the lives of those with disability as well as those without disability.

Along with shifting the responsibility of disability away from the individual and toward society by altering the physical environment, changing language is also important in valuing disability. To say an individual "suffers" from deafness or mental retardation is to make a judgment about the worth and value of these experiences, and of those individuals who have such conditions. The importance of language in shaping the meaning and worth of disability has been emphasized by the "person first" campaign within the disability rights movement. This movement has argued that the term *disabled person* should be replaced by *person with a disability.* That is, the former term emphasizes disability as a master status—as the most salient and defining characteristic of an individual—whereas the latter stresses that people with disability are first and foremost *people* and that their disability is only one aspect of their personhood. This person-first campaign has empowered those with disability while at the same time raising their value in society. However, disability rights activists have launched a backlash against the person-first language that has come to permeate the field of disability studies on the basis that it undermines the importance of their disabilities to their lives. This movement argues that person-first language is a politically correct approach instituted by individuals who claim to speak for those with disability. Both sides of this debate, however, provide evidence that increased social value has been placed on disability. In turn, this is reflected in current public policy initiatives.

At a societal level, we may infer social values by analyzing public policy about disability. A glance at disability policy in the United States, as well as in other developed countries, depicts a formidable change in the way people with disability have been valued in society over the past century. In the past hundred years, we have moved from a society that promoted the principles of eugenics to one that incorporates people with disabilities more fully in social life. Again, this discussion emphasizes the American experience; however, it is, in many ways, typical of most developed Western countries' experience.

Public policy is strongly shaped by social values, and disability policy is no exception. In the United States, we can trace the evolution of social policy and social values regarding those with disabilities. Disability has been a stigmatizing characteristic throughout history, and people with disability have experienced oppression to various degrees. This oppression has resulted from and been legitimized by social policy and has ranged from eugenically driven attempts to eliminate those with disability from our society to extremely paternalistic attempts to protect those with disabilities from the larger society.

Disability was strongly devalued by society in the late nineteenth and early twentieth centuries. Individuals with disabilities were viewed as deviants to be kept away from society at best, as a fatal flaw in society that required elimination at the worst. We have moved past this phase in our history. Beginning in the 1950s but coming to a head in the early 1970s, parents, professionals, and disability rights activists began to demand policy changes. In the 1950s, parents began to form organizations around the specific disability categories that affected their children. These groups soon became instrumental in advocating for disability rights, most particularly for quality schooling for children with disabilities.

Throughout the 1960s, Congress expanded programs to fund education, rehabilitation, and social services for those with disabilities. During 1975, two crucial pieces of legislation were passed: the Education for All Handicapped Children Act (EHCA) and the Developmentally Disabled Assistance and Bill of Rights Act (DD Act). The EHCA guaranteed all school-age children with disabling conditions the right to a free and appropriate public education.

Though these policy advancements indicated a dramatic shift in our social conception of disability, the most significant legislative event was the 1990 passage of the Americans with Disabilities Act (ADA). This act formally outlawed all discrimination on the basis of disability, including discrimination in the workplace, in businesses, schools, transportation, and the like. Furthermore, it mandated, when economically feasible, that public spaces be made accessible to those with mental and physical disabilities. This sweeping legislation was the most profound indication that our society no longer found it appropriate to marginalize those individuals with disabilities. At the heart of the ADA was the aim of making all dimensions of public life available to those individuals with disability and to allow them to participate fully in society.

This is not to imply that the ADA has alleviated all forms of discrimination, nor does it suggest that, as a society, we have eliminated all stigma associated with disability. The ADA is worded so as to allow significant discretion in its interpretation. Still, a trend toward inclusion permeates current policy. This legislative shift is a further indication that society has become more accepting of disability. Rather than deliberately excluding individuals with disabilities from the public sphere of everyday life, the ADA protects the rights of people with disabilities to live their lives fully without environmentally imposed limitation.

Values, then, are clearly significant for how we, as a society, interact with, think about, and provide services for individuals with disabilities. Moreover, these social values play an important role in shaping the ways that individuals value (or devalue) their experience of disability. Culture also influences the social valuation of disability, and the ways in which these values translate into public policy and environmental change. During the past century, society has undergone a notable shift in the ways we value disability. We have moved from a society that has oppressed and hidden those with disabilities to a society that is more accepting of the disability experience. This shift in values has been reflected by a shift in public policy. Moreover, the personal experience and valuation of disability have likely changed as well over this period. People with disabilities are able to accept their disabilities and live in the public sphere in a way that earlier generations of people with disabilities were not. People with disabilities are now legally afforded educational and employment opportunities that were, in earlier times, systematically denied to them. Changes in policy and social values, in turn, have altered how individuals evaluate their bodies and their mental or physical abilities. More accommodating environments and a social awareness of the diversity of human abilities has begun to reduce the stigma associated with the disability experience for many. In the future, these social values may continue to provide those with physical or mental disabilities the ability to live life fully.

—Maryhelen D'Ottavi and
Carrie E. Spearin

See also Empowerment and Emancipation; Disability Policy: United States; People First.®

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VAN GOGH, VINCENT (1853–1890)

Dutch artist

Vincent van Gogh was born in Zundert, the Netherlands. At age 27, after years spent in various failed professions, he decided to become an artist with the help of his brother Theo. In 1886, he moved to Paris to live with Theo, and there he met the Impressionist group. His palette lightened, and in 1888 he left Paris for Arles, a small, picturesque town in the south of France where he achieved full maturity as an artist. In 1888, he had the first of several epileptic seizures and mutilated his ear by severing an artery. In 1889, he voluntarily stayed at St. Remy, a mental hospital, where he was treated for seizures. In the last months of his life, he stayed at Auvers-sur-Oise near Paris and was treated by Dr. Gachet, who was willing to be paid in paintings. Also diagnosed with chronic sunstroke and intoxication from turpentine and absinthe, van Gogh died at age 37 by his own hand. He sold only one painting during his lifetime, yet left behind 1,600 paintings and drawings. His letters to Theo reveal the depression and elation of Vincent's life as a painter as well as his gentleness, love of humanity, and clarity of thought about his art.

—*Katherine Sherwood*

VAN LANDEGHEM, HYPPOLITE (fl. 1865)

European disability activist

The blind polemicist Hyppolite (sometimes given as Hippolyte) Van Landeghem published ca. 1863 a long denunciation of the "exile system" that "immured" blind youths in segregated schools (he had spent 12 years in one), wasting huge sums on buildings and "salaries of sighted officials, who are totally unfit to educate the blind" while the number of blind people thus (mis)educated was tiny compared with those for whom nothing was available. Van Landeghem keenly advocated home education, yet he was severely critical of William Moon's Society for Teaching the Blind at their own homes and of other evangelistic organizations using embossed books: "Restore to a blind man his social rights, give him an opportunity of achieving his own support," and only then expect him to attend to religion (Van Landeghem 1863). He railed against fund-raising to teach blind people in Asia, when 27,000 blind people in the United Kingdom lacked education or employment. Van Landeghem advised blind people to dispense with guides and walk the streets by themselves, after trying this himself for two years in London. A book by Mrs. Hippolyte Van Landeghem (1865) reinforced the message with life histories of notable blind people from Europe and America.

—*Kumur B. Selim*

See also Blind, History of the.

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VEECK, BILL (1914–1986)

American businessman

Bill Veeck was one of the greatest innovators of baseball management while serving as owner and/or manager of four different major league baseball teams. The son of a sportswriter turned president of the Chicago Cubs, Veeck began working in baseball at age 11 as a ticket seller, vendor, and groundskeeper. He was famous for introducing gimmicks and marketing stunts including the exploding scoreboard, giving away live animals, scheduling morning games for late-shift workers, having marriage ceremonies on home plate, and his famous Grandstand Managers Day where he asked fans holding placards with a “yes” or “no” to vote on whether to hit, bunt, steal, or other managerial choices. He once presented his manager with a huge birthday cake, out of which popped a much-needed left-handed pitcher. In 1952, Veeck arranged for midget Eddie Gaedel to bat for the St. Louis Browns. Veeck also introduced innovations that became part of baseball management; shortly after taking over the Chicago White Sox he created a media event by setting up an office in a hotel lobby and purchasing contracts from players from other clubs, introducing free agency into major league baseball.

While still part owner of the Brewers, Veeck served three years in World War II in the U.S. Marines. An accident cost him his right foot and, despite 36 operations over the rest of his life, he lost his leg as well. Veeck never let the loss limit his work, and in one of his most creative stunts, in 1976 Veeck staged a bicentennial-inspired Spirit of ’76 parade on Opening Day—with himself as the peg-legged fifer.

Veeck is also credited for being a major management force toward integrating major league sports. Before entering the military, Veeck secured backing to buy the Philadelphia Phillies and had a plan to stock the club with stars from the Negro leagues, a plan rejected by the baseball commissioner. However, after the war, in 1947, Veeck integrated the American League by hiring Larry Doby, weeks after Jackie Robinson joined the Brooklyn Dodgers of the National League.

—Joseph A. Flaherty

See also Sports and Disability.

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VESTIBULAR DISORDERS

Vestibular disorders refer to a group of problems affecting an individual’s sense of balance. Dizziness, vertigo, unsteadiness, light-headedness, and disequilibrium are some of the words people may use to describe a feeling of imbalance. Most vestibular disorders are transient and improve with observation and occasional symptomatic treatment. However, in rare instances, imbalance can be a sign of a potentially serious disorder.

The vestibular system is composed of a set of balance organs within each inner ear (collectively referred to as the *labyrinth*), nerves connecting the labyrinth to the brain, and various nuclei within the brainstem, cerebellum, and cerebral cortex that interconnect at multiple levels. The brain uses the input from both labyrinths to help determine one’s position in space. If there is a disturbance in input from one side, the asymmetry may be perceived as imbalance. Vision, *proprioception* (the ability to sense one’s position in space with the eyes closed), and *central integration* (the processing by the brain of input from the eyes, ears, head, trunk, and extremities into a meaningful whole) also significantly influence balance and are considered part of the vestibular system.

In addressing complaints of dizziness, physicians must first consider whether symptoms arise from true vestibular dysfunction or from a more general medical cause. Diabetes, cardiac arrhythmia, and hypotension are some of the many disorders that can cause dizziness or exacerbate a true vestibular disorder. Complaints of frank *vertigo* (the illusion of a turning motion) or the presence of *nystagmus* (an involuntary linear or rotary movement of the eye) on physical exam denote a vestibular problem. Once a vestibular lesion is suspected, a distinction is then made as to whether the site of the lesion is inside the brain or brainstem (*central*) or outside (*peripheral*). The pattern of onset (acute, subacute, progressive, intermittent), the duration of dizziness (seconds, minutes, hours, days), and associated signs and symptoms (hearing loss, tinnitus, head trauma) can further help to localize the lesion.

The diagnosis of most vestibular disorders is through a careful history and physical exam. A neurological exam is essential to identify disturbances in gait and balance and to uncover the presence of cranial nerve neuropathies, which may help to localize a lesion. The head-and-neck exam is focused on identifying the presence and direction of nystagmus and ruling out evidence of otologic pathology (a draining ear, mass, membrane perforation), which may suggest the cause of the problem. Once a differential diagnosis is established, additional testing such as an electronystagmogram (ENG) can then help to rule in or out a specific diagnosis.

Vestibular dysfunction can be caused by vascular events (migraine, stroke, hypotension), infections (labyrinthitis, otitis, mastoiditis), trauma to the temporal bone, autoimmune disorders (Cogan syndrome), metabolic derangements (diabetes, hypothyroidism), or neoplasms (vestibular schwannomas). Some diseases are idiopathic, such as benign positional vertigo (BPV) and Meniere's disease. Common peripheral vestibular disorders include BPV, Meniere's disease, vestibular neuronitis, acoustic neuromas, and labyrinthitis. Central vestibular disorders include migraine, multiple sclerosis, vascular insufficiency, cerebellar dysfunction, and Arnold-Chiari malformation, among others.

—John Damrose and
Hamid R. Djalilian

See also Diabetes; Gait Analysis; Multiple Sclerosis; Neurological Impairments and Nervous Disorders; Stroke.

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VETERANS

War has been credited as an impetus for change. Within many fields, war has been responsible for new methods, materials, and organizations. Clearly, war has been responsible for a mass of injuries that result in numbers of disabled people but has also acted as a catalyst to improve medical knowledge and techniques in the treatment of disability. During war, many different types of therapy have been developed that have primarily ensured the survival of those injured and also have produced innovative methods of treatment that have ensured a better quality of life for disabled people.

While wars in the previous centuries produced disabled men, World War I is the one noted for creating enormous numbers of disabled men. Estimates suggest that at least 1.5 million people were left with some sort of disability. Physical and sensory disabilities were augmented by those suffering from neurasthenia or shell shock. Innovations in medicine such as orthopedic surgery ensured that permanent disability was lessened, and often servicemen were made well enough to return to the battlefield and risk being killed once more.

Those who returned home with a disability became the government's responsibility; the Ministry of Pensions was established in 1917. In the United States after the war, three different agencies administered veteran's benefits: the Veterans Bureau, the Bureau of Pensions of the Interior Department, and the National Home for Disabled Volunteer Soldiers. Programs included compensation, insurance, and vocational rehabilitation. Advocate agencies in the United Kingdom such as the British Legion and the Returned Sailors and Soldiers Imperial League of Australia were established in 1921 and 1916, respectively, to look after the interests of disabled ex-servicemen. There were constant disagreements over pensions for disabled ex-servicemen, and the British government was criticized by organizations such as the British Legion for their lack of fiscal support. The United States established its own Veterans Administration in 1930, although there had been provision for disabled veterans since 1776 when, to increase enlistment for the Revolutionary War, pensions were offered to anyone who was disabled in the fighting.

Although World War II was not as devastating in terms of numbers killed as World War I, numbers of people were disabled as a result of the war. As the fighting line was more fluid, civilians were drawn into the field of battle and became disabled as a result of enemy action. New regimes were established to ensure that those who had been permanently disabled were able to be employed elsewhere to assist the war effort. Termed *rehabilitation*, its purpose was to ensure that the effect of the manpower shortage due to mass mobilization was lessened. The Disabled Person's Employment Act of 1944 in Britain established guidelines for the employment of disabled people after the war.

As well as being workers, disabled people were viewed as heroic. Douglas Bader, the famous double amputee, was feted for his bravery flying Spitfires for the Royal Air Force. Some of the most important work on disability was that of neurosurgeon Sir Ludwig Guttmann, at Stoke Mandeville in Aylesbury, England, who worked with servicemen and servicewomen who had incurred spinal injury with resultant paralysis. His efforts to prevent them from sinking into depression and work toward building a stronger body with compensatory muscles through sports had far-reaching implications, as these early competitions evolved into the contemporary Paralympic Games.

In the second half of the twentieth century, wars were conducted on a smaller scale, but numbers of people were disabled as a result of the conflicts. About 75,000 Americans were severely disabled in the Vietnam War. Later conflicts saw complicated disabling conditions such as Gulf War syndrome, which was reported to be caused by exposure to a cocktail of chemical agents. While there were fewer battle casualties in the latter decades of the twentieth century due to advances in technology that distanced the warring parties, the disabling effects of war continue.

—Julie Anderson

See also Disabled Veterans; Posttraumatic Stress Disorder; War.

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VICTOR OF AVEYRON
(ca. 1790–1828)

French "feral child"

Victor is perhaps the best known and most important of the long list of so-called feral children. Often referred to as "the wild boy of Aveyron," Victor is forever associated with the name of his teacher, Jean Marc Gaspard Itard (who also gave Victor his name). For an entire generation of French intellectuals, Victor represented a chance to study what could not ethically be created: a "noble savage" raised in a state of nature uncontaminated by human culture. What could such a child show about the essence of human nature, human capacity? In what some have called the "forbidden experiment," Itard and Victor (and a caretaker, Madame Guerin) spent five intensive years together testing the empiricist notion that the human mind was a blank slate, dependent on the sensory experiences to develop all knowledge and socialization.

Victor was first brought to Paris in 1800 after being captured by townspeople in the region of Aveyron in the south of France. After an initial swirl of public attention and excitement, however, the French *alieniste* Philippe Pinel pronounced his diagnosis that Victor was not the suspected noble savage, normal in faculty but uncontaminated by human society. Pinel declared the child to be an incurable idiot, unimprovable in any way. It was Itard, however, who persisted, obtaining permission to work intensively with Victor, carefully exploring just how much the child could learn and approach normal development.

Itard's account of this five-year experiment, documenting Victor's progress in language, behavior, and other functional skills, is often regarded as one of the earliest attempts at systematic instruction of children with intellectual disabilities. Reminders of the many devices and techniques created by Itard for use in Victor's instruction can still be seen in such settings as Montessori classrooms and in the precise language of behavioral observations.

By 1805, Itard concluded that Victor did, in fact, have unalterable limitations to what he could learn, and Itard abandoned his efforts to document Victor's education. Itard went on to work for several more decades in the education of deaf children. Victor spent his remaining days with his devoted caretaker, Madame Guerin, living an apparently quiet life. Victor died in 1828 of unknown causes.

—Philip M. Ferguson

See also Feral Children; Jean Marc Gaspard Itard.

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▣ VINEYARD DEAFNESS

See Deafness, on Martha's Vineyard

▣ VIOLENCE

No country or generation has been unscathed by violence. It is a phenomenon that has been continuously a part of human history. The universality and pervasiveness of violence are evident in our homes, playgrounds, schools, neighborhoods, worksites, places of public gathering, and nations. More than 1.6 million people die each year worldwide because of violence. Approximately half of these deaths are suicides, one-third are homicides, and one-fifth are related to armed conflict. Many more people are injured as a result of violence. For instance, it is estimated that for every death due to gun violence, three more people sustain gun-related injuries. In 1996, the World Health Assembly adopted a resolution declaring violence a leading worldwide public health problem requiring immediate attention from the professional community. *Violence* is defined by the World Health Organization (WHO) as "The intentional use of physical force or power, threatened or actual, against oneself, another person, or against a group or community, that either results in or has a high likelihood of resulting in injury, death, psychological harm, maldevelopment or deprivation." With this far-reaching definition, the WHO recognizes that violence may manifest in a variety of ways. According to the WHO, violence can be categorized as

1. Self-directed violence (self-destructive and suicidal behavior)
2. Interpersonal violence (family/intimate partner violence and community violence that occurs among acquaintances and strangers)
3. Collective violence (violence by a group of individuals against another group)

Given the magnitude of violence, it is not surprising that there is a direct relationship between violent behavior and disability. Violence has affected the field of disability in four distinct ways. First, there are individuals who have acquired a disability as a result of violence. Typically, these acts have been related to warfare, civil unrest, street violence, and interpersonal disputes. Second, people with disabilities are at an increased risk of being targets of violence and abuse both inside and outside of their homes. Third, there is a belief among the general public that people with certain disabilities (i.e., severe psychiatric disabilities such as schizophrenia and bipolar disorder) are likely to exhibit physically aggressive behavior. However, this belief is not entirely accurate. Individuals who are taking medication for a psychiatric disability are not at an increased risk to exhibit violent acts. Fourth, suicide (self-directed violence) is closely linked to psychiatric disabilities, particularly mood disorders. According to the National Institute on Mental Health, approximately 60 percent of individuals who commit suicide have had a mood disorder (such as major depression, bipolar disorder, or dysthymia). In addition, the field of disability has been embroiled in the controversial debate of physician-assisted suicide, whereby physicians provide individuals who are diagnosed with terminal illnesses or severe/incurable physical pain with the means to end their lives.

ACQUIRING A DISABILITY THROUGH VIOLENCE

Violence is related to disability when one considers the disablement of individuals because of violent acts. Although mortality is commonly used to indicate the magnitude of intentional violence, many more individuals sustain injuries that require medical attention, and a significant proportion become permanently disabled. Prevalence and incidence rates are difficult to determine due to a lack of systematic reporting procedures. Nonetheless, the relationship between violence and disability has been evident throughout human history. Violence-related disabilities occur under a wide range of circumstances, including self-injurious behaviors, suicides, domestic disputes, crime, community violence, civil unrest, political upheaval, and warfare.

War, violence, and disability have a long-standing relationship. One obvious consequence of war is death; another is injury and disability. The outcome of war-related disability was particularly evident during World War I, where an estimated 1.5 million people became disabled. Types of disabilities that were acquired included loss of limbs, blindness, deafness, traumatic brain injuries, and emotional traumas.

War holds a unique position in the disability rights movement because it helped transform attitudes toward those who are disabled. Prior to World War I, individuals with disabilities were often isolated and viewed with pity or apathy. After the war, these attitudes changed as many soldiers acquired their disability while serving their country. Upon their return from military duty, these soldiers were treated with respect by the general public. These changing norms began to influence how people with disabilities were treated in general. Disabled soldiers also brought to their home country a sense of responsibility to assist those with disabilities. In the United States, the Soldier's Rehabilitation Act and Smith-Fess Act were passed in 1918 and 1920, respectively. The Soldier's Rehabilitation Act provided vocational rehabilitation for military personnel, whereas the Smith-Fess Act did the equivalent for civilians.

In addition to warfare, civilians have acquired disabilities as a result of civil unrest and political upheaval. Such circumstances are evident throughout the world (e.g., Afghanistan, Angola, Cambodia, Ethiopia, Kosovo, Rwanda, and Vietnam). These countries have experienced years of internal political conflict, which have led to acts of violence and the disablement of thousands of civilians, including children and women. Given that these individuals typically reside in third world countries, their disabilities are often complicated by conditions of poverty and a lack of assistance and social services. During recent periods of political conflict, land mines have been used with high frequency. These weapons continue to pose a threat even after conflicts have been resolved. For example, as a result of three decades of violence related to political unrest, wars, and international border disputes, Cambodia has more than 30,000 people who have lost limbs following land mine detonation.

Spinal cord injuries as a result of violence have also risen in countries experiencing sociopolitical conflict. In the Republic of South Africa, a recent review of records from a spinal cord injury rehabilitation program indicated that gunshot wounds accounted for 36 percent of spinal cord injuries, a dramatic increase from the past. Similarly, during the 1990s, the United States experienced an extraordinarily high rate of violence-related spinal cord injuries. By 1994, violence accounted for 30 percent of new spinal cord injury cases. The United States has also experienced a rise in youth violence, with shooting sprees occurring across a variety of settings including homes, schools, and city streets.

VIOLENCE AGAINST PEOPLE WITH DISABILITIES

People with disabilities are also at a greater risk of being victims of violence and abuse compared to those without disabilities. This is particularly true for disabled women, children, and elderly persons. Historically, these three groups have been targets for abuse even when the disability status is not considered. In addition, those with disabilities that are considered severe (e.g., intellectual disabilities) are more likely to be abused than those with nonsevere disabilities. Severe disabilities can affect the person's ability to comprehend and/or report the abuse.

Prevalence and incidence rates of violence toward people with disabilities are difficult to determine because of underreporting and varying definitions for violence. Some definitions focus solely on the physical force that is exerted for the purpose of violating, damaging, or abusing. Other definitions extend beyond physical force to include verbal aggression, neglect, and financial exploitation. For the nondisabled population, 10 to 69 percent of women around the world have reported physical abuse by an intimate male partner, approximately 20 percent of women and 5 to 10 percent of men have experienced sexual abuse as children, and 4 to 6 percent of elderly individuals have experienced some form of abuse in their homes. For the disabled population, these abuse figures are even higher. For example, studies of women with intellectual disabilities have reported rates of sexual abuse from 30 to 90 percent.

A number of factors have been associated with violence, abuse, and disability. First, negative attitudes toward people with disabilities may contribute to abusive behavior. For instance, if people with disabilities are judged to be nonintelligent or weak, such beliefs may be used to justify abusive behavior. Second, when abuse occurs, social isolation among people with disabilities may affect their ability to report and/or identify the situation as abusive. Third, the nature of one's disability may pose barriers to reporting (e.g., people with speech disabilities may have difficulty reporting the abuse by telephone). Fourth, people with disabilities may be hesitant to report abuse if they depend on the abuser for care, fear retaliation from the abuser, and/or experience personal shame over the abuse.

The relationship between violence and disability is further complicated when one considers that people with disabilities can be abused in a number of settings, including their homes, schools, hospitals, residential centers, and social service agencies. Thus, potential perpetrators may include spouses, family members, friends, teachers, personal assistance providers, transportation employees, and health care workers. Such abuse is difficult to comprehend because the very individuals who are expected to provide protection and care pose a threat to those who are disabled.

Last, responses to reports of violence and abuse may vary by setting. For example, within social service settings, there may be ineffective procedures to investigate reports of violence. As a result, responses to violence and abuse may be affected by prejudiced attitudes, ignorance of proper protocol, and inadequate investigative skills. Within legal settings, police may harbor prejudiced attitudes toward persons with disabilities, which in turn may affect their investigations. In addition, the rights of people with disabilities may be impinged upon due to inaccessible courtrooms and courtroom proceedings (e.g., the lack of sign language interpreters for those with hearing disabilities during a trial; judges' reluctance to accept testimony of persons with intellectual disabilities). Because of these variables, people with disabilities may have difficulty obtaining justice, support, and other constructive organizational responses when they are violently victimized. Thus, they may be less likely to seek assistance to address instances of abuse.

PERPETUATORS OF VIOLENCE?

A third connection between violence and disability centers on how society views people with psychiatric disabilities. Historically, the general public has harbored the belief that individuals with severe psychiatric disabilities are dangerous and violent. Such perceptions are stronger today than they have been in the past and have been perpetuated by sensationalized headlines and popular media. However, such perceptions are misguided. There are three primary predictors of violence: past history of violence, drug and alcohol abuse, and a serious psychiatric disability *combined* with a failure to take medication. Individuals with severe mental illness who *are* taking their medication are no more dangerous than the general population.

Of the three predictors of violence, a past history of violence is the single most critical piece of information to examine regardless of disability status. The second important predictor is drug and alcohol abuse, and this is also true whether the person does or does not have a psychiatric disability. The third important predictor is the failure to take medication. Individuals who do not take prescribed medication for a psychiatric disability are more likely to commit violent acts than those who take their medication. Specifically, individuals with untreated schizophrenia and bipolar disorder are at risk to exhibit violent behavior.

Another possible predictor of violence is the type of delusion (or irrational belief) a person with a severe psychiatric disability is experiencing. Mental health professionals have long viewed paranoid delusions as a potential precursor of violence. However, the relationship between paranoid delusions and violence is not straightforward. For example, persons may experience delusions that they are famous. Yet this delusion is unlikely to lead to violent acts. Instead, a stronger predictor of violence is the feeling that others are out to cause physical harm, coupled with a feeling that one's mind is dominated by forces beyond one's control. An additional factor that may predict violence is *command auditory hallucinations*. Command auditory hallucinations involve voices telling an individual what to do; such voices may encourage violent behavior. In sum, the relationship between psychiatric disabilities and violence is complex, with a number of factors affecting the potential to act aggressively.

SUICIDE AND DISABILITY

The final link between violence and disability relates to suicide. The relationship between suicide (self-directed violence) and disability is twofold. First, each year approximately 800,000 people die by suicide worldwide, with the highest rates occurring in Eastern European countries and the lowest rates in Latin American countries and a few countries in Asia. Approximately, 30,000 suicides occur in the United States. Although determining the definitive causes of suicides have proven difficult, suicides in many nations are associated with mood disorders. For example, over 90 percent of suicides in the United States are associated with psychiatric disabilities (including depressive disorders, bipolar disorder, schizophrenia, personality disorders, and substance abuse disorders). Advances within psychopharmacology have helped with the treatment of psychiatric disabilities, which in turn help curb suicide ideation and behavior. However, despite medical advances, suicide remains a worldwide problem. In India and China, psychiatric disabilities are less important risk factors. For instance, cross-cultural research indicates that humiliation, shame, economic hardship, examination failure at school, and family disputes were the greatest risk factors for suicide in India.

Second, the fields of disability, medicine, and law have been divided by the issue of physician-assisted suicide. In 2001, the Netherlands became the first country to legalize such a procedure. The law allows individuals who are "suffering unbearably" with "no prospect of improvement" to end their lives, with the assistance of doctors. In the United States, Dr. Jack Kevorkian was the most vocal advocate of assisted suicide. Kevorkian assisted at least 130 individuals with ending their lives, despite legislation prohibiting such action. After much debate and controversy in the United States, physician-assisted suicide was legalized in the state of Oregon by a slim margin, with the passage of the Death with Dignity Act in 1994.

The medical and legal communities remain divided on the issue of physician-assisted suicide. Some medical and legal professionals argue that people should have the option to end severe and incurable physical pain and suffering, highlighting respect for individual autonomy. Others argue that such a legal option perpetuates the erroneous notion that people with untreatable medical conditions lead lives that are not worth living. From the start, prominent disability rights groups have opposed legalization of assisted suicide. They argue that providing such a legal option to individuals with terminal illnesses may generalize to others with treatable conditions (and people with disabilities) who are leading productive and fulfilling lives.

CONCLUSION

Violence has a clear connection to disability. This connection is evident when one considers (a) acquiring a disability through violent acts, (b) abuse and violence against people with disabilities, (c) the misguided belief that people with disabilities are perpetuators of violent behavior, and (d) self-directed violence and suicide. Given the history and extent of violence worldwide, these unfortunate trends are unlikely to dissipate in the near future. However, with the recent recognition of violence as a global public health problem by the World Health Assembly, the professional community worldwide is being urged to discuss and design prevention and intervention efforts to tackle these significant issues.

—Brigida Hernandez and
Erin Hayes

See also Abuse and Hate Crimes; Child Abuse; Crime and Delinquency; Physician-Assisted Suicide; Suicide; War.

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VISIBILITY AND INVISIBILITY

Some physical and mental impairments are clearly visible in the bodies and behavior of people with disabilities, while others are not. The latter are often referred to as “invisible disabilities.” The equally common expression “hidden disabilities” has been criticized for its implication that the disabled person is actively choosing to conceal his or her impairment. Within contemporary disability studies and political movements, *invisible disability* is sometimes used as an umbrella term meant to include all those who have not been represented by the first wave of activism and scholarship: people with mental illnesses, cognitive and learning disabilities, developmental disabilities, and/or chronic physical illnesses. Yet not all of those disabilities are invisible, and not all disabilities traditionally recognized as such are visible. Some of the most compelling accounts of passing as nondisabled, for example, have been written by blind people—yet blindness is not included in the “invisible” umbrella because of a long history of cultural recognition of blindness as disability. Thus, the phrase “invisible disability” carries both a literal and metaphoric meaning—literally referring to impairments that are not visible on a person’s body or behavior, and metaphorically referring to impairments that have not been well represented or recognized in the disability rights movement or scholarship. Some have advocated severing these meanings by referring to literally invisible disabilities as “nonvisible.” However, in current usage, there continues to be considerable overlap and inconsistency in the use of these terms.

People with highly visible impairments, such as amputees, wheelchair users, people with facial markings, and people of short stature, tend to share a common experience of being stared at, often in the context of being pointed out, mocked, touched without permission, or asked intrusive questions. Disability theory, thus, has been deeply concerned with analyzing and counteracting “the stare,” while disability activism has often sought to subvert or reverse this dynamic, as in the title of the 1997 anthology *Staring Back: The Disability Experience from the Inside Out.* The “hypervisibility” experienced by many people with disabilities, which continues to have a significant impact on everyday experience, employment, and relationships, has also been creatively adapted and challenged by many artists and performers with disabilities.

Many other people with disabilities exist in a fluid state of intermittent *invisibility*—as when using a prosthesis, when sitting down, when not communicating, or when taking medication that temporarily conceals an impairment, and *visibility*—as when using a cane, brace, or splint; when speaking in sign language; when asking for assistance with a specific task or activity; or when fluctuating symptoms such as a limp or tic temporarily appear. Even a person traditionally defined as visibly disabled, such as a full-time wheelchair user, can transfer to a sofa, fold her chair away, and join the ranks of the invisibly disabled for a time.

HISTORICAL BACKGROUND

Both social and medical models of disability have traditionally emphasized visible disability, while the status of invisible disability remains contested on many fronts. This emphasis on visibility is part of the overall focus on visualizing the body within Western medicine beginning in the late eighteenth century. The focus of diagnosis and treatment shifted at this time from listening to a patient's descriptions of symptoms to examining the patient's body for visible signs of disease. This shift has been translated into contemporary medicine through the distinction between "subjective" symptoms and "objective" signs, with objective signs taking precedence in determining diagnosis, treatment, accommodations, and benefits.

Historians of medicine and disability have noted that this emphasis on objectivity meant that patients were increasingly treated like objects on display. For example, by the late nineteenth century, many surgical operations in England took place in theaters observed not only by doctors but also by an audience of curious laypeople. The bodies of people with visible disabilities were of particular interest to this audience, and such institutions as the freak show and the "cabinet of oddities" became popular in both Europe and the United States. "Human curiosities" such as amputees, conjoined twins, people of small or large stature, and people with microcephaly were displayed in these settings to audiences whose sense of their own "normality" was produced and reflected through the freakishness projected on people with visible disabilities.

During the same period, Freudian psychoanalysis, with its theories of hysteria and psychosomatism, was gaining credence among a broad group of professionals, including physicians, authors, and crafters of social policy. These theories eventually produced a new explanation of invisible impairments as "all in your head," thus categorizing these impairments as both less exotic than visible ones, and also somehow less "real." In addition, the experience of invisible impairment became highly feminized at this time (such that even men with such impairments were seen as effeminate), and women's reports of their bodily experiences became subjugated to the expertise of the male medical professional. This dynamic continues in the experiences of contemporary women with invisible disabilities, as both studies and anecdotal evidence indicate that women's physical symptoms are taken less seriously and treated less aggressively than those of men and that women are much more likely than men to be referred for psychological evaluation when reporting an invisible physical symptom such as pain or fatigue.

The binary understanding of visible and invisible impairment has influenced even the contemporary social model of disability, which explicitly seeks to refute medical models. Social scientists have suggested that individuals with visible disabilities are more likely to develop a positive disability identity than are invisibly disabled people who can "pass" as normal. Scholars in the humanities have argued that disability itself is defined by a disruption in the visual field. Challenges to these claims have emerged from invisibly disabled scholars who suggest that the dynamics of visibility that oppress some people by "enfreaking" them, oppress others by "invalidating" them. Understandings of disability as "performative" and "rhetorical" are beginning to nuance the emphasis on visible disability prevalent in the first wave of British and American disability studies.

FORM VERSUS FUNCTION

Much of the cultural tension that exists around the questions of visible and invisible disabilities is based on the assumption that form reflects function. In other words, modern society has developed around the ideal that each of its citizens is able to perform in a "normal" capacity unless he or she looks somehow "abnormal." A woman who walks up to an airline counter to request a wheelchair, for example, will usually receive curious glances directed at her legs. The idea that a person can walk ten feet but not a hundred is just as foreign to modern conceptions of disability as the idea that a person can have limbs that look "normal" but do not function normally.

In contemporary systems of entitlements and access, immense suspicion exists that unethical or lazy citizens will take advantage of those systems. Thus, accusations of faking, malingering, or cheating are reported frequently by people with invisible disabilities across a broad range of impairments, including chronic physical illnesses, blindness and low vision, deafness, mental illnesses, and learning disabilities. In many cases, benefits and accommodations are denied to such people, resulting in significant social and economic disadvantage. For this reason, people with invisible impairments tend to remain more closely tied to the medical community, since they must often rely on doctor's certificates to obtain benefits and accommodations. This may be one reason why this population is perceived by some as having a less positive disability identity, according to the social model.

The assumption that form is tied to function also significantly affects people with visible disabilities, as their competence and intelligence may be challenged based on their bodily appearance or assistive devices. Many people with physical impairments that affect only certain functions can be treated as if completely incapacitated. For example, people whose legs are affected by paralysis, cerebral palsy, or multiple sclerosis report being denied driver's licenses in the United States despite their competence with hand controls. People who are nonverbal, communicate through assistive devices, or have speech impairments report being treated as "stupid," "slow," or developmentally delayed due to others' perception of their mental function as tied to their form of communication. This assumption has a serious impact on these individuals' social experience, as well as access to education and employment. Even individuals whose impairment is entirely formal with no effect on function, such as people with facial markings or skin differences, can face discrimination in these areas, thus demonstrating how issues of visibility affect all aspects of disability experience.

—Ellen Samuels

See also Attitudes; Drama and Performance; Stigma; Values.

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VISITABILITY

Unlike home modifications, where supportive features are incorporated to address residents' individual needs, visitability strives to provide a baseline level of accessibility in all new home construction, in hopes of benefiting the entire population. Therefore, *visitability* is an affordable, sustainable, and accessible design approach that targets single-family homes, the only type of housing not covered by the Fair Housing Act or any other federal or state legislation. Originating in Europe, the visitability movement was initiated in the United States in 1986 by Eleanor Smith, a disability rights advocate, and her group Concrete Change. Smith initially used the term *basic home access*, but in 1990 adopted the word *visitability*. Her ultimate goal is to make all new homes not covered by current access regulations "accessible enough" for a visitor with a disability. Thus, a visitable home is not necessarily intended to have a level of accessibility needed by a person with a disability. It is intended to be a residence for *anyone* and to provide access to *everyone*.

THREE PRINCIPLES OF VISITABILITY

There are three fundamental principles of visitability. First, visitability is based on the idea that inclusion of basic architectural access features in all new homes is a civil right and improves every person's ability to live productively and comfortably. People with disabilities should be able to visit their neighbors for mutual assistance, friendship formation, and child care. In most neighborhoods, however, a major barrier to social participation for individuals with disabilities is the lack of opportunity to visit other homes. When only a few houses have full access, people with mobility impairments are confined to their homes for socialization in the neighborhood and segregated from others; when people develop impairments, they must find new places to live or wait for expensive renovations; and when accessible entrances, in particular, are built as renovations, the results are often awkward solutions that reinforce the stereotypes and stigmas often associated with disabilities and accessibility. In response to these circumstances, visitability strives to create an opportunity for all neighbors in a community to socialize, help each other, and interact more effectively. It attempts to break down attitudinal as well as physical barriers to social integration of people with disabilities.

Second, visitability rests on the notion that, through good design, basic accessibility to single-family housing can be provided in most cases with minimal financial cost. The design philosophy contends that access is cost-effective if planned in advance. Incorporating accessible architecture features into housing designs during the early stages of development and before construction remains affordable. Although only a limited number of studies actually have analyzed the specific costs associated with visitability, these studies agree that introducing visitability through retrofitting results in significantly higher costs.

The third principle of visitability suggests that simplicity promotes implementation. Prioritizing access features ensures that the supply of accessible homes will increase more rapidly. Visitability advocates argue that a long list of demands can create the misconception that all access features are equally urgent and therefore must all be included in a home. Many builders and designers may currently perceive this as too difficult to even attempt. However, visitability advocates argue that not everything is of equal urgency. Some access features are more important than others in helping individuals visit with their neighbors.

VISITABILITY AS AN INNOVATION

Visitability's simplicity as a means to promote adoption is compatible with lessons learned from the study of innovation and its diffusion. Everett Rodgers (2002) defines *innovation* as "anything perceived to be new." He argues that it is not the reality that matters but the perception. Although visitability may not require new technology or look radically different, if it is *perceived* as something new, individuals will respond to it as if it *were* new. Because visitability is a new concept to most people, they consider it innovative. Therefore, those who wish to promote visitability need to understand the components of the innovation-decision process. According to Rodgers (2002), "The innovation-decision process is the process though which an individual (or other decision-making unit) passes from first knowledge of an innovation, to the formation of an attitude toward the innovation, to a decision to adopt or reject, to implementation and use of the new idea, and to confirmation of this decision" (p. 216). Rodgers proposes that the adoption of an innovation is a cyclical decision-making process with five activities: obtain knowledge, persuasion of the key decision makers, decision to act on the new idea, implementation, and confirmation.

Moreover, Rodgers argues that the pace of innovation adoption varies greatly. According to him, there are five attributes of innovation that enhance its adoption or diffusion rate: *relative advantage,* in which the diffusion rate is enhanced if there is a clear financial or social advantage for the new idea as compared to the idea or product it would supersede; *compatibility,* whereby if the innovation is congruent with current values, experiences, or needs, its rate of adoption will be faster; *trialability,* an innovation will be adopted more rapidly if it can be experimented with at relatively low cost of time, money, and commitment; *observability,* where the more an innovation is visible to others, the higher its rate of adoption will be; and finally, research by Rodgers's and others discovered that the pace of an innovation is affected by its *complexity*—the more an innovation is perceived to be relatively easy to understand and use, the higher the expected adoption rate (Rogers 2002:223–259).

This last characteristic specifically applies to visitability. In keeping with Rodgers's theory that simplicity promotes implementation, a visitable home is one that meets only three conditions: one zero-step entrance, doorways that are 32 inches wide, and basic access to at least a half bath on the main floor. These three features are considered the most essential for a person with mobility impairments to visit or live in a home, at least temporarily. In response to criticism that these three features are insufficient, Eleanor Smith argues, "What I'm after here is radically changing the way all new houses are built . . . and if you're going to do that, you can't have a long list of demands"

(Truesdale and Steinfeld 2002:3). Visitability advocates believe that once builders learn that visitability is easy to achieve and they receive positive confirmation through sales and consumer acceptance, they will be more likely to expand the list of universal design features they include in the next generation of housing.

VISITABILITY AND NEIGHBORHOODS

Along with individual single-family homes, many advocates and researchers view visitability as a major step toward achieving universal design on a neighborhood level. In acknowledging the valuable role of visitability in developing active communities, Truesdale and Steinfeld (2002) contend that

> visitability, although less than the ideal of a universally designed home, is actually universal design practiced through community and neighborhood planning. It ensures that a basic level of accessibility will be provided in all housing and it opens opportunities for participation in community life. (pp. 7–8)

Visitability provides benefits to a wide range of users, including those with disabilities, their nuclear families, friends, and other relatives who may, from time to time, need to use wheelchairs or other adaptive equipment. Consequently, rather than forcing individuals to remain isolated and confined to their personal surroundings, visitability allows individuals with a variety of abilities to interact with each other and participate in community activities outside of their homes.

THE VISITABILITY MOVEMENT

Recognizing the benefits and growing need for more accessible housing, many state and local jurisdictions have joined the visitability movement. In fact, several municipalities and states across the country have already formalized and enacted visitability programs. Despite their common goal of increasing the supply of accessible housing, these visitability programs vary significantly. The three primary ways they tend to differ are the geographic regions they cover, the scope of features they include, and the strategy by which they are implemented and enforced. For instance, some visitability programs cover housing within an entire state, while others only have jurisdiction over cities and/or counties. In addition, some programs strictly adhere to the three basic accessible features (stepless entrance, wider doorways and hallways, and a half bathroom on the main floor), while others include additional architectural elements such as lever handles, blocking for grab bars in bathroom walls, and accessible environmental controls.

Visitability programs also vary in how they are enforced. Some visitability initiatives are mandatory, whereby builders and homeowners are required by a law or ordinance to include the three visitable features during new construction, while other programs are voluntary. With voluntary programs, builders and consumers are encouraged to include the visitability features (stepless entrance, wider doorways and hallways, and basic access to a half bath on the ground floor), but they are not obligated to do so. There are additional variations within mandatory and voluntary programs. Although the majority of mandatory initiatives apply only to homes built with public funds, a few of these programs apply to both public and private homes. Moreover, with respect to voluntary programs, some programs offer monetary incentives while others involve certification or public awareness campaigns.

Whereas most visitability initiatives specifically apply to new housing, initiatives in all three types of jurisdictions (state, county, and city) do not preclude coverage of substantial renovations and retrofits in their respective guidelines. Incorporating renovations in visitability programs extends the housing market affected by the program to include existing homes. Although this expands the opportunity to increase the supply of accessible housing, it also could retard the advancement of the visitability movement. Encouraging consumers and builders to incorporate accessibility features after initial construction results in higher costs and ultimately reinforces the common misconception that visitability demands substantial spending.

Besides the more than 40 mandatory and voluntary programs already in place, there are numerous efforts to establish visitability programs in other states, counties, and cities across the country. Recent research identified 12 state and 15 local initiatives currently under way (Maisel 2004). While the final outcomes of these initiatives remain uncertain, their emergence symbolizes a growing interest in incorporating more accessibility elements in both public and private housing.

—Jordana L. Maisel and
Edward Steinfeld

See also Accessibility; Home Modification.

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VOCATIONAL REHABILITATION

Vocational rehabilitation (VR) is practiced by rehabilitation counselors employed by the state-federal system, business and industry, insurance companies, and private agencies. The purpose of VR is to enable individuals with disabilities to acquire, resume, or maintain employment, an outcome that is in some way affected by a physical, intellectual, or emotional condition limiting one or more life functions. Rehabilitation counselors assist people in achieving their vocational goals by providing counseling, guidance, and placement services and by arranging for medical, accommodation, and assistive technology services.

Important emphases in the history of VR include vocational training, a civilian program based on eligibility criteria, professionalism, and civil rights. Historians trace the emphasis on vocational training to the industrialization of America. As were all citizens, people with disabilities were poorly prepared for roles in this new industrial society. After considerable political debate, the state-federal VR system emerged as a means for helping people with disabilities become employed following counseling, guidance, and vocational training services.

The state-federal VR system is a major provider of VR services to eligible individuals. Eligibility criteria include the presence of a disability and the presumption of benefit. Although these criteria have not always been applied in an equitable manner, the intention to do so is a strong force motivating the practices of the state-federal VR system.

The commitment to quality services is nowhere more evident than in the growing professionalism in VR. A *qualified provider* of VR services holds both a master's degree in rehabilitation and certification as a rehabilitation counselor (CRC). VR counselors complete a rigorous curriculum, receiving training in medical and psychological aspects of disability, vocational evaluation, independent living, placement, rehabilitation research, counseling, and multicultural/gender issues.

Given the breadth of their training, VR counselors are well prepared to serve individuals with severe disabilities. The theme of severe disability is another important "defining moment" for VR. It is reflected in (a) early legislative commitments to serve people with physical disabilities who wanted to return to work, (b) later legislation that included services for physical restoration and for people with psychiatric and mental retardation diagnoses, (c) emphases in the Rehabilitation Act of 1973 on serving people with severe disabilities, and (d) order of selection priorities in the state-federal system to serve people with the most severe disabilities first.

For a time in VR, the concept of severe disability was viewed primarily from a medical/economic model. The dominant service mode involved medical services to "fix" the person so that he or she could return to a job consistent with residual capacities. Income maintenance via Social Security's disability program represented the only other alternative. Reactions to the medical/economic model and to discriminatory practices eventually gave rise to assertion of civil rights by people with disabilities. Assertion of civil rights in response to paternalistic treatment provided the foundation for the Americans with Disabilities Act (ADA) with its hiring and accommodation protections. It gave rise to a new respect for people with disabilities as individuals with rights to participation and informed choice. It gave rise to consumer protection via Client Assistance Projects (CAPs). It gave rise to an acknowledgment of the importance of multicultural/gender issues and to the need for counselor sensitivity to the impact that these differences have on VR outcomes.

In conclusion, VR is about people and their desires to become and/or remain productive citizens. VR interventions involving vocational evaluation, vocational planning, physical and psychological restoration, and placement have become more comprehensive and professional. They have focused increasingly on meeting the vocational needs of those with the most severe disabilities. Finally, they have become more and more reflective of the agendas of those seeking services, rather than of those providing services.

—Rick Roessler

See also Disability and Career Development; Employability; Employment; Job Retention; Rehabilitation Act of 1973 (United States); Vocational Rehabilitation: Law and Policy.

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VOCATIONAL REHABILITATION: LAW AND POLICY

Vocational rehabilitation (VR) is a process that enables individuals with disabilities to secure, retain, and advance in suitable employment and thereby further their integration or reintegration into society. Services to individuals with disabilities with a vocational or employment emphasis began before the turn of the twentieth century. They were often custodial in nature, and provided in the context of a caretaking role, thereby promoting segregation and exclusion from mainstream activities, including employment. The early perception of people with disabilities as subjects of health, welfare, and charity programs began to be seriously questioned in the early 1900s. Legislatively mandated changes began to occur around the time of World War I. These changes were initially spurred both by the need to train individuals for technical war occupations and replace workers called to fight in World War I, and later the need to return veterans to civilian careers.

Since then, a string of related legislation has added new services and new populations for coverage. A parallel development of services simultaneously occurred in other industrialized countries. Increasingly over the past century, we have moved to a model that highlights independence, equality of opportunity, recognition of unique talents and contribution, environmental and attitudinal barriers to success, and rights-based approaches that contribute to overcoming these barriers, such as workplace accommodation.

Modern VR policies grew out of the feeling that the federal government had an obligation to those who were wounded and became disabled in defense of their country. In 1918, the Veterans Rehabilitation Act (P.L. 65–178) was passed, authorizing VR services for World War I veterans. Services would be provided by the states, supported by federal grant money. Civilians with disabilities were excluded from receiving services under this act, but were provided for in 1920 with the beginnings of the civilian VR program (Smith-Fess Act, P.L. 66–236).

Parallel legislative developments were evolving at this time in other parts of the industrialized world. In Great Britain, the aftercare of disabled soldiers and sailors moved from being one principally of private initiative and financial support pre–World War I to a state matter with the Military and Naval War Pensions Act in 1915. Germany was in a better position than many countries to deal with the issue of VR, although VR was similarly the province of private charity or individual states pre–World War I. Germany was a leader in orthopedic surgery and rehabilitation and therefore had a well-developed network of disability centers, many of which had workshops teaching a variety of trades.

In the United States, the Social Security Act of 1934 (P.L. 74–271) established state-federal VR as a permanent program that could be discontinued only by an act of Congress. This action, however, did not guarantee continuing congressional appropriations. In 1943, the Barden-LaFollette Act (P.L. 78–113) broadened eligibility for rehabilitation services to include people with mental illness and retardation. *Vocational rehabilitation services* were defined as "any services necessary to render a disabled individual fit to engage in a remunerative occupation." This act also brought services for the blind under the umbrella of the state-federal VR support system, where previously they had been handled solely at the state level by state commissions for the blind.

In the post–World War II environment, the growth of VR slowed somewhat. The program was underpublicized and suffered from a lack of finances and of qualified rehabilitation professionals. The Vocational Rehabilitation Act Amendments of 1954 (the Hill-Burton Act, P.L. 83–565) began a new era for rehabilitation. This act provided funding to colleges and universities for the preparation of rehabilitation professionals and expanded services to people with mental illness or mental retardation. It provided funds for the expansion of rehabilitation facilities, extension and improvement of state agencies, and research and demonstration programs. Further amendments during President Lyndon Johnson's War on Poverty in the 1960s expanded programs, provided more federal funding to the states, and allowed states more flexibility in setting up rehabilitation agencies. In a parallel international effort, the International Labour Organization (ILO) Vocational Rehabilitation (Disabled) Recommendation No. 99 was adopted in 1955. This international instrument served as the basis for all national legislation and practice concerning vocational guidance, vocational training, and placement for persons with disabilities.

The next major piece of U.S. legislation affecting rehabilitation was the Rehabilitation Act of 1973 (P.L. 83–112). It introduced the Individualized Written Rehabilitation Program (IWRP) and postemployment services, made provision of services to people with severe handicaps a first priority, and provided special consideration for public safety officers injured in the line of duty. It authorized demonstration projects for independent living, established client assistance pilot projects, and mandated consumer involvement in state agency policy development. It also initiated the first legislation to prohibit discrimination in employment on the basis of disability and to provide access to federally funded programs for persons with disabilities. Subsequent amendments to the Rehabilitation Act have expanded and strengthened services for blindness and deafness and have added support for supported employment as a goal. Consumer empowerment was advanced in 1992 when consumer-controlled State Rehabilitation Advisory Councils were established and clients were given increased choice of employment objectives, providers, and services. In 1983, the ILO adopted the Vocational Rehabilitation and Employment (Disabled Persons) Convention No. 159, requiring member states to formulate national policies on VR.

Most recently, the Workforce Investment Act of 1998 (WIA) (P.L. 105–220) included amendments to the Rehabilitation Act. WIA changed the name of the IWRP to the Individualized Plan for Employment (IPE) and enhanced the collaborative relationship between the consumer and counselor, increased consumer control so customers could develop their own plans, stressed the concept of "presumptive eligibility" for Social Security Disability Insurance (SSDI) beneficiaries and Supplemental Security Insurance (SSI) recipients, expanded access to services promoting linkages with One-Stop Centers and other programs. VR services were expanded to include technical assistance for individuals to pursue self-employment, telecommuting, or small business operation as well.

The evolution in VR legislative and service structure changes over the past century reflects increasing sophistication and advances in medical and technological sciences. Even more profoundly, it represents a change in philosophy toward persons with disabilities. Twenty-first-century models of VR include recognition of the inherent worth of all individuals, including individuals with disabilities, in contributing to society and to the productivity of a national economy. This has changed how we interact with individuals with disabilities in service provision, from a patronizing and caretaking posture to one that is client driven, consumer focused, and personally empowering. This evolution in the way we prepare for, attach to, and advance individuals with disabilities in work has led a push toward quality, integrated, and paid employment. This movement was further supported by other federal laws, policies, and court actions, including the 1999 *Olmstead* decision, the Americans with Disabilities Act of 1990, further reauthorizations of the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act of 1990, and the Ticket to Work and Work Incentives Improvement Act.

As segregated programming options decrease and integrated employment opportunities expand, person-centered planning, self-determination, and consumer-directed services and supports lead the way. As a result of these developments and a paradigm shift in the way we prepare people for work, individuals with disabilities have greater access to competitive and integrated work environments.

Looking forward, there are several significant trends emerging in VR practice. There is increasing recognition that VR services must be provided in a career development context if successful employment outcomes for people with disabilities are to be realized. Therefore, the role of VR counselors must move beyond just initial training and job placement, and include helping people maintain employment and advance in their careers, including home-based small businesses. Populations the VR process is being applied to are also changing, including people with hidden disabling conditions such as mental illness, diabetes, multiple sclerosis, cancer, HIV/AIDS, fibromyalgia, and heart disease, as well as people with age-related conditions such as arthritis and vision, hearing, and orthopedic-related impairments. There also must be an increasing emphasis on providing consultative services to employers and attention to interpersonal and organizational factors that contribute to long-term vocational success.

The contemporary VR process necessitates knowledge and use of workplace supports and accommodations, workplace disability management, and innovative strategies for building partnerships with employers. In addition, VR practitioners must increasingly be aware of the dynamic workplace ecology factors that shape the attitudes and behaviors of coworkers and supervisors toward workers with disabilities.

—Susanne M. Bruyère

See also Disabled Veterans; Job Retention; Rehabilitation Act of 1973 (United States); Vocational Rehabilitation.

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▣ VOCATIONAL REHABILITATION ACT (UNITED STATES)

See Rehabilitation Act of 1973 (United States)

▣ VOTING

People with disabilities have made tremendous political strides over the past few decades, most notably with the passage of the Americans with Disabilities Act (ADA) in 1990. Despite these policy gains, however, recent research suggests that the voice of people with disabilities in American electoral politics is faint. Several studies over the 1992–2000 period showed that voter turnout was 6 to 21 points lower among people with disabilities and was especially low among people with disabilities who are older, nonemployed, or have difficulty in going outside alone.

Voter turnout is the most basic form of political participation in a representative democracy. The turnout of people with disabilities can be important for electoral outcomes and politicians' attention to disability issues. Voting may also have important personal and social effects for individuals with disabilities, affirming their equality as citizens and integration into mainstream society and increasing perceived personal efficacy.

The factors affecting political participation can be divided into three categories: resources ("Are you able to participate?"), psychology ("Do you want to participate?"), and recruitment ("Did anyone ask you to participate?"). Resources include time, money, and civic skills; psychological factors include political interest, civic values,

Table 1 Studies of Voter Turnout (in percentages)

Election Year	*Disability Sample*	*Disability Turnout*	*Nondisability Turnout*	*Gap*
1. 1992	People with SCIs	56	71	15
2. 1994	Nonemployed	33	54	21
3. 1992–1996	Nonemployed	57	71	14
4. 1996	Nonemployed	44	65	21
5. 1996	Disability households	33	49	16
6. 1998	Broad disability sample	54	60	6
7. 2000	Broad disability sample	70	82	12

Note: SCIs = spinal cord injuries.

efficacy, group consciousness, and commitment to specific policies; and political recruitment occurs through formal and informal networks (e.g., work or voluntary organizations). Research on the general population demonstrates that factors in each of these categories strongly influence the likelihood of voting.

Disability can affect voter turnout in a number of ways. Limited resources can depress voter turnout among people with disabilities. They have lower average income and education levels than people without disabilities, and their financial resources are often further constrained by higher expenses for medical care and special equipment. Political recruitment among people with disabilities is limited by their relative isolation. They are more likely than people without disabilities to live alone and face transportation problems, and they are less likely to be involved in community and social activities. Physical isolation can be exacerbated by discriminatory practices such as states' disenfranchisement of some individuals with disabilities, frequent neglect of candidates and parties to recruit people with disabilities, and negative messages about disability conveyed through public policy.

In addition, the psychological effects of living with a disability can be important. The stigma and discrimination faced by many people with disabilities may combine with isolation and diminished resources to decrease feelings of personal efficacy and control, and in turn depress voter turnout. The stigma attached to disability, however, may motivate some individuals to engage in political action, as shown by the growth of the disability rights movement.

EVIDENCE ON VOTER TURNOUT

Voter turnout is generally lower among people with disabilities, as shown in seven studies summarized in Table 1. These seven data sources use very different samples. The first is based on a survey of New Jersey residents with spinal cord injuries (SCIs); the next three are based on nonemployed respondents to national surveys who answered an employment question by saying they have a disability; the fifth is based on a national survey of respondents who said that someone in the household has a disability (although the respondent may not have had a disability); and the final two are based on broader samples of people with disabilities (identified by questions based on the 2000 U.S. Census).

Despite important differences in the samples and disability measures, the results consistently show lower voter turnout among people with disabilities. The first five indicate gaps in the range of 14 to 21 percentage points, while the final two (using broader samples) show gaps of 6 and 12 percentage points. The smaller gaps in the last two samples, which are more representative of the full disability population, reflect a higher proportion of senior citizens, who are generally more likely to vote. After adjusting for differences in age and other demographic characteristics, people with disabilities were found to be 20 percentage points less likely to have voted in 1998. These estimated gaps are large in a practical sense: Based on the 2000 election study, if people with disabilities had voted at the same rate as those without disabilities, there would have been an additional 3.2 million voters in 2000.

The above studies are based on data from the United States. Electoral participation of people with disabilities has become a salient issue in a number of other countries, where there have been a variety of initiatives to decrease the barriers they face in voting. These efforts indicate that people with disabilities are less likely to vote in many countries, but systematic comparisons of turnout are not available outside of the United States.

Absentee voting can be an attractive alternative for people with mobility impairments or other transportation difficulties. Four of these U.S. voting studies indicate that absentee voting is higher among people with disabilities, particularly for those with mobility impairments. Voters with SCIs in 1992 were five times as likely as voters in the general population to vote by absentee ballot (35 vs. 7 percent), while other samples show that voters with disabilities were about twice as likely as those without disabilities to vote by absentee ballot (13 vs. 7 percent in 1994, 14 vs. 8 percent in 1998, and 20 vs. 11 percent in 2000).

TURNOUT PATTERNS AND POSSIBLE EXPLANATIONS

Several studies indicate that turnout continues to be lower on average for people with disabilities even after controlling for a variety of demographic and economic characteristics, but the size of the voting gap varies along several dimensions—particularly age. While voter turnout increases strongly with age in the general population, it rises only weakly with age in the disability population. The result is that voter turnout is slightly depressed among young people with disabilities and much more strongly depressed among senior citizens with disabilities (e.g., in 1998 the turnout gap between people with and without disabilities was less than 10 percentage points among people under age 45, but 30 points among people age 65 or older).

In addition, employment appears to be important: The 1992, 1994, and 1998 election studies found lower turnout among nonemployed people with disabilities, but the 1992 and 1998 studies found that turnout was almost identical between employed working-age people with and without disabilities. Employment may raise voter turnout among people with disabilities due to resource effects (such as higher income), recruitment effects (through increased social contacts at work), psychological effects (such as increased identification with mainstream society and an increased sense of efficacy and interest in public issues), and other reasons. The voting gap is reduced but still exists after controlling for several income, recruitment, and psychological variables in the 1998 study, indicating that the role of employment requires further investigation.

Mobility problems also appear to contribute to the low turnout of people with disabilities. Turnout in 1998 and 2000 was lowest among people who reported difficulty going outside their homes alone. Also, the 1992 and 1998 election studies found that 30 percent of people with disabilities were not able to drive, and voter turnout was 15 to 20 percentage points lower among this group (after controlling for other personal characteristics). Voting clearly does not depend on being able to go outside alone (since one can vote by absentee ballot, or be taken to the polling place by others), suggesting that greater ease of mobility may have important social and psychological effects through increased interaction, feelings of efficacy, and identification with mainstream society.

Turnout of people with disabilities may be discouraged by problems in getting to or using polling places. A 2001 study by the General Accounting Office found that only 16 percent of polling places in 2000 had no potential impediments to access by people with disabilities. In the 2000 election survey, 6 percent of people with disabilities who had voted in the past 10 years reported encountering problems in voting at a polling place, while one-third (33 percent) of all others with disabilities said they would expect problems, compared to only 2 percent of people without disabilities. Based on these figures, an estimated 3.0 million citizens with disabilities either encountered or would expect to encounter difficulties in voting at a polling place. Reported problems include difficulty in getting to or inside the polling place, difficulty once inside the polling place, and general mobility limitations. Inaccessible polling places, apart from the practical difficulties they present, may make people with disabilities feel like second-class citizens who are not fully welcome in the political sphere.

Direct measures of recruitment are available in the 1992–1996, 1998, and 2000 election studies, where people were asked whether they had been contacted or otherwise encouraged to vote by a political party or anyone else. While recruitment is a strong predictor of voter turnout in general, and people with disabilities had fewer such contacts, this accounted for little of their lower turnout.

Psychological factors have been directly examined in several studies. One finding from a 1987 Harris poll indicated that interest in politics is a strong predictor of turnout among people with disabilities, similar to the general population. Feelings of political efficacy—that one is qualified to participate in politics and that the political system is responsive to individuals like oneself—are lower on average among people with disabilities. Regardless, this accounts for only a small part of the turnout gap between people with and without disabilities. The perception that people with disabilities are a minority group was linked to lower voter turnout among people with disabilities in 1984 but not in 1986. Finally, voter turnout in 1998 was especially low among those who had recent onset of disability, suggesting there are psychological effects of learning to live with a disability. These results indicate that psychological factors are important in voter turnout among people with disabilities but do not point to factors that fully explain the turnout gap.

INCREASING VOTER REGISTRATION AND TURNOUT

The voter turnout gap associated with disability is also reflected in voter registration rates: Only 62 percent of citizens with disabilities were registered to vote in 1996, compared to 78 percent of citizens without disabilities. This raises the question of whether people with disabilities face special barriers to registration.

In an effort to decrease barriers to voter registration, the National Voter Registration Act (NVRA) was passed and signed into law in 1993. The NVRA is often called the "Motor Voter Act" because it mandates that citizens be given an opportunity to register at motor vehicle agencies when their driver's licenses are obtained or renewed. More broadly, the NVRA requires states to offer voter registration in conjunction with any business at public service or assistance agencies as well as at offices providing state-funded programs for people with disabilities. In addition, states must provide for mail-in registration procedures, which can be especially helpful to people with mobility limitations.

The NVRA went into effect on January 1, 1995, but full implementation was delayed by the requirement for costly computerized communications between election officials at the state and national levels, and legal challenges by several states. Even in 2000, a survey showed that many agencies were not aware of their NVRA responsibilities. Some states had already implemented similar provisions by the time of the 1994 elections, but those changes did not substantially increase the turnout of nonemployed people with disabilities in that year; also, in 1998 and 2000, only 1 percent of people with disabilities who were registered since the NVRA took effect had done so at a disability or other social service agency. So far, the ability of NVRA reforms to increase voter turnout has been limited, but several studies suggest that registration among relatively uninvolved groups, such as African Americans and young people, has increased. Whether these newly registered citizens capitalize on their eligibility to vote may depend on other factors such as recruitment efforts and the salience of campaign issues.

New computer technologies have expanded the options for accommodating voters with disabilities. The Help America Vote Act (HAVA), passed in 2002, encourages adoption of these technologies, requiring each polling place to have at least one fully accessible voting system by January 1, 2006. In addition, HAVA promotes election access by requiring that each state allow electronic voter registration at disability agencies, all voting-related materials are available in alternative formats, and poll workers are provided disability etiquette training. The implementation and effects of HAVA remain to be seen.

CONCLUSION

In sum, voter turnout is lower among people with disabilities than among the general population. The research has identified several reasons but has not been able to fully explain this gap, indicating that there is still much to learn. While existing research provides only limited insights, it seems likely that both individual and contextual factors—including accessibility problems, legal and policy barriers to participation, and the marginalizing effects of disability policy—play a role in depressing voter turnout among people with disabilities. Policies such as HAVA, aggressive enforcement of polling place accessibility, and increased voter recruitment among people with disabilities could make an important difference.

Higher voter turnout among people with disabilities—which could raise the number of voters in U.S. elections by up to 3.2 million—could have a major impact on electoral outcomes. Such increased turnout could reshape the political landscape, increase the responsiveness of public officials to disability issues, and further contribute to the personal and social empowerment of people with disabilities by affirming their equality and rights as citizens.

—Lisa Schur, Todd Shields, and Kay Schriner

See also Citizenship and Civil Rights; Political Participation.

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VYGOTSKY, LEV SEMYONOVICH (1896–1934)

Russian psychologist

Lev Semyonovich Vygotsky was born in 1896 in Orsha, Belorussia. He was a clinical psychologist, researcher, and theoretician, developing an avant garde approach to disability (defectology, or the general science of deficiency) that grouped together neurobiological, psychological, social, and educational aspects. By bringing new blood to special education, this new science led to the creation of several institutes in Eastern Europe, including Moscow's Institute of Defectology, which Vygotsky directed from 1929 to his death in 1934. He left behind numerous writings, which, under Stalin, took some time to reach Western countries.

Unlike his Western contemporaries, whose conception of disability he found to be negative, static, and too focused on the disabilities themselves, Vygotsky offered a dynamic and multidimensional model of the development of nondisabled and disabled children. The disability may be put to positive use by stimulating compensatory processes that allow development to take new paths. The dynamic forces of compensation, enabled through the flexibility of psychic functions, also require mediation of the sociocultural environment. Indeed, it is the interactions of living with others that form the substrate of development. A disabled child who lacks a sufficiently positive social environment, or who benefits from such an environment too late in life, will encounter greater difficulties.

The richness of this socioconstructivist approach to development has inspired new generations of research in the fields of disability and special education.

—Isabelle Ville

See also Education, International; Psychology; Special Education.

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W

▣ WAR

Except perhaps for the grinding, daily toll of industrial accidents in modern societies during the last two centuries, there has been no more constant a source of disability, whether due to injury or to chronic illness, than war, one of the oldest of human practices. Although this fact is widely acknowledged, it is largely underanalyzed. In the case of both civilians and members of armed forces disabled as a consequence of war, there has been an evident reluctance to come to terms with the price that military conflict has exacted on the bodies and minds of both participants and bystanders. Within the context of that neglect, however, governments, researchers and scholars, and the general public have paid much more attention to the male disabled veterans of military service in conventional, national armed forces than to civilians disabled by war. (We know much less about the historical treatment of disabled veterans in non-Western countries and about those male and female alike who served in unconventional military forces, such as guerilla armies.) Even then, the intensity of this emotional and material generosity shown toward the Western male disabled military veteran has generally declined with time after the war in which the veteran was disabled.

In contrast to disabled veterans, the bystander is not easily assimilated into the romanticized and heroic depictions of warriors that form part, although by no means all, of the representation of those disabled in war, and that provide some of the luster by which wars seem at some emotional and ideological level more acceptable. Relatedly, more resources and energy have been devoted to providing medical, rehabilitation, and reintegration services, including pensions, for disabled military veterans than for civilian war victims. Although disabled military veterans have been pioneers on the frontiers of the welfare state, such that the programs created for them and the methods of organizing assistance by states have later been applied to the general disabled population, there remains in most societies an abiding gap between the social provisioning of the two disabled populations, greatly favoring the veterans. Yet, even the disabled veteran of military service has been a neglected figure in the writing of history and official memories of war. Civilization may indeed require a short memory if it is willing to engage in large-scale violent conflict to resolve its problems. Consequently, we have a subject riddled with gaps and difficulties.

THE DISABLING OF CIVILIANS

Evidence of impairment due to war is at least as old as the narratives of antiquity, but it has grown enormously in modern times. In the more distant past, the lack of highly destructive technology probably limited the number of war victims, while the poor state of medical care doomed large numbers of the injured and ill to a relatively quick death. War-related disability, moreover, could be claimed as one source of misery among many that doomed people to short, unhealthy, and impaired lives. In the modern era, the violence of warfare has spread outward into ever-larger populations, especially because of strategic aerial bombing, which has never been—and probably will never be—precise enough to avoid claiming large numbers of innocents as well as combatants. At the same time, however, medical therapeutics and rehabilitation techniques have become more effective at saving and reclaiming lives, so the number of survivors has grown alongside the number of victims. Yet, in the midst of such trends, the various difficulties, whether moral, psychological, or evidentiary, of coming to terms with the numbers and conditions of civilian victims continue.

To some extent, the problem of neglect is wrapped up in the dense moral fog that surrounds war itself. The calculus of victimology exerts endless pressure on the process of making sense of the consequences of war, as loser and winner contest their claims to both virtue and unjust suffering. World War II provides an illustration of this. The world waited almost 60 years for a study of the lethal and decisive Allied bombing of German cities and towns that concentrated not, as in British and American studies, on the strategy and logistics of aerial campaigns, but on their terrible human consequences. A sustained discussion was certainly needed because while on the official level it was stated that the targets were war industries and military concentration, it was well understood that the bombings were rarely precise and thus, in effect, targeted the civilian population. When that study was finally conducted, it was quite logically written by a German historian, Jorg Friedrich. However, every step of Friedrich's interpretive process, from his estimate of civilian casualties to his effort to establish a moral context for evaluating crimes against the noncombatant German citizens, was littered with the question of German guilt—for beginning the European war, for an especially lethal style of warfare that often targeted civilians, and for the Holocaust. It could hardly be claimed that Hitler's Luftwaffe, and toward the end of the war V-1 "buzz bombs" and V-2 rockets, failed to take their own lethal toll on British urban dwellers. Friedrich's claims that Winston Churchill, an uncompromising exponent of the strategy of aerial assault on urban centers, was a war criminal certainly rang hollow in the United Kingdom and elsewhere.

The same remorseless moral logic has characterized evaluation of the lethal World War II aerial campaigns over Japan, another aggressor nation brutal in the treatment of its adversaries, civilian and military alike, and responsible for the devastating surprise attack on Pearl Harbor that dragged a reluctant United States into war. Even such conventional assaults, comparable to similar raids over Germany in terrorizing civilian populations, as the devastating fire bombing of Tokyo in 1945 that is considered to have killed at least 87,000 civilians and injured 41,000, were dwarfed by the consequences of the deployment of the two atomic bombs in August 1945. There were perhaps 200,000 deaths in Hiroshima and Nagasaki attributable to the blasts by early November 1945. The majority of the dead and injured were civilians. The uniquely alarming injuries sustained by the *hibakusha* (A-bomb survivors), especially those tens of thousands exposed to radiation, have been well known since the immediate aftermath of the war. Their ranks included not only Japanese civilians but also Korean, Chinese, and other Asian forced laborers who were brought to Japan to work in war industries. Fetuses exposed to radiation in the womb were born with severe mental and physical impairments, and severely burned individuals, including most evidently those who were facially disfigured, were seen everywhere on the streets of Hiroshima and Nagasaki.

Americans have never been comfortable with sorting out the human consequences of the atomic bombs. During the occupation of Japan until April 1952, the American victors restricted research and publicity about radiation disease and other consequences of the bombs. The visit to the United States of 25 severely burned and facially disfigured young women, the so-called "Hiroshima maidens," for treatment marked not only a recognition of the civilian victims but a low-intensity, largely private effort to come to terms with the moral problem of these civilian casualties. Organizers of the visit included the Japanese Hiroshima Peace Center, American Quakers, Norman Cousins (the editor of the mass circulation weekly *Saturday Review*), and surgeons at New York's Mt. Sinai Hospital, with the cooperation of the American government, which provided air transportation for the women.

Such private efforts stopped well short of a formal acknowledgment of the toll the atomic bombs took on civilian lives. There is still resistance to such a national accounting. A major debate erupted in the United States as the 50th anniversary of the deployment of the bombs approached. The Smithsonian Institution, in planning for the commemoration of the bombings, stated that it would evaluate the necessity of the bombs and their human consequences and their role in bringing a speedy end to the Asian conflict. Veterans and patriotic groups and conservative politicians and journalists, angered by the seemingly moral equivalence being established between Japan and the United States, combined to create a storm of controversy over any effort to represent the larger issues presented by civilian targets and casualties, and they were successful in scaling back the goals of the exhibit.

Amid such ideological and partisan pressures and the general denial that surrounds the subject of civilian victims of modern warfare, it is perhaps to be expected that what has been done to help them has largely gone unheralded and unanalyzed, especially in nations suffering defeat, and has been done within budgetary constraints that were often tighter for civilian than military war victim programs. Following the two world wars, the spread of rehabilitation facilities and the creation of disability pension schemes served European civilians and military veterans. The programs bore the mark of specific historical circumstances, national traditions, and the qualities of national political leadership, as the examples of post–World War II Britain and Germany suggest. Because British industrial and agricultural workers had been drafted into their jobs and subject to injury, not only in war work but like other civilians in bombing raids, extending to them the same vocational rehabilitation programs created for disabled military veterans seemed just to both planners and the general population, especially in the context of Britain's emergent postwar social democratic mood. The Allies sought to install this sort of program in defeated Germany, but for rather different reasons. To combat militarism, at first the Allies insisted that there be no separate benefit system for disabled German veterans, whose needs the occupiers assimilated into the civilian disability system, then composed heavily of war victims. Because of a continuing national pride in the armed forces and feelings of obligation to those who had fought for their fatherland, even in the face of defeat and the taint of Nazism, the policy was so unpopular among Germans that it threatened to hinder efforts to win over the population in the emerging Cold War rivalry with the Soviet Union, and was gradually compromised. When Germans in the Western zone were allowed to govern themselves in 1949, the new government's first important accomplishment was the reconstruction of the relatively generous war veteran benefits program that had existed in the post–World War I Weimar Republic. In Japan, the restoration of self-government allowed the Japanese to push ahead in developing special services for the *hibakusha,* at first with activities on the local level by doctors in Hiroshima, and then with national legislation in 1957 and 1968 that provided medical, health, and welfare services to victims of the atomic bombs.

Although civilian war victims continue to lack access to the range and quality of services and income subsidies available to disabled military veterans, the moral grounds for debating the effects of war shifted notably in the late twentieth century toward much greater consideration of the consequences of war for the innocent bystander. Counterinsurgency wars, such as the Vietnam War, were especially criticized for insensitivity to casualties among civilians, who were often caught in the crossfire between guerilla and conventional forces. As with the burns caused by napalm in Vietnam, maiming resulting from unexploded ordnance, such as cluster bombs and especially land mines, became the basis for global campaigns of protest and remediation. There was no more powerful symbol of the damage such weapons caused bystanders than the iconic photo taken in 1972 of the nine-year-old Vietnamese girl, Kim Phuc, who was severely burned over 35 percent of her body. A South Vietnamese pilot had dropped napalm on her, members of her family, and other villagers, believing they were involved in an attack on ground troops he was sent to support. Growing awareness of the disastrous effects on civilians of aerial bombing campaigns and strategic missiles put considerable pressure on the United States to develop more precision weaponry and to use it with greater restraint in wars in Afghanistan and Iraq in the early twenty-first century. It was in this moral context, which highlighted the impersonal and random violence of terror from the skies, that it became possible for Jorg Friedrich to offer a moral reevaluation of the Allied bombing campaigns that for years had been viewed as the triumph of Allied air power in pursuit of victory against Nazism.

DISABLED MILITARY VETERANS

Representation

There is no doubt that disabled combat veterans have long been recognized as a source of special moral concern by the societies for which they have fought. They have also evoked intense anxiety and fear. To understand these contradictory responses, it is necessary to understand the ways in which in Western cultures, both warrior and disability discourses influence the understanding of the disabled veteran. The representation of disabled veterans is largely a product of the conflict and negotiation of these discourses, which lie in a state of constant tension, as we see in the ancient Greek narrative of Philoctetes. The root of these tensions lies in gendered assumptions about manhood. On the one hand, like Philoctetes, the warrior may be valorized as a symbol of male power and honor; on the other hand, pity and fear, the common emotions associated with our response to disability, serve to subvert honor and either infantilize and feminize the male or demonize him.

The ideal traits of the warrior have been steeped in ideas of masculine honor because war is the archetypical male experience, forming one of the borders of male and female. The warrior's character traits of courage, toughness, endurance, and a capacity for action have been fairly stable throughout the centuries, although the grounds for heroism have shifted from a chivalric emphasis on individual valor to peer groups' codes of behavior, emphasizing individual obligations to the combat group. Injury and disability incurred in war have been frequently viewed as, in Stephen Crane's ironically intended phrase, a "red badge of courage" for a warrior engaged in the worthy cause. Although wartime governments have sometimes been divided about allowing civilians to learn the extent of death and traumatic injury experienced by fighting men, in the belief that such knowledge was bad for morale, the disabled veteran as warrior hero has served as a particularly potent, public symbol for inspiring war efforts and loyalty to the state. When war ends, however, and memories of it begin to fade amid the general desire to return to a normal peacetime existence, the warrior hero gradually loses his luster and is reduced in stature to a beleaguered disabled man, whose needs may be perceived as both intrusive on the peacetime agenda and expensive. Thus, the generosity that his government and the public showed him through preferential public employment, pensions, vocational rehabilitation, prostheses, and education also begins to be challenged and, in time, even to recede.

As a disabled man, the veteran increasingly comes to be seen not as a warrior, but through the images by which people with disabilities have been conceived. For centuries in Western cultures, people have responded to disability and to disabled veterans with pity and fear. The veterans may evoke pity as innocent sufferers: In the case of veterans conscripted into armies, they are injured through no fault of their own and thus made to experience pain, a loss of autonomy, and exile from the community of the able-bodied, just as the wounded Philoctetes suffered physical exile on an isolated island. While the impulse to feel, if at times excessive, sympathy for the disabled veteran may be quite understandable, it has frequently been manipulated for instrumental purposes, thus popularizing pity. Twentieth-century veterans' organizations, such as the American Legion and a broad array of World War I–era German organizations, learned how easily a democratic polity can be manipulated through the potent, guilt-inducing symbolism of badly injured or ill veterans, especially when backed by powerful veterans' lobbies and bloc voting. Pity would not go unchallenged, however, for during World War I the idea of aggressive normalization through physical restoration and vocational training, which had been propagated first on behalf of the rehabilitation of injured and ill industrial workers in the late nineteenth century, spread among all of the major belligerents, allies and enemies alike. By the final year of that war, it came to constitute a counterdiscourse to traditional ways of conceiving of disabled veterans' postwar prospects; it insisted that every effort be made to return the disabled veterans to the community and to the workforce, and thus to oppose those influences that cast him as a feminized shut-in, lacking a man's place in the world.

The disabled evoke fear because physically and mentally impaired people have historically suggested sinfulness, deformity of the soul, and loss of moral autonomy. These conceptions cast the impaired individual as, alternately, revengeful, bitter, and self-absorbed; dependent, irresponsible, and parasitical; or monstrous. Neuropsychiatric disability also raises more immediate fears, given that it is associated with a direct physical threat to the observer and to social order itself. Although Americans have associated the enraged, antisocial, unpredictable madman possessing advanced weapons training with the Vietnam War veteran suffering from post-traumatic stress disorder, in fact, as Shay and others have suggested, societies have long been haunted by fears of the disruptive potential of men schooled in violence and possessing unpredictable mental states. Two of the earliest domiciliary institutions established for the care of aged and disabled veterans, France's Hôtel des Invalides (1633) and Britain's Chelsea Hospital (1685), were founded partly in the belief that there were many such men and that it was necessary to remove them from the streets in the name of public safety. Impoverished as many of them were and unable to reintegrate themselves into society, they were believed to have turned to begging, picking pockets, and violent thievery.

Public Policy

Protecting society against the disabled veteran, however, has not been the primary reason for the increasingly elaborate and frequently, at least at their inception, generous programs of social assistance that have come to characterize the response of modern societies to disabled veterans. Most Western societies historically have had at least two parallel tracks for assisting those construed to be in need, one for veterans and one for the general civilian population. The former is not only older than the general welfare state, but has been governed by different principles and rules and has been more generous in its provisions. The veterans' provision itself has not been a single entity. Although assistance for both groups has been governed by a common justification, disabled and able-bodied veterans have not been provided for equally. Disabled veterans consistently have been treated better than able-bodied veterans and indeed than perhaps any other cohort in society, including impaired civilians, whether disabled in peace or as bystanders in war. The liberal veteran provision is a consequence of the understanding—widely articulated in seventeenth-century England, in the era of the French Revolution, during the American Civil War by both North and South, and then universally accepted in the twentieth century—that assistance for and recognition of veterans must not be considered charity. Instead it is a reward for—and implicitly, too, an incentive to inspire—service to the state. In the case of disabled veterans, it is also a repayment for a personal sacrifice that is greater than simply time served. Thus, assistance is conceived as earned and a right. While assistance for disabled veterans generally came before that for the general population of veterans, in twentieth-century modern mass democracies, it has been increasingly given generously to all veterans, who now in some societies have life-long entitlements to medical care and education long after they have left the armed forces.

While programs of pension assistance and medical and domiciliary care for injured and ill veterans can be traced back to antiquity and appear here and there in early modern Europe, the dawn of the modern system of assistance for disabled veterans appears in history alongside the appearance of mass conscripted armed forces in the late eighteenth century and thereafter.

In the 1790s, in response to both egalitarian ideology and the invasion of the country by opponents of the Revolution, Revolutionary France briefly democratized pensions and qualifications for residence at the Hôtel des Invalides, which under the Bourbon monarchy had been largely limited to officers, before the pendulum swung backward toward elite privilege under Napoleon. Following the American Civil War, the federal government developed an elaborate and expensive pension system, which was administered by a centralized bureaucracy in Washington that, anticipating the modern welfare state, created a complex process for inspecting and classifying the bodies of disabled veterans of the Union Army. Also established were a network of domiciliary institutions for homeless and disabled veterans (the National Home) throughout the northern and western states, and a program providing prosthetic devices for thousands of amputees. The major European military pension systems, especially the French system adopted in 1831, established pension rates based on the nature and degree of physical injury. Although it borrowed from this practice, the American system departed from European models in allowing popular politics to mold the continuing evolution of its disability pensions. Large budget surpluses resulting from tariff revenues and a competitive electoral politics that thrust the veterans' vote into a position of prominence in national and state elections, led to an enormously expanded population base of the American pension system. It became, in effect, an old age pension for all veterans older than 62 that cost, by 1914, $5 billion annually.

The American pension system served as a negative reference point for efforts in the World War I era that ultimately created the modern system of care and assistance for disabled veterans in Western societies. Its costs, partisan manipulation, and refusal to examine possibilities for disabled veterans' lives other than as permanent clients of the welfare state, all were rejected by those planning and implementing the national programs that emerged out of the unprecedented scope and scale of needs created by men injured in the Great War. At the war's end, 752,000 British veterans, 1,537,000 Germans, just over one million French, 70,000 Canadians, and 200,000 Americans, among others, were classified as disabled or chronically ill as a consequence of service. The positive reference point was provided by the progressivist efficiency ethic of modern industrial society, which conceived of the individual as a social and economic resource to be formed and conserved through rational state planning and, relatedly, by the experience of the successful vocational rehabilitation of victims of industrial accidents.

Although national variations in implementation and administration existed, the conceptual unity among the major belligerents began with a consensus around the goals of both the most complete physical restoration of the individual as possible and aggressive socioeconomic normalization. These goals were conceived of as a *right,* an entitlement that the veterans had earned through sacrifice. However, the ground on which this right was to be constructed shifted subtly from the "sacred debt" to maintenance by the state proclaimed by Revolutionary France. The disabled veteran possessed the right to be restored to the position of a self-supporting, productive modern citizen. The state and cooperating private agencies were to approach the disabled man with practical programs that encouraged him to be rehabilitated. The medical phase of treatment would be accompanied by occupational and physical therapy to accustom him to doing practical, worklike activities while gaining strength and agility. Even before completing medical treatment injured men might be put to useful industrial work, which helped some of the European belligerents to deal with acute wartime labor shortages. The most complete physical restoration possible must have its complement in social and economic restoration in civilian life, an argument recently advanced by civilian rehabilitation specialists, who had begun decades before World War I to apply these same ideas to disabled children and victims of industrial accidents in Britain, Belgium, France, and Germany. The United States had just made a national commitment to civilian rehabilitation in legislation passed only months before the country entered the European war.

Opportunities were to be presented to the disabled veteran for vocational rehabilitation geared to what he could do in spite of his losses. A man's options for work should be fitted not only to physical condition but also to his prior occupation and class origins and to such aspects of the larger social and economic context as local job markets where he was likely to reside. Analogous arrangements were to be created to assist neuropsychiatric casualties and those suffering from chronic illness, the most common of which at the time was tuberculosis. Pension systems, free prosthetics that emphasized function over aesthetics, preference in government employment, and fully subsidized medical care were promised as a reward and as an aid to—not a substitute for—normalization.

During the balance of the twentieth century, public policy sought to improve and to elaborate on, rather than find substitutes for, this program. Everywhere it was installed, the program faced similar problems. Three were especially pressing. First, there was the problem of impersonal administration. The large masses of disabled men dependent on state services came to feel demeaned as cogs in a vast bureaucratic machine, even while they were lauded as heroes. One way of confronting the perpetual complaints about bureaucratic administration, as was done in Canada and the United States, was to include disabled veterans and their organizations in planning and administering programs in the belief that they could do the job more compassionately and efficiently, with more credibility than career civil servants. Second, the problem of containing long-term costs was persistent, especially as the men whom the state was obligated to assist aged and experienced health crises. Governments found that commitments made in the flush of patriotic obligation and in times of economic expansion and fiscal stability ultimately became a burden in hard times. The political costs of cutting benefits were enormous, so governments attempted in World War II to learn one lesson from World War I: The armed forces inducted many men with existing medical and psychological conditions, and these conditions were often worsened by military service. When and where circumstances allowed for systematic manpower planning, as in Australia, Britain, Canada, and the United States, governments raised induction standards to exempt or, in line with wartime labor shortages, provide national service opportunities for men who were already feeble, sick, or emotionally unstable. This policy was geared especially to weeding out those vulnerable to neuropsychiatric breakdowns. Even with pre-induction screening, it was increasingly recognized that neuropsychiatric problems were caused not only by combat, but also by military service that pulled men out of their normal lives and subjected them to psychological pressures that many could not handle. Once viewed as evidence of malingering or cowardice, neuropsychiatric illness became one of many new illnesses and impairments that late twentieth-century armed forces and governments had to take into account. This was the third problem, and it grew more insistent in the late twentieth century. The changing nature of warfare created new sources of disability, such as exposure to radiation among those military personnel ordered to be present near nuclear weapons tests in the 1940s and 1950s, exposure to the chemical poisons that resulted in Agent Orange illness among troops deployed in Southeast Asia, and Gulf War syndrome.

Throughout the twentieth century, governments in the developed world succeeded in achieving improved subsidized medical care, improved vocational rehabilitation, and innovations in prosthetic and assistive devices for disabled veterans. But the way forward was by no means even. Economic contractions limited the ability of governments to fund assistance programs for growing numbers of veterans. In part, fears of escalating costs led to resistance to acknowledging responsibility for the new chronic illnesses caused by the changing conditions of war. Disabled and able-bodied alike, veterans often found that the state was less generous to them than it had been to their grandfathers and fathers who were veterans of previous wars. During the twentieth century, however, the outstanding development in the field of public policy was the growth and improvement in all facets of the disabled veterans' provision.

The Experience of Solidarity

So often is the disabled veteran portrayed in popular culture, journalism, and scholarship as a client of the welfare state that there is a tendency to believe that the ultimate source of his social identity and group formation is his relationship to the state. Disabled veterans' organizations have formed for the purpose of pressuring the state to be more generous in financing entitlements and giving symbolic recognition, and these groups have built solidarity around activity as a political pressure group. While the state has been deeply involved in the lives of disabled veterans, the point is easily exaggerated. There are three distinct sources of the process by which disabled veterans have come to understand themselves as a group and to organize as such: an historical event (participation and injury in a war, in specific historical, cultural, and political contexts); an experience of medical treatment, rehabilitation, and reintegration; and an ongoing relationship with government as a source of material benefits and symbolic recognition. The state is, of course, implicated in all of these, for it is the state that has put men in uniform, cared for them when injured or ill, and assisted them on the path toward normalization. However, each of these sources also owes a great deal to interactions with the able-bodied public, to cultural representations of both disability and veterans, and above all, to a solidarity born of collective experience. While disabled veterans have had a singular and broadly ramifying relationship with the state, they have also had especially close relations with one another, and these relationships have been crucial in forming their identities and political orientations. This collective orientation contrasts with the experience, at least until recently in Western societies, of disabled civilians, which has been individual rather than collective.

At the heart of the collective nature of the disabled veterans' experience is disability itself; those injured in adulthood, after a lifetime of normal activity, have multiple psychological, social, and emotional needs that arise during medical treatment, rehabilitation, and reintegration. These needs hardly can be satisfied by government alone. The veterans' solidarity was built initially on the collective experience of military service, war, and injury. For reasons of efficiency and with an eye to inspiring high morale, military medicine developed the practice in the twentieth century of putting men with the same injuries and illnesses together for treatment, so that alongside the combat unit, the hospital ward and rehabilitation facility have been a *locus classicus* of disabled veterans' identity and group formation. It was in such facilities, through discussions with one another and not simply with doctors, that men came to understand the limits and possibilities of their situation and reached understandings about what for them might be a normalized existence. Lacking the psychological counseling that became widely available in the late twentieth century, disabled veterans of the world wars acted as their own counselors, talking about such essential issues as establishing new relations with parents, wives, children, and girlfriends; dealing with staring and other types of unwanted attention; confronting fears about sexual intimacy; learning to use prosthetics and assistive devices; overcoming environmental obstacles; framing realistic employment aspirations; and above all, avoiding the roleless, self-pitying, and anger-driven life that led frequently to alcohol abuse, probably the most common maladjustment of disabled veterans throughout history.

Cohorts were formed in these institutional settings that ultimately became the basis for smaller veterans' organizations composed of men with common injuries, such as the *Bund Erblindeter Kreiger* in Germany after World War I and, after World War II, the Blinded Veterans Association (BVA) in the United States and the Canadian Paraplegic Association (CPA). Disabled veterans have belonged to the larger veterans' organizations—both the mixed organizations, composed largely of the able-bodied majority of veterans, and the composite organizations, which brought together men with a wide variety of disabilities. It was, however, in these smaller, single-population organizations, built on shared experience and camaraderie, that the most complete synthesis of disabled veterans' needs and aspirations for normalization might be found. In such organizations, too, the struggle against the limitations imposed on people with disabilities was fought. The BVA led protests against New York City municipal health regulations that barred guide dogs from restaurants. One of the CPA's founders, Lt. John Counsell, a spinal cord–injured veteran, successfully campaigned to have the lightweight, self-propelling Everest & Jennings wheelchair made available to Canadian veterans to enhance their mobility.

We are now in a position to see that the disabled veteran's history and self-understanding is significantly more complex than may be grasped by merely considering him a client of the welfare state. At the core of his experience is disability—the negotiations and struggles of living with a disability in societies that frequently resist, at varying levels of consciousness, integrating people with impairments into the social systems of daily life. In this sense, although much—including particularly generous state assistance—has separated the experience of disabled veterans from that of disabled civilians, both populations have taken part in common struggles to win a broader place in the world.

—David A. Gerber

See also Amputation; Disabled Veterans; Ethics; Veterans.

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WHEELCHAIR

A wheelchair is any seating surface (e.g., a chair) that has wheels affixed to complement or replace an individual's ability to move from place to place. This includes everything from large, bulky, manually powered wheeled wicker chairs to high-tech, electric-powered wheelchairs that can climb stairs. In 1932, Herbert A. Everest, a mining engineer with a disability, and Harry C. Jennings, a mechanical engineer, collaborated to design and patent the cross frame wheelchair. They later formed Everest & Jennings, Inc., one of the largest international wheelchair manufacturers. Their design became the standard for the wheelchair industry that exists to this day.

Typically, a wheelchair consists of four wheels: two large wheels in the rear that are used for propelling the wheelchair, and two small wheels in the front that swivel, called casters. The large wheels support the majority of the individual's weight and provide the primary means of propulsion. The casters facilitate maneuverability; they are similar to the casters found on the front of grocery carts. Traditionally, wheelchairs are divided into two categories: manual and electric-powered. These categories are defined by the mechanism used to propel the wheelchair. A manual wheelchair is propelled by human power, and an electric-powered wheelchair is propelled by an electrically based power source (typically a battery and electrical motor).

A manual wheelchair is powered either by the individual using the wheelchair or by an assistant.

The most commonly recognized manual wheelchairs are seen at hospitals and nursing homes. Individuals who have the strength and endurance to independently propel the wheelchair typically use manual wheelchairs. They can propel the wheelchair in different ways. For instance, individuals with a spinal cord injury can use their upper extremities. Individuals who have had a stroke that affects only one side of their body can use one upper extremity and one lower extremity. Individuals who no longer have the strength to walk without a walker or cane or the endurance to walk with one can use their lower extremities. An assistant or attendant propels the manual wheelchair when individuals cannot do it themselves.

Manual wheelchairs can be divided into numerous categories based on their intended use and design. The most basic characteristic that distinguishes manual wheelchairs is the frame design, but wheelchairs are also categorized by style, material, and weight

Style

A standard folding wheelchair has a cross-brace design (X-frame), which allows the wheelchair to fold laterally via a scissor-like action. These wheelchairs are very popular because they can be easily folded for transportation. The limitation to folding frame wheelchairs is that they tend to be heavy and have reduced performance characteristics compared with a rigid frame manual wheelchair. A rigid frame does not incorporate a folding mechanism into the design, thereby significantly improving aesthetics, performance, strength, and weight.

Material

Another feature that distinguishes wheelchairs is the type of material used. Initially, manufacturers used steel in all manual wheelchairs (primarily mild steel) because of its low cost and ease of machinability. The last 20 years has seen numerous advances in the materials used to manufacture wheelchairs. Now they are made using primarily steel, aluminum, and titanium. Steel is limited to standard wheelchairs that have folding frame mechanisms. Aluminum is now used throughout the wheelchair industry, primarily in ultralight wheelchairs and some lightweight wheelchairs. Aluminum has a higher strength-to-weight ratio than mild steel, thereby reducing the overall weight of the wheelchair, and it has the added advantage of being resistant to corrosion. Finally, titanium has begun to appear in ultralight manual wheelchairs, further reducing the weight because of its high strength-to-weight ratio. Titanium also is resistant to corrosion. The key limitations to titanium are its relatively high material costs compared with steel and aluminum and the greater difficulty in machining or welding titanium.

Weight

In general, there are three wheelchair weight categories: standard, lightweight, and ultralight.

Standard wheelchairs are typically folding frame wheelchairs that are manufactured using mild steel. They are the heaviest of manual wheelchairs, usually weighing more than 18 kilograms with limited adjustability in components. These wheelchairs are designed most often for temporary use and are usually found in medical facilities (e.g., hospitals and nursing homes).

Lightweight wheelchairs also are typically folding frame wheelchairs. They have many adjustable components and are available with many features. They also tend to be lighter than standard wheelchairs (typically between 13 and 18 kilograms) because they are usually manufactured using aluminum.

Ultralight wheelchairs have the best performance characteristics of the three weight categories. As expected, these are the lightest-weight wheelchairs (typically less than 13 kilograms) because they are manufactured using aluminum, high-performance steel, or titanium. However, the key difference between lightweight and ultralight wheelchairs, besides weight, is an adjustable rear wheel axle. A horizontally adjustable rear wheel allows for the optimal placement of the rear wheel on the frame. This makes it easier for the individual to reach the rear wheels during propulsion, reducing stress and strain on the upper extremities.

The frame is the most basic unit of a manual wheelchair and the most influential in terms of performance. However, the components that are attached to the frame to generate a functional manual wheelchair are significant as well. The key components are the tires, the wheels, the axles, the casters, the leg rests, and the armrests.

Tires

Wheelchair tires are either solid rubber or pneumatic (air-filled). Solid rubber tires are almost always used with standard wheelchairs and sometimes with lightweight wheelchairs. These tires provide a hard ride and have a high rolling resistance, but they have low wear rates and are low maintenance. Pneumatic tires are almost always used with ultralight wheelchairs and sometimes with lightweight wheelchairs. These tires provide a softer ride, lower rolling resistance, and are lower in weight, but they have high wear rates and are high maintenance (particularly in maintaining appropriate air pressure).

Wheels

The wheels are usually spoked (wired) or molded (mag). Wheel sizes range from 12 to 26 inches in diameter, depending on the purpose of the wheelchair. Molded wheels have low maintenance requirements; however, they are significantly heavier and less responsive than spoked wheels.

Axles

Rear wheel axles are either fixed or quick-release. Like solid rubber and pneumatic tires, fixed axles are almost always used with standard wheelchairs, quick-release axles are almost always used with ultralight wheelchairs, and either fixed or quick-release are used with lightweight wheelchairs. Fixed axles are a bolt and locknut that require tools to remove and attach the rear wheel to the frame. A quick-release mechanism has a button on the end of the axle that allows for easy removal of the tire without any tools. This may be critical for disassembling a wheelchair when transporting it in an automobile. The fixed axle is low maintenance, while the quick-release axle requires frequent monitoring.

Casters

The casters range in size from 3 to 9 inches in diameter, with the majority falling in the 5- to 8- inch range. The caster tires can be solid rubber or pneumatic but are limited to either mag or solid hub wheels.

Leg Rests

The leg rests are fixed, swing-away, or elevating. They consist of a hanger that is attached to the frame and a footplate that supports the individual's feet. Fixed leg rests are integral to the frame; they produce a lighter-weight system since there are fewer components. Swing-away leg rests allow for the removal of the leg rests from the frame in order to facilitate transfers into and out of the wheelchair. Elevating leg rests allow the lower extremities to be positioned at different angles with relation to the seat surface, thereby raising and lowering the leg position. This is often critical to address an individual's specific physiologic issues (e.g., swelling in the lower extremities).

Armrests

The armrests are either fixed height or adjustable height. Armrests facilitate transfers by providing a hand-hold for the individual. They support the upper extremities when the individual is not propelling the wheelchair, and they provide a means for weight-shifting if the individual has the strength to lift his or her bodyweight using the upper extremities.

—Carmen P. DiGiovine

See also Assistive Technology; Seating and Positioning; Wheelchair, Electric; Wheelchair, History of.

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WHEELCHAIR, ELECTRIC

An electric-powered wheelchair (EPW) is propelled by an electrically based power source, typically motors and batteries. An EPW is also referred to as a power wheelchair. The first powered wheelchair appeared during World War I when an engine was added to a manual wheelchair. The demand for the wheelchairs, however, did not exist until nearly 30 years later.

A joystick, similar to that used with a computer game console, is the most basic and common device used to control an EPW. Advancements in control systems allow individuals to control a wheelchair using any voluntary movement. For example, a wheelchair can be controlled using head movement, breath actuation, tongue movement, or lower extremity control. Initially, EPWs were merely heavy-duty, manual folding frame wheelchairs that were powered by lead-acid batteries, motors, drive belts, and pulleys. These conventional power wheelchairs were very simplistic systems. They required the use of the joystick to control the wheelchair's movement, and programmability did not exist. The seating system typically consisted of a sling seat and back upholstery, which significantly limited postural support for the individual.

The advent of the power base allowed for significant mechanical advancements in EPWs. The power base separated the EPW into two components: the base, which provided the mobility, and the seating system, which provided the postural support. At the same time that a shift from a conventional power wheelchair to a power base wheelchair was taking place, significant advancements were occurring in electronic systems. Some of these mechanical and electrical advancements included the ability to add power tilt and recline systems and programmable performance settings (forward speed, turning speed, and acceleration).

Two types of drive mechanisms are used on EPWs: indirect drive and direct drive systems. Indirect drive systems (pulleys and drive belts) are used on conventional EPWs. Direct drive systems (gear box) are used on power base wheelchairs. Today, the vast majority of power wheelchairs use a power base with a direct drive system. Twelve V wet cell and 12 V gel cell batteries are used to provide the current required for EPWs. Typically, two 12 V batteries in series (24 V total) are required. Because of the maintenance requirements of wet cell batteries, gel cell batteries are the battery of choice. Although these batteries are similar in size to batteries used in the automobile industry, automobile batteries cannot be used for EPWs.

EPWs also can be classified based on the location of the drive wheels. There are three types of wheelchairs: front wheel drive, mid- or center wheel drive, and rear wheel drive. Traditionally, rear wheel drive EPWs were preferred because of their similarity to manual wheelchairs in design and maneuverability. However, center wheel drive wheelchairs have gained popularity because they provide increased maneuverability.

Push-rim–activated power assisted wheelchairs (PAPAWs) incorporate features of both manual and electric-powered wheelchairs. A PAPAW typically consists of an ultralight manual wheelchair with an external power source (batteries and motors). It complements an individual's ability to manually propel the wheelchair rather than replaces that ability, as is done with an EPW. The push-rim contains sensors that detect the direction and magnitude of force applied to it by the individual. The motors are then activated and assist in the propulsion of the wheelchair.

—Carmen P. DiGiovine

See also Assistive Technology; Seating and Positioning; Wheelchair; Wheelchair, History of.

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WheelchairNet (www.wheelchairnet.org)

WHEELCHAIR, HISTORY OF

Wheeled chairs have a long history. The earliest representation of a wheeled chair is an image on a sixth-century Chinese sarcophagus, although like the wheel and the chair, the history of wheelchairs probably dates back to 3500 B.C. It is possible that wheeled chairs entered Europe around the twelfth century, along with the wheelbarrow, but the first recorded use of self-propelled chairs by disabled people was not until the seventeenth century. Johann Hautsch made several rolling chairs for occasional use in Nuremberg during the early 1600s, and a disabled watchmaker named Stephan Farfler made a three-wheeled chair that he could propel by use of a rotary handle on the front wheel in around 1655. Mechanical "invalid chairs" (*wheelchair* is an idiom of the twentieth century) that employed a range of cranks and rotary devices increased in use from the late seventeenth century. They were designed as a means of transport primarily for the wealthy. By the beginning of the eighteenth century, wheelchairs began to appear in surgical and medical instrument catalogues as vehicles to transport patients. Styled like armchairs, these wood, wicker, or iron machines, with large wheels at the front and one caster at the rear for balance, were ornate, heavy, and cumbersome.

A variety of forms of the bath chair, originally designed around 1750 by James Heath of Bath to transport the sick to take the waters at the pump room or to bathe in the baths, dominated the British scene in the nineteenth and early twentieth centuries. The bath chair was halfway between an apparatus for injured, sick, or disabled people and a rickshaw-like mode of transport used by wealthy Victorians. Toward the middle of the nineteenth century, wooden wheelchairs with caned seats and backs also appeared, especially in the United States, where Civil War veterans used them. However, despite the introduction of wire-spoke wheels and rubber tires (borrowed from the bicycle) at the end of the nineteenth century, few wheelchairs during the first half of the twentieth century facilitated independent mobility outdoors.

The 1950s in both Britain and the United States saw the ascendancy of the relatively lightweight, tubular-steel folding wheelchair. The most celebrated example of this design is probably the Everest & Jennings (E&J) single X-brace folding wheelchair, first developed in 1933 by Herbert Everest (a wheelchair user since 1919 after a mining accident) and his partner Harry Jennings. However, the "invention" of the E&J wheelchair was not an isolated event. Chester Hockney had patented a tubular-steel folding wheelchair in 1907, and in Britain J. and A. Carters offered a wooden "folding" wheelchair in 1902. An American contemporary of E&J, Samuel Duke, also developed a tubular-steel folding wheelchair in 1934 from which he started the American Wheel Chair Co., and Dingwall & Son (Engineers) Ltd. marketed the first British tubular-steel folding wheelchair in 1948.

In contrast to earlier wheelchair designs, the folding tubular-steel wheelchairs afforded wheelchair users the ability to leave the home and travel for the first time. In addition to their ability to interface with other forms of transportation, folding tubular-steel wheelchairs were around half the weight of their wooden predecessors, and with large propelling-wheels at the rear and casters at the front, they were better able to negotiate steps and curbs.

In both North America and Britain, the rise to dominance of the tubular-steel folding wheelchair was due in no small part to the actions of the state. Shortly after World War II, both the U.S. Veterans Administration and the Canadian Department of Veteran Affairs began to supply E&J wheelchairs to disabled veterans. These lucrative contracts enabled E&J to grow into the most successful wheelchair company in the United States, holding a near monopoly on the North American prescription market by the 1960s. In Britain, too, the monopoly of the state-run wheelchair service, with its concentration on standardization, facilitated the ascendancy of the tubular-steel folding wheelchair when the Ministry of Health designed and distributed its own version (the Ministry Model 8).

Equally important, however, the ascendancy of the lightweight folding wheelchair design was due to wheelchair users' increasing control of the technology. Whereas World War I produced colossal numbers of soldiers returning with missing limbs, to which the technical solution was the prosthesis, World War II and the mass production of penicillin by 1945 resulted in a new constituency of *active* wheelchair users: people surviving with spinal injuries. The burgeoning of state-organized resettlement and rehabilitation services, including rehabilitation engineering, raised expectations among this group of being independent. The polio epidemics of the late 1940s and early 1950s, thalidomide in the 1960s, and the Vietnam War in the 1960s and 1970s all had a similar effect.

In matters of wheelchair design, wheelchair users were predominantly concerned with making the technology lighter, more reliable, and higher performing. Although wheelchair manufacturers in both Britain and the United States adopted this innovative path, it was from wheelchair sports that the ultralightweight revolution drew inspiration. Emerging from independent shifts in rehabilitation practices and philosophy following World War II (initiated by Ludwig Guttmann in Britain and Tim Nugent in the United States), wheelchair sports generated groups of wheelchair athletes who began to tinker with their wheelchairs to improve performance. During the next 40 years, this experimentation eventually challenged dominant thinking about wheelchair design and set the tone for manual wheelchair technology at the end of the twentieth century. The symbol of this sea change was Motion Designs' Quickie, an ultralightweight rigid-frame wheelchair developed by Marilyn Hamilton, Jim Okamoto, and Don Helman in 1979. Quickie transformed the orthodoxy of what an "everyday" wheelchair should look like and how it should function. Reworking innovations developed by wheelchair athletes such as Jeff Minnebraker, Motion Designs introduced color, aesthetics, and high performance to the mass wheelchair market.

Powered wheelchairs first emerged in a form that people with severe impairments could use in the late 1940s and 1950s. Despite a range of designs that existed during this period, it was George J. Kline's development of a friction motor and joystick in 1953 that influenced the form of powered wheelchairs for the next two decades: standard wheelchairs with motorized attachments. Designs for powered mobility progressed through the 1950s and 1960s, and more robust indoor/outdoor designs such as Raymond Biddle's BEC wheelchair emerged. The late 1960s also saw the introduction of proportional controllers by the Motorette Corporation and Penny & Giles, along with the greater use of microprocessors and computer technologies in wheelchair controllers.

Special or adaptive seating was another important innovation in wheelchair design that emerged from pediatric services in both Europe and North America during the early 1970s. Innovators in special seating were motivated by finding technological solutions to the problem of pressure sores and support for skeletal deformities, joint instability, and unusual body dimensions, but inextricably linked with those solutions was the idea that this technology would facilitate social inclusion for people with severe and complex physical impairments. Originally, seating engineers designed their seats as inserts, but during the 1980s, they worked with wheelchair manufacturers to develop a separate chassis on which to mount either standard or special/adaptive seating. This innovation led to one of the most significant design changes in powered wheelchairs in the 1990s: the power chassis, which divorced wheelchair design from the anthropometric and ergonomic considerations of seating.

In the early twenty-first century, wheelchair design is reaching for the stature of high technology with the introduction of the IBOT and the push-rim–activated power-assisted wheelchair (PAPAW). The IBOT, developed by Independence Technology, is a powered wheelchair that incorporates gyroscopes and computer technology to enable it to stand, be in motion at standing height, negotiate steps and curbs, and travel over a variety of uneven terrains. The PAPAW, currently marketed by a number of large wheelchair manufacturers, is a hybrid of powered and manual wheelchair technologies that employs motors to supplement the power applied by the user to one or both push-rims during propulsion or braking. It remains to be seen whether either design will dominate wheelchair provision in the future.

—Brian Woods and
Nick Watson

See also Assistive Technology; Participation; Physical Activity; Seating and Positioning; Wheelchair; Wheelchair, Electric.

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WILHELM II, EMPEROR

(1859–1941)

German emperor

Wilhelm II was, from 1888 to 1918, the last German emperor and Prussian king. Under his reign, the German Empire, the so-called Wilhelmian Empire founded in 1870/1871, was transformed from a backward agrarian country into one of the leading industrial nations of Europe. However, the great European and global ambitions of Germany led to World War I, which in turn led to 10 million casualties. The end of the war was essentially also the end of the German monarchy.

Emperor Wilhelm II was born on January 27, 1859, as Prince Friedrich Wilhelm Albert Victor. He was the first child of Prince Friedrich Wilhelm of Prussia, later Emperor Friedrich III, and his wife, Victoria, Princess Royal of England. Because of a difficult breech birth, Wilhelm II's left arm was paralyzed and about 15 centimeters shorter than the right. It was debated whether or not his brain was damaged during birth because of a lack of oxygen. His physical impairment had great biographical and historical consequences because it did not fit with the social image of a crown prince. His mother, in particular, could never come to terms with it. Numerous often cruel attempts at therapy and a merciless education from his tutor shaped the childhood of Wilhelm II and most likely led to his later rejection of his parents and their liberal outlook. His cruel tricks and violent verbal attacks, which occasionally had serious consequences for foreign policy, were well known. Early in his life, Wilhelm II's psychological health was doubted by his own family, as well as by contemporary psychiatrists.

After studying law and political science in Bonn, marrying Auguste Viktoria in 1881, and receiving military training, Wilhelm II took over the reign from his father, who had ruled only briefly. His political influence varied during his 30-year reign. Wilhelm II embodied the many ambivalences of his epoch: He encouraged scientific and technical development and enlarged the Navy to satisfy his global militaristic ambitions. His relentless fight against the Social Democrats, his antiparliamentary stance, and his unrealistic sentiment about the God-given rights of the monarchy exacerbated internal political conflicts. In November 1918 Wilhelm II fled to Doorn, in the Netherlands, to escape the first German Republic and, most likely, to avoid being indicted as a war criminal.

He lived there until his death on June 14, 1941. He hoped until the last that the monarchy would be reinstated, and apparently he could not see any fundamental contradictions between National Socialism and his own political views. Not least his notorious anti-Semitic diatribes made clear that there were important ideological continuity lines in German politics.

—Petra Lutz

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WILLOWBROOK STATE SCHOOL

Willowbrook State School in New York was conceived in the late 1930s by parents and professionals concerned about those who were then called "mentally deficient." When proposed, it was intended to be a state-of-the-art facility to care for and educate such persons. As such, it joined the ranks of many large American institutions that were also proposed and built for such purposes. These had begun to be constructed in the United States during the mid-nineteenth century and continued to be built into the twentieth century. Such places were part of society's overall efforts to provide for the welfare of people who, before around 1850, had no avenues for education and self-betterment. At first, the schools tended to be relatively small places whose basic purpose was to educate residents and, if possible, return them to their communities. Over time, with the advent of the scientific movement of eugenics—a viewpoint that created fear of people who were seen as having genetic abnormalities—institutions became less educational and more custodial. In the 1920s and 1930s, they regularly practiced sterilization of residents as part of society's solution to what was called "the menace of the feebleminded." Conditions in New York institutions worsened significantly during the Depression and again during World War II.

The immediate reasons for Willowbrook State School's construction on Staten Island stemmed from parents' perceived need for such an institution near New York City. A multipurpose hospital located on Randall's Island had been closed down. Parents in New York City in the 1930s began to lobby for a school to be built and formed a coalition with professionals from the American Association on Mental Deficiency. Staten Island was considered the ideal place; it was within the City of New York but geographically isolated since no bridge or tunnel linked it to the other boroughs. Staten Island was physically near, yet socially isolated and invisible, a clear pattern in the location of many institutions across the country. Despite community resistance, $12 million was allotted for construction at the Willowbrook site.

Thus, Willowbrook State School was built in the late 1930s, an era when the government provided resources for many public works. This explains why its buildings are similar to other institutions built at the same time, to some degree sharing certain basic architectural features. Willowbrook was designed to serve as home, school, and work for as many as 2,000 residents. It was to take mainly residents from the city, but also it was intended to house those who lived in other New York State institutions and schools, which during the 1930s and 1940s had become increasingly overcrowded. It was to have state-of-the-art facilities and training for staff.

Just before Willowbrook was to open, World War II began. From 1940 until 1947, the grounds served as Halloran Veterans Hospital, which was operated by the military. After the war, a prolonged battle emerged between New York State and the Chiefs of Staff about returning the facility to New York State for its original purpose. In 1947, the Chiefs of Staff relented to public pressure, and Willowbrook State School received its first students with developmental disabilities. Between 1947 and 1954, veterans and disabled persons shared the facility. Governor Dewey found himself in a difficult position of having to be sympathetic to both the pleas of veterans who wanted Willowbrook to remain their home and those of parents who needed placements for their children. Eventually the veterans were forced to leave but not without resistance.

The school's initial years of operation were documented in the only borough-specific daily newspaper in New York City, the *Staten Island Advance.* Some articles also appeared in the *New York Times* and *New York Post.* These articles reveal the hopefulness of the situation when the school first opened. Willowbrook quickly became the largest employer on Staten Island, and the care of the residents, while perhaps primitive and scientifically naïve by current standards, bore no resemblance to the neglectful and abusive conditions that came later in its history. In its early years Willowbrook was one of the more progressive and well-informed institutions of its type. There was even a staff-training manual, a rarity for the era. This is not to say that there was no abuse in these early years, as evident from oral histories of persons who came to Willowbrook during this time. The first major case of abuse reported in the newspapers occurred in 1952.

Willowbrook accepted "patients" quite easily. All that was needed was a physician saying that the child or adult required evaluation. This could be done at the facility itself, which resulted in a "drop-off" policy.

Census figures taken from newspaper accounts indicate a rapid initial growth in Willowbrook's population, including the admission of many young children. During the 1950s, there was evidence of some overcrowding, and with federal funds, the facility built additional buildings in the early 1960s to accommodate a larger and younger population. During this same period, the quality of life on the wards at Willowbrook appeared to deteriorate significantly. This occurred for primarily two reasons. First was the broadening of the admission criteria so that almost any person, with or without disability, could and would be admitted. Willowbrook began to be used as a warehouse for the "socially undesirable" of New York City, and this led to a great increase in the number of people living there. As many as 6,000 patients lived on the grounds, and at least a substantial minority had no disability. The second reason for deteriorating conditions was that New York State experienced a terrible budget shortfall during the 1960s, and the City cut the budget in all service sectors. This combination of census increases and financial cuts led to an increase in the resident-to-staff ratio at Willowbrook. In 1965, Robert Kennedy compared conditions at the school to a "snake pit." Given the number of patients at Willowbrook, the manipulation of parents to consent to medical research, and many family members' relative lack of concern, the staff used the residents during this era in various forms of medical experimentation, which while technically legal at the time were by today's standards illegal and unethical. This included the purposeful infection with hepatitis of children who had intellectual disabilities.

With so many people living at Willowbrook, with so few people taking care of them, and with a lapse in government support or oversight, a social disaster occurred. In fairness, such disasters occurred not only at Willowbrook but also at institutions all over the United States during this period. There appears to have been an epidemic lack of social conscience. As bad as conditions were at Willowbrook, it may not have been the worst of institutions in the United States. During this period, children and adults with and without disability who found themselves in institutions such as Willowbrook were systematically subjected to the most abusive and neglectful living conditions, outside of the concentration camps in World War II and the Civil War, perhaps ever created in the history of the United States. Because of overcrowding and inadequate resources, conditions on the wards at Willowbrook became "sub–kennel-like." Neils Erik Bank-Mikkelsen, a Danish visitor to the school in the 1960s, remarked, "In Denmark we don't let our cattle live this way."

In the early 1970s, additional budget cuts created nearly unbelievable conditions at Willowbrook. Staff-to-resident ratios were as low as 1 or 2 to 70. This essentially meant that no supervision at all was possible on many wards. The feeding time for children who could not feed themselves fell to approximately three minutes. Many "patients" were starving, and some died from asphyxiating food while being fed. During the early 1970s, a situation already completely unacceptable on moral or legal grounds became exacerbated, intolerable, and without precedent in American civil society.

Despite newspaper articles that exposed the conditions at Willowbrook, nothing was done. Jane Curtin of the *Staten Island Advance* wrote several articles about Willowbrook and documented the conditions there with photographs. Parents who had children at Willowbrook, particularly the Parents Benevolent Association, began to protest the intolerable situation. In the early 1970s, these parents were joined by professional staff employed at the school.

Finally, in early 1972, at the invitation of Dr. Michael Wilkins, one of the physicians allied with the parent group, a young television reporter for the ABC network, Geraldo Rivera, was given a key to one of the wards and "invited" to Willowbrook to record conditions (Rivera 1972). This event was to change the course of history for people with developmental disabilities. Rivera arrived on the Willowbrook campus unannounced and with a television crew. Without permission, he and crew entered building number six and videotaped. Rivera's tapes were broadcast nationally. They graphically depicted the neglect and abuse of children and adults. The images were accompanied by a narrative describing the smell of feces, urine, and death. The videos showed children and adults unclothed, lying in their own filth, and some restrained in straitjackets, sitting on the floors in crowded, unsupervised "day rooms." Rivera's tapes were so graphic, so condemning, that their national broadcast virtually began a movement to close institutions like Willowbrook overnight.

The parents who had been demonstrating, but "shouting in the wind" as one of them put it, were joined by various groups and filed a lawsuit in federal court over the inhumane living conditions. This lawsuit began the legal processes that resulted in the signing of the Willowbrook Consent Decree in 1975. Lawyers for the plaintiffs, that is, individuals and organizations representing the interests of the more than 5,000 residents who lived at Willowbrook at the time, and lawyers for New York State spent several years working out a detailed agreement about the process for and conditions of closing Willowbrook. The consent decree, a monumental legal agreement, became a model for similar decrees around the nation. The signing into law of the Willowbrook Consent Decree by Governor Hugh Carey is another chapter in the legacy of Willowbrook and one of the most significant events in the civil rights movements by and for people with developmental disabilities. Its history is documented in the 1984 book *The Willowbrook Wars* by Rothchild and Rothchild. It is important to consider not only the negative heritage of Willowbrook but also its positive legal impact on the civil rights of this population.

The Willowbrook Consent Decree created what is known as the Willowbrook class. The class contained anyone who resided at Willowbrook at the time the decree was signed into law. The consent decree described the conditions of placement that had to be met for anyone in the class, down to the number of towels he or she was to have. The decree created a very detailed system of monitoring and oversight of the class members, including the Commissioner's Task Force on Willowbrook that directly evaluated class members' current living situations. The obligations specified in the consent decree are to be met until the last of the "class clients," as they are sometimes referred to, pass on. This means, incidentally, that the Willowbrook case, in some form or another, is one of the longest open cases in American legal history. Since March 1993, the Willowbrook Consent Decree has been legally known as the Willowbrook Permanent Injunction.

Partly because New York State had decided to decrease its populations in all state institutions and state schools, in 1978 it created the Office of Mental Retardation and Developmental Disabilities (OMRDD). It was the OMRDD that oversaw the closure of Willowbrook. The late 1970s through Willowbrook's closure on September 17, 1987, represents yet another important story in Willowbrook's legacy. During this time, a partnership among the State, OMRDD, and not-for-profit agencies created neighborhood and community-based supports and services for former residents of institutions such as Willowbrook. This was the era of "communitization" and "normalization," when huge steps forward were made in the civil rights movement for people with developmental disabilities. This is a particularly fascinating period and one not well documented either in books or in films.

It is very difficult to generalize about the current welfare of persons who lived at Willowbrook. How people have coped with their experiences at Willowbrook varies widely. Some were broken, perhaps irretrievably. Others were deeply scarred, and these scars are still visible in their behavior today. Still others have seemingly left Willowbrook behind in their lives. From their behavior, one cannot tell they were ever there.

In 1993, the College of Staten Island moved to its current location, the converted campus of the Willowbrook State School. The State spent more than $400 million for redesign and reconstruction. Some old buildings were torn down, and new ones were built. Almost all of the old structures have been refaced, and there is very little indication of the site's previous use. One sees instead a beautiful and expansive college campus. While such a refitting is both remarkable and praiseworthy, perhaps the one thing we should take away from the history of Willowbrook is to "never forget."

—David Goode

See also Abuse and Hate Crimes; Children with Disabilities, Rights of; Community Living and Group Homes; Institutionalization and Segregation.

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WITCHCRAFT

Technically, the term *witchcraft* hinders an understanding of the phenomenon that it intends to identify. Rather than a descriptive term referring to the practice of magical or diabolical arts, most scholars prefer *witch-hunting* because it redirects attention to those better understood as persecuted on behalf of economic, gender, racial, physical, and cognitive differences. *Witch-hunting,* then, identifies the practice of attempting to slander individuals—almost always women—on the basis of social transgressions. One can find episodes of witch-hunting throughout history, but often epidemics of witch-hunting broke out during times of extreme social duress. Specifically, charges of witchcraft were made against an individual who challenged established authorities—those who violated entrenched codes of appearance, economic stability, or belief. While such practices of slanderous accusation originated in Europe, this entry focuses on the variant strain of such behavior as it evolved in seventeenth-century United States.

SEVENTEENTH-CENTURY NEW ENGLAND

Perhaps because witch-hunting was common in Europe, the Euro-American colonies participated in similar accusations from the very beginning of settlement life. Laws on witchcraft in the colonies all evolved from the 1604 English Statute (1 Jac. I, c. 12) that made "being a witch" punishable by death. Accusations of witchcraft were closely related to the experience of personal misfortune or a significant fall in social status. One consistent characteristic of witchcraft inquiries revolved around the accused and the accuser's health. Witches were often individuals who practiced midwifery in secret. Medical efforts by women led to suspicions among male authorities that the accused were exceeding their assigned roles in the domestic sphere. While mothers were expected to care for family members, treating others beyond that circle was considered illegal. Furthermore, the onset of inexplicable illness, bodily pains, and disability played key parts in the trial of witches; marks on and bodily ills in children, for instance, often prompted parents to worry about the source of such afflictions. In other cases, bodily blemishes discovered upon investigation of the accused's naked body provided convincing evidence of impropriety. In this sense, witch-hunting finds its grounding in interpretations of bodily vulnerability and difference. Those charged as witches were often accused of "looking different," and thus a hierarchy of appearance and functionality serves as a context for suspicions of witchcraft.

One of the earliest records of witch-hunting (1638) reveals that the case of Jane Hawkins of Boston turned on the fact that she had performed as a midwife during the "monstrous birth" in that year (Hall, 1991: 19). Since the Puritan magistrates considered "deformed fetuses" a sign of disfavor from God—therefore continuing the most ancient of ideologies about congenital disability—those present for such events were sometimes accused as a group. In Hawkins's case, she had been under suspicion for some time because she gave community women oil of mandrakes to facilitate their ability to conceive. Such acts angered a patriarchal establishment in that they violated conventions of gender-based authority. As a result, Hawkins was expelled from the colony with the consequent order that she not "meddle in surgery, drinks, plasters, or oils, not to question matters of religion, except with the elders' satisfaction" (Hall, 1991: 20). The mother of the disabled fetus, Mary Dwyer, also left the colony but returned to profess her faith as a Quaker in 1657. She was executed by the government in 1660 for heresy. While suspicions ran high during the seventeenth century toward women practicing the "medical arts," the birth of a visibly disabled child served as material evidence against those women who challenged the status quo. Two other Quaker women, Mary Fisher and Ann Austin, were stripped and searched for demonic "marks" during the 1650s. In each of these cases, bodies considered "deviant" prompted invasive investigations and secured the fate of those involved.

Symptoms considered disabling, such as seizures, deafness, vomiting, violent pains, or sickness, did not necessarily lead to accusations against the individuals affected; rather, such "disturbances of the body" often prompted others in the vicinity to be accused of supernatural manipulation. During outbreaks of witch-hunting, the different body itself was targeted as a sign and symptom of one's confederation with demonic forces. In 1648, Margaret Jones was hanged for causing disabling symptoms in those she touched; like Jane Hawkins, she too was suspected of practicing midwifery on the margins of colonial society. Jones's trial consisted of neighbors testifying that the accused had exchanged angry words with them for various reasons. One is struck while reading court testimonies from this period by the degree to which an accusation of witchcraft could be prompted by ordinary conflicts between residents—a missing utensil, a dropped dinner, or disagreements over land borders. All of these mundane events serve as legitimate evidence for an inquiry into witchcraft during this period.

Besides disease, disability, and congenital "deformity," charges of witchcraft also accompanied those who experienced bouts of severe mania, depression, or other psychiatric conditions. While such swings of emotion and cognitive states must have been relatively common among those living on the edge of what Puritan writers referred to as a "waste and howling wilderness," altered states of perception could lead to persecution. For instance, in 1641, colonist Mary Johnson was convicted of thievery. This conviction led the accused to confess to forming a compact with the devil and witnessing visions of the devil encouraging her while working in the fields and performing labors for her. This "voluntary" admission was the first recorded confession of witchcraft in the colonies, and Johnson was executed as a result (Hall, 1991: 23). Furthermore, one woman who was tried for slandering another with the accusation of witch was found not guilty based on the fact that she was "deprived of natural reason when she expressed those words charged on her" (Hall, 1991: 134). In 1671, Elizabeth Knapp was accused of being possessed because of her bodily mannerisms such as uncontrolled shrieks and outbursts of wild laughter. Readers of these transcripts encounter a number of individuals who profess their consort with demons in order to establish a state of mind that differed radically from that of most community members. Thus, some individuals went to their deaths while embracing the truth of an alternative psychiatric state of mind (what we might term "mental illness" today) in the guise of a confession of witchcraft. During these trials, the accused had no recourse to legal representation.

As mentioned earlier, once a charge of witchcraft was made credible through corroborating testimonies of malfeasance or "strange behavior," most individuals were physically searched for "witches' teats" or other discernible stigmata. Those who believed in witchcraft thought that witches met with devils at night, taking on the form of shape-shifting animals to suckle the devils. In other cases multiple bruises, moles, or visible blemishes could serve as physical confirmation of one's guilt.

By 1692, these relatively individual and isolated cases of consort with the devil turned into an unabashed rout of Satan as a conspiratorial presence controlling certain community members. The majority of charges during the Salem witch trials were similar to the previous cases cited here: seizures, possessions, monstrous babies, blemishes and deformities, personal misfortunes, and mental illness. When a group of girls experienced symptoms of "diabolical possession," the community hunted down scapegoats. The first three to be arrested—Sarah Good, Sarah Osbourne, and a West Indian slave named Tituba—led to a wider net of conspiracy, and ultimately, at least 19 individuals were executed for their presumed roles in these events. Early on in the public panic, evidence presented suggested that the conspiracy was so great that witching practices included formal meetings in the woods with Satan, the observation of black Sabbath, and covenant signings.

Witch-hunting brought together a powerful social alchemy of physical and spiritual realms. While disability status proved central to nearly every witching episode, disability itself did not automatically result in condemnation. While all witches presumably had "marks" that exposed their allegiance to the devils, many of the accusers used their own experiences of bodily vulnerability as the impetus for charges against another. Such instances help to describe the degree to which communities will pursue extravagant explanations for the existence of bodily, sensory, and cognitive variations. As with many other phenomena, bodies seem to cycle through periods of greater or lesser vulnerability; such perceptions seem, in part, to be based on our socially derived investments in homogeneity and the contingencies of health. They also condition ways in which we experience our own bodies as sources of discrimination, ridicule, and fragility. Of course, the witch trials resolved nothing that they set out to cure. Rather, they succeeded in deepening cultural obsessions with disability as a marker of maligned social identities.

—David T. Mitchell

See also Normality; Religion; Stigma.

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WOMEN

See Family; Feminism; Progressive Era Women in Special Education

WOOLF, VIRGINIA (1878–1941)

British writer

Virginia Woolf wrote experimental novels, essays, and political tracts that reflect on British traditions, Victorian behaviors, and the myriad changes that occurred in the modern era prior to World War I. She also wrote about her reflections on the root causes of a series of mental breakdowns that she experienced throughout her life, and linked her experience of collapse to creative output. Her first recorded episodes of mental anguish occurred around the deaths of each of her parents, although throughout her life she sought extended rest cures in nursing homes. During the same time period that the father of psychoanalysis, Sigmund Freud, was expatiating on a "talking cure," Woolf herself wrote about the creative potential to be found after periods of bleakness. Much of her writing depicts characters experiencing their environment in oppressive ways. Characters find it necessary to creatively resolve social and artistic undertakings, from paintings, to relationships, to dinner parties, and these efforts are salves that also supply readers with reasons to live. Many of her contemporaries and acquaintances, including her husband, believed that Woolf experienced bouts of manic depression, which might today be labeled as "bipolar disorder."

Woolf herself would seemingly indicate the material causes of mental anguish. *A Room of One's Own* (1929) focuses on the material necessities that would enable women to make more significant contributions to social thought and academic work. With male privilege a paramount feature of intellectual life, Woolf theorizes that feelings of suffocation in women likely derive from patriarchy. Particularly in her first novel, *The Voyage Out* (1915), she implies that the constraints of femininity result in suffocating mental illness. Exclusion from voting, education, governance, and citizenship results in women achieving much less than their potential. Judith Shakespeare, a character invented by Woolf to express this idea, lies buried at the crossroads while her male counterpart, William, achieves an "androgynous mind" and goes on to write masterful drama.

The later *Mrs. Dalloway* (1925) connects the depression of a conservative politician's wife who feels the pressures and demands of staging a successful dinner party to a disabled veteran's death wishes as he undergoes a rehabilitation regime that requires him to avow manliness. Many of Woolf's works concern the dissolution and restructuring of identity as a matter of social imposition. She puzzles over how female identity requires acquiescence to domination and the role of reflecting back an image to a man of twice his natural size. Catering to masculine cultural biases prevents women from undertaking their own careers, either as individual subjects or as artists in their own right.

In "On Being Ill," Woolf contends that illness merits as much literary attention as love, warfare, and jealousy; she delves into the separate experience of the world that is the vantage of the bedridden. Her work sits at the cusp of a series of literary narratives that seek to vivify body travails, mental anguish, and artistic resolutions to such psychic troubles. Although

Woolf records feeling intense personal negation and depression, she is not immune from the eugenicist ideas of her own era. Feminist scholar Cora Kaplan recounts Woolf's recording of her own repulsion toward her "vacant-eyed" and "idiot" sibling Laura (1870–1945) (Caplan, 2000: 314), who died in an institution. This kind of disavowal expresses what contemporary theorists consider a social hierarchy, under eugenics, of passable—as opposed to offensive—disabilities. Disability disavowal, or the participation in a hierarchy of functional "severity," has always troubled efforts at collective organizing for both feminist and disability politics.

—Sharon L. Snyder

See also Gender; Siblings of People with Disabilities.

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WORK INCENTIVES

Work incentives can take many forms. To understand their application, one must first understand that there are three primary stakeholders in the employment process—the employment candidate, the employer, and any third parties that may support the employment placement process. While most employers would state that securing a qualified employee is incentive enough, often various incentives are available to support the employment outcomes of certain groups in the employment sector that are either not represented or underrepresented. These incentives are intended to encourage the employment candidate to seek work, encourage third party service providers to support the placement of specific types of employment candidates, and encourage the employer to make certain accommodations in the workplace or underwrite additional costs associated with providing certain types of work supports.

Incentives for employment candidates that support individual career development, job placement, and employment retention and advancement take many forms. These incentives are typically offered by federal or state government agencies in recognition of the fact that a person who receives certain types of disability benefits and public entitlements and who returns to work will be more self-sufficient and less reliant on public programs. The benefit is not only to the individual, who is able to be more self-sufficient, but also to the government through savings associated with decreased or terminated entitlements and the communities in which the individual is now working and contributing. The Social Security Administration (SSA) offers a few of these types of incentives as part of their return-to-work agenda for people with disabilities. In addition to the examples illustrated below, similar work incentives exist for individuals who receive veterans' benefits, subsidized housing, Temporary Assistance for Needy Families, and other public entitlements.

The SSA administers two benefit programs for individuals with disabilities: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). SSI is a means-tested disability benefit program that provides benefit assistance to individuals who demonstrate economic need and who are 65 or older or have a disability. SSDI benefits are paid to individuals, and their dependents, who have been employed and have paid Social Security taxes under the Federal Insurance Contributions Act (FICA). The legislative history of both the SSI and SSDI programs reveals the desire of Congress to provide every opportunity and encouragement to the blind and individuals with disabilities to return to gainful employment. During the past 20 years, legislative and regulatory changes in the SSI and SSDI programs have been enacted to incorporate work incentives aimed at reducing the risks and costs associated with the loss of benefit support and medical services as a result of returning to work.

Work incentive provisions administered by the SSA can help people with disabilities in three significant ways. First, they can help individuals pay for services or items that they need in order to work and help them to maintain, or in some cases even increase, their cash benefits until they are stably employed. Second, work incentives such as the Plan for

Achieving Self Support (PASS), Impairment Related Work Expense (IRWE), and Blind Work Expense (BWE) enable people with disabilities to recover expenses they incur while working. Finally, extended Medicaid provided under Section 1619(b) of the Social Security Act and the Medicaid Buy-In Program and Medicare Extensions incorporated into the Ticket to Work Act remove disincentives associated with working and possibly losing health care. The goals of the work incentive programs are to assist individuals to achieve gainful employment, increase independence, facilitate empowerment, and acquire self-support.

Incentives for employers fall into two primary categories: (a) tax credits and deductions for providing specific accommodations and removing physical barriers to the workplace, and (b) financial reimbursement for wage and training offsets. However, these should not overshadow the myriad of other incentives that exist for hiring individuals with disabilities. A study by the Dupont Corporation in 1990 reported several incentives, among them the fact that 97 percent of workers with disabilities rated average or above in safety and 90 percent rated average or above in performance of their specific job duties. Second to the contributions of a qualified employee with a disability are other financial incentives for diversifying the workforce.

Tax deductions and credits offered to employers as incentives are administered by the U.S. Internal Revenue Service (IRS). The Removal of Architectural Barriers Tax Deduction allows employers to deduct expenses from their tax liability for making a worksite facility or public transportation vehicle more accessible to both the elderly and individuals with disabilities. The maximum deduction is $15,000. The Disabled Access Tax Credit is a financial incentive for eligible small businesses that for the preceding year did not have more than 30 full-time employees or more than $1 million in gross receipts. Eligible expenses under this credit are those that enable the business to comply with requirements set forth under the Americans with Disabilities Act. The maximum credit in any given year is $5,000, and the credit cannot exceed the tax liability for the year. There is a $250 deductible, and only 50 percent of the eligible access expenses after the deductible is applied are allowed. The Work Opportunity Tax Credit (WOTC) is another incentive authorized by the Small Business Job Protection Act of 1996. The WOTC is a federal tax credit that encourages employers to hire certain protected groups of job seekers (including individuals with disabilities that meet certain eligibility criteria) by reducing the employers' federal income tax liability by as much as $2,400 per qualified new worker. Provisions are also allowed for part-time workers and qualified summer youth workers. A final group of incentives for employers are those classified as On-the-Job Training Programs. These are typically administered by the Workforce Development System or State or Federal Vocational Rehabilitation System and provide the employer a financial offset to cover wages during certain training periods of new employment.

A final group of stakeholders in the employment process are service providers. These are community private and public for-profit and not-for-profit entities typically charged with assisting and supporting individuals with disabilities in securing, retaining, and advancing in employment. Incentives for this important stakeholder typically take the form of reimbursement for services and supports rendered. Service providers are usually engaged in contractual relationships with state agencies to accept referrals and deliver employment-related services and supports. However, many service providers are not solely reliant on these fee-for-service structures and may be benefactors of philanthropic trusts, charities, and other fund-raising activities. Deviating from this more traditional fee-for-service structure are outcomes-based models or incentives. Under this paradigm, service providers are paid for specific employment outcomes achieved, not the actual services and supports rendered leading to the outcome. Some systems weight the amount of the actual incentive based on the outcome achieved, and variations in this paradigm place value-added emphasis on the self-determination and empowerment of the individual being supported. One example of this new paradigm is the Ticket to Work and Self-Sufficiency Program administered by the SSA.

The Ticket to Work and Work Incentives Improvement Act of 1999 included a provision to establish the Ticket to Work and Self-Sufficiency Program, which allows SSDI and SSI beneficiaries to seek employment services, vocational rehabilitation services, and other supports of their choosing needed to obtain, retain, or maintain employment and reduce their dependence on cash benefit programs. The Ticket to Work Program is voluntary, and a beneficiary who has been issued a ticket may use it to obtain services and jobs from any Employment Network (EN) he or she chooses or to the State Vocational Rehabilitation Agency (SVRA), so long as that EN or SVRA is willing to accept the ticket. In turn, once the ticket is accepted, the EN or SVRA provides employment services, vocational rehabilitation services, and other support services to assist the beneficiary in obtaining, regaining, and maintaining self-supporting employment as specified in the beneficiary's Individualized Work Plan (IWP), if developed with an EN, or Individualized Plan for Employment (IPE), if developed with the SVRA. The EN or SVRA will receive payment only if the beneficiary achieves certain work-related outcomes. At any time, a beneficiary can retrieve his or her ticket from an EN or SVRA and reassign it to another, so long as ticket eligibility requirements continue to be met.

—Thomas P. Golden

See also Employability; Employment; Job Analysis and Placement; Job Retention; Job Training; Right to Work.

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WORKERS' COOPERATIVES

A worker cooperative is a business owned by some or all of its employees. Members of the worker cooperative work in the business and govern and manage it. Worker cooperatives are democratically run. Each worker-member has one vote in decisions about business policies, working conditions, and other matters related to how the business is run. This contrasts with other business structures in which the number of votes corresponds to the number of shares owned in the company. In larger cooperatives, members elect representatives to the board of directors. Some worker cooperatives employ workers who are not worker-owners.

Worker cooperatives have a long international history and have developed in different regions as a result of different influences. The consistent theme is the intent to create and maintain meaningful work at fair wages, in businesses that are owned and run by the workers as well as being part of the social and economic fabric of the community. Worker cooperatives are one type of cooperative business; others include supplier cooperatives (e.g., agricultural cooperatives) and consumer cooperatives (e.g., housing cooperatives).

Global and national associations and federations such as the International Co-operative Alliance (ICA) and the Canadian Co-operative Association (CCA) have articulated the principles and values followed by worker cooperatives. In addition to the democratic nature of the business, these principles include open and voluntary membership and the equitable sharing of income and profits with members after some reinvestment in the operation of the co-op. Emphasis is also placed on education, training, and information for members and the public.

A strong emphasis in these businesses is "cooperation among cooperatives." Each cooperative aims to use services and products created by other cooperatives. Cooperatives share a concern for their communities and try to contribute socially and economically to the sustainable development of their respective communities locally, nationally, and internationally.

Worker cooperatives operate in many sectors, from farming to manufacturing, home care service to auto repair. Worker co-ops can be set up as for-profit or not-for-profit operations, with any surpluses returning to members. They can be small or large: The Mondragon worker cooperatives, founded in Spain in 1956, have grown to be one of the largest complexes of cooperatives with more than 60,000 workers and 150 businesses.

There are three ways that worker cooperatives can directly benefit persons with disabilities:

1. The cooperative may include people with disabilities in its membership and give specific attention to policies and practices that support workers with disabilities. For example, attention may be given to disability benefits, the inclusion of support personnel, or flexible work hours.
2. The cooperative may be set up specifically by or with people with disabilities to create meaningful work for them. Worker cooperatives may be initiated by social service agencies attempting to help their client obtain more meaningful work, with the intention that the cooperatives will become independently operated over time.
3. The cooperative may be structured to provide services to people with disabilities. Recent examples include Cooperative Home Care Associates in New York, Home Care Associates in Philadelphia, and Cooperative Care in rural Wisconsin.

Some countries have promoted cooperatives through economic and social policies. In several countries, worker cooperatives and other business models sharing some of the characteristics or values of worker cooperatives have developed for people who have experienced long-term unemployment or underemployment, including those with disabilities. These include the self-help cooperatives of the 1930s, social firms, and consumer businesses. In contrast to these, Employee Stock Ownership Plan businesses are more than 50 percent employee owned and do not have mandates to support workers with disabilities.

Currently, worker cooperatives appear to be enjoying renewed interest and growth, and cooperative businesses are evolving with support from governments interested in assisting workers from vulnerable groups or locales to achieve economic success in several countries around the world.

—Lynn Cockburn

See also Employment; Right to Work.

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WORKSITE MODIFICATION

Worksite modification represents an area of assistive technology that combines the principles of human factors, ergonomics, safety, and disability. Worksite modification has become an important strategy in the provision of reasonable accommodation required under the Americans with Disabilities Act (ADA). As a result, worksite modification services may be requested by employers or vocational rehabilitation counselors with state or community agencies. They may also be requested in worker's compensation situations when a worker is trying to return to a jobsite.

An accurate job description is necessary when considering worksite modification services. The description should not merely tell how the job has been physically done in the past but should describe the functional requirements of the job. For example, "transporting shipping boxes to pick-up area" would be more accurate than "carrying shipping boxes. . . ." The job description should also include expected productivity levels so that the outcomes of worksite modification efforts can be quantified.

Other key components of worksite modification services are an analysis of how the elements of the job description are being performed and an accurate description of consumer abilities. These components enable the consumer and service provider to consider different work techniques or a different layout of the equipment, so that the consumer can use his or her abilities to do the job.

Human factors and ergonomics are useful in analyzing the relationship between the worker and elements of the workstation. For office applications, the addition of seating that provides adequate support and adjustability is often involved. Being able to vary one's position throughout the workday can help reduce the development of discomfort such as low back pain. Also, adequate arm support and positioning can address issues faced by individuals with carpal tunnel syndrome.

When equipment is involved, it may involve modifying equipment already at the workstation or introducing new equipment. When changes are made to existing equipment, consideration must be given to shared use of tools or machinery and maintenance of all safety features designed into the original equipment.

New equipment may include commercially available devices made for the public and perhaps not used for the specific job, or devices made specifically for individuals with disabilities. Use of commercially available devices enables the benefits of mass production and quality control to be realized.

Where there is no commercially available device to use or modify, custom-designed, custom-fabricated devices are an option. These custom devices are often low-tech and low-cost. Jigs and fixtures may be used, for example, to stabilize parts being worked on or to reduce the number of steps involved in performing repetitive work tasks.

Worksite modifications are often valuable to all workers present at the jobsite. This may become evident at shared workstations or when several workers are doing the same job. Professionals involved in worksite modification may include rehabilitation engineers, occupational therapists, physical therapists, or ergonomists. The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) has a special interest group on Job Accommodations.

—Glenn Hedman

See also Assistive Technology; Right to Work.

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WORLD BANK

The World Bank is an international organization that provides long-term loans, grants, technical assistance, and advice to help developing nations reduce poverty and increase their economic growth. The World Bank is one of the largest sources of aid to developing nations, annually providing more than $20 billion to fund hundreds of projects. The bank's loans and grants are given primarily to the poorer nations of the world to fund projects that are often not attractive to private investors. Many of these nations use the funds to establish industries, implement environmental programs, and conduct infrastructure projects, including the construction of dams, electrical facilities, and roads.

The World Bank is a family of institutions technically known as the World Bank Group. Originally, the World Bank consisted of only one institution, the International Bank for Reconstruction and Development (IBRD), which began operating in 1946. Later, four other affiliated institutions were formed and joined the group. They include the International Finance Corporation (ICF), established in 1956; the International Development Association (IDA), established in 1960; the International Center for Settlement of Investment Disputes (ICSID), established in 1966; and the Multilateral Investment Guarantee Agency (MIGA), established in 1988.

The World Bank Group provides aid principally through the IBRD and the IDA. The IBRD raises most of its funds on the world's financial markets and lends to developing nations at interest rates that tend to be somewhat below those of commercial banks and with longer maturities. By comparison, the IDA aims to promote economic development through providing concessionary finance from funds contributed every three years by individual donor nations. The IFC promotes private sector investment by supporting high-risk sectors and countries. The MIGA provides political risk insurance (guarantees) to investors in and lenders to developing nations. The ICSID settles investment disputes between foreign investors and their host nations.

Member nations own the World Bank Group, and they are jointly responsible for how the bank is financed and how its money is spent. Specifically, the IBRD is owned by 184 member nations, while the other agencies of the bank are owned by 140 to 176 members.

A president and board of 24 executive directors manage the day-to-day operations of the World Bank Group. The member nations of the bank or their constituencies appoint the executive directors. The executive directors elect the president of the bank. The president is traditionally an individual from the United States because it is the largest economy in the world and has the greatest share of investments in the bank. The president is elected for a five-year renewable term. He or she chairs meetings of the board of executive directors and is responsible for the overall management of the bank. The current president of the World Bank Group is Paul D. Wolfowitz, who has been president since 2005.

The World Bank Group employs approximately 9,300 people, including economists, financial analysts, educators, environmental scientists, and engineers. The bank's employees work in the organization's Washington, DC, headquarters or in one of its 109 country offices.

During the World Bank's 60-year history, its focus has changed a number of times. Initially, the bank was almost exclusively concerned with the reconstruction of Europe and Japan after World War II. During the 1950s and 1960s, the bank's funds were relatively limited, and they were largely directed into infrastructure projects such as building electric power stations and transportation systems. During the 1970s and 1980s, the bank's funds greatly increased, and the magnitude of its lending commitments rose. There was a new interest in alleviating poverty, and the bank began lending more funds to developing nations. During the 1990s, with the fall of the Soviet Union, the bank increasingly made loans to fund new developing markets and private economic activities in Eastern Europe.

THE MISSION, PRINCIPLES, AND VALUES OF THE WORLD BANK

Mission (last updated June 30, 2003)

> Our dream is a world free of poverty.
>
> To fight poverty with passion and professionalism for lasting results.
>
> To help people help themselves and their environment by providing resources, sharing knowledge, building capacity, and forging partnerships in the public and private sectors.
>
> To be an excellent institution able to attract, excite, and nurture diverse and committed staff with exceptional skills who know how to listen and learn.

Our Principles

> Client centered, working in partnership, accountable for quality results, dedicated to financial integrity and cost-effectiveness, inspired and innovative.

Our Values

> Personal honesty, integrity, commitment; working together in teams—with openness and trust; empowering others and respecting differences; encouraging risk-taking and responsibility; enjoying our work and our families.

Over the years, the World Bank has been strongly criticized by academics, political activists, and nongovernmental organizations. Some believe the bank has been too conservative in its lending practices and has not done as much as it could to help the poorer nations of the world. Others believe the bank has given too many loans to poor nations and saddled them with inordinate debt, which they cannot possibly afford to repay. When they do not repay, the bank has mandated draconian structural changes to their economies without giving due regard to the effects of such changes on the nation's social progress and political stability.

In the United States, both the political left and right have criticized the World Bank. Some on the political left want the bank to allow the poorest nations to cancel repayment of their loans so they can devote more of their resources to health and education. Debt forgiveness, however, shrinks the bank's income and thus perhaps its future loans. In contrast, some on the political right want to leave all development to private enterprise. The World Bank, however, receives most of its income from loans to middle-income nations and then turns some of the modest profit on these loans to help poorer nations.

Starting in 2000, the World Bank has become increasingly concerned with how to include disabled persons in the economies and societies of developing nations. To address this issue, the bank has undertaken several activities. For example, the bank is working to expand and improve the collection of disability data in developing countries. It established an online clearinghouse to make documents concerning the disabled readily available to its member nations and the general public. It sponsored several international conferences on disability and development. The first conference was held in December 2002 and the second in December 2004. The bank also recently launched an educational program aimed at incorporating the various dimensions of disability into development policies and practices at the urban and municipal levels. The bank's first course on disability issues, held in Guatemala in May 2004, emphasized the inclusion of the disabled in urban transportation, housing, financing, and other areas.

In the future, the World Bank will face many daunting challenges. It will have to reduce poverty in developing nations while their populations continue to grow. The bank will also need to increasingly address the growing plight of poor nations in sub-Saharan Africa. Many of these nations are experiencing the effects of the HIV/AIDS pandemic, which is rapidly reversing many of the economic and social gains made during the past 50 years. As a result of HIV/AIDS, an entire generation of people is being lost, the number of persons with disabilities is increasing, average life expectancy is decreasing, and infant and childhood mortality is increasing. To reverse the effects of this devastating disease, the economies, health care, and educational systems of these nations will need to be greatly strengthened—and in some cases totally rebuilt.

—Ross M. Mullner

See also Developing World; Economic and Social Development, International; Poverty.

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▣ WORLD HEALTH ORGANIZATION

The World Health Organization (WHO) is the specialized agency within the United Nations (UN) concerned with protecting and improving the world's public health. WHO's main objective is to attain the highest possible level of health for all people of the world. The organization very broadly defines health as "a state of complete physical, mental, and social well being and not merely the absence of disease or infirmity." WHO improves health by setting norms and standards, providing countries with technical advice and assistance, and advocating changes in public health policies. WHO is also the world's foremost source of international information concerning demographic and health trends, the occurrence and burden of chronic and infectious diseases and disabilities, and the provision of public health, medical, and environmental health services by countries.

HISTORY

A number of international public health organizations preceded the World Health Organization. The WHO can trace its history back to 1851 when 12 countries met at the first International Sanitary Conference held in Paris, France. Other organizations that were forerunners of WHO include the International Office of Public Health established in 1907 in Paris and the League of Nations' International Health Organization established in 1923 in Geneva, Switzerland. After World War II, when the League of Nations was broken up, the members of the newly formed United Nations met in New York to discuss establishing a new international health organization. They drafted the constitution of the WHO, which stated that the proposed organization's overall purpose was the promotion and pursuit of "the attainment by all people of the highest possible level of health." With the ratification of its constitution by member nations, the WHO came into formal existence in 1948.

During its initial years, WHO focused its activity on the demands of post–World War II reconstruction, including the rebuilding of health services in war-affected countries. In the 1960s and early 1970s, WHO worked primarily on mass campaigns for the prevention, control, and eradication of malaria, tuberculosis, and sexually transmitted diseases. It also conducted activities to improve maternal and child health, environmental sanitation, and nutrition. In the late 1970s, WHO worked with other national and international organizations to help stop the spread of the ancient deadly infectious disease smallpox. Through its efforts, smallpox was the first disease in human history ever to be eradicated. Starting in the early 1980s and continuing to the present, WHO has broadened its focus to include treating and preventing chronic diseases, improving environmental conditions caused by air and water pollution, providing health care technology, and ensuring the production and distribution of essential pharmaceuticals to member states. WHO has also become the world's "health conscience" by actively promoting human rights and the principle of equity in health among all people of the world, including persons with disabilities. According to WHO's constitution, "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political, economic, or social condition."

ORGANIZATIONAL STRUCTURE

The organizational structure of the WHO has changed little since its establishment in 1948. WHO is open to all member states of the United Nations, along with other nonmember nations or states that are invited to participate. Since its inception WHO has attempted to have universal membership, reflecting the belief that health concerns cannot be confined within national boundaries but require cooperation across all countries. Currently, the WHO is organized into four divisions: the World Health Assembly, the Executive Board, the Secretariat, and the Director General.

The World Health Assembly is the supreme decision-making body of WHO. It is composed of representatives from 191 member states. All member states are represented in the assembly's plenary and legislative body. Delegations of member states consist of not more than three delegates most qualified by their technical competence in the field of health, preferably representing the national health administration of each member state. Representatives of relevant international organizations and recognized nongovernmental organizations are also permitted to attend the assembly as observers. The Health Assembly's main functions are to decide major public health policy questions and to determine the overall policy direction of WHO's six-year General Programme of Work. The assembly also supervises the financial policies of WHO and reviews and approves the organization's budget. The assembly has the authority to adopt regulations in such fields as sanitary and quarantine requirements; determine the nomenclature for diseases and causes of death; and establish standards with respect to safety, purity, and potency of biological, pharmaceutical, and similar products. These regulations are binding unless member states choose to opt out from them. The assembly meets annually, usually in May. Each member state has one vote. In practice, the majority of the World Health Assembly's decisions are presented as recommendations or resolutions, and most decisions are made by consensus.

The Executive Board is the executive body of WHO that works to put into action the decisions and policies of the World Health Assembly. It consists of 32 members. Specifically, the board prepares the agenda and program of work for the next meeting of the Health Assembly. The board also is empowered to take emergency measures in case of epidemics or disasters. The World Health Assembly elects member states that will sit on the Executive Board. It is customary that at least three of the five permanent members of the United Nations Security Council (i.e., China, France, Russia, the United Kingdom, and the United States) serve on the Executive Board at any given time. Upon election, board members serve in a personal capacity as health experts rather than as representatives of particular governments. Executive Board members serve a three-year term. Each year there is a rotating turnover of one third of the membership. The board meets twice yearly, in January and after the World Health Assembly meeting in May.

The Secretariat is the administrative and technical staff of the WHO. It consists of about 5,000 public health, medical, economic, and support staff and other experts. Members of the Secretariat work at WHO's global headquarters, in the organization's six regional offices, and at field offices in countries throughout the world. WHO's Secretariat focuses its work on articulating consistent, ethical, and evidence-based policy and advocacy positions; managing information by assessing trends and comparing performance; setting the agenda for and stimulating research and development; catalyzing change through technical and policy support in ways that stimulate cooperation and action and help to build sustainable national and intercountry capacity; negotiating and sustaining national and global partnerships; setting, validating, monitoring, and pursuing the proper implementation of norms and standards; and stimulating the development and testing of new technologies, tools, and guidelines for disease control, risk reduction, health care management, and service delivery.

The Director General heads the Secretariat. Nominated by the Executive Board and elected by the World Health Assembly, the Director General is appointed for a period of five years. Among the primary responsibilities of the Director General are appointing Secretariat staff, preparing annual financial statements, and drafting WHO's proposed program budget.

The global headquarters of the World Health Organization is located in Geneva, Switzerland. The organization also has six regional offices: WHO Regional Office for Africa, located in Brazzaville, Republic of the Congo; WHO Regional Office for Europe, located in Copenhagen, Denmark; WHO Regional Office for South-East Asia, located in New Delhi, India; WHO Regional Office for the Americas/ Pan-American Health Organization, located in Washington, DC; WHO Regional Office for the Eastern Mediterranean, located in Cairo, Egypt; and WHO Regional Office for the Western Pacific, located in Manila, the Philippines.

The regional offices were created because of the early recognition that effective international health cooperation requires both global and local actions, and because some of the regions already had international health organizations (i.e., the Pan American Health Organization), which were incorporated into the WHO. Each region is managed by a director and has its own staff. The regions are responsible for the policies and activities in their respective geographic areas.

DISABILITY-RELATED ACTIVITIES

The WHO undertakes many activities to identify, help, and protect people with disabilities. Specifically, it works to ensure the human and legal rights of persons with disabilities, provides community-based rehabilitation services to treat the disabled, conducts various surveys to estimate the worldwide extent of disabilities, and develops, tests, and widely disseminates measures of disability.

The WHO's Disability and Rehabilitation team (DAR), for example, attempts to ensure equal opportunity and promote the human rights of people with disabilities by supporting member states in framing and implementing policies and involving community participation. Major activities of the DAR include establishing methods to quickly identify and reduce the impact of impairment, improving access to rehabilitation facilities and services, integrating rehabilitation services into nations' primary health care systems, promoting community-based rehabilitation programs, and strengthening the interactions among people with disabilities, health care workers, professionals, and the community.

To measure the extent of disabilities in populations and to determine worldwide trends in the occurrence of disabilities, the DAR periodically conducts surveys. Based on the results of a recent survey (2003), the DAR estimates about 600 million people, or up to 10 percent of the world's population, experienced some type of disability that caused difficulties in common daily activities. It found that 80 percent of the world's disabled lived in low-income countries. In addition, the majority of people with disabilities are poor and lack access to basic services, including rehabilitation facilities. The survey also found that the world's disabled population is increasing because of such factors as population growth, medical advances that preserve and prolong life, war injuries, landmines, the spread of HIV and AIDS, malnutrition, chronic disease conditions, substance abuse, accidents, and environmental damage. These factors are creating an overwhelming global demand for health and rehabilitation services.

The DAR publishes a number of guidelines, technical documents, and reports on disabilities and rehabilitation. Many of its publications are available in hardcopy and online. All of them are in English, and some are also available in Arabic, French, and Spanish.

To measure the extent, severity, level of impairment, and treatment of mental health disorders, the WHO World Mental Health Consortium is currently conducting the largest cross-national mental health survey ever undertaken. This face-to-face household interview survey of adults representing the general population of several countries asks respondents to assess if, during the previous 12 months, they had or were treated for a variety of mental disorders (i.e., anxiety, mood, impulse control, and substance abuse disorders). The ongoing survey will interview nearly one-quarter of a million people in 28 countries.

Survey results from more than 60,000 respondents from 14 countries indicate that mental disorders are common and often undertreated. In developed countries (Belgium, France, Germany, Italy, the Netherlands, Spain, Japan, and the United States) between 36 and 50 percent of people with serious mental disorders were untreated in the year prior to the interview. In less-developed countries (China, Columbia, Lebanon, Mexico, Nigeria, and Ukraine), the problem was even greater, with 76 to 85 percent receiving no treatment. The level of impairment associated with serious mental disorders in all countries was found to be staggering. Persons with serious disorders reported they were so debilitated that they lost their ability to function for between 30 and 80 days during the same period.

The WHO also periodically attempts to determine the global burden of disease by measuring the impact of the loss of healthy life from a large number of infectious and chronic diseases and injuries. The global burden of disease combines the loss of life from premature death with the loss of healthy life from disability. Disability is measured in units of disability-adjusted life years. Calculation of the disease burden is based on a number of assumptions that involve decisions about ethical values or social preferences. The key factors are the potential years of life lost from death; the discount rate, or extent of time preference for human life and health; and the disability weights used to convert life lived with a disability to a common measure of premature death. The concept of the global burden of disease has been widely used by developing countries to calculate the relative cost effectiveness of health interventions as a basis of policy reform.

Finally, the WHO has developed and promoted several standardized measures of disability. It first issued a standardized classification of disability in 1980 when it published the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The ICIDH, however, suffered from several conceptual and technical problems and was difficult to use. In 1993, the WHO began an international collaborative process for substantially revising it. With the participation of 65 countries, the group developed various drafts of a new classification of disabilities and extensively field-tested them to ensure reliability, validity, and comparability across cultures, languages, age groups, and genders. In 2001, the WHO issued the International Classification of Functioning, Disability, and Health (ICF).

The ICF provides a common framework for describing and measuring disability at both the individual and the population levels. It incorporates both a medical and a social model of disability. Briefly, the ICF identifies three dimensions of human functioning: body function (physiological functions of body systems including psychological functions), activity (the execution of a task or action by an individual), and participation (involvement in a life situation). Decreases in these dimensions are viewed as dimensions of disability. Disability is broadly defined in terms of impairments (problems in body function or structure such as a significant deviation or loss), activity limitations (difficulties an individual may have in executing activities), and participation restrictions (problems an individual may experience participating in life situations). The ICF can be used to classify specific categories of functioning in these disability dimensions, with qualifiers to assess severity and to identify whether the category is being used as a capacity or a performance. The ICF is available from the WHO in English, French, Spanish, Arabic, Chinese, and Russian. A multilingual CD-ROM version is also available.

—Ross M. Mullner

See also Developing World; Health; International Classification or Functioning, Disability, and Health (ICF/ICIDH); Translating Theory and Research into Practice.

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Directory of nongovernmental organizations working officially with WHO (http://www.who.int/ina-ngo)

Directory of the United Nations (http://www.unsystem.org)

World Health Organization Offices:

WHO Headquarters, Geneva, Switzerland (http://www.who.int)

WHO Regional Office for Africa, Harare, Zimbabwe (http://www.afro.who.int/)

WHO Regional Office for the Americas/Pan American Sanitary Bureau, Washington, DC: (http://www.paho.org)

WHO Regional Office for the Eastern Mediterranean, Alexandria, Egypt (http://www.emro.who.int/index.asp)

WHO Regional Office for Europe, Copenhagen, Denmark (http://www.who.dk)

WHO Regional Office for South-East Asia, New Delhi, India (http://www.whosea.org)

WHO Regional Office for the Western Pacific, Manila, the Philippines (http://www.wpro.who.int)

WULFF, HILDE (1898–1972)

German social worker and children's advocate

Hildegard Wulff was a German social worker who founded and ran homes for children with physical impairments. In addition, she was active in the Women's and Disability Rights movements. Wulff was born on January 7, 1898—the daughter of an industrialist family in Ruhrgebiet, West Germany—and contracted polio at the age of two years. Her father exhausted all medical possibilities hoping for her stabilization and recovery. Indeed, her long clinic and hospital stays caused a separation between Hilde Wulff and both of her sisters and excluded her from educational possibilities. These essential childhood experiences later turned Wulff toward the vocation of social work and the foundation of homes for physically disabled children. In 1921, she established the pediatric home "Urdenbach" in Düsseldorf. From 1923 onward, she involved herself with the "Selbsthilfebund der Körperbehinderten" (Self-Help Alliance of the Physically Handicapped; 1919–1931), the first emancipatory self-help organization representing the interests of the physically disabled in Germany.

At this time, Wulff was already fighting for an inclusive education of both disabled and "healthy" children in public schools. In April 1933, just a few months after the National Socialists seized power, Wulff founded the Children's Home "Neu-Westend" in Berlin. From 1935 until the mid-1960s, she ran the home "Im Erlenbusch" in Hamburg. During the Third Reich, she probably housed political and racial victims of Nazi persecutions in both places. For political reasons, Wulff resigned from the "Selbsthilfebund der Körperbehinderten," which had developed into the National Socialist and racial hygienic–oriented successor organization "Reichsbund der Körperbehinderten" (Reich Organization of the Physically Disabled). She and the children she cared for all survived the National Socialist period. On July 23, 1972, Wulff died in her home in Hamburg.

—Petra Fuchs

See also Childhood, Youth, and Adolescence; Eugenics: Germany; Nazism.

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X

XENODISABILITY

The neologism *xenodisability* (*xeno* meaning foreign) is designed to be synonymous with *zoodisability* (*zoo* meaning animal). Both terms refer to disability in the animal world—that is, foreign from the human.

In 1995, a group of schoolchildren on a field trip near Henderson, Minnesota, found that 11 of 22 frogs they encountered had limb and eye deformities. Since that time, biologists across North America have noted that frogs with limb anomalies—absent, deformed, or extra legs—are being born at a prodigious rate. Evidence now suggests that farming techniques have changed soil contents, promoting the growth of a parasite that induces these deformities in frogs. Like the canary's extreme sensitivity to gas, which made it an early warning system for coal miners, animal disability can be a harbinger of problems to come in the relationship between human beings and the environment. But the meaning of such problems is far greater for humankind.

The place of disabilities in the animal world, as it relates to humans, is many faceted. Humans' reasoning about animals with disabilities is sometimes indicative of humans' own social peculiarities. The thirteenth-century physician Aldebrandino of Sienna was curious about why humans are unable to walk when they are born, as other animals can. He concluded that the mother's menstrual blood poisons the human child, and only after the blood has been cleansed from the child's body is it able to walk. Disability in humans is partly revealed by comparison with animals, and vice versa. By comparing ourselves with other creatures, we have "determined" that our opposable thumbs have been critical to our developmental advantage, increasing our functional abilities in comparison with the species-level "disability" of nonprimates.

Animals are also widely used in more focused research, both as models for conditions that disable humans (e.g., the mouse model for Rett syndrome) and as test subjects for interventions, at either the mechanical or the cellular/molecular level (e.g., both large and small animals used in stroke studies).

At the cultural level, animals have been a ready symbolic or metaphoric venue for disabilities for millennia, as in descriptions such as "blind as a bat." Literature abounds with disabled animals, even stutterers, like the cartoon character Porky Pig. But observing the culture of real animals with disabilities has been equally valuable, if only more recent. Jane Goodall noted that chimpanzees exhibit some mutual wound-tending behavior when one of their number is hurt. Since the 1950s, Japanese macaques have been observed to have significant rates of physical disabilities. One study found the incidence at birth to be nearly 15 percent. Although the study found that infant mortality for macaques with disabilities was three times that of those without malformations, maternal "caretaking" evidently overrules natural selection, as many survive. One research team is now making a concentrated study of these mother-infant dyads.

While we study macaques and other primates with disabilities, these same species are trained as assistants to human beings with disabilities, just as dogs and other animals are. Xeno/zoodisability is a field with rich potential for increasing our understanding of the meaning of disability.

—Walton O. Schalick III

See also Rett Syndrome.

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INDEX

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CHRONOLOGY

1500 BCE Egypt: The Ebers Papyrus, a medical textbook, devotes an entire chapter to eye diseases. It also shows that deafness is well understood and that clinical knowledge has developed.

400 BCE Graeco-Anatolian Hippocratic writings coin the word e*pilepsy* for a convulsive condition they view as a disease rather than a possession or punishment. Today, it is estimated that more than 80 percent of the 40 million people who currently have epilepsy throughout the world have little access or no access to contemporary treatments.

300 BCE China: *The Yellow Emperor's Internal Classic* is the first text to outline acupuncture. Ordinances on emergency relief for the disabled date to the Han Dynasty, 206 BCE–AD 220. Fiscal and administrative disability classification date at least to the Tang Dynasty, 618–907.

1250–1350 High point of medieval medicalization during which theoretical explanations for conditions gain currency in Western Europe. Prior to this time, in the most general of terms, lay explanations held more sway, ranging from the superstitious to the spiritual to the vindictive. With the founding of the universities, medical theory, typified by the four humors, became more influential in governmental, legal, and elite social circles. Disabling conditions like epilepsy, strokes, and paralyses, as well as psychiatric conditions, increasingly fell under the social control of doctors.

1400 Turkey: Deaf people work in the Ottoman Court from the 15th to the 20th centuries. Sign language becomes a recognized means of communication among both hearing and deaf courtiers.

1593 England: The origins of disability as a social and political category emerge with the first state disability benefits being enacted by Parliament for those disabled in war.

1593 Europe and the United States: English Parliament initiates Europe's first national system of benefits for rank-and-file disabled veterans. The first veterans' homes—France's Hôtel des Invalides, Britain's Chelsea Hospital, and Frederick the Great's Invalidenhaus in Berlin—are established in 1633, 1685, and 1748, respectively. Following the American Civil War, the U.S. government responds with a system of homes, preferences in government hiring, land grants, free prosthetics, and pensions for disabled veterans (however, southern veterans were limited to usually scanty state pensions).

1601 England: The Poor Law is passed to provide family and community support for those unable to make a living for themselves.

1604 Laws on witchcraft in the colonies all evolve from a 1604 English Statute that makes "being a witch" punishable by death. During outbreaks of witch-hunting, the "different" body itself is targeted as a sign and symptom of one's confederation with demonic forces.

1697 England: The first English workhouse for people with mental and physical disabilities is established in Bristol in 1697.

1704 Bethlem Hospital in the United States has 130 residents housing the "furiously mad."

1714 Canada: The Bishop of Quebec opens the first building in Canada exclusively for the confinement of mentally disturbed individuals. It is adjacent to Quebec General Hospital.

1749 France and England: Denis Diderot pens one of the most influential treatises on the blind and education in his *Letter on the Blind* in which he argues that the blind can be educated. In 1784, Valentin Haüy opens the first school for the blind in Paris. He perfects a system of raised *letters* to enable the blind to read. In 1828, Louis Braille modifies a raised *dot* system invented by Charles Barbier, which is used today by blind persons to read and communicate. In 1847, William Moon, an Englishman, develops an embossed script based on Roman capitals that blind adults can learn to read in a few days. It is the first reading system for the blind to be widely adopted across the world, but because it is costly to print, the Braille system, which can be produced by blind individuals for themselves, overtakes Moon's system.

1755 France, the United States, and Germany: The Abbé Charles-Michel de l'Épée establishes the first state-supported school for the training of young deaf children, where he teaches sign language. The school serves as an inspiration for the establishment of other European schools and has a dramatic impact on social attitudes toward the deaf. In 1817, Thomas Gallaudet and Laurent Clerc establish the Asylum for the Deaf (now American School for the Deaf) in Hartford, Connecticut. Clerc imports the French sign system, which influences the makeup of contemporary American Sign Language (ASL). In 1778, Samuel Heinicke establishes a school in Leipzig, Germany, where the "oral method" is used.

1800 France: Victor of Aveyron, a "feral child" found in southern France, is brought to Paris. Jean Marc Gaspard Itard, a French physician, develops a systematic training program for the boy and works intensively with him for five years. Itard considered his attempt at educating Victor to be a failure because the boy did not learn to use a language. Nevertheless, Itard's disciples, including Edouard Séguin, Maria Montessori, and Alfred Binet, continue his work by establishing classes for children considered to be "mentally retarded."

1802 France: The world's first pediatric hospital, L'Hôpital des Enfants Malades, is founded.

1817 The American School for the Deaf is founded in Hartford, Connecticut. It is the first school for disabled children in the Western Hemisphere.

1817 James Parkinson, a London physician, describes what is to become known as Parkinson's disease.

1817 Thomas Gallaudet and Laurent Clerc open the American Asylum for the Education of the Deaf and Dumb in Hartford, Connecticut.

1828 Frenchman Louis Braille, blind from childhood, modifies a raised-dot system of code, one of the most important advances in blind education. It not only allows the blind to read at a much faster rate but also makes it possible for the blind to be teachers of the blind. UNESCO creates the World Braille Council in 1952.

1829 France: Louis Braille publishes an explanation of his embossed dot code.

1832 Samuel Gridley Howe is chosen to direct what is later to be called the Perkins School for the Blind in Boston. It becomes the model for schools around the nation. Laura Bridgman and Helen Keller attend Perkins. In 1837, Ohio establishes the first state-sponsored school for the blind.

1834 England: The English Poor Law Amendment stipulates five categories of those unable to work: children, the sick, the insane, defectives, and the aged and infirm. This sets the stage for the development of specialty institutions that isolate the disabled from the community.

1841 P. T. Barnum purchases Scudder's American Museum in New York City. This moment is considered to be the beginning of the "Golden Age" of freaks, which persists until the 1940s. The tension

between freaks and disability rights comes to a head in 1984, when disability rights activist Barbara Baskin successfully lobbies the New York State Fair to remove Sutton's Incredible Wonders of the World Sideshow, featuring a limbless man who performs as the "Frog Boy," from the midway.

1843 Due to the influence of Dorothea Dix, an American social reformer, the Massachusetts legislature allocates funds to greatly expand the State Mental Hospital at Worcester. Dix also plays an instrumental role in the creation of 32 mental hospitals and becomes nationally known for her reform efforts. By the late 1840s, Dix focuses on developing a national plan that addresses the treatment of people with mental illness.

1846 William Thomas Green Morton discovers anesthesia and in 1867 Joseph Lister provides a model for antisepsis. These new technologies play a central role in the future of aesthetic surgery as well as surgical intervention for every type of disability that calls for it. Penicillin is discovered in 1929, cutting mortality rates in hospitals dramatically.

1848 The North Carolina School for the Deaf begins the first publication for Deaf persons with its school newspaper, *The Deaf Mute.* First published in 1907, the *Matilda Ziegler Magazine for the Blind* is an ongoing Braille publication.

1848 Samuel Gridley Howe founds the first residential institution for people with mental retardation at the Perkins Institution in Boston.

1851 In the United States there are 77 residential institutions for children, 1,151 by 1910, and 1,613 by 1933. By the 1950s and 1960s, family members and politicians throughout Western Europe, Canada, and the United States push for the deinstitutionalization of people with disabilities.

1851 The first International Sanitary Conference is held in Paris, France, with 12 countries participating. It leads to the World Health Organization, the WHO, which formally comes into existence in 1948.

1857 Edward Miner Gallaudet, youngest son of Thomas Hopkins Gallaudet, establishes the Columbian Institution for the Instruction of the Deaf, Dumb, and Blind, located in Washington D.C. Its college division, eventually known as the National Deaf-Mute College, is the world's first institution of higher education for deaf people. Abraham Lincoln signs its charter on April 8, 1864; today it is known as Gallaudet University.

1857 English philosopher Herbert Spencer is first to use the expression "survival of the fittest." The application of his idea in combination with Charles Darwin's theories in his 1859 book, *The Origin of the Species,* is called Social Darwinism. It is widely accepted and promoted in Germany in the 1920s and leads Adolf Hitler to express prejudice against the weak, sick, and disabled.

1863 Louis Agassiz, a significant American naturalist, advocates the permanence of different races and worries about the "tenacious influences of physical disability" if races were mixed.

1864 Germany: Karl Ferdinand Klein, teacher for deaf-mutes, and Heinrich Ernst Stotzner are considered the founding fathers of the *training school,* which calls for schools to be created for less-capable children with the goal of improving their lot. Training schools remain in effect today, but critics maintain that there is an over-representation of socially and economically underprivileged students in this type of setting experiencing little academic success.

1868 Sweden: The Stockholm Deaf Club is the first recorded organization of people with disabilities.

1870 England and Wales: Education for children with disabilities begins when universal elementary education is first introduced around this time. From 1895 onward, schools for "defective" children spring up. In 1899, Alfred Eichholz, an inspector of special education, draws up key recommendations, which leave their mark on the historic 1994 Education Act legislation. In 1978, the Warnock report

introduces the term *special needs education,* which soon gains acceptance worldwide. With the 1994 UNESCO Salamanca Statement and Framework for Action on Special Needs Education, a major shift in organizing educational services for children with disabilities is confirmed internationally.

1876 ◆ Isaac Newton Kerlin, Edouard Séguin, and others establish the Association of Medical Officers of American Institutions for the Idiotic and Feeble-Minded Persons. Today, it is known as the American Association on Mental Retardation. Séguin, who staunchly believes in the educability of those with significant cognitive disabilities, is styled as "apostle to the idiots," by Pope Pius X, reflecting the attitude of the time.

1880 ◆ The United States National Association of the Deaf (NAD), the first organization of deaf or disabled people in the Western Hemisphere, is established. In 1964, the Registry of Interpreters for the Deaf (RID) is formed to establish a national body of professionals who are trained and certified to enable communication between deaf, signing persons and nondeaf, speaking persons.

1880 ◆ Helen Keller is born in Tuscumbia, Alabama. An illness at the age of 19 months leaves her totally deaf and blind. In 1887, Anne Sullivan, recently graduated from Perkins Institution for the Blind, joins the Keller household as Helen's teacher and remains Keller's companion for nearly 50 years. For many, Keller's story is the quintessential overcoming narrative.

1881 ◆ The Chicago City Council enacts the first American "ugly law" forbidding "any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself to public view."

1882 ◆ The first major federal immigration law in the United States, the Immigration Act of 1882, prohibits entry to "lunatics," "idiots," and persons likely to become unable to take care of themselves. Most of the restrictions that apply specifically to disability are removed from U.S. law in 1990. Today, disabled immigrants are still denied an entry visa if they are deemed "likely to become a public charge."

1887 ◆ Walter Fernald serves as superintendent of the Massachusetts School for the Feeble-Minded (now known as the Fernald Center) from 1887 to 1924. Unlike most of his colleagues, Fernald moderates some of his earlier extreme views and eventually develops one of the country's largest "parole" systems for moving institutional residents back into smaller, community-based residences.

1887 ◆ The American Orthopaedic Association is founded. German and British counterparts are founded in 1901 and 1918, respectively.

1895 ◆ The chiropractic profession is founded. This type of care is used to relieve musculoskeletal pain, one of the most common causes of disability.

1899 ◆ Maria Montessori and a colleague open the Scuola Magistrale Ortofrenica in Rome, an educational institute for disabled children and a training institute for instructors. Her method relies on the concept of sensory-based instruction as a means for developing intellectual competence. Her methods allow the child the greatest possible independence in order to foster his or her own development (the child's own inner "building plan").

1904 ◆ Sir Francis Galton, half first cousin of Charles Darwin, defines the term e*ugenics* (which he coined in 1883) in a paper he presents to the Sociological Society on May 16. He argues for planned breeding among the "best stock" of the human population, along with various methods to discourage or prevent breeding among the "worst stock." Galton also develops the idea for intelligence tests. The term *feeblemindedness* is defined as broadly as possible and is widely used by eugenic social reformers to conflate myriad social problems. Further naming, classification, and labeling provides eugenicists with a troubling rationale for treating people with coercion, disrespect, and profound inhumanity. Persons within the various categories of sub-normality become particularly vulnerable

to state-sanctioned segregation, institutional confinement, and enforced sterilization. Eugenics is widely practiced in Europe, the United States, and Canada, culminating in the systemic murder of more than 260,000 disabled people by the Nazis between 1939 and 1945. Today, the so-called new eugenics, known as "human genetics," appeals to the needs of the individual. Critics (some of the first in Germany), however, criticize individualistic eugenic approaches and disclose the connections between human genetics, national socialist racial hygiene, and eugenics.

1905 Alfred Binet and Theodore Simon publish the first intelligence scale, known as the Binet-Simon Test.

1908 The publication of Clifford Beers's *A Mind That Found Itself* initiates the mental health hygiene movement in the United States. Speaking out against mistreatment and neglect within the system, Beers establishes the Connecticut Committee of Mental Hygiene, which expands in 1909, becoming the National Committee for Mental Hygiene and is now known as the National Mental Health Association. In 1940 there are 419,000 patients in 181 state hospitals. In 1943, the patient-doctor ratio is 277:1, and by the mid-1950s in New York state alone, there are 93,000 inpatients. The Bazelon Center for Mental Health Law, founded in 1972 by a group of committed lawyers and professionals in mental health and mental retardation, attempt to improve mental health service provision through individual and class action suits. In 1980, a group of these lawyers form the National Association of Rights Protection and Advocacy (NARPA). One-third of its board of directors must identify themselves as current or former recipients of mental health care. The association is committed to the abolishment of all forced treatment.

1908 Pastor Ernst Jakob Christoffel establishes a home in Turkey for blind and otherwise disabled and orphaned children. This grows into Christoffel-Blindenmission (CBM), an independent aid organization of Christians of various denominations united to help disabled people in third world countries. Today, it supports more than 1,000 development projects in 108 countries. In 1999, CBM, other agencies, and the World Health Organization initiate VISION 2020: The Right to Sight, a global initiative for the elimination of avoidable blindness by the year 2020.

1909 Germany: The German Organization for the Care of Cripples is created as an umbrella organization for the care of the physically disabled. The Prussian Cripples' Care Law of 1920 for the first time provides a right to medical care and scholarly and occupational education for this group.

1912 Henry H. Goddard publishes *The Kadikak Family,* supports the beliefs of the eugenics movements, and helps create a climate of hysteria in which human rights abuse of the disabled, including institutionalization and forced sterilization, increases. In 1927, the U.S. Supreme Court, in *Buck v. Bell,* rules in favor of forced sterilization of people with disabilities, further fueling eugenics movements—the number of sterilizations increases.

1914 By this date, Sigmund Freud develops his most enduring influence on the study of disability, namely, the theory of psychosomatic illness in which a psychopathological flaw is given corporeal form as a symptom, thereby establishing the notion that people succumb to disease or disability because they feel guilty about past or present repressed desires.

1918 The Smith-Sears Veterans Rehabilitation Act passes, authorizing VR services for World War I veterans. In 1916, the National Defense Act marks the beginning of the U.S. government's supportive attitude toward rehabilitation. In 1920, the Smith-Fess Act marks the beginnings of the civilian VR program. The Social Security Act of 1935 establishes state-federal VR as a permanent program that can be discontinued only by an act of Congress.

1919 Edgar "Daddy" Allen establishes what becomes known as the National Society for Crippled Children. In the spring of 1934, the organizational launches its first Easter "seals" money-making campaign. Donors place seals on envelopes containing their contributions. The seal is so well-known that it

becomes part of the organization's official name. Today, Easter Seals assists more than one million children and adults with disabilities and their families annually through a nationwide network of more than 500 service sites. During the 1920s, Franklin D. Roosevelt inspires the March of Dimes.

1920 ◆ At about this time, the Shriners open hospitals for the care of crippled children. President Herbert Hoover establishes a "Children's Charter" in 1928 highlighting the need to attend to the needs of crippled children.

1921 ◆ Franklin D. Roosevelt contracts poliomyelitis. Despite damage to his legs (which makes him a wheelchair user) and deep depression, through enormous rehabilitative effort, he eventually re-enters politics and becomes president of the United States. His triumph over personal disability becomes legendary. Critics, however, fault him for choosing to minimize his disability in what is called his "splendid deception." He establishes a center for the treatment of polio patients in Warm Springs, Georgia, called the Georgia Warm Springs Foundation (1927), which hires medical specialists from Atlanta to direct orthopedics. In 1937, President Roosevelt becomes the prime mover behind the National Foundation for Infantile Paralysis Research.

1921 ◆ Mary L. McMillan (Molly) establishes the American Women's Physical Therapeutic Association, which is known today as the American Physical Therapy Association (APTA).

1921 ◆ The American Foundation for the Blind is established.

1921 ◆ Canada: Researchers isolate the hormone insulin. In 1922, Frederick Banting, Charles Best, J. B. Collip, and J.R.R. Macleod produce and test the pancreatic extract on people with diabetes, for which they are awarded a Nobel Prize. Insulin becomes a wonderful treatment for diabetes, but not a cure.

1921 ◆ France: Three historical waves of advocacy movements can be identified beginning with the National Federation of Injured Workers (FNAT) in 1921 and other organizations that focus essentially on the protection of rights. Another factor that stimulates advocacy groups in the first wave is the wounded veterans of World Wars I and II. A second wave dates from the period after World War II. Many advocacy groups form between 1950 and 1970, such as the Union of Associations of Parents of Maladjusted Children (UNAPEI) in 1960. A third wave finds a gradual emergence of three types of associations: those that run specialized facilities (for example, Living Upright, which, in 1970, leads to the creation of the first group living facility); those interested in trade unions; and those represented by user-advocate associations. Financing comes in large part from public funds, thereby creating a government-association partnership.

1922 ◆ The founding of Rehabilitation International sets the stage for the establishment of other international organizations of and for people with disabilities that link together throughout the world. Later international organizations include, among numerous others, the World Federation of the Deaf (1951), Inclusion International (1962), the International Association for the Scientific Study of Intellectual Disability (1964), Disabled Peoples' International (1981), and the International Disability Alliance (1999).

1925 ◆ The American Speech-Language-Hearing Association, today the American Academy of Speech Correction, is established to provide high-quality services for professionals in speech-language pathology, audiology, and speech and hearing science, and to advocate for people with communication disabilities.

1928 ◆ Charles Nicolle is the first deaf person to be awarded a Nobel Prize.

1929 ◆ Seeing Eye establishes the first dog guide school in the United States.

1930 ◆ The Veterans Administration is created to administer benefits, promote vocational rehabilitation, and return disabled veterans to civil employment. There is a record of provision for disabled veterans in the United States since the Revolutionary War and the Civil War. After World War I, three agencies administer veteran's benefits.

1932 Herbert A. Everest, a mining engineer with a disability, and Harry C. Jennings collaborate to design and patent the cross-frame wheelchair, which becomes the standard for the wheelchair industry that exists today. Developed during World War I, the first powered wheelchair appears, but doesn't gain popularity for another 30 years.

1935 President Franklin D. Roosevelt signs the Social Security Act of 1935 on August 14. Beginning in 1956, SSA amendments provide disability benefits.

1935 By 1935, in the United States more than 30 states pass laws allowing for the compulsory sterilization of those deemed genetically unfit in state and federal institutions. By 1970, more than 60,000 people are sterilized under these laws.

1935 As a result of being denied participation in the Works Progress Administration (WPA), six young people with disabilities hold a sit-in at the offices of New York City's Emergency Relief Bureau, demanding jobs in non-segregated environments and explicitly rejecting charity. The League of the Physically Handicapped is born out of this activism and operates in New York from 1935 to 1938. The League identifies social problems that remain issues today.

1935 Peer support in the United States is traced to the establishment of Alcoholics Anonymous in this year. Interest in peer support increases in the 1960s and is adopted by the disabled community. Movements, such as the Center for Independent Living, and groups, such as the National Spinal Cord Injury Association, make peer support one of their major activities.

1936 The American Academy of Physical Medicine & Rehabilitation is founded, leading to the approval of the American Board of Physical Medicine & Rehabilitation by the American Medical Association in 1947.

1937 The Fair Housing Act of 1937 passes with a mandate to assist the poor, a group that includes people with disabilities, by creating public housing. However, it is not until the Rehabilitation Act of 1973 that housing law specifically deals with discrimination faced by individuals with disabilities in housing programs that receive federal funding. The 1988 amendment to the Fair Housing Act of 1968 extends protection for people with disabilities beyond those of Section 504 of the Rehabilitation Act to include private housing.

1939 The Nazi regime institutes the Aktion T4 program in Germany. Children and, later, adults with disabilities are selectively killed both in hospitals and in special centers. The program was officially terminated by Adolf Hitler in August 1941, but practitioners "informally" continued it through a phase historians have called "wild euthanasia."

1940 State activists for the blind, including Jacobus Broek, come together in Wilkes-Barre, Pennsylvania, to charter the National Federation of the Blind (NFB). In 1957, the NFB publishes the first edition of the *Braille Monitor,* which is still in print today. In 1960, dissatisfied NFB members form the American Council of the Blind (ACB).

1940 Paul Strachan establishes the American Federation of the Physically Handicapped, the nation's first cross-disability, national political organization.

1942 The American Psychiatric Association develops a position statement in favor of the euthanasia of children classified as *idiots* and *imbeciles.*

1943 The LaFollette-Barden Act, also known as the Vocational Rehabilitation Amendments, adds physical rehabilitation to federally funded vocational rehabilitation programs.

1943 The United Nations is established on October 24 by 51 countries. The global Programme on the Disability is the lead program concerning disability. Many other types of programs, activities, and instruments include the 1975 Declaration on the Rights of Disabled Persons, the 1981 International Year of

Disabled Persons, the 1982 World Programme of Action Concerning Disabled Persons, the 1983–1992 UN Decade of Disabled Persons, and the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In 1988, the first UN Disability Database (DISTAT) publishes statistics from 63 national studies covering 55 countries and the 2001 publication presents 111 national studies from 78 countries, indicating a growing interest worldwide for the collection of usable data. In 2005, a UN Ad Hoc Committee continues to consider a Convention on the Rights of Disabled Persons that is a legally binding human rights instrument. Today the UN membership totals 191 countries.

1943 ◆ Sweden: In possibly the first reference to the concept of normalization, the most significant driving force in the ongoing closure of state-run or state-funded institutions for people with a disability is made by the Committee for the Partially Able-Bodied, established by the Swedish Government. Through the advocacy of people such as Niels Erik Bank-Mikkelsen, normalization, with its profound positive effect on the lives of people who were once removed and segregated from society, remains relevant today.

1944 ◆ Richard Hoover invents long white canes known as Hoover canes that are used by many blind people.

1944 ◆ The word *genocide* first appears in a book by a Polish lawyer Raphael Lemkin titled *Axis Rule in Occupied Europe* in which he describes Nazi Germany's practices but also seeks the adoption of legal restrictions so that genocide will not occur. In 1948, the United Nations adopts a declaration and then a convention on genocide that describe both against whom genocide might be directed and acts constituting genocide. Article 6 of the Rome Statute of the International Criminal Court (ICC), established in 2002, uses language identical to that in the UN convention to define genocide. More than 90 countries are parties to the ICC, but not the United States.

1945 ◆ President Harry Truman signs into law an annual National Employ the Handicapped Week. In 1952, it becomes the Presidents' Committee on Employment of the Physically Handicapped, a permanent organization, which reports to the President and Congress.

1945 ◆ Canada: Lyndhurst Lodge, the first specialized rehabilitation center for spinal cord injury (SCI) in the world, and the Canadian Paraplegic Association, the first association in the world administered by individuals with SCI, are established.

1946 ◆ The first chapter of what will become the United Cerebral Palsy Association, Inc. is established in New York City. It is chartered in 1949, and along with the Association for Retarded Children, it becomes a major force in the parents' movement of the 1950s.

1946 ◆ The National Mental Health Foundation is founded by attendants at state mental institutions who aim to expose abusive conditions. Their work is an early step toward deinstitutionalization.

1946 ◆ The National Institutes of Mental Health (NIMH) are founded in the United States.

1946 ◆ Europe: The European Union is founded on September 17 in Paris. It consistently shows its commitment to eliminating discrimination on many fronts through joint declarations, resolutions, directives, and action programs. With regard to disability, the European Union supports actions in favor of people with disabilities, principally in the form of European Social Fund interventions. Action programs aim at facilitating the exchange of information between member states and nongovernmental organizations with a view to identifying good practices, integrating people with disabilities into society, and raising awareness of related issues. The EU Council of Ministers Recommendation on the Employment of Disabled People (1986) calls on member states to "eliminate negative discrimination by reviewing laws, regulations and administrative provisions to ensure that they are not contrary to the principle of fair opportunity for disabled people." Further

steps are taken in 1996 when a communication on equality of opportunities for disabled people sets out a new European disability strategy that promotes a rights-based approach, rather than a welfare-type approach. This is strengthened in 1997 when the heads of state act to strengthen Article 13 of the European Community Charter of Fundamental Social Rights of Workers (1989), giving the European Community specific powers to take action to combat a broad spectrum of discrimination that includes disability.

1948 ◆ The National Paraplegia Foundation is established as the civilian branch of the Paralyzed Veterans of America.

1948 ◆ The World Health Organization is established. The WHO actively promotes human rights and the principle of equity in health among all people of the world, including persons with disabilities. Today it consists of 191 member states, but strives for universal membership. In 1980, the WHO publishes the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and issues a revised version in 2001, the International Classification of Functioning, Disability, and Health (ICF).

1948 ◆ The United Nations General Assembly adopts the "Universal Declaration of Human Rights," which promotes and affirms the fundamental rights to life, liberty, and security; to medical care and social services; and to the benefit from scientific progress and its uses.

1948 ◆ Sir Ludwig Guttmann organizes the first Stoke Mandeville (England) Games for the Paralysed, thus launching the Paralympic movement. The Games become international in 1952. In 1960, the first Paralympic Summer games are held in Rome and the first Paralympic Winter Games follow in 1976. The Paralympic Games are multi-disability, multi-sport competitions and have become the second-largest sporting event in the world, only after the Olympic Games.

1948 ◆ World War II bomber pilot and war hero Leonard Cheshire establishes what is to become the largest charitable supplier of services for disabled people in the United Kingdom. In the 1960s, the resistance of disabled people who live in one Leonard Cheshire home, Le Court, plays a major role in establishing the British disabled people's movement. In the late 1990s, the Leonard Cheshire organization establishes the Disabled People's Forum, which is run by disabled people and supports disabled people's involvement and empowerment.

1949 ◆ Timothy Nugent founds the National Wheelchair Basketball Association, and the first Annual Wheelchair Basketball Tournament takes place.

1949 ◆ Europe: The Council of Europe, an intergovernmental organization, is founded. Its activities cover all major issues facing European society other than defense. Human dignity, equal opportunities, independent living, and active participation in the life of the community form the heart of the Council of Europe's activities in relation to people with disabilities. The European Social Charter of 1961 and its revision in 1996 include specific wording and expand the rights of individuals with disabilities.

1950 ◆ The Social Security Amendments of 1950 provide federal-state aid to the permanently and totally disabled (APTD), which serves as a limited prototype for future Social Security assistance programs for disabled people.

1950 ◆ The National Mental Health Association is formed with the mission to continue 1908-advocate Clifford W. Beers's goals of "spreading tolerance and awareness, improving mental health services, preventing mental illness, and promoting mental health."

1950 ◆ The National Association for Retarded Children (NARC) is established by families in Minneapolis. It is the first and most powerful parent-driven human-services lobby in the nation to emerge in the 1950s.

1950 Amniocentesis is developed by a Uruguayan obstetrician. Later, advanced prenatal testing provides a battery of powerful medical tools to predict risk of disability and provide information to parents about their pregnancies.

1951 With the founding of the World Federation of the Deaf, the deaf community becomes international.

1953 Francis Crick and James Watson propose a three-dimensional structure for the DNA molecule. The paper they publish also gives clues to genetic mechanisms. Today, more than 6,000 monogenic disorders have been identified, and these affect approximately 1 in 200 live births.

1955 The polio vaccine, developed by Dr. Jonas Salk, becomes available, thus ending polio epidemics in the Western world. A new oral vaccine, developed by Dr. Albert B. Sabin, is approved for use in 1961.

1956 Social Security Disability Insurance (SSDI) becomes available through amendments to the Social Security Act of 1935 (SSA) for those aged 50–64. Other important amendments to SSA include the following: 1958: provides for dependents of disabled workers; 1960: removes age limit; 1965: Medicare and Medicaid provide benefits within the framework of the SSA (until 1977); 1967: provides benefits to widows and widowers over the age of 50; 1972: Supplemental Security Income (SSI) establishes a needs-based program for the aged, blind, and disabled; 1984: the Social Security Disability Reform Act responds to the complaints of hundreds of thousands of people whose disability benefits have been terminated; 1996: President Clinton signs the Personal Responsibility and Work Opportunity Reconciliation Act, making it more difficult for children to qualify as disabled for SSI purposes.

1959 The UN Declaration of the Rights of the Child is adopted; the UN Convention on the Rights of the Child is adopted in 1989. A central principle of both documents is access to education for all children including those with disabilities. In 1993, a related UN document, the Standard Rules for the Equalization of Opportunity, extends this to preschool children, and in 1994, UNESCO's Salamanca Statement and Framework for Action specifies the provision of special education for children with disabilities or learning difficulties. These documents constitute a universal bill of rights that can serve as a framework in the development of national policies worldwide.

1961 The American Council of the Blind is established.

1961 Europe: The European Social Charter (ESC) protects "the right of physically and mentally disabled persons to vocational training, rehabilitation and social resettlement." In 1996, it is revised, updated, and expanded to take account of social changes.

1961 Michel Foucault's work *The History of Madness in the Classical Age* becomes obligatory reading for those concerned with the archaeology of madness and its treatments. It continues to be an academic *rite de passage.*

1962 Battered child syndrome is defined. Researchers estimate that the incidence of maltreatment of children with disabilities is between 1.7 and 3.4 times greater than of children without disabilities.

1962 Russia: The Moscow Theater of Mime and Gesture is the first professional deaf theater in the world. It has been in continuous operation for more than 40 years and has staged more than 100 classic and modern plays.

1963 Congress enacts new legislation to ensure funding for a comprehensive program of research on mental retardation through the National Institute on Child Health & Human Development. In 1965, the Office of Economic Opportunity launches the Elementary and Secondary Education Act (ESEA), commonly known as Project Head Start. The goal is to prevent developmental disability by providing increased opportunities for disadvantaged children in the preschool years.

1963 The Developmentally Disabled Assistance and Bill of Rights Act (DD ACT) is authorized, with its last reauthorization in 1996. It focuses on individuals with developmental disabilities such as intellectual disability, autism, cerebral palsy, epilepsy, and hearing and visual impairments, among others.

1964 The Civil Rights Act is passed. It becomes the model for future disability rights legislation.

1964 France: L'Arche is established. By the beginning of the twentieth-first century, it includes more than 113 communities in 30 countries. "The Ark" is a distinctive style of community living, based on "core members" and "assistants," who view their commitment as sharing life *with* people with disabilities, rather than as caregivers.

1965 Newly enacted Medicare and Medicaid provide national health insurance for both elderly (over 65) and disabled persons.

1965 The Vocational Rehabilitation Amendments of 1965 are passed. They provide federal funds for the construction of rehabilitation centers and create the National Commission on Architectural Barriers to Rehabilitation of the Handicapped.

1965 The Autism Society of America is founded.

1967 Deaf actors establish the National Theatre of the Deaf (NTD). It is the world's first professional deaf theater company and the oldest continually producing touring theater company in the United States. Today, after almost 40 years, the NTD chronicles over 6,000 performances. The National Theatre Workshop for the Handicapped begins in 1977 and the Other Voices Project in 1982. These groups are among the earliest groups formally to place the disability experience at the heart of their creative endeavors.

1967 Heart transplantation is introduced. This technology is preceded by open-heart surgery developed in the 1950s and coronary bypass and internal pacemakers in the1960s. The Framingham Heart Study begins in 1948. It collects data over the next decades that help identify major risk factors contributors to heart disease.

1967 Paul Lemoine in France in 1967 and Kenneth Jones and David Smith in the United States in 1973 independently describe the condition fetal alcohol syndrome (FAS), which comprises a recognizable pattern of birth defects attributable to the adverse effects of maternal alcohol abuse during pregnancy.

1967 England: St. Christopher's Hospice in South London opens. It is the first attempt to develop a modern approach to hospice and palliative care.

1968 Congress enacts the Architectural Barriers Act. The ABA requires access to facilities designed, built, altered, or leased with federal funds.

1968 The Fair Housing Amendments to the Civil Rights Act of 1968 guarantees civil rights of people with disabilities in the residential setting. The amendments extend coverage of the fair housing laws to people with disabilities and establish accessible design and construction standards for all new multifamily housing built for first occupancy on or after March 13, 1991.

1968 Sweden: The origins of People First® go back to a meeting of parents of children with intellectual disabilities whose motto is "we speak for them." However, the people with disabilities in attendance wish to speak for themselves and start their own self-advocacy group. Similar groups quickly spread to England and Canada. The name People First is chosen at a conference held in Salem, Oregon, in 1974. People First is an international self-advocacy organization run by and for people with intellectual disabilities to work on civil and human rights issues.

1970 ◆ Landmark legal cases such as *Diana v. State Board of Education* (1970; Latino students) and *Larry P. v. Riles* (1971–1979; minority students) challenge biases inherent in standardized testing procedures used to identify students as eligible for special education. Both cases call into question the widespread use of "scientifically" objective measures to gauge intellectual ability. Today, despite reforms, a disproportionate number of students from racial, ethnic, and linguistic minorities continue to be placed in special education classes.

1970 ◆ Japan: The Disabled Persons' Fundamental Law (DPFL) becomes one of the 27 fundamental laws that stipulate basic principles in each policy area. Major revision takes place in 1993 reflecting a progress of guiding principles in disability policy that are deeply influenced by international movements such as the International Year of Disabled Persons (1981) and the UN Decade of Disabled Persons (1983–1992). Disability Studies as well as modern disability movements are born this same year, when members of Aoi Shiba, a group of people with cerebral palsy, protest publicly for the first time against sympathetic views toward the killing of disabled children by their parents. Aoi Shiba and other disability movements join in the establishment of Disabled Peoples' International in 1981. In 1986, the Rehabilitation Engineering Society of Japan (RESJA) is established. In 1992, disability movements in Japan initiate the Asian and Pacific Decade of Disabled Persons 1993 to 2002. The Japan Society for Disability Studies is established in 2003 and a unified national organization, Japan Disability Forum (JDF), is established in 2004.

1970 ◆ United Kingdom: The Chronically Sick and Disabled Persons Act (CSDPA) strengthens the provisions in the 1948 National Assistance Act (NAA). Later, the Disability Discrimination Acts of 1995 and 2005, together with the Disability Rights Commission Act of 1999, constitute the primary source of antidiscrimination legislation for disabled people.

1971 ◆ A U.S. District Court decision in *Wyatt v. Stickney* is the first important victory in the fight for deinstitutionalization.

1971 ◆ WGBH Public Television establishes the Caption Center, which provides captioned programming for deaf viewers.

1971 ◆ Gerontologist M. Powell Lawton defines *functional assessment* as any systematic attempt to objectively measure the level at which a person is functioning in a variety of domains. Over 30 years later, functional assessment, in combination with *outcomes analysis,* is considered one of the "basic sciences" of rehabilitation. In 1980, the World Health Organization proposes a series of definitions, which have a profound impact on the assessment of functional status and outcomes in rehabilitation. It is modified and revised in 1993 and 2001.

1971 ◆ The Declaration on the Rights of Mentally Retarded Persons (UN 1971), the Declaration on the Rights of Disabled Persons (UN 1975), and the World Programme of Action Concerning Disabled Persons (UN 1982) indicate the emergence of a global discourse of rights for disability.

1972 ◆ A group of people with disabilities (including Ed Roberts, John Hessler, and Hale Zukas), known as the Rolling Quads, living together in Berkeley, California, formally incorporate as the Center for Independent Living (CIL). This first CIL in the country becomes the model for Title VII of the Rehabilitation Act of 1973. In the late 1980s and early 1990s the group's advocacy efforts help pass the Americans with Disabilities Act (ADA). CILs are always controlled by disabled people. Accepted by most people as the birth of the modern independent living movement, the Berkeley concept migrates to other countries. In 1999, a global summit on independent living is held in Washington D.C. The summit brings together more than 70 countries. The Washington Declaration that comes out of the conference establishes a set of basic principles. In 1996, the Ed Roberts Campus, an international center and a service facility, is created in Berkeley, California, in memory of Edward V. Roberts, founder of the independent living concept.

1972 ◆ A young television reporter for the ABC network, Geraldo Rivera, is given a key to one of the wards at Willowbrook State School on Staten Island, New York. Established in the late 1930s as a state-of-the-art facility for the "mentally deficient," by 1972, Willowbrook becomes a warehouse for the "socially undesirable" of New York City, with a substantial minority having no disability at all. The inhumane conditions deteriorate to the extent that a visitor remarks, "In Denmark we don't let our cattle live this way." Rivera's exposé leads to a lawsuit that results in the Willowbrook Consent Decree of 1975, which creates a detailed system of monitoring and oversight of all residents living there at that time, to be met until the last of the "class clients," as they are sometimes referred to, pass on. The property has since been sold to a college.

1972 ◆ Paul Hunt's call for a consumer group to promote the views of actual and potential residents of institutional homes for the disabled in the United Kingdom results in the establishment of the Union of the Physically Impaired against Segregation (UPIAS). The group's aim is to formulate and publicize plans for alternative forms of support in the community. Hunt is regarded by many disability activists as the founder of the modern disabled people's movement.

1972 ◆ New Zealand: Three key pieces of legislation pass have long-term effects on the disabled community: the 1972 no-fault Accident Compensation Act that provides monetary compensation to victims based on level of impairment suffered; the 1975 Disabled Persons Community Welfare Act, giving assistance to disabled people, parents, and guardians, as well as voluntary associations; and the Human Rights Act of 1977, which does not include disability as a recognized grounds for discrimination. Today, disabled populations in New Zealand continue to fight to establish an identity as disabled people rather than a group needing "welfare." One task is to promote legislation that includes disability as a group against whom discrimination is outlawed.

1973 ◆ The Rehabilitation Act of 1973 lays the foundation for the disability rights movement. Its Section 504 asserts that people with disabilities have equal rights that prevent discrimination based on their disability in programs or activities that receive federal funding. This is the first major nationwide antidiscriminatory legislation designed to protect disabled Americans. These rights are further protected with the landmark Americans with Disabilities Act (ADA) of 1990.

Section 501 of the Act requires affirmative action and nondiscrimination in employment by federal agencies of the executive branch. Section 502 creates the Access Board, which grows out of the 1965 National Commission on Architectural Barriers to Rehabilitation of the Handicapped. As a result of the commission's June 1968 report, Congress enacts the Architectural Barriers Act (ABA). Section 503 requires that to receive certain government contracts, entities must demonstrate that they are taking affirmative action to employ people with disabilities. The enduring hallmark of the act, Section 504, provides that no otherwise qualified individual with a disability shall, solely by reason of his or her disability, be excluded from the participation in, denied the benefits of, or subjected to discrimination under any program or activity receiving federal funds. However, it would take five years of lobbying and protesting before the American Coalition of Citizens with Disabilities (ACCD) wins the release of regulations that allow Section 504 to be implemented.

The Act is in many ways the direct predecessor to the ADA. However, the primary focus is vocational training and rehabilitation, and over the next half-century, disability law and advocacy move from the medical (medical issues) and vocational (often a justification for welfare and benefits) models to a civil rights model, which seeks to remove the barriers that impede the full integration of people with disabilities into society.

1973 ◆ The term *mainstreaming* emerges within the educational jargon associated with the Education for All Handicapped Children Act (EHA), the early U.S. legislation subsequently reauthorized as the Individuals with Disabilities Act (IDEA) in 1990.

1973 ◆ Ronald Mace is the driving force behind the creation of the first accessible state building code in the United States (North Carolina, 1974) and in the drafting of national accessibility codes and

standards. He coins the term *universal design* to capture and promote his expanded philosophy of "design for all ages and abilities"—curb cuts being his favorite example.

1973 Washington D.C. introduces the first handicap parking stickers. The Federal-Aid Highway Act funds curb cuts.

1974 First Lady Betty Ford and investigative reporter Rose Kushner are diagnosed with breast cancer. They help break the public silence on this topic. In 1954, Terese Lasser begins Reach to Recovery, a program of volunteers who have previously undergone radical mastectomies who provide emotional support to hospitalized women who have just had the operation. Today, one in eight women is diagnosed with breast cancer during her lifetime.

1975 The Education for All Handicapped Children Act, the first separate federal legislation authorizing special education for children and youth, passes, due, in part, to the advocacy efforts of a group of parents. In 1990, it becomes known as the Individuals with Disabilities Education Act, or IDEA.

1975 The Developmentally Disabled Assistance and Bill of Rights Act, providing federal funds for programs that provide services for people with developmental disabilities, passes.

1975 The Association of Persons with Severe Handicaps (TASH) is founded. It calls for the end of aversive behavior modification and deinstitutionalization of people with disabilities.

1975 The UN General Assembly adopts the Declaration on the Rights of Disabled Persons, which states that all persons with disabilities have the same rights as other people. This document is not legally binding and can be attributed in part to a UN Ad Hoc Committee set up in 2001 to consider a Convention on the Rights of Disabled Persons that is legally binding.

1975 United Kindom: The Union of the Physically Impaired against Segregation (UPIAS) publishes a paper that redefines the term *disability,* which becomes known as the social model of disability as it radically transforms the way disabled people see themselves and their place in society.

1976 The Higher Education Act of 1965, which establishes grants for student support services aimed at fostering an institutional climate supportive of low-income and first-generation college students, is amended to include individuals with disabilities. In March 1978, the Association on Handicapped Student Service Programs in Post-Secondary Education is founded. It later becomes the Association on Higher Education and Disability (AHEAD).

1976 Sponsored by Ralph Nader's Center for the Study of Responsive Law, the Disability Rights Center is founded in Washington D.C.

1977 Protesting the federal government's delayed enactment of the rules and regulations for the implementation of the Rehabilitation Act of 1973, disabled activists on April 1 organize protests at the federal offices of the Department of Health and Human Services in various cities across the United States. In San Francisco, protesters hold the regional offices hostage for 28 days, gaining national attention and resulting in an agreement with federal officials for the rapid establishment of the rules and regulations to implement Section 504 of the Act.

1977 Max Cleland is appointed to head the U.S. Veterans Administration. He is the first severely disabled person to hold this post.

1977 S. Z. Nagi defines *disability* as an individual's performance of tasks and activities related to achievement of social roles—a distinct concept, different from *impairment*. It is further formalized with the introduction of the World Health Organization's International Classification of Impairments, Disabilities, and Handicaps in 1980 and further refined in 2001 in its International

Classification of Functioning, Disability, and Health. Nagi's model is used as the basis for the Americans with Disabilities Act, for almost all disability social policy in the United States, and for statistics at the United Nations and in Europe.

1978 ◆ The Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 and the Adoption Assistance and Child Welfare Act of 1980 promote the adoption of children with special needs, including disabilities.

1978 ◆ The Atlantis Community, the second independent living center in the country after Berkeley, is established in Denver, Colorado, in 1975. On July 5–6, 1978, twenty disabled activists from the Atlantis Community block buses with their wheelchairs and bodies and bring traffic to a standstill at a busy downtown intersection. This act of civil disobedience results in the American Disabled for Accessible Public Transit, the original name for the American Disabled for Attendant Programs Today, or ADAPT.

1978 ◆ Legislation creates the National Institute on Handicapped Research. In 1986, it is renamed the U.S. National Institute on Disability and Rehabilitation Research (NIDRR). Its mission is to contribute to the independence of persons of all ages who have disabilities. It is located in the Department of Education under the Office of Special Education and Rehabilitation Services.

1978 ◆ The World Health Organization starts to promote the concept of community-based rehabilitation (CBR) as a means of helping people with disabilities in the developing world. It emerges, in part, from the WHO primary health care campaign Health for All by the Year 2000. Around the same time, in Western countries, home-visiting programs in which a trained worker regularly visits the family to advise on ways of promoting child development become one of the success stories of modern disability services. Among the best-known programs are those based on a model originating in Portage, Wisconsin, and now used in many countries.

1978 ◆ England: The Warnock report introduces the term *special needs education.* It marks a major shift in organizing educational services for children with disabilities and results in the new conceptualization of special needs education. This change is confirmed internationally by the Salamanca Statement and Framework for Action on Special Needs Education at the UNESCO's Conference held in Salamanca in 1994. This theoretical shift is marked with the change of the term *integration* to *inclusion* or *inclusive education.*

1978 ◆ USSR: The Action Group to Defend the Rights of the Disabled is established to advocate for legal rights for Soviets with disabilities.

1979 ◆ The Disability Rights Education and Defense Fund (DREDF) establishes itself as a leading cross-disability civil rights law and policy center. It is founded by people with disabilities and parents of children with disabilities. Because its philosophy is closely aligned with other civil rights struggles, in 1981, DREDF is invited to join the executive committee of the national's largest coalition of civil rights groups, the Leadership Conference on Civil Rights. In 1987, DREDF establishes the Disability Rights Clinical Legal Education Program and begins teaching disability rights law at the University of California's Boalt Hall School of Law.

1979 ◆ The National Alliance for the Mentally Ill (NAMI) is founded. NAMI is an advocacy and education organization.

1979 ◆ Germany: The first Cripples' Group is founded as a cross-disability group with emancipatory aims. In an attempt to reinterpret disability in positive terms, the cofounders choose the term *Krüppel* over handicapped or disabled.

1979 ◆ Nicaragua: The Organization of the Revolutionary Disabled is set up in the wake of the Sandinista victory.

1980 ◆ The California Governor's Committee on Employment of People with Disabilities and entertainment and media industry professionals establish the Media Access Office (MAO).

1980 ◆ About the time Congress is considering passage of the ADA (1990), marketers begin to acknowledge the economic potential of the disabled community; consequently, the appearance of disabled characters in consumer goods advertising mushroom and ability-integrated advertising becomes much more commonplace. Organizations such as MAO and NOD (National Organization on Disability) provide advertising strategies and guidance.

1980 ◆ The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), an interdisciplinary association composed of individuals interested in technology and disability, is founded.

1980 ◆ The World Health Organization's International Classification of Impairments, Disabilities, and Handicaps (ICIDH), a groundbreaking, but controversial, classification system is tentatively released for trial purposes with the goal of uniform information collection worldwide. It has a negligible impact on disability statistics or data collection; however, researchers argue that it is a vast improvement over available tools. It is renamed and vastly revised in 2001.

1980 ◆ England: Graeae Theatre Group, composed of disabled actors, directors, and other theater professionals, is founded in London by Nabil Shaban and Richard Tomlinson. It takes its name from the the Graeae of Greek mythology, three gray-haired sisters who shared one eye and one tooth. Graeae's first production is *Sideshow*.

1980 ◆ Netherlands: The Liliane Foundation starts by assisting 14 children. In 2002, it helps 31,982 children spread over 80 countries. The Foundation's efforts are directed primarily toward children with disabilities living at home. Its aim is to have direct contact with the child within the home situation and to assist the personal growth and happiness of the child, thus providing "tailor-made" assistance.

1980 ◆ Taiwan: The Physically and Mentally Disabled Citizens Protection Law is promulgated. It guarantees legal rights for the disabled and creates a significant improvement in their welfare. Although most of the disabled people in Taiwan still struggle to earn their due respect, today, public awareness of this group is emerging gradually and significantly.

1980 ◆ United Kingdom and Europe: The Black Report (*Report of the Working Group on Inequalities in Health)* is published. Among other groups it targets disabled people for better conditions that lead to better health. The report does not find favor with the Conservative government, but begins to be implemented under the Labour government in 1997. With its central theme of equity, the report plays a central role in the shaping of the World Health Organization's Common Health Strategy of the European Region.

1981 ◆ The Reagan Administration begins to amend and revoke disability benefits, a policy that continues throughout his administration and leads several disabled people who are in despair over the loss of their benefits to commit suicide.

1981 ◆ Justin Dart, recognized as the founder of the Americans with Disabilities Act (ADA, 1990), is appointed to be vice-chair of the National Council on Disability. The council drafts a national policy on equal rights for disabled people; the document becomes the foundation of the ADA.

1981 ◆ The Committee on Personal Computers and the Handicapped is established in Illinois, an indicator of the disabled community's interest in information technology (IT) accessibility, but in order to stimulate the development of suitable products, activists lobby for legislative protections, which are included in the Americans with Disabilities Act of 1990. In 2000, a suit brought by the National Federation of the Blind against AOL is suspended when AOL agrees to make its software accessible by April 2001. The World Wide Web Accessibility Initiative (WAI) launches in 1997. It raises the level of awareness of disability accessibility issues within the Internet community, especially among those who design and implement web pages.

1981 ◆ The first reported cases of AIDS in the United States appear in June. Today, the World Health Organization estimates that worldwide, approximately 40 million people are living with HIV/AIDS; 22 million men, women, and children have died; and 14,000 new infections are contracted every day. Around the world, in the year 2003, the AIDS epidemic claims an estimated 3 million lives, and almost 5 million people acquire HIV, 700,000 of them children. Currently, 6 million people infected with HIV in the developing world are estimated to need access to antiretroviral therapy to survive, but only 400,000 have this access.

1981 ◆ Disabled Peoples' International (DPI) is officially founded at a meeting in Singapore. The establishment of such international organizations around this time represents the disability movement becoming a global social movement instead of a national one. DPI is directed by persons with disabilities working in human rights advocacy. It sponsors World Assemblies, which are held every four years to develop a multiyear action plan. The most recent one is held in 2002 in Sapporo, Japan, where delegates from more than 100 countries come together. A leading slogan for DPI and other disability groups, coined in the early 1990s, is "nothing about us without us."

1981 ◆ The International Year of Disabled Persons encourages governments to sponsor programs that assimilate people with disabilities into mainstream society. Despite the positive worldwide effects it has, the UN program also creates some angry activists with disabilities who protest against the charity approach officially adopted for the event. Consequently, the activists build their own infrastructure consisting of counseling and advocacy facilities as well as job creation programs.

1981 ◆ Australia: Australia's modern disability policy takes shape after the 1981 International Year of Disabled Persons. Examples: The 1980s see a shift away from institutional care; the Commonwealth Disability Service Act provides a framework for the provision of disability services; and in 1991, the federal Disability Reform Package maximizes the employment of disabled. In 1995, a legal decision represents a watershed in telecommunications policy for people with disabilities when a commission's inquiry finds the national carrier, Telstra, guilty of discrimination against people with severe hearing or speech impairments. The success of the action results in the Telecommunications Act of 1997, which includes new provisions for the deaf community.

1981 ◆ Mexico: The Program of Rehabilitation Organized by Disabled Youth of Western Mexico begins as a rural community-based rehabilitation program.

1981 ◆ Soweto: The Self Help Association of Paraplegics begins as an economic development project.

1981 ◆ United Kingdom: Disabled people set up the British Council of Disabled Persons (BCOPD), the United Kingdom's national organization of disabled people, to promote their full equality and participation in UK society.

1981 ◆ Zimbabwe: The National Council of Disabled Persons, initially registered as a welfare organization, becomes a national disability rights group.

1982 Disability Studies originates with the formation of the Society for the Study of Chronic Illness, Impairment, and Disability. In 1986, it officially changes its name to the Society for Disability Studies (SDS). Disability Studies is a critical field of study based in human and social science.

1982 *In re Infant Doe* (commonly known as the Baby Doe case) launches the debate as to whether parents or medical authorities should choose to let a disabled infant die rather than provide the necessary medical treatment and nourishment essential to sustain life. In response to this and other cases, the U.S. Department of Health and Human Services creates a rule maintaining it unlawful for any federally funded hospital to withhold medical treatment from disabled infants. In 1984, the U.S. Congress enacts the Child Abuse Amendments, which calls for the medical treatment of newborns with disabilities unless the child would die even with medical intervention. The issue makes it to the U.S. Supreme Court in 1986 with the *Bowen v. American Hospital Association* case. The Court holds that denying treatment to disabled infants does not constitute legally protected discrimination under Section 504 of the Rehabilitation Act and that hospitals and physicians are to implement the decision of the parents. The decision results in the passage of the Child Abuse Prevention and Treatment Act Amendments of 1984. In the year 2000, a scholar argues that the Amendments, presidential commission writings, and disability advocates “have all combined to ensure that most babies who can benefit from medical interventions do receive them.”

1982 Disability Awareness in Action (DAA) and other groups such as the Disabled Peoples’ International (DPI) and International Disability Alliance (IDA) are the driving force behind the globalization of disability issues through the World Program of Action (1982), the United Nations Standard Rules of Equalization of Opportunities for People with Disabilities (1993), the World Summit for Social Development (1995), and the Education for All Framework for Action (2000), as well as the current campaign to secure a UN convention on the rights of disabled people.

1982 The National Council on Independent Living (NCIL) is formed in the United States. It provides an excellent example of leadership for people with disabilities by people with disabilities.

1982 Canada: The Charter of Rights and Freedoms section of the Constitution provides protection to persons with disabilities.

1982 France: Handicap International is founded in Lyon. It is active in various areas associated with all the causes of handicaps, both traumatological (land mines, road accidents) and infectious (polio, leprosy). In the 1990s it begins working on mental disability issues as a result of experience with Romanian orphanages and the war in the Balkans. In 1992, Handicap International creates its first two mine clearance programs and in 1997 it is the joint winner of the Nobel Peace Prize for its leading role in the fight against landmines.

1983 Rights-based approaches to disability rapidly gain currency in many developing countries since the UN Decade of Disabled Persons, 1983–1992. UNESCAP’s Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-Based Society for People with Disabilities in Asia and the Pacific sets the priorities for the extended Decade of Disabled Persons, 2003–2012.

1983 Access and accessibility are concepts discussed throughout the World Programme of Action Concerning Disabled Persons passed by the UN General Assembly. The General Assembly in 1993 passes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

1983 England: The first Covent Garden Day of Disabled Artists is held in London.

1983 Thailand: DPI-Thailand is established.

1984 The Access Board issues the “Minimum Guidelines and Requirements for Accessible Design,” which today serves as the basis for enforceable design standards. The 1990 Americans with

Disabilities Act (ADA) expands the board's mandate to include developing the accessibility guidelines for facilities and transit vehicles. The Rehabilitation Act Amendments of 1998 give the Access Board additional responsibility for developing accessibility standards for electronic and information technology. In 2001, Section 508 of federal law establishes design standards for federal websites, making them accessible to individuals with disabilities.

1985 ◆ The U.S. Department of Health and Human Services issues the first comprehensive national minority health study, which shows racial disparity in health and concludes that the difference in mortality is not acceptable. In 1998, studies indicate that racial disparity has not improved as much as hoped; consequently, President Bill Clinton launches an initiative that sets a national goal of eliminating disparities in six key areas by the year 2010. Some of these areas include diseases and conditions considered to be disabling as well as life threatening.

1986 ◆ The Air Carrier Access Act (ACAA) passes. It requires the U.S. Department of Transportation to develop new regulations that ensure that disabled people are treated without discrimination in a way consistent with the safe carriage of all passengers. The relevant regulations, Air Carrier Access rules, are published in March 1990.

1986 ◆ The National Council on the Handicapped publishes its report *Toward Independence.* It recommends that "Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities" and suggests that the law be called "the Americans with Disabilities Act." In its 1988 follow-up report, *On the Threshold of Independence,* the council takes the somewhat unusual step of publishing its own draft of the ADA bill.

1986 ◆ The Equal Opportunities for Disabled Americans Act allows recipients of federal disability benefits to retain them even after they obtain work, thus removing a disincentive that keeps disabled people unemployed.

1986 ◆ Australia: The Disability Services Act provides that a person with disability has the right to achieve his or her individual capacity for physical, social, emotional, and intellectual development. In 1992, the Disability Discrimination Act supports nondiscrimination in education and training. It also makes it unlawful to discriminate in relation to access to premises, including public transportation.

1986 ◆ Canada: The Employment Equity Act mandates the institution of positive policies and practices to ensure that persons in designated groups, including persons with disabilities, achieve at least proportionate employment opportunities.

1986 ◆ England: The first issue of the magazine *Disability Arts in London* (DAIL) is produced in London.

1986 ◆ Southern Africa: The Southern Africa Federation of the Disabled is formed as a federation of nongovernmental organizations of disabled persons.

1988 ◆ The Technology Act (Technology-Related Assistance for Individuals with Disabilities Act of 1988 and its 1994 amendments), and, in 1998, the Assistive Technology Act (AT) provide financial assistance to states to support programs of technology-related assistance for individuals with disabilities of all ages. The1988 act defines *assistive technology* (AT). The Americans with Disabilities Act of 1990 prohibits discrimination against people with disabilities in employment, public institutions, commercial facilities, transportation, and telecommunications, which includes accessibility to all entrances, bathrooms, program areas, and parking spaces as well as interpreters for the deaf and Braille and large-print materials for the blind. The Telecommunications Act of 1996 requires the telecommunication industry to make equipment that will support transmission of information in forms accessible to people with disabilities including broadband and television program captioning. By 2000, approximately 10 percent of the U.S. population uses AT devices and/or modifications to their home, work, or school that allow them to participate in major life activities.

1988 Congress introduces a series of amendments to the Civil Rights Act of 1968, including a prohibition of housing discrimination against people with disabilities. These amendments are known as the Fair Housing Act Amendments of 1988.

1988 China: Deng Pufang, a wheelchair user and son of the late Chinese leader Deng Xiaoping, is the driving force behind a series of laws and programs initiated to improve life for the disabled. In 1984, he sets up the China Welfare Fund for Disabled Persons and, in 1988, the China Disabled Persons' Federation, which endeavors to improve public images of disabled people. Today, there are 60 million disabled people in China.

1989 The European Network on Independent Living (ENIL) is set up. It focuses on personal assistance as a key component of independent living.

1990 ADAPT, the American Disabled for Attendant Programs Today, originally called the American Disabled for Accessible Public Transit, continues to gain public awareness through tactics of civil disobedience until regulations are finally issued with the passage of the Americans with Disabilities Act (ADA).

The ADA passes, after ADAPT uses tactics of civil disobedience, in the tradition of other civil rights movements, in one of the largest disability rights protests to date (600 demonstrators), the "Wheels of Justice March," during which dozens of protesters throw themselves out of their wheelchairs and begin crawling up the 83 marble steps to the Capitol to deliver a scroll of the Declaration of Independence. The following day 150 ADAPT protesters lock wheelchairs together in the Capitol rotunda and engage in a sit-in until police carry them away one by one.

George H.W. Bush signs the ADA on July 26. It provides employment protections for qualifying persons with disability. It is the most prominent and comprehensive law prohibiting discrimination on the basis of disability in the United States, expanding the mandate of Section 504 of the Rehabilitation Act of 1973 to eliminate discrimination by prohibiting discrimination in employment, housing, public accommodations, education, and public services.

In June 2000, the National Council on Disability issues a report, *Promises to Keep: A decade of Federal Enforcement of the Americans with Disabilities Act,* which includes 104 specific recommendations for improvements to the ADA enforcement effort. On December 1, 2004, the council issues a final summary report, *Righting the ADA,* in order to address "a series of negative court decisions [that] is returning [Americans with disabilities] to 'second-class citizen' status that the Americans with Disabilities Act was supposed to remedy forever."

1990 The ADA requires public entities and businesses to provide effective communication to individuals with disabilities. Title IV of the ADA mandates that nationwide telecommunication systems be accessible to persons with speech or hearing disabilities. The Federal Communications Commission (FCC) requires relay services to be in place by July 26, 1993. The Telecommunications Act of 1996 adds provisions to the Communications Act of 1934 that requires manufactures and providers of telecommunications equipment and services to ensure accessibility to persons with disabilities. In 2000, President Bill Clinton establishes regulations governing the accessibility to people with disabilities of the electronic and information technology used within the federal government.

1990 The Individuals with Disabilities Education Act (IDEA) is enacted. It guarantees the right to free and appropriate education for children and youth with disabilities and focuses on higher expectations, mainstreaming students where possible, and an increased federal rule in ensuring equal educational opportunity for all students. IDEA requires schools to provide a free and appropriate public education to eligible children with disabilities. It also requires schools to develop an individualized education plan (IEP) for each child and placement in the least restrictive environment (LRE) for their education. IDEA is amended in 1997 and reauthorized again in 2004 as the Individuals with Disabilities Education Improvement Act.

1990 ◆ Legislation establishes the National Center for Medical Rehabilitation Research (NCMRR), whose mission is to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of persons with disabilities. It has primary responsibility for the U.S. Government's medical rehabilitation research that is supported by the National Institutes of Health (NIH).

1990 ◆ The World Declaration on Education for All (EFA) is adopted in Jomtien, Thailand, by more than 1,500 persons representing the international community. Article 23 of the UN Convention on the Rights of the Child states that disabled children have the right to a "full and decent life" and that member nations provide free education and training to disabled children whenever possible in order to provide the "fullest possible social integration and individual development." UNESCO is the lead UN organization for special needs education.

1990 ◆ Korea: The disability movement celebrates the passage of the Employment Promotion Act for People with Disabilities. The government imposes control over the disabled population in the 1960s and 1970s by forwarding institutionalization under the banner of "protection," promoting sterilization, and violating the rights of disabled people in general. The 1981 International Year of Disabled Persons influences the government, and new laws, such as the Welfare Law for Mentally and Physically Handicapped, are enacted, and the human rights of disabled people becomes the dominant rhetoric of the disability movement.

1990 ◆ United Kingdom: The National Disability Arts Forum is launched at the UK-OK Conference at Beaumont College in Lancashire, UK.

1991 ◆ The Resolution on Personal Assistance Services is passed at the International Personal Assistance Symposium. Personal assistance services are the most critical services for individuals. Critical aspects of these services are that they must be available up to 24 hours a day, 7 days a week, to people of all ages, and with access to governmental payments. In the United States alone, personal assistance services affect the lives of more than 9.6 million citizens with disabilities.

1991 ◆ Australia: The federal Disability Reform Package is introduced; the Disability Discrimination Act, which covers issues of discrimination in education, is enacted in 1992; and the Commonwealth Disability Strategy, designed to provide equal access to government services for people with disabilities, is first introduced in 1994 and then revised in 2000. During the 1990s similar discrimination legislation emerges in other countries, such as New Zealand's Human Rights Act, the U.K.'s Disability Discrimination Act, Israel's Disabled Persons Act, Canada's Human Rights Act, and India's Disabled Person's Act.

1991 ◆ China: The most important laws and initiatives reside in the 1991 Law on Protection of Disabled Persons and a series of National Work Programs for Disabled Persons (1988, 1991, 1996, 2001), which integrate disability into the government's Five-Year Plans. China participates heavily in the United Nations Decade of Disabled Persons, 1983–1992, and initiates the Asia Pacific Decade of the Disabled Persons, 1993–2002. China continues to collaborate with UN projects involving the disabled and will host the 2007 International Special Olympics in Shanghai.

1991 ◆ Serbia and Montenegro: From the 1960s to the 1980s, post–World War II Yugoslavia is lauded for being a socially advanced nonaligned nation, but the contemporary wars that decimate Yugoslavia begin in 1991, and today there are more than one million disabled citizens, refugees, and casualties due to the wars. Disabled people in Serbia and Montenegro (formally named the Federal Republic of Yugoslavia—FRY) are left with shattered pieces of the spent past with little hope for the near future. Although the FRY constitution prescribes special protection of disabled persons in accordance with legal provisions and Serbia is party to numerous UN documents and acts, a disabled expert in 2004 admits that discrimination against persons with disability in Serbia and Montenegro is a

long-term problem that people without disability tend to ignore. Two of the most effective advocacy groups making in-roads today are the Association of Students with Disabilities and the Center for Independent Living in Belgrade.

1992 ◆ The UN Economic and Social Commission of Asia and the Pacific (ESCAP) proclaims a 10-year program known as the Asian and Pacific Decade of Disabled Persons 1993–2002 with goals of full participation and equality for persons with disabilities.

1993 ◆ The United Nations publishes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which becomes the international legal standards for disability programs, laws, and policies. Although not legally enforceable this instrument sets an inclusive and antidiscriminatory standard that is used when national policies are developed. It marks a clear shift from the rehabilitation and prevention paradigm to the human rights perspective on disability.

1993 ◆ Slovak Republic: The Czech and Slovak Republics separate into two independent countries. They both join the European Union in 2004. In Slovakia, a large number of highly innovative and resourceful grassroots nongovernmental organizations emerge to address the human rights, quality-of-life, and independent living priorities of citizens with disabilities. They pursue this mission, however, with extremely limited resources and with varying degrees of support from a multiparty parliament.

1993 ◆ Sweden: The Independent Living Institute (ILI) is founded.

1994 ◆ Two networks, one for elderly persons and the other for persons with disabilities, join together to form the U.S. National Coalition on Aging and Disability. In following years, policy makers and advocates begin to see the benefits of merging some services.

1994 ◆ Germany: The disability rights movement is successful in using for its own aims the reform of the German constitution, which is made necessary by the reunification process. An amendment to the constitution forbids discrimination on the grounds of disability. Other such laws as the Rehabilitation of Participation Law (2001) and the Federal Equal Rights Law (2002) are formulated with the active contribution of disability rights activists, and in 2003, the official German program of the European Year of People with Disabilities is organized by a prominent activist.

1994 ◆ Sweden: The Swedish Disability Act (LSS) comes into force. It expands the 1985 Special Services Act. The LSS is also more ambitious than its predecessor, calling for "good living conditions" rather than just an "acceptable standard of living."

1995 ◆ The National Council on Disability, a federal agency, makes recommendations to the president and Congress on disability issues. Among other issues, it calls for the end to the use of aversives (techniques of behavior control such as restraints, isolation, and electric shocks) because they are abusive, dehumanizing, and psychologically and physically dangerous. Other organizations follow, such as the Autism National Committee in 1999, TASH in 2004, and the International Association for the Right to Effective Treatment in 2003.

1995 ◆ The Commission for Case Management Certification (CCMC) incorporates. Case management is a process of care planning and coordination of the services and resources used by people with disabilities and their families.

1995 ◆ Europe: The Association for the Advancement of Assistive Technology in Europe (AAATE) is founded as an interdisciplinary association devoted to increasing awareness, promoting research and development, and facilitating the exchange of information. AAATE is composed of more than 250 members from 19 countries. It interacts with sister organizations in North America, Japan, and Australia to advance assistive technology worldwide. The Tokushima Agreement, signed in 2000 by AAATE, the Rehabilitation Engineering and Assistive Technology Society of North America

(RESNA), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation and Assistive Technology Association (ARATA), promotes exchange of information and collaboration.

1995 ◆ United Kingdom: The campaign for antidiscrimination legislation begins in earnest with the emergence of the disability movement in the late 1970s. The Disability Discrimination Act of 1995 (DDA) together with the Disability Rights Commission Act of 1999 constitute the primary source of antidiscrimination legislation for disabled people in the United Kingdom. The Disability Discrimination Act 2005 extends the protection.

1996 ◆ There are 1.4 million fewer disabled older persons in the United States than would have been expected if the health status of older people had not improved since the early 1980s.

1996 ◆ Advocates for mental health parity such as the National Alliance for the Mentally Ill (NAMI; 1979) believe that mental illnesses are real illnesses and that health insurance and health plan coverage for treatment should be equal with coverage of treatment for all other illnesses. Due in part to advocacy, the Mental Health Parity Act becomes law in 1996. In 1999, mental illness ranks first in causing disabilities among many industrialized nations, including the United States, which experiences a loss of productivity in this year of $63 billion. In the United States, 5 to 7 percent of adults suffer from serious mental disorders and 5 to 9 percent of children suffer from serious emotional disturbances that severely disrupt their social, academic, and emotional functioning.

1996 ◆ Costa Rica: Approval of a law called Equal Opportunities for People with Disabilities is a turning point for the population with disabilities, which is among the most excluded sectors of society. The law is inspired in part by the United Nations Standard Rules on the Equalization of Opportunities for Disabled People (1993). Disability experience in Costa Rica is definitely transformed as a result of the mandates of this generic law, as people with disabilities and their families start to use this legal instrument as a strategy to empower themselves.

1996 ◆ Europe: Created in 1996, the European Disability Forum (EDF) is today the largest independent, trans-European organization that exists to represent disabled people in dialogue with the European Union (EU) and other European authorities. Its mission is to promote equal opportunities for disabled people and to ensure disabled citizens full access to fundamental and human rights through its active involvement in policy development and implementation in the EU. The EDF has national councils in 17 European countries and has 127 member organizations. The European Year of People with Disabilities 2003 is one of the EDF's most important campaigns.

1996 ◆ India: The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, becomes law. It is the first legislation for equal opportunities for disabled people. Prior to this, disabled persons receive services but not legal protection. Improvements in conditions begin in 1981 with the International Year of Disabled Persons. India is a signatory to the UN resolution of 1976 establishing it and is thereby committed to improving the lot of the disabled. The Lunacy Act of 1912 is repealed and the National Mental Health Act is passed in 1987. Nonetheless, with approximately 70 million disabled people residing in India (in a population of over a billion), the government does not include the domain of disability in the 2001 census, which reflects the attitudinal barriers in acknowledging the disabled identity.

1997 ◆ Government expenditures on behalf of persons with disabilities may total as much as $217.3 billion (taking into account the costs that would be expected among persons with disabilities in the absence of the disability), the equivalent of 2.6 percent of the gross domestic product in the United States for 1997.

1997 ◆ The landmark 1997 UNESCO Universal Declaration on the Human Genome and Human Rights frames the actual application of the new scientific developments raised by genetics. As a policy

statement, it provides the first signs that genetics will be applied in ways that maintain human rights. In 2003, the Council of Europe and the council's Steering Committee in Bioethics issue policy statements in a working document titled Application of Genetics for Health Purposes. In the case of gene therapy, in 1994, the Group of Advisors on the Ethical Implications of Biotechnology of the European Commission voices concern regarding equity, maintaining that all genetic services that are available for the entire population should be equally available for persons of disability. Today, UNESCO's Human Genome Organization's Ethics Committee, the World Health Organization, the Council of Europe, and consumer organizations such as Inclusion International, Rehabilitation International, and Disabled Peoples' International play major roles in translating genetic innovations into health service and public health fields, helping develop policies that focus on the general recognition, respect, and protection of the rights to which all people, whether disabled or nondisabled, are entitled. Concerns related to the possible undermining of human rights are expressed in 2003 when Disabled People's International demands a prohibition on compulsory genetic testing.

1997 Colombia: The General Act for People with Disabilities, also known as the Disability Act: Law for Opportunity, passes. The 2003–2006 National Plan of Attention to Persons with Disabilities estimates that 18 percent of the general population has some type of disability. Despite the existence of at least 37 disability-related legal policies (2001), the government provides limited spending on programs that protect the rights of people with disabilities, and the lack of enforcement of rights remains a major concern. Today's awareness efforts include marathons with the participation of the general population to raise money for educational programs for children with special needs, Special Olympics, new organizations such as the Colombian Association for the Development of People with Disabilities, and media awareness campaigns.

1998 President Bill Clinton issues an executive order ensuring that the federal government assumes the role of a model employer of adults with disabilities.

1998 President Clinton signs into law the Rehabilitation Act of 1973 Amendments. Section 508 requires that electronic and information technology (EIT), such as federal websites, telecommunications, software, and information kiosks, must be usable by persons with disabilities.

1998 Ireland: The Irish Employment Equality Act entitles all individuals, including disabled persons, equal treatment in training and employment opportunities. The Education Act of 1998 requires schools to provide education to students that is appropriate to their abilities and needs. The Education for Persons with Disabilities Bill passes in 2003. A Disability Bill published in 2001 fails to underpin a rights-based approach and is withdrawn amid a storm of protest in 2002; a redrafting of a new Disability Bill is suffering from continuing delays. Traditionally, Irish voluntary organizations play a reactionary role in the development of services for people with disabilities and a key role as pressure groups trying to keep disability issues on the political agenda.

1999 The National Center on Physical Activity and Disability (NCPAD) is established as an information and resource center that offers people with disabilities, caregivers, and professionals the latest information on fitness, recreation, and sports programs for people with disabilities.

1999 Established by a panel of experts brought together to evaluate the UN Standard Rules on the Equalization of Opportunities for Persons with Disability, the International Disability Alliance (IDA) encourages cross-disability collaboration and supports the participation of international disability organizations in the elaboration of a proposed UN convention on disability.

1999 England: The first disability film festival, Lifting the Lid, is held at the Lux Cinema in London.

2000 ◆ The National Telability Media Center collects documentation of 3,000+ newsletters, 200 magazines, 50 newspapers, 40 radio programs, and 40 television programs dedicated to disability in the United States alone. *The Ragged Edge, Mainstream* (Internet-based), and *Mouth* are examples of disability rights-focused publications.

2000 ◆ *Healthy People 2000,* the second edition of the Surgeon General's report on health promotion and disease prevention (the first edition published in 1979), includes some reference to the health and well-being of people with disabilities, but few data are available. In the mid-1990s, the U.S. Department of Health and Human Services begins a dialogue with the Centers for Disease Control and Prevention to include people with disabilities in the third edition, *Healthy People 2010.* The resulting report includes more than 100 objectives that include "people with disabilities" as a subpopulation for data gathering.

2000 ◆ The World Bank, increasingly concerned with how to include disabled persons in the economies and societies of developing nations, establishes an online clearinghouse to make documents concerning the disabled readily available to member nations and the general public and holds its first course on disability issues in 2004 in Guatemala.

2000 ◆ Africa: The African Decade of Persons with Disabilities, 2000–2009, is adopted by the Declaration of the Organization of African Unity. The African Network of Women with Disabilities (2001) and the community-based rehabilitation organization CBR Africa Network (CAN) are examples of the many activities that result from the African Decade.

2000 ◆ Brazil is one of the few countries to include an entire section on disability in its 2000 census. Results show that 14.5 percent of the population, roughly 24 million people, report having some form of disability, the poorest region, the northeast, reporting the highest percentage and the richest, in the south, the lowest. People with disabilities in the first half of the twentieth century have no voice or representation. In 1932, the first Pestalozzi Society, a community-based school for children with intellectual disabilities, is founded. By the end of the twentieth century, there are 146 Pestalozzi Societies and more than 1,700 chapters of the Association of Parents and Friends of the Exceptional. The first center for independent living is established in 1988 (CVI-RIO). In 1992 and 1995, CVI-RIO organizes two international conferences on disability issues called DefRio, out of which comes "Goals of the ILM," a document that delineates the basis for the independent living movement in Brazil; however, financial support is not provided by the government, creating a struggle for sustainability. Brazil has progressive policies toward disability. The constitution includes sections on the rights of people with disabilities, and laws have been passed with regard to accessibility, education, and employment.

2000 ◆ Europe: A European Community directive requires all member states to have introduced antidiscrimination laws in the fields of employment and training by the end of 2006. It seeks to establish a general framework for equal treatment in employment and occupation and to render unlawful discrimination based on, among other categories, disability. The European Union Charter of Fundamental Rights sets out in a single text, for the first time in the EU's history, the whole range of civil, political, economic, and social rights of European citizens. Disability is included in the general nondiscrimination clause (Article 21), but Article 26 specifically states that the Union recognizes and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community.

2000 ◆ The Human Genome Project (HGP), an international effort to specify the 3 billion pairs of genes that make up the DNA sequence of the entire human genome, produces its first draft in June 2000. Formally begun in October 1990, it is completed in 2003.

2001 President Clinton declares in Executive Order No. 13217 the commitment of the United States to community-based alternatives for individuals with disabilities. This ensures that the *Olmstead v. L.C.* decision (1999), which mandates the right for persons with disability to live in the least-restrictive setting with reasonable accommodations, is implemented in a timely manner. The executive order directs federal agencies to work together to tear down the barriers to community living.

2001 In the United States, census data indicate that only 48 percent of citizens 25 to 64 years old with severe disabilities have health insurance compared with 80 percent of individuals with nonservere disabilities and 82 percent of nondisabled Americans. Women with disabilities in general are more likely to live in poverty than men. Minorities with disabilities are more likely to live in poverty than nonminorities with disabilities. In 2003, in the United States, about 28 percent of children with disabilities live in poor families compared with 16 percent of all children.

2001 A UN Ad Hoc Committee begins discussions for a legally binding convention under the draft title Comprehensive and Integral Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Its fifth session is held in early 2005.

2001 A new World Health Organization classification of people with disabilities, the International Classification of Functioning, Disability, and Health (ICF), replaces the old International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The ICF definition shifts the focus from disability as an innate deficit (“medical model”) to disability as constructed through the interaction between the individual and the environment (“social model”). This shift encourages a focus on the kinds and levels of interventions appropriate to the needs of individuals.

2001 UNESCO launches pilot education projects for disabled children in Cameroon, the Dominican Republic, Egypt, Ghana, India, Madagascar, Mauritius, Nicaragua, Paraguay, South Africa, Vietnam, and Yemen. The global initiative Education for All 2000 has as its primary millennium development goal universal education by the year 2015.

2002 The U.S. Supreme Court rules that executing persons with mental retardation is unconstitutional.

2002 Disabled Peoples’ International’s 2002 Sapporo Platform, developed by 3,000 delegates from more than 90 countries, urges members to take every opportunity to seek publicity and awareness in order to change negative images of disabled people.

2002 Canada: The Canadian International Development Bank announces the approval of the Canada-Russia Disability Program, a four-year $4 million project, focusing on education, disability studies, social work practice, social policy, and information dissemination.

2003 A national survey that updates the Disability Supplement to the 10-year-old National Health Interview Survey highlights barriers to care among the uninsured. The uninsured are four times as likely to postpone care and three times as likely to go without needed supplies.

2003 The National Association of Social Workers (NASW) issues a policy statement that discusses their core values with respect to working with people with disabilities, including self-determination, social justice, and dignity and worth of the person. The statement emphasizes that social workers are responsible to take action with people who have disabilities in advocating for their rights to fully participate in society.

2003 The Disability Awareness in Action (DAA) database contains a total of 1,910 reports of known abuse affecting nearly 2.5 million disabled people. In the area of education alone, it documents

118 cases affecting 768,205 people in 67 countries. Responding to this documentation and other reports, the United Nations Commission on Human Rights creates the Global Rights campaign to address human rights abuses. Disability rights organizations use this information to insist on a UN convention on the rights of disabled people that would be legally binding on nation-states.

2003 The International Association for the Study of Pain has more than 6,700 members, representing more than 100 countries and 60 disciplinary fields. Chronic pain is one of the leading causes of recurrent and permanent disability in the developed world today, yet less than 1 percent of the U.S. National Institutes of Health's budget supports research into mechanisms and management of pain. The U.S. Congress declares 2000–2010 the Decade of Pain Control and Research.

2004 The *Journal of Gene Medicine* (January) reports that 636 gene therapy clinical trials are completed or ongoing, involving 3,496 patients. The first gene therapy clinical trials begin in the early 1990s.

Today Seventy to eighty percent—approximately 400 million—of the world's disabled people (600 million, or 10 percent of the world's population) live in the developing world, and of the world's poorest of the poor, 20 to 25 percent are disabled. In most countries, 1 out of 10 persons has a disability. Many international efforts are under way to address poverty and disability, such as those of the Action on Disability Development and the Chronic Poverty Research Centre.

Today E-health is the use of emerging interactive telecommunications technologies such as the Internet, interactive TV, kiosks, personal digital assistants, CD-ROMs, and DVD-ROMs to facilitate health improvement and health care services, including those with disabilities. E-health relies on environments that use a variety of technologies that can compensate for the lack of sensory ability. Telerehabilitation is an example of services delivered information technology and telecommunication networks.

Today Celebrating difference is the mantra and visible manifestation of disability culture in all regions of the world.

SEARCHING FOR AND EVALUATING WEBSITES

Anne Armstrong

The Internet, or Web, provides a vast number of channels through which researchers can find information on virtually any subject. The expansiveness of the Web can be daunting to new researchers. On the other hand, researchers often assume that they have mastered the Web in its entirety when indeed they have merely scratched the surface in terms of the numbers of resources they have consulted and searches they have performed.

Because the field of disability studies is continually evolving and inherently multidisciplinary, Web searchers can draw on previously conducted research from disciplines within the humanities, social sciences, and health sciences. This guide aims to expose beginning researchers to a mixture of general and subject-specialized Web-based search tools, as well as strategies for performing sophisticated Web searches and criteria for evaluating websites. In addition to its broad subject coverage, the field of disability studies differs from most fields in that many researchers may themselves have disabilities affecting their ability to perform research on the Web. For this reason, this description concludes with an overview of accessibility issues on the Web and suggestions for further reading.

OVERVIEW OF WEB-BASED RESEARCH TOOLS

When approaching Web searching, researchers should be aware of the multitude of search tools available to them, in addition to the varying purposes of these tools. Many users approach Web searching with the assumption that "everything is in Google," but this is a limiting misconception. No single search engine contains everything on the Web. Furthermore, all search engines function differently and rank results differently. Therefore, sampling various search tools increases the comprehensiveness of results on any topic. This discussion outlines multiple types of search tools available on the Web and offers potential starting points for Internet research on issues related to disability studies, whether from a health sciences, social sciences, or humanities perspective.

The Web-based search tools outlined in this chapter include general search engines, subject-specialized search engines, directories, indexes, catalogs, and Listservs. It is important to note that different types of search tools cover different parts of the Web. The Web is composed of layers. The top layer is detectible by general search engines, while a deeper layer termed "the invisible Web" can be penetrated only by specialized search engines, indexes, and catalogs. Readers should be aware that because the Web is in a constant state of flux, currently available resources may become obsolete over time, and newer, more sophisticated search tools will undoubtedly evolve.

General Search Engines

Most people who have searched the Web are familiar with sites such as Google, HotBot, or Lycos, which allow them to enter a string of keywords into a search box to retrieve a list of relevant websites (see Table 1). These sites, referred to as search engines, search the Web by means of a program called a *spider* (also

Table 1 Selected General Search Engines

Name	*URL*
AltaVista	www.altavista.com
Excite	www.excite.com
GO	www.go.com
Google	www.google.com
HotBot	www.hotbot.com
Lycos	www.lycos.com
Yahoo!	www.yahoo.com

called a *robot* or *crawler*). Since search engines tend to index millions of websites, they are most useful for entering specific search terms rather than broad concepts such as disability studies.

While Web searchers tend to pick a favorite search engine and return to it repeatedly, it is important to note that different search engines produce varying results, and that a truly comprehensive Web searcher should compare the results of multiple search engines. The variation between search engines can be attributed to differences between the spiders fueling the search engines as well as differences in the level of indexing and the order in which results are ranked. While some search engines index the full text of documents, others may index only the first page, or merely the *meta-tags*, which are lines of code containing keywords. Web searchers should be aware that developers of websites may intentionally increase their usage of certain words or meta-tags to increase the prominence of their website among search results. This practice has been referred to as *spamdexing* and is most prevalent among the developers of commercial websites advertising products and services. Due to the constant fluctuation of the Web, no search engine is entirely up-to-date; results produced by identical searches can vary greatly from one day to the next, even when one is using the same search engine.

Table 2 Examples of Subject-Specialized Search Engines

Name	*URL*	*Subject Coverage*
Center for International Rehabilitation Research Information and Exchange (CIRRIE)	http://cirrie.buffalo.edu	Rehabilitation research
FamilyDoctor.org	http://familydoctor.org	Health sciences
FirstGov	www.firstgov.gov	Government
Google's Uncle Sam	www.google.com/unclesam	Government
Health*Web*	www.healthweb.org	Health sciences
Mayo Clinic	www.mayoclinic.com	Health sciences
MedlinePlus	http://medlineplus.gov	Health sciences
National Center for the Dissemination of Disability Research (NCDDR)	www.ncddr.org	Disability studies
Social Science Information Gateway (SOSIG)	www.sosig.ac.uk	Social sciences
Thomas	http://thomas.loc.gov/	Legislative information
Voice of the Shuttle	http://vos.ucsb.edu	Humanities
*Web*MD	www.webmd.com	Health Sciences

Subject-Specialized Search Engines

Subject-specialized search engines (also referred to as subject portals) developed by educational institutions, associations, government agencies, and corporate entities narrow the broad scope of the Web, providing a focused channel by which researchers can search for information when they have determined the discipline from which their topic stems. Examples of such search engines are listed in Table 2. While subject-specialized search engines index considerably fewer websites and documents than general search engines, the information contained within them has been preselected, ideally by experts within a given field. Many subject-specialized search engines expose searchers to parts of the "invisible Web" not indexed by general search engines. Subject-specialized search engines can ease the research process by whittling down the Web to a more manageable size. However, researchers who use them should take the time to view the criteria for selection of

information contained within them. This information is usually posted within online "help" or "about" pages on the home page.

Table 3 contains search tools that have been developed distinctly for the purpose of locating specialized search engines by subject.

Table 3 Resources for Finding Subject-Specialized Search Engines

Name	*URL*
CompletePlanet	www.completeplanet.com
Direct Search	www.freepint.com/gary/direct.htm
InfoMine	www.infomine.com
Invisible Web Directory	www.invisible-web.net
Librarians' Index to the Internet	www.lii.org
Search Engine Colossus	www.searchenginecolossus.com

Directories

Directories are hierarchically arranged subject guides composed of websites chosen by or recommended to editors of the directory (Table 4). Usually, directories follow a template in which major subject categories such as health, sciences, social sciences, or humanities are posted on the top-level page. Each of these links leads to lists of narrower subcategories. The links on the second level lead to narrower subcategories, and so on. A sample hierarchy from the directory created by Google (available at http://directory.google.com) lists the following subject breakdown: Society → Disabled → Disability studies.

Directories provide Web searchers with the ability to browse recommended resources in various subject areas without having to enter specific search terms. Other useful attributes of directories are that they often contain summaries and evaluations of websites.

Table 4 Selected Directories

Name	*URL*
eBlast	www.eblast.com
Google Directory[a]	http://directory.google.com
Internet Public Library	www.ipl.org
LookSmart	www.looksmart.com
Yahoo! Directory[a]	www.yahoo.com

a. These sites contain both directories and general search engines.

Article Indexes

Article indexes allow researchers to search by topic for published articles in magazines and scholarly journals. Researchers could certainly locate journal and magazine articles using a freely available search engine such as Google, but they would merely be skimming the surface of what has been published. While the Web provides access to *more* content, it does not provide comprehensive access to research published in journal articles. Article indexes are for the expressed purpose of finding journal articles. With a few exceptions (such as PubMed, an article index of health sciences journals developed and maintained by the National Library of Medicine), article indexes are not freely available on the Web. Libraries purchase subscriptions to multiple article indexes covering a wide spectrum of disciplines. The indexes available through a given library are often dictated by the curriculum of the college or university that the library serves. Thus, large research institutions offer a greater number of specialized article indexes than smaller institutions and public libraries. Due to licensing agreements between article index providers and libraries, off-site access to indexes is usually limited to faculty and students of a college or university. However, there are many libraries that allow members of the public to use their article indexes from within the library. A local public library would be a good starting place for those not connected with academic or commercial organizations.

Since article indexes are proprietary products developed by companies for sale to libraries, they tend to offer specialized search features that are not always available on freely available search engines. These features include subject headings, thesauri, abstracts (summaries of articles), and frequently the full text of articles. Researchers should familiarize themselves with online tutorials, "help" screens, and "about" pages to increase the effectiveness of their searching.

Freely available article indexes relevant to disability studies include the following:

- PubMed: A product of the National Library of Medicine, which includes more than 14 million citations for biomedical articles dating back to the 1950s. URL: http://www.ncbi.nlm.nih.gov/entrez

- CIRRIE: Center for International Rehabilitation Research Information and Exchange, a database containing more than 24,000 citations of international research published from 1990 to the present. URL: http://cirrie.buffalo.edu

Catalogs

While researchers can search indexes to find articles on specific topics, they can search online catalogs to find books. Some catalogs list the books available at individual libraries, while others contain the holdings of multiple libraries and institutions. The individual catalogs of public libraries and universities are usually freely available on the Web. The most comprehensive catalog is called WorldCat, developed by an organization called OCLC (Online Computer Library Center). WorldCat lists books available at public and academic libraries throughout the world. Like most article indexes, WorldCat is not freely available on the Web and must be accessed through a library.

Listservs

Listservs are mailing lists on the Internet that facilitate online discussions on various subjects. They allow researchers within a given field to communicate about scholarly issues via email. People customarily sign up for Listservs by sending an e-mail to the Listserv address stating that they wish to subscribe. Several Listservs related to disability studies are listed in Table 5. In addition, Web searchers can perform a search on a database called tile.net to search for Listservs by topic.

SEARCH STRATEGIES

Since search capabilities vary from site to site, Web searchers should use online "help" screens and tutorials to learn search tips and strategies for improving their search results. Some search techniques common to several Web-based search tools are summarized below.

Quotation Marks

When entering a search, users should enter phrases in quotation marks to stipulate that they would like the results to contain a specific word combination and order. For instance, multiword concepts such as "disability studies," "adaptive technology," and "section 508" should be entered within quotation marks. Proper names can also be entered within quotation marks.

Table 5 Disability Studies Listservs

Name	*URL*
ADA-LAW	http://listserv.nodak.edu/archives/ada-law.html
Disability-Research Discussion List	http://www.leeds.ac.uk/disability-studies/discuss.htm
Disability Studies at Yahoo.com	http://www.groups.yahoo.com/group/disabilitystudies
Disabled Student Services in Higher Education (DSSHE-L)	http://listserv.acsu.buffalo.edu/archives/dsshe-l.html
Women's International Linkage on Disability (D-WILD)	http://groups.yahoo.com/group/d-wild

Truncation

Truncation symbols allow Web searchers to simultaneously search for multiple endings of a given word. For instance, assuming that the asterisk is the designated truncation symbol in a search engine, entering the word "impair*" would produce results including all forms of the word after the root, including "impair," "impaired," "impairment" and "impairments." In addition to adding truncation symbols to the end of words, users may also insert internal truncation symbols if there are potential variations for the spelling of the middle of a word. For instance, entering the word "colo*r" would simultaneously search for the words "color" and "colour." "Help" screens or "search tips" usually list the designated truncation symbol for a given database.

Boolean Logic

Developed by the English mathematician George Boole, Boolean logic is a mathematical framework that Web searchers can apply to broaden or refine their searches. There are three words, or *operators*, that Web searchers can use to combine their keywords to perform more complex searches: AND, OR, and NOT. The three Boolean operators are summarized below, along with potential applications. It is important to read the online "help" section of a database before performing a Boolean search, as Boolean searching does not work in all databases.

Using the Boolean Operator "AND"

Combining words with "AND" narrows a search, as the database retrieves only items that contain *all* the words entered. The second search example below will produce fewer results than the first, since there are three keywords that must appear within the content of each result.

"disability studies" AND theory
"disability studies" AND theory AND history

Using the Boolean Operator "OR"

Entering the term "OR" between keywords stipulates that any, but not all, of the words entered must appear within the search results. Using "OR" is a way of searching for synonyms or related terms when there are multiple words for the same concept. The example below shows how you could broaden your search if you wanted to search for multiple adaptive technology applications in a search engine. The second search example will potentially produce more results than the first, since there is an additional keyword that the results could include.

JAWS OR "Ruby OpenBook"
JAWS OR "Ruby OpenBook" or "window eyes"

Using the Boolean Operator "NOT"

Entering the Boolean operator "NOT" after a word stipulates that the word should not appear within the results. Using "NOT" in a search can be particularly useful if a word is frequently used in multiple contexts and you wish to eliminate results dealing with a particular topic. In the example below, the second search will ideally eliminate items relating to the state of New Mexico, given that the researcher is looking for information on legislation related to disabilities in the country of Mexico. The use of NOT can be too limiting. The second search would eliminate results that discussed both Mexico and New Mexico.

Disabilities AND legislation AND Mexico
Disabilities AND legislation AND Mexico NOT "new mexico"

Nesting

Nesting allows Web searchers to simultaneously search for multiple search terms relating to the same topic. The grouping of synonymous terms within parenthesis is referred to as nesting, as multiple terms relating to the same idea are clustered together as a single concept. When using nesting, the words within the parenthesis are connected by the Boolean operator "OR."

To find information about software for people who are visually impaired, search results are increased by using nesting to group multiple words for each facet of the topic:

(software or "adaptive technology") AND ("visually impaired" or blind)

Plus and Minus Signs

Most general search engines allow users to enter plus or minus signs before a particular word. Entering a plus sign before a word (e.g., +ADA) stipulates that the word must appear within the search results. A minus sign before a word (e.g.,–mobility) stipulates that the word should not appear within the results. Since some search engines also use plus and minus signs as substitutes for Boolean operators, it is important to view online "help" or "search tips."

Search Limits

Most search engines allow users to limit their results by date, language, or document type. Limiting capabilities vary from site to site and are customarily outlined in online "help" screens. In general, article indexes have more sophisticated limiting capabilities than search engines that are freely available on the Web.

EVALUATING WEBSITES

A researcher weighing the quality of a journal article faces a lesser challenge than a researcher considering a website as a potential resource. The publishing industry applies labels to periodicals of varying type: Scholarly journals, popular magazines, trade publications, and newspapers comprise the major categories. Articles submitted to scholarly journals undergo a peer review process by experts in a given field. If in doubt as to the suitability of journal for scholarly purposes, a researcher can consult a directory of periodicals such as *Ulrich's Periodicals Directory,* which indicates whether or not a journal is peer reviewed.

The fact that the Web has no comparable methods of control complicates the task of determining whether a website is appropriate for research purposes. While websites produced by certain types of agencies and organizations certainly undergo a form of *internal*

review, the Web is a free forum; people can post anything they want, and no one has the right to force to take it down if it fails to meet certain standards of quality or accuracy. To complicate the matter, inaccurate or inexpert information can hide like a wolf in the sheep's clothing of sophisticated graphics, layout, and design. The Web has no peer review process to ensure quality. While none of the evaluation criteria outlined below can provide the final word as to the suitability of a website for scholarly use, a researcher who searches the Web with multiple evaluation criteria in mind expedites the process of finding quality information.

Authorship

When determining the credibility of a website, researchers should use multiple techniques to determine the credentials of the author as well as the character of the organization hosting, or sponsoring, the site. If individuals are listed as authors, researchers should take steps to determine their credentials and reputation in the field by performing a search in a general search engine to find biographical information or other documents written about the author. This will also produce references to the author on the sites of other authors within a field. Researchers can also consult a number of biographical sources available at libraries, such as *Who's Who in the America* or sources tailored to particular fields of study, such as *Who's Who in Science and Engineering.*

Website addresses, or URLs (Uniform Resource Locators) can also provide hints as to author affiliations and potential bias. Personal websites are often hosted on commercial ISP (Internet Service Provider) Web servers such as aol.com, or geocites.com. URLs of personal websites often contain first or last names, as well as percent (%) or tilde (~) signs. While personal websites may contain authoritative information, researchers should question why the same content does not appear on a site sponsored by an educational or research organization.. Was the site created as a pastime or to serve as a forum for airing personal views? Or does the site reflect serious scholarship backed up by other credentials and research published in scholarly publications?

Every website URL ends with a *domain name*, usually a series of three letters preceded by a period. The domain name denotes the type of institution that hosts the website and can often provide clues as to the purpose or potential bias of a site. Common domain names include the following:

Educational sites: .edu
Government sites: .gov, .mil, or country codes (e.g., .uk = United Kingdom, .au = Australia, .do = Dominican Republic)
Nonprofit organization sites: .org
Commercial sites: .com

Most URLs contain multiple levels separated by slashes (e.g., http://www.nod.org/stats/). To learn more about the sponsor or publisher of a particular site, you can remove levels of the URL one by one to see where the site is hosted and determine the character of the sponsoring entity. For instance, if a site is hosted on the site of an association, viewing the mission statement on the home page of the association can provide clues as to the bias or purpose of the content. When judging the credentials of the publishing entity, researchers should look for contact information and institutional logos. In general, sites devoid of identifying information or contact numbers and addresses should raise suspicion.

Audience

When evaluating a site, researchers should determine whether the content succeeds in addressing the stated audience through tone and presentation. Sites for adults should not have a childlike appearance or tone. Likewise, sites may be deliberately overrun by technical language or jargon to confuse or mislead a particular audience. High-quality sites clearly define their intended purpose.

Currency

Medical research findings or population statistics may become obsolete at a faster rate than research in the humanities. Web researchers should check sites for copyright dates and the date of the last update. Broken links are a sign of neglect, as they may indicate that URLs have changed or become obsolete since the last update of the site. To verify the currency of information on a site, researchers should check for several sites covering the same subject matter.

Accuracy

Determining accuracy involves further research to ensure that the claims or findings on a site are substantiated by other sources. If a site presents original research, the methods of the research and instruments used should be clearly explained, as well as potential limitations of the research. If authors make claims or conclusions, they should cite their

sources, and these sources should be tracked down to ensure their existence and authenticity. Websites should contain a list of works cited or footnotes on par with any print book or article. Since websites sometimes include fabricated resources, and erroneous or incomplete citations, sources should be verified using library tools such as indexes and catalogs. Lists of works cited with multiple errors reflect irresponsible research. If a website contains links, the links should be checked. Researchers should be wary of websites populated by broken links or links to defunct websites.

Quality

In general, sites that are poorly organized or sloppy should be approached with caution. Shoddy design may point to further weaknesses. Poor grammar and spelling errors are also red flags.

Bias

While bias is not always a negative attribute, Web searchers should be cognizant of bias as the search for information. The bias of a website can be partially discerned by the domain name (as discussed above under "Authorship"). Commercial websites may be motivated by the goal to market a product or service. Nonprofit organizations may promote a political agenda. While bias may be clearly stated in mission statements and "about" pages, many websites deliberately shroud their bias. Thorough research involves consulting additional sources to determine the history and activities of a particular organization. If a site contains links to other sites, those links should be checked to discern the character and activities of the other organizations listed. If a site is sponsored by other organizations, researchers should consider the relationship between the sponsors and the creators of the site.

Special Considerations for Evaluating Health Information on the Web

The American Medical Association (AMA) has published "Guidelines for Medical and Health Information Sites on the Internet" outlining evaluation criteria for websites publishing health information, whether for consumers or health professionals. While these guidelines are technically enforced only on sites sponsored by the AMA or affiliated organizations, they could be applied to all sites containing health information. Many of these guidelines mirror the previously outlined criteria for evaluating all websites, but there are certain factors that are heavily emphasized in the AMA guidelines, including the importance of peer review by experts in the field, the importance of clearly identifying sources of funding, an explanation of the relationship between individual researchers and the institutions sponsoring the research, the importance of clearly stating the purpose and intended audience of a site, and the need to address the stated audience in a consistent and effective tone. Seven criteria for assessing the quality of health information on the Internet have been developed by the Health Summit Working Group (Health Information Technology Institute 1999).

Information on health-related websites should be verified by checking sources such as journal articles, books, and other websites. These measures are needed as health information on the Web frequently includes unsubstantiated claims.

OVERVIEW OF ACCESSIBILITY ISSUES ON THE WEB

Disability studies research is unique in that many scholars in the field have disabilities that may impact their ability to effectively search the Web. While in many ways the Web "evens the playing field" by making a vast number of resources available electronically, inaccessible design frequently places barriers on Web searchers with disabilities.

Principles of Web accessibility have been developed by the World Wide Web Consortium's (W3C) Web Accessibility Initiative (WAI). The WAI establishes guidelines for creating accessible websites, browsers, and authoring tools to increase the ease of use of the Web for users with disabilities. Multiple scenarios outlining potential challenges to Web searchers with disabilities are summarized in a W3C working draft titled "How People with Disabilities Use the Web" (2001). Among other scenarios, the document emphasizes that many Web searchers with cognitive or visual disabilities use OCR (optical character recognition) software, which reads Web page text and transmits the information to a speech synthesizer and/or refreshable Braille display. Many users with visual disabilities use text-based Internet browsers instead of standard graphical browsers. The successful use of these tools requires that images on websites be accompanied by descriptive text and *ALT tags*. ALT tags are textual labels that appear on the computer screen when a mouse moves over an image. Since visually impaired

Web searchers often enlarge Web-based text using screen magnification programs, Web designers must create pages with nonfixed font sizes that can be altered as necessary. These are only a few of the issues facing Web searchers with disabilities. Other population groups with disabilities discussed in the guidelines include individuals with cognitive disabilities, hearing impairment, and mobility-related disabilities. Readers should consult the WAI website for the complete guidelines (http://www.w3.org/WAI/).

To support the goals of WAI, an online tool called Bobby™ helps website developers test the accessibility of their sites and adhere to accessibility guidelines. By entering a URL into the Bobby website, a Web developer can generate a report outlining which features of the site need to be adjusted to make it "Bobby compliant" and adhere to both W3C accessibility guidelines and guidelines established by the U.S. government's Section 508, a 1998 amendment to the Rehabilitation Act requiring that all federal agencies make their electronic and information technology accessible to people with disabilities. Complete information about these guidelines can be found on the Section 508 website (www.section508.gov).

CONCLUSION

While "one-stop shopping" in Google may be tempting, there is no single search engine leading to everything on the Web. Comprehensive and effective research in disability studies involves consulting multiple search tools, including but not limited to general search engines, subject-specialized search engines, directories, and indexes. In addition to using multiple search tools, Web searchers should experiment with multiple search strategies to maximize the effectiveness of their searching. As there are no standards of quality on the Web, researchers should apply multiple evaluation criteria to every website, verifying that research findings posted on sites are supported by other sources. Web accessibility is a crucial component to disability studies, as the Web has the potential to deliver equal content to all users but frequently presents barriers to people with disabilities by failing to adhere to standards of accessible design. Researchers can develop an awareness of accessibility issues on the Web by familiarizing themselves with the standards outlined by W3C's Web Accessibility Initiative and Section 508.

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UC Berkeley Library, "Finding Information on the Internet: A Tutorial," http://www.lib.berkeley.edu/TeachingLib/Guides/Internet/FindInfo.html

University of Illinois at Chicago, Library the Health Sciences Peoria, "Finding Information on the Internet: Evaluating Web Sites," http://www.uic .edu/depts/lib/lhsp/resources/evaluate.shtml

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Tim Lowly. *Beacon: Bless the Bastard.* 1991. 48" by 60." Tempera on panel. Reprinted by generous permission of the artist.

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READER'S GUIDE

The Reader's Guide is provided to help readers locate entries and primary sources by topical category. It classifies the A–Z entries (Volumes I–IV) and primary source documents (Volume V) into twenty-five categories: Accessibility, Arts, Biographies, Children and Infants, Deafness and Deaf Culture, Disability Studies, Economics and Employment, Education, Ethical Issues, Experience of Disability, Health and Medicine, Health Care, History of Disability, Information Technology, Language of Disability, Law and Social Policy, Models, Organizations, Politics, Rehabilitation, Rehabilitative Engineering and Assistive Technology, Religion, Science, Sports, and Therapies. Some entries and documents may appear in more than one category.

Page numbers for primary source documents and illustrations can be found in the Table of Contents and List of Illustrations for Volume V, which appear in the front matter of each volume, and in the index.

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International Disability Organizations
League of the Physically Handicapped
Leonard Cheshire
Liliane Foundation
National Center for Medical Rehabilitation Research (United States)
National Institute on Disability and Rehabilitation Research (NIDRR) (United States)
People First
Rehabilitation Engineering and Assistive Technology Society of North America (RESNA)
Rehabilitation Engineering Society of Japan (RESJA)
Union of the Physically Impaired against Segregation (UPIAS)
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World Bank
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German Movement of Mentally Disabled People
League of the Physically Handicapped
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Not Dead Yet
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ILLUSTRATIONS: A NOTE TO THE READER

The illustrations in Volume V offer the reader examples of how disability has been viewed in a variety of cultures across thousands of years, from ancient Egypt and medieval Europe to nineteenth-century America and twenty-first-century Japan. The visual elements in Volume V are not intended to illustrate specific documents. Instead, they invite the reader to explore the history of disability through images of the myriad ways in which disability has been viewed by artists and politicians, religious leaders and movie directors, and contemporary disability rights activists from Mumbai to Chicago.

This visual history of disability complements both the documentary history presented through primary sources in Volume V and the many entries in Volumes I through IV that deal with the history of disability throughout the world. We encourage you to use these images to enlarge your understanding of how men and women over the centuries have experienced and conceptualized the complex phenomenon of disability and its meaning for individuals and cultures.

TOWARD A HISTORY OF DISABILITY IN PRIMARY SOURCES

Throughout history, disability has provided opportunities for the display of bodily aberration. This exhibitionistic tendency often seeks to cater to prurient human interests about embodied differences while also referencing physical and cognitive variations as a metaphor for human calamity. Whether this demand to conceptualize disability involves the revision of physical space, communication modes, the provision of care, or bodily compensation, the need to interpret difference among human communities remains relatively consistent. It is the one possible "universal" claim that the materials included in this volume demonstrate. The uniqueness of bodies and minds causes us to encounter the degree to which the made-world proves exclusionary. For instance, the ancient Greek temple at Delphi once had a series of ramped slopes visitors traversed to arrive at the oracle. Only later did the Romans insert marble stairs, which effectively cut off access to the hallowed site for many. Likewise, some two millennia later, the disabled physicist Stephen Hawking's visit to India prompted the government to construct a variety of ramps and other accommodations so that he could visit various historic sites. This instant access (however flawed, in that bathrooms remained inaccessible, and usable transportation continued to be nonexistent) had previously been resisted for years, despite Indian disabled peoples' active protests and requests. Our external and attitudinal environments require alteration, because they are so often organized around invented obstacles. Our environments are created to meet inflexible standards—they presume a set of common bodily capacities, and those who don't conform find themselves left out.

While this point may seem obvious, it has a rather serious set of consequences for disabled people. As populations experience their bodies as "mis-fit" for routine participation, they not only find themselves excluded but also experience constant scrutiny regarding their insufficiencies. Human communities have found it much easier to contemplate the inadequacies of bodies rather than the inadequacies of human-made spaces. Thus, disability arrives at our own moment as one of the most thought-about differences in history. This history proves both rich and disturbing. As one traces out the history of disabled peoples, a seemingly inevitable encounter with ways of conceptualizing differences of all kinds comes to the forefront. Whether we read prophecies of ancient Sumer distilled from the analysis of disabled fetuses; the origin stories of Shinto, Native American, and African communities, which often turn on warnings about the devaluation of disabled bodies; the miraculous cure missions of religious and secular prophets' scientifically backed efforts to rid nations of their disabled populations; the establishment of utopian communities both with and without disabled bodies; spaces of cultural segregation transformed into creative communities of alternative embodiment; or the ironic reversals of disability rights movements holding up mirrors to expose various degrading cultural contexts, disability perseveres as a site of difference that we cannot live without. One might say that disabled peoples' bodies, therefore, provide the impetus to contemplate the inadequacies of places, peoples, and beliefs. The common practice of exhibiting disabled people as fools, oddities, marvels, and misfits brings these tensions forth. However, this exhibitionistic tendency among many cultures becomes a matter of grave concern for those designated as "deviant" or "deficient."

This volume compiles transhistorical and transcultural materials pertinent to a consideration of disabled people's lives. We intend it as a starting point for the analysis of disability as a difference of great social import. Despite the enormity of the task, even an encyclopedic undertaking of this scale can be offered in only the most cursory way. Consequently, we do not claim to provide an exhaustive collection of disability history to any extent. However, the materials gathered here seek to shore up two insufficiencies in our current disability knowledge base: (a) the state of the field of disability history has only recently generated significant scholarly attention; and (b) this first effort at compiling primary source materials on disability unveils that the history of human differences has been relegated to the dustbin of human concerns. Often like the bodies that they describe, discussions of disabled people (under any name) have been erased from historical records. Without an adequate interpretive lens with which to approach the historical situation of disability, individual and collective experiences remain only vaguely comprehended. Not only do the materials gathered herein represent fragments of fragments of our current disability knowledge base (in fact, we have assembled the bulk of material in Volume V as brief excerpts from longer works), these materials demonstrate the degree to which our thinking about the history of embodied differences has only begun.

There are few recognized traditions of discussion about disability by disabled people, for instance—although this volume identifies disabled perspectives operating in every cultural and historical moment. Nor does this volume's overrepresentation of U.S. and European sources provide a reliable glimpse into those cultural locations beyond the "West." We have tried to draw from an international archive of materials, but ultimately, even these materials provide little more than glimpses of Western thinkers contemplating disability in cultures markedly alien to their own sensibilities. Thus, the "non-Western" sources here prove interesting largely to the extent that they help capture a portrait of displaced Westerners contemplating disability as a metaphor for their own feelings of displacement. The culturally alienated spend a significant amount of time imposing their own understanding of bodily estrangement upon those who may or may not experience their lives in this manner. While entries can be found from distinctive cultural traditions such as Africa, the Middle East, Korea, and Australia, they show disability as a continuing topic of concern for English-speaking subjects. Additionally, they also underscore how many observers actively look for disability in other cultures as a barometer of insufficient "modernity" when contrasted with the viewer's home culture.

In this volume, we use the term *disability* to serve as a retrospective label across periods that did not use the designation to group or describe those classified as exceptionally variant. Consequently, the identification of disability history is a self-consciously undertaken task, one that proves thoroughly retrospective and, therefore, imposed to a degree from our own historical moment. For our purposes, disability provides a nodal point from which to gather experiences that share little in common beyond a stigmatized existence based on perceived biologically based differences. Readers will find the language of other historical moments referencing bodies as monstrous, crippled, lame, mute, deaf and dumb, lunatic, and so on. But the volume endeavors to bring these referencing strategies together to construct a shared history, a history of those identified as exceptionally different because of real or perceived incapacities of some major life function. As in the Americans with Disabilities Act (1990), we emphasize "perceived" differences, because the language of human embodiment occurs fully within the domain of representation.

One common point that we'd like this work to demonstrate, then, is the contingent status of "deviance." Given that differences worthy of special social recognition change radically from era to era (in fact, one could potentially use these shifts to reliably mark historical periods themselves), disability cannot be said to *exist*. Differences worthy of note in any period come fully mediated by language and the particularity of cultural investments. The clarity behind identifications of human variance proves consistently unstable, and what passes for a devalued difference in one period often loses import in another. Like bodies, language tends to break down in its goal of describing difference in a reliable, universal, and transhistorical manner. This lack of a definitional heart to disability defines bodies that *differ* from each other as much as they are believed to depart from the norms. As norms shift, so do expressions of embodiment qualifying as exceptional.

Portrayals of disability often situate subjects as those to be viewed, consumed, gazed upon, and gawked at by others secure in their positions of normalcy. The contemplation of disability—the meaning-making acts spawned by human differences—situates observers with the power to evaluate one variation as acceptable and another as pathological. In doing so, the definers solidify their own membership among the norms as an effect of designating others as deficient. Encounters with variation arrive replete with evaluative notions of deficiency. To some extent, we have lost even the medieval ability to marvel at the range of variations that exist or to experience awe at the adaptive capacities of all human beings in general. When we delve into histories of disability, it is difficult not to be struck by the degree to which disabled lives have been explained by others. The voices of disabled people—particularly in nonartistic media—are largely absent in the various proclamations of medicine, policy, law, philosophy, and so forth. As an effort to compensate for this rhetorical insufficiency, we have constructed this volume as a dialectic between artistic and other explanatory forms. Not that the arts themselves do not falter in this arena, but they represent a historical conversation that sometimes yields significant disabled subjectivities.

Whereas artists and literary authors may occupy their own marginalized societal roles, their portrayal of disabled people can often be mined for unexpected insights. For instance, in Raphael's last painting, *The Transfiguration* (1517–1520), the "lunatic boy" in the lower right corner is presented as an object of spectacle. Those who gaze, gesture, and point would mark his extreme difference from their own bodies. His awkwardly twisting body, perhaps rigid from hypertonia, becomes an opportunity to solidify the assembled audience's sense of self-possession. Further, those of us examining the painting participate in a parallel viewing situation; our own autonomy may be confirmed as participants in the witnessing of the "lunatic boy" as Other. His spastic body separates him from the flowing anonymity of the bodies of the gazers. Yet, perhaps ironically, Raphael makes their replicated physical uniformity blend each into the other while the lunatic body remains unintegrated. With this portrayal, Raphael provides a window onto a significant swath of disability history. The disabled individual is infantilized and patronized in her or his portrayal; the different body is first *set off* from the majority and then *set out* as visual fodder for consumption. The excessiveness of this objectifying process becomes so noticeable that the reader of this volume may find him- or herself struck by the sheer repetition of the situation—whether it occurs in the town square, on the freak show stage, in televisual disease-of-the-week dramas, or in the privacy of the medical office.

Yet, the patronization of disabled subjects forms only one base upon which the triangular foundation of disability rests. If we return to the Raphael painting momentarily, we may also realize the reluctance—even terror—of those seeking an intervention on the lunatic boy's behalf. If we imagine the figure frozen by the painter in the midst of a seizure that the gathered crowd cannot adequately restrain, then the scene transforms from one of passivity into an odd power exercised. While the application of a treatment—in this case the disciples' contemplation of miraculous cure once Christ has left them alone—seeks to domesticate and manage the contorting body before them, the effort becomes an operation on the theater of the lunatic boy's presumed grotesquerie. His difference must be mastered to alleviate his "suffering" perhaps, but the real struggle resides in the gathered crowd's discomfort. The lunatic boy's loss of control—bound up in the representation of seizure, spasticity, and temporary immobilization—seems orchestrated from elsewhere, perhaps through some more metaphysical line of communication. *The Transfiguration* leaves those in the lower half of the painting encumbered by the material scene of disability, while the boy alone gestures toward the transfiguration taking place in the top half of the painting. His difference provides a vantage point that others fail to realize—without him, the scene above would go unremarked.

An ironic reversal has occurred, and disability, treated as misfortune by those around the boy, proves unexpectedly revelatory. Situating disability at this important nexus—as an object of scrutiny, as the power of the stigmatized, and as alternative vision—shows us that human variation elicits strong (and sometimes opposing) sensations. Some viewers stare, while others look away with expressions of repulsion or, at best, consternation. But the visceral nature of responses to the disabled body becomes a vantage point from which we may view the world anew. As the religious and medical communities become fixated on the material "problem" before them, efforts to tame, manage, or contain the power of difference are countered by the alternative economy of disability-based desire. When they have sought to give voice to their experiences, disabled people often position their own interests quite differently. Rather than the restitution of their bodies to some less conspicuous existence, disabled people seek redress of a wider social network of obstacles, as if the body were not an isolated entity but rather an active participant in a socially mediated process. This adjusted analytical focus from individual insufficiency to socially created deviance informs the social model of disability. Rather than faulty bodies, the social model seeks to recognize faulty systems of human devising.

The entries in this volume provide myriad examples of ways to view disability, but its ultimate objective remains committed to influencing perceptions. The collection seeks to expose the process of seeing human differences as received belief rather than naturalized divisions. Just as the British philosopher John Berger (1973), in his aptly entitled book *Ways of Seeing,* explains that the figure of Vanity (usually portrayed as a nude woman holding a mirror in narcissistic rapture) represents an expression of the artist's desire rather than her own, our effort here follows a similar strategy. Rather than simply accepting historical depiction, we want to offer these works as the product of interests devised largely outside of disabled peoples' perspectives. Repeated images of short-statured people as maniacal dwarfs, blind people as metaphysical seers, individuals with epilepsy as demonically possessed, and limping figures as archetypal villains receive their power through generational reiteration. These visions are detrimental not merely because they undermine the ability of disabled people to fully participate in activities of culture making, but also because they bestow a deterministic fate. Disability often leads one to be scorned on behalf of a socially bestowed fate as beggar, idol, and pariah.

One result of this approach to disability is that disability-based social marginalization becomes misrecognized as the product of individual incapacities. In his painting *The Cripples* (1568), the Flemish painter Brueghel bitterly scribbled on the back of the portrait: "Cripples go and be prosperous!"—as if a reduction to panhandling on the streets provides a secretly lucrative occupation based on the sympathies of unsuspecting passersby. The foxtails pinned to the beggars' clothes evidence the work of those who would approach disabled bodies to glean "luck" or to fend off their own potential vulnerabilities. In treating disabled people as the objects of social ritual, the community is denied even the basic right of self-reflection. Such has been the case for other devalued communities, such as women and people of color. It is rare that one witnesses a disabled subject staring back at the viewer in full possession of his or her humanity. Moments where disabled people return the gaze rather than function as the pure object of others' scrutiny can be found in works such as Velasquez's *Las Meninas,* where the royal dwarf stares out knowingly from the scene. But parallel depictions are few and far between.

At the same time, and in spite of this treatment, disabled people have used their rejected bodies as sites of cultural transformation. The history of artistic expression presented in this volume may also be viewed as surprisingly synonymous with the expressive creativity of people with disabilities. Discussions of the works of disabled artists have often avoided the question of the impact of their bodies on their work, as in the cases of Claude Monet—visual impairment; Henri Toulouse-Lautrec—short-statured; Paul Klee—scleroderma; Edvard Munch—schizophrenia; Francisco Goya—deafness; Vincent van Gogh—mental illness; Auguste Renoir—arthritis; and Frida Kahlo—spina bifida. However, we would like to present the work of individuals such as these as an opportunity to imagine how the unique visions of their work draw directly from their experiences of disability. Many have portrayed their experiences directly, as in Goya's renditions of deafness or Kahlo's depictions of her scarred body, back brace, physicians, and lengthy confinements to her bed. Likewise, van Gogh painted his own medical attendants and his cell at the Arles institution. Because disabled people have found themselves restricted to rather narrow locations, their work explores that space as if it were a universe unto itself.

In addition to the impoverishment of the visual arts, one would find literature equally depreciated by the absence of disabled peoples' poems and stories. For instance, we would lose the work of key literary figures such as Homer—blind; John Milton—blind; Samuel Johnson—Tourette's syndrome; Alexander Pope—scoliosis; Lord Byron—Little's disease; John Keats—tuberculosis; Emily Dickinson—visual impairment; Walt Whitman—mobility impairment; Stephen Crane—tuberculosis; Virginia Woolf—depression; James Joyce—visual impairment; Jorge Luis Borges—blind; Flannery O'Connor—lupus; and others. In truth, if one were to subtract disability experience from the traditions identified here, we would immediately lose much innovation in the history of all arts. All of these individuals sought to transform cultural attitudes about human differences by exploring disability experience as distinctive in its own right.

The conflicts identified and even generated by such representations are certainly formidable. Each image arrives saturated with the workings of power as certain bodies become targets for pathological ascriptions. As Foucault argues, "History is at war with the body." This volume pays homage to the wages of this war on bodies deemed disabled by virtue of capacity, aesthetic, race, gender, and class. We recognize such portrayals as static patterns of narrative investment.

Our intention is to open up these representations for scrutiny as a step toward cultivating a need for further nuance. If language determines interpretive options to a significant extent, then exposing the limits of meaning gestures toward a more complex register of narrative possibilities. Likewise, many of these excerpts expose the extent to which disability has served as a productive arena of contemplation. Those who have explored disability experiences as a meaningful aspect of human embodiment (rather than outside of or somehow apart from other experiences) demonstrate that we fail if we continue to view bodies as passively imprinted by environments. Rather, bodies serve as active mediators of our interactions between ourselves, others, and the environments we inhabit.

Finally, while bodies can function as a source of division between individuals and communities, feelings of estrangement produced by these encounters are hardly inevitable. Instead, they largely come from a historical lack of intimacy with bodily, sensory, and cognitive differences. As disabled people found themselves incarcerated, segregated, isolated, and ostracized (sometimes voluntarily but usually imposed by others), their social invisibility further alienated them from those who moved more freely in the world. Their absence increased a distance from others and made their pending reintegration even less likely.

Without the participation of disabled people, environments continue to be imagined for the use of a narrow range of capacities; without the participation of disabled people, we all grow desensitized to our own bodies; without the participation of disabled people, our own vulnerability seems more threatening; without the participation of disabled people, we allow ourselves to imagine human existence as independent rather than interdependent; without the participation of disabled people, we ultimately deny variation in the name of a destructive and mythical homogeneity. In other words, rather than existing on the fringes of embodied experience, disability is central to our ability to envision ourselves in meaningful ways.

As psychiatric institutions in Nazi Germany systematically exterminated "lives unworthy of life," the net of in-valid bodies expanded. Those who participated in the exterminations participated in hedonistic rituals such as parties on the occasion of the 10,000th killing, staff orgies, and brutal devaluations of each other. The devaluation of disabled lives is ultimately tantamount to a disregard for all lives.

Yet, in spite of the devastation wrought by the advent of institutionalization, disabled people participated in developed social networks of their own. Asylums, institutions, clinics, hospitals, and segregated schools all became sites of community development where disabled people created a refuge for the value of variation. These cordoned-off sites sometimes became havens as well as alienating locations. They served as source for the cultivation of shared politics and critique—the two values that most define shared human endeavor. Many of us are unfamiliar with these alternative social groupings, and thus the materials here help to better acquaint readers with the specificity of an "outside" community now made newly available for contemplation. One might use this volume as a means for exploring the ways in which even derided embodiment gives birth to an alternative economy of difference. All of these facets of disability experience have remained relatively unthought. The materials presented here seek to dispel this defining lack of familiarity to whatever extent possible.

Note

1. Philip Sandblom, author of *Creativity and Disease* (1997), has researched birth records kept by Kahlo's doctor that diagnose her with spina bifida.

Reference

Berger, John. 1973. *Ways of Seeing.* New York: Viking Press.

Sandblom, Philip. 1997. *Creativity and Disease: How Illness Affects Literature, Art, and Music*. London: Marion Boyers.

ACKNOWLEDGMENTS

In many ways, all books are collective efforts. They come about, as Virginia Woolf wrote, as the distillation of generations of thinking in common. This is absolutely the case in the work of creating an encyclopedia. One contributor referred to the collection project throughout its design as the Cyclops. He thus invoked the monstrosity behind the mission making us all Dr. Frankensteins when many had felt themselves instead an ally of the monster. But he also invoked the mundane monster-making that an odyssey must find in concealed places—”look, here be monsters.”

Such an intellectual, cultural, geographical, and historical undertaking inevitably resonates with an eighteenth-century effort to catalogue all species and name every item. Nothing could be further from the case with the volume before you. In this case, given no financial incentive and little potential scholarly credit, those who extended their efforts in the name of this project did so out of a deep commitment to the cultivation of disability history. Volume 5, in particular, developed as an extended international effort with scholars contributing sources from five continents. Without the input, wisdom, community, and scrupulous scholarly contributions of our editorial team, we could not have completed this project.

Consequently, the editors, both formal and informal, for this primary source volume merit full credit for the range of sources and outreach efforts of the materials represented herein. We all recognized that the task before us was not really feasible given the state of interest and early point in the advent of global transmission technologies so we sought to confine our tracking efforts to themes and strands of available resources. A serious caveat, then: This volume represents collective efforts but is by no means exhaustive or even representative. Instead, it reflects the range that we could pull together in a limited amount of time and with minimal financial resources as well as the serious barriers of restricting this volume to English text sources alone. In spite of these factors, the participants acknowledged here went to great lengths to make the volume as international as possible.

A significant contribution to the ancient history section of this volume has been collected and introduced by Martha Rose. She worked from beginning to end on this project and assured that materials from Greece, Rome, and other early civilizations gave the volume serious historical sweep. Likewise, Kerry Wood organized and introduced important materials from the Old and New Testament on disability. Penny Richards provided materials from women's literature and history, education, and disability parenting literature, as well as various insertions into nineteenth- and early twentieth-century sources for the United States. Kumur B. Selim, who worked to improve the non-Western range of the volume despite its representational barriers, contributed materials from many locations and across all time periods. Without this contribution, the volume would be further impoverished as to what it might tell us about disability in non-western contexts. To an endlessly giving colleague Tobin Siebers, we offer our appreciation for work in European and American sources of the Romantic period. David Gerber provided expert guidance on the inclusion of materials pertinent to disabled veterans in the United States. Disability historian Sandy Suffian added some of her own previously untapped sources with respect to institutional history in Africa, Israel, and elsewhere. In Germany, we were fortunate to have the leadership provided by Anne Waldschmidt to ensure that the history of German disabled people and institutions were adequately

addressed. Anne orchestrated her own editorial team to assure the volume of historical scope and cross disability sources from German literature and history. Similarly, Helen Meekosha did the same for sources on disability history in Australia. She gathered up scholars, activists, and community participants from many sectors and professions, all of whom made important additions to an oft neglected geographical locale rich in disability history. Further, we want to acknowledge Yerker Andersson, who assembled his own impressive group of scholars in the field of Deaf Studies and Deaf History. This volume only scratches the surface of the international undertakings that are underway in deaf history. Whatever merits this volume may have go to the credit of these individuals who worked and contributed of their time, materials, and expertise on behalf of their shared commitment to the need for developing a comparative disability history. Finally, we acknowledge the work of Eunjung Kim, who researched important sources from the history of disability in Korea to include in this compilation. The significant contributions of all our editors make this volume a monument in collective scholarly output. They have our sincere thanks for their generosity, candor, and expertise.

As we neared completion of the final section on globalization, British disability film historian Paul Darke provided as with a timely set of stills from the history of disability in cinema. He also provided access to his voluminous disability stamp collection from around the world. For these two important contributions alone, we owe Paul a great debt. We received several important disability sources in Japan from our friend Patrick Drazen, whose knowledge of Japanese popular culture never ceases to amaze us. In a parallel effort, we offer our deep appreciation to Yangling Li, who researched some key Chinese sources for the twentieth century. Japanese disability advocate Nagase Osamu and Indian disability scholar and activist Meenu Bhambhani contributed visual and textual sources from their country's respective disability civil rights movements. Serbian disability scholar and activist Vladimir Cuk generously provided materials to include the activities of the Serbian disabled students' movement. Disability activists, scholars, and archivists in Canada, Australia, and Britain also pitched in to have their movements represented. Many thanks to Tomato Lichy, Mitzi Waltz, Karen Soldatic, Graeme Bacque, Geoffrey Reaume, Penny Bould, and Lilith Finkler—and particularly Tony Baldwinson, who also provided visual materials from the history of blind individuals in Britain and the Soviet Union. We are greatly heartened by these global commitments and also by those who believe they matter enough to record the real life experiences of disabled constituencies everywhere with care and insight.

Sara Vogt, a researcher who also pursues scholarship in comparative studies of U.S. and German disability policy, skillfully translated German language source materials. Ingrid Hoffman at the University of Minnesota also undertook crucial German translation work along with Liz Winters from her outpost in St. Louis. Without the expertise of anti-psychiatry researcher Pamela Wheelock, this volume would find itself largely bereft of materials documenting the U.S. anti-psychiatry movement from the 1950s onward. The combined efforts of these scholars proved the sole reason why the volume was able to include these primary source texts. Such donated participation has proven essential in helping us demonstrate the international scope of political struggles around disability and other marginalized peoples.

Of course, no volume such as this can come to fruition without a committed and knowledgeable administrative staff. Most importantly we want to recognize Michelle Jarman, who, in addition to providing key sources herself, also led an early research, collection, and proofreading effort in which many Ph.D. students in disability studies at the University of Illinois participated. Michelle's scrupulous skills in review and research are greatly appreciated. Those who assisted locally in bringing the volume to realization include Michael Gill, Eunjung Kim, Sharon Lamp, Yanling Li, Sarah Rose, Mark Sherry, Shilpaa Anand, Heather Stone, Terri Thrower, Sara Vogt, Carlos Drazen, and Pamela Wheelock. Each contributed of their time, expertise, scholarly imagination, and good will. Their collaborative work together on the Sage encyclopedia project has resulted in the generative formation for a new graduate student organization, the Disability History and Culture Collective at the University of Illinois in Chicago.

Another critical impetus for the planning of this volume came in a faculty and teacher summer institute in disability studies sponsored by the first National Endowment for the Humanities. The scholars who contributed their time, expertise, and readings for this institute formed the initial skeleton of the current volume. Those who participated in the Including Disability in K-12 project include Linda Ware, Douglas Baynton,

Helen Deutsch, Jim Ferris, Martha Rose, David Gerber, Martha Stoddard Holmes, Carrie Sandahl, Tobin Siebers, Rosemarie Garland-Thomson, and Brenda Brueggemann. Their fine work—individually and collectively—has continued to prod and inspire our own. This volume is very much the fruit of their labors as well.

Additionally, longtime colleagues and newer research associates who participated as members of the American and Canadian faculty research group at the Einstein Forum for the 2004 summer institute on T-4 and the legacies of eugenics deserve recognition here as well. All showed remarkable potential for collective scholarship in action on the crossings among German, U.S., and Canadian disability history. The Germany summer institute participants include Adrienne Asch, Brenda Brueggemann, Sally Chivers, Sumi Colligan, Gerald O'Brien, Ingrid Hoffman, Nicole Markotic, Sandy O'Neill, Walton Schalick, Rosemarie Garland Thomson, Kanta Kochar-Lindgren, Debjani Mukherjee, Sara Vogt, Pamela Wheelock, and Emma Mitchell. Our month-long stint with this group gave us all a career's worth of future research topics as well as a camaraderie rarely experienced among academics engaged in a shared intellectual enterprise.

Of course, for us, no project would be complete without the input, investment, and counseling provided by artist Riva Lehrer. Her vision and creative insight give our own musings a sense of grander insight, cultural necessity, and aesthetic belonging. Lehrer's ability to recognize connections across seemingly unlike things has cultivated our understanding of history as belonging to the different as well as the differentiated. Additionally, our acquaintance with Brian Zimmerman has re-fueled our commitments to reading as an occupation of significance. Their presence in this volume is significant even if largely absent on the surface of things (but, then again, this is how they contribute some of their greatest work).

In a larger sense, the entire encyclopedia project would not have occurred without the leadership of Gary Albrecht and the other participants in Sage's interdisciplinary "Noah's Ark." Jerome Bickenbach and Walton Schalick deserve particular recognition as disability scholars of integrity who worked alongside of us to pull off this massive endeavor. Our admiration of the scholarship, leadership capacities, and integrity of these individuals remains high. Our especial appreciation go to Tamar Heller, Joe Flaherty, Eduardo Encinas, and Dudley Childress, who participated in the long march of meetings that ultimately culminated in this five-volume work.

And, finally, to the "Buffy the Vampire Slayer" fan club who didn't need to imagine another world in order to understand the importance of this one. As Buffy once said, "You know what they say–those of us who failed history . . . doomed to repeat it in summer school." Let's hope we all have summers off from this time forward as a result of good historical karma.

ABOUT THE ENCYCLOPEDIA COVERS: VISUALIZING VARIATION

Sharon L. Snyder

The five covers for the *Encyclopedia of Disability* represent a selection of artistic impressions across a range of cultures, time periods, and multiple disabilities. They also render some of the unique orbits for the complex relationships that disability experiences provoke. Each is purposively nontragic and discourages pathos or too easy sentiment. Instead, the covers emphasize the creative and self-inventive side of disability experience. All make disability a window onto diverse landscapes for the body different.

Taken collectively, they may even suggest an odd refuge in disability—the degree to which incapacities can be viewed as protecting us, and motivating creative agency, even as they may render us most vulnerable. Perhaps someone such as Frida Kahlo, who lived so intensely in her body, could identify the lure of incapacity to this extent. She wrote in her diaries:

> We take refuge in, we take flight into irrationality, magic, abnormality, in fear of the extraordinary beauty of truth of matter and dialectics, of whatever is healthy and strong—we like being sick to protect ourselves. Someone—something—always protects us from the truth—Our own ignorance and fear. (*The Diary* 1995:248–249)

Thought about in such a way, disability no longer means a condition, an incapacity, or lack that belongs to a body, but rather a product of the interactions between self, society, body, and the variety of interactions (from political economies to personal commitments) that they engender. Disabled bodies, then, are artifacts—found or experienced while saturated with the meaning of our own investments, concerns, hopes, and insignificance in the world.

That the relations precipitated by human differences so often become detrimental to people with disabilities, turning even families or institutions devoted to their care into warehouses or danger zones, does not lessen their significance. Analysis of disability from a social perspective reveals the extent to which cultures prove creative at inventing endless varieties of human diminishment. In response, one finds counter-creativity demanded of disabled people. Their own livelihood, and sometimes their very lives, can rely on an ability to subvert supernatural views held about their conditions, contest medical fascination with their corporeality as "specimens," or spend years finding the means to escape confinement from back wards, closets, and institutions. The art depicted on the covers of this five-volume set, then, present us with this multisided nature of disability experience. Each portrays individuals both marked as undeniably different and actively transforming of the social terms of their reception.

The bronze sculpture of the Nigerian King Oba (cover of Volume IV) speaks directly to this idea of disability as urgently necessary renegotiation of the terms by which the nondisabled may see us. The king stands between the dual supports of his personal assistants with his mudfish legs on full display to the viewer. Rather than a story of personal diminishment by paralysis, the king explains his condition, contrariwise, as a deepening of his power. Mudfish represented a revered species in Nigerian culture at the time of this event. A king who awakens to discover himself immobile—particularly when the appearance of physical or cognitive disability in a ruler results, by law, in exile or execution from his subjects—can avert certain catastrophe only by such inventive quick thinking. Instead of concealing his paralysis, the king parades his body transformation before more lethal rumors can begin to circulate.

The Oba's explanation for his sudden mobility impairment draws directly upon insider understanding: Difference of form does not equate with absence of kingly capacity. Legs bow out and gradually modify into the heads and forelegs of the mudfish as the product of a powerful formulation of the meaning of body changes. The king tells his subjects that he can now pass between earthly and spiritual realms just as the mudfish navigate land and sea as half-reptile and half-fish. Circling the human figures, a series of four amphibian heads stare out as totemic sentries. The artist admires the flexibility of such an in-between space occupied by the Oba in his claimed role as a mediator now between human assistants and animal protectors.

Both Oba and artist participate in the recognition that variation exists across species and hence offers to us a rich array of explanations for the value of bodily configurations that might otherwise be cast out as undesirable. The sculpture posits continuity to natures, creatures, cohabitants, in a portrayal of paralysis: mudfish legs, human assistants with partially truncated torsos, pineapples, elephant trunk, snake, and swamp tangle. All life forms mesh in a symbiotic system of mutual belonging despite intense differences of capacity. Diversity teems across the bronze figure's vertical and horizontal axes. A celebration of varying capacities from human to animal culminates in the exhibition of Oba's bowing legs in order that variations across bodies in nature can provide context for a human body with paralyzed legs without a lessening of value.

The nineteenth-century Japanese triptych *Hua T'o Treating an Instance of Necrosis on the Arm of the Warrior Guan Yu* (cover of Volume III, 1853) by the famous printmaker Utagawa Kuniyoshi, depicts a historical event from fourteenth-century China. To the far left of the work we witness a surgeon, dwarfed in the presence of the massive body of Guan Yu, plying his trade in spite of the recreational distractions taking place around him. The physician, Hua T'o, meaning "miracle working doctor" (or "divine physician" based on the Japanese word *shenyi*), concentrates on a lesion eating away at the general's right arm. His localized treatment effort contrasts with the social frivolity portrayed in the rest of the painting. Medicine pursues its healing art as the world continues on indifferent to the work of bodily salvage. In this reading, we could situate ourselves as admirers of precise medical application as the "patient" stubbornly pursues other desires with a reckless lack of concern: Medicine works against time and gross inattention to attend to human vulnerability. We are situated as admirers of medical technique; the physician's perseverance is sustained in spite of activities that might prove distracting to the treatment effort.

Likewise, a viewer of the painting may also contemplate the work as a commentary on war. Bodies are wantonly exposed to violence and disability, disease, and death. Human wreckage is exposed as the primary product of militarized clashes between individuals, tribes, and nations. The painting depicts Guan Yu calmly receiving treatment following a battle wound caused by a poison arrow. The warrior ignores the cleaning of the wound down to the bone as an example of the power of the first administration of anesthetic. He has adopted an attitude that places his body as fully secondary to more immediate concerns, whether the task at hand is a battle or gamesmanship. In the unfinished disability play *The Deformed Transformed* (1822), the renowned Romantic poet Lord Byron, argued that masculine able-bodiedness seemed to require that men put their healthy bodies at risk of violation, as if they could not feel their lives as "real" enough without exposing themselves to the potential of disability. The thrill of physical threats pursued and then evaded. The painting of Hua T'o suggests a similar reading in that the development of necrosis suggests a near-gangrenous wound progressing to the point of a serious medical condition. A poor result might yield the loss of a limb or disuse of his arm because the general has refused to attend to the initial laceration in a timely manner. This patient inattention to the poisoning produces an even graver medical predicament. From this vantage point, a viewer might choose to indict the warrior's indifference to his own health concerns or grow further weary of war's destruction.

Alternatively, one may also glimpse a cultivated demeanor in Guan Yu's laissez-faire attitude toward medical attention. We might draw an interesting parallel to the experience of medicalization by disabled persons—particularly in the case of individuals who have spent significant time "under the knife." While medicine demands the full attention of the patient to participate in its own healing mission, those exposed to continuous medical care often refuse this singular attention paid to their bodies. Undergoing medical care requires a multitasking mission, or the rest of one's life comes to a full stop. In this view, we might think of medicine as the disruptive event against which the rest of one's life must be experienced. A certain capacity develops among disabled people to handle their other "business" as the medical industry rages around them. In fact, there's a form of patient *cool* where one refuses to allow a medical event to eclipse the myriad other demands on one's life—such an attitude can be found on display in the Kuniyoshi print as the game of Go continues in the face of surgery. In fact, the medical activity is reduced to a mere third of the triptych while the game occupies the remainder of the artist's interest. The social interaction requires as much seriousness as the presence of necrosis itself.

Likewise, Tim Lowly's *Beacon (Bless the Bastard)* (cover of Volume V, 1991) emphasizes independent coexistence among bodies occupying shared space. Rocks, river, grass, and other earthly elements populate the scene with an adult care provider and a disabled child positioned a few feet away. The two female figures, out of doors and beyond the traditional confines of domesticity, do not show shame or efforts to hide from the world's discomfort with disability. The caregiver looks off in the distance responding to some unknown force with a stem wielded over her shoulder in the gesture of a blessing. Behind and below the caregiver, a child (the artist's daughter Temma) lies on a bright blue pallet that cushions her from the ground—the same ground on which her mother's bare feet are firmly planted. The disabled girl's body, illuminated in the landscape and sprawled beneath the sky, wears a one-piece playsuit with socks and shoes, carefully swaddled despite the apparent warmth of the day. The relationship between the two figures, emphasized by the colors in the child's garment and repeated in the mother's striped dress, openly proclaims their identification. This is Temma's consciously placed residence in the world; she might be lying there contemplating a future yet to be articulated by the adults around her. The daughter's figure, aimed like a magnetic compass arrow toward the bridge in the upper left canvas, serves as a beacon to the artist, and, in this landscape, literally could be cast in a red outfit as if a signal translated from one location to another. The way a painter selects and places a subject onto a canvas in a highly self-conscious act parallels how Temma's caregiver has consciously situated her in this setting. In other works, Temma lies near a muddy puddle, a pond, on a day bed, across a desert floor, near a wooded river stream; her figure a geographic nomad yet without apparent mobility. These portraits capture Temma's vantage point as contemplative of universes unrevealed in ordinary landscapes—and strangely altered by the insertion of a disabled body. The historical absence of disabled people in routine places makes every appearance potentially transgress audience expectations. Conversely, every insertion undermines the belief that there are some places disabled persons should not go.

Just below the bridge, a small group clusters around a makeshift stone altar and, in a rather ritualistic manner, evokes a history of atonement practices. These ritualistic acts often occur in response to a mystery disability seems to evoke. Why me? Or what did I do to deserve this fate? Or what does this difference mean for the community? Are we culpable in some way? Piled stones reference all the hard things humans negotiate, arrange, and work with, just as the allegorical landscape offers hugely divergent elements, from spongy riverbed to wooden platform, to inhabit. Each formation seems to be selected for its yielding principles. Fjords—irregular land and water masses—remind us of the nonstandard geometries of embodiment and mirror the daughter's figure akimbo on land. Bodies of water and of land encroach on and define each other—clearly etched by nonregimented and unpredictable shorelines. The work on the makeshift altar occurs while the determined "blessing" of the mother above also redoubles as a fending off of outside forces and even our gaze, as viewers prying into a private scene. As if we must first fathom the precision of the mother's expression and gesture in the foreground before gaining access to the proceedings beyond her, she stands as a cautious gatekeeper before the rest of the painting.

The subtitle, *Bless the Bastard,* refers not to the child but to the concept of flinging back insults with a shield of mercy. The artist explains the idea as a matter of how one might bless those who curse one with additional punch. The mother's determined motions, her turning outward and her gesture toward the past, and her daughter's resident outside location, present them as participants in a fully parallel existence. The story of disability unveils that even the most ordinary outing requires a variety of self-conscious placements and protective gestures.

Finally, a white building perched near the skyline in the upper-right-hand corner recalls, as well, the Olson house on the upper horizon of Andrew Wyeth's famous painting *Christina's World.* As in the Lowly work, the house in Wyeth's painting also makes a young disabled woman's predicament into an allegory. The disabled figure in each work lies in the foreground staring off into the distance—relatively immobile or alternatively mobile in body but imaginatively engaged in future prospects unknown to, and unimagined by, viewers. In *Beacon,* the far-off residence appears like a temple amid a landscape that is filled with objects that catch a viewer's eye. Each item serves as a potential enhancement or barrier to navigation across it. Certainly, both disability paintings place a demand on the viewer to acknowledge these scenes as complete worlds. In them an ordinary morning scene, the forthrightly mundane world, is lent a hue of studied complexity toward a disability's self-conscious placement therein. *Beacon* offers Temma's figure as a guidepost rather than repulsion. The disability-wise gestures of the figures themselves are understood to occur in the face of a modern hyperrational clarity that would dispense with disability experience as some all-too-obvious tragedy. The paintings provide a lesson in how to live in the world with severe disability. Both ask us to reexamine this premise by requiring that we look closely enough to discern the disability coordinates of lives that might at first glance appear wasted.

Whereas Lowly and Wyeth represent intimate works about disability by nondisabled artists, Frida Kahlo's work supplies an example of artistic traditions spawned by disabled artists themselves (cover of Volume I). Responses to the disability context of Kahlo's work and life have ranged from incredulity to simple disability disavowal: "Frida Kahlo—she's a national treasure. How could she be a disabled woman?" Contrariwise, the complex disability perspectives that inform her subject matter and the terms of her artistic exploration can become so central that disability interests may overwhelm all else in her work. Certainly, few artists since the Middle Ages made the topic of personal suffering such a wellspring for creative figuration. For disability critics, one must note the inventiveness that informs Kahlo's access to artistic practices, from painting on canvasses suspended over her bed to laptop easels to the elaborate journal she kept detailing her pain, confinement, and multiple surgeries (including the amputation of her right leg in 1955). Such investments in the ability of art to provide her with immense joy "in spite of my long illness" led her to have her four-poster bed dismantled and reconstructed in the national museum of Mexico City. The unusual accommodation occurred on an evening prior to the one exhibition during her lifetime in her home country for the purpose of being able to view the exhibit herself in comfort.

Kahlo's life, whether conceived as utterly conditioned by disability or as having disability merely incidental to it, has served as the topic of children's books and films. Controversies rage over the terms and origins of her multiple impairments. Some have identified her disability as resulting from a bus accident when she was 16 years old in 1926; others with the effects of polio contracted at the age of 6; and still others, such as Philip Sandblom author of *Creativity and Disease* (1997), propose that she was born with the congenital condition of spina bifida, which she spent her life concealing. We may be discussing some combination of all of these events in one body as well. These discussions are as interesting for the fears and concerns interpreters express about the meanings of congenital (as opposed to acquired) disabilities for stories of artistic achievement. Acquired disability makes one a hapless victim of circumstances while congenital disability signifies a status as metaphysical pawn.

Nevertheless, the latter attribution of spina bifida as an initial source of her disabilities becomes most provocative given her preoccupation with the spinal column in her work. Her paintings commonly depict Mexico as an ionic column with wings. In addition, she also uses duality or twinning such as in her work, *The Two Fridas* (1939), where we see her heart beating and a circulatory system that feeds the nearby identical body image with which she clasps hands. The work depicted here, painted in 1946 amid a flurry of surgeries and hospital stays, *Arbol de la Esperanza Mantente Firme* (*Tree of Hope—Stand Firm!*), associates an ironic meaning to the figure holding a back brace in one half and wounds along the supine figure's spine in the other. The sense of strength that Kahlo must have felt in herself—particularly through her political commitments to Communist revolution—resound as both a plea (make me strong in the face of pain) and a command to others (stand firm in your political convictions). These words, *"arbol de la esperanza mantente firme,"* which one of her biographers, Hayden Herrera, identified as the lyrics to a song she knew, would also appear a year later in a diary entry celebrating the 30th anniversary of the Bolshevik revolution. For Kahlo, debilitating physical anguish could be offset to some degree with a merger of disability and political images in that both coexist without eclipsing the other: The most disabled also embody the fiercest commitments for social justice. The two often become a self-referencing system in the body of her works.

Compositionally, the contrasted backgrounds of night and day suggest a confluence of binary associations between light and dark, health and illness, passive hospital patient and active revolutionary. Yet the painting throws such easy oppositions into question in that all coexist, and enlightenment may come from either source. The more medical image appears in the day where one might expect to find her more "public"—that is, less vulnerable—self. Thus, the work is an emblem of Kahlo's artistic *oeuvre* in that these versions of the self do not simply balance the subject but rather serve as wellsprings for creative vision in their own right. The pink brace grasped securely in the hands of the formally dressed figure who waves a small flag contrasts with the night and small moon on the right side of the canvas. The body of the fully draped figure situated at a perfect right angle to the reposed figure on the wheeled operating table function as two supports along the canvas's vertical and horizontal planes. The figure on the left displays open seeping wounds across a back that is exposed between pulled-apart sheets as if to unveil her body in a surgical cut-away.

Likewise, spinal lesions echo across both halves of the painting. They duplicate cracks and ridges that split dry earth across which the stretcher seems precariously perched. This yawning crevasse is exactly the same size as the wheeled bed. A surreal glittery ball stands for the sun, and her flowery headdress hovers suspended in this cosmic stratosphere. The velvet dress suggests a more formal version of the Aztec clothing that she wore throughout her adult life. It's also a chosen legacy rescued from a colonized past. Hence the more surreal aspect of this painting: The body left behind, ruptured, and lying across night and day is juxtaposed to the upright, dressed red figure who gazes at the viewer while holding the brace in full display. It also appears that the seated figure wears a similar corset-like apparatus beneath the dress because the bulbous endings appear around her chest and match the same design of the brace in her hands. In a *Time* magazine article of April 27, 1953, Kahlo insisted that "I never painted dreams. I painted my own reality" (p. 90). The painting may most of all render homage to her prosthetic back brace and her investments in it. Today, one can find the same pink back brace with personal decorations in a visit to her home, now a national museum. In either case, both portraits echo with Kahlo's disability markers that worked to flaunt, as opposed to mask them, from the viewer.

Kahlo's work has been often attributed to the influence of northern Dutch painters such as Pieter Brueghel the Elder, and particularly, Hieronymus Bosch (Jeroen Van Aken: 1450–1516). While Brueghel painted mimetic images of everyday northern peasant life, Bosch's impact on Kahlo is often identified through his portrayals of bizarre imaginings such as the events captured in his work *Extraction of the Stone of Madness (The Cure of Folly)* (ca. 1475) (cover of Volume II). Whereas Kahlo followed Vincent van Gogh in portraying her physicians in respectful portraits as a sign of appreciation, Bosch participates in a less reverent approach. In this painting, Bosch satirizes the medieval medical practice of removing stones from the head as a treatment for madness, traumatic brain injury, and insanity. In addition, the other two onlookers—a friar and a nun—represent alternative religious domains where madness was commonly addressed with alms and prayer. Thus, Bosch assembles the surgery's audience carefully in his effort to draw the three figures into the net of this parody—as if every charlatan, barber, and pious practitioner of his day comes together in this unholy gathering to witness someone else's suffering. Their own moral stature in the community depends on catering to those residing among the "less fortunate."

The subject of the surgery—a patient drawn in the guise of various "fools" of the day—undergoes a risky intervention. Hopes for release from such conditions as insanity resulted in a willingness to expose oneself to disastrous—and often life-threatening—efforts to alleviate symptoms. Similar practices for the treatment of mental illness were widespread in Bosch's day. Evidence also suggests that in spite of critiques such as this one, the practice continued into the Renaissance where similar procedures are documented as late as the sixteenth century. Like Kahlo, Bosch rarely ventured far from home, and his works include details of familiar scenes within a tightly circumscribed area. Yet, as in this work, Bosch's paintings place the rituals of life in question by unveiling the violence that often resides just beneath the surface. Consequently, *Extraction of the Stone of Madness* suggests that "deviant" behavior may be found on both sides of the treatment divide.

Bosch's painting, inspired by various folk tales and critiques of the physicians' guilds of his time, appears fairytale-like in its allegorical assemblage of medical and religious personnel. In each figure, the primary treatment tools come on display—from the barber's scalpel to the friar's chalice-like vessel to the nun who balances a book on her head. The physician applies his effort directly to the body, the male priest talks and gestures toward the patient during the ordeal as if performing an exorcism of demons, and the nun looks on in contemplation as if patiently awaiting inspiration from the text above. Each intervention strategy seems poised to encourage equal levels of suspicion. Rather than a stone, the surgery results in the extraction of a flower from the man's head. This is a curious object in that the flower appears much more at home in the naturalistic setting while the human practitioners seem out of place. The town situated off in the distance further emphasizes their displacement. As one commentator puts it:

> Moreover, this work of art bears the inscription 'Master, take away the stone, my name is Lubbert Das." It is worth pointing out that Lubbert Das was a comical character that originates in the Dutch literature of that time. The stone is represented as a flower (tulip) on the head of the patient near the surgeon's knife, because of the similarity between the words tulip (*tulp*) and madness in Dutch. (Babiloni et al. 2003:1)

This direct parallel between organic life and insanity may suggest Bosch's effort to equate both objects with the forces of nature that ultimately evade human control.

While madness may be commonly represented as severe distraction from the applications of daily living, only the patient's gaze breaks the painting's plane as he looks out uncertainly toward the artist capturing the event and/or the hapless viewer consuming the event. His look of personal concern contrasts with the concentrated efforts of the others as they attend directly to the site of conflict—namely, his brain as resident location for the "disorder"—and thus the "patient's" objectification turns out to be at least threefold on behalf of the barber, artist, and viewer. We participate as consumers of the discomforting scene. Bosch captures the worst kind of medical theater, one that not only subjects one to painful procedures of dubious merit but also is witnessed by others to further deepen the stigma.

The painting also comments on a long-standing belief in medicine that the body functions as symptomatic surface for otherwise ephemeral "cognitive" phenomena (i.e., madness in this case). Without a tangible bodily location, medicine would prove at a loss as to how to proceed in its material correctives. The concept of a "stone" of madness then takes an abstract matter of behavior perceived as deviant and objectifies it in physical terms. Thus, various bodily zones get targeted as the seat/source of intangible phenomena. In the eugenics period (1840–1940), "idiocy" was theorized as a lack of control of the will, and "docile" bodies were targeted through physical exercises, concentration rituals (e.g., standing in one place for minutes at a time), and hygienic grooming practices—a presentable body represents a compliant citizen. In each instance, exerting force on the physical body provided a route through which to impose control over minds.

In sum, these artistic works demonstrate that disability is both a product of specific local contexts *and* shared, even global, disability perspectives. Africa, Japan, the United States, Mexico, and the Netherlands all contribute to a multinational mosaic of disability representation; in doing so, disability transcends geography, culture, and history in its situation as a metaphorical and pragmatic device of social meaning making. The question "What do we do with our disabled people?" resonates in most cultures and across historical moments. In the midst of its invocation as perpetual crisis, disability can expose ruses to the control and mastery of human variation, give expression to individual assertions of difference and group identity, portray indifference or excruciating investment in the denial of deviance, resignify incapacity into unexpected ability, or provide opportunities of interdependency among human vulnerabilities in search of mutual support. On each cover of Volumes I through V, disability serves as the medium through which artists—and, consequently, the viewers of their art—may ponder cultural responses to the persistence of human heterogeneity. Difference prompts myriad social schemes of suppression in futile efforts to contain variation within a narrower range of expression. Artists of disability are not in any way immune to the homogenizing projects of cultures, but their work gives us perspective on how we might improve the future by contemplating the limitations of tolerance in our past.

Further Readings

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ABOUT THE GENERAL EDITOR

Gary L. Albrecht is Professor of Public Health and of Disability and Human Development at the University of Illinois at Chicago. His current work focuses on the quality of life of disabled people based on National Institutes of Health (NIH)–funded studies of disabled women experiencing the menopausal transition and a study of disability risk in the United Kingdom, France, and the United States. Complementary work on the experience of disability in the inner city has been funded by the National Institute on Disability and Rehabilitation Research (NIDRR). He is past Chair of the Medical Sociology Section of the American Sociological Association, a member of the Executive Committee of the Disability Forum of the American Public Health Association, an early member of the Society for Disability Studies, and an elected member of the Society for Research in Rehabilitation (UK). He has received the Award for the Promotion of Human Welfare and the Eliot Freidson Award for the book *The Disability Business: Rehabilitation in America.* He also has received a Switzer Distinguished Research Fellowship, Schmidt Fellowship, New York State Supreme Court Fellowship, Kellogg Fellowship, National Library of Medicine Fellowship, World Health Organization Fellowship, the Lee Founders Award from the Society for the Study of Social Problems, the Licht Award from the American Congress of Rehabilitation Medicine, and the University of Illinois at Chicago Award for Excellence in Teaching.

He has been elected Fellow of the American Association for the Advancement of Science (AAAS) and is a frequent Visiting Fellow at the University of Oxford and Scholar in Residence at the Maison des Sciences de l'Homme, Paris. He has led scientific delegations in rehabilitation medicine to the Soviet Union and the People's Republic of China and served on study sections, grant review panels, and strategic planning committees on disability in Australia, Canada, the European Community, France, Ireland, Poland, Sweden, South Africa, the United States, and the World Health Organization, Geneva. His most recent books are *The Handbook of Social Studies in Health and Medicine* (Sage, 2000, edited with Ray Fitzpatrick and Susan Scrimshaw) and the *Handbook of Disability Studies* (Sage, 2001, edited with Katherine D. Seelman and Michael Bury).

ABOUT THE EDITORS OF VOLUME V

David T. Mitchell is Associate Professor of Disability Studies at the University of Illinois at Chicago. From 2000 to 2004, he served as Director of the first Ph.D. program in disability studies. He has also served as president of the Society for Disability Studies and as Chair and founding member of the Modern Language Association's Committee on Disability Issues. He has served on the Board of Directors for Chicago's Independent Living Center, Progress Center, and as an editor on numerous editorial boards including that of the journal *Disability & Society*. He earned his Ph.D. from the Program in American Culture at the University of Michigan, Ann Arbor.

Most recently, Dr. Mitchell has been concerned with the inclusion and advancement of students with disabilities in higher education. Disability studies takes as its charge the goal of making classrooms and the university more accessible. Similarly, fields of inquiry need to become more answerable for their embedded assumptions about disability. Part of this work involves querying the role that disabled persons play as objects for different kinds of knowledge acquisition about them. Consequently, he directed the first National Endowment for the Humanities Summer Institute in Disability Studies for Educators. In addition, he has traveled and lectured extensively on these and other disability studies topics, in the United States, Canada, Germany, Ireland, Russia, Britain, and Costa Rica. In 2004, he codirected a seminar project team that researched euthanasia murder files and original documentation from psychiatric institutions in National Socialist Germany. This commission remains committed to making the history of disability genocide more known, studied about, and understood.

He is coauthor of *Cultural Locations: Discourses of Disability* (2005), coeditor of *Eugenics in America: A History in Primary Sources* (2005), coauthor of *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), coeditor of *The Body in Physical Difference: Discourses of Disability* (1998), coeditor of a special issue of *Disability Studies Quarterly* on disability studies in the humanities, and coeditor of a special issue on disability issues in writing by the American author Herman Melville for the journal *Leviathan*.

Sharon L. Snyder is Assistant Professor in the Department of Disability and Human Development at the University of Illinois at Chicago. She is a founding member of the Modern Language Association's Committee on Disability Issues and of the Disability Studies Discussion Group. As a faculty member in the first Ph.D. program in disability studies in the United States, she has developed graduate courses including disability in film, the history of eugenics, representational history, globalization and political economies, and curriculum development for disability studies. In 2004, she directed the Legacies of Eugenics, a DAAD (German Academic Exchange Service) seminar for U.S. and Canadian faculty at the Einstein Forum, Potsdam, Germany. She has codirected a National Endowment for the Humanities Summer Institute and served as a faculty lecturer at the University of Costa Rica.

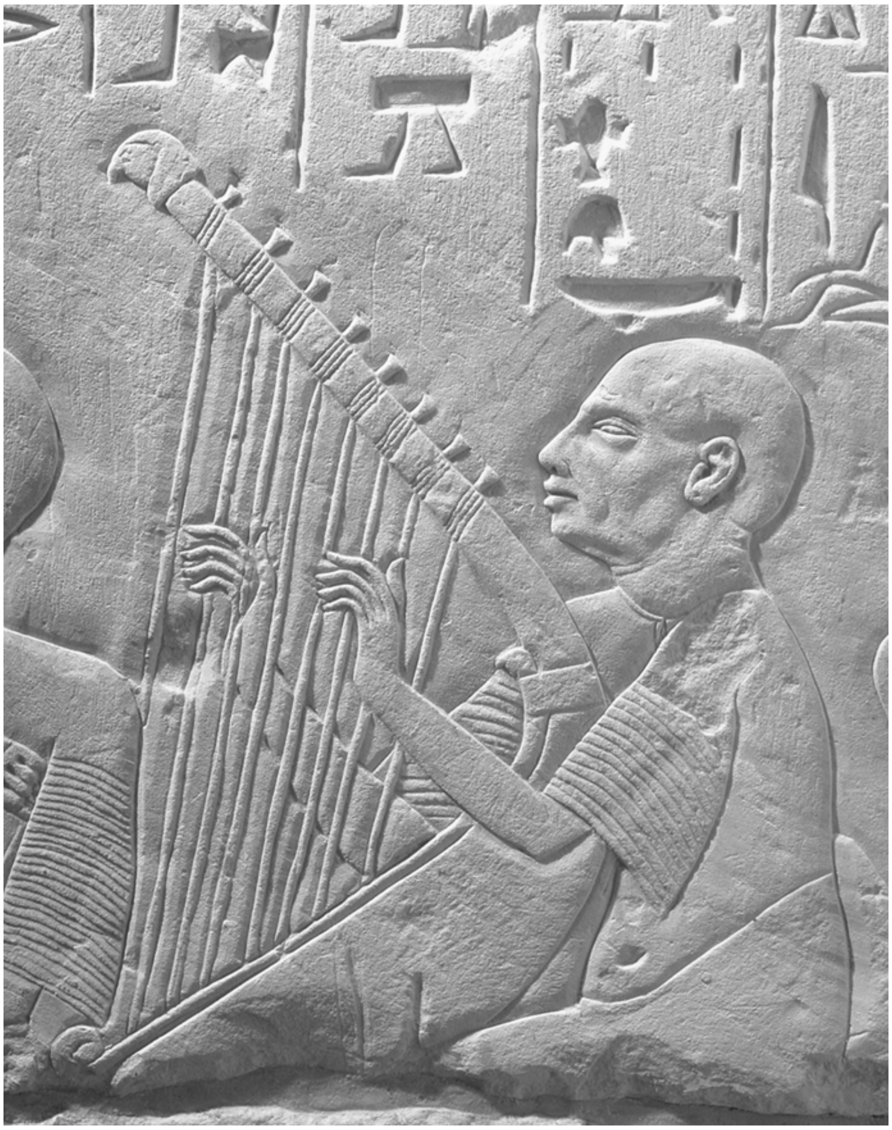
Dr. Snyder is coauthor of *Cultural Locations of Disability* (2005), coeditor of *Eugenics in America* (2005), coeditor of *Disability Studies: Enabling the Humanities* (2003), coauthor of *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), and coeditor of the first collection of essays on disability studies in the humanities, *The Body and Physical Difference: Discourses of Disability* (1997). As the series editor for Corporealities: Discourses of Disability, she has been instrumental in encouraging scholarly work in the new analytical field of disability studies. Her essays on disability theory, disability culture, and representational history have been published widely and translated for many international professional journals.

The founder of the independent production company Brace Yourselves Productions, she is also a documentary filmmaker whose work includes *Self-Preservation: the Art of Riva Lehrer, Disability Takes on the Arts, A World without Bodies*, and *Vital Signs: Crip Culture Talks Back*. Awards for her films include the Festival Grand Prize at Rehabilitation International's Film Festival, Achievement and Merit Awards at Superfest, and Best of the Festival at Moscow's Breaking Down Barriers.

Part One

Origins of Disability

▣ The Ancient World ▣ The Bible ▣ The Middle Ages



Blind harpist, Nineteenth Dynasty. One of the oldest traditions involves the participation of blind and visually impaired individuals in the profession of music. This detail of a relief was created during the Nineteenth Dynasty, New Kingdom (ca. 1250 bce).

Source: Rijksmuseum van Oudheden, Leiden, The Netherlands. Photo credit: Erich Lessing/Art Resource, New York.

The Ancient World: Sumeria/Mesopotamia

Proverbs from Ki-en-gir (Sumer) (2000 BCE)*

As an early agricultural empire, the Mesopotamian valley hosted the cultivation of a complex system of management that oversaw the investment, production, and distribution of crops throughout the region. Written on clay tablets, the proverbs excerpted below are primarily secular beliefs that seek to sort out the consequences of various virtues and vices associated with human differences. Most proverbs also demonstrate uneven power relationships between disabled and nondisabled participants.

In the city of the lame, the halt are couriers.

How [. . .] the halt stand up?

After a lion had caught a "bush-pig," he roared, "Until now your flesh has not filled my mouth, but your squeals have made me deaf!"

Being strong does not compare to having intelligence.

A fool who was "overwhelmed" at his behind stuck his hand into his behind.

A man whose knees are paralyzed. Nintu has not conceived him, as they say.

A lame man spoke as follows to his mother: "At a place where a man sleeps on a couch let it not please his bones!" His mother spoke as follows: "As if (?) you were afraid of anything, when (?) have we seen you running?"

A lame man saw some runners. "The people who disappeared, where did they go?" he asked.

A lame man came running out from [. . .] and spoke as follows: "As long as I was lame, I could not have done it!"

The poor man caused all kinds of trouble for the wealthy man [. . .] a lasting skin disease.

The lame (?) took a reed basket. For (?) his words a man beats him.

His mother was lame, and his arms are paralyzed.

Source: Alster, Bendt, ed. and trans. 1997. *Proverbs of Ancient Sumeria: The World's Earliest Proverb Collections*. New York: CDL Press.

*A word followed by "(?)" indicates uncertainty on the part of the translator. Lacunae in the text are indicated by [. . .].

The Babylonian Theodicy (ca. 2000 BCE)

This text was created in the form of a dialogue between two actors—one who plays the role of a skeptic (or longtime sufferer) and one who functions as a believer. In this excerpt, the speaker argues that his lot has been so unfair that even cripples and fools enjoy higher social standing.

Your reasoning is a cool breeze, a breath of fresh air for mankind,
Most particular friend, your advice is excellent,
Let me put but one matter before you;
Those who seek not after a god can go the road of favor,
Those who pray to a goddess have grown poor and destitute,
Indeed, in my youth I tried to find out the will of my god,

Mythological "scarface" genie from Baktriana, in eastern Iran. Late third to early second century BCE. The "scarface" genie has a body covered with snake scales. It wears a skirt, and its long facial scar symbolizes a destructive ritual.

Source: Louvre, Paris. Erich Lessing/Art Resource, New York.

With prayer and supplication I besought my goddess.
I bore a yoke of profitless servitude,
My god decreed for me poverty instead of wealth
A cripple rises above me, a fool is ahead [of] me,
Rogues are in the ascendant, I am demoted.

Among the friend's standard pious replies, we find:

Adept scholar, master of erudition,
You blaspheme in the anguish of your thoughts,
Divine purpose is as remote as innermost heaven,
It is too difficult to understand, people cannot understand it.

Source: Pritchard, James B., ed. 1958. Pp. 160–168 in *The Ancient Near East: Volume II. A New Anthology of Texts and Pictures.* Princeton, NJ: Princeton University Press.

Hammurabi's Code of Laws
(ca. 1780 BCE)

Following a genealogy of the royal lineage of Hammurabi, a list of some 282 laws make up the Babylonian kingdom's judicial code. Among these laws are the familiar prescriptions of bodily injuries as atonement for various crimes (e.g., an eye for an eye, a tooth for a tooth).

Code of Laws

Battery

195. If a son strike his father, they shall cut off his fingers.

196. If a man destroy the eye of another man, they shall destroy his eye.

197. If one break a man's bone, they shall break his bone.

198. If one destroy the eye of a freeman or break the bone of a freeman, he shall pay one mina of silver.

199. If one destroy the eye of a man's slave or break a bone of a man's slave he shall pay one-half his price.

200. If a man knock out a tooth of a man of his own rank, they shall knock out his tooth.

201. If one knock out the tooth of a freeman, he shall pay one-third mina of silver.

202. If a man strike the person of a man (*i.e.,* commit an assault) who is his superior, he shall receive sixty strokes with an ox-tail whip in public.

203. If a man strike another man of his own rank, he shall pay one mina of silver.

209. If a man strike a man's daughter and bring about a miscarriage, he shall pay ten shekels of silver for her miscarriage.

210. If that woman die, they shall put his daughter to death.

211. If, through a stroke, he bring about a miscarriage to the daughter of a freeman, he shall pay five shekels of silver.

212. If that woman die, he shall pay one-half mina of silver.

Physicians

215. If a physician operate on a man for a severe wound (or make a severe wound upon a man) with a bronze lancet and save the man's life; or if he open an

abscess (in the eye) of a man with a bronze lancet and save that man's eye, he shall receive ten shekels of silver (as his fee).

216. If he be a freeman, he shall receive five shekels.

217. If it be a man's slave, the owner of the slave shall give two shekels of silver to the physician.

218. If a physician operate on a man for a severe wound with a bronze lancet and cause the man's death; or open an abscess (in the eye) of a man with a bronze lancet and destroy the man's eye, they shall cut off his fingers.

221. If a physician set a broken bone for a man or cure his diseased bowels, the patient shall give five shekels of silver to the physician.

Source: Harper, Robert Francis, trans. 1904. *The Code of Hammurabi, King of Babylon, About 2250 B.C.,* 2nd ed. Chicago: University of Chicago Press.

The Laws of Eshunna (ca. 1770 BCE)*

Dadusha of Eshunna was one of the first to document laws in the Babylonian language. The document consists of 60 paragraphs. It begins with the establishment of tariffs and then discusses ships and grain, family and slaves, physical wounds, animals, and the construction of houses. In this excerpt from the section on physical wounds, injuries to various body parts are assigned a hierarchical sum in terms of their value to the injured.

42: If a man bites the nose of a(nother) man and severs it, he shall pay 1 mina of silver. (For) an eye (he shall pay) 1 mina of silver; (for) a tooth 1/2 mina; (for) an ear 1/2 mina; (for) a slap in the face 10 shekels of silver.

43: If a man severs a(nother) man's finger, he shall pay two-thirds of a mina of silver.

44: If a man throws a(nother) man to the floor in an *altercation* and breaks his *hand,* he shall pay 1/2 mina of silver.

45: If he breaks his foot, he shall pay 1/2 mina of silver.

46: If a man assaults a(nother) man and breaks his [. . .], he shall pay two-thirds of a mina of silver.

47: If a man *hits* a(nother) man *accidentally,* he shall pay 10 shekels of sliver.

Source: Schley, Donald G., trans. 1985. "Law." Chapter 10 in *The Ancient Orient: An Introduction to the Study of the Ancient Near East,* Wolfram Von Soden, ed. Grand Rapids, MI: William B. Eerdmans.

*Lacunae in the text are indicated by [. . .].

Ludlul Bêl Nimeqi (Sumerian Wisdom Text: *Man and His God*) (ca. 1700 BCE)*

Zugagib, one of the early kings of Sumer, is said to have ruled for 840 years. His story in this excerpt provides striking images of suffering and the attendant amelioration that healing can offer. Many scholars believe this document to be an early source for the biblical tale of Job.

53. [He who made woman] and created man Marduk, has ordained (?) that he be encompassed with sickness (?) [. . .]

54. And [. . .] in whatever [. . .]
He said: "How long will he be in such great affliction and distress?
What is it that he saw in his vision of the night?"
"In the dream Ur-Bau appeared
A mighty hero wearing his crown

55. A conjurer, too, clad in strength,
Marduk indeed sent me;
Unto Shubshi-meshri-Nergal he brought abundance;
In his pure hands he brought abundance. . . ."

58. . . . He approached (?) and the spell which he had pronounced (?) . . .

59. He sent a storm wind to the horizon;
To the breast of the earth it bore a blast
Into the depth of his ocean the disembodied spirit vanished (?);
Unnumbered spirits he sent back to the under-world.
The [. . .] of the hag-demons he sent straight to the mountain.

60. The sea-flood he spread with ice;
The roots of the disease he tore out like a plant.
The horrible slumber that settled on my rest
Like smoke filled the sky [. . .]
With the woe he had brought, unrepulsed and bitter, he filled the earth like a storm.

61. The unrelieved headache which had overwhelmed the heavens
He took away and sent down on me the evening dew.
My eyelids, which he had veiled with the veil of night
He blew upon with a rushing wind and made clear their sight.
My ears, which were stopped, were deaf as a deaf man's

62. He removed their deafness and restored their hearing.
My nose, whose nostril had been stopped from my mother's womb—
He eased its deformity so that I could breathe.
My lips, which were closed he had taken their strength—
He removed their trembling and loosed their bond.

63. My mouth which was closed so that I could not be understood—
He cleansed it like a dish, he healed its disease.
My eyes, which had been attacked so that they rolled together—
He loosed their bond and their balls were set right.
The tongue, which had stiffened so that it could not be raised

64. He relieved its thickness, so its words could be understood.
The gullet which was compressed, stopped as with a plug—
He healed its contraction, it worked like a flute.
My spittle which was stopped so that it was not secreted—
He removed its fetter, he opened its lock.

The Omen Series Summa Izbu

(ca. 1300 BCE)*

These tablets, compiled in the Mesopotamian region over a period of 2000 years, recorded predictions of good or bad events (including events of national significance) thought to be signaled by the birth of a human or animal with a physical deformity. According to Leichty, "Late in the Middle Babylonian period," the records were systematized in order "to cover all the possible [occurrences] of abnormal births" (p. 24). Some examples not included in the excerpt include the following: "If a woman of the palace gives birth to a deaf child—the possessions of the king will be lost" (p. 70), and "If a woman of the palace gives birth, and (the child) has six fingers on its left hand, the prince will plunder the land of his enemy" (p. 71).

If a woman is pregnant, and her foetus cries—the land will experience mis-fortune.

If a woman gives birth to a male idiot—troubles; scattering of the house of the man.

If a woman gives birth to a female idiot—the house of the man will [. . .]

If a woman gives birth to a male dwarf—troubles; the house of the man will be scattered.

If a woman gives birth to a female dwarf—correspondingly.

If a woman gives birth to a boy cripple—the house of the man will suffer.

If a woman gives birth to a girl cripple—the house of the man will be scattered; ditto (i.e., will suffer).

If a woman gives birth to a male form—good news will arrive in the land.

If a woman gives birth to a female form—that house will get ahead; he (i.e., the father) will have good luck.

If a woman gives birth to a blind child—the land will be disturbed; the house of the man will not prosper.

If a woman gives birth to [. . .]—that city will experience destruction outside (?).

If a woman gives birth to a cripple (lit. a contorted one)—the land will be disturbed; the house of the man will be scattered.

If a woman gives birth to a deaf child—that house will prosper outside (of its city).

Source: Pritchard, James B., ed. 1958. Pp. 148–160 in *The Ancient Near East: Volume II. A New Anthology of Texts and Pictures.* Princeton, NJ: Princeton University Press.

*A word followed by "(?)" indicates uncertainty on the part of the translator. Lacunae in the text are indicated by [. . .].

If a woman gives birth to a giant, either male or female—a sinful man impregnated that woman in the street.

If a woman gives birth to a child with two faces—the reign of a despotic king will be changed.

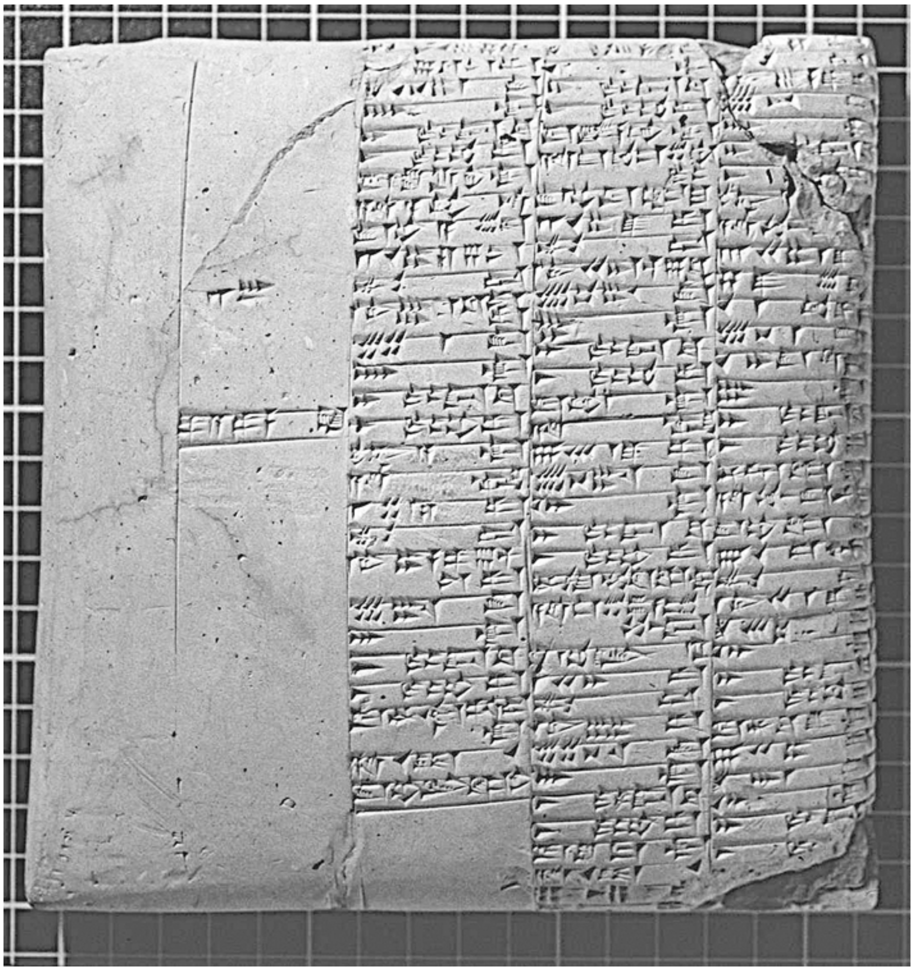
If a woman gives birth to an albino (?)—that house will not prosper.

If a woman gives birth to half of a human form—that house will be scattered.

If a woman gives birth, and (the child) is half a cubit tall, he is bearded, he can talk, he can walk, and he has teeth; his is called "*tigrilu*"—reign of Nergal; a fierce attack; there will be a mighty person in the land; pestilence; one street will be hostile to the other; one house will plunder the other.

If a woman gives birth to two boys—there will be hard times in the land; the land will experience unhappiness; there will be bad times for the house of their father.

If a woman gives birth to two boys, and they have one abdomen (between them)—(there will be) dissension (between) man and wife; the house [. . .].



Ancient Sumerian cuneiform tablet (1300 BCE) describing a science of foretelling future events from the features of disabled fetuses and irregularly shaped animal livers.

Source: British Museum, London. Photo credit: Sharon Snyder.

If a woman gives birth to two (children), and they are joined like the "Bull(god), son of Samas"—the king will conquer his enemies.

If a woman gives birth to two (children), and they are connected at their spine, but their faces are opposite (each other)—the land's gods will leave it; (there will be) dissension (between) the king and his sons.

If a woman gives birth to two (children), and they have neither nose nor feet—the land of the king will become waste.

If a woman gives birth to twins for a second time—that land will disappear; the house of the man will be scattered.

If a woman gives birth to twins, and they are joined at their rib(s)—two will rule the land which one ruled.

If a woman gives birth to twins, and they are joined at their rib(s), and the right one has no right hand—an enemy will defeat me in battle, and diminish the land, (and) make it weak; he will defeat my army.

If a woman gives birth to twins, and ditto (i.e. they are joined at their ribs), and the left one has no left hand—you will defeat the enemy in battle, and correspondingly.

Source: Leichty, Erle, ed. and trans. 1970. *The Omen Series Summa Izbu*. Locust Valley, NY: Augustin.

*A word followed by "(?)" indicates uncertainty on the part of the translator. Lacunae in the text are indicated by [. . .].

The god Besh, usually shown as a dwarf, is a domestic god, protector of women in childbirth, and is also associated with music and dance.

Source: Temple of Hathor, Dendera, Egypt. Photo credit: Erich Lessing/Art Resource, New York.

Nabonidus and His God (539 BCE)

The excerpt below records a fragment of the words of the prayer said by King Nabonidus of Babylonia after being cured of the ulcer that had afflicted him for seven years. Two facts about Nabonidus can be corroborated by referring to other texts: Nabonidus was believed to have a mental illness, and he insulted the Babylonian clergy by being monotheistic. The text below may have been modified to fit the prohibitions on priestly purity identified in Leviticus.

Words of the prayer, said by Nabonidus, king of Babylonia, the great king, when afflicted with an ulcer on command of the most high God in Temâ:

I, Nabonidus, was afflicted with an evil ulcer for seven years, and far from men I was driven, until I prayed to the most high God. And an exorcist pardoned my sins. He was a Jew from among the children of the exile of Judah, and said: "Recount this in writing to glorify and exalt the name of the most high God." Then I wrote this: "When I was afflicted for seven years by the most high God with an evil ulcer during my stay at Temâ, I prayed to the gods of silver and gold, bronze and iron, wood, stone and lime, because I thought and considered them gods [. . .]

Source: Pritchard, James B., ed. 1958. Pp. 108–112 in *The Ancient Near East: Volume II. A New Anthology of Texts and Pictures.* Princeton, NJ: Princeton University Press.

The Zend-Avesta

(6th c. BCE ?)

The Avesta, the earliest sacred text of Zoroastrianism, dates possibly from the sixth century BCE, and its meanings are not entirely transparent to modern interpreters. One section, the Vendidad (more correctly transcribed as Videvdat), gives an early sketch of an imagined "new world," utopia, or paradise, from which disability, disease, and behavioral weaknesses are excluded, perhaps by selective breeding or eugenics (Vendidad, Fargard II, 27–37, pp. 17–19 in this translation). The disabilities and unpleasant behavior seem to be attributed to the activity of Angra Mainyu, the power of darkness in the Avestan cosmology. Some interpreters understand the list of "disabilities" as referring to moral depravity rather than to physical impairment.

Fargard II

21 (42). The Maker, Ahura Mazda, of high renown in the Airyana Vaêgô, by the good river Dâitya, called together a meeting of the celestial gods.

The fair Yima, the good shepherd, of high renown in the Airyana Vaêgô, by the good river Dâitya, called together a meeting of the excellent mortals.

To that meeting came Ahura Mazda, of high renown in the Airyana Vaêgô, by the good river Dâitya; he came together with the celestial gods.

To that meeting came, the fair Yima, the good shepherd, of high renown in the Airyana Vaêgô, by the good river Dâitya; he came together with the excellent mortals.

22 (46). And Ahura Mazda spake unto Yima, saying:

'O fair Yima, son of Vîvanghat! Upon the material world the fatal winters are going to fall, that shall bring the fierce, foul frost; upon the material world the fatal winters are going to fall, that shall make snowflakes fall thick, even an aredvî deep on the highest tops of mountains.

23 (52). And all the three sorts of beasts shall perish, those that live in the wilderness, and those that live on the tops of the mountains, and those that live in the bosom of the dale, under the shelter of stables.

24 (57). Before that winter, those fields would bear plenty of grass for cattle: now with floods that stream, with snows that melt, it will seem a happy land in the world, the land wherein footprints even of sheep may still be seen.

25 (61). Therefore make thee a Vara, long as a riding-ground on every side of the square, and thither bring the seeds of sheep and oxen, of men, of dogs, of birds, and of red blazing fires.

Therefore make thee a Vara, long as a riding-ground on every side of the square, to be an abode for men; a Vara, long as a riding-ground on every side of the square, to be a fold for flocks.

26 (65). There thou shalt make waters flow in a bed a hâthra long; there thou shalt settle birds, by the evergreen banks that bear never-failing food. There thou shalt establish dwelling places, consisting of a house with a balcony, a courtyard, and a gallery.

27 (70). Thither thou shalt bring the seeds of men and women, of the greatest, best, and finest kinds on this earth; thither thou shalt bring the seeds of every kind of cattle, of the greatest, best, and finest kinds on this earth.

28 (74). Thither thou shalt bring the seeds of every kind of tree, of the greatest, best, and finest kinds on this earth; thither thou shalt bring the seeds of every kind of fruit, the fullest of food and sweetest of odour. All those seeds shalt thou bring, two of every kind, to be kept inexhaustible there, so long as those men shall stay in the Vara.

29 (80). There shall be no humpbacked, none bulged forward there; no impotent, no lunatic; no poverty, no lying; no meanness, no jealousy; no decayed tooth, no leprous to be confined, nor any of the brands wherewith Angra Mainyu stamps the bodies of mortals.

30 (87). In the largest part of the place thou shalt make nine streets, six in the middle part, three in the smallest. To the streets of the largest part thou shalt bring a thousand seeds of men and women; to the streets of the middle part, six hundred; to the streets of the smallest part, three hundred. That Vara thou shalt seal up with the golden ring, and thou shalt make a door, and a window self-shining within.

31 (93). Then Yima said within himself: 'How shall I manage to make that Vara which Ahura Mazda has commanded me to make?'

And Ahura Mazda said unto Yima: 'O fair Yima, son of Vîvanghat! Crush the earth with a stamp of thy heel, and then knead it with thy hands, as the potter does when kneading the potter's clay.'

32. And Yima did as Ahura Mazda wished; he crushed the earth with a stamp of his heel, he kneaded it with his hands, as the potter does when kneading the potter's clay. [Paragraph 32 is found in an alternate version of the text.]

33 (97). And Yima made a Vara, long as a riding-ground on every side of the square. There he brought the seeds of sheep and oxen, of men, of dogs, of birds, and of red blazing fires. He made Vara, long as a riding-ground on every side of the square, to be an abode for men; a Vara, long as a riding-ground on every side of the square, to be a fold for flocks.

34 (101). There he made waters flow in a bed a hâthra long; there he settled birds, by the evergreen banks that bear never-failing food. There he established dwelling places, consisting of a house with a balcony, a courtyard, and a gallery.

35 (106). There he brought the seeds of men and women, of the greatest, best, and finest kinds on this earth; there he brought the seeds of every kind of cattle, of the greatest, best, and finest kinds on this earth.

36 (110). There he brought the seeds of every kind of tree, of the greatest, best, and finest kinds on this earth; there he brought the seeds of every kind of fruit, the fullest of food and sweetest of odour. All those seeds he brought, two of every kind, to be kept inexhaustible there, so long as those men shall stay in the Vara.

37 (116). And there were no humpbacked, none bulged forward there; no impotent, no lunatic; no poverty, no lying; no meanness, no jealousy; no decayed tooth, no leprous to be confined, nor any of the brands wherewith Angra Mainyu stamps the bodies of mortals.

38 (123). In the largest part of the place he made nine streets, six in the middle part, three in the smallest. To the streets of the largest part he brought a thousand seeds of men and women; to the streets of the

middle part, six hundred; to the streets of the smallest part, three hundred. That Vara he sealed up with the golden ring, and he made a door, and a window self-shining within.

39 (129). O Maker of the material world, thou Holy One! What (lights are there to give light) in the Vara which Yima made? [The material in parentheses is found in an alternate version of the text.]

40 (131). Ahura Mazda answered: 'There are uncreated lights and created lights. There the stars, the moon, and the sun are only once (a year) seen to rise and set, and a year seems only as a day.

41 (33). 'Every fortieth year, to every couple two are born, a male and a female. And thus it is for every sort of cattle. And the men in the Vara which Yima made live the happiest life.'

42 (137). O Maker of the material world, thou Holy One! Who is he who brought the law of Mazda into the Vara which Yima made?

Ahura Mazda answered: 'It was the bird Karshipta, O holy Zarathu*s*tra!'

43 (140). O Maker of the material world, thou Holy One! Who is the lord and ruler there?

Ahura Mazda answered: 'Urvata*d*-nara, O Zarathu*s*tra! and thyself, Zarathu*s*tra.'

Source: Darmesteter, James, trans. 1880. *Sacred Books of the East: Vol. 4. The Zend-Avesta: Part I. The Vendidad.* Oxford, UK: Oxford University Press.

The Uruk Incantation
(ca. 3rd c. BCE)

The Uruk incantation is an example of spoken chants offered by incantation priests in temple. It may have been written around 1600 BCE by Sin-leqe-unnini, the master scribe of the Gilgamesh epic during the Kassite period in Mesopotamia. The following excerpt invokes miraculous cures for various disabilities.

I have taken a (magic) bond from the wooden roof, in silence, from the threshold of the gate. I have put it underneath my tongue. I have entered a house full of words, a tongue-tied table, a mixing bowl (full) of poison. When they saw me, the house full of words fell silent, the tongue-tied table was upset, the mixing bowl (full) of poison was poured out.

I have been successful, and I am successful . . . before adults and children, women and men, . . . and those assembled and sitting at the gate, before so-and-so, from *everything.*

Remove, drive out pains! Defective one, be wh(ole)! Lame one, run! Find companions, excessive one! *Finally*, (you all) rise!

Speak, dumb one! Rise, silent one!

Who is angry, who is enraged, who is clothed in the garment of anger, (has) fire in his mouth, (has) *mixtures (of spittle)* underneath his tongue? So-and-so, the son of so-and-so, is angry and enraged, is clothed in the garment of anger, (has) fire in his mo[uth], (has) *mixtures (of spittle)* underneath his tongue, I am wise . . .

I have taken a (magic) knot from [*the threshold?*], soundless(ly), from the room [(*below*) *the roof*]. I have entered into the presence of so-and-so . . . I have made him take off the garment of anger. I have clothed him in the garment of . . . I have taken the fire from his mouth, the *mixtures (of spittle)* from underneath [his tongue]. My good things from his mouth [*come forth*], my evil things from *his posterior* [. . .], before adults and children, women and men, [. . . and those assembled] and sitting at the gate, and before s[o-and-so . . .].

[*Remove, drive out pains!*] Defective one, [be whole]! Lame one, run! Find companions, excessive one! *Finally,* (you all) rise!

Speak dumb one! Rise, silent one!

Source: Pritchard, James B., ed. 1958. Pp. 220–221 in *The Ancient Near East: Volume II. A New Anthology of Texts and Pictures.* Princeton, NJ: Princeton University Press.

Story of Enkidu (Wolf Child)
(2nd c. BCE)

The Epic of Gilgamesh, possibly from the second millennium BCE, appears to include an early description of a "feral child and young man" named Enkidu. He is primitive and hairy, was raised on wild asses' milk, eats grass with gazelles and drinks at cattle's water holes, and is unfamiliar with ordinary human food and drink. After his seduction and education by a temple prostitute, Enkidu joins Gilgamesh in his quest. He experiences an episode of paralysis but recovers and helps his friend in battle. Many conflicting interpretations of this part of the epic have been proposed.

So the Goddess of Creation took and formed in her mind
This image, and there it was conceived—in her mind, and it was made of material
That composes the Great God,
He of the Firmament.
She then plunged her hands down into water and pinched off a little clay.
She let it drop in the wilderness
Thus the noble Enkidu was made. For this was he the very strength of Ninurta, the God of War, was his form, rough bodied, long hair,
His hair waved like corn filaments—Yes, like the hair of that goddess
Who is the corn, she, Nisaba. Matted hair was all over his body, like the skins of the cattle.
Yes, like the body of that god.
Who is the cattle, he, Samugan.
This Enkidu was innocent of mankind.
He knew not the cultivated land.
Enkidu was in the hills
With the gazelles—
They jostled each other
With all the herds
He too loved the water-hole.
But one day by a water hole
A trapper met him
Yes, face to face,
Because the herds of wild game
Had strayed into his territory.
On three days face to face—
Each day the trapper was terrified,
Frozen stiff with fear.
With his game he went home,
Unable to speak, numb with fright.
The trapper's face altered, new—
A long journey does that to one,
Gives a new visage upon returning—
The trapper, his heart all awe, told his father:
'Father, what a man! No other like him! He comes from the hills, strongest alive!
A star in heaven his strength,
Of the star essence of An, the Sky Father
Over the hills with the beasts
Eating grass
Ranges across all your land,
Goes to the wells.
I fear him, stay far away.
He fills in my pits
Tears up my game traps
Helps the beasts escape;
Now all the game slips away—
Through my fingers.'
His father opened his mouth,
Told the son, the trapper:
'My son, in Uruk lives Gilgamesh.
None can withstand him,
None has surpassed him,
As a star in heaven his strength
Of the star-essence of An, the Sky Father.
Go to Uruk, find Gilgamesh
Praise the wild man's strength ask for a temple hierodule from the Temple of Love,
Such a child of pleasure;
Bring her and let her power of woman
Subdue this wild man.
When he goes to the wells,
He will embrace the priestess
And the wild beasts will reject him.'
To Uruk the trapper went
And said to Gilgamesh:
'Like no other, wild,
Roaming in the pastures,
A star in heaven his strength
Of the star-essence of An, the Sky Father.
I am afraid, stay far away; he helps the beasts escape
Fills in my pits
Tears up my game traps.'
Gilgamesh said:
'Trapper, return,
Take a priestess, child of pleasure—
When he goes to the wells
He will embrace the priestess
And the wild beasts will reject him.'
Then returned with the hierodule
And three days to the drinking hole,
There sat down
Hierodule facing the trapper,
Waiting for the game.
First day, nothing.
Second day, nothing.
Third day, yes.
The herds came to drink, and Enkidu—
Glad for the water were the small wild beasts,
And Enkidu was glad for the water—
He of the gazelles and wild grass,
Born in the hills.
The priestess saw this man
Wild from the hills.
'There, woman,' the trapper,

'Bare your breasts now;
This is he,
Have no shame, delay not,
Welcome his love,
Let him see you naked,
Let him possess your body.
As he approaches, take off your clothes,
Lie with him, teach him,
The savage, your art of woman,
For as he loves you, then
The wild beasts, his companions,
They will reject him.'
She had no shame for this,
Made herself naked
Welcomed his eagerness
Incited him to love,
Taught the woman's art.
Six days, seven nights,
That time lying together,
Enkidu had forgotten his home
Had forgotten the hills
After that time he was satisfied.
Then he went back to the wild beasts—
But the gazelles saw him and ran,
The wild beasts saw him and ran.
Enkidu would follow, but weak,
His strength gone through woman;
Wisdom was in him,
Thoughts in his head— a man's.
So he returned to the priestess.
At her feet he listened intently
'You have wisdom, Enkidu.
Now you are as a god.
Why the beasts? Why the hills?
Come to Uruk of the strong walls
To Inanna's Temple of Love,
And to the Eanna,
Where the Sky God An can be found.
Gilgamesh is there, strong,
Raging like a wild bull, over all
Is his strength.'
Favourably as he speaks, he hears her words.
He comes to know his own heart
And his desire to find a friend.
He tells her, the priestess:
'Take me, girl, to the sacred pure
Dwelling of Love and Sky God's house
Where lives Gilgamesh of perfect strength,
He who rages like a bull over all,
And I will summon him forth and challenge him
And I will shout in Uruk:
"I am the mightiest!
Yes, I can change the order of what is!
Anyone born on the steppe is mighty and has strength"'
'Then let us go that he may see your face
And I will show you Gilgamesh, for I know well where he is.
Come Enkidu, to Uruk of ramparts,
Where all are dressed for festival,
Where each day is a festival,
Where there are boys,
Where there are girls,
Deliciously ripe and perfumed,
Who drive the great ones from their fretted couches
To you, Enkidu, of joy in life
I will show Gilgamesh of joy in life
See him, see his face
Radiant is his manhood, of full-bodied vigour
His body ripe with beauty in every part.
So exceeding you in strength,
Needing no sleep by day or by night.
Restrain your folly, Enkidu.
Gilgamesh—Shamash the Sun is proud,
Also An, the God of Firmament,
Also valiant Enlil, his son,
And Enki, his son also—
All have given wisdom.
Before you come from the open plains
Gilgamesh will have dreamed of it.'
And so Gilgamesh rose from his bed
And to his mother, in revealing dreams, said:
'Mother, I saw in a dream last night
That there were stars in heaven
And a star descended upon me like unto
The essence of An, the Sky God.
I tried to lift it up, but it was too heavy for me,
I tried to move it, but it would not be moved.
The land of Uruk was around it,
The land was placed round about it.
All the people were pressing towards it.
All the nobles also came round it,
And all my friends kissed its feet.
I was drawn towards it as to a woman
And I laid it at your feet
And you said it was my equal.'
She, the Wise, the Custodian of Knowledge,
Says to her lord—
She, Ninsun, Custodian of Knowledge,
Says to Gilgamesh:

'Your equal was a star of heaven
Which descended upon you like unto
The essence of An who is the God of the Firmament
You tried to lift it but it would not be moved
And I called it your equal, comparing it to you.
You were drawn to it as to a woman.
The meaning of this
Is of a strong friend who saves his companion
He is the strongest of the land; he has strength.
As a star in heaven his strength,
The strength of An of the Firmament and his host.
So that you are drawn to him overwhelmingly.
And this means he will never forsake you.
Such is your dream.'
Gilgamesh says again to his mother:
'Mother, another dream
In Uruk of the ramparts lay an axe—All were gathered around it,
Uruk-land was standing round about it.
The people pressed towards it;
I laid it at your feet.
I was drawn to it as to a woman.
For you called it my equal.'
She, the Wise Custodian of Knowledge, says to her son—
'The axe is a man
You were drawn to it as to a woman
For I called it your equal
And it was to rival you.
This means a strong friend standing by his friend
He is the strongest of the land; he has strength.
The essence of An of the Firmament, is his,
So strong is he.'
Gilgamesh then spoke to his mother
'Now according to the word of God Enlil
Let a counsellor and friend come to me
That I may acquire a companion
And to him I shall be friend and counsellor also.'
And as Gilgamesh revealed his dream
The girl was speaking to Enkidu
As they sat together.

Source: Temple, Robert, trans. 1991. *The Epic of Gilgamesh.* London: Rider.

The Ancient World: South Asia

Caraka Samhita
(400–200 BCE)

This ancient text, which helped establish the philosophical foundations of Indian medicine, describes the ideal characteristics of a physician. According to the Caraka, health and disease are not necessarily predetermined, and life may be prolonged by human efforts.

3.8.8: He should be peaceful, noble in disposition, incapable of any mean act, with straight eyes, face and nose, with slim body, having a clean and red tongue, without distortion of teeth or lips, with clear voice (i.e. with voice neither indistinct nor nasal), preserving, without egotism, intelligent, endowed with powers of reasoning and good memory, with broad mind, inclined to medical study either because of being born in the family of physicians or by natural aptitude, with eagerness to have the knowledge of truth, with no deformity of body and no defect of sense-organs, by nature modest and gentle, contemplating on the true nature of things, without anger and without addiction, endowed with good conduct, cleanliness, good habits, love, skill and courtesy, desirous of the welfare of all living beings, devoid of greed and laziness and having full loyalty and attachment to the teacher.

4.2.31–38: The mind is indeed bound by passion and ignorance and, in the absence of knowledge, all disorders are brought about by them. This mind along with its disorders and the force of past actions are the causes of transmigration of the self from life to life as well as for righteous and unrighteous conduct.

Source: Sharma, P. V., trans. 1981. Pp. ix–xxxii in *Caraka Samhita.* Varanasi, India: Chaukhamba Orientalia.

Jataka Tales: "The Tricky Wolf and the Rats" (3rd C. BCE)

The Buddhist Jatakas consist of some 538 lively stories of events during the incarnations of the Buddha, compiled perhaps in the third century BCE. *They were handy teaching tools, ranging from short to very long, each embodying one or more moral lessons. Itinerant monks spread them across South and East Asia over centuries, and many different language versions exist. Several Jatakas are specifically on disability themes, and disabled people appear casually in many others. Some portray unexpected features, such as a warrior dwarf, a cripple who is an ace stone-thrower, and a blind sea pilot who sees more with his hands than other men do with two eyes.*

Once upon a time a Big Rat lived in the forest, and many hundreds of other Rats called him their Chief.

A Tricky Wolf saw this troop of Rats, and began to plan how he could catch them. He wanted to eat them, but how was he to get them? At last he thought of a plan. He went to a corner near the home of the Rats and waited until he saw one of them coming. Then he stood up on his hind legs.

The Chief of the Rats said to the Wolf, "Wolf, why do you stand on your hind legs?"

"Because I am lame," said the Tricky Wolf. "It hurts me to stand on my front legs."

"And why do you keep your mouth open?" asked the Rat.

"I keep my mouth open so that I may drink in all the air I can," said the Wolf. "I live on air; it is my only food day after day. I can not run or walk, so I stay here. I try not to complain." When the Rats went away the Wolf lay down.

The Chief of the Rats was sorry for the Wolf, and he went each night and morning with all the other Rats to talk with the Wolf, who seemed so poor, and who did not complain.

Each time as the Rats were leaving, the Wolf caught and ate the last one. Then he wiped his lips, and looked as if nothing had happened.

Each night there were fewer Rats at bedtime. Then they asked the Chief of the Rats what the trouble was. He could not be sure, but he thought the Wolf was to blame.

So the next day the Chief said to the other Rats, "You go first this time and I will go last."

They did so, and as the Chief of the Rats went by, the Wolf made a spring at him. But the Wolf was not quick enough, and the Chief of the Rats got away.

"So this is the food you eat. Your legs are not so lame as they were. You have played your last trick, Wolf," said the Chief of the Rats, springing at the Wolf's throat. He bit the Wolf, so that he died.

And ever after the Rats lived happily in peace and quiet.

Source: Babbitt, Ellen C., trans. 1922. "The Tricky Wolf and the Rats." Pp. 11–14 in *More Jataka Tales.* New York: Appleton-Century.

▣ *The Mahabharata*

(3rd c. BCE)

The blind King Dhritarashtra appears throughout the Mahabharata—not really in the battle books, but he is there in the background having the awful scenes verbally described to him, which is how we also get to hear about it all. Some mention is included of "idiots," "stupidity," "fools," "undeveloped mind," and so forth, yet it is clear that the use of such terms ranges from descriptions of people with what is now called mental handicap or intellectual disability (identifiable through references to a lack of spiritual discernment) to mere personal abuse.

Adi Parva

[Editor's note: The following provides paraphrases of relevant sections of the *Mahabharata,* with explanatory notes in brackets where necessary and occasional quotations for especially important points.]

[Several reasons were offered to explain Dhritarashtra's blindness, as follows.]

I Dhritarashtra refers to his blindness as being among the reasons why he could not prevent the dispute between his sons and nephews.

LXVII Dhritarashtra was blind through his mother's fault and the wrath of the Rishi.

CVI [Note that in this section, for *blind,* J. A. B. van Buitenen's translation (1973, 1975) has "with the eyesight of wisdom."] To perpetuate the Bharata line the Rishi Dwaipayana (Vyasa) is called upon to impregnate the widows of his half-brother Vichitravirya. The first of these princesses, afraid of the rishi's grim appearance, closes her eyes in fear and keeps them shut. The son (Dhritarashtra) is thereby doomed to be born blind. The second widow keeps her eyes open, but she is pale with fear. Her son, Pandu (i.e., "the pale") is therefore pale. The first widow is later asked to try for a second son, but she sends her Sudra maid instead. From her, Vidura is born.

[Debates ensue about blindness as an appropriate reason to exclude Dhritarashtra from becoming king.]

CIX Pandu becomes king, Dhritarashtra being disqualified by his blindness, Vidura by having a Sudra mother.

CX King Suvala, with some qualms, gives his daughter Gandhari to wed the blind Dhritarashtra. Gandhari takes to wearing a blindfold, through respect for her future husband.

CXXXVI Dhritarashtra regrets that, because he is blind, he cannot see the weapons skills display given by his sons on the completion of their education. As it proceeds, Vidura describes the feats to Dhritarashtra, Kunti and Gandhari.

CXLIII Discussion of whether it was right that Dhritarashtra, being blind, took over the kingdom after Pandu's death.

CXLVII Blind men given as an example of ignorance.

Sabha Parva

[Editor's note: Early medical attitudes toward human variation and further discrimination experienced by Dhritarashtra.]

V Instruction from the Rishi Narada to King Yudhishthira includes the questions:

> Seekest thou to cure bodily diseases by medicines and fasts, and mental illness with the advice of the aged? I hope that the physicians engaged in looking after thy health are well conversant with the eight kinds of treatment and are all attached and devoted to thee.

Bodhisattva Avalokitesvara with 1,000 arms. One definition of disability identifies social perceptions of human forms based on too much or too little body. The supernatural powers of gods are often identified in this manner, but it is unclear what impact this presentation mode had on the experiences of disabled people of the time. Frontal view. Chinese wood sculpture, 160 120 50 cm.

Source: Musée des Arts Asiatiques-Guimet, Paris. Photo by Thierry Ollivier. Photo credit: Réunion des Musées Nationaux/Art Resource, New York.

V “Cherishest thou like a father, the blind, the dumb, the lame, the deformed, the friendless, and ascetics that have no homes?”

X The husband of Uma, three-eyed Mahadeva, is described as being surrounded by hundreds and thousands of spirits, “some of dwarfish stature, some of fierce visage, some hunch-backed,” and so on.

XVII Vrihadratha, king of Magadha, marries twin wives but has no son. He obtains a blessed mango, which his wives divide and eat. They conceive, and each bears half a baby, which their two midwives wrap and throw out at the back door. A rakshasa woman, Jara, collects and unites the pieces, which then become a living child, Jarasandha.

XXIII Before unarmed combat between Jarasandha and Bhima, a priest brings “various excellent medicines for restoring lost consciousness and alleviating pain.”

XXX Among various conquests by Sahadeva is “a wild tribe by the name of the Kerakas who were men with one leg.”

XLII Sisupala is born with three eyes and four hands. His parents, the king of Chedi and his wife, consider abandoning the child, but a voice forbids them. Many visitors come to see the monster. Later the child’s spare arms fall off and the third eye disappears when he is placed on the lap of Damodara.

L Among the visitors failing to gain admission to the court of King Yudhishthira are some tribes with three eyes, some with eyes on their foreheads, and many with only one leg.

LI Yajnaseni (Draupadi) daily attends to the needs of everybody, “including even the deformed and the dwarfs,” before taking food herself.

LV The “weak-minded” Dhritarashtra, “deprived of reason by Fate,” gives in to the plan to seize the wealth of Pandu’s sons by gambling.

LXIII Vidura, knowing that his rebukes to Dhritarashtra and Duryodhana are unwelcome, tells the king that “if thou wishest to hear words that are agreeable to thee, in respect of all acts good or bad, ask thou women and idiots and cripples or persons of that description.”

LXXII Dhritarashtra, trying to placate Pandu’s sons after their defeat in the first gambling match, appeals to them with the fact that he is “old and blind.”

LXXX Sanjaya remarks to Dhritarashtra, about Duryodhana, that “The gods first deprive that man of his reason unto whom they send defeat and disgrace.”

Vana Parva

II Saunaka counsels Yudhishthira for depression:

> Sensible physicians first seek to allay the mental sufferings of their patients by agreeable converse and the offer of desirable objects. And as a hot iron bar thrust into a jar makes the water therein hot, even so doth mental grief bring on bodily agony. And as water quenches fire, so doth true knowledge allay mental disquietude. And the mind attaining ease, the body findeth ease also.

XLIX Dhritarashtra complains that "seeing me void of eye-sight, and incapable of exerting myself actively, my wretched son, O charioteer, believeth me to be a fool, and listeneth not to my words."

LXX King Nala, after abandoning his wife Damayanti, goes to Ayodhya and becomes charioteer to king Rituparna. He adopts the name Vahuka, his appearance becomes "unsightly," and he has short arms as a result of an encounter with a snake (LXVI). [Others say he became a dwarf or was "deformed."]

CVII People were harassed by the "dull-headed sons of Sagara." One of them, Asamanjas, "used to seize by the throat the feeble children of the townsmen, and threw them while screaming into the river."

CXIX Valarama censures Dhritarashtra's behavior, saying that "He doth not now see with his mind's eye how he hath become so sightless, and on account of what act he hath grown blind among the kings of this entire earth."

CXXXII–CXXXIV Account of Ashtavakra (i.e., "crooked in eight parts of the body"). The learned Kahoda's wife becomes pregnant. The fetus, already well-versed in the Vedas, criticizes mistakes in his father's reading, causing Kahoda to curse his child to be crooked in eight parts. The sage is then defeated in debate by Vandin and forfeits his life at the court of king Janaka. Later, Ashtavakra goes to Janaka but is turned away by a warder. Ashtavakra asserts his right of way, as a Brahmin, over "the blind, the deaf, the women, carriers of burdens, and the king respectively." He gains admittance and defeats Vandin in debate. Kahoda reappears and says, "Weak persons may have sons endued with strength; dunces may have intelligent sons; and the illiterate may have sons possessed of learning." Later, Ashtavakra enters the river Samanga, and his limbs are straightened.

CXXXVI–CXXXVII Yavakri, attempting to flee into his father's Agnihotra room, is prevented and seized by "a blind Sudra warder."

CXLIX Among advice on statecraft, from Hanuman to Bhima: In secret affairs, women, sots, boys, covetous or mean-minded persons, and "he that betrayeth signs of insanity" should not be consulted. Dunces "should in all affairs be excluded."

CLXLIX Advice on religious practice from Markandeya to King Yudhishthira: "If they that are to be employed in *Sraddhas* happen to be dumb, blind, or deaf, care should be taken to employ them along with Brahmanas conversant with the Vedas."

CCVI Markandeya connects the decay of virtue to kingly sins:

> And when all this taketh place the subjects of the kingdom begin to decay. And it is then, O Brahmana, that ill-looking monsters, and dwarfs, and hunchbacked and large-headed wights, and men that are blind or deaf or those that have paralysed eyes or are destitute of the power of procreation, begin to take their birth. It is from the sinfulness of kings that their subjects suffer numerous mischiefs.

> CCVIII
>
> The diseases from which man suffer, are undoubtedly the result of their own *karma.* They then behave like small deer at the hands of hunters, and they are racked with mental troubles. And, O Brahmana, as hunters intercept the flight of their game, the progress of those diseases is checked by able and skilful physicians with their collections of drugs.

CCXXIX Various spirits are described that oppress children. Some causes of madness are given, such as seeing gods in a dream.

> The man who loses his reason on account of his mind being demoralised with vices, runs mad in no time, and his illness must be remedied according to methods prescribed in the *Sastras*. Men also run mad from perplexity, from fear, as also on beholding hideous sights. The remedy lies in quieting their minds. There are three classes of spirits, some are frolicsome, some are gluttonous, and some sensual. Until men attain the age of three score and ten, these evil influences continue to torment them, and then fever becomes the only evil spirit that afflicts sentient beings.

CCLXLII–CCLXLVI Savitri marries the son of blind, exiled King Dyumatsena. When Yama comes to take her husband, Savitri pleads strongly with him, obtaining a return of the eyesight and kingdom of Dyumatsena and eventually winning back her husband's life. When Dyumatsena's usurper has been killed, his subjects demand that Dyumatsena return, saying "Whether possessed of sight or not, even he shall be our king!"

Udyoga Parva

XXX Yudhishthira, sending greetings via Sanjaya, includes the entire court of Dhritarashtra, including "the many hump-back and lame ones" among the servants, and inquires after the welfare of those who are

> defective in limb, those that are imbecile, the dwarfs to whom Dhritarashtra gives food and raiment from motives of humanity, those that are blind, and all those that are aged, as also to the many that have the use only of their hands being destitute of legs.

XXXIII Vidura, imparting wisdom proverbs to Dhritarashtra: "Of the five senses beholding to man, if one springeth a leak, then from that single hole runneth out all his intelligence, even like water running out from a perforated leathern vessel."

XXXIV Vidura to Dhritarashtra:

> He to whom the gods ordain defeat, hath his senses taken away, and it is for this that he stoopeth to ignoble deeds. When the intellect becometh dim and destruction is nigh, wrong, looking like right, firmly sticketh to the heart.

LXIV Honey from the northern mountain, Gandhamadana, which would cause a sightless man to obtain sight.

LXIX Men deprived of sense by avarice and desire, are "like blind men [falling into pits] when led by the blind."

LXXI Dhritarashtra says that he envies sighted people who may see the beauty of Vasudeva.

XCII Vidura notes that "no wise man would spend his breath for nothing, like a singer before the deaf"; he notes also that the sons of Kuru have been "blinded by prosperity and pride."

CXXX Duryodhana and friends plot to seize Krishna when he acts as the Pandavas' ambassador to Dhritarashtra. Satyaki describes them as "like idiots and children desiring to seize a blazing fire by means of their garments."

CXLVII Bhishma to Duryodhana: "Thy father was born blind, and in consequence of this congenital defect of a sense, he could not become king."

CXLIX Dhritarashtra informs Duryodhana that even his own great-grandfather Devapi, the eldest of three princes, could not inherit the kingdom because he had a skin disease. "The gods do not approve a king that is defective of a limb." [Any distinction between absent limb and skin disease is not made clear.]

Drona Parva

LI Brahma instructs Death to "kill all creatures including idiots and seers at my command."

CXLII "It is evident that with the decrepitude of the body one's intellect also becomes decrepit" [spoken as an insult].

CLXXXII One of the celestial weapons was snatched "like a fruit from the hand of a cripple, with a withered arm, by a strong person."

CCII The companions of Mahadeva (or Rudra) are

> celestial beings of diverse forms, some of whom are dwarfs, some have matted locks, some with bald heads, some with short necks, some with large stomachs, some with huge bodies, some possessed of great strength and some of long ears. All of them, O Partha, have deformed faces and mouths and legs and strange attires.

Karna Parva

IV Refers to Dhritarashtra as one "who had knowledge only for his eye"—with footnote "A respectful epithet for a blind man."

Sauptika Parva

VI

> One should not cast weapons upon kine, Brahmanas, kings, women, friends, one's own mother, one's own preceptor, a weak man, an idiot, a blind man, a sleeping man, a terrified man, one just risen from sleep, an intoxicated person, a lunatic and one that is heedless.

Stree Parva

XII When the Pandavas go to meet Dhritarashtra, Krishna presents the blind king with an iron statue, in place of Bhima. The king seizes this and crushes it in his embrace, suffering much bruising and vomiting blood as a result. He believes he has killed Bhima, and after the passion has passed, they tell him that he has destroyed an iron statue.

Santi Parva (i)

IX Yudhishthira decides to give up earthly glory. "Without conversing with anybody, I shall assume the outward form of a blind and deaf idiot, while living in contentment."

XIV Draupadi complains that Yudhishthira has gone mad:

> That person who through dullness of intellect acts in this way never succeeds in winning prosperity. The man that treads along the path of madness should be subjected to medical treatment by the aid of incense and collyrium, of drugs applied through the nose, and of other medicines.

XVI "Without doubt, mental diseases spring from physical ones. Similarly physical diseases spring from mental ones." "Goodness, passion and darkness [*sattvas, rajas, tamas*] are the three attributes of the mind. The existence of these three in harmony is the sign of [mental] health."

XXIII Story of a person who ate fruit to which he was not entitled and suffered amputation of both hands. On bathing in a sacred stream, his hands are restored.

XXV "If the Time does not come, the infant does not acquire power of speech."

XXV "They that are highly stupid and they that are masters of their souls enjoy happiness here. They however, that occupy an intermediate place suffer misery."

XXVI "That men give unto the undeserving and refrain from giving unto the deserving is due to inability to discriminate between the deserving and the undeserving. For this reason the practice of even the virtue of charity is difficult."

XXXVII A virtuous man would not make a gift [probably refers to a formal gift, not to alms] to various listed people, including to

> one that is insane, or unto a thief, or unto a slanderer, or unto an idiot, or unto one that is pale of hue, or unto one that is defective of a limb, or unto a dwarf, or unto a wicked person

XLIII "The puissant king, with great compassion, extended his favours to the destitute and the blind and the helpless by giving them food, clothes and shelter."

LXIX When the king's city is under threat, "all beggars, eunuchs, lunatics, and mimes" should be driven out of town.

LXXXIII

> There should be no dwarfs, no hump-backed persons, no one of an emaciated constitution, no one who is lame or blind, no one who is an idiot, no woman, and no eunuch, at the spot where the king holds his consultations. Nothing should move there before or behind, above or below, or in transverse directions.

XC

> When the king does not restrain vice, a confusion of castes follows, and sinful *Rakshasas,* and persons of neutral sex, and children destitute of limbs or possessed of thick tongues, and idiots, begin to take birth in even respectable families.

CLVII Might makes right, and therefore it is prudent to overlook wrongs done by a stronger person "even as one should overlook (from compassion) the acts of a child, an idiot, or one that is blind or deaf."

CLX The only problem with self-control is that "a person who has self-control is regarded by men as weak and imbecile."

CLXIII "Compassion proceeds from a sight of the helpless and miserable persons with whom the world abounds. That sentiment disappears when one understands the strength of virtue." [Compassion, like any sort of passion, is a weakness to be overcome. If a righteous person acts in a kindly way toward a disabled person, it should be out of the realization of duty, rather than because of the passing sentiment.]

Anusasana Parva (i)

XVII Reference to "the sciences of palmistry and phrenology and other branches of knowledge treating of the physical frame as the indicator of mental peculiarities."

XXIII

> All Brahmanas that have been outcasted (on account of the commission of heinous sins), as also Brahmanas that are idiots and out of mind, do not deserve to be invited to Sraddhas in which offerings are made to either the deities or the *Pitris.* That Brahmana who is afflicted with leucoderma, or he that is destitute of virility, or he that has got leprosy,

> or he that has got phthisis or he that is labouring under epilepsy (with delusions of the sensorium), or he that is blind, should not, O king, be invited.

XXIV "Thou shouldst know that man to be guilty of Brahmanicide who robs the blind, the lame, and idiots of their all."

XXVI

> Those who, although possessed of the physical ability, do not seek to have a sight of the auspicious Ganga of sacred current, are, without doubt, to be likened to persons afflicted with congenital blindness or those that are [deaf] or those that are destitute of the power of locomotion through palsy or lameness

XXVI "Verily, Ganga . . . is competent to bestow the fruition of all their wishes upon them that are blind, them that are idiots, and them that are destitute of all things."

Anusasana Parva (ii)

XXXVIII On the weaknesses of women:

> Even those women that are loved by their husbands and treated with great respect, are seen to bestow their favours upon men that are hump-backed, that are blind, that are idiots, or that are dwarfs. Women may be seen to like the companionship of even those men that are destitute of the power of locomotion or those men that are endued with great ugliness of features.

XL Sakra, capable of assuming any form, "sometimes appears as an idiot destitute of all intelligence."

LXI "The king should protect the wealth of those that are old, of those that are minors, of those that are blind, and of those that are otherwise disqualified."

LXXXV An unwise parrot is informed that a speech defect will be inflicted on it. "Like that of a child or an old man, thy speech shall be sweet and indistinct and wonderful."

XC At Sraddhas, unworthy Brahmanas should not be invited. "A Brahmana that is blind stains sixty individual[s] of the line; one that is destitute of virile power a hundred; while one that is afflicted with white leprosy stains as many as he looks upon, O king."

XCIX "One that steals a light becomes blind. Such a man has to grope through darkness (in the next world) and becomes destitute of resplendence."

CIV

> One should not taunt a person that is defective of a limb or that has a limb in excess, or one that is destitute of learning, or one that is miserable, or one that is ugly or poor, or one that is destitute of strength.

CIV Advice on the choice of a wife and the importance of avoiding

> a woman that is deficient of any limb . . . as also one that has any malformation; as also one that has been born in the race to which one's mother belongs. . . . or one that is afflicted with leprosy, or born in a family in which there has been epilepsy.

CXXVI Vishnu points out that the sight of a Brahmana of dwarfish stature is lucky, because he took such a disguise when defeating Vali.

CXLV Refers to those who do, and those who do not, make charitable gifts to blind, distressed, or mendicant people.

CXLV Why are some men born blind? Their eyes had earlier coveted their neighbor's wife.

CXLVI Even a woman can accumulate merit, if she feeds distressed, blind, or destitute Brahmanas.

Aswamedha Parva

VII A Brahmana, "raving like a lunatic," stated, "I am afflicted with a cerebral disorder, and, I always act according to the random caprices of my own mind."

XXXVI Very sinful men sink down to take birth in the brute creation, becoming

> immobile entities, or animals, or beasts of burden; or carnivorous creatures, or snakes, or worms, insects, and birds; or creatures, of the oviparous order, or quadrupeds of diverse species, or lunatics, or deaf or dumb human beings, or men that are afflicted by dreadful maladies and regarded as unclean.

Others slowly make progress upward. "Coming to sinful births and becoming Chandalas or human beings that are deaf or that lisp indistinctly, they attain to higher and higher castes."

LIX Krishna returns home, amid great celebrations: "Gifts were being ceaselessly made to those that were distressed, or blind, or helpless."

XC At the end of Yudhishthira's horse sacrifice, where "all the poor, the blind, and the helpless ones had been gratified," a mongoose arrives and announces that the horse sacrifice was worth less than the small quantity of barley given away by a certain Brahmana engaged in ascetic practices.

Asramavasika Parva

V "Apes and birds and other animals that can imitate human beings should all be excluded from the council chamber, as also idiots and lame and palsied individuals."

XV Sighted Kunti walks ahead, with eye-bandaged Gandhari's hand on her shoulder; blind Dhritarashtra follows, with his hand on Gandhari's shoulder.

XXXV Vyasa has arranged for the living to meet with the dead. He then grants sight to Dhritarashtra so that he can actually see his sons for the first time, even after they have died.

Source: Ganguli, Kisari Mohan, trans. 1883–1896. *The Mahabharata of Krishna-Dwaipayana Vyasa.* Available at http://www.sacred-texts.com/hin/maha/

The Ancient World: East Asia

▣ Analects of Confucius
(ca. 500 BCE)

These sayings of the famous Chinese philosopher Confucius were compiled and expanded after his death. In these comments, we find Confucius's notion of virtue defined by his idea of positive character traits to which one should aspire. The analects include a variety of behaviors prescribed for encounters with disabled people.

6.8: Leprosy

Po Niu was sick and Confucius came to see him. He held his hand through the window and said, "He is dying! How awful it is that this kind of man should be sick like this! How awful it is that this kind of man should be sick like this!"

9:9: Blindness

If the master saw someone in mourning, or in full ceremonial dress, or a blind person, even if they were young, he would collect himself. If he had to pass by them, he would do it quickly.

10:16: Blindness

In bed he avoids lying in the posture of a corpse. When at home he does not use ritual attitudes. When appearing before anyone in mourning, however well he knows him, he must put on altered expression, and when appearing before anyone in sacrificial garb, or a blind man, even informally, he must be sure to adopt the appropriate attitude. On meeting anyone in deep mourning he must bow across the bar of his chariot; he also bows to people carrying and he should rise to his feet. Upon hearing a sudden clap of thunder or a violent gust of wind, he must change countenance.

15.41: Blindness

The music master, Mien, having called upon him, when they came to the steps, the Master said, "Here are the steps." When they came to the mat for the guest to sit upon, he said, "Here is the mat." When all were seated, the Master informed him, saying, "So and so is here; so and so is here."

The music master, Mien, having gone out, Tsze-chang asked, saying, "Is it the rule to tell those things to the music master?"

The Master said, "Yes. This is certainly the rule for those who lead the blind."

16:6: Blindness

Confucius said: "There are three common mistakes made by those who are of rank:

(1) To speak when there is nothing to be said; this is imprudence.

(2) To be silent when there is something to be said; this is deception.

(3) To speak without paying attention to the expression on the person's face; this is called blindness."

18:5: Madness

Chieh Yü, the madman of Ch'u, came past Master K'ung, singing as he went:

Oh phoenix, phoenix
How dwindled is your power!
As to the past, reproof is idle,
But the future may yet be remedied.
Desist, desist!

Great in these days is the peril of those who fill office.

Master K'ung got down, desiring to speak with him; but the madman hastened his step and got away, so that Master K'ung did not succeed in speaking to him.

Source: Legge, James, trans. 1861. *The Chinese Classics: Analects of Confucius.* Oxford, UK: Clarendon Press.

Taoist Scripture: Chuang-Tzu
(ca. 3rd c. BCE)

These writings, dating from the fourth to second centuries BCE, include disabled people in the Seven Inner Chapters (that portion of the work considered most likely to have been written by Chuang-Tzu himself), and some of the disabled people described are depicted as being advanced on the Way. Chuang-tzu (Zhuangzi) may have been the first to imagine a social dimension to disability, suggesting that a powerful spirit may, as a result of the defects in the society in which it is born, inhabit a deformed human shape. This writing includes many disabled characters and illustrates the Taoist belief that nature should remain as it is rather than be fixed or altered by human intervention.

There was a hunchback named Su. His jaws touched his navel. His shoulders were higher than his head. His neck bone stuck out toward the sky. His viscera were turned upside down. His buttocks were where his ribs should have been. By tailoring, or washing, he was easily able to earn his living. By sifting rice he could make enough to support a family of ten. When orders came down for a conscription, the hunchback walked about unconcerned among the crowd. And similarly, in government conscription for public works, his deformity saved him from being called. On the other hand, when it came to government donations of grain for the disabled, the hunchback received as much as three chung and of firewood, ten faggots. And if physical deformity was thus enough to preserve his body until the end of his days, how much more should moral and mental deformity avail!

Deformities, or Evidence of a Full Character

In the state of Lu there was a man, named Wang T'ai, who had had one of his legs cut off. His disciples were as numerous as those of Confucius. Ch'ang Chi asked Confucius, saying, "This Wang T'ai has been mutilated, yet he has as many followers in the Lu State as you. He neither stands up to preach nor sits down to give discourse; yet those who go to him empty, depart full. Is he the kind of person who can teach without words and influence people's minds without material means? What manner of man is this?"

"He is a sage," replied Confucius, "I wanted to go to him, but am merely behind the others. Even I will go and make him my teacher,—why not those who are lesser than I? And I will lead, not only the State of Lu, but the whole world to follow him."

"The man has been mutilated," said Ch'ang Chi, "and yet people call him 'Master.' He must be very different from the ordinary men. If so, how does he train his mind?"

"Life and Death are indeed changes of great moment," answered Confucius, "but they cannot affect his mind. Heaven and earth may collapse, but his mind will remain. Being indeed without flaw, it will not share the fate of all things. It can control the transformation of things, while preserving its source intact."

"How so?" asked Ch'ang Chi. "From the point of view of differentiation of things," replied Confucius, "we distinguish between the liver and the gall, between the Ch'u State and the Yueh State. From the point of view of their sameness, all things are One. He who regards things in this light does not even trouble about what reaches him through the senses of hearing and sight, but lets his mind wander in the moral harmony of things. He beholds the unity in things, and does not notice the loss of particular objects. And thus the loss of his leg is to him as would be the loss of so much dirt."

"But he cultivates only himself," said Ch'ang Chi. "He uses his knowledge to perfect his mind, and develops his mind into the Absolute Mind. But how is it that people flock around him?"

"A man," replied Confucius, "does not seek to see himself in running water, but in still water. For only what is itself still can instill stillness into others. The grace of earth has reached only the pines and cedars; winter and summer alike, they are green. The grace of God has reached to Yao and to Shun, who alone attained rectitude. Happily he was able to rectify himself and thus become the means through which all were rectified. For the possession of one's original (nature) is evidenced in true courage.

"A man will, single-handed, brave a whole army. And if such a result can be achieved by one in search of fame through self control, how much greater courage can be shown by one who extends his sway over heaven and earth and gives shelter to all things, who, lodging temporarily within the confines of a body with contempt for the superficialities of sight and sound, brings his knowledge to level all knowledge and whose mind never dies! Besides, he (Wang T'ai) is only awaiting his appointed hour to go up to Heaven. Men indeed flock to him of their own accord. How can he take seriously the affairs of this world?"

Shent'u Chia had only one leg. He studied under Pohun Wujen ("Muddle-Head No-Such-Person") together with Tsech'an of the Cheng State. The latter said to him, "When I leave first, do you remain behind. When you leave first, I will remain behind." Next day, when they were again together sitting on the same mat in the lecture-room, Tsech'an said, "When I leave first, do you remain behind. Or if you leave first, I will remain behind. I am now about to go. Will you remain or not? I notice you show no respect to a high personage. Perhaps you think yourself my equal?"

"In the house of the Master," replied Shent'u Chia, "there is already a high personage (the Master). Perhaps you think that you are the high personage and therefore should take precedence over the rest. Now I have heard that if a mirror is perfectly bright, dust will not collect on it, and that if it does, the mirror is no longer bright. He who associates for long with the wise should be without fault. Now you have been seeking the greater things at the feet of our Master, yet you can utter words like these. Don't you think you are making a mistake?"

"You are already mutilated like this," retorted Tsech'an, "yet you are still seeking to compete in virtue with Yao. To look at you, I should say you had enough to do to reflect on your past misdeeds!"

"Those who cover up their sins," said Shent'u Chia, "so as not to lose their legs, are many in number. Those who forget to cover up their misdemeanors and so lose their legs (through punishment) are few. But only the virtuous man can recognize the inevitable and remain unmoved. People who walked in front of the bull's-eye when Hou Yi (the famous archer) was shooting, would be hit. Some who were not hit were just lucky. There are many people with sound legs who laugh at me for not having them. This used to make me angry. But since I came to study under our Master, I have stopped worrying about it. Perhaps our Master has so far succeeded in washing (purifying) me with his goodness. At any rate, I have been with him nineteen years without being aware of my deformity. Now you and I are roaming in the realm of the spiritual, and you are judging me in the realm of the physical. Are you not committing a mistake?" At this Tsech'an began to fidget and his countenance changed, and he bade Shent'u Chia to speak no more.

There was a man of the Lu State who had been mutilated, by the name of Shushan No-toes. He came walking on his heels to see Confucius; but Confucius said, "You were careless, and so brought this misfortune upon yourself. What is the use of coming to me now?" "It was because I was inexperienced and careless with my body that I hurt my feet," replied No-toes. "Now I have come with something more precious than feet, and it is that which I am seeking to preserve. There is no man, but Heaven shelters him; and there is no man, but the Earth supports him. I thought that you, Master, would be like Heaven and Earth. I little expected to hear these words from you."

"Pardon my stupidity," said Confucius. "Why not come in? I shall discuss with you what I have learned." But No-toes left. When No-toes had left, Confucius said to his disciples, "Take a good lesson. No-toes is one-legged, yet he is seeking to learn in order to make atonement for his previous misdeeds. How much more should those who have no misdeeds for which to atone?"

No-toes went off to see Lao Tan (Laotse) and said, "Is Confucius a Perfect One or is he not quite? How is it that he is so anxious to learn from you? He is seeking to earn a reputation by his abstruse and strange learning, which is regarded by the Perfect One as mere fetters."

"Why do you not make him regard life and death, and possibility and impossibility as alternations of one and the same principle," answered Lao Tan, "and so release him from these fetters?"

"It is God who has thus punished him," replied No-toes. "How could he be released?"

Duke Ai of the Lu State said to Confucius, "In the Wei State there is an ugly person, named Ait'ai (Ugly) T'o. The men who have lived with him cannot stop thinking about him. Women who have seen him, would say to their parents, 'Rather than be another man's wife, I would be this man's concubine.' There are scores of such women. He never tries to lead others, but only follows them. He wields no power of a ruler by which he may protect men's lives. He has no hoarded wealth by which to gratify their bellies, and is besides frightfully loathsome. He follows but does not lead, and his name is not known outside his own State. Yet men and women alike all seek his company. So there must be some thing in him that is different from other people. I sent for him, and saw that he was indeed frightfully ugly. Yet we had not been many months together before I began to see there was something in this man. A year had not passed before I began to trust him. As my State wanted a Prime Minister, I offered him the post. He looked sullenly before he replied and appeared as if he would much rather have declined. Perhaps he did not think me good enough for him! At any rate, I gave the post to him; but in a very short time he left me and went away. I grieved for him as for a lost friend, as though there were none left with whom I could enjoy having my kingdom. What manner of man is this?"

"When I was on a mission to the Ch'u State," replied Confucius, "I saw a litter of young pigs sucking their dead mother. After a while they looked at her, and then all left the body and went off. For their mother did not look at them any more, nor did she seem any more to have been of their kind. What they loved was their mother; not the body which contained her, but that which made the body what it was. When a man is killed in battle, his coffin is not covered with a square canopy. A man whose leg has been cut off does not value a present of shoes. In each case, the original purpose of such things is gone. The concubines of the Son of Heaven do not cut their nails or pierce their ears. Those (servants) who are married have to live outside (the palace) and cannot be employed again. Such is the importance attached to preserving the body whole. How much more valued is one who has preserved his virtue whole? Now Ugly T'o has said nothing and is already trusted. He has achieved nothing and is sought after, and is offered the government of a country with the only fear that he might decline. Indeed he must be the one whose talents are perfect and whose virtue is without outward form!"

"What do you mean by his talents being perfect?" asked the Duke. "Life and Death," replied Confucius, "possession and loss, success and failure, poverty and wealth, virtue and vice, good and evil report, hunger and thirst, heat and cold—these are changes of things in the natural course of events. Day and night they follow upon one another, and no man can say where they spring from. Therefore they must not be allowed to disturb the natural harmony, nor enter into the soul's domain. One should live so that one is at ease and in harmony with the world, without loss of happiness, and by day and by night, share the (peace of) spring with the created things. Thus continuously one creates the seasons in one's own breast. Such a person may be said to have perfect talents."

"And what is virtue without outward form?"

"When standing still," said Confucius, "the water is in the most perfect state of repose. Let that be your model. It remains quietly within, and is not agitated without. It is from the cultivation of such harmony that virtue results. And if virtue takes no outward form, man will not be able to keep aloof from it."

Some days afterwards Duke Ai told Mintse saying, "When first I took over the reins of government, I thought that in guiding the people and caring for their lives, I had done all my duty as a ruler. But now that I have heard the words of a perfect man, I fear that I have not achieved it, but am foolishly squandering my bodily energy and bringing ruin to my country. Confucius and I are not prince and minister, but friends in spirit."

Hunchback-Deformed-No-Lips spoke with Duke Ling of Wei and the Duke took a fancy to him. Big-Jar-Goiter spoke with Duke Huan of Ch'i, and the Duke took a fancy to him. As for the well-formed men, he thought their necks were too scraggy. Thus it is that when virtue excels, the outward form is forgotten. But mankind forgets not that which is to be forgotten, forgetting that which is not to be forgotten. This is forgetfulness indeed!

And thus the Sage sets his spirit free, while knowledge is regarded as extraneous growths—agreements are for cementing relationships, goods are only for social dealings, and the handicrafts are only for serving commerce. For the Sage does not contrive, and therefore has no use for knowledge; he does not cut up the world, and therefore requires no cementing of relationships; he has no loss, and therefore has no need to acquire; he sells nothing, and therefore has no use for commerce. These four qualifications are bestowed upon him by God, that is to say, he is fed by God. And he who is thus fed by God has little need to be fed by man.

He wears the human form without human passions. Because he wears the human form he associates with men. Because he has not human passions the questions of right and wrong do not touch him. Infinitesimal indeed is that which belongs to the human; infinitely great is that which is completed in God.

Hueitse said to Chuangtse, "Do men indeed originally have no passions?"

"Certainly," replied Chuangtse.

"But if a man has no passions," argued Hueitse, "what is it that makes him a man?"

"Tao," replied Chuangtse, "gives him his expressions, and God gives him his form. How should he not be a man?"

"If then he is a man," said Hueitse, "how can he be without passions?"

"Right and wrong (approval and disapproval)," answered Chuangtse, "are what I mean by passions. By a man without passions I mean one who does not permit likes and dislikes to disturb his internal economy, but rather falls in line with nature and does not try to improve upon (the materials of) living."

"But how is a man to live this bodily life," asked Hueitse. "He does not try to improve upon (the materials of) his living?"

"Tao gives him his expression," said Chuangtse, "and God gives him his form. He should not permit likes and dislikes to disturb his internal economy. But now you are devoting your intelligence to externals, and wearing out your vital spirit. Lean against a tree and sing; or sit against a table and sleep! God has made you a shapely sight, yet your only thought is the hard and white."

Joined Toes

Joined toes and extra fingers seem to come from nature, yet, functionally speaking they are superfluous. Goiters and tumors seem to come from the body, yet in their nature, they are superfluous. And (similarly), to have many extraneous doctrines of charity and duty and regard them in practice as parts of a man's natural sentiments is not the true way of Tao. For just as joined toes are but useless lumps of flesh, and extra fingers but useless growths, so are the many artificial developments of the natural sentiments of men and the extravagances of charitable and dutiful conduct but so many superfluous uses of intelligence. People with superfluous keenness of vision put into confusion the five colors, lose themselves in the forms and designs, and in the distinctions of greens and yellows for sacrificial robes. Is this not so?

Of such was Li Chu (the clear-sighted). People with superfluous keenness of hearing put into confusion the five notes, exaggerate the tonic differences of the six pitch-pipes, and the various timbres of metal, stone, silk, and bamboo of the Huang-chung, and the Ta-lu. Is this not so? Of such was Shih K'uang (the music master). People who abnormally develop charity exalt virtue and suppress nature in order to gain a reputation, make the world noisy with their discussions and cause it to follow impractical doctrines. Is this not so? Of such were Tseng and Shih.

People who commit excess in arguments, like piling up bricks and making knots, analyzing and inquiring into the distinctions of hard and white, identities and differences, wear themselves out over mere vain, useless terms. Is this not so? Of such were Yang and Mo.

All these are superfluous and devious growths of knowledge and are not the correct guide for the world. He who would be the ultimate guide never loses sight of the inner nature of life. Therefore with him, the united is not like joined toes, the separated is not like extra fingers, what is long is not considered as excess, and what is short is not regarded as wanting. For duck's legs, though short, cannot be lengthened without dismay to the duck, and a crane's legs, though long, cannot be shortened without misery to the crane. That which is long in nature must not be cut off, and that which is short in nature must not be lengthened. Thus will all sorrow be avoided. I suppose charity and duty are surely not included in human nature. You see how many worries and dismays the charitable man has! Besides, divide your joined toes and you will howl: bite off your extra finger and you will scream. In the one case, there is too much, and in the other too little; but the worries and dismays are the same. Now the charitable men of the present age go about with a look of concern sorrowing over the ills of the age, while the non-charitable let loose the desire of their nature in their greed after position and wealth. Therefore I suppose charity and duty are not included in human nature. Yet from the time of the Three Dynasties downwards what a commotion has been raised about them! Moreover, those who rely upon the arc, the line, compasses, and the square to make correct forms injure the natural constitution of things. Those who use cords to bind and glue to piece together interfere with the natural character of things. Those who seek to satisfy the mind of man by hampering it with ceremonies and music and affecting charity and devotion have lost their original nature. There is an original nature in things. Things in their original nature are curved without the help of arcs, straight without lines, round without compasses, and rectangular without squares; they are joined together without glue and hold together without cords. In this manner all things live and grow from an inner urge and none can tell how they come to do so. They all have a place in the scheme of things and none can tell how they come to have their proper place. From time immemorial this has always been so, and it may not be tampered with. Why then should the doctrines of charity and duty continue to remain like so much glue or cords, in the domain of Tao and virtue, to give rise to confusion and doubt among mankind? Now the lesser doubts change man's purpose, and the greater doubts change man's nature. How do we know this? Ever since the time when Shun made a bid for charity and duty and threw the world into confusion, men have run about and exhausted themselves in the pursuit thereof. Is it not then charity and duty which have changed the nature of man?

Therefore I have tried to show that from the time of the Three Dynasties onwards, there is not one who has not changed his nature through certain external things. If a common man, he will die for gain. If a scholar, he will die for fame. If a ruler of a township, he will die for his ancestral honors. If a Sage, he will die for the world. The pursuits and ambitions of these men differ, but the injury to their nature resulting in the sacrifice of their lives is the same. Tsang and Ku were shepherds, and both lost their sheep. On inquiry it appeared that Tsang had been engaged in reading with a shepherd's stick under his arm, while Ku had gone to take part in some trials of strength. Their pursuits were different, but the result in each case was the loss of the sheep. Po Yi died for fame at the foot of Mount Shouyang.

Robber Cheh died for gain on the Mount Tungling. They died for different reasons, but the injury to their lives and nature was in each case the same. Why then must we applaud the former and blame the latter? All men die for something, and yet if a man dies for charity and duty the world calls him a gentleman; but if he dies for gain, the world calls him a low fellow. The dying being the same, one is nevertheless called a gentleman and the other called a low character. But in point of injury to their lives and nature, Robber Cheh was just another Po Yi. Of what use then is the distinction of 'gentleman' and 'low fellow' between them? Besides, were a man to apply himself to charity and duty until he were the equal of Tseng or Shih, I would not call it good. Or to savors, until he were the equal of Shu Erh (famous cook), I would not call it good. Or to sound, until he were the equal of Shih K'uang, I would not call it good. Or to colors, until he were the equal of Li Chu, I would not call it good. What I call good is not what is meant by charity and duty, but taking good care of virtue. And what I call good is not the so-called charity and duty, but following the nature of life. What I call good at hearing is not hearing others but hearing oneself. What I call good at vision is not seeing others but seeing oneself. For a man who sees not himself but others, or takes possession not of himself but of others, possessing only what others possess and possessing not his own self, does what pleases others instead of pleasing his own nature. Now one who pleases others, instead of pleasing one's own nature, whether he be Robber Cheh or Po Yi, is just another one gone astray. Conscious of my own deficiencies in regard to Tao, I do not venture to practise the principles of charity and duty on the one hand, nor to lead the life of extravagance on the other.

On Tolerance

Of old, the Yellow Emperor first interfered with the natural goodness of the heart of man, by means of charity and duty. In consequence, Yao and Shun wore the hair off their legs and the flesh off their arms in endeavoring to feed their people's bodies. They tortured the people's internal economy in order to conform to charity and duty. They exhausted the people's energies to live in accordance with the laws and statutes. Even then they did not succeed. Thereupon, Yao (had to) confine Huantou on Mount Ts'ung, exile the chiefs of the Three Miaos and their people into the Three Weis, and banish the Minister of Works to Yutu, which shows he had not succeeded. When it came to the times of the Three Kings, the empire was in a state of foment. Among the bad men were Chieh and Cheh; among the good were Tseng and Shih. By and by, the Confucianists and the Motseanists arose; and then came confusion between joy and anger, fraud between the simple and the cunning, recrimination between the virtuous and the evil-minded, slander between the honest and the liars, and the world order collapsed.

Then the great virtue lost its unity, men's lives were frustrated. When there was a general rush for knowledge, the people's desires ever went beyond their possessions. The next thing was then to invent axes and saws, to kill by laws and statutes, to disfigure by chisels and awls. The empire seethed with discontent, the blame for which rests upon those who would interfere with the natural goodness of the heart of man.

In consequence, virtuous men sought refuge in mountain caves, while rulers of great states sat trembling in their ancestral halls. Then, when dead men lay about pillowed on each other's corpses, when cangued prisoners jostled each other in crowds and condemned criminals were seen everywhere, then the Confucianists and the Motseanists bustled about and rolled up their sleeves in the midst of gyves and fetters! Alas, they know not shame, nor what it is to blush!

Until I can say that the wisdom of Sages is not a fastener of cangues, and that charity of heart and duty to one's neighbor are not bolts for gyves, how should I know that Tseng and Shih were not the singing arrows (forerunners) of (the gangsters) Chieh and Cheh? Therefore it is said, "Abandon wisdom and discard knowledge, and the empire will be at peace."

The Yellow Emperor sat on the throne for nineteen years, and his laws obtained all over the empire. Hearing that Kuangch'engtse was living on Mount K'ungt'ung, he went there to see him, and said, "I am told that you are in possession of perfect Tao. May I ask what is the essence of this perfect Tao? I desire to obtain the essence of the universe to secure good harvests and feed my people. I should like also to control the yin and yang principles to fulfill the life of all living things."

"What you are asking about," replied Kuangch'engtse, "is merely the dregs of things. What you wish to control are the disintegrated factors thereof. Ever since the empire was governed by you, the clouds have rained before thickening, the foliage of trees has fallen before turning yellow, and the brightness of the sun and moon has increasingly paled. You have the shallowness of mind of a glib talker. How then are you fit to speak of perfect Tao?"

The Yellow Emperor withdrew. He resigned the Throne. He built himself a solitary hut, and sat upon white straw. For three months he remained in seclusion, and then went again to see Kuangch'engtse.

The latter was lying with his head towards the south. The Yellow Emperor approached from below upon his knees. Kowtowing twice upon the ground, he said, "I am told that you are in possession of perfect Tao. May I ask how to order one's life so that one may have long life?"

Kuangch'engtse jumped up with a start. "A good question indeed!" cried he. "Come, and I will speak to you of perfect Tao. The essence of perfect Tao is profoundly mysterious; its extent is lost in obscurity.

"See nothing; hear nothing; guard your spirit in quietude and your body will go right of its own accord.

"Be quiet, be pure; toil not your body, perturb not your vital essence, and you will live forever.

"For if the eye sees nothing, and the ear hears nothing, and the mind thinks nothing, your spirit will stay in your body, and the body will thereby live for ever.

"Cherish that which is within you, and shut off that which is without for much knowledge is a curse.

"Then I will take you to that abode of Great Light to reach the Plateau of Absolute Yang. I will lead you through the Door of the Dark Unknown to the Plateau of the Absolute Yin."

Source: Legge, James, trans. 1890. *The Complete Chuang Tzu.* Oxford, UK: Clarendon Press.

▣ *The Kojiki* (712 CE)

In the following legend from The Kojiki, a historical compilation that includes many ancient Japanese legends, unusual births are explained by looking to the sexual relationship of the parents. Specifically, this selection describes the offspring of Izanagi and Izanami, whose children included the Japanese islands as well as various disabled children whom they did not acknowledge as their own. By consulting the gods, they learn that their children's deformities arose from the fact that the wife initiated the sexual contact that led to their procreation.

Part I. The Birth of the Deities

Courtship of the Deities: The Male-Who-Invites and the Female-Who-Invites

Having descended from Heaven on to this island, they saw to the erection of a heavenly august pillar, they saw to the erection of a hall of eight fathoms. Then Izanagi, the Male-Who-Invites, said to Izanami, the Female-Who-Invites, "We should create children"; and he said, "Let us go around the heavenly august pillar, and when we meet on the other side let us be united. Do you go around from the left, and I will go from the right." When they met, Her Augustness, the Female-Who-Invites, spake first, exclaiming, "Ah, what a fair and lovable youth!" Then His Augustness said, "Ah what a fair and lovable maiden!" But afterward he said, " It was not well that the woman should speak first!" The child which was born to them was Hiruko (the leech-child), which when three years old was still unable to stand upright. So they placed the leech-child in a boat of reeds and let it float away. Next they gave birth to the island of Aha. This likewise is not reckoned among their children.

Hereupon the two deities took counsel, saying: "The children to whom we have now given birth are not good. It will be best to announce this in the august place of the Heavenly deities." They ascended forthwith to Heaven and inquired of Their Augustnesses the Heavenly deities. Then the Heavenly deities commanded and found out by grand divination, and ordered them, saying: "they were not good because the woman spoke first. Descend back again and amend your words." So thereupon descending back, they again went round the heavenly august pillar. Thereupon his Augustness the Male-Who-Invites spoke first: "Ah! what a fair and lovely maiden!" Afterward his younger sister Her Augustness the Female-Who-Invites spoke: "Ah! what a fair and lovely youth!" Next they gave birth to the Island of Futa-na in Iyo. This island has one body and four faces, and each face has a name. So the Land of Iyo is called Lovely-Princess; the Land of Sanuki is called Princess-Good-Boiled-Rice; the Land of Aha is called the Princess-of-Great-Food, the Land of Tosa is called Brave-Good-Youth. Next they gave birth to the islands of Mitsu-go near Oki, another name for which islands is Heavenly-Great-Heart-Youth. This island likewise has one body and four faces, and each face has a name. So the Land of Tsukushi is called White-Sun-Youth; the Land of Toyo is called Luxuriant-Sun-Youth; the Land of Hi is called Brave-Sun-Confronting-Luxuriant-Wondrous-Lord-Youth; the Land of Kumaso is called Brave-Sun-Youth. Next they gave birth to the Island of Iki, another name for which is Heaven's One-Pillar. Next they gave birth to the Island of Tsu, another name for which is Heavenly-Hand-Net-Good-Princess. Next they gave birth to the Island of Sado. Next they gave birth to Great-Yamato-the-Luxuriant-Island-of-the-Dragon-fly, another name for which is Heavenly-August-Sky-Luxuriant-Dragon-fly-Lord-Youth. The name of "Land-of-the-Eight-Great-Islands" therefore originated in these eight islands having been born first. After that, when they had returned, they gave birth to the Island of Koo-zhima in Kibi, another name for which island is Brave-Sun-Direction-Youth. Next they gave birth to the Island of Adzuki, another name for which is Oho-Nu-De-Hime. Next they gave birth to the Island of Oho-shima, another name for which is Oho-Tamaru-Wake. Next they gave birth to the Island of Hime, another name for which is Heaven's-One-Root. Next they gave birth to the Island of Chika, another name for which is Heavenly-Great-Male. Next they gave birth to the islands of Futa-go, another name for which is Heaven's Two-Houses. (Six islands in all from the Island of Ko in Kibi to the Island of Heaven's-Two-Houses.)

Source: Chamberlain, Basil Hall, trans. 1883. *The Kojiki.* Tokyo: Asiatic Society of Japan.

The Ancient World: Africa

▣ *The Satire of the Trades*
(2025–1700 BCE)

A Middle Kingdom work preserved in later Ancient Egyptian literature. The stories document the difficulties and sufferings of workers in various trades.

The beginning of the teaching which the man of Tjel named Dua-Khety made for his son named Pepy, while he sailed southwards to the Residence to place him in the school of writings among the children of the magistrates, the most eminent men of the Residence.

So he spoke to him: Since I have seen those who have been beaten, it is to writings that you must set your mind. Observe the man who has been carried off to a work force. Behold, there is nothing that surpasses writings! They are a boat upon the water. Read then at the end of the Book of Kemyet this statement in it saying: As for a scribe in any office in the Residence, he will not suffer want in it.

When he fulfills the bidding of another, he does not come forth satisfied. I do not see an office to be compared with it, to which this maxim could relate. I shall make you love books more than your mother, and I shall place their excellence before you. It is greater than any office. There is nothing like it on earth. When he began to become sturdy but was still a child, he was greeted (respectfully). When he was sent to carry out a task, before he returned he was dressed in adult garments.

I do not see a stoneworker on an important errand or in a place to which he has been sent, but I have seen a coppersmith at his work at the door of his furnace. His fingers were like the claws of the crocodile, and he stank more than fish excrement.

Every carpenter who bears the adze is wearier than a fieldhand. His field is his wood, his hoe is the axe. There is no end to his work, and he must labor excessively in his activity. At nighttime he still must light his lamp.

The jeweler pierces stone in stringing beads in all kinds of hard stone. When he has completed the inlaying of the eye-amulets, his strength vanishes and he is tired out. He sits until the arrival of the sun, his knees and his back bent at (the place called) Aku-Re. ["his back bent": Tables were used only rarely in ancient Egypt. Most craftsmen worked crouching with their workpieces on the ground.]

The barber shaves until the end of the evening. But he must be up early, crying out, his bowl upon his arm. He takes himself from street to street to seek out someone to shave. He wears out his arms to fill his belly, like bees who eat (only) according to their work. ["The barber shaves": Considering the tools they had, shaving must have been pretty exhausting for the barber and quite an ordeal for his client. Copper and bronze tools are not known for their razor-sharp edges.]

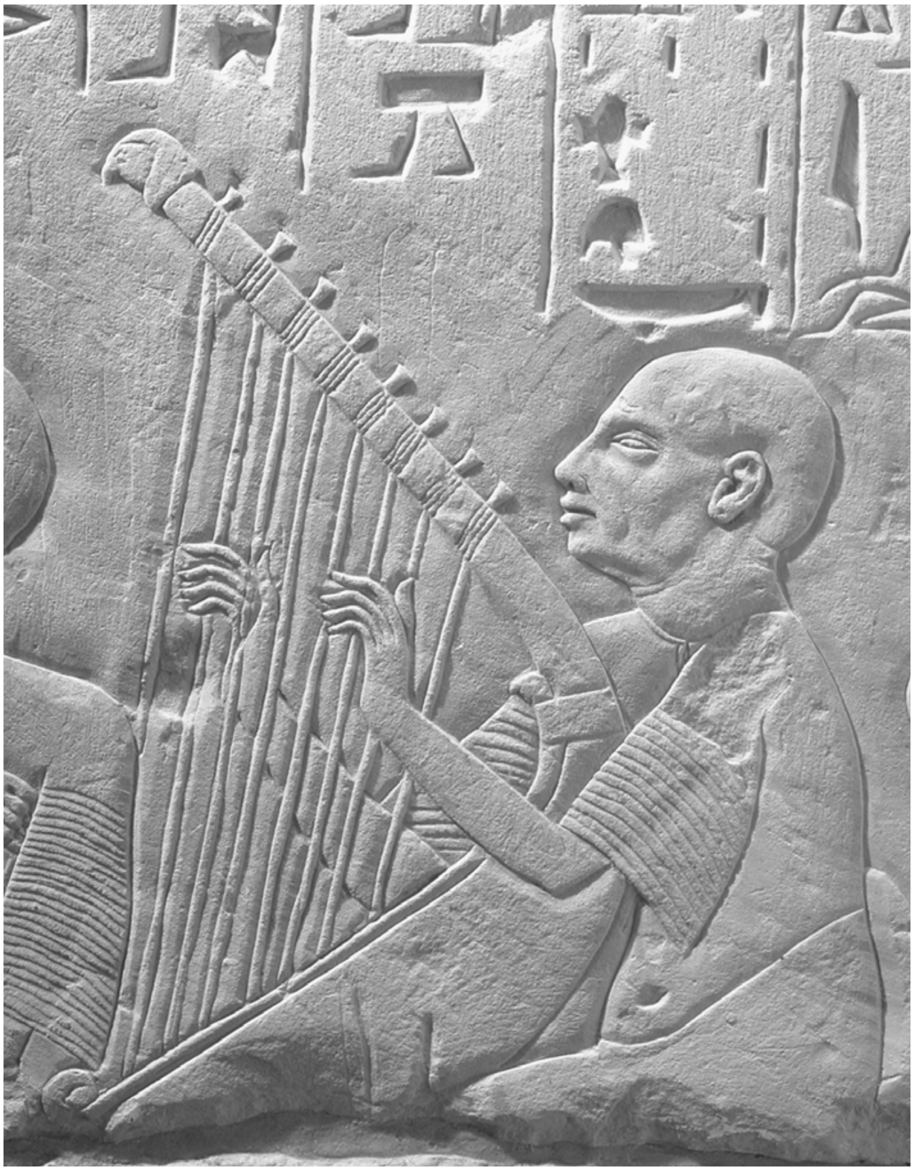
The reed-cutter goes downstream to the Delta to fetch himself arrows. He must work excessively in his activity. When the gnats sting him and the sand fleas bite him as well, then he is judged.

The potter is covered with earth, although his lifetime is still among the living. He burrows in the field more than swine to bake his cooking vessels. His clothes being stiff with mud, his head cloth consists only of rags, so that the air which comes forth from his burning furnace enters his nose. He operates a pestle with his feet with which he himself is pounded, penetrating the courtyard of every house and driving earth into every open place.

I shall also describe to you the bricklayer. His kidneys are painful. When he must be outside in the wind, he lays bricks without a garment. His belt is a cord for his back, a string for his buttocks. His strength has vanished through fatigue and stiffness, kneading all his excrement. He eats bread with his fingers, although he washes himself but once a day. [“His kidneys are painful”: much of the work was done bending over while lifting quite heavy loads.]

It is miserable for the carpenter when he planes the roof-beam. It is the roof of a chamber 10 by 6 cubits. A month goes by in laying the beams and spreading the matting. All the work is accomplished. But as for the food which is to be given to his household (while he is away), there is no one who provides for his children.

The vintner carries his shoulder-yoke. Each of his shoulders is burdened with age. A swelling is on his neck, and it festers. He spends the morning in watering leeks and the evening with corianders, after he has spent the midday in the palm grove. So it happens that he sinks down (at last) and dies through his deliveries, more than one of any other profession.



Blind harpist. One of the oldest traditions involves the participation of blind and visually impaired individuals in the profession of music. This detail of a relief was created during the Nineteenth Dynasty, New Kingdom (ca. 1250 BCE).

Source: Rijksmuseum van Oudheden, Leiden, The Netherlands. Photo credit: Erich Lessing/Art Resource, New York.

The fieldhand cries out more than the guinea fowl. His voice is louder than the raven’s. His fingers have become ulcerous with an excess of stench. When he is taken away to be enrolled in Delta labour, he is in tatters. He suffers when he proceeds to the island, and sickness is his payment. The forced labour then is tripled. If he comes back from the marshes there, he reaches his house worn out, for the forced labor has ruined him.

The weaver inside the weaving house is more wretched than a woman. His knees are drawn up against his belly. He cannot breathe the air. If he wastes a single day without weaving, he is beaten with 50 whip lashes. He has to give food to the doorkeeper to allow him to come out to the daylight.

The arrow maker, completely wretched, goes into the desert. Greater than his own pay is what he has to spend for his she-ass for its work afterwards. Great is also what he has to give to the fieldhand to set him on the right road to the flint source. When he reaches his house in the evening, the journey has ruined him.

The courier goes abroad after handing over his property to his children, being fearful of the lions and the Asiatics. He only knows himself when he is back in Egypt. But his household by then is only a tent. There is no happy homecoming.

The furnace-tender, his fingers are foul, the smell thereof is as corpses. His eyes are inflamed because of the heaviness of smoke. He cannot get rid of his dirt, although he spends the day at the reed pond. Clothes are an abomination to him. [In a country where wood was rare and any combustible matter might serve as fuel, the use of clean-burning charcoal was probably not widespread.]

The sandal maker is utterly wretched carrying his tubs of oil. His stores are provided with carcasses, and what he bites is hides.

The washerman launders at the riverbank in the vicinity of the crocodile. I shall go away, father, from the flowing water, said his son and his daughter, to a more satisfactory profession, one more distinguished than any other profession. His food is mixed with filth, and there is no part of him which is clean. He cleans the clothes of a woman in menstruation. He weeps when he spends all day with a beating stick and a stone there. One says to him, dirty laundry, come to me, the brim overflows.

The fowler is utterly weak while searching out for the denizens of the sky. If the flock passes by above him, then he says: would that I might have nets. But God will not let this come to pass for him, for He is opposed to his activity.

I mention for you also the fisherman. He is more miserable than one of any other profession, one who is at his work in a river infested with crocodiles. When the totalling of his account is made for him, then he will lament. One did not tell him that a crocodile was standing there, and fear has now blinded him. When he comes to the flowing water, so he falls as through the might of God.

See, there is no office free from supervisors, except the scribe's. He is the supervisor!

But if you understand writings, then it will be better for you than the professions which I have set before you. Behold the official and the dependent pertaining to him. The tenant farmer of a man cannot say to him: Do not keep watching me. What I have done in journeying southward to the Residence is what I have done through love of you. A day at school is advantageous to you. Seek out its work early, while the workmen I have caused you to know hurry on and cause the recalcitrant to hasten.

I will also tell you another matter to teach you what you should know at the station of your debating. Do not come close to where there is a dispute. If a man reproves you, and you do not know how to oppose his anger, make your reply cautiously in the presence of listeners.

If you walk to the rear of officials, approach from a distance behind the last. If you enter while the master of the house is at home, and his hands are extended to another in front of you, sit with your hand to your mouth. Do not ask for anything in his presence. But do as he says to you. Beware of approaching the table. ["But do as he says to you": i.e., but react to him when addressed.]

Be serious, and great as to your worth. Do not speak secret matters. For he who hides his innermost thoughts is one who makes a shield for himself. Do not utter thoughtless words when you sit down with an angry man. ["Be serious, and great as to your worth": i.e., be serious with anyone greater in dignity when you sit down with an angry man, but take your seat with the reliable.]

When you come forth from school after midday recess has been announced to you, go into the courtyard and discuss the last part of your lesson book.

When an official sends you as a messenger, then say what he said. Neither take away nor add to it. He who abandons a chest of books, his name will not endure. He who is wise in all his ways, nothing will be hidden from him, and he will not be rebuffed from any station of his.

Do not say anything false about your mother. This is an abomination to the officials. The offspring who does useful things, his condition is equal to the one of yesterday. Do not indulge with an undisciplined man, for it is bad after it is heard about you. When you have eaten three loaves of bread and swallowed two jugs of beer, and the body has not yet had enough, fight against it. But if another is satiated, do not stand, take care not to approach the table.

See, you send out a large number. You hear the words of the officials. Then you may assume the characteristics of the children of men, and you may walk in their footsteps. One values a scribe for his understanding, for understanding transforms an eager person. You are to stand when words of welcome are offered. Your feet shall not hurry when you walk. Do not approach a trusted man, but associate with one more distinguished than you. But let your friend be a man of your generation.

See, I have placed you on the path of God. The fate of a man is on his shoulders on the day he is born. He comes to the judgement hall and the court of magistrates which the people have made. See, there is no scribe lacking sustenance, (or) the provisions of the royal house. It is Meskhenet who is turned toward the scribe who presents himself before the court of magistrates. Honour your father and mother who have placed you on the path of the living. Mark this, which I have placed before your eyes, and the children of your children.

I have placed you on the path of God: Abundance is on the path of the god the court of magistrates which the people have made: that court of officials is the one allotting people to him.

It has come to an end in peace.

Source: Ermann, A., trans; Dollinger, André, ed. and annotated. 2004. "The Satire of the Trades, or, The Instructions of Dua-Khety." Available at http://nefertiti.iwebland.com/texts/instructions_of_kheti.htm

"Fire from Heaven!" A Story of the Wagogo

Africa contributes many Origin tales to the world's heritage as well as many stories in which people travel in search of fire. Some Origin accounts address disability and may embody a code of inclusive practice with disabled people. An intriguing story from the Wagogo people of Tanzania involves all these elements, plus some sharp psychology, a deity running a competition game show, and an ending that appeals to women everywhere.

Long ago there was no fire on earth; so a man went up into the sky to look for fire. When he got to the first heaven he met a number of individuals who were only half men (i.e. having only one side) whereupon he commenced to laugh, and they asked him whether he was laughing at their deformity, and he replied in the affirmative, saying that there were no such people in his country. He then ascended higher until he reached the second heaven, where he saw men walking on their heads. They, too, asked him whether he was laughing at them; and he replied in the affirmative. Not yet having found fire, he ascended still higher, until he got to the third heaven, when he saw men going on their knees; and they also asked him if he was laughing at their deformity, and he replied as he did before, in the affirmative. In reply to his enquiries about fire they told him that he had almost arrived at his destination; and they told him to go straight on until he came to God's house, where he would find God himself standing outside, as that was the place where he was always to be found. He pursued his course as directed, and was not long before he reached the abode of *Mulungu* (God), which was situated in the fourth heaven. Everywhere the sight was ravishing. The man approached near and saluted *Mulungu.* The salutation being over *Mulungu* asked him what brought him there. He replied saying he had come in search of fire, as in his country there was no fire. *Mulungu* showed him a room in which to sleep and told him that on the morrow he would find fire. Next morning *Mulungu* came and called him and showed him a room in which the most beautiful vessels were placed, all of which had covers; but besides the very beautiful vessels there were two other very inferior vessels placed by themselves. He chose a very beautiful pot and went outside, where he met *Mulungu,* who told him to remove the cover. Having done so he found ashes and charcoal in the pot. Whereupon he asked, 'Lord, have you no fire?' *Mulungu* replied saying, 'How was it that on the journey here you laughed at my children? Is there nothing lacking in your country, and if so what has brought you here?' Thereupon he ordered him to return to his home.

A second and a third man went who had the same experience. At last a woman went; and when she got to the first heaven, the one-sided people came to greet her, and she sang and they danced; and when she was tired of singing, the strange beings showed her the way without her asking any questions. When she got to the second and third heavens she also sang and the inhabitants danced; and when they asked her whether people in her country had deformities, she said many were afflicted in that way, and she went on to tell them that some walked on their ears, others on their toes, and others again were blind. When she had rested she resumed her journey, and ere long she arrived at the house of *Mulungu.* He (*Mulungu*) asked her her business, and when she had told her errand he showed her a room in which to sleep the night. The next morning he called her and showed her the lovely vessels which he had previously shown to the three men and told her to choose one; but she shrank from doing so, fearing to touch such lovely vessels. Glancing, however, in the direction of the two inferior pots she summoned up courage to take one of them. Having chosen a pot she went outside and saw *Mulungu,* who told her to uncover the pot; and when she had done so, lo! there was the long-looked-for fire inside! Mulungu praised her for the way in which she behaved toward his children on her way thither; and he presented her with an ox in recognition of her kindness. Here she remained two days feasting on the meat, and on the third day *Mulungu* told her she might go and take the fire with her, which would be sufficient for all the world. It was a day of great rejoicing when the woman returned to the earth. Multitudes came to hear the news and to procure fire from the pot. The men with one accord applauded the woman, and declared that the women have more sense than the men.

Source: Cole, H. 1902. "Notes on the Wagogo of German East Africa." *Journal of the Anthropological Institute of Great Britain and Ireland* 32:305–338.

The Ancient World: Pre-Columbian Americas

▣ The Legend of the Pyramid of the Dwarf (569–1000 CE)

John Stephens transcribed this story in 1840 from the local inhabitants of Uxmal (the site in present-day Mexico of an ancient Mayan city) in 1840. Note that this transcription is only one of many versions of this story, suggesting its importance in the imagination of the community.

There was an old woman who lived in a hut that was located on the exact spot where the finished pyramid now stands. This old woman was a witch who one day went into mourning that she had no children. One day, she took an egg and wrapped it in cloth and placed it in a corner of her small hut. Every day she went to look at the egg until one day it hatched and a small creature, closely resembling a baby, came from the enchanted egg.

The old woman was delighted and called the baby her son. She provided it with a nurse and took good care of it so that within a year it was walking and talking like a man. It stopped growing after a year and the old woman was very proud of her son and told him that one day he would be a great Lord or King.

One day, she told her son to go the House of the Governor and challenge the King to a trial of strength. The dwarf didn't want to go at first but the old woman insisted and so to see the King he went. The guards let him in and he threw down his challenge to the King. The King smiled, and told the dwarf to lift a stone that weighed three *arrobas* (75 pounds). At this the dwarf cried and ran back to his mother. The witch was wise, and told her son to tell the King that if the King would lift the stone first, then he would lift it also. The dwarf returned and told the King what his mother told him to say. The king lifted the stone and the dwarf did the same. The King was impressed, and a little nervous, and tested the dwarf for the rest of the day with other feats of strength. Each time the King performed an act, the dwarf was able to match it.

The King became enraged that he was being matched by a dwarf, and told the dwarf that in one night he must build a house higher than any other in the city or he would be killed. The dwarf again returned crying to his mother who told him to not lose hope, and that he should go straight to bed. The next morning the city awoke to see the Pyramid of the Dwarf in its finished state, larger than any other building in the city.

The King saw this building from his palace and was again enraged and summoned the dwarf. The King told the dwarf he had one final test of strength. The dwarf had to collect two bundles of *Cogoil* wood, a very strong and heavy wood, and the king would break the wood over the head of the dwarf, and after that the dwarf could have his turn to break the wood over the King's head.

The dwarf again ran to his mother for help. She told him not to worry and placed an enchanted tortillia on his head as a crown. The trial was performed in front of all the great men of the city. The King broke the whole of his bundle over the dwarfs head one at a time without hurting or bothering the dwarf in the least. The King then tried to bow out of his challenge, but in front of all the [city's] great men he knew he had no choice but to go ahead and let the dwarf have his turn.

The second stick of the bundle broke the Kings skull into pieces and he fell dead at the foot of the dwarf who[m] everyone acknowledged as the new King.

The dwarf returned to tell his mother what had transpired, but found that she had died. But she died happy to know that her son had indeed become King.

Legend has it that in the town of Mani, seventeen leagues distant, there is a deep well that opens into a cave that leads all the way to Merida. In this cave, on the bank of a stream under the shade of a large tree, sits an old woman . . . with a serpent by her side. She begs occasionally or sells water. Not for money, but for a *criatura* or baby to feed to her serpent.

This old woman is the mother of the dwarf.

Source: Stephens, John, trans. 1840. *Pyramid of the Dwarf.* Available at http://ancientsites.com/aw/Post/259572

▣ Ee-ee-toy's Song: When He Made the World Serpents

At this point in the story three key Pima Gods, Ee-ee-toy, Toehahvs, and Juhwerta Mahkai, decide to have a contest to make the best first people to occupy the land. However, unbeknownst to the others, Mahkai has already invented a people to begin civilization, and he seeks to protect their privilege by making imperfect dolls.

I know what to do;
I am going to move the water
Both ways.

But the water was still running in the valleys, and Ee-ee-toy took a hair from his head and made it into a snake—*Vuck-vahmuhtl.* And with this snake he pushed the waters south, but the head of the snake was left lying to the west and his tail to the east.

But there was more water, and Ee-ee-toy took another hair from his head and made another snake, and with this snake pushed the rest of the water north. And the head of this snake was left to the east and his tail to the west. So the head of each snake was left lying with the tail of the other.

And the snake that has his tail to the east, in the morning will shake up his tail to start the morning wind to wake the people and tell them to think of their dreams.

And the snake that has his tail to the west, in the evening will shake up his tail to start the cool wind to tell the people it is time to go in and make the fires and be comfortable.

And they said: "We will make dolls, but we will not let each other see them until they are finished."

And Ee-ee-toy sat facing the west, and Toehahvs facing the south, and Juhwerta Mahkai facing the east.

And the earth was still damp and they took clay and began to make dolls. And Ee-ee-toy made the best. But Juhwerta Mahkai did not make good ones, because he remembered some of his people had escaped the flood thru a hole in the earth, and he intended to visit them and he did not want to make anything better than they were to take the place of them. And Toehahvs made the poorest of all.

Then Ee-ee-toy asked them if they were ready, and they all said yes, and then they turned about and showed each other the dolls they had made.

And Ee-ee-toy asked Juhwerta Mahkai why he had made such queer dolls.

"This one," he said, "is not right, for you have made him without any sittingdown parts, and how can he get rid of the waste of what he eats?"

But Juhwerta Mahkai said: "He will not need to eat, he can just smell the smell of what is cooked."

Then Ee-ee-toy asked again: "why did you make this doll with only one leg—how can he run?" But Juhwerta Mahkai replied: "He will not need to run; he can just hop around."

Then Ee-ee-toy asked Toehahvs why he had made a doll with webs between his fingers and toes—"How can he point directions?" But Toehahvs said he had made these dolls so for good purpose, for if anybody gave them small seeds they would not slip between their fingers, and they could use the webs for dippers to drink with.

And Ee-ee-toy held up his dolls and said: "These are the best of all, and I want you to make more like them." And he took Toehahv's dolls and threw them into the water and they became ducks and beavers. And he took Juhwerta Mahkai's dolls and threw them away and they all broke to pieces and were nothing.

And Juhwerta Mahkai was angry at this and began to sink into the ground; and took his stick and hooked it into the sky and pulled the sky down while he was sinking. But Ee-ee-toy spread his hand over his dolls, and held up the sky, and seeing that Juhwerta Mahkai was sinking into the earth he sprang and tried to hold him and cried, "Man, what are you doing! Are you going to leave me and my people here alone?"

But Juhwerta Mahkai slipped through his hands, leaving in them only the waste and excretion of his skin. And that is how there is sickness and death among us.

Source: Lloyd, J. William, trans. 1911. *Aw-aw-tam Indian Nights: The Myths and Legends of the Pimas.* Available at http://www.sacred-texts.com/nam/sw/ain/ain07.htm

Ciqneqs Myth

Using the fieldwork of J. P. Harrington as a basis, Thomas Blackburn compiled oral narratives of the Chumash Indians from coastal California. Ciqneqs myths are similar to European tales about cognitively disabled individuals, such as "simple Simon."

Once there was a village with only a few families living in it, and in two of these families there was a man and woman who married one another when they came of age. After their marriage, they began to have children, and their first twelve children were all boys. The last, however, was a girl. The children all grew up, and one day it was discovered that the girl was pregnant. . . . [section about a makeshift paternity test omitted here]

When the child was born the brothers called the ?alaxlaps to come and name him. (The ?alaxlaps was a kind of priest. He could tell whether or not a person would be fortunate in his transactions, and also by the planet of a person what would be his or her fate. He was an anatomist, physiognomist, and astrologer.) The ?alaxlaps asked who the child's father was. One brother said to ask the child's mother. Then the mother said her baby was a sowing of the clouds. When the ?alaxlaps heard this, he said to her: "Ah, girl, you were born to be happy. For it is your lot to give birth to this child of the clouds. Name him Ciqneqs."

When the child, Ciqneqs, grew old enough to go on errands, there was an old woman in the village who was his grandmother's sister. This old lady was very much inclined to be a sorceress. Ciqneqs knew about this. One day one of his uncles asked the boy to take his old woman over to his camp on the beach where he was clamming. She was quite old and was blind. Ciqneqs led the old lady to the camp, which was close to a precipice. Noticing this, the boy left the old woman at the camp and looked over the cliff. He saw there was a cave at the foot of the cliff that would be covered by water at high tide, but which was now dry, and that there were many large rocks scattered around the entrance.

He went back to the old woman and said: 'Let's go a little further.' He gave her her cane and led her down the edge of the cliff into the cave. He told her: 'While you're here, I'm going over to the house and I'll return.' Then he left quietly. Once outside the cave, he began to pile up stones until the entrance was completely blocked. Sometime later, the uncle noticed that it was high tide and thought to ask Ciqneqs how the old woman was. 'No animal will harm her,' said Ciqneqs. 'Is she away from the reach of the tide?' asked the uncle. 'Yes,' said the boy. Later, another old woman, missing her neighbor, told the uncle: 'You had better go and see what Ciqneqs has done with his grandmother's sister.' The uncle went, and not finding the old lady anywhere returned and said: 'She is not there.' Then the other old lady said to Ciqneqs: 'What did you do with her?' The boy answered: 'I put her in a cave.' 'Why did you put her in there?' 'She fooled the world too much by means of her black magic.' Then the old woman exclaimed: 'You really are a child of the clouds, and only the clouds can punish you. But we must be patient with you, because if the clouds punish you by means of a deluge of water, the punishment will fall on us also.'

Editors' Note: There are other Ciqneqs stories, but this one has most of the usual elements: taking orders literally, giving weird or cryptic answers to all inquiries, and going unpunished because he's a "child of the clouds." He frustrates the Yowoyow, the devil, in another story, with his strange conversational style, until the devil gives up and goes away disgusted. He sings a creepy song to scare away his fellow villagers, ending with the line, "I am son of the dead, and therefore I am hungry." He kills a little brother in his care by misconstruing the directions his parents left him. He tries to bed his sister after misunderstanding his grandmother's instructions to marry. "Siqneqs did many other stupid things, but his parents always sent him on errands anyway," explains one storyteller. "And even today, when parents scold their children they're apt to say, 'That's just like Siqneqs!'"

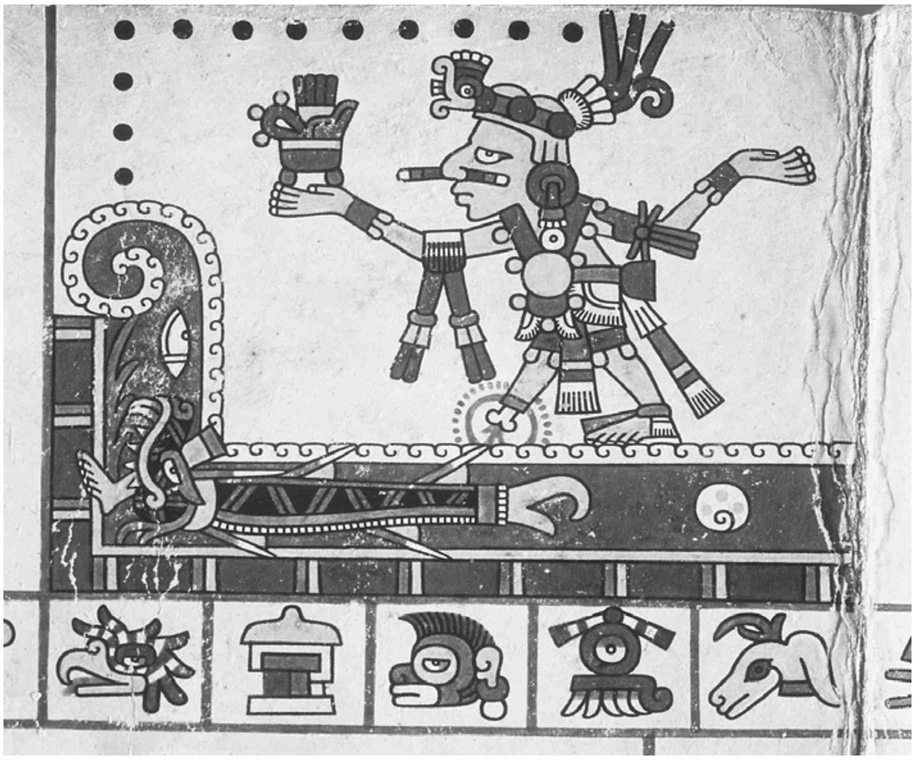
Source: Blackburn, Thomas C. 1975. *December's Child: A Book of Chumash Oral Narratives*. Berkeley: University of California Press.

Qöyáwaima (Oraíbi)

An ethnographical account of the legends, myths, and stories of the Hopi. A number of the stories address disability as a key, providing moments of revelation that are revered in the tribal histories.

42. The Blind Man and the Lame Man

A long time ago there was an earthquake at Oraíbi. It was a very nice day; people had eaten their breakfast



Tezcatlipoca tempting the Earth Monster. A panel from the Codex Fejervary-Mayer shows how Tezcatlipoca tempted the Earth Monster to the surface of the great waters by using his foot as bait. In swallowing his foot, she loses her lower jaw. As a result of this disability she was unable to sink, and thus the earth was created from her body. Mayan manuscript, Mixtec style, with date glyphs. Beaten deer skin and limewash.

Source: Liverpool Museum, Liverpool, Great Britain. Photo credit: Werner Forman/Art Resource, New York.

as usual, and were happy. Then towards noon the earth and the houses began to move and to tremble, and very soon there was a great noise like thunder, but nothing could be seen and the people did not know where it came from. They ran to their houses and everywhere to see what was the matter. Sometime in the afternoon the earth trembled very much, and a large piece of ground sank down at Skeleton gulch (Másvövee), so called because at one time a great many slain people were thrown there. This is situated about half a mile northeast of Oraíbi; the piece that sank down reached nearly to the village of Oraíbi. There was also a very large crack right on the public square or plaza of the village.

By this time the people got frightened very much, and all left the village, running toward the north. In the village there lived in one of the houses a blind man, and in another house a cripple who could not walk. When these noticed that some serious disturbance was taking place, they got very much frightened, and the blind man called over to the cripple asking for information. The latter answered that the earth had been trembling and the village had been in motion, and that all the people had left the village. The cripple then asked the blind man to come over to his house. The blind man asked the cripple to come over to his house, but after a while the cripple prevailed, and the blind man, taking a stick and feeling his way before himself, tried to reach the house of the cripple, the latter directing him which way to go. When he had arrived at the house the cripple said: “Let us also flee. You carry me on your back, and I shall show you the way.” This they did, the cripple turning the head of the blind man in the direction in which he wanted him to turn and to go. Thus they left the village, also in a northerly direction, following the others.

A short distance north of the village a large elk met them, coming from the north. “O my! what is that?” the cripple said, on the back of the blind man. “What is it?” the latter asked. “Something very large. It is nearly black, and yet it is not quite black.” The blind man, who had been a great hunter in his youth, when he still had his eyesight, at once suspected what it might be, and asked for details, and soon concluded that it must be an elk. Before leaving the village the blind man had suggested that they take a bow and arrows along so that, in case they needed some food, they could kill some game. When they had come opposite the elk the cripple suggested that the blind man shoot the elk, as his own hands were also somewhat crippled, and he was unable to handle a bow. He put an arrow on the bow, and the blind man got the bow ready, the cripple doing the aiming for him. The elk was now standing west of them, and at the proper time the cripple told the blind man to shoot. He shot and killed the elk.

They were now very anxious to roast some of the meat, but had nothing to skin the animal or cut the meat with; so they went there and with one of their arrows they dug out the eyes of the elk. The blind man then, being directed by the lame man, gathered some sticks of wood and they built a fire, starting the fire by rubbing wood and fire sticks together. They placed the two eyes on the fire and waited. When the eyes got very hot they burst with a great report. "Hihiyá!" the men exclaimed, and both jumped up, the lame man finding that he could walk, and the blind man finding his eyes opened. "Ishutí," the blind man said. "What is it (hintí)?" "My eyes are open." "Yes, and I can walk," the other man replied. By this time it had become evening. "Now let us remain awake all night," the man who had been blind said, "because if we go to sleep my eyes might stick together again." "Yes, if I lie down I might find that I cannot walk again in the morning," the other one replied. So the first one handed the other a small twig of ö'cvi (Ephedra), saying to him, "If you see that I go to sleep, you prick my eyes so that I awake." The other one handed the blind man, as we shall call him for brevity's sake, also some prickly weed, saying, "If you see me sit down you prick my body so that I remain standing." Thus they remained awake all night watching each other.

Early in the morning they concluded that they would follow the tracks of the inhabitants of the village who had fled. They finally found them in a timber quite a distance to the north. "What has happened to you?" they said. "Why, you were blind and lame, and now you can see and walk." "Yes," they said, "something has happened to us: and now let us go back again to the village. There is nothing the matter there any more." So the people all returned to the village, these two taking the lead, and that is the reason why Oraíbi is again inhabited. If these two had not brought the people back they would never have returned.

Source: Voth, H. R., trans. 1905. *The Traditions of the Hopi* (Field Columbian Museum Publication 96, Anthropological Series Vol. 8). Chicago: Field Columbian Museum.

The Ancient World: Norse Culture

▣ "The Death of Balder" (ca. 1250 CE)

The name of Balder (or Baldr) means "the glorious," but he was also identified as the "god of tears." He was the son of Odin and Frigg and described as one of the wisest gods in Norse mythology. The excerpt below occurs on the heels of Balder's foreboding dream about his own death. As a protective measure, his mother, Frigg, asks all things not to hurt him, but she doesn't ask the mistletoe, because it seems young and harmless. Later, disguised as an old woman, the trickster Loki makes a dart out of mistletoe and tricks the blind god Hod into throwing it at Balder, precipitating his death. Thus, the story becomes a tale of Loki's treachery toward other gods' singular weaknesses.

A servant hurried up and offered Loki wine. Loki drained the cup at one draught and then sauntered across the spacious hall, behind the semi-circle of the gods and their followers. He sidled up to Hod and poked him in the ribs.

'That can only be Loki,' said Hod.

'None other,' said a voice in his ear.

'Well?' said Hod.

'Why don't you join in? Why aren't you throwing darts at your brother?'

'Because I can't see where he is,' said Hod.

Loki sucked his cheeks.

'Another thing,' said Hod. 'I have no weapon.'

'This is not as it should be,' said Loki with measured indignation. 'They do wrong to ignore you—and your brother.'

Hod's expression did not alter. He had long since learned to accept his fate. 'Nothing comes,' he said, 'of ranking resentment.'

Hod's words were drowned in a roar of laughter.

'What is that?' he asked.

'Only more of the same,' said Loki. 'A dart well aimed. But now it's your turn, Hod. You should pay your respects like everybody else.'

'I have no weapon,' Hod repeated.

'Take this twig then,' said Loki, and he put the sharpened mistletoe between Hod's hands. 'I'll show you where he's standing. I'll stand behind you and guide your hand.'

Loki's eyes were on fire now. His whole body was on fire. His face was ravaged by wolfish evil and hunger.

Hod grasped the mistletoe and lifted his right arm. Guided by Loki, he aimed the dart at his brother Balder.

The mistletoe flew through the hall and it struck Balder. It pierced him and passed right through him. The god fell on his face. He was dead.

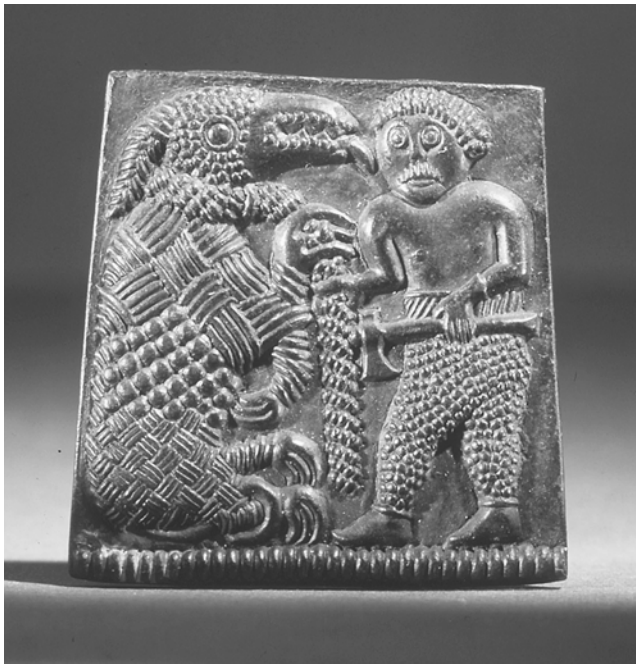
There was no sound in Gladsheim, no sound, only the roaring of silence. The gods could not speak. They looked at the fairest and most wise of them all, shining and lifeless, they could not even move from where they stood to lift him.

The gods stared at each other and then they turned to stare at Hod and Loki. They had no doubt. They were all of one mind about who had caused Balder's death and yet none of them were able to take vengeance.

The ground of Gladsheim was hallowed and no one was ready to shed blood in the sanctuary.

Hod could not see the fearsome gaze of that gathering. Loki could not withstand it. He loped towards the doors of Gladsheim and slunk away into the darkness.

Source: Mabie, Hamilton Wright, trans. 1901. *Norse Stories Retold from the Eddas.* New York: Dodd, Mead and Company. Available at http://www.mainlesson.com/display.php?author=mabie&book=norse&story=balder



Tyr, the original sky god of the Germanic tribes, with a chained wolf, Fenrir, whom Tyr fettered at the cost of his own hand. Although the other Norse gods laugh at his willingness to sacrifice a bodily appendage, the story emphasizes the heroism of suffering on behalf of the community. Sixth century, bronze. Matrix used in the manufacture of helmet plaques.

Source: Torslunda Parish, Oland, Sweden. Statens Historiska Museet, Stockholm, Sweden. Photo credit: Werner Forman/Art Resource, New York.

▣ "The Binding of the Wolf"

(ca. 1250 CE)

The wolf, Fenrir (Fenrer in this version), is the oldest child of the trickster god Loki (Loke in this version) and the giantess Angrboda. Of all the gods, only Tyr is brave enough to feed Fenrir as he roams the fields of Asgard. As the gods grow increasingly leery of the wolf's size and power they decide to try and bind him with a variety of strong materials. Finally, the dark dwarves of Svartalfheim create a silky rope that can hold the wolf. However, in the process of binding the wolf, Tyr loses his hand and forearm. As a result, Tyr's shortened arm becomes a symbol of personal sacrifice for the good of others.

Loke looked like a god and had many of the wonderful gifts which the gods possessed, but at heart he was one of those giants who were always trying to cross Bifrost, the shining rainbow-bridge, at the heavenly end of which Heimdal kept guard day and night, with eyes so keen that in the darkness as easily as in the light he could see a hundred miles distant, and with ears so sharp that he could hear the noiseless blossoming of the grass in the deepest valley, and the growing of the wool upon the backs of sheep browsing along the hill-tops. Loke had the mind of the gods, who were always working to bring order and beauty into the world, but he had the heart of the giants, who were striving to undo the good and cover the earth with howling storms and icy desolation. After he had been in Asgard for a time he wanted to get back to Jotunheim, where his true home was. There he married a terrible giantess, and three children were born to him, more repulsive than their mother, Hel, the Midgard-serpent, and the Fenris-wolf. These monsters grew to be very strong and horrible to look upon before the gods thought of destroying them; but one day, as Odin looked over the worlds from his throne, a shadow fell upon his face, for he saw how powerful the children of Loke were becoming, and he knew they would work endless mischief and misery for gods and men; so he sent some of the gods to bring the monsters to Asgard. It was a strange sight when Loke's children were brought into heaven, Hel's terrible face turning into stone every one who looked, unless he were a god; the Midgard-serpent coiling its immense length into great circles over which the glittering eyes wandered restlessly; and the Fenris-wolf growling with a deep, cruel voice. Odin looked sternly at Loke, the evil god who had brought such savage beings among men, and then with a dark brow he cast Hel down into the dusky kingdoms of the dead, and hurled the snake into the deep sea, where he grew until he coiled around the whole earth; but Fenrer, the wolf, was permitted to grow up in Asgard. He was so fierce that only Tyr, the sword-god, could feed him. He roamed about Asgard, his huge body daily growing stronger, and his hungry eyes flashing more and more fiercely.

After a time another shadow fell upon Odin's face, for Fenrer was fast becoming the most terrible enemy of the gods, and the oracles who could look into the future, said that at the last great battle he would destroy Odin himself. So Odin called all the gods together, and as they came into the great hall the wolf crouched at the door, with a look that made even their strong hearts shudder.

"Our most dangerous enemy is growing stronger every day under our roof and by our hands," said

Odin, "and we shall cease to be gods if we are so blind as to nourish our own destroyer."

"Kill him!" muttered some one.

"No," said Odin; "although he is to devour me, no blood shall stain the sacred seats of the gods."

"Chain him!" said Thor.

That was a good plan, they all agreed, but how was it to be done?

"Leave that to me," answered Thor, full of courage, for he had done many wonderful things, and there was nothing of which he was afraid.

That night the fires in the great smithy blazed and roared so fiercely that the heavens far around were lighted with the glow, and in the dusky light the strong forms of the gods moved to and fro as they worked on the chain with which they meant to bind the Fenris-wolf. All night Thor's mighty strokes rang on the hard iron, and when the morning came the chain was done, and they called it Leding. Then the gods called Fenrer, spread out the chain, and asked him to show his wonderful strength by breaking it.

The wolf knew better than the gods how strong he had grown, and that the breaking of Leding would be a very small matter for him; so he permitted them to bind the great links around his shaggy body and about his feet, and to rivet the ends so fast that it seemed as if nothing on earth could ever break them apart again. When it was all done, and Thor's eyes were beginning to smile at his success, the wolf got quietly upon his feet, stretched himself as easily as if a web of silk were cast over him, snapped the massive chain in a dozen places, and walked off, leaving the gods to gather up the broken links.

"He has grown terribly strong," said Odin, looking at the great pieces of iron.

"Yes," answered sturdy Thor, "stronger than I thought; but I will forge another chain, which even he cannot break."

Again the red glow shone in the sky over Asgard, the fires flashed and blazed, and the great hammers rang far into the night, and the next day the mighty chain Drome, twice as strong as Leding, was finished.

"Come, Fenrer," said Thor, "you already famous for your strength; if you can break this chain no [one] will ever be able to deny your strength, and you will win great honour among gods and men."

The wolf growled as he looked at the great chain, for he knew that the gods feared him and wanted to make him harmless. He knew also that he could break the chain which they had forged with so much toil to bind him with, and so he let them fasten him as before. When all was done, the gods began to smile again, for they had made the strongest chain that ever was or could be made, and now surely the wolf was forever harmless.

But Fenrer knew better than they. He rose slowly, with the massive links bound closely about him, shook himself fiercely, stretched himself, and then with a mighty effort dashed himself on the ground; the earth shook, the chain burst, and its links flew through the air and buried themselves in the ground, so tremendous was the effort with which the wolf freed himself. A fierce joy gleamed in his eyes as he walked away with deep growls, leaving the gods to console themselves as best they might, for there were no more chains to be made.

Long and anxiously they talked together, but no one could think of anything which could hold Fenrer until Odin called to Skirner, Frey's swiftest messenger: "Go to Svartalfheim as fast as the flash of Thor's hammer, and the dwarfs shall make us an enchanted chain which even he cannot break."

Skirner was off almost before Odin had done speaking. Travelling over land and sea he soon came to the dark entrance of the under-world where the dwarfs lived, and in a very short time he was in the dusky home of the wonderful little workers in iron. They were rushing about with black faces and dirty hair when Skirner called them together and said, "You must make for the gods an enchanted chain so slight that Fenrer will be willing to be bound by it, and so strong that when he has allowed himself to be tied he cannot break loose again."

The dwarves whispered together for a few moments, and then scattered in every direction; for they were going to make the most wonderful chain that was ever put together, and there were many things to be looked after before it could be done. Skirner sat in the darkness until the busy little workers had finished the band, and then he carried it quickly to Asgard, where all the gods were waiting anxiously for his coming and Fenrer was stealthily stealing from place to place through the city. Skirner spread the string out for the gods to look at, and they could hardly believe it was strong enough. It was very long, but so small and soft that it seemed no more than silken twine; it was made out of such things as the sound of a cat's footsteps, the roots of the mountains, the breath of a fish, and the sinews of a bear, and nothing could break it.

The gods were so happy in the hope of being relieved of their enemy that they could not thank

Skirner enough. They all went to a rocky island in a lake called Amsvartner, taking the wolf with them. Thor showed the silken twine to Fenrer. "You have broken Leding and Drome," he said, "and now you will break this also, although it is somewhat stronger than one would think, to look at it."

Then he handed the magic cord from one god to another and each tried to break it, but no one succeeded.

"We cannot do it," they all said after it had been handed around the circle, "but Fenrer can."

The wolf looked at it suspiciously.

"It is such a slender thread," he answered, "that I shall get no credit if I break it, and if it is made with magic, slight as it looks I shall never get loose from it again."

The gods looked at one another and smiled.

"Oh, you will easily break so slim a band as that," they replied, "since you have already broken the heaviest chains in the world; and if you cannot break it we will loosen you again."

"If you bind me so fast that I am not able to get myself free, I shall get little help from you," said the wolf truthfully enough. "I am very unwilling to have this twine bound about me; but that you may not be able to call me cowardly, I will do it if some one of you will lay his hand in my mouth as a pledge that there is no deceit about this thing."

The gods looked at each other when they heard these words. Fenrer had spoken the truth, there was no denying that. He must be chained now, however, or they would all be destroyed; but who would lose a hand to save the rest? Thor's hands were needed to swing the hammer against the giants, and everybody could think of some very good reason why his hand should not be lost. There was an awful pause, and then Tyr, the god of honour and courage, who had never stood still when he ought to go forward, stretched out his right hand and laid it in the wolf's hungry mouth.

Then the gods bound the slender cord tightly around Fenrer, fold on fold, winding its whole length about him and tying the ends tightly together. It was so slight that it seemed as if it must break in fifty places as soon as the wolf began to stretch himself. So perhaps thought Fenrer himself; but the harder he strove to break loose, the closer the cord drew about him. He sprang from side to side, he threw himself on the ground, he stretched his mighty limbs with all his strength, but the twine only cut the deeper. Then a mighty rage filled the wolf because he had suffered himself to be deceived, his eyes flamed with fury, and the foam ran out of his mouth. The gods were so delighted when they found the wolf really fast at last that they began to laugh, all except brave Tyr, who lost his right hand.

They took the wonderful silken chain and drew it through the middle of a rock and sunk the rock so deep in the earth that nothing but an earthquake could stir it. Fenrer, wild with pain and rage, rushed from side to side so violently that the earth rocked beneath him, and opening his tremendous jaws sprang upon the gods; whereupon they thrust a sword into his cruel jaws so that the hilt stood on his lower jaw and the point pierced the roof of the mouth.

So the Fenris-wolf was bound and made fast to the rocky island, his jaws spread far apart, foaming and growling until the last great day.

Source: Mabie, Hamilton Wright, trans. 1901. *Norse Stories Retold from the Eddas.* New York: Dodd, Mead and Company. Available at http://www.mainlesson.com/display.php?author=mabie&book=norse&story=wolf

The Ancient World: Greece

▣ Tiresias

Tiresias sits at the origin of a long tradition of blind prophets who, though they have lost their literal vision, compensate by seeing accurately into the future. This excerpt provides a well-known nineteenth-century commentary on his ancestry and his powers of foresight.

Early in the contest Eteocles consulted the soothsayer Tiresias as to the issue. Tiresias in his youth had by chance seen Minerva bathing. The goddess in her wrath deprived him of his sight, but afterwards relenting gave him in compensation the knowledge of future events. When consulted by Eteocles, he declared that victory should fall to Thebes if Menoeceus, the son of Creon, gave himself a voluntary victim. The heroic youth, learning the response, threw away his life in the first encounter.

Source: Bulfinch, Thomas. 1855. *Bulfinch's Mythology: The Age of Fables or Stories of Gods and Heroes.* Available at http://etext.library.adelaide.edu.au/b/bulfinch/thomas/b93fab/chap23.html

▣ Homer, the *Iliad* (ca. 750 BCE)

The Homeric writings contain several references to disabled people and provide hints about the meaning of disability. In both passages, the appearance of the person is noted; in Thersites' case, his appearance is noted disparagingly; in the case of Hephaestus, it is merely described. Note, though, that both Thersites and Hephaestus are playing important community roles. Regardless of physical appearance, Thersites is a soldier; Hephaestus is a craftsman.

From Book 2

The rest now took their seats and kept to their own several places, but Thersites still went on wagging his unbridled tongue—a man of many words, and those unseemly; a monger of sedition, a railer against all who were in authority, who cared not what he said, so that he might set the Achaeans in a laugh. He was the ugliest man of all those that came before Troy—bandy-legged, lame of one foot, with his two shoulders rounded and hunched over his chest. His head ran up to a point, but there was little hair on the top of it. Achilles and Ulysses hated him worst of all, for it was with them that he was most wont to wrangle; now, however, with a shrill squeaky voice he began heaping his abuse on Agamemnon. The Achaeans were angry and disgusted, yet none the less he kept on brawling and bawling at the son of Atreus.

"Agamemnon," he cried, "what ails you now, and what more do you want? Your tents are filled with bronze and with fair women, for whenever we take a town we give you the pick of them. Would you have yet more gold, which some Trojan is to give you as a ransom for his son, when I or another Achaean has taken him prisoner? Or is it some young girl to hide and lie with? It is not well that you, the ruler of the Achaeans, should bring them into such misery. Weakling cowards, women rather than men, let us sail home, and leave this fellow here at Troy to stew in his own meeds of honour, and discover whether we were of any service to him or no. Achilles is a much better man than he is, and see how he has treated him—robbing him of his prize and keeping it himself. Achilles takes it meekly and shows no fight; if he did, son of Atreus, you would never again insult him."

Thus railed Thersites, but Ulysses at once went up to him and rebuked him sternly. “Check your glib tongue, Thersites,” said be, “and babble not a word further. Chide not with princes when you have none to back you. There is no viler creature come before Troy with the sons of Atreus. Drop this chatter about kings, and neither revile them nor keep harping about going home. We do not yet know how things are going to be, nor whether the Achaeans are to return with good success or evil. How dare you gibe at Agamemnon because the Danaans have awarded him so many prizes? I tell you, therefore—and it shall surely be—that if I again catch you talking such nonsense, I will either forfeit my own head and be no more called father of Telemachus, or I will take you, strip you stark naked, and whip you out of the assembly till you go blubbering back to the ships.”

Hephaestus, god of fire, bronzework, and craftsmen, is returned to Olympus by his nondisabled brother, Dionysus. The story explains the contest of Zeus’s decision to exclude Hephaestus from the domain of the gods. The image uses the common visual identifier of an inverted foot to characterize his mobility impairment. Black-figured Attic amphora, end of sixth century BCE. Terra cotta, height 40 cm, diameter 27.3 cm.

Source: Kunsthistorisches Museum, Vienna, Austria. Photo credit: Erich Lessing/Art Resource, New York.

On this he beat him with his staff about the back and shoulders till he dropped and fell a-weeping. The golden sceptre raised a bloody weal on his back, so he sat down frightened and in pain, looking foolish as he wiped the tears from his eyes. The people were sorry for him, yet they laughed heartily, and one would turn to his neighbour saying, “Ulysses has done many a good thing ere now in fight and council, but he never did the Argives a better turn than when he stopped this fellow’s mouth from prating further. He will give the kings no more of his insolence.”

From Book 14

Thereon laughter-loving Venus said, “I cannot and must not refuse you, for you sleep in the arms of Jove who is our king.”

As she spoke she loosed from her bosom the curiously embroidered girdle into which all her charms had been wrought—love, desire, and that sweet flattery which steals the judgement even of the most prudent. She gave the girdle to Juno and said, “Take this girdle wherein all my charms reside and lay it in your bosom. If you will wear it I promise you that your errand, be it what it may, will not be bootless.”

When she heard this Juno smiled, and still smiling she laid the girdle in her bosom.

Venus now went back into the house of Jove, while Juno darted down from the summits of Olympus. She passed over Pieria and fair Emathia, and went on and on till she came to the snowy ranges of the Thracian horsemen, over whose topmost crests she sped without ever setting foot to ground. When she came to Athos she went on over the waves of the sea till she reached Lemnos, the city of noble Thoas. There she met Sleep, own brother to Death, and caught him by the hand, saying, “Sleep, you who lord it alike over mortals and immortals, if you ever did me a service in times past, do one for me now, and I shall be grateful to you ever after. Close Jove’s keen eyes for me in slumber while I hold him clasped in my embrace, and I will give you a beautiful golden seat, that can never fall to pieces; my clubfooted son Vulcan shall make it for you, and he shall give it a footstool for you to rest your fair feet upon when you are at table."

From Book 18

And Juno answered, "Dread son of Saturn, why should you say this thing? May not a man though he be only mortal and knows less than we do, do what he can for another person? And shall not I—foremost of all goddesses both by descent and as wife to you who reign in heaven—devise evil for the Trojans if I am angry with them?"

Thus did they converse. Meanwhile Thetis came to the house of Vulcan, imperishable, star-bespangled, fairest of the abodes in heaven, a house of bronze wrought by the lame god's own hands. She found him busy with his bellows, sweating and hard at work, for he was making twenty tripods that were to stand by the wall of his house, and he set wheels of gold under them all that they might go of their own selves to the assemblies of the gods, and come back again—marvels indeed to see. They were finished all but the ears of cunning workmanship which yet remained to be fixed to them: these he was now fixing, and he was hammering at the rivets. While he was thus at work silver-footed Thetis came to the house. Charis, of graceful head-dress, wife to the far-famed lame god, came towards her as soon as she saw her, and took her hand in her own, saying, "Why have you come to our house, Thetis, honoured and ever welcome—for you do not visit us often? Come inside and let me set refreshment before you."

The goddess led the way as she spoke, and bade Thetis sit on a richly decorated seat inlaid with silver; there was a footstool also under her feet. Then she called Vulcan and said, "Vulcan, come here, Thetis wants you"; and the far-famed lame god answered, "Then it is indeed an august and honoured goddess who has come here; she it was that took care of me when I was suffering from the heavy fall which I had through my cruel mother's anger—for she would have got rid of me because I was lame. It would have gone hardly with me had not Eurynome, daughter of the ever-encircling waters of Oceanus, and Thetis, taken me to their bosom. Nine years did I stay with them, and many beautiful works in bronze, brooches, spiral armlets, cups, and chains, did I make for them in their cave, with the roaring waters of Oceanus foaming as they rushed ever past it; and no one knew, neither of gods nor men, save only Thetis and Eurynome who took care of me. If, then, Thetis has come to my house I must make her due requital for having saved me; entertain her, therefore, with all hospitality, while I put by my bellows and all my tools."

On this the mighty monster hobbled off from his anvil, his thin legs plying lustily under him. He set the bellows away from the fire, and gathered his tools into a silver chest. Then he took a sponge and washed his face and hands, his shaggy chest and brawny neck; he donned his shirt, grasped his strong staff, and limped towards the door. There were golden handmaids also who worked for him, and were like real young women, with sense and reason, voice also and strength, and all the learning of the immortals; these busied themselves as the king bade them, while he drew near to Thetis, seated her upon a goodly seat, and took her hand in his own, saying, "Why have you come to our house, Thetis honoured and ever welcome—for you do not visit us often? Say what you want, and I will do it for you at once if I can, and if it can be done at all."

Thetis wept and answered, "Vulcan, is there another goddess in Olympus whom the son of Saturn has been pleased to try with so much affliction as he has me? Me alone of the marine goddesses did he make subject to a mortal husband, Peleus son of Aeacus, and sorely against my will did I submit to the embraces of one who was but mortal, and who now stays at home worn out with age. Neither is this all. Heaven vouchsafed me a son, hero among heroes, and he shot up as a sapling. I tended him as a plant in a goodly garden and sent him with his ships to Ilius to fight the Trojans, but never shall I welcome him back to the house of Peleus. So long as he lives to look upon the light of the sun, he is in heaviness, and though I go to him I cannot help him; King Agamemnon has made him give up the maiden whom the sons of the Achaeans had awarded him, and he wastes with sorrow for her sake. Then the Trojans hemmed the Achaeans in at their ships' sterns and would not let them come forth; the elders, therefore, of the Argives besought Achilles and offered him great treasure, whereon he refused to bring deliverance to them himself, but put his own armour on Patroclus and sent him into the fight with much people after him. All day long they fought by the Scaean gates and would have taken the city there and then, had not Apollo vouchsafed glory to Hector and slain the valiant son of Menoetius after he had done the Trojans much evil. Therefore I am suppliant at your knees if haply you may be pleased to provide my son, whose end is near at hand, with helmet and shield, with goodly greaves fitted with ancle-clasps, and with a breastplate, for he lost his own when his true comrade fell at the hands of the Trojans, and he now lies stretched on earth in the bitterness of his soul."

And Vulcan answered, "Take heart, and be no more disquieted about this matter; would that I could hide him from death's sight when his hour is come, so surely as I can find him armour that shall amaze the eyes of all who behold it."

Mars, Venus, and Vulcan, *by Jacopo Robusti Tintoretto (1518–1594). Illustration of the well-known myth of Vulcan's (the Roman name for the disabled god Hephaistos) discovery of the goddess of beauty's infidelity to him with the god of war, Mars. Unlike the Athenians, who erected a major temple to the crook-footed god, the Romans tended to lavish more attention on his debasement.*

Source: Art Resource, New York.

Source: Butler, Samuel, trans. 1898. *The Iliad by Homer.* Available at http://www.iclasses.org/assets/literature/iliad.cfm

▣ Homer on Hephaistos

(ca. 750 BCE)

In this excerpt from the Odyssey, *Hephaistos, the crook-footed Greek god, sets a trap to catch Venus and Mars in the midst of an affair. Hephaistos pleads to Jove for help because he has been cuckolded because of his lameness.*

Now Venus was just come in from a visit to her father Jove, and was about sitting down when Mars came inside the house, and said as he took her hand in his own, "Let us go to the couch of Vulcan: he is not at home, but is gone off to Lemnos among the Sintians, whose speech is barbarous."

She was nothing loth, so they went to the couch to take their rest, whereon they were caught in the toils which cunning Vulcan had spread for them, and could neither get up nor stir hand or foot, but found too late that they were in a trap. Then Vulcan came up to them, for he had turned back before reaching Lemnos, when his scout the sun told him what was going on. He was in a furious passion, and stood in the vestibule making a dreadful noise as he shouted to all the gods.

"Father Jove," he cried, "and all you other blessed gods who live for ever, come here and see the ridiculous and disgraceful sight that I will show you. Jove's daughter Venus is always dishonouring me because I am lame. She is in love with Mars, who is handsome and clean built, whereas I am a cripple—but my parents are to blame for that, not I; they ought never to have begotten me. Come and see the pair together asleep on my bed. It makes me furious to look at them. They are very fond of one another, but I do not think they will lie there longer than they can help, nor do I think that they will sleep much; there, however, they shall stay till her father has repaid me the sum I gave him for his baggage of a daughter, who is fair but not honest."

The Forge of Vulcan *(1576), by Jacopo Robusti Tintoretto (1518–1594). A late Italian Renaissance painting of the disabled god Vulcan's supervision of the forge, emphasizing his stature as an innovator of technology for bodies. The painting portrays Vulcan's legs as massive and muscular to foreground his ability. Images known as Classical tend to drop out any identification of disability.*

Source: Art Resource, New York.

On this the gods gathered to the house of Vulcan. Earth-encircling Neptune came, and Mercury the bringer of luck, and King Apollo, but the goddesses stayed at home all of them for shame. Then the givers of all good things stood in the doorway, and the blessed gods roared with inextinguishable laughter, as they saw how cunning Vulcan had been, whereon one would turn towards his neighbour saying:

"Ill deeds do not prosper, and the weak confound the strong. See how limping Vulcan, lame as he is, has caught Mars who is the fleetest god in heaven; and now Mars will be cast in heavy damages."

Thus did they converse, but King Apollo said to Mercury, "Messenger Mercury, giver of good things, you would not care how strong the chains were, would you, if you could sleep with Venus?"

"King Apollo," answered Mercury, "I only wish I might get the chance, though there were three times as many chains—and you might look on, all of you, gods and goddesses, but would sleep with her if I could."

The immortal gods burst out laughing as they heard him, but Neptune took it all seriously, and kept on imploring Vulcan to set Mars free again. "Let him go," he cried, "and I will undertake, as you require, that he shall pay you all the damages that are held reasonable among the immortal gods."

"Do not," replied Vulcan, "ask me to do this; a bad man's bond is bad security; what remedy could I enforce against you if Mars should go away and leave his debts behind him along with his chains?"

"Vulcan," said Neptune, "if Mars goes away without paying his damages, I will pay you myself." So Vulcan answered, "In this case I cannot and must not refuse you."

Thereon he loosed the bonds that bound them, and as soon as they were free they scampered off, Mars to Thrace and laughter-loving Venus to Cyprus and to Paphos, where is her grove and her altar fragrant with burnt offerings. Here the Graces bathed her, and anointed her with oil of ambrosia such as the immortal gods make use of, and they clothed her in raiment of the most enchanting beauty.

Thus sang the bard, and both Ulysses and the seafaring Phaeacians were charmed as they heard him.

Source: Butler, Samuel, trans. 1900. *The Odyssey.* Republished 2004. eBooks@Adelaide. Available at http://etext.library.adelaide.edu.au/h/homer/h8o/index.html

▣ Plato, *Republic*

(380–370 BCE)

Plato, the fifth-/fourth-century philosopher and mentor to Aristotle, devises a highly regulated utopian state in *his* Republic*, a philosophical analysis of justice. Sometimes taken as evidence of actual Greek practice, this model community—a utopia, after all—does not resemble familiar Greek patterns. In other passages (not excerpted here), in contrast to the actual classical Greek world, some women have roles of leadership (451 c–457 c); the family is abolished (457 c–461 e); and the city's inhabitants do not disagree with each other (462 a–466 d). In the* Laws*, written many years after his* Republic*, Plato again comments on the perfect community, suggesting that one might be exempt from marrying someone "suffering from defects of mind or body." Plato's musings confirm the established practice in ancient Greece: one married whom one was contracted to marry, regardless of aesthetic or mental characteristics. The following excerpt is in the form of a dialogue between different individuals.*

These, he said, and none other; for what can be more ridiculous than for them to utter the names of family ties with the lips only and not to act in the spirit of them?

Then in our city the language of harmony and concord will be more often heard than in any other. As I was describing before, when anyone is well or ill, the universal word will be "with me it is well" or "it is ill."

Most true.

And agreeably to this mode of thinking and speaking, were we not saying that they will have their pleasures and pains in common?

Yes, and so they will.

And they will have a common interest in the same thing which they will alike call "my own," and having this common interest they will have a common feeling of pleasure and pain?

Yes, far more so than in other States.

And the reason of this, over and above the general constitution of the State, will be that the guardians will have a community of women and children?

That will be the chief reason.

And this unity of feeling we admitted to be the greatest good, as was implied in our comparison of a well-ordered State to the relation of the body and the members, when affected by pleasure or pain?

That we acknowledged, and very rightly.

Then the community of wives and children among our citizens is clearly the source of the greatest good to the State?

Certainly.

And this agrees with the other principle which we were affirming—that the guardians were not to have houses or lands or any other property; their pay was to be their food, which they were to receive from the other citizens, and they were to have no private expenses; for we intended them to preserve their true character of guardians.

Right, he replied.

Both the community of property and the community of families, as I am saying, tend to make them more truly guardians; they will not tear the city in pieces by differing about "mine" and "not mine"; each man dragging any acquisition which he has made into a separate house of his own, where he has a separate wife and children and private pleasures and pains; but all will be affected as far as may be by the same pleasures and pains because they are all of one opinion about what is near and dear to them, and therefore they all tend toward a common end.

Certainly, he replied.

And as they have nothing but their persons which they can call their own, suits and complaints will have no existence among them; they will be delivered from all those quarrels of which money or children or relations are the occasion.

Of course they will.

Neither will trials for assault or insult ever be likely to occur among them. For that equals should defend themselves against equals we shall maintain to be honorable and right; we shall make the protection of the person a matter of necessity.

That is good, he said.

Yes; and there is a further good in the law; viz., that if a man has a quarrel with another he will satisfy his resentment then and there, and not proceed to more dangerous lengths.

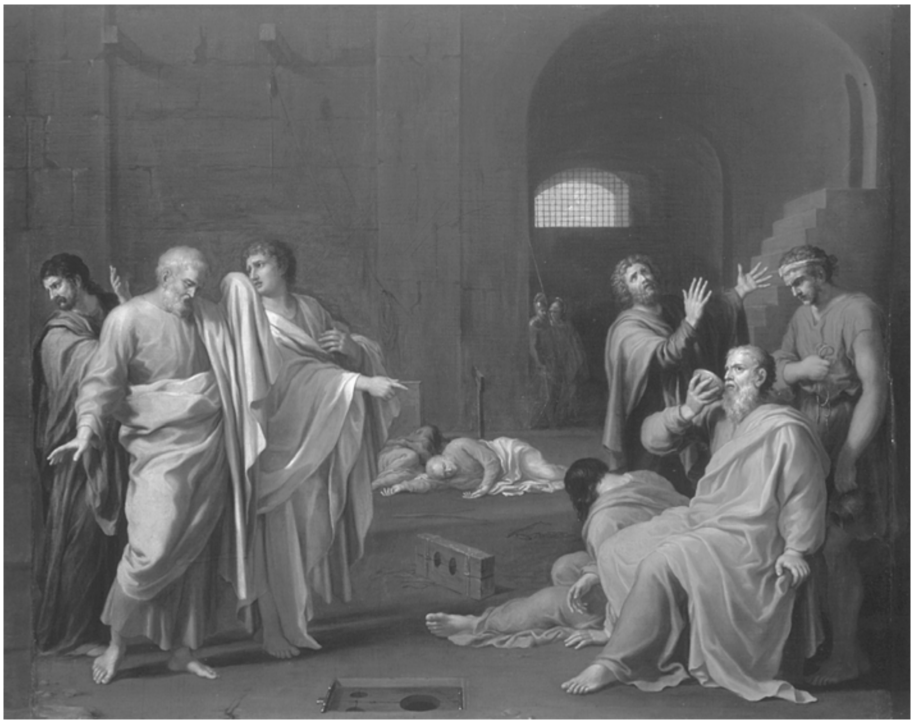
Certainly.

To the elder shall be assigned the duty of ruling and chastising the younger.

Clearly.

Nor can there be a doubt that the younger will not strike or do any other violence to an elder, unless the magistrates command him; nor will he slight him in any way. For there are two guardians, shame and fear, mighty to prevent him: shame, which makes men refrain from laying hands on those who are to them in the relation of parents; fear, that the injured one will be succored by the others who are his brothers, sons, fathers.

That is true, he replied.



The Death of Socrates *(1650), by Charles Alphonse Dufresnoy (1611–1668). Recreation of Socrates' death sentence. Socrates was required to drink a draft of hemlock by an Athenian jury who found him guilty of corrupting the city's youth and interfering with religious practices. The German philosopher Nietzsche comments that Socrates was the "ugliest man in Greece" because of his facial deformity and that his philosophy championed the beauty of intellect as a redress for his society's emphasis on surface appearance. Oil on canvas, 122 155 cm.*

Source: Galleria Palatina, Palazzo Pitti, Florence, Italy. Photo credit: Alinari/Art Resource, New York.

Then in every way the laws will help the citizens to keep the peace with one another?

Yes, there will be no want of peace.

And as the guardians will never quarrel among themselves there will be no danger of the rest of the city being divided either against them or against one another.

None whatever.

I hardly like even to mention the little meannesses of which they will be rid, for they are beneath notice: such, for example, as the flattery of the rich by the poor, and all the pains and pangs which men experience in bringing up a family, and in finding money to buy necessaries for their household, borrowing and then repudiating, getting how they can, and giving the money into the hands of women and slaves to keep—the many evils of so many kinds which people suffer in this way are mean enough and obvious enough, and not worth speaking of.

Yes, he said, a man has no need of eyes in order to perceive that.

Source: Spens, H., trans. 1906. *The Republic.* London: Dent.

Aristotle, *Politics* (ca. 350 BCE)

In his Politics, *the fourth-century* BCE *philosopher Aristotle proposes the ideal society. He suggests that the intelligence of men is constitutionally determined, and that men should take roles according to their constitution. In this excerpt, Aristotle goes on to suggest that in the ideal state, "no deformed child shall be reared."*

From Book VII:

Since the legislator should begin by considering how the frames of the children whom he is rearing may be as good as possible, his first care will be about marriage—at what age should his citizens marry, and who are fit to marry? In legislating on this subject he ought to consider the persons and the length of their life, that their procreative life may terminate at the same period, and that they may not differ in their bodily powers, as will be the case if the man is still able to beget children while the woman is unable to bear them, or the woman able to bear while the man is unable to beget, for from these causes arise quarrels and differences between married persons. Secondly, he must consider the time at which the children will succeed to their parents; there ought not to be too great an interval of age, for then the parents will be too old to derive any pleasure from their affection, or to be of any use to them. Nor ought they to be too nearly of an age; to youthful marriages there are many objections—the children will be wanting in respect to the parents, who will seem to be their contemporaries, and disputes will arise in the management of the household. Thirdly, and this is the point from which we digressed, the legislator must mold to his will the frames of newly-born children. Almost all these objects may be secured by attention to one point. Since the time of generation is commonly limited within the age of seventy years in the case of a man, and of fifty in the case of a woman, the commencement of the union should conform to these periods. The union of male and female when too young is bad for the procreation of children; in all other animals the offspring of the young are small and in-developed, and with a tendency to produce female children, and therefore also in man, as is proved by the fact that in those cities in which men and women are accustomed to marry young, the people are small and weak; in childbirth also younger women suffer more, and more of them die; some persons say that this was the meaning of the response once given to the Troezenians—the oracle really meant that many died because they married too young; it had nothing to do with the ingathering of the harvest. It also conduces to temperance not to marry too soon; for women who marry early are apt to be wanton; and in men too the bodily frame is stunted if they marry while the seed is growing (for there is a time when the growth of the seed, also, ceases, or continues to but a slight extent). Women should marry when they are about eighteen years of age, and men at seven and thirty; then they are in the prime of life, and the decline in the powers of both will coincide. Further, the children, if their birth takes place soon, as may reasonably be expected, will succeed in the beginning of their prime, when the fathers are already in the decline of life, and have nearly reached their term of three-score years and ten.

Thus much of the age proper for marriage: the season of the year should also be considered; according to our present custom, people generally limit marriage to the season of winter, and they are right. The precepts of physicians and natural philosophers about generation should also be studied by the parents themselves; the physicians give good advice about the favorable conditions of the body, and the natural philosophers about the winds; of which they prefer the north to the south.

What constitution in the parent is most advantageous to the offspring is a subject which we will consider more carefully when we speak of the education of children, and we will only make a few general remarks at present. The constitution of an athlete is not suited to the life of a citizen, or to health, or to the procreation of children, any more than the valetudinarian or exhausted constitution, but one which is in a mean between them. A man's constitution should be inured to labor, but not to labor which is excessive or of one sort only, such as is practiced by athletes; he should be capable of all the actions of a freeman. These remarks apply equally to both parents.

Women who are with child should be careful of themselves; they should take exercise and have a nourishing diet. The first of these prescriptions the legislator will easily carry into effect by requiring that they shall take a walk daily to some temple, where they can worship the gods who preside over birth. Their minds, however, unlike their bodies, they ought to keep quiet, for the offspring derive their natures from their mothers as plants do from the earth.

As to the exposure and rearing of children, let there be a law that no deformed child shall live, but that on the ground of an excess in the number of children, if the established customs of the state forbid this (for in our state population has a limit), no child is to be exposed, but when couples have children in excess, let abortion be procured before sense and life have begun; what may or may not be lawfully done in these cases depends on the question of life and sensation.

And now, having determined at what ages men and women are to begin their union, let us also determine how long they shall continue to beget and bear offspring for the state; men who are too old, like men who are too young, produce children who are defective in body and mind; the children of very old men are weakly. The limit then, should be the age which is the prime of their intelligence, and this in most persons, according to the notion of some poets who measure life by periods of seven years, is about fifty; at four or five years or later, they should cease from having families; and from that time forward only cohabit with one another for the sake of health; or for some similar reason.

As to adultery, let it be held disgraceful, in general, for any man or woman to be found in any way unfaithful when they are married, and called husband and wife. If during the time of bearing children anything of the sort occur, let the guilty person be punished with a loss of privileges in proportion to the offense.

Source: Jowett, Benjamin, trans. 1900. *The Politics of Aristotle.* New York: Colonial Press.

Lysias 24, "On the Refusal of a Pension" (ca. 404 BCE)

Lysias 24 was probably meant for presentation—whether or not it actually was presented—before the Athenian Boule, the council that ran the affairs of state on behalf of the entire citizen body. The speech probably dates to the closing years of the fifth century BCE. *The defendant had been classed among the unable and had been receiving a state pension. Now, the pension was in danger of being rescinded. The defendant was obviously disabled in the modern sense of the term, yet he could not merely display his disabled body before the Boule as proof that he deserved to keep the pension. Rather, he had to point to conditions such as his aged mother, whom he had to support. This document points to the ancient lack of codification and assumptions about people with what we call disabilities.*

I can almost find it in me to be grateful to my accuser, gentlemen of the Council, for having involved me in these proceedings. For previously I had no excuse for rendering an account of my life; but now, owing to this man, I have got one. So I will try to show you in my speech that this man is lying, and that my own life until this day has been deserving of praise rather than envy; for it is merely from envy, in my opinion, that he has involved me in this ordeal.

But I ask you, if a man envies those whom other people pity, from what villainy do you think such a person would refrain? Is it possible that he hopes to get money by slandering me? And if he makes me out an enemy on whom he seeks to be avenged, he lies; for his villainy has always kept me from having any dealings with him either as a friend or as an enemy.

So now, gentlemen, it is clear that he envies me because, although I have to bear this sore misfortune, I am a better citizen than he is. For indeed I consider, gentlemen, that one ought to remedy the afflictions of the body with the activities of the spirit; for if I am to keep my thoughts and the general tenor of my life on the lever of my misfortune, how shall I be distinguished from this man?

Well, in regard to those matters, let these few words of mine suffice; I will now speak as briefly as I can on the points with which I am here concerned. My accuser says that I have no right to receive my civil pension, because I am able-bodied and not classed as disabled, and because I am skilled in a trade which would enable me to live without this grant.

In proof of my bodily strength, he instances that I mount on horseback; of the affluence arising from my trade, that I am able to associate with people who have means to spend. Now, as to the affluence for my trade and the nature of my livelihood in general, I think you are all acquainted with these: I will, however, make some brief remarks of my own.

My father left me nothing, and I have only ceased supporting my mother on her decease two years ago; while as yet I have no children to take care of me. I possess a trade that can give me but slight assistance: I already find difficulty in carrying it on myself, and as yet I am unable to procure someone to relieve me of the work. I have no other income besides this dole, and if you deprive me of it I might be in danger of finding myself in the most grievous plight.

Do not, therefore, gentlemen, when you can save me justly, ruin me unjustly; what you granted me when I was younger and stronger, do not take from me when I am growing older and weaker; not, with your previous reputation for showing the utmost compassion even towards those who are in no trouble, be moved now by this man to deal harshly with those who are objects of pity even to their enemies; nor, by having the heart to wrong me, cause everyone else in my situation to despond. And indeed, how extraordinary the case would be, gentlemen! When my misfortune was but simple, I am found to have been receiving this pension; but now, when old age, diseases, and the ills that attend on them are added to my trouble, I am to be deprived of it!

The depth of my poverty, I believe, can be revealed more clearly by my accuser than by anyone else on earth. For if I were charged with the duty of producing tragic drama, and should challenge him to an exchange of property, he would prefer being the producer ten times over to making the exchange once. Surely it is monstrous that he should now accuse me of having such great affluence that I can consort on equal terms with the wealthiest people, while, in the event of such a thing as I have suggested, he should make that choice. Why, what could be more villainous?

As to my horsemanship, which he has dared to mention to you, feeling neither awe of fortune nor shame before you, there is not much to tell. For I, gentlemen, am of the opinion that all who suffer from some affliction make it their single aim and constant study to manage the condition that has befallen them with the least amount of discomfort. I am such an one, and in the misfortune that has stricken me I have devised this facility for myself on the longer journeys that I find necessary.

But the strongest proof, gentlemen, of the fact that I mount horses because of my misfortune, and not from insolence, as this man alleges, is this: if I were a man of means, I should ride on a saddled mule, and would not mount other men's horses. But in fact, as I am unable to acquire anything of the sort, I am compelled, now and again, to use other men's horses.

Well, I ask you, gentlemen, is it not extraordinary that, if he saw me riding on a saddled mule, he would hold his peace, for what could he say?—and then, because I mount borrowed horses, he should try to persuade you that I am able-bodied; and that my using two sticks, while others use one, should not be argued by him against me as a sign of being able-bodied, but my mounting horses would be advanced by him as a proof to you that I am able-bodied? For I use both aids for the same reason.

So utterly has he surpassed the whole human race in impudence that he tries with his single voice to persuade any of you on this point, gentlemen, what hinders me from drawing a lot for election as one of the nine archons, and you from depriving me of my obol as having sound health, and voting it unanimously to this man as being a cripple? For surely, after you have deprived a man of the grant as being able-bodied, the law officers are not going to debar this same person, as being disabled, from drawing a lot!

Nay, indeed you are not of the same opinion as he is, nor is he either, and rightly so. For he has come here to dispute over my misfortune as if over an heiress, and he tries to persuade you that I am not the sort of man that you all see me to be; but you—as is incumbent on men of good sense—have rather to believe your own eyes than this person's words. . . .

For insolence is not likely to be shown by poor men laboring in the utmost indigence, but by those who possess far more than the necessaries of life; nor by men disabled in body, but by those who are still young and have a youthful turn of mind.

For the wealthy purchase with their money escape from the risks that they run, whereas the poor are compelled to moderation by the pressure of their want. The young are held to merit indulgence from their elders; but if their elders are guilty of offence, both ages unite in reproaching them.

The strong are at liberty to insult whomsoever they will with impunity, but the weak are unable either to beat off their aggressors when insulted, or to get the better of their victims if they choose to insult. Hence it seems to me that my accuser was not serious in speaking of my insolence, but was only jesting; his purpose was, not to persuade you that such is my nature, but to set me in a comic light, as a fine stroke of fancy.

He further asserts that my shop is the meeting place of a number of rogues who have spent their own money and hatch plots against those who wish to preserve theirs. But you must all take note that these statements of his are no more accusations against me than against anyone else who has a trade, nor against those who visit my shop any more than those who frequent other men of business.

For each of you is in the habit of paying a call at either a perfumer's or a barber's or a shoemaker's shop, or wherever he may chance to go,—in most cases, it is to the tradesmen who have set up nearest the marketplace, and in fewest, to those who are farthest from it. So if any of you should brand with roguery the men who visit my shop, clearly you must do the same to those who pass their time in the shops of others; and if to them, to all the Athenians: for you are all in the habit of paying a call and passing your time at some shop or other.

But really I see no need for me to be so very particular in rebutting each one of the statements that he has made, and to weary you any longer. For if I have argued the principal points, what need is there to dwell seriously on trifles in the same way as he does? But I beg you all, gentlemen of the Council, to hold the same views concerning me as you have held till now.

Do not be led by this man to deprive me of the sole benefit in my country of which fortune has granted me a share, nor let this one person prevail on you to withdraw now what you all agreed to grant me in the past. For, gentlemen, since Heaven had deprived us of the chiefest things, the city voted us this pension, regarding the chances of evil and of good as the same for all alike.

Surely I should be the most miserable of creatures if, after being deprived by my misfortune of the fairest and greatest things, the accuser should cause me the loss of that which the city bestowed in her thoughtful care for men in my situation. No, no, gentlemen; you must not vote that way. And why should I find you thus inclined?

Because anyone has ever been brought to trial at my instance and lost his fortune? There is nobody who can prove it.

Well, is it that I am a busybody, a hot head, a seeker of quarrels?

That is not the sort of use I happen to make of such means of subsistence as I have. That I am grossly insolent and savage? Even he would not allege this himself, except he should wish to add one more to the series of his lies. Or that I was in power at the time of the Thirty, and oppressed a great number of the citizens? But I went into exile with your people to Chalics, and when I was free to live secure as a citizen with those persons I chose to depart and share your perils.

I therefore ask you, gentlemen of the Council, not to treat me, a man who has committed no offence, in the same way as those who are guilty of numerous wrongs, but to give the same vote as the other Councils did on my case, remembering that I am neither rendering an account of State moneys placed in my charge, nor undergoing now an inquiry into my past proceedings in any office, but that the subject of this speech of mine is merely an obol.

In this way you will all give the decision that is just, while I, in return for that, will feel duly grateful to you; and this man will learn in the future not to scheme against those who are weaker than himself, but only to overreach his equals.

Source: Lamb, W. R. M., trans. 1930. *Lysias, with an English Translation.* Cambridge, MA: Harvard University Press.

▣ Herodotus (5th c. BCE)

Herodotus is known as the "father of history," and his work, from the fifth century BCE, is indeed the earliest complete history that survives. Herodotus weaves fact and fancy; among his reports and tall tales we can find clues to the lives of people with disabilities. In his tale of the Babylonian marriage market, for example, we see that deformed women were considered ugly, but not unmarriageable. The blind Scythian slaves are examples of blind people with professions, in contrast to the common ancient image of blind people as bards and beggars. The tale of King Darius and his injury reflects a world in which a simple fall can result in permanent disability, even for the most powerful person on earth. Darius's cruelty is highlighted in the following selection, but also highlighted is the ability of a group of disabled men to guard a camp. (See Barry Baldwin. 1967. "Medical Grounds for Exemptions from Military Service at Athens." Classical Philology 62: 42–43.) Finally, we see the individual, nonmedicalized nature of prosthetic devices in the tale of Hegesistratus and his makeshift (and highly unlikely) prosthetic foot.

1.196

This is the equipment of their persons. I will now speak of their established customs. The wisest of these, in our judgement, is one which I have learned by inquiry is also a custom of the Eneti in Illyria. It is this: once a year in every village all the maidens as they attained marriageable age were collected and brought together into one place with a crowd of men standing around. Then a crier would display and offer them for sale one by one, first the fairest of all; and then, when she had fetched a great price, he put up for sale the next most attractive, selling all the maidens as lawful wives. Rich men of Assyria who desired to marry would outbid each other for the fairest; the ordinary people, who desired to marry and had no use for beauty, could take the ugly ones and money besides; for when the crier had sold all the most attractive, he would put up the one that was least beautiful, or crippled, and offer her to whoever would take her to wife for the least amount, until she fell to one who promised to accept least; the money came from the sale of the attractive ones, who thus paid the dowry of the ugly and the crippled. But a man could not give his daughter in marriage to whomever he liked, nor could one that bought a girl take her away without giving security that he would in fact make her his wife. And if the couple could not agree, it was a law that the money be returned. Men might also come from other villages to buy if they so desired. This, then, was their best custom; but it does not continue at this time; they have invented a new one lately [so that the women not be wronged or taken to another city]; since the conquest of Babylon made them afflicted and poor, everyone of the people that lacks a livelihood prostitutes his daughters.

3.129–130

Not long after this, it happened that Darius twisted his foot in dismounting from his horse while hunting so violently that the ball of the ankle joint was dislocated from its socket. Darius called in the best physicians of Egypt, whom he had until now kept near his person. But by violently twisting the foot they made the injury worse; and for seven days and nights the king could not sleep because of the pain. On the eighth day, when he was doing poorly, someone who had heard in Sardis of the skill of Democedes of Croton told Darius of him; and he told them to bring him as quickly as possible. When they found him among the slaves of Oroetes, where he was forgotten, they brought him along, dragging his chains and dressed in rags.

Darius asked him when he was brought in if he were trained in medicine. He refused to admit it, for he was afraid that if he revealed himself he would be cut off from Hellas for good. It was clear to Darius, however, that he was trained in deceit, and he ordered those who had brought him to bring along scourges and goads. Then he confessed, saying that his training was not exact, but that he had associated with a physician and had a passing acquaintance with medicine. But when Darius turned the case over to him and Democedes applied Greek remedies and used gentleness instead of the Egyptians' violence, he enabled him to sleep and in a short time had him well, although Darius had had no hope of regaining the use of his foot.

4.2

Now the Scythians blind all their slaves, because of the milk they drink; and this is how they get it; taking tubes of bone very much like flutes, they insert these into the genitalia of the mares and blow into them, some blowing while others milk. According to them, their reason for doing this is that blowing makes the mare's veins swell and her udder drop. When done milking, they pour the milk into deep wooden buckets, and make their slaves stand around the buckets and shake the milk; they draw off what stands on the surface and value this most; what lies at the bottom is less valued. This is why the Scythians blind all prisoners whom they take: for they do not cultivate the soil, but are nomads.

4.135

This was Gobryas' advice, and at nightfall Darius followed it. He left the men who were worn out, and those whose loss mattered least to him, there in the camp, and all the asses, too, tethered. His reasons for leaving the asses, and the infirm among his soldiers, were the following; the asses, so that they would bray; the men, who were left because of their infirmity, he pretended were to guard the camp while he attacked the Scythians with the fit part of his army. Giving this order to those who were left behind, and lighting campfires, Darius made all haste to reach the Ister. When the asses found themselves deserted by the multitude, they brayed the louder for it; and the Scythians heard them and assumed that the Persians were in the place.

9.37

Mardonius' sacrifices also foretold an unfavorable outcome if he should be zealous to attack first, and good if he should but defend himself. He too used the Greek manner of sacrifice, and Hegesistratus of Elis was his diviner, the most notable of the sons of Tellias. This man had been put in prison and condemned to die by the Spartans for the great harm which he had done them. Being in such bad shape inasmuch as he was in peril of his life and was likely to be very grievously maltreated before his death, he did something which was almost beyond belief; made fast in iron-bound stocks, he got an iron weapon which was brought in some way into his prison, and straightway conceived a plan of such courage as we have never known; reckoning how best the rest of it might get free, he cut off his own foot at the instep.

This done, he tunneled through the wall out of the way of the guards who kept watch over him, and so escaped to Tegea. All night he journeyed, and all day he hid and lay hidden in the woods, till on the third night he came to Tegea, while all the people of Lacedaemon sought him. The latter were greatly amazed when they saw the half of his foot which had been cut off and lying there but were unable to find the man himself.

This then is the way in which he escaped the Lacedaemonians and took refuge in Tegea, which at that time was unfriendly to Lacedaemon. After he was healed and had made himself a foot of wood, he declared himself an open enemy of the Lacedaemonians. Yet the enmity which he bore them brought him no good at the last, for they caught him at his divinations in Zacynthus and killed him.

Source: Rawlinson, George, trans. 1858–1860. *The History of Herodotus.* Republished 1910. London: J. M. Dent.

Hippocrates (ca. 400 BCE)

The Hippocratic corpus is a compilation of material that spans the fifth through the second centuries BCE. *It includes writings by the author credited with the discovery of rational medicine, Hippocrates himself, although nothing is identified securely. The corpus also includes writings by the students of Hippocrates and other medical writers. The corpus is especially valuable in that it provides vivid descriptions of people with what we would call physical disability. Classical art in general portrayed mathematically perfect bodies, with the exception of comedic and mythological figures. The examples from the corpus that follow show the experimental, itinerant, and occasionally charlatan nature of the medical profession. Some documents suggest that the ancient physician might be more likely to cause permanent disability than to prevent it. Note also that amputation appears to be a passive matter (i.e., the limbs fall off of their own accord); that limb dislocations and other complications were common enough to be categorized; and that variants of gait are described thoroughly (in "On Joints"). "On the Sacred Disease" discusses the disease we now know as epilepsy, which was termed the sacred disease in Hippocrates' time and was believed to result from divine causes. In his discussion of the disease, Hippocrates expounds his conviction that all diseases, even epilepsy, resulted from natural mechanisms.*

"On Fractures"

Part 1

In treating fractures and dislocations, the physician must make the extension as straight as possible, for this is the most natural direction. But if it incline to either side, it should rather turn to that of pronation, for there is thus less harm than if it be toward supination. Those, then, who act in such cases without deliberation, for the most part do not fall into any great mistake, for the person who is to have his arm bound, presents it in the proper position from necessity, but physicians who fancy themselves learned in these matters, are they who commit blunders. There is no necessity for much study, then, in order to set a broken arm, and in a word, any ordinary physician can perform it; but I am under the necessity of giving the longer directions on this subject, because I know physicians who have the reputation of being skilled in giving the proper positions to the arm in binding it up, while in reality they are only showing their own ignorance. But many other things in our art are judged of in this manner, for people rather admire what is new, although they do not know whether it be proper or not, than what they are accustomed to, and know already to be proper; and what is strange, they prefer to what is obvious. I must now state what the mistakes of medical men are, which I wish to unteach, and what instructions I have to give as the management of the arm; for what I have to say regarding it, will apply to the other bones in the body.

Part 2

The arm, then, for that is the subject we were treating of, was presented in the prone position to be bound, but the physician forced his patient to hold it as the archers do when they project the shoulder, and in this position he bound it up, thinking within himself that he was acting according to Nature, and in proof of this he pointed out that all the bones in the fore-arm were thus in a straight line, and that the integuments both inside and outside, were also in a straight line, and that the flesh and nerves (tendons?) were thus put in their natural position, and he appealed to what happens in archery, as a proof of this. And so saying, and so doing, he is looked up to as a sage; and yet he forgets that in all the other arts and performances, whether executed by strength or dexterity, what is reckoned the natural position is not the same, and that in the same piece of work it may happen that the natural position of the right arm is not the same as that of the left. For there is one attitude in throwing the javelin, and another in slinging, another in casting stones, another in boxing, and another in a state of repose. And whatever arts one examines, it will be found that the natural position of the arms is not the same in each, but that in every case the arms are put into the attitude which suits best with the instrument that is used, and the work to be performed.

Part 9

The human foot is composed of several small bones like the hand. These bones therefore are scarcely ever broken, unless the skin at the same time be wounded by some sharp and heavy body. The treatment of such injuries, therefore, will be delivered under the head of wounds. But if any bone be moved from its place, or a joint of the toes be luxated, or any of the bones of the part called the tarsus be displaced, it must be forced back again to its place as described with regard to the hand; and is to be treated with cerate, compresses, and bandages, like the fractures, with the exception of the splints; and is to be secured tightly in the same way, and the bandages renewed on the third day; and the patient thus bandaged should return the same answers as in fractures, as to the bandages feeling tight or slack. All these bones recover perfectly in twenty days, except those that are connected with the bones of the leg, and are in a line with them. It is advantageous to lie in bed during the whole of this time; but the patients, thinking light of the complaint, have not perseverance to do this, and they walk about before they get well; wherefore many of these do not make a perfect recovery. And often the pain puts them in mind of the injury; and deservedly, for the feet sustain the weight of the whole body. When, therefore, they walk about before they are whole, the joints which have been luxated are cured incompletely; and, on that account, while walking about, they have pains in the leg from time to time.

Part 11

In persons who jumping from any high object pitch upon their heel with great force, the bones are separated, and the veins pour forth their contents, owing to the contusion of the flesh surrounding the bone, and hence a swelling and much pain supervene. For this bone (os calcis) is not a small one, protrudes beyond the line of the leg, and is connected with important veins and tendons; from the back tendon of the leg is inserted into this bone.

Part 13

Sometimes the bones connected with the foot are displaced, sometimes both bones with their epiphysis; sometimes the whole epiphysis is slightly moved, and sometimes the other bone. These cases are less troublesome than the same accidents at the wrist, if the patients will have resolution to give them rest. The mode of treatment is the same as that of the other, for the reduction is to be made, as of the other, by means of extension, but greater force is required, as the parts of the body concerned are stronger in this case. But, for the most part, two men will be sufficient, by making extension in opposite directions, but, not withstanding, if they are not sufficiently strong, it is easy to make more powerful extension in the following way: having fixed in the ground either the nave of a wheel, or any such object, something soft is to be bound round the foot, and then some broad thongs of ox-skin being brought round it, the heads of the thongs are to be fastened to a pestle or any other piece of wood, the end of which is to be inserted into the nave, and it, the pestle, is to be pulled away, while other persons make counter-extension by grasping the shoulders and the ham. It is also sometimes necessary to secure the upper extremity otherwise; this if you desire to effect, fasten deeply in the ground a round, smooth piece of wood, and place the upper extremity of the piece of wood at the perineum, so that it may prevent the body from yielding to the pulling at the foot, and, moreover, to prevent the leg while stretched, from inclining downward; some person seated at this side should push back the hip, so that the body may not turn round with the pulling, and for this purpose, if you think fit, pieces of wood may be fastened about the armpits on each side. . . .

Part 15

And when both bones of the leg are broken without a wound of the skin, stronger extension is required. We may make extension by some of the methods formerly described, provided the bones ride over one another to a considerable degree. But extension by men is also sufficient, and for the most part two strong men will suffice, by making extension and counterextension. Extension must naturally be made straight in a line with the leg and thigh. And in both cases they are to be bandaged while in a state of extension, for the same position does not suit with the leg and the arm. For when the fractured bones of the arm or fore-arm are bandaged, the fore-arm is suspended in a sling, and if you bind them up while extended, the figures of the fleshy parts will be changed in bending the arm at the elbow, for the elbow cannot be kept long extended, since persons are not in the custom of keeping the joint long in this form, but in a bent position, and persons who have been wounded in the arm, and are still able to walk about, require to have the arm bent at the elbow-joint. But the leg, both in walking and standing, is habitually extended, either completely or nearly so, and is usually in a depending position from its construction, and in order that it may bear the weight of the rest of the body. Wherefore it readily bears to be extended when necessary, and even when in bed the limb is often in this position. And when wounded, necessity subdues the understanding, since the patients become incapable of raising themselves up, so that they neither think of bending the limb nor of getting up erect, but remaining lying in the same position.

"On the Sacred Disease"

But this disease seems to me to be no more divine than others; but it has its nature such as other diseases have, and a cause whence it originates, and its nature and cause are divine only just as much as all others are, and it is curable no less than the others, unless when, the form of time, it is confirmed, and has become stronger than the remedies applied. Its origin is hereditary, like that of other diseases. For if a phlegmatic person be born of a phlegmatic, and a bilious of a bilious, and a phthisical of a phthisical, and one having spleen disease, of another having disease of the spleen, what is to hinder it from happening that where the father and mother were subject to this disease, certain of their offspring should be so affected also? As the semen comes from all parts of the body, healthy particles will come from healthy parts, and unhealthy from unhealthy parts. And another great proof that it is in nothing more divine than other diseases is, that it occurs in those who are of a phlegmatic constitution, but does not attack the bilious. Yet, if it were more divine than the others, this disease ought to befall all alike, and make no distinction between the bilious and phlegmatic.

But the brain is the cause of this affection, as it is of other very great diseases, and in what manner and from what cause it is formed, I will now plainly declare. The brain of man, as in all other animals, is double, and a thin membrane divides it through the middle, and therefore the pain is not always in the same part of the head; for sometimes it is situated on either side, and sometimes the whole is affected; and veins run toward it from all parts of the body, many of which are small, but two are thick, the one from the liver, and the other from the spleen. And it is thus with regard to the one from the liver: a portion of it runs downward through the parts on the side, near the kidneys and the psoas muscles, to the inner part of the thigh, and extends to the foot. It is called vena cava. The other runs upward by the right veins and the lungs, and divides into branches for the heart and the right arm. The remaining part of it rises upward across the clavicle to the right side of the neck, and is superficial so as to be seen; near the ear it is concealed, and there it divides; its thickest, largest, and most hollow part ends in the brain; another small vein goes to the right ear, another to the right eye, and another to the nostril. Such are the distributions of the hepatic vein. And a vein from the spleen is distributed on the left side, upward and downward, like that from the liver, but more slender and feeble. . . .

And the disease called the Sacred arises from causes as the others, namely, those things which enter and quit the body, such as cold, the sun, and the winds, which are ever changing and are never at rest. And these things are divine, so that there is no necessity for making a distinction, and holding this disease to be more divine than the others, but all are divine, and all human. And each has its own peculiar nature and power, and none is of an ambiguous nature, or irremediable. And the most of them are curable by the same means as those by which any other thing is food to one, and injurious to another. Thus, then, the physician should understand and distinguish the season of each, so that at one time he may attend to the nourishment and increase, and at another to abstraction and diminution. And in this disease as in all others, he must strive not to feed the disease but endeavor to wear it out by administering whatever is most opposed to each disease, and not that which favors and is allied to it. For by that which is allied to it, it gains vigor and increase, but it wears out and disappears under the use of that which is opposed to it. But whoever is acquainted with such a change in men, and can render a man humid and dry, hot and cold by regimen, could also cure this disease, if he recognizes the proper season for administering his remedies, without minding purifications, spells and all other illiberal practices of a like kind.

Source: Adams, Francis, trans. 1849. *On Fractures, by Hippocrates.* London. Available at http://classics.mit.edu/Hippocrates/fractur.1.1.html

Source: Adams, Francis, trans. 1849. *On the Sacred Disease, by Hippocrates.* London. Available at http://classics.mit.edu/Hippocrates/sacred.html

Sophocles, from *Philoctetes* (Performed in 409 BCE)

After being bitten by an asp at a ceremonial altar, Philoctetes develops a festering wound and lives in extreme pain. His fellow sailors decide to abandon him on an island on the way to war at Troy. As the war begins to go badly, Neoptolemus is sent back to retrieve Heracles' bow, which had been given to Philoctetes as a gift. The weapon turns out to be the key that ensures the Athenians' success against the Trojans.

Chorus I have heard a rumor, but never seen with my eyes, how the man who once approached the bed of *Zeus* was bound upon a swift wheel by the almighty son of *Cronus*. But of no other mortal do I know, either by hearsay or by sight, that has encountered a doom so repugnant as this of *Philoctetes*. For though he had wronged no one by force or thievery, but conducted himself fairly towards the fair, he was left to perish so undeservedly. I truly marvel how—how in the world—as he listened in solitude to the breakers rushing around him, he kept his hold upon a life so full of grief. . . .

Neoptolemus Please, come on. Why so silent with no apparent cause? And why are you paralyzed?

Philoctetes Ai, ai!

Neoptolemus What is the matter?

Philoctetes Nothing serious—go on, son.

Neoptolemus Are you in pain from the disease that frequents you?

Philoctetes No, indeed no. I think it is better now.—Gods, oh!

Neoptolemus Why do you groan like this and call on the gods?

Philoctetes That they may come to me with power to save and soothe.—Ai! Ai!

Neoptolemus What troubles you? Speak, do not keep so silent. It is plain enough that you are suffering somehow.

Philoctetes I am destroyed, boy—I can never conceal my suffering when you are close. Ah! Ah! It shoots through me, shoots straight through! Oh, the pain, the misery! I am destroyed, boy—I am devoured! Ah, by the gods I beg you, if you have a sword ready to hand, strike at my ankle—cut it off now! Do not spare my life! Quick, boy, quick!

Neoptolemus What new thing has come on you so suddenly that you wail for yourself with these loud shrieks?

Philoctetes You know, son.

Neoptolemus What is it?

Philoctetes You know, boy.

Neoptolemus What ails you? I do not know.

Philoctetes How could you not know? Oh, oh!

Neoptolemus Yes, terrible is the burden of your disease.

Philoctetes Terrible beyond telling! Oh, pity me!

Neoptolemus What shall I do?

Philoctetes Do not betray me because of fear. This plague comes only now and then,—perhaps when she has been sated with her roamings elsewhere.

Neoptolemus Ah, poor wretch! Poor man, truly for all your sufferings! Shall I support you, or somehow offer a helping hand?

Philoctetes No, no. But take this bow of mine—as you earlier asked of me—and keep it in your care and safe until this present bout with my disease is past. For indeed sleep takes me as soon as this pain passes away, nor can it cease before then. But you must allow me to sleep in peace. And if those men come in the meantime, then by the gods I forbid you willingly or unwillingly, or by any skilled trickery, to give up this bow to them, lest you bring destruction at once on yourself and on me, who am your suppliant.

Neoptolemus Have no fears as to my caution. The bow shall pass into no hands but yours and mine. Give it to me, and may good luck accompany it!

Philoctetes There, take it boy. And humble yourself before the jealous gods, so that the bow may not prove baneful for you, as it did for me and for him who owned it before me.

Neoptolemus O gods, grant this to the two of us! And grant us a voyage prosperous and unimpeded, to whatever goal the god may deem right and that our mission provides!

Sophocles, *Oedipus the King*
(Performed ca. 421 BCE)

In one of Sophocles' best-known works, Oedipus discovers that he has inadvertently killed his father and married his mother, Jocasta, in order to ascend the throne of Thebes. The first excerpt below demonstrates his anguish at this knowledge and his self-destructive pursuit of the truth of his heritage. The scene ends with Oedipus's blinding as a metaphor for the disastrous insight he has acquired. The second excerpt consists of the final lines of the tragedy. Blindness is portrayed at its most dramatic: it is sudden, horrifying, divine retribution. Oedipus will now be forced into exile, newly blinded, his life worse than death. The drama of blindness appears frequently in Greek literature and other media, but it hardly represents the lives of the ordinary blind people. The gradual onset of blindness from cataracts or other disease does not make for a tale of high drama, nor do tales of villagers who adjusted to failing sight.

Oedipus He says that I am Laius' murderer.
Jocasta Of his own knowledge, or by some one taught?
Oedipus Yon scoundrel seer suborning. For himself,
He takes good care to free his lips from blame.
Jocasta Leave now thyself, and all thy thoughts of this,
And list to me, and learn how little skill
In arts prophetic mortal man may claim;
And of this truth I'll give thee proof full clear.
There came to Laius once an oracle
(I say not that it came from Phœbus' self,
But from his servants) that his fate was fixed
By his son's hand to fall—his own and mine:
And him, so rumour runs, a robber band
Of aliens slew, where meet the three great roads.
Nor did three days succeed the infant's birth,
Before, by other hands, he cast him forth,
Maiming his ankles, on a lonely hill.
Here, then, Apollo failed to make the boy
His father's murderer; nor did Laius die
By his son's hand. So fared the oracles;
Therefore regard them not. Whate'er the God
Desires to search he will himself declare.

Oedipus *[trembling]* O what a fearful boding! thoughts disturbed
Thrill through my soul, my queen, at this thy tale.

Jocasta What means this shuddering, this averted glance?

Oedipus I thought I heard thee say that Laius died,
Slain in a skirmish where the three roads meet?

Jocasta So was it said, and still the rumours hold.

Oedipus Where was the spot in which this matter passed?

Jocasta They call the country Phocis, and the roads
From Delphi and from Daulia there converge.

Oedipus And time? what interval has passed since then?

Jocasta But just before thou camest to possess
And rule this land the tidings were proclaimed.

Oedipus Great Zeus! what fate hast thou decreed for me?

Jocasta What thought is this, my Œdipus, of thine?

Oedipus Ask me not yet, but tell of Laius' frame,
His build, his features, and his years of life.

Jocasta Tall was he, and the white hairs snowed his head,
And in his face not much unlike to thee.

Oedipus Woe, woe is me! so seems it I have plunged
All blindly into curses terrible.

Jocasta What sayest thou? I shudder as I see thee.

Oedipus Desponding fear comes o'er me, lest the seer
Has seen indeed. But one thing more I'll ask.

Jocasta I fear to speak, yet what thou ask'st I'll tell.

Oedipus Went he in humble guise, or with a troop
Of spearmen, as becomes a man that rules?

Jocasta Five were they altogether, and of them
One was a herald, and one chariot had he.

Oedipus Woe! woe! 'tis all too clear.

Antistrophe A

Oedipus Ah, friend,
You are my steadfast servant still,
You still remain to care for me, blind.

Alas! Alas!
You are not hid from me; I know you clearly,
And though in darkness, still I hear your voice.

Chorus O dreadful doer, how did you so endure
To quench your eyes? What daimon drove you on?

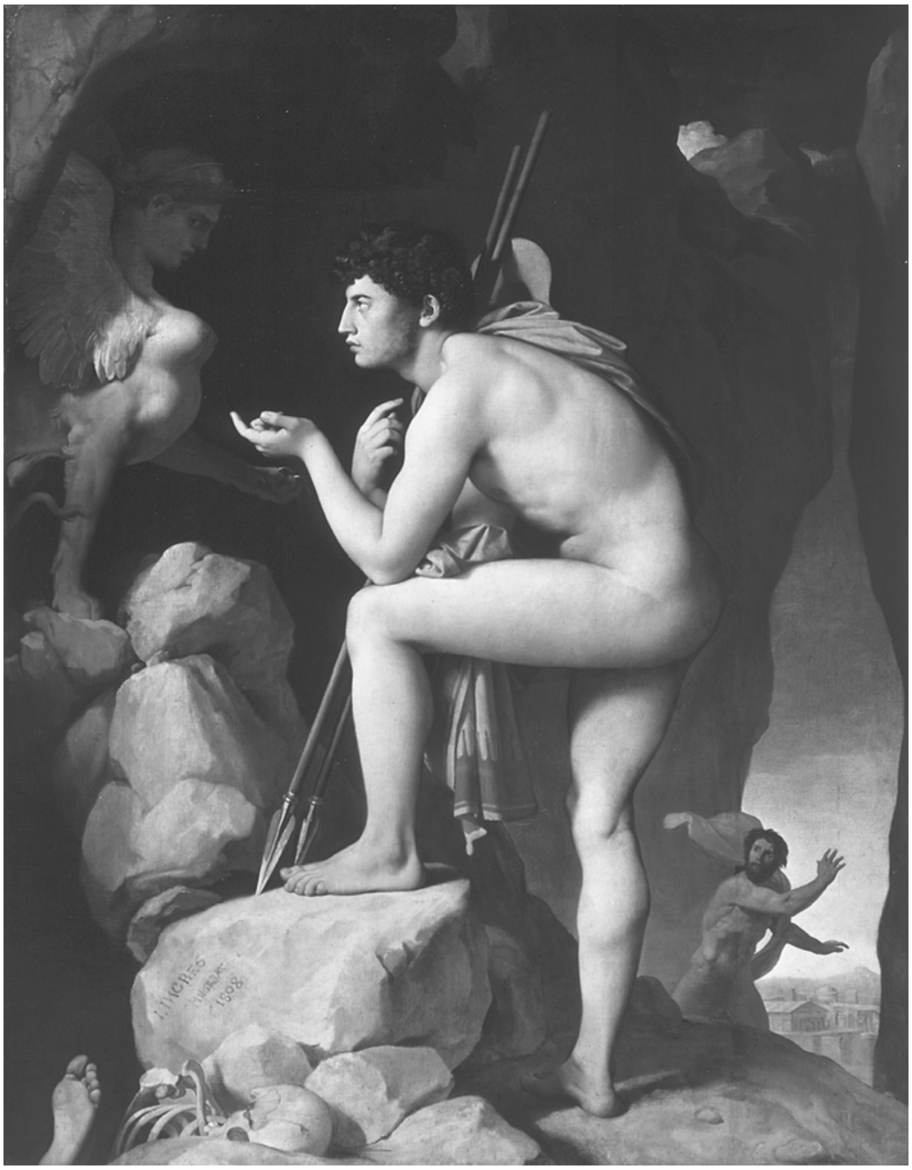
Strophe B

Oedipus Apollo it was, Apollo, friends
Who brought to pass these evil, evil woes of mine.
The hand of no one struck my eyes but wretched me.
For why should I see,
When nothing sweet there is to see with sight?

Chorus This is just as you say.

Oedipus What more is there for me to see,
My friends, what to love,
What joy to hear a greeting?
Lead me at once away from here,
Lead me away, friends, wretched as I am,
Accursed, and hated most
Of mortals to the gods.

Chorus Wretched alike in mind and in your fortune,
How I wish that I had never known you.



Oedipus and the Sphinx *(1808), by Jean Auguste Ingres (1780–1867). Oedipus, who was disabled as an infant when his father pinned his ankles and had him left on a hillside to die of exposure, walked with a limp. In this portrait, he is poised to answer the sphinx's riddle: "What walks on four legs in the morning, two legs at noon, and three legs in the evening?" As one who uses a cane, Oedipus realizes the answer is "Man," who crawls as a baby, walks upright in his youth and adulthood, and eventually needs assistive aids as he ages. The sphinx's designation as monstrously feminine leads her to commit suicide when her riddle is unraveled. Oil on canvas, 189 144 cm.*

Source: Louvre, Paris. Photo credit: Scala/Art Resource, New York.

Antistrophe B

Oedipus May he perish, whoever freed me
From fierce bonds at my feet,
Snatched me from death and saved me, doing me no joy.
For if then I had died, I should not be
So great a grief to friends and to myself.

Chorus This also is my wish.

Oedipus I would not have come to murder my father,

Nor have been called among men
The bridegroom of her from whom I was born.
But as it is I am godless, child of unholiness,
Wretched sire in common with my father.
And if there is any evil older than evil left,
Is it the lot of Oedipus.

Chorus I know not how I could give you good advice,
For you would be better dead than living blind.

Oedipus That how things are was not done for the best—
Teach me not this, or give me more advice.
If I had sight I know not with what eyes
I could ever face my father among the dead,
Or my wretched mother. What I have done to them
Is too great for a noose to expiate.
Do you think the sight of my children would be a joy
For me to see, born as they were to me?
No, never for these eyes of mine to see.
Nor the city, nor the tower, nor the sacred
Statues of gods; of these I deprive myself,
Noblest among the Thebans, born and bred,
Now suffering everything. I tell you all
To exile me as impious, shown by the gods
Untouchable and of the race of Laius.
When I uncovered such a stain on me,
Could I look with steady eyes upon the people?
No, No! And if there were a way to block
The spring of hearing, I would not forbear
To lock up wholly this my wretched body.
I should be blind and deaf.—For it is sweet
When thought can dwell outside our evils.
Alas, Cithaeron, why did you shelter me?
Why did you not take and kill me at once, so I
Might never reveal to men whence I was born?
O Polybus, O Corinth, O my father's halls,
Ancient in fable, what an outer fairness,
A festering of evils, you raised in me.
For now I am evil found, and born of evil.
O the three paths! Alas the hidden glen,
The grove of oak, the narrow triple roads
That drank from my own hands my father's blood.
Do you remember any of the deeds
I did before you then on my way here
And what I after did? O wedlock, wedlock!
You gave me birth, and then spawned in return
Issue from the selfsame seed; you revealed
Father, brother, children, in blood relation,
The bride both wife and mother, and whatever
Actions are done most shameful among men.
But it is wrong to speak what is not good to do.
By the gods, hide me at once outside our land,
Or murder me, or hurl me in the sea
Where you shall never look on me again.
Come, venture to lay your hands on this wretched man.
Do it. Be not afraid. No mortal man
There is, except myself, to bear my evils.

Chorus Here is Creon, just in time for what you ask
To work and to advise, for he alone
Is left in place of you to guard the land.

Oedipus Alas, what word, then, shall I tell this man?
What righteous ground of trust is clear in me,
As in the past in all I have done with him evil?

Creon Oedipus, I have not come to laugh at you,
Nor to reproach you for your former wrongs.
(To the attendants)
If you defer no longer to mortal offspring,
Respect at least the all-nourishing flame
Of Apollo, lord of the sun. Fear to display
So great a pestilence, which neither earth
Nor holy rain nor light will well receive.
But you, conduct him to the house at once.
It is most pious for the kin alone
To hear and to behold the family sins.

Oedipus By the gods, since you have plucked me from my fear,
Most noble, facing the most vile man,
Hear me one word—I will speak for you, not me.

Creon What desire do you so persist to get?

Oedipus As soon as you can, hurl me from this land
to where no mortal man will ever greet me.

Creon I would do all this, be sure, but I want first
To find out from the god what must be done.

Oedipus His oracle, at least, is wholly clear;
Leave me to ruin, an impious parricide.

Creon Thus spake the oracle. Still, as we stand
It is better to find out sure what we should do.

Oedipus Will you inquire about so wretched a man?

Creon Yes. You will surely put trust in the god.

Oedipus I order you and beg you, give the woman
Now in the house such a burial as you yourself
Would want. Do last rites justly for your kin.
But may this city never be condemned—
My father's realm—because I live within.
Let me live in the mountains where Cithaeron
Yonder has fame of me, which father and mother
When they were alive established as my tomb.
There I may die by those who sought to kill me.
And yet this much I know, neither a sickness
Nor anything else can kill me. I would not
Be saved from death, except for some dread evil.
Well, let my fate go wherever it may.
As for my sons, Creon, assume no trouble;
They are men and will have no difficulty
Of living wherever they may be.
O my poor grievous daughters, who never knew
Their dinner table set apart from me,
But always shared in everything I touched—
Take care of them for me, and first of all
Allow me to touch them and bemoan our ills.
Grant it, lord,
Grant it, noble. If with my hand I touch them
I would think I had them just as when I could see.
(Creon's attendants bring in Antigone and Ismene.)
What's that?
By the gods, can it be I hear my dear ones weeping?
And have you taken pity on me, Creon?
Have you had my darling children sent to me?
Do I speak right?

Creon You do. For it was I who brought them here,
Knowing this present joy your joy of old.

Oedipus May you fare well. For their coming may the spirit
That watches over you be better than mine.
My children, where are you? Come to me, come
Into your brother's hands, that brought about
Your father's eyes, once bright, to see like this.
Your father, children, who, seeing and knowing nothing,
Became a father whence he was got himself.
I weep also for you—I cannot see you—
To think of the bitter life in days to come
Which you will have to lead among mankind.
What citizens' gatherings will you approach?
What festivals attend, where you will not cry
When you go home, instead of gay rejoicing?
And when you arrive at marriageable age,
What man, my daughters, will there be to chance you,
Incurring such reproaches on his head,
Disgraceful to my children and to yours?
What evil will be absent, when your father
Killed his own father, sowed seed in her who bore him,
From whom he was born himself, and equally
Has fathered you whence he himself was born.
Such will be the reproaches. Who then will wed you?
My children, there is no one for you. Clearly
You must decay in barrenness, unwed.
Son of Menoeceus—since you are alone
Left as a father to them, for we who produced them
Are both in ruin—see that you never let
These girls wander as beggars without husbands,
Let them not fall into such woes as mine.
But pity them, seeing how young they are
To be bereft of all except your aid.
Grant this, my noble friend, with a touch of your hand.
My children, if your minds were now mature,
I would give you much advice. But pray this for me,
To live as the time allows, to find a life
Better than that your siring father had.

Creon You have wept enough here, come, go inside the house.

Oedipus I must obey, though nothing sweet.

Creon All things are good in their time.

Oedipus Do you know in what way I go?

Creon Tell me, I'll know when I hear.

Oedipus Send me outside the land.

Creon You ask what the god will do.

Oedipus But to the gods I am hated.

Creon Still it will soon be done.

Oedipus Then you agree?

Creon What I think not I would not say in vain.

Oedipus Now lead me away.

Creon Come then, but let the children go.

Oedipus Do not take them from me.

Creon Wish not to govern all,
For what you ruled will not follow you through life.

Chorus Dwellers in native Thebes, behold this Oedipus
Who solved the famous riddle, was your mightiest man.
What citizen on his lot did not with envy gaze?
See to how great a surge of dread fate he has come!
So I would say a mortal man, while he is watching
To see the final day, can have no happiness
Till he pass the bound of life, nor be relieved of pain.

Source: Storr, F., trans. 1912–1913. Lines 730–780 in *Oedipus the King by Sophocles.* London. Available at http://www.underthesun.cc/Classics/Sophocles/OedipusRex/OedipusRex3.html

Diodorus of Sicily, Book XVII.69 (50 BCE)

In this excerpt, Diodorus sets up the "barbaric" nature of the Persians to contrast with the benevolence of Alexander the Great. While not unbiased journalism, the account offers insight into the connection between ability, disability, and identity in social and economic terms.

At this point in his advance [Alexander] was confronted by a strange and dreadful sight, one to provoke indignation against the perpetrators and sympathetic pity for the unfortunate victims. He was met by Greeks bearing branches of supplication. They had been carried away from their homes by previous kings of Persia and were about eight hundred in number, most of them elderly. All had been mutilated, some lacking hands, some feet, and some ears and noses. They were persons who had acquired skills or crafts and had made good progress in their instruction; then their other extremities had been amputated and they were left only those which were vital to their profession. All the soldiers, seeing their venerable years and the losses which their bodies had suffered, pitied the lot of the wretches. Alexander most of all was affected by them and unable to restrain his tears.

They all cried with one voice and besought Alexander to help them in their misfortunes. The king called their leaders to come forward and, greeting them with a respect in keeping with his own greatness of spirit, promised to make it a matter of utmost concern that they should be restored to their homes. They gathered to debate the matter, and decided that it would be better for them to remain where they were rather than to return home. If they were brought back safely, they would be scattered in small groups and would find their abuse at the hands of Fortune an object of reproach as they lived on in their cities. If, however, they continued living together, as companions in misfortune, they would find a solace in their mutilation in the similar mutilation of the others. So they again appeared before the king, told him of their decision, and asked him to give them help appropriate to this proposal. Alexander applauded their decision and gave each of them three thousand drachmae, five men's robes and the same number for women, two yoke of oxen, fifty sheep, and fifty bushels of wheat. He made them also exempt from all royal taxes and charged his administrative officials to see that they were harmed by no one.

Source: Welles, C. Bradford, trans. 1983. [Vol. VIII, pp. 315–319]. Cambridge, MA: Harvard University Press.

The Ancient World: Rome

▣ Julius Caesar, *Civil Wars* (ca. 1st c. BCE)

Caesar, whose assassination in 44 BCE signaled the end of the Roman Republic, wrote about his military exploits in the third person. This excerpt offers a glimpse of the permanent physical disabilities that men would have experienced as the result of warfare, which was the expected state of affairs in almost all phases of Roman history.

Book 3, Chapter 53

Thus six engagements having happened in one day, three at Dyrrachium, and three at the fortifications, when a computation was made of the number of slain, we found that about two thousand fell on Pompey's side, several of them volunteer veterans and centurions. Among them was Velerius, the son of Lucius Flaccus, who as praetor had formerly had the government of Asia, and six military standards were taken. Of our men, not more than twenty were missing in all the action. But in the fort, not a single soldier escaped without a wound; and in one cohort, four centurions lost their eyes. And being desirous to produce testimony of the fatigue they under went, and the danger they sustained, they counted to Caesar about thirty thousand arrows which had been thrown into the effort; and in the shield of the centurion Scaeva, which was brought to him, were found two hundred and thirty holes. In reward for this man's services, both to himself and the public, Caesar presented to him two hundred thousand pieces of coppery money, and declared him promoted from the eighth to the first centurion. For it appeared that the fort had been in a great measure saved by his exertions; and he afterward very amply rewarded the cohorts with double pay, corn, clothing, and other military honors.

Source: McDevitte, W. A., & W. S. Bohn, trans. 1869. *The Civil Wars by Julius Caesar.* New York: Harper & Brothers.

▣ Plutarch on Cicero (2nd c. CE)

Plutarch cared more about portraying the internal characteristics of great Greek and Roman men than about portraying their historical contexts. His commentaries demonstrate the Roman penchant for equating appearance with character and for interpreting nature as providing physical "deformities" as warnings. The name "Cicero" has become a byword for rhetoric, yet Plutarch explains that his name comes from a physical peculiarity, not a grand tradition.

He who first of that house was surnamed Cicero seems to have been a person worthy to be remembered; since those who succeeded him not only did not reject, but were fond of the name, though vulgarly made a matter of reproach. For the Latins call a vetch Cicer, and a nick or dent at the tip of his nose, which resembled the opening in a vetch, gave him the surname of Cicero.

Cicero, whose story I am writing, is said to have replied with spirit to some of his friends, who recommended him to lay aside or change the name when he first stood for office and engaged in politics, that he would make it his endeavor to render the name of Cicero more glorious than that of the Scauri and Catuli. And when he was quæstor in Sicily, and was making an offering of silver plate to the gods, and had inscribed his two names, Marcus and Tullius, instead of the third he jestingly told the artificer to engrave the figure of a vetch by them. Thus much is told us about his name.

Of his birth it is reported, that his mother was delivered without pain or labor, on the third of the new Calends, the same day on which now the magistrates of Rome pray and sacrifice for the emperor. It is said, also, that a vision appeared to his nurse, and foretold the child she then suckled should afterwards become a great benefit to the Roman States.

Source: Dryden, John, trans. Reprinted 1909–1914. *Plutarch's Lives.* New York: P. F. Collier & Son Company.

Juvenal, Excerpts from *Satire 2* (2nd c. CE)

Juvenal and Martial were Roman satirists of the early imperial period (Juvenal died ca. 130 CE). Juvenal writes stinging barbs against what he perceives as corrupt Roman society. No one is immune from his bitter commentary, and it is interesting to note that people with what we would call disabilities are not in any special category. Rather, they are mocked side by side with ugly people, smelly people, and pretentious people. While Juvenal makes fun of people whom we would categorize as disabled today, he is equally likely to jeer at anyone who crosses the hierarchical social boundaries of early imperial Rome. (See Walters, Jonathan. 1998. "Making a Spectacle: Deviant Men, Invective, and Pleasure." Arethusa ["Vile Bodies: Roman Satire and Corporeal Discourse"] 31:355–367.)

They don't talk so much; their passion is rather for silence; They keep their hair cut short, but oh, those wonderful eyebrows! I like Peribomius better; at least he's honest about it, Shows what he is by his walk and his glances, so I can excuse him, Him and his likes, whose urge is frank enough for forgiveness. Worse, much worse, are the ones who denounce, with a Hercules' anger, Vice, and waggle their tongues about Virtue, and waggle their rear ends. Sextus does things that Varillus observes and remarks, "How disgusting!" Yet he does them himself. A white man can sneer at a Negro, A cripple's a joke to the sound, but this is too much, that the Gracchi Scream to high heaven against people they call rabble rousers. This is confusion confounded, Verres denouncing a robber, Milo opposed to assassins, Catiline chiding Cethegus, Clodius damning adulterers, the second triumvirate shouting "down with proscription"! We had, and not long since, such a fellow Who, in true tragic style, joined fornication with incest, Then re-enacted the code which would horrify all human beings, Not to say Venus and Mars, and while he was doing so, Julia Rid her fertile womb of blobs that resembled her uncle. Is it not perfectly right, therefore, that the vilest of sinners Hate these hypocrites? If they snap at you, turn on them, bite them!. . .

Umbricius has much on his mind. "Since there's no place in the city," He says, "For an honest man, and no reward for his labors, Since have less today than yesterday, since by tomorrow That will have dwindled still more, I have made my decision. I'm going To the place where, I've heard, Daedalus put off his wings, While my white hair is still new, my old age in the prime of its straightness, While my fate spinner still has yarn on her spool, while I'm able Still to support myself on two good legs, without crutches. Rome, good-bye! Let the rest stay in the town if they want to, Fellows like A, B, and C, who make black white at their pleasure, Finding it easy to grab contracts for rivers and harbors, Putting up temples, or cleaning out sewers, or hauling off corpses, Or, if it comes to that, auctioning slaves in the market . . . Rubrius, looking no better, came next. He wasn't a noble. That may have been reassuring, but then, he had been convicted Of an old offense, and one that is better not mentioned. Worse than the sodomite Nero, who lashed other pathics with satire. Montanus was there. He was late because of the size of his belly. Curly the Cur was there, who reeks, in the morning, with odors That would outsink the smell of at least two funeral parlors. Pompey was there, an informer whose whisper could cut your throat, Fuscus, whose battles were planned in hallways of Parian marble, Tactics just the right sort to suit the vultures of Poland. Careful Veiento came, and with him the deadly Catullus Burning with love for a girl he had never seen. What a portent, Even for times like these! He was blind, but a flattering fawner, Sinister, one who belonged with the beggars infesting the bridges, Swarming out to the wheels, or blowing the richer ones kisses. No one was more amazed at the fish than he was; he gestured Toward the left as he spoke; it happened to be on his right. That was always his way, if he praised some Cilician bruiser Or the stage machines that lift the boys to the awnings. Veiento was almost as bad; carried away by his frenzy Almost into a trance, he presently vaticinated: "Omens of triumph I see, my Lord. Thou wilt capture a monarch Foreign-born like this turbot, Arviragus of the Britons.

This I can tell by the spiky fins erect on the backbone." Fabricius went on and on; the only thing he omitted Was the place where the fish spawned and the actual date of its birthday. . . .

Cheer when they find, for once, a citizen rare and distinguished. True nobility lies in more than a name and a title. We call somebody's dwarf an Atlas; his black boy is Swansdown, We label some ugly lopsided girl Europa; and mongrels, Mangy and worthless, the kind that try to lick oil from dry vessels, We call Lion, or Tiger, or Pard, or whatever roars loudest. So, beware lest your title is given in any such spirit, (that one's title be assigned as an opposite and therefore a spiteful joke)—Lest "The Victor of Crete" means Crete's where you took such a beating.

Sources: Ramsay, G. G., ed. and trans. 1918. Juvenal, *Satires*. London: Loeb Classical Library.

Martial, *Epigrams 12.93; 14.210, 212, 213* (1st c. CE)

Like Juvenal, Martial was also a Roman satirist of the early imperial period (Martial died ca. 104 CE). Martial's epigrams, quite vile by today's standards, also highlight various physical characteristics as amusing or distasteful, but also on an individual basis, not an institutionalized one. Martial's epigrams on disabled people are interspersed with others that mock golddiggers, liars, and sycophants.

Sexualization of Dwarfs

Labulla has found a way to kiss her lover in her husband's presence. She keeps on kissing her dwarf fool. The lover immediately catches hold of him while he is still damp with many kisses and sends him back charged with his own kisses to the smiling lady of the house. How much greater a fool is the husband!

Idiot

His stupidity does not lie, is not feigned by wily art. He that is witless to excess has his wits.

Dwarf

If you looked only at the man's head, you would believe him Hector; if you saw him standing, you would think him Astyanax.

Buckler

Wont often to be defeated and to be victorious rarely, this will be to you a buckler, but the shield of a dwarf.

Polyphemus, slave of my friend Severus, your size and aspect are such that the cyclops himself might be amazed at you. But Scylla is no smaller. If you put the two savage monsters together, each will become the terror of the other.

Unwilling any longer to bear and suffer the coursings hither and thither, the early morning rounds, and the haughty salutations of the powerful, Caelius started to feign the gout. In his anxiety to prove it genuine, he anoints and bandages his healthy feet and walks with laboring tread. See what the cultivation and art of pain can do. Caelius stopped feigning the gout.

Source: Davis, William Stearns, ed. 1912–1913. *Readings in Ancient History: Illustrative Extracts from the Sources.* 2 Vols. Boston: Allyn & Bacon.

Seneca the Younger, Excerpt from *Apocolocyntosis* (1st c. CE)

Seneca the Younger, the Stoic politician and philosopher who had the misfortune of serving as tutor to Emperor Nero, composed this lighthearted satire that mocks the deification of Nero's predecessor, Claudius. Emperor Claudius was known for his limp and his indistinct speech, perhaps a stutter, which is the subject of the mockery in the Apocolocyntosis, sometimes translated as the "Pumpkinification of Claudius." (See Braund, Susanna Morton, and Paula James. 1998. "Quasi Homo: Distortion and Contortion in Seneca's Apocolocyntosis." Arethusa ["Vile Bodies: Roman Satire and Corporeal Discourse"] 31:285–311.)

[1] I wish to record an occurrence which took place in heaven on the third day before the Ides of October, in the new year which began our fortunate era. I am not going to be diverted by either fear or favor. I shall tell the unvarnished truth. If anybody asks me where I got my information, I say at once, I'll not answer if I don't want to. Who is going to make me? I know I have been free to do as I like since the day when he died who had made the proverb true: One must be born either king or fool. If I please to answer, I shall say what comes to my tongue. Who ever demanded affidavits from an historian? Still, if I must produce my

authority, apply to the man who saw Drusilla going heavenward; he will say he saw Claudius limping along in the same direction. Willy-nilly, he has to see everything that happens in heaven; for he is the superintendent of the Appian road, by which you know both the divine Augustus and Tiberius Caesar went to join the gods. If you ask this man he will tell you privately; in presence of more than one he'll never speak a word. For since the day when he took oath in the Senate that he had seen Drusilla going up to heaven and in return for such good news nobody believed him, he has declared in so many words that he'll not testify about anything, not even if he should see a man murdered in the middle of the Forum. What I have heard from him, then, I state positively and plainly, so help him!

[2] Now was come the season when Phoebus
had narrowed the daylight,
Shortening his journey, while sleep's dim
hours were left to grow longer;
Now victorious Cynthia was widening the
bounds of her kingdom;
Ugly-faced Winter was snatching away the
rich glories of Autumn,
So that the tardy vintager, seeing that Bacchus
was aging,
Hastily, here and there, was plucking the clusters forgotten.

I presume I shall be better understood if I say that the month was October and the day October thirteenth; the exact hour I cannot tell you—it's easier to get philosophers to agree than timepieces—but it was between noon and one o'clock.

"Too clumsily put!" you will say. "All the poets are unsatisfied to describe sunrises and sunsets, so that they are even tackling the middle of the day: are you going to neglect so good an hour?"

Phoebus already had passed the highest point
of his circuit,
Wearily shaking the reins as his car drew
nearer the evening,
Leading away the half-spent light on [his]
down-dipping pathway.

[3] Claudius began to give up the ghost, but couldn't find a way out for it. Then Mercury, who had always had a fancy for his character, led aside one of the three Fates and said: "Why, O hard-hearted woman, do you let the wretched man be tormented? Isn't he ever to have a rest, after being tortured so long? It is the sixty-fourth year that he has been afflicted with life. What grudge have you got against him and the nation? For once let the prophets tell the truth, who have been taking him off every year, every month even, since he was made emperor. And still it's no wonder if they go wrong and nobody knows his hour; for nobody ever made any account of his being born. Do what is necessary:

'Give him over to death: let a better man reign
in his place.'"

But Clotho remarked, "I swear I intended to give him a trifle more time, till he should make citizens out of the few that are left outside—for he had made up his mind to see everybody, Greeks, Gauls, Spaniards, Britons, wearing togas. However, since it is perhaps a good thing to have a few foreigners left as a nucleus, and since you wish it, it shall be attended to." Then she opened a bandbox and brought out three spindles; one was that of Augurinus, the next was Baba's, the third Claudius.' "I will have these three die at short intervals within a year," she said, "and not send him off unattended. For it isn't right that one who has been in the habit of seeing so many thousands of people following him about, going ahead of him, and all around him, should all of a sudden be left alone. For a while he will be satisfied with these boon-companions."

[4] Thus having spoken she wound up the
thread on his spindle neglected,
Breaking off the royal days of his stupid
existence.
Lachesis, waiting meanwhile, with tresses
charmingly ordered,
Crowning the locks on her brow with a wreath
of Pierian laurel,
Drew from a snowy fleece white strands
which, cleverly fashioned,
Under her artful fingers began with new colors
to glisten:—
Spun to a thread that drew the admiring gaze
of her sisters.
Changed was the common wool, until as a
metal most precious,
Golden the age that was winding down in that
beautiful fillet.
Ceaselessly they too labored; and bringing the
finest of fleeces,
Gayly they filled her hands, for sweet was the
duty allotted.

She, in her eagerness, hastened the work, nor
was conscious of effort;
Lightly the soft strands fell from the whirling
point of her spindle,
Passing the life of Tithonus, passing the life-
time of Nestor.
Phoebus came with his singing, and, happy in
anticipation,
Joyously plied the plectrum, or aided the work
of the spinners:
Kept their hearts intent, with his song beguil-
ing their labor.
While beyond thought they rejoiced in their
brother's music, their hands spun,
Busily twining a destiny passing all human
allotment,
Wrought through the spell of Phoebus' lyre
and his praise, as he bade them:
"Stay not your hands, O Fateful Sisters, but
make him a victor
Over the barriers that limit the common life-
time of mortals;
Let him be blessed with a grace and a beauty
like mine, and in music
Grant him no meaner gifts. An age of joy shall
he bring men
Weary for laws that await his restoring. Like
Lucifer comes he,
Putting the scattered stars to flight, or like
Hesper at nightfall,
Rising when stars return; or e'en as the Sun,—
when Aurora
First has dispelled the dark and blushingly led
forth the morning,—
Brightly gleams on the world and renews his
chariot's journey,
So cometh Caesar; so in his glory shall Rome
behold Nero.
Thus do his radiant features gleam with a
gentle effulgence,
Graced by the flowing locks that fall
encircling his shoulders."

Thus Apollo. But Lachesis, who herself, too, had a fondness for the handsomest of men, wrought with generous hand, and bestowed upon Nero many years from her own store. As for Claudius, however, everybody gave orders

With joy and great content to send him out of doors.[1]

And indeed he did go up the flume, and from that moment ceased to appear to be alive. He expired, moreover, while listening to comic actors, so you understand it isn't without reason that I am afraid of those fellows. His last words that were heard among men were these, after a louder utterance in the locality where he expressed himself the more easily: "Oh, dear! I think I have hurt myself."[2] Whether he had, I don't know; at any rate he was in the habit of hurting everything.

[5] What happened afterward on earth it is superfluous to describe. For you know very well, and there is no danger that things which the universal joy had impressed upon the memory will slip from it; no one forgets his own good fortune. Listen to what happened in heaven: it is on the authority of the narrator. The news was brought to Jupiter that somebody had come, a rather tall man, quite gray-headed; that he was threatening something or other, for he kept shaking his head; and that he limped with his right foot. The messenger said he had asked of what nation he was, but his answer was mumbled in some kind of an incoherent noise; he didn't recognize the man's language, but he wasn't either Greek or Roman or of any known race. Then Jupiter told Hercules, who had traveled all over the world and was supposed to be acquainted with all the nations, to go and find out what sort of a man it was. Hercules at the first sight was a good deal disturbed, even though he was one who didn't fear any sort of monsters. When he beheld the aspect of this unknown specimen, its extraordinary gait, its voice belonging to no earthly creature but more like that of the monsters of the deep, hoarse and inarticulate, he thought that a thirteenth labor had come to him. When he looked more carefully, however, it appeared to be a man. He approached him and thus spoke, as was easiest for a Greek chap:

Who and whence art thou, and where are thy city and
parents?

Claudius was delighted to find literary people there, hoping there would be some place for his histories. So he, too, in a Homeric verse, indicating himself to be Caesar, said:

Hence from Ilium the winds have among the Cicones
cast me.

But the following verse would have been truer, and equally Homeric:

There their city I wasted; the people I slaughtered.

[6] And he would have imposed upon the guileless Hercules, had not Fever been there, who alone had left her shrine and come with him. All the other divinities he had left behind at Rome. She said, "It is simple nonsense that he is giving you. I tell you—I who have lived with him for so many years—he was born at Lugudunum; you behold one of Marcus' citizens. As I'm telling you, he was born sixteen miles from Vienna, a genuine Gaul. And so as a Gaul ought to do, he captured Rome. Take my word for it, he was born at Lugudunum, where Licinus reigned for many years. But you, who have tramped more lands than any wandering muleteer, ought to know men from Lugudunum and that there are a good many miles between the Xanthus and the Rhone." At this point Claudius fired up and angrily grumbled as loudly as he could. What he was saying, nobody understood, except that he commanded Fever to be led away to punishment. With the familiar gesture of his limp hand, that was steady enough for the one purpose of decapitating people as he was accustomed, he had ordered her head to be struck off. You would suppose all those present were his freedmen, so little attention did any one pay him. [7] Then Hercules said, "Listen to me and stop talking nonsense. You have come to a place where the mice gnaw iron. Tell me the truth, quick, or I'll knock the silliness out of you." And in order to be more terrifying, he struck the attitude of a tragedian and said:

"Declare at once the place you call your natal town,
Or else, by this tough cudgel smitten, down you go!
This club has slaughtered many a mighty potentate.
What's that, that in a muffled voice you're trying to say?
Where is the land or race to own your shaky head?
Speak out. Oh, I remember when afar I sought
The triple-bodied king's domains, whose famous herd
From the western sea I drove to the city of Inachus,
I saw a hill above two rivers, towering high
In face of Phoebus rising each day opposite,
Where the broad Rhone pours by in swiftly moving flood,
And Arar, pausing ere it lets its waters go,
Silently laves the borders of its quiet pools.
Is that the land that nursed you when you first drew breath?"

These things he said with spirit, and boldly enough. All the same, he was inwardly a good deal afraid of the *madman's blow.* Claudius, seeing the mighty hero, forgot his nonsense and perceived that while no one had been a match for him at Rome, here he didn't have the same advantage; a cock is master only on his own dunghill. So, as well as could be made out, this is what he appeared to say: "I did hope that you, Hercules, bravest of the gods, would stand by me before the others, and if any one had asked me who could vouch for me, I should have named you, who know me best. For if you recall, I was the one who held court before your temple all day long during the months of July and August. You know how many troubles I had there, listening to the lawyers day and night; and if you had fallen among those fellows, though you may think that you are pretty courageous, you would have preferred to clean Augeas' stables. I have cleaned out much more filth. But since I want"—[3]

[8] "It's no wonder you have made an assault upon the senate-house; nothing is closed to you. Only tell us what sort of a god you want him to be made. He cannot be an *Epicurean god, neither having himself any care nor causing any to others.* A Stoic? How can he be 'round,' as Varro says, 'without head or prepuce'? Yet there is something in him of the Stoic god, now I see. He has neither heart nor head. By Hercules, though, if me had asked this favor of Saturn, whose festival month the Saturnalian prince kept going the whole year long, he wouldn't have got it; and surely he wouldn't of Jove, whom so far as he possibly could he convicted of incest. For he put to death Silanus his son-in-law, just because the man preferred that his sister, prettiest of all the girls, so that everybody called her Venus, should be called his Juno. 'Why his sister?' you say,—in fact, I ask it. Think, you blockhead. At Athens that sort of thing is halfway allowed; at Alexandria altogether. 'But since at Rome,' you say, 'the mice live on dainties.' He's going to straighten our crooked ways! He doesn't know what goes on in his own chamber, and now 'he searches the regions of heaven.' He wants to become a god. Isn't he satisfied that he has a temple in Britain; that the barbarians worship him and beseech him as a god that they may *find him a merciful madman?*"

[9] At length it occurred to Jove that while ordinary persons are staying in the senate-house it is not permitted to express an opinion nor to argue. "I had allowed you to ask questions, Conscript Fathers," he said, "but you have brought out simply rubbish. I want

you to observe the rules of the Senate. What will this person, whoever he is, think of us?"

When the said individual had been sent out, Father Janus was the first to be asked his opinion. He had been elected afternoon consul for the first of July, being a very shrewd man, who always sees *at once both forward and backward.* He spoke at some length, and fluently, because he lives in the Forum; but the stenographer could not follow, and therefore I do not report him, for fear of misquoting what he said. He said a good deal about the importance of the gods, and that this honor ought not to be given commonly. "Once," said he, "it was a great thing to be made a god, but now you have made the distinction a farce. And so lest my remarks seem to be dealing with personalities rather than with the case, I move that from this day forward no one shall be made a god, from among all those who *eat the fruit of the corn-land* or those whom the *fruitful corn-land* feeds. Whoever contrary to this decree of the Senate shall be made, called, or depicted as a god, is to be given to the hobgoblins, and to get a thrashing among the newly hired gladiators at the next show."

The next to be asked his opinion was Diespiter the son of Vica Porta, who was himself also a consul-elect, and a money-changer; by this business he supported himself, and he was accustomed to sell citizenships in a small way. Hercules approached him politely and gave him an admonitory touch on the ear. Accordingly he expressed his opinion in these words: "Whereas the divine Claudius is by blood related to the divine Augustus and no less also to the divine Augusta, his grandmother, who was made a goddess by his own orders, and whereas he far surpasses all mortals in wisdom, and it is for the public interest that there be some one who can join Romulus in 'eating of boiling hot-turnips,' I move that from this day the divine Claudius be a god, with title equally as good as that of any one who has been made so before him, and that this event be added to the Metamorphoses of Ovid."

The opinions were various, and Claudius seemed to be winning the vote. For Hercules, who saw that his iron was in the fire, kept running to this one and that one, saying, "Don't go back on me; this is my personal affair. And then if you want anything, I'll do it in my turn. One hand washes the other."

[10] Then the divine Augustus arose at the point for expressing his opinion, and discoursed with the utmost eloquence. "I call you to witness, Conscript Fathers," said he, "that since I was made a god, I have never addressed you; I always mind my own business. And I can no longer disguise my feelings nor conceal the distress that shame makes all the greater. Was it for this that I secured peace on land and sea? For this did I make an end of civil wars? For this did I found the city on a basis of law, adorn it with monuments, that—what to say, Conscript Fathers, I cannot discover. All words are beneath my indignation. So in desperation I must take to the phrase of that most clever man, Messala Corvinus, 'I am ashamed of my authority.' This fellow, Conscript Fathers, who doesn't seem to you as if he could disturb a fly, used to kill people as easily as a dog stops to rest. But why should I enumerate the many great men? I have no heart to lament public calamities when I behold those of my own family. And so I will pass over the former and describe these. For I know, even if my sister doesn't know [as they say in Greek], *my knee is nearer than my shin.* That fellow whom you see there, hiding under my name for so many years, has shown his gratitude to me by slaying the two Julias, my great-granddaughters, one by the sword, the other by starvation, and L. Silanus, one of my great-great-grandsons. We shall see, Jupiter, whether in a bad case, and one which is certainly your own, you are going to be just. Tell me, divine Claudius, why you condemned any one of the men and women whom you put to death before you understood their cases, or even listened to them. Where is this kind of thing customary? [11] It's not the way in heaven. Here is Jupiter, now, who has been ruling for so many years. One person's leg he has broken, Vulcan's whom

> Snatching him by the foot, he hurled from the heavenly
> threshold;

and he got angry at his wide and hung her up, but he didn't kill her, did he? But you have put to death Messalina, to whom I was as much a great-uncle as I was to you. 'I don't know,' you say? May the gods be hard on you! It is more shameful that you didn't know it than that you killed her. He has never ceased to follow up the dead-and-gone C. Caesar. The latter had killed his father-in-law; Claudius here, his son-in-law besides. Gaius forbade the sons of Crassus to be called Magnus; this man returned him the name, but took off his head. He killed in one household Crassus, Magnus, Scribonia, the Tristionias, and Assario; and they were aristocrats too, and Crassus besides so stupid that he was even qualified to reign. Now do you want to make this man a god? Look at his body, born when the gods were angry. And finally, if he can say three consecutive words together, he can have me as his slave. Who will worship this god? Who will believe in him? As long as you make such gods as he, nobody will believe that you are gods yourselves. In short, Conscript Fathers, if I have behaved myself honorably among you, if I have not answered anybody in an ungentlemanly manner, avenge my injuries. This is the resolution which I have to offer;" and he read as follows from his tablet: "Since the divine Claudius has killed his father-in-law Appius Silanus, his two sons-in-law Magnus Pompeius and L. Silanus, his daughter's father-in-law Crassus Frugi, a man as like himself as one egg is to another, Scribonia his daughter's mother-in-law, his wife Messalina, and others too numerous to mention, I propose that strict punishment be meted out to him, that he be granted no rest from adjudicating cases, and that he be got out of the way as soon as possible, departing from heaven within thirty days and from Olympus within three."

There was a division of the house, and this resolution was carried. Without delay the Cyllenian dragged him by the nape of his neck off from heaven toward the lower regions,

> "Whence they say no man returns."

[12] While they were going down the Via Sacra, Mercury inquired what such a crowd of people could mean: whether it was Claudius' funeral. And indeed it was a most elegant and elaborate display, so that you would easily recognize that a god was being carried off to burial. There was so great a crowd of trumpeters, hornblowers, and players upon every kind of brass instruments, so great a concord, that even Claudius could hear it. Everybody was joyful and in high spirits. The Roman people walked about like free men. Only Agatho and a few pettifoggers were weeping, but their grief was plainly heartfelt. The real lawyers were coming out of their hiding-places, pale and thin, scarcely drawing breath, like people who were just coming to life again. One of them, when he had seen the pettifoggers getting their heads together and lamenting their calamity, came up and said, "I told you the Saturnalia wouldn't last forever." Claudius, when he saw his own funeral, understood that he was dead. For in a mighty *great chorus* they were chanting a dirge in anapests:

> "Pour forth your tears, lift up woful voices;
> Let the Forum echo with sorrowful cries.
> Nobly has fallen a man most sagacious,
> Than whom no other ever was braver,
> Not in the whole world.
> He in the quick-sped race could be victor
> Over the swiftest; he could rebellious
> Parthians scatter, chase with his flying
> Missiles the Persian, steadiest-handed,
> Bend back the bow which, driving the foeman
> Headlong in flight, should pierce him afar, while
> Gay-coated Medes turned their backs to disaster.
> Conqueror he of Britons beyond the
> Shores of the known sea:
> Even the dark-blue-shielded Brigantes
> Forced he to bend their necks to the fetters
> That Romulus forged, and Ocean himself
> To tremble before the Roman dominion.
> Mourn for the man than whom no one more
>   quickly
> Was able to see the right in a lawsuit,
> Only at hearing one side of the quarrel,—
> Often not either. Where is the judge now
> Willing to listen to cases the year through?
> Thou shalt be given the office resigned thee
> By him who presides in the court of the shades,
> The lord of a hundred cities Cretaean.
> Smite on your breasts, ye shysters forsaken,
> With hands of despair, O bribe-taking crew;
> Ye too, half-fledged poets, now should bewail;
> And ye above all, who lately were able
> To gather great gains by shaking the dice-box."

[13] Claudius was delighted with his praises, and desired to stay longer to look on. But the Talthybius of the gods laid a hand on him and pulled him away, with his head covered so that nobody could recognize him, across the Campus Martius, and between the Tiber and the Arcade went down to the lower world. The freedman Narcissus had already gone ahead by a short cut to be ready to receive his patron, and as the latter was approaching he ran up, all sleek from the bath, and said: "What's this? Gods, among men?" "Hurry up," said Mercury, "and announce that we are coming." In less time than it takes to tell it, Narcissus skipped out. All the way being down hill, the descent was easy. And so, in spite of his gout, he came in twinkling to Pluto's door, where lay Cerberus, or as Horace says, "the beast with the hundred heads." Narcissus was a trifle scared—he had been accustomed to have a white dog as a pet—when he saw that huge, hairy black dog, which, on my word, is one that you wouldn't like to meet in the dark. And with a

loud voice he said, "Claudius is coming." Then a crowd began to come forward with clapping of hands and chanting: *"We have got him; let us rejoice!"* Among them were C. Silius the consul-elect, Iuncus the ex-praetor, Sextus Traulus, M. Helvius, Trogus, Cotta, Vettius Valens, and Fabius, Roman knights whom Narcissus had ordered to execution. In the middle of this company of singers was Mnester the dancer, whom Claudius had made shorter for the sake of appearances. To Messalina—the report that Claudius had come quickly spread—they gathered; first of all, the freedmen Polybius, Myron, Harpocras, Amphaeus, and Pheronactus, all of whom Claudius had sent ahead in order that he might not be anywhere unprepared; then the two prefects Justus Catonius and Rufrius Pollio; then the Emperor's friends Saturnius Lusius and Pedo Pompeius and Lupus and Celer Asinius, of consular rank; finally his brother's daughter, his sister's daughter, his sons-in-law, his father-in-law, his mother-in-law, in fact all his relatives; and forming in line they came to meet Claudius. When he had seen them, he exclaimed: *"Plenty of friends, everywhere!* How did you come here?" Then said Pedo Pompeius: "What are you talking about, you cruel villain? 'How?' did you ask? Well, who else but you has sent us here, you murderer of all your friends? Come to the court of justice. I'll show you where our tribunal is."

[14] He led him to the bar of Aeacus, who conducted the trial under the Cornelian law against assassins. He asked that the court would enter the name, and recorded the accusation: Senators killed, thirty-five; Roman knights, two hundred and twenty-one; other persons, as many as the sands on the seashore. No one was found as counsel for the accused until at length P. Petronius came forward, an old boon companion of his, a man skilled in the Claudian tongue, and asked for a postponement. It was not granted. Pedo Pompeius spoke for the prosecution with loud shouts. The attorney for the defense wanted to begin his reply. Aeacus, most equitable of persons, forbade him and condemned Claudius after hearing only one side, saying: *"Right will be done him if he be treated as he treated others."* Then there was a tremendous silence. Everybody was struck dumb by the novelty of the procedure. They said the thing never happened before. To Claudius it seemed more unjust than new. Over the nature of the penalty there was a long discussion, as to what would be an appropriate sentence for him. Various ones said that if they made Tantalus' suffering too long he would perish of thirst unless somebody came to his rescue; and that poor Ixion's wheel ought at last to be stopped. But it was decided that no release should be given to any of the old ones, lest Claudius should sometime hope for the same in his turn. It was decided that a new punishment ought to be arranged, that for him must be devised some vain task and the hope of gratifying some desire, without end or consummation. Then Aeacus commanded him to gamble with a bottomless dice-box. And already he had begun to search for his constantly escaping dice and to accomplish nothing; for

> [15] Every time when he wanted to throw
> from his clattering dice-box,
> Both of the dice escaped him by way of the
> hole in the bottom.
> Then when he gathered them up and once
> more ventured to play them,
> Over again they gave him the slip, and kept
> him pursuing,
> Constantly baffling his hopes by skipping
> away through his fingers,
> Always trickily sliding through with the same
> old deception,—
> Tiresome as when poor Sisyphus reaches the
> top of his mountain
> Vainly to feel his burden go rolling back from
> his shoulders.

Suddenly C. Caesar appeared and began to claim him as a slave. He produced witnesses who had seen Claudius getting thrashed by him with whips, with rods, and with his fists. The man was adjudged to C. Caesar; Caesar presented him to Aeacus; the latter delivered him to Menander his freedman, to be his law-clerk.

Notes

1. Greek quotations in the original are in the translation indicated by italics.
2. Camden's note: This is euphemistic to the point of incomprehensibility. The actual Latin ('*vae me, puto, concacavi me*') should instead be translated as "Oh, dear! I think I have soiled myself."
3. Perhaps here Claudius begins the persuasion which proved effective with Hercules. The break which follows in the MSS., if due, as is supposed, to the loss of even only one leaf from the archetype from which they are all derived, would seem to have included in the gap more incidents than have been suggested in the various attempts to fill it.

Source: Ball, Allan Perley, trans. 1902. *Apocolocyntosis.* New York: Columbia University Press. Available at http://www.forumromanum.org/literature/apocolocyntosis.html

Livy, Excerpts from *The History of Rome* (1st c. BCE)

The official historian of Rome under Augustus, Livy (died 17 CE) looked to the Golden Age of Rome for precedents and examples of its grandeur and right to rule the world. These excerpts from his writings are accounts of bad omens, formulaic in tone. Interestingly, a child whose sex cannot be determined is as horrifying as speaking oxen and rivers of blood. (See Bloom, Amy. 2002. Normal. *New York: Random House, for a commentary on the modern horror of ambiguously sexed people; see pp. 101–102, 119–120 in Garland, Robert. 1995.* The Eye of the Beholder. *Ithaca, NY: Cornell University Press, for a discussion of the ancient interpretations.)*

It was further decided that before the consul left the City certain portents should be expiated. Various places had been struck by lightning: the statue of Jupiter on the Alban Mount and a tree near his temple, a grove at Ostia, the city wall and temple of Fortune at Capua and the wall and one of the gates at Sinuessa. Some people asserted that the water at Alba had run blood and that in the sanctuary of the temple of Fors Fortuna in Rome a statuette in the diadem of the goddess had fallen of itself on to her hand. It was confidently believed that at Privernum an ox had spoken and that a vulture had flown down on to a booth in the crowded forum. At Sinuessa it was reported that a child was born of doubtful sex, these are commonly called androgyni—a word like many others borrowed from the Greek, a language which readily admits compound words—also that it had rained milk and that a boy had been born with an elephant's head. These portents were expiated by sacrifices of full-grown victims, and a day was appointed for special intercessions at all the shrines. . . .

Prior to the departure of the consuls religious observances were kept up for nine days owing to the fall of a shower of stones at Veii. As usual, no sooner was one portent announced than reports were brought in of others. At Menturnae the temple of Jupiter and the sacred grove of Marica were struck with lightning, as were also the wall of Atella and one of the gates. The people of Menturnae reported a second and more appalling portent; a stream of blood had flowed in at their gate. At Capua a wolf had entered the gate by night and mauled one of the watch. These portents were expiated by the sacrifice of full-grown victims, and special intercessions for the whole of one day were ordered by the pontiffs. Subsequently a second nine days' observance was ordered in consequence of a shower of stones which fell in the Armilustrum. No sooner were men's fears allayed by these expiatory rites than a fresh report came, this time from Frusino, to the effect that a child had been born there in size and appearance equal to one four years old, and what was still more startling, like the case at Sinuessa two years previously, it was impossible to say whether it was male or female. The diviners who had been summoned from Etruria said that this was a dreadful portent, and the thing must be banished from Roman soil, kept from any contact with the earth, and buried in the sea. They enclosed it alive in a box, took it out to sea, and dropped it overboard. . . .

Whatever money was discovered was to be replaced, and the deficit made up; and should it be thought necessary expiatory sacrifices were to be offered in accordance with the instructions of the pontiffs on the previous occasions. Their anxiety to atone for the violation of the temple was made all the keener by the simultaneous announcements of portents from numerous localities. In Lucania it was alleged that the heavens had been on fire; at Privernum the sun had been glowing red through the whole of a cloudless day; at the temple of Juno Sospita in Lanuvium a terrible noise was heard in the night. Numerous monstrous births were also reported amongst the Sabines a child was born of doubtful sex; another similar case was discovered where the child was already sixteen years old; at Frusino a lamb was yeaned with a head like a pig; at Sinuessa a pig was littered with a human head, and on the public domain-land in Lucania a foal appeared with five feet. These were all regarded as horrid and monstrous products of a nature which had gone astray to produce strange and hybrid growths; the hermaphrodites were looked upon as of especially evil omen and were ordered to be at once carried out to sea just as quite recently in the consulships of C. Claudius and M. Nero similar ill-omened births had been disposed of.

Source: Roberts, Canon, trans. 1905. *Livy: The History of Rome, Vol. 4.* London: J. M. Dent & Sons. Excerpts are from 27.11.1–6; 27.37.1–7; 31.12.5–10 in the original work.

Pliny the Elder (23–79 CE), Excerpts from *Natural History*

Pliny the Elder, who lived in the first century CE, wrote his Natural History, from which the following excerpts are taken, to compile thousands of facts, observations, and historical data. These include fanciful ethnographic data about peculiar physical features from little-known places, and, within the known world, reports of hermaphrodites, the transmission of disabling conditions from parent to child, and commentary on human stature. Perhaps the most interesting selection is Pliny's brief mention of Quintus Pedius, "born dumb." (See Gourevitch, Danielle. 1991. "Un enfant muet de naissance s'exprime par le dessin: à propos d'un cas rapporté par Pline l'Ancien." L'Evolution Psychiatrique *56:889–893.)*

Book 6, Chapter 35

At the present day there are reported to be forty-five other kinds of Ethiopians. But the whole race was called Aetheria, and then Atlantia, and finally it took its name from Aethiops the son of Vulcan. It is by no means surprising that the outermost districts of this region produce animal and human monstrosities, considering the capacity of the mobile element of fire to mould their bodies and carve their outlines. It is certainly reported that in the interior on the east side there are tribes of people without noses, their whole face being perfectly flat, and other tribes that have no upper lip and others no tongues. Also one section has the mouth closed up and has no nostrils but only a single orifice through which it breathes and sucks in drink by means of oat straws, as well as grains of oat, which grows wild there, for food. Some of the tribes communicate by means of nods and gestures instead of speech; and some were unacquainted with the use of fire before the reign of King Ptolemy Lathyrus in Egypt. Some writers have actually reported a race of Pygmies living among the marshes in which the Nile rises. On the coast, in a region that we shall describe later, there is a range of mountains of a glowing red color, which have the appearance of being on fire.

Book 7, Chapter 2

Beyond the Nasamones and adjacent to them Calliphanes records the Machlyes, who are Androgyni and perform the function of either sex alternately. Aristotle adds that their left breast is that of a man and their right breast that of a woman. Isogonus and Numphodorus report that there are families in the same part of Africa that practice sorcery, whose praises cause meadows to dry up, trees to wither and infants to perish. Isogonus adds that there are people of the same kind among the Triballi and the Illyrians, who also bewitch with a glance and who kill those they stare at for a longer time, especially with a look of anger, and that their evil eye is most felt by adults; and that what is more remarkable is that they have two pupils in each eye. Apollonides also reports women of this kind in Scythia, who are called the Bitia, and Phylarchus also the Thibii tribe and many others of the same nature in Pontus, whose distinguishing marks he records as being a double pupil in one eye and the likeness of a horse in the other, and he also says that they are incapable of drowning. . . .

Indians have union with wild animals and the offspring is of mixed race and half animal; that among the Calingi, a tribe of the same part of India, women conceive at the age of five and do not live more than eight years, and that in another part men are born with a hairy tail and extremely swift, while others are entirely covered by their ears.

Book 7, Chapter 3

Recently on the day of the obsequies of his late Majesty Augustus a certain woman of the lower orders named Fausta at Ostia was delivered of two male and two female infants, which unquestionably portended the food shortage that followed. We also find the case of a woman in the Peloponnese who four times produced quintuplets, the greater number of each birth surviving. In Egypt also Trogus alleges cases of seven infants born at a single birth.

Persons are also born of both sexes combined—what we call Hermaphrodites, formerly called androgyny and considered as portents, but now as entertainments. Pompey the Great among the decorations of his theatre placed images of celebrated marvels, made with special elaboration for the purpose by the talent of eminent artists; among them we read of Eutychis who at Tralles was carried to her funeral pyre by twenty children and who had given birth 30 times, and Alcippe who gave birth to an elephant—although it is true that the latter case ranks among portents, for one of the first occurrences of the Marsian War was that a maidservant gave birth to a snake, and also monstrous births of various kinds are recorded among the ominous things that happened. Claudius Caesar writes that a hippo-centaur was born in Tessaly and died the same day; and in his reign we actually saw one that was brought here for him from Egypt preserved in honey. One case is that of an infant at Saguntum that at once went back into the womb, in the year in which that city was destroyed by Hannibal.

Book 7, Chapter 12

It is also well known that sound parents may have deformed children and deformed parents sound children or children with the same deformity, as the case may be; that some marks and moles and even scars reappear in the offspring, in some cases a birthmark on the arm reappearing in the fourth generation (we are told that in the Lepidus family three children were born, though not all in succession, with a membrane over the eyes); and indeed that other children have resembled their grandfather, and that also there has been a case of twins of which one resembled the father and the other the mother, and one of a child who resembled his brother like a twin although born a year later. . . .

A fisherman in Sicily not only resembled the proconsul Sura in appearance but actually reproduced his gape while speaking and his tongue-tied stammering utterance.

Book 7, Chapter 16

It is known that at the age of three a person's measurement is half his future stature. But it is almost a matter of observation that with the entire human race the stature on the whole is becoming smaller daily, and that few men are taller than their fathers as the conflagration that is the crisis towards which the age is now verging is exhausting the fertility of the semen. When a mountain in Crete was cleft by an earthquake a body 69 feet in height was found, which some people thought must be that of Orion and others of Otus. The records attest that the body of Orestes dug up at the command of an oracle measured 10 ft. 6 in. Moreover, the famous bard Homer nearly 1000 years ago never ceased to lament that mortals were smaller of stature than in the old days. In the case of Naevius Pollio the annals do not record his height, but they show that it was deemed portentous, because he was almost killed by the people flocking round him. The tallest person our age has seen was a man named Gabbara brought from Arabia in the principate of his late Majesty Claudius who was 9 feet in height. Under his late Majesty Augustus there were two persons 6 inches taller, whose bodies on account of this remarkable height were preserve[d] in the tomb in Sallust's Gardens; their names were Pusio and Secundilla. When the same emperor was head of the state the smallest person was a dwarf 2 feet 5 inches high named Conopas, the pet of his granddaughter Julia, and the smallest female was Andromeda, a freedwoman of Julia Augusta. Marcus Varro states that the Knights of Rome Manius Maximus and Marcus Tullius were 3 feet high, and we have ourselves seen their bodies preserved in coffins. It is a matter of common knowledge that persons are born 18 inches high and some taller, who complete their life's course at the age of three.

We find in the records that at Salamis the son of Euthymenes grew to 4 feet 6 inches in his third year; he walked slowly, was dull of sense, became sexually quite mature, had a bass voice, and was carried off by a sudden attack of paralysis when he turned three. We ourselves recently saw almost all these features except sexual maturity in a son of the Knight of Rome Cornelius Tacitus, Deputy Finance Minister in Belgic Gaul. The Greeks call these cases "perverts," but in the Latin country there is no name for them.

Book 11, Chapter 37

Man is the only animal whose eyes are liable to distortion, which is the origin of the family names Squint-eye and Blinky. From the eyes also came the name of One-eye that used to be given to persons born blind in one eye, and that of eyelet given to persons both of whose eyes were small; the One-eye family received the name of an injury done to one of them.

Book 11, Chapter 52

When animals are born with extra limbs these are useless, as is always the case when a human being is born with a sixth finger. In Egypt it was decided to rear a monstrosity, a human being with another pair of eyes at the back of the head, though he could not see with these.

For my own part I am surprised that Aristotle not only believed but also published his belief that our bodies contain premonitory signs of our career. But although I think this view unfounded, and not proper to be brought forward without hesitation lest everybody should anxiously seek to find these auguries in himself, nevertheless I will touch upon it, because so great a master of the sciences as Aristotle has not despised it. Well then, he puts down as signs of a short life few teeth, very long fingers, a leaden complexion and an exceptional number of broken creases in the hand; and on the other side he says that those people are long-lived who have sloping shoulder, one or two long creases in the hand, more than thirty-two teeth, and large ears. Yet he does not, I imagine, note all these attributes present in one person, but separately, trifling things, as I consider them, though nevertheless commonly talked about. In a similar manner among ourselves Trogus, himself also one of the most critical authorities, has added some outward signs of character which I will append in his own words: 'When the forehead is large it indicates that the mind beneath it is sluggish; people with a small forehead have a nimble mind, those with a round forehead . . .'

Book 28, Chapter 10

The blood let from any part of the patient himself makes, we are told by Orpheus and Archelaus, a very efficacious application for quinsy; efficacious too if applied to the mouth of those who have fainted in an epileptic fit, for they rise up immediately. Some say the big toes should be pricked and the drops of blood applied to the face, or that a virgin should touch it with her right thumb; hence their conclusion that epileptics should eat virgin meat. Aeschines the Athenian used the ash of excrements for quinsy, sore tonsils, sore uvula, and carcinomata. This medicament he called botryon.

Book 34, Chapter 6

Nor are people ashamed to buy these at a price equal to the pay of a military tribune, although they clearly take even their name from the lighted candles they carry. At the sale of a chandelier of this sort by the instructions of the auctioneer (named Theon) selling it there was thrown in as part of the bargain the fuller Clesippus a humpback and also of a hideous appearance in other respects besides, the lot being bought by a woman named Gegania for 50,000 Sesterces. This woman gave a party to show off her purchases, and for the mockery of the guests the man appeared with no clothes on; his mistress conceiving an outrageous passion for him admitted him to her bed and later gave him a place in her will thus becoming excessively rich he worshipped the lampstand in question as a divinity and so caused this story to be attached to Corinthian lampstands in general, thought the claims of morality were vindicated by his erecting a noble tombstone to perpetuate throughout the living world for all time the memory of Gegania's shame.

Book 35, Chapter 7

There was also a celebrated debate on the subject of painting held between some men of eminence which must not be omitted, when the former consul and winner of a triumph Quintus Pedius, who was appointed by the Dictator Caesar as his joint heir with Augustus, had a grandson Quintus Pedius who was born dumb; in this debate the orator Messala, of whose family the boy's grandmother had been a member, gave the advice that the boy should have lessons in painting, and his late lamented Majesty Augustus also approved of the plan. The child made great progress in the art, but died before he grew up.

Source: Bostock, John, and H. T. Riley, trans. 1855. *Pliny the Elder: The Natural History.* London: Henry G. Bohn.

Tacitus, Excerpts from the *Annals* (1st/2nd c. CE)

The historian Tacitus, who wrote the Annals in the first century CE*, compares his beloved fallen Republic (in which he never lived) with the Augustan principate, which he perceives as corrupt and dangerous. In these excerpts, Tacitus paints a picture of a failed Augustus by pointing to his old age and "sickly frame." Augustus's successor, Tiberius, is characterized by his taciturn gloominess. Tacitus continues to disparage Augustus's successors by reporting their own physical and mental characteristics and by reporting the company they kept, including people who were deformed in both physique and etiquette. (See Robert Garland's third chapter, "The Roman Emperor in his Monstrous World." 1995. Pp. 45–58 in* The Eye of the Beholder, *Ithaca, NY: Cornell University Press, for further discussion.)*

Annals 1.4.1

Thus the State had been revolutionized, and there was not a vestige left of the old sound morality. Stript of equality, all looked up to the commands of a sovereign without the least apprehension for the present, while Augustus in the vigour of life, could maintain his own position, that of his house, and the general tranquility. When in advanced old age, he was worn out by a sickly frame, and the end was near and new prospects opened, a few spoke in vain of the blessings of freedom, but most people dreaded and some longed for war.

Annals 1.76.12

Drusus presided over a show of gladiators which he gave in his own name and in that of his brother Gaermanicus, for he gloated intensely over bloodshed, however cheap its victims. This was alarming to the populace, and his father had, it was said, rebuked him. Why Tiberius kept away from the spectacle was variously explained. According to some, it was his loathing of a crowd, according to others, his gloomy temper, and a fear of contrast with the gracious presence of Augustus. I cannot believe that he deliberately gave his son the opportunity of displaying his ferocity and provoking the people's disgust, although even this was said.

Annals 12.49.1

Julius Pelignus was then procurator of Cappadocia, a man despised alike for his feebleness of mind and his grotesque personal appearance. He was however very intimate with Claudius, who, when in private life, used to beguile the dullness of his leisure with the society of jesters.

Annals 15.34–35

There an incident occurred, which many thought unlucky, though to the emperor it seemed due to the providence of auspicious deities. The people who had been present, had quitted the theatre, and the empty building then fell in without harm to anyone. Thereupon Nero in an elaborate ode thanked the gods, celebrating the good luck which attended the late downfall, and as he was on his way to cross the sea of Hadria, he rested awhile at Beneventum, where a crowded gladiatorial show was being exhibited by Vatinius. The man was one of the most conspicuously infamous sights in the imperial court, bred as he had been, in a shoemaker's shop, of a deformed person and vulgar wit, originally introduced as a butt. After a time he grew so powerful by accusing all the best men, that in influence, wealth, and ability to injure, he was pre-eminent even in that bad company.

Source: Church, Alfred John, and William Jackson Brodribb, trans. ca. 1888. Tacitus, P. Cornelius. *The Annals.* Available at http://classics.mit.edu//Tacitus/annals.html

▣ Suetonius, Excerpts from the *Lives* (110 CE)

On one hand, Suetonius (born 69 CE) had access to imperial primary source material and was a contemporary of many of his biographical subjects. On the other hand, he wrote not only to inform but also to entertain, and his accounts of the Roman rulers are lurid and exaggerated. Still, we can find clues about how Suetonius's audience might have perceived disability. Alongside Julius Caesar's epilepsy, Caligula's mental and physical sickness, and Claudius's and Domitian's various characteristics, we see the sort of imperial disdain for physical variation that Suetonius's contemporary, Tacitus, also reports.

The Deified Julius, Chapter 43

Caesar is said to have been tall, fair, and well-built, with a rather broad face and keen, dark-brown eyes. His health was sound, apart from sudden comas and a tendency to nightmares which troubled him towards the end of his life; but he twice had epileptic fits while on campaign. He was something of a dandy, always keeping his head carefully trimmed and shaved; and had been accused of having certain other hairy parts of his body depilated with tweezers. His baldness was a disfigurement which his enemies harped upon, much to his exasperation; he used to comb the thin strands of hair forward from his poll, and of all the honors voted him by the Senate and People, none pleased him so much as the privilege of wearing a laurel wreath on all occasions—he constantly took advantage of it.

His dress was, it seems, unusual: he had added wrist-length sleeves with fringes to his purple-striped senatorial tunic, and the belt which he wore over it was never tightly fastened—hence Sulla's warning to the aristocratic party: “Beware of that boy with the loose clothes!”

The Deified Augustus

Chapter 43

None of Augustus’ predecessors had ever provided so many, so different, or such splendid public shows. He records the presentation of four Games in his own name and twenty-three in the names of other city magistrates who were either absent or could not afford the expense. Sometimes plays were shown in all the various city districts, and on several stages, the actors speaking the appropriate local language; and gladiators fought not only in the Forum or the Amphitheatre, but in the Circus and Enclosure as well; or the show might, on the contrary, be limited to a wild-beast hunt. He also held athletic competitions in the Campus Martius, for which he put up tiers of wooden seats; and dug an artificial lake beside the Tiber, where the present Caesarian Grove stands, for a mock sea-battle. On these occasions he posted guards in different parts of the city to prevent ruffians from turning the emptiness of the streets to their own advantage. Chariot-races and foot-races took place in the Circus, and among those who hunted the wild beasts were several volunteers of distinguished family. Augustus also ordered frequent performances of the Troy Game by two troops, of older and younger boys; it was an admirable tradition, he held, that the scions of noble houses should make their public debut in this way. When Nonius Asprenas fell from his horse at one performance and was crippled, Augustus comforted him with a golden torque and the hereditary surname of ‘Torquatus.’ Soon afterwards, however, he discontinued the Troy Game, because Asinius Pollio the orator attacked it bitterly in the House; his grandson, Aeserninus, having broken a leg too.

Chapter 67

Augustus behaved strictly but graciously and kindly towards his dependants and slaves, and honored some of his freedmen, such as Licinus, Celadus, and others, with his close intimacy. A slave named Cosmus, who had complained of him in the vilest terms, was punished merely by being put in irons. Once, when Augustus and his steward Diomedes were out walking together and a wild boar suddenly charged at them, Diomedes took fright and dodged behind his master. Augustus later made a joke of the incident, though he had been in considerable danger, preferring to call Diomedes a coward than anything worse—after all, his action had not been premeditated. Yet, when one Polus, a favorite freedman, was convicted of adultery with Roman matrons, Augustus ordered him to commit suicide; and sentenced Thallus, an imperial secretary to have his legs broken for divulging the contents of a letter—his fee had been twenty-five gold pieces. And because Gaius Caesar’s tutor and attendants used their master’s sickness and subsequent death as an excuse for arrogant, greedy behavior in his province, Augustus had them flung into a river with weights tied around their necks.

Chapter 83

As soon as the Civil Wars were over Augustus discontinued his riding and fencing exercises on the Campus Martius and used, instead, to play catch with two companions, or hand-ball with several. But soon he was content to go riding, or take walks, muffled in a cloak or blanket, that ended with a sprint and some jumping. Sometimes he went fishing as a relaxation; sometimes he played at dice, marbles, or nuts in the company of little boys, and was always on the lookout for ones with pretty faces and cheerful chatter, especially Syrians and Moors–he loathed people who were dwarfish or in any way deformed, regarding them as freaks of nature and bringers of bad luck.

The Life of Tiberius, Chapter 61

Soon Tiberius broke out in every sort of cruelty and never lacked for victims: these were, first, his mother’s friends and even acquaintances; then those of his grandsons and daughter-in-law; finally, those of Sejanus. With Sejanus out of the way his savageries increased; which proved that Sejanus had not, as some thought, been inciting him to commit them, but merely providing the opportunities that he demanded. Nevertheless, in Tiberius’ brief and sketchy autobiography we find him daring to assert that Sejanus had been killed because he had found him persecuting Nero and Drusus, the sons of Germanicus; the fact being that he had himself put Nero to death when Sejanus was already an object of suspicion, and Drusus after he had fallen from power. A detailed list of Tiberius' barbarities would take a long time to compile; I shall content myself with a few samples. Not a day, however holy, passed without an execution; he even desecrated New Year's Day. Many of his men victims were accused and punished with their children—some actually by their children—and the relatives forbidden to go into mourning. Special awards were voted to the informers who had denounced them and, in certain circumstances, to the witnesses too. An informer's word was always believed. Every crime became a capital one, even the utterance of a few careless words. A poet found himself accused of slander—he had written a tragedy which presented King Agamemnon in a bad light—and a historian had made the mistake of describing Caesar's assassins, Brutus and Cassius, as 'the last of the Romans.' Both these authors were executed without delay, and their works—though once publicly read before Augustus, and accorded general praise—were called in and destroyed. Tiberius denied those who escaped a prison sentence not only the solace of reading books, but the privilege of talking to their fellow-prisoners. Some of the accused, on being warned to appear in court, felt sure that the verdict would be 'guilty' and, to avoid the trouble and humiliation of a trial, stayed at home and severed an artery; yet Tiberius' men bandaged their wounds and hurried them, half-dead, to prison. Others obeyed their summons and then drank poison in full view of the Senate. The bodies of all executed persons were flung on the Stairs of Mourning, and dragged to the Tiber with hooks—as many as twenty a day, including women and children. Tradition forbade the strangling of virgins; so, when little girls had been condemned to die in this way, the executioner began by violating them. Tiberius used to punish with life those who wished to die. He regarded death as a comparatively light affliction, and on hearing that a man named Carnulus had forestalled his execution by suicide, exclaimed: 'Carnulus has got away!' Once, during a gaol inspection, a prisoner begged to be put out of his misery; Tiberius replied: 'No, we are not yet friends again.' An ex-consul has recorded in his memoirs that he attended a banquet at which Tiberius was suddenly asked loudly by a dwarf, standing among a group of jesters near the table: 'What of Paconius? Why is he still alive after being charged with treason?' Tiberius told him to hold his saucy tongue; but a few days later requested the Senate to make a quick decision about Paconius' execution.

Doctor bleeding a patient and dwarf carrying a hare. The scene on this vase details common medical treatments in ancient Greece for various illnesses. The person of short stature may demonstrate some integration of disabled people into the medical arts. Ceramic, red figure aryballos, 480–470 BCE.

Source: Louvre, Paris. Photo credit: Réunion des Musées Nationaux/Art Resource, New York.

▣ Aretaeus of Cappadocia, "The Wandering Womb" (2nd c. CE)

Aretaeus of Cappadocia, a contemporary of Galen, accepts the basic Hippocratic doctrines about hysteria but adds dramatic analogy to his account.

In the middle of the flanks of women lies the womb, a female viscus, closely resembling an animal; for it is moved of itself hither and thither in the flanks, also upwards in a direct line to below the cartilage of the thorax, and also obliquely to the right or to the left, either to the liver or spleen; and it likewise is subject to prolapsus downwards, and, in a word, it is altogether erratic. It delights, also, in fragrant smells, and advances towards them; and it has an aversion to fetid smells, and flees from them; and, on the whole, the womb is like an animal within an animal.

When, therefore, it is suddenly carried upwards, and remains above for a considerable time, and violently compresses the intestines, the woman experiences a choking, after the form of epilepsy, but without convulsions. For the liver, diaphragm, lungs and heart are quickly squeezed within a narrow space; and therefore loss of breathing and of speech seems to be present. And, moreover, the carotids are compressed from sympathy with the heart, and hence there is heaviness of head, loss of sensibility, and deep sleep.

And in women there also arises another affection resembling this form, with sense of choking and loss of speech, but not proceeding from the womb; for it also happens to men, in the manner of catalepsy. But those from the uterus are remedied by fetid smells, and the application of fragrant things to the female parts; but in the others these things do no good; and the limbs are moved about in the affection from the womb, but in the other affection not at all. Moreover, voluntary and involuntary tremblings . . . but from the application of a pessary to induce abortion, powerful congelation of the womb, the stoppage of a copious haemorrhage, and such like.

If, therefore, upon the womb's being moved upwards, she begins to suffer: there is sluggishness in the performance of her offices, prostration of strength, atony, loss of the faculties of her knees, vertigo (and the limbs sink under her), headache, heaviness of the head, and the woman is pained in the veins on each side of the nose.

But if they fall down they have heartburn . . . in the hypochondriac regions; flanks empty, where is the seat of the womb; pulse intermittent, irregular, and failing; strong sense of choking; loss of speech and of sensibility; respiration imperceptible and indistinct; a very sudden and incredible death, for they have nothing deadly in their appearance; in color like that of life, and for a considerable time after death they are more ruddy than usual; eyes somewhat prominent, bright, not entirely fixed, but yet not very much turned aside.

But if the uterus be removed back to its seat before the affection comes to a conclusion, they escape the suffocation. When the belly rumbles there is moisture about the female parts, respiration thicker and more distinct, a very speedy rousing up from affection, in like manner as death is very sudden; for as it readily ascends to the higher regions, so it readily recedes. For the uterus is buoyant, but the membranes, its supporters, are humid, and the place is humid in which the uterus lies; and, moreover, it flees from fetid things. And seeks after sweet; wherefore it readily inclines to this side and to that, like a log of wood, and floats upwards and downwards. For this reason the affection occurs in young women, but not in old. For in those in whom the age, mode of life, and understanding is more mobile, the uterus also is of a wandering nature; but in those more advanced in life, the age, mode of living, understanding, and the uterus are of a steady character. Wherefore this suffocation from the womb accompanies females alone.

But the affections common to men happen also to the uterus, such as inflammation and haemorrhage, and they have the common symptoms, namely, fever, asphyxia, coldness, loss of speech. But in haemorrhage the death is even more sudden, being like that of a slaughtered animal.

Source: Adams, F., trans. 1856. *Aretaeus, On the Causes and Symptoms of Acute Diseases 2, Excerpts. London:* Sydenham Society.

Soranus, *Gynecology*
(2nd c. CE)

Soranus of Ephesus wrote a treatise on gynecology that influenced medical practice for centuries. He is generally admired for his efforts to dispel superstitious beliefs about the female reproductive system. In the selection excerpted here, his ideas regarding what women should do to avoid bearing "misshapen" children illustrate the familiar efforts to determine the causes of physical disability.

1.36 The best time for fruitful intercourse is when menstruation is ending and abating, when urge and appetite for coitus are present, when the body is neither in want nor too congested and heavy from drunkenness and indigestion, and after the body has been rubbed down and a little food been eaten and when a pleasant state exists in every respect. 'When menstruation is ending and abating,' for the time before menstruation is not suitable, the uterus already being overburdened and in an unresponsive state because of the ingress of material and incapable of carrying on two motions contrary to each other, one for the excretion of material, the other for receiving.

1.39.2 In order that the offspring may not be rendered misshapen, women must be sober during coitus because in drunkenness the soul becomes the victim of strange fantasies; this, furthermore, because the offspring bears some resemblance to the mother as well not only in body but in soul.

Source: Temkin, Oswei, trans. 1991. *Soranus' Gynecology.* Baltimore, MD: Johns Hopkins University Press.

Galen on Psychological Origins of Hysteria (2nd c. CE)

In this rare case history of elegant deductive analysis, the Greek physician and philosopher Galen of Pergamum observes that apparently physical ailments can sometimes have psychological causes. This idea was not rediscovered until the twentieth century.

I was called to see a woman who was stated to be sleepless at night and to lie tossing about from one position to another. Finding she had no fever, I made a detailed inquiry into everything that had happened to her especially considering such factors as we know to cause insomnia. But she either answered little or nothing at all, as if to show that it was useless to question her. Finally, she turned away, hiding herself completely by throwing the bedclothes over her whole body, and laying her head on another small pillow, as if desiring sleep.

After leaving I came to the conclusion that she was suffering from one of two things: either from a melancholy dependent on black bile, or else trouble about something she was unwilling to confess. I therefore deferred till the next day a closer investigation of this. Further, on first arriving, I was told by her attendant maid that she could not at present be seen; and on returning a second time, I was told the same again. So I went yet a third time, but the attendant asked me to go away, as she did not want her mistress disturbed. Having learned, however, that when I left she had washed and taken food in her customary manner, I came back the next day and in a private conversation with the maid on one subject and another I found out exactly what was worrying the patient. And this I discovered by chance.

After I had diagnosed that there was no bodily trouble, and that the woman was suffering from some mental uneasiness, it happened that, at the very time I was examining her, this was confirmed. Somebody came from the theatre and said he had seen Pylades dancing. Then both her expression and the color of her face changed. Seeing this, I applied my hand to her wrist, and noticed that her pulse had suddenly become extremely irregular. This kind of pulse indicates that the mind is disturbed; thus it occurs also in people who are disputing over any subject. So on the next day I said to one of my followers that, when I paid my visit to the woman, he was to come a little later and announce to me, 'Morphus is dancing today.' When he said this, I found that the pulse was unaffected. Similarly also on the next day, when I had an announcement made about the third member of the troupe, the pulse remained unchanged as before. On the fourth evening I kept very careful watch when it was announced that Pylades was dancing, and noticed that the pulse was very much disturbed. Thus I found out that the woman was in love with Pylades, and by very careful watch on the succeeding days my discovery was confirmed.

Similarly too I diagnosed the case of a slave who administered the household of another wealthy man, and who sickened in the same way. He was concerned about having to give an account of his expenses, in which he knew that there was a considerable sum wanting; the thought of this kept him awake, and he grew thin with anxiety. I first told his master that there was nothing physically wrong with the old man, and advised an investigation to be made as to whether he feared his master was about to ask an account of the sums he had entrusted to him and for this reason was worried, knowing that a considerable amount would be found wanting. The master told me I had made a good suggestion, so in order to make the diagnosis certain I advised him to do as follows: he was to tell the slave to give him back all the money he had in hand, lest, in the event of his sudden death, it should be lost, owing to the administration passing into the hands of some other servant whom he did not know: for there would be no use asking for an account from such a one. And when the master said this to him, he felt sure he would not be questioned. So he ceased to worry, and by the third day had regained his natural physical condition.

Now what was it that escaped the notice of previous physicians when examining the aforesaid woman and the aforesaid slave? For such discoveries are made by common inductions if one has even the smallest acquaintance with medical science. I suppose it is because they have no clear conception of how the body tends to be affected by mental conditions. Possibly also they do not know that the pulse is altered by quarrels and alarms that suddenly disturb the mind.

Source: Brock, A. J., trans. 1916. *Galen, On Prognosis 6.* Loeb Classical Library Series.

▣ Justinian, *Institutes* (535 CE)

During his reign in the sixth century, the Byzantine emperor Justinian codified centuries of Roman law. The excerpts here show that disability was categorized pragmatically, not medically. From the legal perspective, insanity was an issue of marriage and inheritance; deafness (along with the status of female, child, or slave) was an issue of the ability to give legal testimony. Physical disability directly linked to financial consequence.

Book 1, Section 10. Marriage

Roman citizens are bound together in lawful matrimony when they are united according to law, the males having attained the age of puberty, and the females a marriageable age, whether they are fathers or sons of a family; but, of the latter, they must first obtain the consent of their parents, in whose power they are. For both natural reason and the law require this consent; so much so, indeed, that it ought to precede the marriage. Hence the question has arisen, whether the daughter of a madman could be married, or his son marry? And as opinions were divided as to the son, we decided that as the daughter of a madman might, so may the son of a madman marry without the intervention of the father, according to the mode established by our *constitutio*.

Book 1, Section 23. Curatorship

Males arrived at the age of puberty, and females of a marriageable age, receive curators, until they have completed their twenty-fifth year; for, although they have attained the age of puberty, they are still of an age which makes them unfit to protect their own interests.

1. Curators are appointed by the same magistrates who appoint tutors. A curator cannot be appointed by testament, but if appointed, he may be confirmed in his office by a decree of the praetor of *praeses*.

2. No adolescent is obliged to receive a curator against his will, unless in case of a lawsuit, for a curator may be appointed for a particular special purpose.

3. Madmen and prodigals, although past the age of twenty-five, are yet placed under the curatorship of their *agnati* by the law of the Twelve Tables. But, ordinarily, curators are appointed for them, at Rome, by the prefect of the city or the praetor: in the provinces, by the *praesides,* after inquiry into the circumstances has been made.

4. Persons who are of unsound mind, or who are deaf, mute, or subject to any perpetual malady, since they are unable to manage their own affairs, must be placed under curators.

Book 2, Section 10. The Making of Wills

5. All the witnesses may seal the testament with the same seal; for, as Pomponius says, what if the engraving on all seven seals were the same? And a witness may use a seal belonging to another person.

6. Those persons can be witnesses with whom there is *testamenti factio.* But women, persons under the age of puberty, slaves, madmen, dumb persons, deaf persons, prodigals restrained from having their property in their power, and persons declared by law to be worthless and incompetent to witness, cannot be witnesses.

Book 3, Intestate Succession

3. *Sui heredes* may become heirs, without their knowledge, and even though insane; for in every case in which inheritances may be acquired without our knowledge, they may also be acquired by the insane. At the death of the father, ownership in an inheritance is at once continued; accordingly, the authority of a tutor is not necessary, as inheritances may be acquired by *sui heredes* without their knowledge: neither does an insane person acquire by assent of his curator, but by operation of law.

Book 4, Section 3. The Lex Aquilia

9. The words above quoted “the greatest value the thing has possessed at any time within a year previously,” mean that if your slave is killed, being at the time of his death lame, maimed, or one-eyed, but having been within a year quite sound and of considerable value, the person who kills him is bound to pay not his actual value, but the greatest value he ever possessed within the year. Hence, this *action* may be said to be penal, as a person is bound under it not only for the damage he has done, but for much more; and, therefore, the *action* does not pass against his heir, as it would have done if the condemnation had not exceeded the amount of the actual damage.

Source: Moyle, J. B., trans. 1913. *The Institutes of Justinian.* Available at http://www.thelatinlibrary.com/law/institutes

The Bible:
Hebrew Scriptures—Old Testament

▣ Isaac's Blindness: Jacob Takes the Blessing

The story of the deception of Isaac and the theft of his blessing by Jacob is generally attributed to the Yahwist source and dated to the mid-tenth century BCE. *Here, Isaac's blindness is the result of the natural aging process. Isaac's blindness is mentioned only in this passage, where it provides the context for Jacob's deception. While the deception is possible because of Isaac's blindness, Jacob finds it necessary to deceive his father for his purposes since his father retains all the social status and familial power of the patriarch, which remain intact when he becomes disabled. While the reader is led to pity Isaac, it is because of his dysfunctional family rather than because of his age and disability.*

Genesis 27:1–45

27:1 Isaac had grown old and his eyesight was fading. He summoned his elder son Esau.

'My son.'

'Yes.'

27:2 'I am old and I have no idea when I will die.

27:3 Now take your equipment, your dangler and bow, and go out in the field to trap me some game.

27:4 Make it into a tasty dish, the way I like it, and bring it to me to eat. My soul will then bless you before I die.'

27:5 Rebecca had been listening while Isaac was speaking to Esau, his son. Esau went out to the field to trap some game and bring it home.

27:6 Rebecca said to her son Jacob, 'I just heard your father speaking to your brother Esau. He said,

27:7 'Bring me some game and prepare it into something tasty. I will eat it and bless you in God's presence before I die.'

27:8 Now, my son, listen to me. Heed my instructions carefully.

27:9 Go to the sheep and take two choice young kids. I will prepare them with a tasty recipe, just the way your father likes them.

27:10 You must then bring it to your father, so that he will eat it and bless you before he dies.'

27:11 'But my brother Esau is hairy,' replied Jacob. 'I am smooth-skinned.

27:12 Suppose my father touches me. He will realize that I am an impostor! I will gain a curse rather than a blessing!'

27:13 'Let any curse be on me, my son,' said the mother. 'But listen to me. Go, bring me what I asked.'

27:14 [Jacob] went and fetched what his mother had requested. She took [the kids] and prepared them, using the tasty recipe that [Jacob's] father liked best.

27:15 Rebecca then took her older son Esau's best clothing, which she had in her keeping, and put them on her younger son Jacob.

27:16 She [also] placed the young goats' skins on his arms and on the hairless parts of his neck.

27:17 Rebecca handed to her son Jacob the delicacy, and the bread she had baked.

27:18 He came to his father. 'Father.'

'Yes. Who are you, my son?'

27:19 'It is I, Esau, your first-born,' said Jacob. 'I have done as you asked. Sit up, and eat the game I trapped, so that your soul will bless me.'

27:20 'How did you find it so quickly, my son?' asked Isaac.

'God your Lord was with me.

27:21 'Come closer to me,' said Isaac to Jacob. 'Let me touch you, my son. Are you really Esau or not?'

27:22 Jacob came closer to his father Isaac, and [Isaac] touched him. He said, 'The voice is Jacob's voice, but the hands are the hands of Esau.'

27:23 He did not realize who it was because there was hair on [Jacob's] arms, just like those of his brother Esau. [Isaac] was about to bless him.

27:24 'But are you *really* my son Esau?'

'I am.'

27:25 'Then serve me [the food]. I will eat the game that my son trapped, so that my soul may bless you.'

[Jacob] served it, and [Isaac] ate. He then brought [Isaac] some wine, and he drank it.

27:26 His father Isaac said to him, 'Come closer and kiss me, my son.'

27:27 [Jacob] approached and kissed him. [Isaac] smelled the fragrance of his garments, and blessed him.

He said, 'See, my son's fragrance is like the perfume of a field blessed by God.

27:28 'May God grant you the dew of heaven and the fat of the earth, much grain and wine.

27:29 Nations will serve you; governments will bow down to you. You shall be like a lord over your brother; your mother's children will prostrate themselves to you. Those who curse you are cursed, and those who bless you are blessed.'

27:30 Isaac had finished blessing Jacob, and Jacob had just left his father Isaac, when his brother Esau came back from his hunt.

27:31 He had also prepared a delicacy and brought it to his father. 'Let my father get up and eat his son's venison,' he said, 'so that your soul may bless me.'

27:32 'Who are you?' asked his father Isaac.

'I am your first-born, Esau,' he replied.

27:33 Isaac was seized with a violent fit of trembling. 'Who . . . where . . . is the one who trapped game and just served it to me? I ate it all before you came and I blessed him. The blessing will remain his.'

27:34 When Esau heard his father's words, he let out a most loud and bitter scream. 'Bless me too, Father,' he pleaded.

27:35 'Your brother came with deceit, and he already took your blessing.'

27:36 'Isn't he truly named Jacob (*Ya'akov*)! He went behind my back (*akav*) twice. First he took my birthright, and now he took my blessing!'

[Esau] pleaded, 'Couldn't you have saved me a blessing too?'

27:37 Isaac tried to answer. 'But I made him like a lord over you,' he said. 'I have given him all his brothers as slaves. I have associated him with the grain and the wine. Where . . . what . . . can I do for you, my son?'

27:38 Esau said to his father, 'Is there only one blessing you have, my father? Father! Bless me too!' Esau raised his voice and began to weep.

27:39 His father Isaac then replied and said, 'The fat places of the earth can still be your dwelling, and [you can still have] the dew of heaven.

27:40 But you shall live by your sword. You may have to serve your brother, but when your complaints mount up, you will throw his yoke off your neck.'

27:41 Esau was furious at Jacob because of the blessing that his father had given him. He said to himself, 'The days of mourning for my father will be here soon. I will then be able to kill my brother Jacob.'

27:42 Her older son's plans were reported to Rebecca. She sent word and summoned her younger son Jacob. 'Your brother Esau is consoling himself by planning to kill you,' she said.

27:43 'Now, my son, listen to me. Set out and flee to my brother Laban in Charan.

27:44 Remain with him awhile until your brother's anger has subsided.

27:45 When your brother has calmed down from his rage against you, and has forgotten what you have done to him, I will send word and summon you home. But why should I lose you both on the same day?'

Source: Landsberg, Max, trans. 1917. Book of Genesis. In *The Hebrew Bible in English.* Jewish Publication Society. Available at http://www.mechon-mamre.org/e/et/et0.htm

▣ Jacob's Limp

The story of Jacob wrestling with a supernatural being at the Jabbok River is generally attributed to the Yahwist source and dated to the mid-tenth century BCE. *While the nature of the creature that confronts Jacob remains uncertain, it is clearly perceived by Jacob (and reflected in his new name, Israel) that his true struggle has been with God. Jacob becomes disabled in this struggle, not by a blow, but by a touch. Both the new name and the limp are signs not only of the blessing Jacob receives but the renewal of the patriarchal* *covenant with the ancestor of the nation Israel. As a sign of the covenant, later generations of Israel participate symbolically in Jacob's disability by not eating the meat of the thigh muscle. Jacob's disability is mentioned only in this passage.*

Genesis 32:22–32

32:22 He sent the gifts ahead of him, and spent the night in the camp.

32:23 In the middle of the night he got up, and took his two wives, his two handmaids, and his eleven sons, and sent them across the Jabbok River shallows.

32:24 After he had taken them and sent them across, he also sent across all his possessions.

32:25 Jacob remained alone. A stranger [appeared and] wrestled with him until just before daybreak.

32:26 When [the stranger] saw that he could not defeat him, he touched the upper joint of [Jacob's] thigh. Jacob's hip joint became dislocated as he wrestled with [the stranger].

32:27 'Let me leave!' said [the stranger]. 'Dawn is breaking.'

'I will not let you leave unless you bless me.'

32:28 'What is your name?'

'Jacob.'

32:29 'Your name will no longer be said to be Jacob, but Israel (*Yisra'el*). You have become great (*sar*) before God and man. You have won.'

32:30 Jacob returned the question. 'If you would,' he said, 'tell me what *your* name is.'

'Why do you ask my name?' replied [the stranger]. He then blessed [Jacob].

32:31 Jacob named the place Divine Face (*Peniel*). [He said,] 'I have seen the Divine face to face, and my soul has withstood it.'

32:32 The sun rose and was shining on him as he left Peniel. He was limping because of his thigh.

Source: Landsberg, Max, trans. 1917. Book of Genesis. In *The Hebrew Bible in English.* Jewish Publication Society. Available at http://www.mechon-mamre.org/e/et/et0.htm

▣ Purity Laws

The Priestly Purity Laws are attributed to the Priestly source, which dates to the time of the Babylonian Exile, from the mid-sixth to mid-fifth centuries BCE*. Leviticus 13 and 14 deal with visible skin blemishes and apply to the whole community. Anyone who has a blemish is institutionally marginalized from the community until he or she can provide proof that the blemish is gone. Leviticus 21:16–23 deals with the full range of disabilities and applies only to the Aaronide priestly caste. Here the prohibition applies only to serving in the priestly office. Aaronides who are unable to serve are still guaranteed all the benefits of the Aaronide priestly status. In all cases, the prohibitions are concerned with ritual purity rather than community health.*

Leviticus 13

The Leprous Curse

13:1 God spoke to Moses and Aaron, saying:

13:2 If a person has a [white] blotch, discoloration or spot on the skin of his body, and it [is suspected] of being a mark of the leprous curse on his skin, he shall be brought to Aaron, or to one of his descendants, who are the priests.

13:3 The priest shall examine the mark on [the person's] skin, and if the hair on the mark has turned white, and the mark appears to have penetrated the skin, then it is the leprous curse. As soon as the priest sees it, he shall declare it unclean.

13:4 However, if there is a [white] spot on the skin, but it does not appear to have penetrated the skin and its hair has not turned white, then the priest shall quarantine the affected person for seven days.

13:5 The priest shall examine [the person] on the seventh day and if the mark has not increased in size, the priest shall quarantine [the victim] for an additional seven days.

13:6 The priest shall examine [him again] on the seventh day, and if the mark has faded or if it has not spread, the priest shall declare [the person] clean, since it is merely a white discoloration. [The person] must immerse [his body and] clothing, and he is then clean.

13:7 However, if the white discoloration increases in size on the skin after it was shown to the priest, who purified it, [the person] must show it to the priest again.

13:8 If the priest sees that the rash has increased in size on the skin, [he] shall declare [the person] unclean, since it is the leprous curse.

Healthy Skin in a Spot

13:9 When a person [is suspected of] having the leprous curse, he shall be brought to the priest.

13:10 If the priest sees that there is a white blotch on the skin, and it has turned the hair white or that there is an area of healthy skin inside the blotch,

13:11 then it is a chronic leprosy in his skin, and the priest must declare it unclean. He shall not quarantine it, since it is obviously unclean.

13:12 [This is the law] if the leprous area spreads over the skin, so that it covers all the skin of the afflicted person from head to foot, wherever the priest can see it.

13:13 When the priest sees that the leprous discoloration has covered all [the person's] skin, he shall declare the afflicted person clean. As long as he has turned completely white, he is clean.

13:14 However, on the day that healthy skin appears on [the person] he is unclean.

13:15 When the priest sees the healthy skin, he shall declare [the person] unclean. The healthy skin is a sign of uncleanness, since it is the leprous curse.

13:16 If the healthy skin turns white again, [the person] shall come back to the priest.

13:17 When the priest sees that the afflicted person has turned [completely] white, the priest shall declare him clean, and he is then ritually pure.

Leprosy on an Infection

13:18 [This is the law] when there is an infection on the body and it heals.

13:19 If a white blotch or bright pink spot then develops where the infection was, it must be shown to the priest.

13:20 The priest shall examine it, and if it appears to have penetrated the skin and its hair has turned white, it is the leprous curse that has erupted over the infection.

13:21 However, if the priest examines it, and it does not have white hair, nor does it appear to have penetrated the skin since it is a dull white, the priest shall quarantine the person for seven days.

13:22 If this spot then increases in size on the skin, the priest shall declare it unclean, since it is the curse.

13:23 However, if the spot remains stable and does not expand, it is scar tissue from the infection, and the priest shall declare it clean.

Leprosy on a Burn

13:24 [This is the law] when there is a burn on the body, and a bright pink or white spot appears where the burn has healed.

13:25 The priest shall examine it, and if the hair on the spot has turned white, and [the spot] appears to have penetrated the skin, it is the leprous curse breaking out on the burn. Since it is the leprous curse, the priest shall declare it unclean.

13:26 However, if the priest examines it, and the spot does not have white hair, and it is a dull white which does not appear to have penetrated the skin, then the priest shall quarantine it for seven days.

13:27 On the seventh day, the priest shall examine it, and if it has increased in size on the skin, the priest shall declare it unclean, since it is the leprous curse.

13:28 However, if the spot remains stable and does not increase in size, or if it has faded, then it is a discoloration due to the burn. Since it is merely scar tissue from the burn, the priest shall declare it clean.

Bald Patches

13:29 [This is the law] if a man or woman has an affliction on the head or beard.

13:30 The priest shall examine the affliction, and if it appears to have penetrated the skin and has fine blond hairs in it, the priest shall declare it unclean. Such a bald mark is a sign of the leprous curse on the head or beard.

13:31 However, if, when the priest examines the bald patch, [the affliction] does not appear to have penetrated the skin, but it does not have black hair in it, the priest shall quarantine the person afflicted by the bald patch for seven days.

13:32 On the seventh day, the priest shall examine the mark. If the bald mark has not increased in size, and if there is no blond hair in it so that the mark does not appear to have penetrated the skin,

13:33 [the person] shall shave himself, without shaving off the bald patch. The priest shall then quarantine [the person having] the bald patch for a second seven day period.

13:34 The priest shall examine the bald patch on the seventh day, and if the area of fallen hair has not increased in size, or if [the affliction] does not appear to have penetrated the skin, the priest shall declare it clean. [The person] must then immerse his [body and] clothing, and he is clean.

13:35 However, if the bald patch increases in size after he has cleansed himself,

13:36 the priest must examine it [again]. If the bald patch has increased in size, the priest need not look for blond hairs, since it is [automatically] unclean.

13:37 But if the bald patch remains the same, or if the black hair grows on it, then the bald patch has healed and it is clean. The priest shall declare [the person] clean.

Dull White Spots

13:38 If the skin of a man's or woman's body becomes covered with white spots,

13:39 the priest shall examine it. If the skin is [merely] covered with dull white spots, it is a simple rash breaking out on the skin, and it is clean.

Baldness

13:40 If a man loses the hair on his head, it is simple baldness, and he is clean.

13:41 Similarly, if he loses hair near his face, it is merely a receding hairline and he is clean.

13:42 However, if he has a bright pink mark on his bald spot or where his hairline has receded, it may be a sign of the leprous curse on his bald spot or hairless forehead.

13:43 The priest shall examine it, and if the blotch on his bald spot or hairless forehead is bright pink, then [it is] like leprosy on the skin of his body.

13:44 The person is considered afflicted by the leprous curse, and he is unclean. Since he is unclean, and the mark is on his head, the priest must declare him unclean.

13:45 When a person has the mark of the leprous curse, his clothing must have a tear in it, he must go without a haircut, and he must cover his head down to his lips. 'Unclean! Unclean!' he must call out.

13:46 As long as he has the mark, he shall remain unclean. Since he is unclean, he must remain alone, and his place shall be outside the camp.

Discoloration of Garments

13:47 [This is the law] when a garment has the mark of the leprous curse. It can be woolen cloth, linen cloth,

13:48 linen or wool [threads meant for] the warp or woof, leather, or anything made of leather.

13:49 If a bright green or bright red area appears in the cloth, leather, warp or woof [thread], or in any leather article, [it may be] the mark of the leprous curse, and it must be shown to the priest.

13:50 The priest shall examine the mark, and quarantine the affected [article] for seven days.

13:51 On the seventh day, he shall examine the affected area, and if the mark has increased in size on the cloth, the warp or woof [thread], the leather, or the article crafted from leather, then it is a malignant leprous mark, and it is unclean.

13:52 The cloth, the warp or woof [thread], whether wool or linen, or the leather article containing the spot must be burned. Since it is a malignant leprosy, it must be burned in fire.

13:53 However, if, when the priest examines it, the mark has not expanded in the garment, the warp or woof [thread], or the leather article,

13:54 the priest shall order the article having the mark to be scrubbed and then quarantined for a second seven-day period.

13:55 After the mark has been scrubbed [and quarantined], the priest shall examine the article, and if the mark has not changed in appearance, then [even if] it has not expanded, it is unclean and must be burned. It is a mark of decay [that can be] on the smooth or fluffy side [of the cloth].

13:56 If the priest examines it after it has been scrubbed [and quarantined], and the mark has faded from the cloth, then he shall tear off [the mark] from the cloth, the leather, or from the warp or woof [threads].

13:57 If [the mark] then appears again in the [same] cloth, warp or woof [thread] or leather item, it is infected, and [the article] having the mark must be burned in fire.

13:58 If the mark is removed when the cloth, warp or woof [thread] or leather article is scrubbed, [the article] shall be immersed this second time, and it is clean.

13:59 This is the [entire] law concerning the mark of the leprous curse in wool or linen cloth, in warp or woof [thread], or in any leather item, through which it is rendered clean or unclean.

Leviticus 14

Purification of a Leper

14:1 God spoke to Moses, saying:

14:2 This is the law concerning the leper when he is purified and placed under the jurisdiction of the priest.

14:3 The priest shall go outside the camp, where he shall examine the leper to determine that the leprous mark has healed.

14:4 The priest shall then order that for the person undergoing purification there be taken two live kosher birds, a piece of cedar, some crimson [wool], and a hyssop branch.

14:5 The priest shall give orders that one bird be slaughtered over fresh spring water in a clay bowl.

14:6 He shall then take the live bird together with the piece of cedar, the crimson wool, and the hyssop. Along with the live bird, he shall dip [the other articles] into the spring water mixed with the blood of the slaughtered bird.

14:7 He shall then sprinkle [this mixture] seven times on the person undergoing purification from the leprous curse, thus rendering him clean. He shall send the living bird away toward the fields.

14:8 The person undergoing purification shall then immerse his clothing, and [the priest] shall shave off all the person's hair. He shall then immerse in a mikvah and thus complete [the first part] of the purification process. He may return to the camp, but he must remain outside his tent for seven days.

14:9 On the seventh day, [the priest] shall shave off all [the person's] hair. His head, beard, eyebrows and other [body] hair must all be shaved off. He shall then immerse his clothing and body in a mikvah and he is clean.

14:10 On the eighth day, he shall take two unblemished [male] sheep, one unblemished yearling female sheep, three-tenths [of an ephah] of the best grade wheat flour mixed with oil as a meal offering, and one log of [olive] oil.

14:11 The priest tending to the purification process shall stand [all these items] and the person undergoing purification before God at the Communion Tent entrance.

14:12 The priest shall take one [male] sheep and present it as a guilt offering along with the log of oil. He shall wave them in the manner prescribed for a wave offering before God.

14:13 He shall then slaughter the sheep in the same place where burnt offerings and sin offerings are slaughtered, in a holy place. This guilt offering is holy of holies, and it is just like a sin offering to the priest.

14:14 The priest shall take some of the guilt offering's blood and place it on the right ear lobe, right thumb, and right big toe of the person undergoing purification.

14:15 The priest shall take some of the log of oil and pour it into the palm of [another] priest's hand.

14:16 [This second] priest shall then dip his right forefinger into the oil in his left hand, and with his finger, sprinkle some oil before God seven times.

14:17 The priest shall place some of the oil in his hand on the right ear, right thumb, and right big toe of the person undergoing purification, over the guilt offering's blood.

14:18 The priest shall then place the rest of the oil in his hand on the head of the person undergoing purification. In this manner, the priest shall make atonement for him before God.

14:19 The priest shall then sacrifice the sin offering to remove the defilement for the person undergoing purification. After that, he shall slaughter the burnt offering,

14:20 and the priest shall present the burnt offering and the meal offering on the altar. The priest shall thus make atonement for him, and [the person] is then ritually clean.

The Poor Leper's Offering

14:21 If [the leper] is poor and cannot afford [the above sacrifices], he shall take one [male] sheep as a guilt offering. This shall be the wave offering to atone for him. [He shall also take] one-tenth [ephah] of the best grade wheat meal mixed with oil as a meal offering, and a log of olive oil.

14:22 [In addition, he shall bring] two turtle doves or two young common doves, as he can afford, one for a sin offering, and one for a burnt offering.

14:23 On the eighth day of his purification, he shall bring them to the priest, to the Communion Tent entrance, before God.

14:24 The priest shall take the guilt offering sheep and the log of oil, and wave them in the motions prescribed for a wave offering before God.

14:25 He shall slaughter the guilt offering sheep. The priest shall take the blood of the guilt offering and place it on the right ear lobe, the right thumb, and the right big toe of the person undergoing purification.

14:26 The priest shall then pour some of the oil onto the left hand of [another] priest.

14:27 With his right finger, [this second] priest shall sprinkle some of the oil on his left hand seven times before God.

14:28 The priest shall place some of the oil from his hand on the right ear lobe, right thumb and right big toe of the person undergoing purification, right over the place where the blood of the guilt offering [was put].

14:29 The priest shall then place the rest of the oil that is in his hand on the head of the person undergoing purification. [With all this] he shall make atonement for [the person] before God.

14:30 He shall then prepare one of the turtle doves or young common doves that [the person] was able to afford.

14:31 [Taking this offering] that the person could afford, [the priest] shall sacrifice one [bird] as a sin offering and one as a meal offering, [and then present] the meal offering. The priest shall thus make atonement before God for the person undergoing purification.

14:32 The above is the [entire] law concerning the person who has the mark of the leprous curse on him, and who cannot afford [more] for his purification.

Discoloration in Houses

14:33 God spoke to Moses and Aaron, saying:

14:34 When you come to the land of Canaan, which I am giving to you as an inheritance, I will place the mark of the leprous curse in houses in the land you inherit.

14:35 The owner of the house shall come and tell the priest, 'It looks to me as if there is [something] like a [leprous] mark in the house.'

14:36 The priest shall give orders that the house be emptied out before [any] priest comes to see the mark, so that everything in the house will not become unclean. Only then shall a priest come to see the house.

14:37 He shall examine the mark [to determine if] the mark on the wall of the house consists of penetrating streaks that are bright green or bright red, which appear to be below [the surface of] the wall.

14:38 [If they are,] the priest shall leave the house [and stand just outside] the entrance of the house. The priest shall then quarantine the house for seven days.

14:39 On the seventh day, he shall return and examine [it to determine] whether or not the mark has expanded on the wall of the house.

14:40 [If it has], the priest shall give orders that [people] remove the stones having the mark, and that they throw [the stones] outside the city in an unclean place.

14:41 He shall then have the inside of the house scraped off all around [the mark], and [the people doing it] shall discard the removed dust outside the city in an unclean place.

14:42 [The people] shall take other stones to replace the [removed] stones. [The owner] shall then plaster the [entire] house with new clay.

14:43 If, after the stones have been removed and the house has been scraped and replastered, the mark comes back

14:44 the priest shall return and examine it. If the mark has spread in the house [again], it is a malignant leprous mark which is unclean.

14:45 [The priest] must [order that] the house be demolished, and its stones, wood and all the clay from the house shall be brought outside the city to an unclean place.

14:46 As long as the house is in quarantine, anyone entering it shall be unclean until evening.

14:47 If one [remains in the house long enough to] relax, he must immerse [both his body and] his clothing. [However] he must immerse his clothing [only if he has remained] in the house [long enough] to eat [a small meal].

14:48 However, if the priest returns [at the end of the seven days] after the house has been replastered, and he sees that the mark has not reappeared in the house, then the mark has gone away and the priest shall declare the house clean.

14:49 To purify the house, he shall order two birds, a piece of cedar, some crimson wool, and a hyssop branch.

14:50 He shall slaughter one bird over fresh spring water in a clay bowl.

14:51 He shall then take the piece of cedar, the hyssop, the crimson wool, and the live bird, dip them in the blood of the slaughtered bird and fresh spring water and sprinkle it on the house seven times.

14:52 Thus, with the bird's blood and spring water, along with the live bird, cedar wood, hyssop and crimson wool, he shall purify the house.

14:53 He shall then send the live bird outside the city toward the fields. [In this manner] he shall make atonement for the house, and it is then clean.

14:54 The above is the [entire] law for every leprous mark, bald patch,

14:55 leprous mark in a garment or house,

14:56 and [white] blotch, discoloration or spot [on the skin],

14:57 so that decisions can be rendered as to the day one is rendered clean and the day one is rendered unclean. This is the [entire] law concerning the leprous curse.

Leviticus 21: 16–23: Priestly Purity

21:16 God spoke to Moses, telling him to

21:17 speak to Aaron as follows:

Anyone among your descendants who has a blemish may not approach to present his God's food offering.

21:18 Thus, any blemished priest may not offer sacrifice.

[This includes] anyone who is blind or lame, or who has a deformed nose or a misshapen limb.

21:19 [Also included] is anyone who has a crippled leg, a crippled hand,

21:20 who is a hunchback or a dwarf, who has a blemish in the eye, who has severe eczema or ringworm, or who has a hernia.

21:21 Any descendant of Aaron the priest who has a blemish may not approach to present God's fire offering. As long as he has a blemish, he may not approach to present his God's food offering.

21:22 [Still] he may eat the food offerings of his God, both from the holy of holies and from the holy.

21:23 But he may not come to the cloth partition [in the sanctuary], and he may not approach the altar if he has a blemish. He shall thus not defile that which is holy to Me, since I am God [and] I sanctify it.

Source: Dembitz, L. N., trans. 1917. Book of Leviticus. In *The Hebrew Bible in English*. Jewish Publication Society. Available at http://www.mechon-mamre.org/e/et/et0.htm

▣ Mephibosheh: The Prince with a Disability

The story of Mephibosheth (or Meribbaal—1 Chronicles 8:34, 9:40) is part of the Deuteronomic history dated to the seventh and sixth centuries BCE. The events of the narrative are set in the tenth century BCE. Although Mephibosheth's disability results from an accident following the judgment of God on his grandfather Saul, Mephibosheth's disability is never portrayed as part of that judgment. He is disabled because of a childhood accident, which is explanation enough (4:4). On first reading, it appears that David takes pity on Mephibosheth, the prince with a disability, in 9:1–13. However, if the passage is read in parallel to the encounter between Saul and David in 1 Samuel 24:8–22, we see that Mephibosheth has become the threat to David's throne that David had been to the throne of Saul. David is bound by covenant to Jonathan, Mephibosheth's father, and by promise to Saul to show loyalty to Mephibosheth, and so he cannot raise his hand against Mephibosheth. David's call of Jonathan to his own table is an act of control, not of charity. Mephibosheth's neutral stance during the revolt of Absalom must be interpreted in light of his claim to the throne and the possible fall of the House of David and the return of the House of Saul. It is interesting to note that Mephibosheth has no qualms about using his disability—and poor attendant care—as an excuse for his actions.

2 Samuel 4:4; 9:1–13; 16:1–4; 19:24–30

4:4 Now Jonathan, Saul's son, had a son that was lame of his feet. He was five years old when the tidings came of Saul and Jonathan out of Jezreel, and his nurse took him up, and fled; and it came to pass, as she made haste to flee, that he fell, and became lame. And his name was Mephibosheth.

9:1 And David said: 'Is there yet any that is left of the house of Saul, that I may show him kindness for Jonathan's sake?'

9:2 Now there was of the house of Saul a servant whose name was Ziba, and they called him unto David; and the king said unto him: 'Art thou Ziba?' And he said: 'Thy servant is he.'

9:3 And the king said: 'Is there not yet any of the house of Saul, that I may show the kindness of God unto him?' And Ziba said unto the king: 'Jonathan hath yet a son, who is lame on his feet.'

9:4 And the king said unto him: 'Where is he?' And Ziba said unto the king: 'Behold, he is in the house of Machir the son of Ammiel, in Lo-debar.'

9:5 Then king David sent, and fetched him out of the house of Machir the son of Ammiel, from Lo-debar.

9:6 And Mephibosheth, the son of Jonathan, the son of Saul, came unto David, and fell on his face, and prostrated himself. And David said: 'Mephibosheth!' And he answered: 'Behold thy servant!'

9:7 And David said unto him: 'Fear not; for I will surely show thee kindness for Jonathan thy father's sake, and will restore thee all the land of Saul thy father; and thou shalt eat bread at my table continually.'

9:8 And he bowed down, and said: 'What is thy servant, that thou shouldest look upon such a dead dog as I am?'

9:9 Then the king called to Ziba, Saul's servant, and said unto him: 'All that pertained to Saul and to all his house have I given unto thy master's son.

9:10 And thou shalt till the land for him, thou, and thy sons, and thy servants; and thou shalt bring in the fruits, that thy master's son may have bread to eat; but

Mephibosheth thy master's son shall eat bread continually at my table.' Now Ziba had fifteen sons and twenty servants.

9:11 Then said Ziba unto the king: 'According to all that my lord the king commandeth his servant, so shall thy servant do; but Mephibosheth eateth at my table as one of the king's sons.'

9:12 Now Mephibosheth had a young son, whose name was Mica. And all that dwelt in the house of Ziba were servants unto Mephibosheth.

9:13 But Mephibosheth dwelt in Jerusalem; for he did eat continually at the king's table; and he was lame on both his feet.

16:1 And when David was a little past the top, behold, Ziba the servant of Mephibosheth met him, with a couple of asses saddled, and upon them two hundred loaves of bread, and a hundred clusters of raisins, and a hundred of summer fruits, and a bottle of wine.

16:2 And the king said unto Ziba: 'What meanest thou by these?' And Ziba said: 'The asses are for the king's household to ride on; and the bread and summer fruit for the young men to eat; and the wine, that such as are faint in the wilderness may drink.'

16:3 And the king said: 'And where is thy master's son?' And Ziba said unto the king: 'Behold, he abideth at Jerusalem; for he said: To-day will the house of Israel restore me the kingdom of my father.'

16:4 Then said the king to Ziba: 'Behold, thine is all that pertaineth unto Mephibosheth.' And Ziba said: 'I prostrate myself; let me find favour in thy sight, my lord, O king.'

19:24 And the king said unto Shimei: 'Thou shalt not die.' And the king swore unto him.

19:25 And Mephibosheth the son of Saul came down to meet the king; and he had neither dressed his feet, nor trimmed his beard, nor washed his clothes, from the day the king departed until the day he came home in peace.

19:26 And it came to pass, when he was come to Jerusalem to meet the king, that the king said unto him: 'Wherefore wentest not thou with me, Mephibosheth?'

19:27 And he answered: 'My lord, O king, my servant deceived me; for thy servant said: I will saddle me an ass, that I may ride thereon, and go with the king; because thy servant is lame.

19:28 And he hath slandered thy servant unto my lord the king; but my lord the king is as an angel of God; do therefore what is good in thine eyes.

19:29 For all my father's house were deserving of death at the hand of my lord the king; yet didst thou set thy servant among them that did eat at thine own table. What right therefore have I yet? or why should I cry any more unto the king?'

19:30 And the king said unto him: 'Why speakest thou any more of thy matters? I say: Thou and Ziba divide the land.'

Source: Drachman, Bernard, trans. 1917. Book of II Samuel. In *The Hebrew Bible in English.* Jewish Publication Society. Available at http://www.mechon-mamre.org/e/et/et0.htm

▣ David's Curse

The story of David's conquest of Jerusalem in the tenth century BCE is part of the Deuteronomic history dated to the seventh and sixth centuries BCE. This is one of the most difficult passages in the Deuteronomic history to understand. Two interpretations predominate. One is that the Jebusites are so confident of their defenses that they taunt David, implying that those who are disabled can hold the city against him. The second interpretation is that this is sympathetic magic cursing with a disability anyone who attacks the city.

2 Samuel 5:6–8

5:6 And the king and his men went to Jerusalem against the Jebusites, the inhabitants of the land, who spoke unto David, saying: 'Except thou take away the blind and the lame, thou shalt not come in hither'; thinking: 'David cannot come in hither.'

5:7 Nevertheless David took the stronghold of Zion; the same is the city of David.

5:8 And David said on that day: 'Whosoever smiteth the Jebusites, and getteth up to the gutter, and taketh away the lame and the blind, that are hated of David's soul—.' Wherefore they say: 'There are the blind and the lame; he cannot come into the house.'

Source: Drachman, Bernard, trans. 1917. Book of II Samuel. In *The Hebrew Bible in English.* Jewish Publication Society. Available at http://www.mechon-mamre.org/e/et/et0.htm

▣ God's Promise to Israel

Isaiah uses apocalyptic imagery in these passages to describe the hope of restoration that God is promising to a repentant Israel. That the "deaf shall hear," "the *blind shall see," "the lame shall leap," and "the speechless sing" stress apocalyptic paradox and reversal rather than healing of a medical condition. This stress on reversal is best seen in Isaiah 29:17, where the cedars of Lebanon are replaced by fertile fields and fertile fields are replaced by forests. Both cedars and fertile fields are desirable, so the stress is not on an improved condition but on the reversal where the impossible becomes possible. Isaiah 35:5–7, where the parallel is between arid and wet lands, may imply greater desirability of the reversal of the disability.*

Isaiah 29:17–21

29:17 Is it not yet a very little while, and Lebanon shall be turned into a fruitful field, and the fruitful field shall be esteemed as a forest?

29:18 And in that day shall the deaf hear the words of a book, and the eyes of the blind shall see out of obscurity and out of darkness.

29:19 The humble also shall increase their joy in the Lord, and the neediest among men shall exult in the Holy One of Israel.

29:20 For the terrible one is brought to nought, and the scorner ceaseth, and all they that watch for iniquity are cut off;

29:21 That make a man an offender by words, and lay a snare for him that reproveth in the gate, and turn aside the just with a thing of nought.

Isaiah 35:5–7

35:5 Then the eyes of the blind shall be opened, and the ears of the deaf shall be unstopped.

35:6 Then shall the lame man leap as a hart, and the tongue of the dumb shall sing; for in the wilderness shall waters break out, and streams in the desert.

35:7 And the parched land shall become a pool, and the thirsty ground springs of water; in the habitation of jackals herds shall lie down, it shall be an enclosure for reeds and rushes.

Source: Book of Isaiah. 1917. In *The Hebrew Bible in English.* Jewish Publication Society. Available at http://www.mechon-mamre.org/e/et/et0.htm

The Bible: Apocrypha

▣ Tobit's Blindness

Tobit, dating to the third or second century BCE, *tells the story of a righteous Jewish exile who loses his vision because of natural causes, complicated by medical treatment; however, his blindness is perceived as a sign of God's displeasure. Tobit's vision is restored through angelic intervention in the form of a magical, quasi-medical treatment.*

Tobit 2:9–11

2:9 On the same night I returned from burying him, and because I was defiled I slept by the wall of the courtyard, and my face was uncovered.

2:10 I did not know that there were sparrows on the wall and their fresh droppings fell into my open eyes and white films formed on my eyes. I went to physicians, but they did not help me. Ahikar, however, took care of me until he went to Elymais.

2:11 Then my wife Anna earned money at women's work.

Tobit 3:7–17

3:7 On the same day, at Ecbatana in Media, it also happened that Sarah, the daughter of Raguel, was reproached by her father's maids,

3:8 Because she had been given to seven husbands, and the evil demon Asmodeus had slain each of them before he had been with her as his wife. So the maids said to her, "Do you not know that you strangle your husbands? You already have had seven and have had no benefit from any of them.

3:9 Why do you beat us? If they are dead, go with them! May we never see a son or daughter of yours!"

3:10 When she heard these things she was deeply grieved, even to the thought of hanging herself. But she said, "I am the only child of my father; if I do this, it will be a disgrace to him, and I shall bring his old age down in sorrow to the grave."

3:11 So she prayed by her window and said, "Blessed art thou, O Lord my God, and blessed is thy holy and honored name for ever. May all thy works praise thee for ever.

3:12 And now, O Lord, I have turned my eyes and my face toward thee.

3:13 Command that I be released from the earth and that I hear reproach no more.

3:14 Thou knowest, O Lord, that I am innocent of any sin with man,

3:15 and that I did not stain my name or the name of my father in the land of my captivity. I am my father's only child, and he has no child to be his heir, no near kinsman or kinsman's son for whom I should keep myself as wife. Already seven husbands of mine are dead. Why should I live? But if it be not pleasing to thee to take my life, command that respect be shown to me and pity be taken upon me, and that I hear reproach no more."

3:16 The prayer of both was heard in the presence of the glory of the great God.

3:17 And Raphael was sent to heal the two of them: to scale away the white films of Tobit's eyes; to give Sarah the daughter of Raguel in marriage to Tobias the son of Tobit, and to bind Asmodeus the evil demon, because Tobias was entitled to possess her. At that very moment Tobit returned and entered his house and Sarah the daughter of Raguel came down from her upper room.

Source: Book of Tobit. 1946. *Revised Standard Version of the Bible.* National Council of Churches of Christ in America. Available at http://www.piney.com/ApocTobit.html

The Bible:
Christian Scriptures—New Testament

▣ The Birth of John the Baptist

Luke 1:5–25 records the annunciation of the birth of John the Baptist, which comes to fruition in Luke 1:57–66. During the annunciation, Gabriel declares that Zechariah, John's father, will be mute "because you did not believe my words." While this is often interpreted as punishment, its function within the annunciation genre is as a "sign." Indeed, the pregnancy of his wife Elizabeth will serve as the "sign" in the better known annunciation to Mary in Luke 1:36 after her parallel questioning in Luke 1:34. It is interesting that in the birth narrative, as Zechariah's temporary disability comes to an end, either the author or his vocally normative characters make the assumption that because Zechariah is mute he must also be deaf in Luke 1:62.

Luke 1:5–25

1:5 In the time of Herod king of Judea there was a priest named Zechariah, who belonged to the priestly division of Abijah; his wife Elizabeth was also a descendant of Aaron.

1:6 Both of them were upright in the sight of God, observing all the Lord's commandments and regulations blamelessly.

1:7 But they had no children, because Elizabeth was barren; and they were both well along in years.

1:8 Once when Zechariah's division was on duty and he was serving as priest before God,

1:9 he was chosen by lot, according to the custom of the priesthood, to go into the temple of the Lord and burn incense.

1:10 And when the time for the burning of incense came, all the assembled worshipers were praying outside.

1:11 Then an angel of the Lord appeared to him, standing at the right side of the altar of incense.

1:12 When Zechariah saw him, he was startled and was gripped with fear.

1:13 But the angel said to him: "Do not be afraid, Zechariah; your prayer has been heard. Your wife Elizabeth will bear you a son, and you are to give him the name John.

1:14 He will be a joy and delight to you, and many will rejoice because of his birth,

1:15 for he will be great in the sight of the Lord. He is never to take wine or other fermented drink, and he will be filled with the Holy Spirit even from birth.

1:16 Many of the people of Israel will he bring back to the Lord their God.

1:17 And he will go on before the Lord, in the spirit and power of Elijah, to turn the hearts of the fathers to their children and the disobedient to the wisdom of the righteous—to make ready a people prepared for the Lord."

1:18 Zechariah asked the angel, "How can I be sure of this? I am an old man and my wife is well along in years."

1:19 The angel answered, "I am Gabriel. I stand in the presence of God, and I have been sent to speak to you and to tell you this good news.

1:20 And now you will be silent and not able to speak until the day this happens, because you did not believe my words, which will come true at their proper time."

1:21 Meanwhile, the people were waiting for Zechariah and wondering why he stayed so long in the temple.

1:22 When he came out, he could not speak to them. They realized he had seen a vision in the temple, for he kept making signs to them but remained unable to speak.

1:23 When his time of service was completed, he returned home.

1:24 After this his wife Elizabeth became pregnant and for five months remained in seclusion.

1:25 "The Lord has done this for me," she said. "In these days he has shown his favor and taken away my disgrace among the people."

Luke 1:57–66

1:57 When it was time for Elizabeth to have her baby, she gave birth to a son.

1:58 Her neighbors and relatives heard that the Lord had shown her great mercy, and they shared her joy.

1:59 On the eighth day they came to circumcise the child, and they were going to name him after his father Zechariah,

1:60 but his mother spoke up and said, "No! He is to be called John."

1:61 They said to her, "There is no one among your relatives who has that name."

1:62 Then they made signs to his father, to find out what he would like to name the child.

1:63 He asked for a writing tablet, and to everyone's astonishment he wrote, "His name is John."

1:64 Immediately his mouth was opened and his tongue was loosed, and he began to speak, praising God.

1:65 The neighbors were all filled with awe, and throughout the hill country of Judea people were talking about all these things.

1:66 Everyone who heard this wondered about it, asking, "What then is this child going to be?" For the Lord's hand was with him.

Source: Gospel of Luke. 1978. *New International Version of the Bible. International Bible* Society. Available at http://www.ibs.org/niv/index.php

▣ The Centurion's Faith in the Suffering Servant

Three accounts of healing take place in these verses: the man who was a leper, the servant with paralysis, and Peter's mother-in-law, who has a fever. These represent three different physical categories. While leprosy and paralysis might both be considered disabilities in contemporary society, they were seen as very different in ancient Israel and were treated very differently. While paralysis was a physical disability, leprosy was a physical impurity that required cleansing more than healing. Thus we have impaired purity, physical disability, and physical illness addressed in these passages. The faith of the centurion is not a condition for healing but is a motivation for healing. His faith's primary function is to prefigure the inclusion of Gentiles as followers of Christ. The primary purpose of these healings as stated in Matthew 8:17 is not to exhibit Jesus' power, as in many synoptic healings, but to identify him as the suffering servant of God fulfilling Isaiah 53:4, who does not erase disability but takes it upon himself.

Matthew 8:1–17

8:1 When he came down from the mountainside, large crowds followed him.

8:2 A man with leprosy came and knelt before him and said, "Lord, if you are willing, you can make me clean."

8:3 Jesus reached out his hand and touched the man. "I am willing," he said. "Be clean!" Immediately he was cured of his leprosy.

8:4 Then Jesus said to him, "See that you don't tell anyone. But go, show yourself to the priest and offer the gift Moses commanded, as a testimony to them."

8:5 When Jesus had entered Capernaum, a centurion came to him, asking for help.

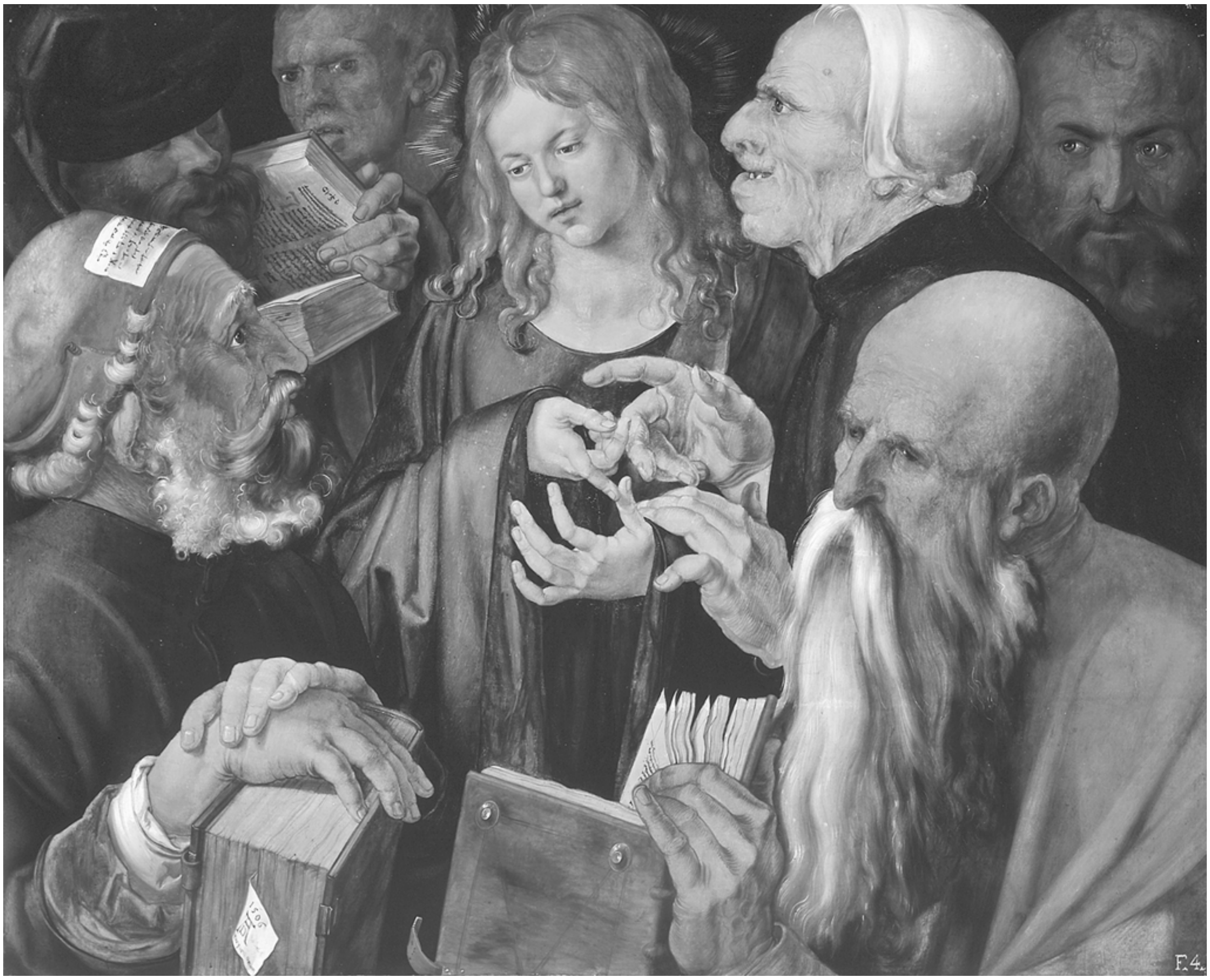
8:6 "Lord," he said, "my servant lies at home paralyzed and in terrible suffering."

8:7 Jesus said to him, "I will go and heal him."

8:8 The centurion answered, "Lord, I'm not worthy for you to come under my roof. Just say the word, and my servant will be healed.

8:9 For I am also a man under authority, having under myself soldiers. I tell this one, 'Go,' and he goes; and tell another, 'Come,' and he comes; and tell my servant, 'Do this,' and he does it."

8:10 When Jesus heard it, he marveled, and said to those who followed, "Most certainly I tell you, I haven't found so great a faith, not even in Israel.



Christ among the Doctors, *by Albrecht Dürer (1471–1528). Here, the German artist Dürer portrays Christ arguing with a gathering of arrogant doctors who thrust their sacrosanct doctrines at him in refutation of his scriptural teachings. The work seems to hold up the idealism of youth against a malevolent portrait of the inflexibility of belief that accompanies old age and empirical dogma.*

Source: Fundacion Coleccion Thyssen-Bornemisza, Madrid. Photo credit: Scala/Art Resource, New York.

8:11 I tell you that many will come from the east and the west, and will sit down with Abraham, Isaac, and Jacob in the Kingdom of Heaven,

8:12 but the children of the Kingdom will be thrown out into the outer darkness. There will be weeping and gnashing of teeth."

8:13 Then Jesus said to the centurion, "Go! It will be done just as you believed it would." And his servant was healed at that very hour.

8:14 When Jesus came into Peter's house, he saw his wife's mother lying sick with a fever.

8:15 He touched her hand, and the fever left her. She got up and served him.

8:16 When evening came, they brought to him many possessed with demons. He cast out the spirits with a word, and healed all who were sick;

8:17 that it might be fulfilled which was spoken through Isaiah the prophet, saying: "He took our infirmities, and bore our diseases."

Source: Gospel of Matthew. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

▣ Jesus and the Demoniac

These three passages identify demon possession as the cause of muteness and deafness. This etiology cannot be generalized to other cases of disability. These healing exorcisms pit Jesus against both the demonic forces and the religious opponents who claim he works his healings by demonic power. The demonic etiology of the disabilities in these few cases sets the stage for Jesus to declare "If Satan casts out Satan, he is divided against himself; how then will his kingdom stand? . . . But if it is by the Spirit of God that I cast out demons, then the kingdom of God has come to you" (Matthew 12:26, 12:28).

Matthew 9:32–33

32. While they were going out, a man who was demon-possessed and could not talk was brought to Jesus.

33. And when the demon was driven out, the man who had been mute spoke. The crowd was amazed and said, "Nothing like this has ever been seen in Israel."

Matthew 12:22–32

12:22 Then they brought him a demon-possessed man who was blind and mute, and Jesus healed him, so that he could both talk and see.

12:23 All the multitudes were amazed, and said, "Can this be the son of David?"

12:24 But when the Pharisees heard it, they said, "This man does not cast out demons, except by Beelzebul, the prince of the demons."

12:25 Knowing their thoughts, Jesus said to them, "Every kingdom divided against itself is brought to desolation, and every city or house divided against itself will not stand.

12:26 If Satan casts out Satan, he is divided against himself. How then will his kingdom stand?

12:27 If I by Beelzebul cast out demons, by whom do your children cast them out? Therefore they will be your judges.

12:28 But if I by the Spirit of God cast out demons, then the Kingdom of God has come upon you.

12:29 Or how can one enter into the house of the strong man, and plunder his goods, unless he first bind the strong man? Then he will plunder his house.

12:30 "He who is not with me is against me, and he who doesn't gather with me, scatters.

12:31 Therefore I tell you, every sin and blasphemy will be forgiven men, but the blasphemy against the Spirit will not be forgiven men.

12:32 Whoever speaks a word against the Son of Man, it will be forgiven him; but whoever speaks against the Holy Spirit, it will not be forgiven him, neither in this age, nor in that which is to come.

Luke 11:14–15

11:14 Jesus was driving out a demon that was mute. When the demon left, the man who had been mute spoke, and the crowd was amazed.

11:15 But some of them said, "By Beelzebub, the prince of demons, he is driving out demons."

Source: Gospels of Matthew and Luke. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

▣ Jesus Heals a Man's Hand

This account is one of a series of accounts that describe a confrontation between Jesus and the Pharisees regarding the observance of the Law. In each account, Jesus uses rabbinic argumentation to justify his healing on the Sabbath. While there are variations between the method and content of the argument in the three accounts, all agree that the healing of the man's disability is a great enough "good" to justify the "work" of healing on the Sabbath.

Matthew 12:9–14

12:9 Going on from that place, he went into their synagogue,

12:10 And a man with a shriveled hand was there. Looking for a reason to accuse Jesus, they asked him, "Is it lawful to heal on the Sabbath?"

12:11 He said to them, "If any of you has a sheep and it falls into a pit on the Sabbath, will you not take hold of it and lift it out?

12:12 How much more valuable is a man than a sheep! Therefore it is lawful to do good on the Sabbath."

12:13 Then he said to the man, "Stretch out your hand." So he stretched it out and it was completely restored, just as sound as the other.

12:14 But the Pharisees went out and plotted how they might kill Jesus.

Mark 3:1–6

3:1 Another time he went into the synagogue, and a man with a shriveled hand was there.

3:2 Some of them were looking for a reason to accuse Jesus, so they watched him closely to see if he would heal him on the Sabbath.

3:3 Jesus said to the man with the shriveled hand, "Stand up in front of everyone."

3:4 Then Jesus asked them, "Which is lawful on the Sabbath: to do good or to do evil, to save life or to kill?" But they remained silent.

3:5 He looked around at them in anger and, deeply distressed at their stubborn hearts, said to the man, "Stretch out your hand." He stretched it out, and his hand was completely restored.

3:6 Then the Pharisees went out and began to plot with the Herodians how they might kill Jesus.

Luke 6:6–11

6:6 On another Sabbath he went into the synagogue and was teaching, and a man was there whose right hand was shriveled.

6:7 The Pharisees and the teachers of the law were looking for a reason to accuse Jesus, so they watched him closely to see if he would heal on the Sabbath.

6:8 But Jesus knew what they were thinking and said to the man with the shriveled hand, "Get up and stand in front of everyone." So he got up and stood there.

6:9 Then Jesus said to them, "I ask you, which is lawful on the Sabbath: to do good or to do evil, to save life or to destroy it?"

6:10 He looked around at them all, and then said to the man, "Stretch out your hand." He did so, and his hand was completely restored.

6:11 But they were furious and began to discuss with one another what they might do to Jesus.

Source: Gospels of Matthew, Mark, and Luke. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

▣ The People Praise God for Healing

The gospels frequently use summary statements such at that found in Matthew 15:30–31 to verify the power of Jesus in a general summary statement as the narrative transitions from one account to another. They serve to show that the healings reported in detail are only a sample of a much wider practice in the ministry of Jesus.

Matthew 15:30–31

15:30 Great crowds came to him, bringing the lame, the blind, the crippled, the mute and many others, and laid them at his feet; and he healed them.

15:31 The people were amazed when they saw the mute speaking, the crippled made well, the lame walking and the blind seeing. And they praised the God of Israel.

Source: Gospel of Matthew. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

▣ The Son of David

The Gospel of Matthew, excluding the introduction of Jesus in Matthew 1:1, uses the title "Son of David" for Jesus only in relation to healing narratives, as seen in the two passages below and in Matthew 12:22–32. Matthew 21:14–17 is particularly significant in this regard. Only in Matthew is Jesus hailed as "Son of David" as he enters Jerusalem and proceeds to the Temple on Palm Sunday. Only in Matthew does he heal others once he reaches the Temple. Matthew portrays Jesus as greater than David by reversing and transcending the report of David's triumphal entry into Jerusalem in 2 Samuel 5:6–8, in which "the lame and the blind, those whom David hates" are banned from the Temple when David declares "The blind and the lame shall not come into the house."

Matthew 20:29–34

20:29 As Jesus and his disciples were leaving Jericho, a large crowd followed him.

20:30 Two blind men were sitting by the roadside, and when they heard that Jesus was going by, they shouted, "Lord, Son of David, have mercy on us!"

20:31 The crowd rebuked them and told them to be quiet, but they shouted all the louder, "Lord, Son of David, have mercy on us!"

20:32 Jesus stopped and called them. "What do you want me to do for you?" he asked.

20:33 "Lord," they answered, "we want our sight."

Christ Healing the Blind at Jericho, *by Nicolas Poussin (1594–1665). St. Matthew (20:29–34) describes an incident of Jesus' miraculous cure of two blind men near Jericho.*

Source: Louvre, Paris. Photo by R. G. Ojeda. Photo credit: Réunion des Musées Nationaux/Art Resource, New York.

20:34 Jesus had compassion on them and touched their eyes. Immediately they received their sight and followed him.

Matthew 21:14–17

21:14 The blind and the lame came to him at the temple, and he healed them.

21:15 But when the chief priests and the teachers of the law saw the wonderful things he did and the children shouting in the temple area, "Hosanna to the Son of David," they were indignant.

21:16 "Do you hear what these children are saying?" they asked him.

"Yes," replied Jesus, "have you never read, 'From the lips of children and infants you have ordained praise'?"

21:17 And he left them and went out of the city to Bethany, where he spent the night.

Source: Gospel of Matthew. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

Disability for the Sake of the Kingdom

This passage stresses that spiritual disability, specifically one that leads an individual to endanger another's spiritual life, is a far greater disability than one that is merely physical. It is better to be saved with a disability than to be damned with an able body. The *passage is parabolic, of course, and it relies for its dramatic impact on a normative abhorrence of disability.*

Mark 9:43, 45, 47

9:43 If your hand causes you to sin, cut it off. It is better for you to enter life maimed than with two hands to go into hell, where the fire never goes out. . . .

9:45 And if your foot causes you to sin, cut it off. It is better for you to enter life crippled than to have two feet and be thrown into hell. . . .

9:47 And if your eye causes you to sin, pluck it out. It is better for you to enter the kingdom of God with one eye than to have two eyes and be thrown into hell.

Source: Gospel of Mark. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

▣ Invitation to a Wedding Feast

Dinners play a crucial role in the Gospel of Luke, where Jesus is honored as a guest by the religious elite, who are in turn offended by his frequent dining with sinners. Such meals represent the ultimate of social acceptance. Jesus is the guest of one of these social and religious elite in Luke 14. Jesus tells his host that he should invite, and thus socially accept, "the poor, the crippled, the lame, and the blind." It is significant that these disability groups are grouped with "the poor" in this passage, since "the poor" are the exalted class in Luke. Jesus then tells a parable about the Kingdom of God where the socially acceptable elite refuse to come to the feast but the poor and those with disabilities will be invited and thus will be those who enter the Kingdom of God.

Luke 14:13–24

14:13 "But when you make a feast, ask the poor, the maimed, the lame, or the blind;

14:14 and you will be blessed, because they don't have the resources to repay you. For you will be repaid in the resurrection of the righteous."

14:15 When one of those who sat at the table with him heard these things, he said to him, "Blessed is he who will feast in the Kingdom of God!"

14:16 Jesus replied: "A certain man was preparing a great banquet and invited many guests.

14:17 At the time of the banquet he sent his servant to tell those who had been invited, 'Come, for everything is now ready.'

14:18 "But they all alike began to make excuses. The first said, 'I have just bought a field, and I must go and see it. Please excuse me.'

14:19 "Another said, 'I have just bought five yoke of oxen, and I'm on my way to try them out. Please excuse me.'

14:20 "Still another said, 'I just got married, so I can't come.'

14:21 "The servant came back and reported this to his master. Then the owner of the house became angry and ordered his servant, 'Go out quickly into the streets and alleys of the town and bring in the poor, the crippled, the blind and the lame.'

14:22 " 'Sir,' the servant said, 'what you ordered has been done, but there is still room.'

14:23 "Then the master told his servant, 'Go out to the roads and country lanes and make them come in, so that my house will be full.

14:24 I tell you, not one of those men who were invited will get a taste of my banquet.'"

Source: Gospel of Luke. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

▣ Jesus Heals a Paralytic

The earliest account of the healing of the man with paralysis is probably that found in the Gospel of Mark (first century CE*). Here a clear distinction is made between sin and disability. The Markan evangelist does not tell us why the man's friends brought him to Jesus. Jesus' act of compassion is the forgiveness of sins, which he sees as the man's true need. The act of healing, which is separate from the act of forgiveness, is meant solely as a sign of power for the religious leaders who are watching the event. The accounts of the same event in the Gospels of Matthew and Luke share this focus on the forgiveness of sins.*

Mark 2:1–12

2:1 A few days later, when Jesus again entered Capernaum, the people heard that he had come home.

Christ Heals the Paralytic *(1579–1581), by Jacopo Robustic Tintoretto (1518–1594). Tintoretto's rendition of Jesus healing a man at the pool of Bethesda in Jerusalem who had been unable to walk for 38 years.*

Source: Scuola Grande di S. Rocco, Venice. Photo credit: Scala/Art Resource, New York.

2:2 So many gathered that there was no room left, not even outside the door, and he preached the word to them.

2:3 Some men came, bringing to him a paralytic, carried by four of them.

2:4 Since they could not get him to Jesus because of the crowd, they made an opening in the roof above Jesus and, after digging through it, lowered the mat the paralyzed man was lying on.

2:5 When Jesus saw their faith, he said to the paralytic, "Son, your sins are forgiven."

2:6 Now some teachers of the law were sitting there, thinking to themselves,

2:7 "Why does this fellow talk like that? He's blaspheming! Who can forgive sins but God alone?"

2:8 Immediately Jesus knew in his spirit that this was what they were thinking in their hearts, and he said to them, "Why are you thinking these things?

2:9 Which is easier: to say to the paralytic, 'Your sins are forgiven,' or to say, 'Get up, take your mat and walk'?

2:10 But that you may know that the Son of Man has authority on earth to forgive sins. . . ." He said to the paralytic,

2:11 "I tell you, get up, take your mat and go home."

2:12 He got up, took his mat and walked out in full view of them all. This amazed everyone and they praised God, saying, "We have never seen anything like this!"

Matthew 9:1–8

9:1 Jesus stepped into a boat, crossed over and came to his own town.

9:2 Some men brought to him a paralytic, lying on a mat. When Jesus saw their faith, he said to the paralytic, "Take heart, son; your sins are forgiven."

9:3 At this, some of the teachers of the law said to themselves, "This fellow is blaspheming!"

9:4 Knowing their thoughts, Jesus said, "Why do you entertain evil thoughts in your hearts?

9:5 Which is easier: to say, 'Your sins are forgiven,' or to say, 'Get up and walk'?

9:6 But so that you may know that the Son of Man has authority on earth to forgive sins. . . ." Then he said to the paralytic, "Get up, take your mat and go home."

9:7 And the man got up and went home.

9:8 When the crowd saw this, they were filled with awe; and they praised God, who had given such authority to men.

Luke 5: 17–26

5:17 One day as he was teaching, Pharisees and teachers of the law, who had come from every village of Galilee and from Judea and Jerusalem, were sitting there. And the power of the Lord was present for him to heal the sick.

5:18 Some men came carrying a paralytic on a mat and tried to take him into the house to lay him before Jesus.

5:19 When they could not find a way to do this because of the crowd, they went up on the roof and lowered him on his mat through the tiles into the middle of the crowd, right in front of Jesus.

5:20 When Jesus saw their faith, he said, "Friend, your sins are forgiven."

5:21 The Pharisees and the teachers of the law began thinking to themselves, "Who is this fellow who speaks blasphemy? Who can forgive sins but God alone?"

5:22 Jesus knew what they were thinking and asked, "Why are you thinking these things in your hearts?

5:23 Which is easier: to say, 'Your sins are forgiven,' or to say, 'Get up and walk'?

5:24 But that you may know that the Son of Man has authority on earth to forgive sins. . . ." He said to the paralyzed man, "I tell you, get up, take your mat and go home."

5:25 Immediately he stood up in front of them, took what he had been lying on and went home praising God.

5:26 Everyone was amazed and gave praise to God. They were filled with awe and said, "We have seen remarkable things today."

The Transfiguration, *by Raphael (1483–1520). The Italian painter Raphael died just before completing this version of Christ's ascension into Heaven. In the lower right corner parents and neighbors of a "lunatic boy" present him to the disciples seeking a miraculous cure. Without Christ they appear doubtful about their ability to fulfill the request. In the midst of the chaos around this contorted body, the body seems to be the only one aware of the events taking place in the top half of the painting.*

Source: Pinacoteca, Vatican Museums, Vatican State. Photo credit: Scala/Art Resource, New York.

Source: Gospels of Matthew, Mark, and Luke. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/ index.php

The Healing of the Blind Man, *by El Greco (Domenikos Theotokopoulos, 1541–1614). Early Venetian paintings by the Spanish master El Greco (meaning "The Greek") such as this one demonstrate how the painter was influenced by Tintoretto's figural compositions and the use of deep spatial recesses. The theme of healing persons who were blind was an often rendered episode from Jesus' life. The story is interpreted to symbolize the revelation of faith through erasure of disability by the prophet. In the same way that the blind were given the faculty of sight by Jesus, so were the faithful supposed to be able to recognize the power of faith through the church.*

Source: Galleria Nazionale, Parma, Italy. Photo credit: Scala/Art Resource, New York.

Bartimaeus: A Blind Beggar Receives His Sight

The Gospels of Mark and Luke relate (first century CE) the story of the healing of a blind man named Bartimaeus ("Son of Timaeus"). Here Jesus rejects the attempt to socially marginalize the person with a disability, yet he does not presume that the disability is the source of the man's concern. Jesus asks what the man desires before he heals him.

Mark 10:46–52

10:46 Then they came to Jericho. As Jesus and his disciples, together with a large crowd, were leaving the city, a blind man, Bartimaeus (that is, the Son of Timaeus), was sitting by the roadside begging.

10:47 When he heard that it was Jesus of Nazareth, he began to shout, "Jesus, Son of David, have mercy on me!"

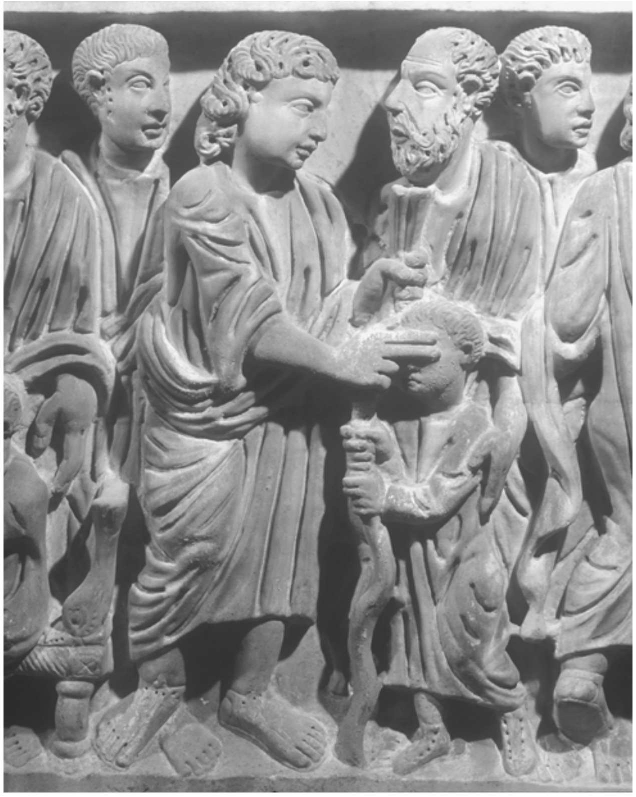
10:48 Many rebuked him and told him to be quiet, but he shouted all the more, "Son of David, have mercy on me!"

10:49 Jesus stopped and said, "Call him." So they called to the blind man, "Cheer up! On your feet! He's calling you."

10:50 Throwing his cloak aside, he jumped to his feet and came to Jesus.

10:51 "What do you want me to do for you?" Jesus asked him.

The blind man said, "Rabbi, I want to see."



Christ Heals a Blind Man*. Relief (third century CE) on an early Christian sarcophagus. Like the paintings by El Greco and Lucas van Leyden, this relief depicts the healing of a man who is blind as a sign of Jesus' power as a prophet of God.*

Source: Mezzocamino, Via Ostiense, Rome. Cat. 41. Museo Nazionale Romano (Terme di Diocleziano), Rome. Photo credit: Erich Lessing/Art Resource.

10:52 "Go," said Jesus, "your faith has healed you." Immediately he received his sight and followed Jesus along the road.

Luke 18: 35–43

18:35 As Jesus approached Jericho, a blind man was sitting by the roadside begging.

18:36 When he heard the crowd going by, he asked what was happening.

18:37 They told him, "Jesus of Nazareth is passing by."

18:38 He called out, "Jesus, Son of David, have mercy on me!"

18:39 Those who led the way rebuked him and told him to be quiet, but he shouted all the more, "Son of David, have mercy on me!"

18:40 Jesus stopped and ordered the man to be brought to him. When he came near, Jesus asked him,

18:41 "What do you want me to do for you?"

"Lord, I want to see," he replied.

18:42 Jesus said to him, "Receive your sight; your faith has healed you."

18:43 Immediately he received his sight and followed Jesus, praising God. When all the people saw it, they also praised God.

Source: Gospels of Mark and Luke. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

Jesus Heals a Man Born Blind

The Gospel of John (first century CE) relates this account of the healing of a man with congenital blindness. Jesus rejects the association made by his disciples between the man's disability and sin. The passage is based on the inferred metaphorical contrast between the physical blindness of the healed man and the spiritual blindness of the synagogue leaders. The man's experience as the marginalized "other" frees him from the normative perspective of the visually able community.

John 9:1–41

9:1 As he went along, he saw a man blind from birth.

9:2 His disciples asked him, "Rabbi, who sinned, this man or his parents, that he was born blind?"

9:3 "Neither this man nor his parents sinned," said Jesus, "but this happened so that the work of God might be displayed in his life.

9:4 As long as it is day, we must do the work of him who sent me. Night is coming, when no one can work.

9:5 While I am in the world, I am the light of the world."

9:6 Having said this, he spit on the ground, made some mud with the saliva, and put it on the man's eyes.

9:7 "Go," he told him, "wash in the Pool of Siloam" (this word means Sent). So the man went and washed, and came home seeing.

9:8 His neighbors and those who had formerly seen him begging asked, "Isn't this the same man who used to sit and beg?"

9:9 Some claimed that he was.

Others said, "No, he only looks like him."

But he himself insisted, "I am the man."

9:10 "How then were your eyes opened?" they demanded.

9:11 He replied, "The man they call Jesus made some mud and put it on my eyes. He told me to go to

Christ Healing the Blind at Jericho, *by Lucas van Leyden (1494–1538). John (9:1–7) narrates how Christ restored the sight of a man blind from birth. The cure involved placing an ointment on the eyes of the man and then sending him to wash in a pool. Upon the man's return, the blindness was cured. Likewise, St. Matthew (20:29–34) describes a similar incident of miraculous cure for two blind men near Jericho.*

Source: Hermitage, St. Petersburg, Russia. Photo credit: Scala/Art Resource, New York.

Siloam and wash. So I went and washed, and then I could see."

9:12 "Where is this man?" they asked him.

"I don't know," he said.

The Pharisees Investigate the Healing

9:13 They brought to the Pharisees the man who had been blind.

9:14 Now the day on which Jesus had made the mud and opened the man's eyes was a Sabbath.

9:15 Therefore the Pharisees also asked him how he had received his sight. "He put mud on my eyes," the man replied, "and I washed, and now I see."

9:16 Some of the Pharisees said, "This man is not from God, for he does not keep the Sabbath."

But others asked, "How can a sinner do such miraculous signs?" So they were divided.

9:17 Finally they turned again to the blind man, "What have you to say about him? It was your eyes he opened."

The man replied, "He is a prophet."

9:18 The Jews still did not believe that he had been blind and had received his sight until they sent for the man's parents.

9:19 "Is this your son?" they asked. "Is this the one you say was born blind? How is it that now he can see?"

9:20 "We know he is our son," the parents answered, "and we know he was born blind.

9:21 But how he can see now, or who opened his eyes, we don't know. Ask him. He is of age; he will speak for himself."

9:22 His parents said this because they were afraid of the Jews, for already the Jews had decided that anyone who acknowledged that Jesus was the Christ would be put out of the synagogue.

9:23 That was why his parents said, "He is of age; ask him."

9:24 A second time they summoned the man who had been blind. "Give glory to God," they said. "We know this man is a sinner."

9:25 He replied, “Whether he is a sinner or not, I don’t know. One thing I do know. I was blind but now I see!”

9:26 Then they asked him, “What did he do to you? How did he open your eyes?”

9:27 He answered, “I have told you already and you did not listen. Why do you want to hear it again? Do you want to become his disciples, too?”

9:28 Then they hurled insults at him and said, “You are this fellow’s disciple! We are disciples of Moses!

9:29 We know that God spoke to Moses, but as for this fellow, we don’t even know where he comes from.”

9:30 The man answered, “Now that is remarkable! You don’t know where he comes from, yet he opened my eyes.

9:31 We know that God does not listen to sinners. He listens to the godly man who does his will.

9:32 Nobody has ever heard of opening the eyes of a man born blind.

9:33 If this man were not from God, he could do nothing.”

9:34 To this they replied, “You were steeped in sin at birth; how dare you lecture us!” And they threw him out.

Spiritual Blindness

9:35 Jesus heard that they had thrown him out, and when he found him, he said, “Do you believe in the Son of Man?”

9:36 “Who is he, sir?” the man asked. “Tell me so that I may believe in him.”

9:37 Jesus said, “You have now seen him; in fact, he is the one speaking with you.”

9:38 Then the man said, “Lord, I believe,” and he worshiped him.

9:39 Jesus said, “For judgment I have come into this world, so that the blind will see and those who see will become blind.”

9:40 Some Pharisees who were with him heard him say this and asked, “What? Are we blind too?”

9:41 Jesus said, “If you were blind, you would not be guilty of sin; but now that you claim you can see, your guilt remains.

Source: Gospel of John. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

The Healing at the Pool of Bethesda

The Gospel of John (first century CE) relates the account of a man who has waited for years to be healed at a miraculous pool. Jesus asks the man if he actually wants to be healed, and the man responds with an excuse. Jesus bypasses the excuse by healing the man directly. The account parallels the account of the man born blind in John 9:1–41. Here the man healed betrays Jesus to the religious leaders as opposed to defending him, as in John 9.

John 5:1–15

5:1 Some time later, Jesus went up to Jerusalem for a feast of the Jews.

5:2 Now there is in Jerusalem near the Sheep Gate a pool, which in Aramaic is called Bethesda and which is surrounded by five covered colonnades.

5:3 Here a great number of disabled people used to lie—the blind, the lame, the paralyzed.

5:4 From time to time an angel of the Lord would come down and stir up the waters. The first one into the pool after each such disturbance would be cured of whatever disease he had.

5:5 One who was there had been an invalid for thirty-eight years.

5:6 When Jesus saw him lying there and learned that he had been in this condition for a long time, he asked him, “Do you want to get well?”

5:7 “Sir,” the invalid replied, “I have no one to help me into the pool when the water is stirred. While I am trying to get in, someone else goes down ahead of me.”

5:8 Then Jesus said to him, “Get up! Pick up your mat and walk.”

5:9 At once the man was cured; he picked up his mat and walked.

The day on which this took place was a Sabbath,

5:10 and so the Jews said to the man who had been healed, “It is the Sabbath; the law forbids you to carry your mat.”

5:11 But he replied, “The man who made me well said to me, ‘Pick up your mat and walk.’”

5:12 So they asked him, “Who is this fellow who told you to pick it up and walk?”

5:13 The man who was healed had no idea who it was, for Jesus had slipped away into the crowd that was there.

5:14 Later Jesus found him at the temple and said to him, “See, you are well again. Stop sinning or something worse may happen to you.”

5:15 The man went away and told the Jews that it was Jesus who had made him well.

Source: Gospel of John. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

▣ Jesus and John the Baptist

While in prison, John sends his disciples to Jesus to ask for verification of Jesus' messianic status. Jesus does not give a direct answer but through the symbolic action of healing claims to be fulfilling the promise of Isaiah 29:17–21 and Isaiah 35:5–7. The stress is not on Jesus' compassion on those perceived as less fortunate but on the sign of apocalyptic reversal.

Matthew 11:2–6

11:2 When John heard in prison what Christ was doing, he sent his disciples

11:3 to ask him, "Are you the one who was to come, or should we expect someone else?"

11:4 Jesus replied, "Go back and report to John what you hear and see:

11:5 The blind receive sight, the lame walk, those who have leprosy are cured, the deaf hear, the dead are raised, and the good news is preached to the poor.

11:6 Blessed is the man who does not fall away on account of me."

Luke 7:18–23

7:18 John's disciples told him about all these things. Calling two of them,

7:19 He sent them to the Lord to ask, "Are you the one who was to come, or should we expect someone else?"

7:20 When the men came to Jesus, they said, "John the Baptist sent us to you to ask, 'Are you the one who was to come, or should we expect someone else?'"

7:21 At that very time Jesus cured many who had diseases, sicknesses and evil spirits, and gave sight to many who were blind.

7:22 So he replied to the messengers, "Go back and report to John what you have seen and heard: The blind receive sight, the lame walk, those who have leprosy are cured, the deaf hear, the dead are raised, and the good news is preached to the poor.

7:23 Blessed is the man who does not fall away on account of me."

Source: Gospels of Matthew and Luke. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

▣ The Disciples Heal at the Temple

The Lukan evangelist (first century CE*) relates this account of the healing of the mobility-impaired beggar in order to show that the power and authority of Jesus now reside with Peter and the apostles. Jesus' disciples are presented here as his heirs by their exhibition of his healing power, which they perform "in the name of Jesus Christ of Nazareth." This is not presented as an act of one who is more powerful for one who is less fortunate. Peter's claim "Silver or gold I do not have" places him with the poor honored by the author of Acts. This is an act of shared empowerment by two equals who are socially marginalized but who are exalted in the power of the Gospel that Peter preaches. Whereas the community provides for the livelihood of the beggar through charity, the life he lives remains marginal. Peter provides for his reintegration into the community—seen in his entry into the temple—by means of healing. (See also Acts 9:32–35; see also a story of Paul's ability to heal in Acts 14:8–10.)*

Acts 3:1–10

3:1 One day Peter and John were going up to the temple at the time of prayer—at three in the afternoon.

3:2 Now a man crippled from birth was being carried to the temple gate called Beautiful, where he was put every day to beg from those going into the temple courts.

3:3 When he saw Peter and John about to enter, he asked them for money.

3:4 Peter looked straight at him, as did John. Then Peter said, "Look at us!"

3:5 So the man gave them his attention, expecting to get something from them.

3:6 Then Peter said, "Silver or gold I do not have, but what I have I give you. In the name of Jesus Christ of Nazareth, walk."

3:7 Taking him by the right hand, he helped him up, and instantly the man's feet and ankles became strong.

3:8 He jumped to his feet and began to walk. Then he went with them into the temple courts, walking and jumping, and praising God.

3:9 When all the people saw him walking and praising God,

3:10 they recognized him as the same man who used to sit begging at the temple gate called Beautiful, and they were filled with wonder and amazement at what had happened to him.

Source: Acts of the Apostles. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

Followers in the Power of Christ

The summary of the work of Philip in Samaria found in Acts 8:5–8 recalls summary statements about the work of Jesus in such passages as Matthew 15:30–31. This parallel is intentional and serves to show that the power of Jesus is manifested in his follower as he proclaims him as the Messiah or Christ. This same sharing in the power of Christ is exhibited by Paul in Acts 14:8–18. Here, however, the mistaken conclusion that Paul and Barnabas are Hermes and Zeus provides the opportunity to clarify that this divine power does not originate with the followers but originates with God. The phrase "he had faith to be healed" in Acts 14:9 would probably be better translated "he had faith to be saved."

Acts 8:5–8

8:5 Philip went down to a city in Samaria and proclaimed the Christ there.

8:6 When the crowds heard Philip and saw the miraculous signs he did, they all paid close attention to what he said.

8:7 With shrieks, evil spirits came out of many, and many paralytics and cripples were healed.

8:8 So there was great joy in that city.

Acts 14:8–18

14:8 In Lystra there sat a man crippled in his feet, who was lame from birth and had never walked.

14:9 He listened to Paul as he was speaking. Paul looked directly at him, saw that he had faith to be healed.

14:10 and called out, "Stand up on your feet!" At that, the man jumped up and began to walk.

14:11 When the crowd saw what Paul had done, they shouted in the Lycaonian language, "The gods have come down to us in human form!"

14:12 Barnabas they called Zeus, and Paul they called Hermes because he was the chief speaker.

14:13 The priest of Zeus, whose temple was just outside the city, brought bulls and wreaths to the city gates because he and the crowd wanted to offer sacrifices to them.

14:14 But when the apostles Barnabas and Paul heard of this, they tore their clothes and rushed out into the crowd, shouting:

14:15 "Men, why are you doing this? We too are only men, human like you. We are bringing you good news, telling you to turn from these worthless things to the living God, who made heaven and earth and sea and everything in them.

14:16 In the past, he let all nations go their own way.

14:17 Yet he has not left himself without testimony: He has shown kindness by giving you rain from heaven and crops in their seasons; he provides you with plenty of food and fills your hearts with joy."

14:18 Even with these words, they had difficulty keeping the crowd from sacrificing to them.

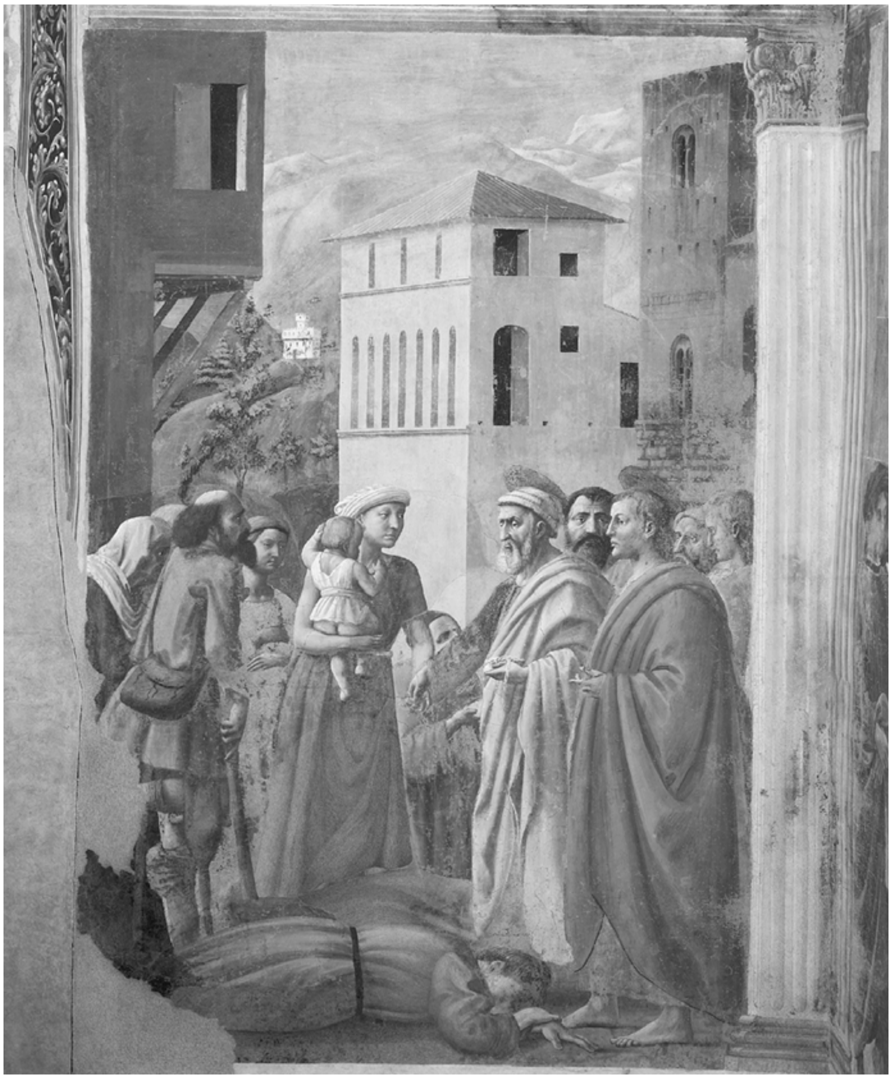
Source: Acts of the Apostles. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

Blinding Power

While divine power in the New Testament is usually exhibited by healing disabilities, there are two events where divine power is shown through blinding rather than healing. These events are described in the accounts of the conversion of Saul of Tarsus (in Acts 9:1–19 as well as Paul's retelling of the event in Acts 22:4–16) and the blinding of Elymas Bar-Jesus by the Holy Spirit through that same Paul. While both of these blindings prove to be temporary, there is a significant difference. While Paul tells Bar-Jesus that he will be "blind for a while," Paul's own blindness seems to have been a permanent disability that required the healing intervention of Ananias, who proclaimed healing and the filling of the Holy Spirit in one sentence. In this instance, it is reported that "something like scales fell from his eyes, and his sight was restored."

Acts 9:1–19

9:1 Meanwhile, Saul was still breathing out murderous threats against the Lord's disciples. He went to the high priest



Distributing Alms and the Death of Ananias *(Anonymous). In addition to Tabitha's resurrection and other tales of cure, the Book of Acts (9:32–43) provides an example of the cure of Ananias (also Aeneas): "And it came to pass, as Peter passed throughout all quarters, he came down also to the saints which dwelt at Lydda. And there he found a certain man named Aeneas, which had kept his bed eight years, and was sick of the palsy. And Peter said unto him, 'Aeneas, Jesus Christ maketh thee whole: arise, and make thy bed. And he arose immediately.'"*

Source: Brancacci Chapel, S. Maria del Carmine, Florence, Italy. Photo credit: Erich Lessing/Art Resource, New York.

9:2 and asked him for letters to the synagogues in Damascus, so that if he found any there who belonged to the Way, whether men or women, he might take them as prisoners to Jerusalem.

9:3 As he neared Damascus on his journey, suddenly a light from heaven flashed around him.

9:4 He fell to the ground and heard a voice say to him, "Saul, Saul, why do you persecute me?"

9:5 "Who are you, Lord?" Saul asked.

9:6 "I am Jesus, whom you are persecuting," he replied. "Now get up and go into the city, and you will be told what you must do."

9:7 The men traveling with Saul stood there speechless; they heard the sound but did not see anyone.

9:8 Saul got up from the ground, but when he opened his eyes he could see nothing. So they led him by the hand into Damascus.

9:9 For three days he was blind, and did not eat or drink anything.

9:10 In Damascus there was a disciple named Ananias. The Lord called to him in a vision, "Ananias!"

"Yes, Lord," he answered.

9:11 The Lord told him, "Go to the house of Judas on Straight Street and ask for a man from Tarsus named Saul, for he is praying.

9:12 In a vision he has seen a man named Ananias come and place his hands on him to restore his sight."

9:13 "Lord," Ananias answered, "I have heard many reports about this man and all the harm he has done to your saints in Jerusalem.

9:14 And he has come here with authority from the chief priests to arrest all who call on your name."

9:15 But the Lord said to Ananias, "Go! This man is my chosen instrument to carry my name before the Gentiles and their kings and before the people of Israel.

9:16 I will show him how much he must suffer for my name."

9:17 Then Ananias went to the house and entered it. Placing his hands on Saul, he said, "Brother Saul, the Lord—Jesus, who appeared to you on the road as you were coming here—has sent me so that you may see again and be filled with the Holy Spirit."

9:18 Immediately, something like scales fell from Saul's eyes, and he could see again. He got up and was baptized,

9:19 and after taking some food, he regained his strength.

Acts 22:4–16

22:4 I persecuted the followers of this Way to their death, arresting both men and women and throwing them into prison,

22:5 as also the high priest and all the Council can testify. I even obtained letters from them to their brothers in Damascus, and went there to bring these people as prisoners to Jerusalem to be punished.

22:6 "About noon as I came near Damascus, suddenly a bright light from heaven flashed around me.

22:7 "I fell to the ground and heard a voice say to me, 'Saul! Saul! Why do you persecute me?'

22:8 "'Who are you, Lord?' I asked.

22:9 "'I am Jesus of Nazareth, whom you are persecuting,' he replied. My companions saw the light, but they did not understand the voice of him who was speaking to me.

22:10 "'What shall I do, Lord?' I asked.

22:11 "'Get up,' the Lord said, 'and go into Damascus. There you will be told all that you have been assigned to do.' My companions led me by the hand into Damascus, because the brilliance of the light had blinded me.

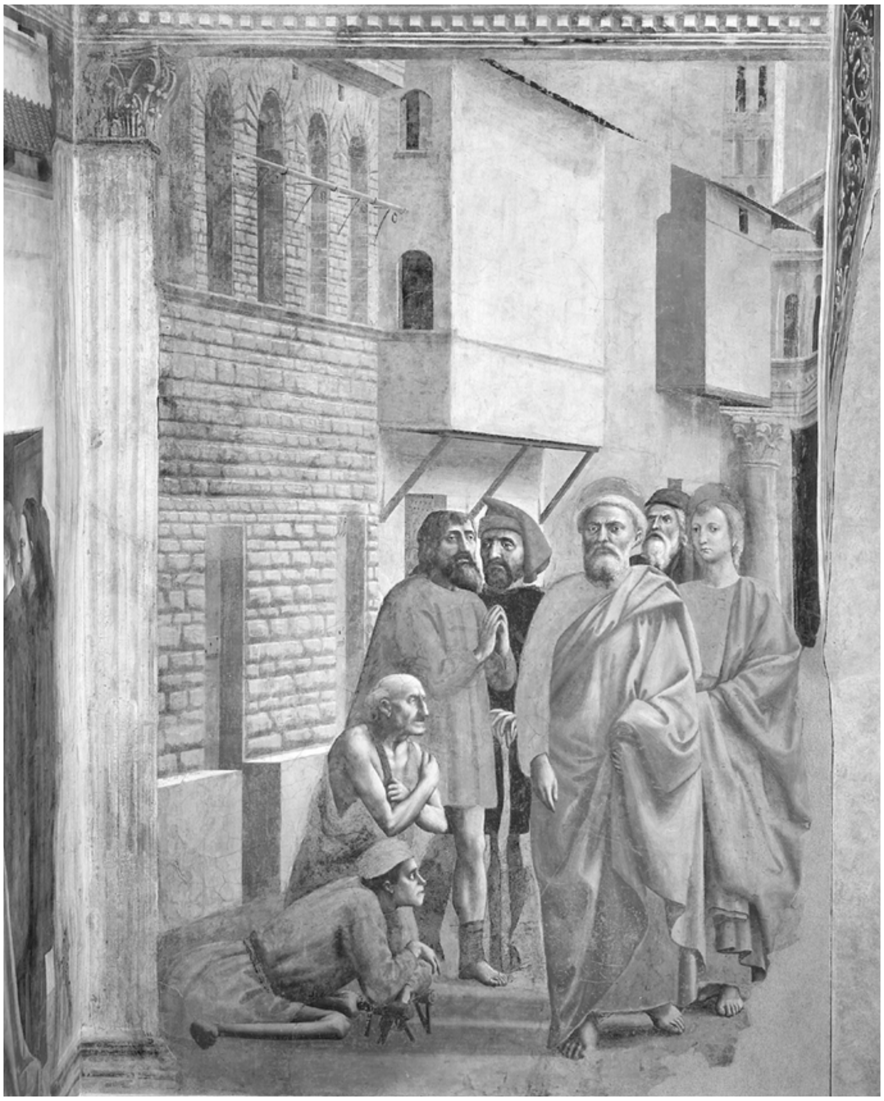
22:12 "A man named Ananias came to see me. He was a devout observer of the law and highly respected by all the Jews living there.

22:13 "He stood beside me and said, 'Brother Saul, receive your sight!' And at that very moment I was able to see him.

22:14 "Then he said: 'The God of our fathers has chosen you to know his will and to see the Righteous One and to hear words from his mouth.

22:15 "'You will be his witness to all men of what you have seen and heard.

22:16 "'And now what are you waiting for? Get up, be baptized and wash your sins away, calling on his name.'"



St. Peter Healing a Cripple with His Shadow *by Masaccio (1401–1428). In the Acts of the Apostles (5:12–14), this episode is recounted immediately after the story of Ananias, which is illustrated in the fresco* Distributing Alms and the Death of Ananias *in the same chapel.*

Source: Brancacci Chapel, S. Maria del Carmine, Florence, Italy. Photo credit: Scala/Art Resource, New York.

Acts 13:6–12

13:6 They traveled through the whole island until they came to Paphos. There they met a Jewish sorcerer and false prophet named Bar-Jesus,

13:7 Who was an attendant of the proconsul, Sergius Paulus. The proconsul, an intelligent man, sent for Barnabas and Saul because he wanted to hear the word of God.

13:8 But Elymas the sorcerer (for that is what his name means) opposed them and tried to turn the proconsul from the faith.

13:9 Then Saul, who was also called Paul, filled with the Holy Spirit, looked straight at Elymas and said,

13:10 "You are a child of the devil and an enemy of everything that is right! You are full of all kinds of deceit and trickery. Will you never stop perverting the right ways of the Lord?

13:11 Now the hand of the Lord is against you. You are going to be blind, and for a time you will be unable to see the light of the sun."

13:12 Immediately mist and darkness came over him, and he groped about, seeking someone to lead him by the hand. When the proconsul saw what had happened, he believed, for he was amazed at the teaching about the Lord.

Source: Acts of the Apostles. 1978. *New International Version of the Bible.* International Bible Society. Available at http://www.ibs.org/niv/index.php

The Middle Ages

Saint Augustine, *The City of God* (ca. 410 CE)

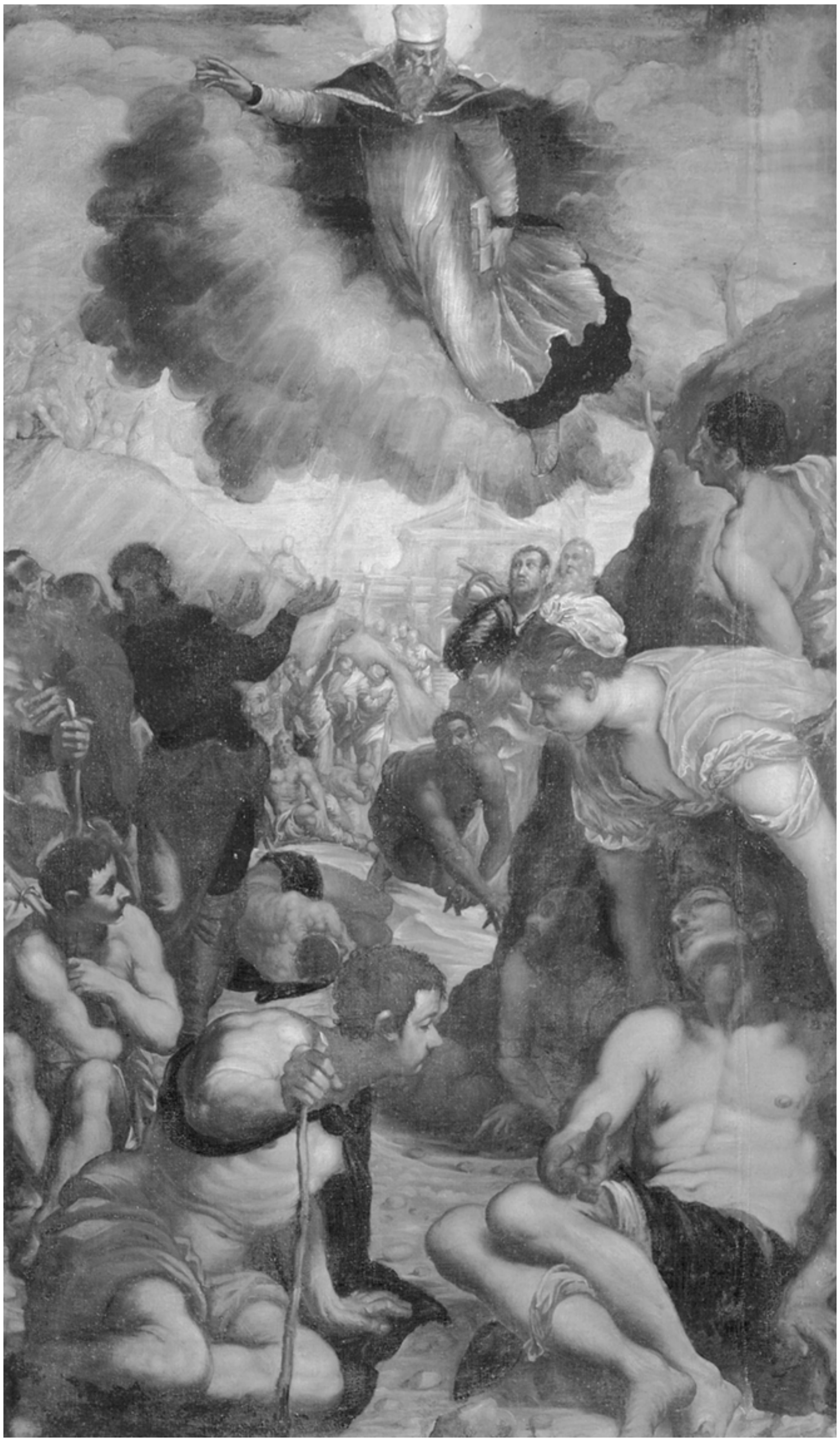
The Christian writers of the late Roman Empire incorporated familiar subject matter of earlier writers, often reshaping customary motifs to fit the Christian perspective. Augustine (354–430 CE*) discusses peculiarities of the human body in much the same style as Pliny the Elder, but he goes beyond presenting them as ethnographic curiosities by placing them within the plan of the Christian God.*

Book XVI, Chapter 8

Whether certain monstrous races of men are derived from the stock of Adam or Noah's sons.

It is also asked whether we are to believe that certain monstrous races of men, spoken of in secular history, have sprung from Noah's sons, or rather, I should say, from that one man from whom they themselves were descended. For it is reported that some have one eye in the middle of the forehead; some, feet turned backwards from the heel; some, a double sex, the right breast like a man, the left like a woman, and that they alternately beget and bring forth: others are said to have no mouth, and to breathe only through the nostrils; others are but a cubit high, and are therefore called by the Greeks "Pigmies": they say that in some places the women conceive in their fifth year, and do not live beyond their eighth. So, too, they tell of a race who have two feet but only one leg, and are of marvellous swiftness, though they do not bend the knee: they are called Skiopodes, because in the hot weather they lie down on their backs and shade themselves with their feet. Others are said to have no head, and their eyes in their shoulders; and other human or quasi-human races are depicted in mosaic in the harbor esplanade of Carthage, on the faith of histories of rarities. What shall I say of the Cynocephali, whose dog-like head and barking proclaim them beasts rather than men? But we are not bound to believe all we hear of these monstrosities. But whoever is anywhere born a man, that is, a rational, mortal animal, no matter what unusual appearance he presents in color, movement, sound, nor how peculiar he is in some power, part, or quality of his nature, no Christian can doubt that he springs from that one protoplast. We can distinguish the common human nature from that which is peculiar, and therefore wonderful.

The same account which is given of monstrous births in individual cases can be given of monstrous races. For God, the Creator of all, knows where and when each thing ought to be, or to have been created, because He sees the similarities and diversities which can contribute to the beauty of the whole. But He who cannot see the whole is offended by the deformity of the part, because he is blind to that which balances it, and to which it belongs. We know that men are born with more than four fingers on their bands or toes on their feet: this is a smaller matter; but far from us be the folly of supposing that the Creator mistook the number of a man's fingers, though we cannot account for the difference. And so in cases where the divergence from the rule is greater. He whose works no man justly finds fault with, knows what He has done. At Hippo-Diarrhytus there is a man whose hands are crescent-shaped, and have only two fingers each, and his feet similarly formed. If there were a race like him, it would be added to the history of the curious and wonderful. Shall we therefore deny that this man is descended from that one man who was first created? As for the Androgyni, or Hermaphrodites, as they are called, though they are rare, yet from time to time there appears persons of sex so doubtful, that it remains uncertain from which sex they take their name; though it is customary to give them a masculine name, as the more worthy. For no one ever called them Hermaphroditesses. Some years ago, quite within my own memory, a man was born in the East, double in his upper, but single in his lower half—having two heads, two chests, four hands, but one body and two feet like an ordinary man; and he lived so long that many had an opportunity of seeing him. But who could enumerate all the human births that have differed widely from their ascertained parents? As, therefore, no one will deny that these are all descended from that one man, so all the races which are reported to have diverged in bodily appearance from the usual course which nature generally or almost universally preserves, if they are embraced in that definition of man as rational and mortal animals, unquestionably trace their pedigree to that one first father of all. We are supposing these stories about various races who differ from one another and from us to be true; but possibly they are not: for if we were not aware that apes, and monkeys, and sphinxes are not men, but beasts, those historians would possibly describe them as races of men, and flaunt with impunity their false and vainglorious discoveries. But supposing they are men of whom these marvels are recorded, what if God has seen fit to create some races in this way, that we might not suppose that the monstrous births which appear among ourselves are the failures of that wisdom



St. Augustine Healing the Plague Victims, *by Jacopo Robusti Tintoretto (1518–1594). Tintoretto portrays the devotion of St. Augustine to the victims of plague. The saints were most often invoked to ask for healing; to prevent shipwrecks, fires, and famines; or even to obtain material or spiritual help. In this respect, it seems that St. Anne was the most solicited of all saints, followed by the Holy Virgin Mary, St. Joseph, and St. Augustine.*

Source: Uffizi, Florence, Italy. Photo credit: Scala/Art Resource, New York.

whereby He fashions the human nature, as we speak of the failure of a less perfect workman? Accordingly, it ought not to seem absurd to us, that as in individual races there are monstrous births, so in the whole race there are monstrous races. Wherefore, to conclude this question cautiously and guardedly, either these things which have been told of some races have no existence at all; or if they do exist, they are not human races; or if they are human, they are descended from Adam.

Book X, Chapter 16

Whether those angels who demand that we pay them divine honour, or those who teach us to render holy service, not to themselves, but to God, are to be trusted about the way of life eternal.

What angels, then, are we to believe in this matter of blessed and eternal life?—those who wish to be worshipped with religious rites and observances, and require that men sacrifice to them; or those who say that all this worship is due to one God, the Creator, and teach us to render it with true piety to Him, by the vision of whom they are themselves already blessed, and in whom they promise that we shall be so? For that vision of God is the beauty of a vision so great, and is so infinitely desirable, that Plotinus does not hesitate to say that he who enjoys all other blessings in abundance, and has not this, is supremely miserable. Since, therefore, miracles are wrought by some angels to induce us to worship this God, by others, to induce us to worship themselves; and since the former forbid us to worship these, while the latter dare not forbid us to worship God, which are we to listen to? Let the Platonists reply, or any philosophers, or the theurgists, or rather, periurgists,—for this name is good enough for those who practise all such arts. In short, let all men answer,—if, at least, there survive in them any spark of natural perception which as rational beings, they possess when created,—let them, I say tell us whether we should sacrifice to the gods or angels who order us to sacrifice to them, or to that One to whom we are ordered to sacrifice by those who forbid us to worship either themselves or these others. If neither the one party nor the other had wrought miracles, but had merely uttered commands, the one to sacrifice to themselves, the other forbidding that, and ordering us to sacrifice to God, a godly mind would have been at no loss to discern which command proceeded from proud arrogance, and which from true religion. I will say more. If miracles had been wrought only by those who demand sacrifice for themselves, while those who forbade this, and enjoined sacrificing to the one God only, thought fit entirely to forego the use of visible miracles, the authority of the latter was to be preferred by all who would use, not their eyes only, but their reason. But since God, for the sake of commending to us the oracles of His truth, has, by means of these immortal messengers, who proclaim His majesty and not their own pride, wrought miracles of surpassing grandeur, certainty, and distinctness, in order that the weak among the godly might not be drawn away to false religion by those who require us to sacrifice to them and endeavour to convince us by stupendous appeals to our senses, who is so utterly unreasonable as not to choose and follow the truth, when he finds that it is heralded by even more striking evidences than falsehood?

As for those miracles which history ascribes to the gods of the heathen,—I do not refer to those prodigies which at intervals happen from some unknown physical causes, and which are arranged and appointed by Divine Providence, such as monstrous births, and unusual meteorological phenomena, whether startling only, or also injurious, and which are said to be brought about and removed by communication with demons, and by their most deceitful craft,—but I refer to these prodigies which manifestly enough are wrought by their power and force, as, that the household gods which Aeneas carried from Troy in his flight moved from place to place; that Tarquin cut a whetstone with a razor; that the Epidaurian serpent attached himself as a companion to Aesculapius on his voyage to Rome; that the ship in which the image of the Phrygian mother stood, and which could not be moved by a host of men and oxen, was moved by one weak woman, who attached her girdle to the vessel and drew it, as proof of her chastity; that a vestal, whose virginity was questioned, removed the suspicion by carrying from the Tiber a sieve full of water without any of it dropping: these, then, and the like, are by no means to be compared for greatness and virtue to those which, we read, were wrought among God's people. How much less can we compare those marvels, which even the laws of heathen nations prohibit and punish,—I mean the magical and theurgic marvels, of which the great part are merely illusions practiced upon the senses, as the drawing down of the moon, "that," as Lucan says, "it may shed a stronger influence on the plants"? And if some of these do seem to equal those which are wrought by the godly, the end for which they are wrought distinguishes the two, and shows that ours are incomparably the more excellent. For those miracles commend the worship of a plurality of gods, who deserve worship the less the more they demand it; but these of ours commend the worship of the one God, who, both by the testimony of His own Scriptures, and by the eventual abolition of sacrifices, proves that He needs no such offerings. If, therefore, any angels demand sacrifice for themselves, we must prefer those who demand it, not for themselves, but for God, the Creator of all, whom they serve. For thus they prove how sincerely they love us, since they wish by sacrifice to subject us, not to themselves, but to Him by the contemplation of whom they themselves are blessed, and to bring us to Him from whom they themselves have never strayed. If, on the other hand, any angels wish us to sacrifice, not to one, but to many, not, indeed, to themselves, but to the gods whose angels they are, we must in this case also prefer those who are the angels of the one God of gods, and who so bid us to worship Him as to preclude our worshipping any other. But, further, if it be the case, as their pride and deceitfulness rather indicate, that they are neither good angels nor the angels of good gods, but wicked demons, who wish sacrifice to be paid, not to the one only and supreme god, but to themselves, what better protection against them can we choose than that of the one God whom the good angels serve, the angels who bid us sacrifice, not to themselves, but to Him whose sacrifice we ourselves ought to be?

Book XXI, Chapter 8

That it is not contrary to nature that, in an object whose nature is known, there should be discovered an alteration of the properties which have been known as its natural properties.

. . . For we say that all portents are contrary to nature; but they are not so. For how is that contrary to nature that happens by the will of God, since the will of so mighty a Creator is certainly the nature of each created thing? A portent, therefore, happens not contrary to nature, but contrary to what we know as nature. But who can number the multitude of portents recorded in profane histories? Let us then at present fix our attention on this one only that concerns the matter in hand. What is there so arranged by the Author of the nature of heaven and earth as the exactly ordered course of the stars? What is there established by laws so sure and inflexible? And yet, when it pleased Him who with sovereignty and supreme power regulates all He has created, a star conspicuous among the rest by its size and splendor changed its color, size, form, and, most wonderful of all, the order and law of its course! . . .

For who that thoughtfully observes the countless multitude of men, and their similarity of nature, can fail to remark with surprise and admiration the individuality of each man's appearance, suggesting to us, as it does, that unless men were like one another, they would not be distinguished from the rest of the animals; while unless, on the other hand, they were unlike, they could not be distinguished from one another, so that those whom we declare to be like, we also find to be unlike? And the unlikeness is the more wonderful consideration of the two; for a common nature seems rather to require similarity. And yet, because the very rarity of things is that which makes them wonderful, we are filled with much greater wonder when we are introduced to two men so like, that we either always or frequently mistake in endeavoring to distinguish between them.

Source: Dods, Marcus, ed. and trans. 1948. *The City of God.* Vol. 1. New York: Hafner.

▣ Al-Jahiz, *The Book of Animals*, IV, 404–405 (776–868 CE)

Al-Jahiz lived at Basra (now in Iraq) and was among the most famous and prolific writers of the great Arab civilization. He was of unpleasant appearance, was "goggle-eyed" (=jahiz), and later in life suffered various disabling ailments. His remarks about different degrees of deafness, and the dispersal of sound, suggest that these points were well understood in the Arab centers of learning in the ninth century, a point seldom (if ever) mentioned by writers about medieval deafness.

Theologians say that your dumb man is deaf: his inability to speak is due not to any malformation of the tongue, but to the fact that having never heard sounds, articulated or otherwise, he does not know how to produce them. Not all deaf people are completely dumb, and there are also degrees of deafness.

[The text now provides some examples of loud noises that some deaf people can hear.]

Others can hear words if spoken in their ear, but otherwise they hear nothing, even if the speaker raises his voice; if the speaker positions himself so that the sound goes right into their ear, they understand perfectly, whereas if he speaks just as loudly into the air, the sound of his voice not being concentrated and conducted along a canal into the brain, they do not understand.

Source: Pellat, C., ed., and D. M. Hawke, trans. 1969. "Kitab al-Hayawan" [The life of animals]. In *The Life and Works of Jahiz.* London: Routledge & Kegan Paul.

Al-Mas'udi (ca. 896–956 CE)

Al-Mas'udi provided more information on everyday life and humor than most historians do, including stories of disabled people, often in relation to the Caliph ruling at the time. Many of these present unexpected roles for disabled people.

[An intimate of Ma'mun related that the Caliph told him:] 'Nothing has ever left me so speechless as the answers given by three people.' [The third incident follows:] The inhabitants of Kufa had joined together to complain to me of their governor, a man whose policies and behaviour had my entire approval. I had this reply conveyed to them: 'Although I know all there is to know about this man, I have nevertheless resolved to grant you an audience tomorrow morning. Choose, therefore, a delegate who will speak for you, for I know how prolix you are.'

They answered me as follows:

'The only man whom we feel is worthy to carry on a discussion in the presence of the Caliph is afflicted with deafness. However, if the Commander of the Faithful will be kind enough to tolerate this, perhaps he will do us the honour of letting us know.'

I agreed to bear patiently with their delegate and, on the very next day, the deputation arrived. I had the deaf man brought in. I invited those present to sit and then I asked him what their grievances against the governor were.

'Commander of the Faithful,' he replied, 'he is the worst governor in the world. The year you appointed him, we had to sell our clothes and furniture; the next year, our savings and land; and now, in the third year, we are forced to leave our homes in order to beseech the Commander of the Faithful, that, touched by our sufferings, he may do us the great favour of ordering his removal.'

'You are lying, you bastard!' I cried. 'He is a man whose policies and behaviour I admire, as I honour his piety and wisdom. I chose him for you on purpose, because I know well how often you revolt against those who govern you.'

'My lord,' the speaker replied, 'what you say is true and it is I who lied, but since you so admire the piety, loyalty, integrity, justice and moderation of this governor, why have you left him exclusively with us all these years, to the prejudice of so many other cities, the interests of which Almighty God has confided to your care, as he has confided ours? Set him therefore over these other lands, that he may grant them, in their turn, the treasures of moderation and justice which he has lavished on us.'

'Get out!' I said, 'and may God refuse you His protection. I agree to dismiss your governor.'

[The wit of a blind man, Abu al-Ayna (d. 895), was much celebrated. Mas'udi gives some examples, but he notes also a shrewd reflection by Abu al-Ayna on his own disability. In 860, he had gone to see the Caliph Mutawakkil, who was charmed by his conversation. Mutawakkil asked Abu al-Ayna about his attitude to wine.]

'I would not be able to drink only a little,' replied Abu al-Ayna, 'and I make a fool of myself in public when I drink a lot.'

'Let your scruples alone,' went on Mutawakkil, 'and be our guest.'

Abu al-Ayna answered:

'I am blind. Now a man in my state makes sudden movements, he wanders out of his path and does not observe what others see in him. All those who are here lavish their attentions on you, but I need the care of another. Now it could be that you might look at me with a contented eye, yet be inwardly irritated; or you might appear irritated, hiding your inner satisfaction, and I, being unable to distinguish one state from the other, would be lost. I therefore prefer to hold tight to my safety rather than run the risk of danger.'

Source: Lunde, P., and C. Stone, ed. and trans. 1989. Pp. 193–194 in *The Meadows of Gold. The Abbasids, by Mas'udi.* London: Kegan Paul International.

▣ Anselm of Canterbury, *Proslogion* (ca. 1070–1100)

Anselm of Canterbury, a Benedictine monk who became archbishop of Canterbury, wrote several theological treatises that influenced the development of scholastic theology in the centuries after his death. The Proslogion aims to prove God's existence by means of the "ontological argument" that God can be understood as "that greater than which cannot be thought." This argument, however, depending as it does on intellect, seems to require an account of how a cognitively disabled person might come to know God. The Proslogion thus includes a discourse on the fool's ability to conceive of God, starting with the familiar verse from the Psalms, "The fool says in his heart, 'There is no God.'" Anselm's ideas were answered by the monk Gaunilo, whose rebuttal follows the selection from Anselm.

Chapter 4: How the Fool Managed to Say in His Heart That Which Cannot Be Thought

How in the world could he have said in his heart what he could not think? Or how indeed could he not have thought what he said in his heart, since saying it in his heart is the same as thinking it? But if he really thought it because he said it in his heart, and did not say it in his heart because he could not possibly have thought it—and that seems to be precisely what happened—then there must be more than one way in which something can be said in one's heart or thought. For a thing is thought in one way when the words signifying it are thought, and it is thought in quite another way when the thing signified is understood. God can be thought not to exist in the first way but not in the second. For no one who understands what God is can think that he does not exist. Even though he may say those words in his heart he will give them some other meaning or no meaning at all. For God is that greater than which cannot be thought. Whoever understands this also understands that God exists in such a way that one cannot even think of him as not existing.

Thank you, my good God, thank you, because what I believed earlier through your gift I now understand through your illumination in such a way that I would be unable not to understand it even if I did not want to believe you existed.

Gaunilo: How Someone Writing on Behalf of the Fool Might Reply to All This

To one who questions whether (or simply denies that) there exists something of such a nature that nothing greater can be imagined, it is said that its existence is proved in the first place by the fact that anyone denying it already has it in his thought, since upon hearing it said he understands what is said; and in the second place by the fact that what he understands necessarily exists not only in the mind but in reality as well. Thus its existence is proved, because it is a greater thing to exist in reality as well than to exist in the mind alone, and if it exists only in the mind, then what exists in reality as well will be greater, and thus that which is greater than all else will be less than something else and not greater than all else, which is nonsense. Thus what is greater than all else must necessarily exist, not only in the mind (which has already been acknowledged to be the case), in reality as well, or else it could not be greater than all else.

But perhaps the fool could reply that this thing is said to exist in my mind only in the sense that I understand what is said. For could I not say that all sorts of false and completely nonexistent things exist in my mind since when someone speaks of them I understand what is said? Unless perhaps what is being said here is that one entertains this particular thing in the mind in a completely different way than one thinks of false or doubtful things, and thus what is being said is that having heard this particular thing I do not merely think it but understand it, for I cannot think of this thing in any other way except by understanding it, and that means understanding with certainty that it actually exists. But if this is true, then in the first place there will be no difference between first entertaining that thing in the mind and then understanding that it exists. Imagine the case of that picture which is first in the painter's mind, then exists in reality. It seems unthinkable that, once such an object was spoken or the words heard, the object could not be thought not to exist in the same way God can be thought not to exist. For if God cannot be thought not to exist, then what is the point of launching this whole argument against someone who might deny that something of such a nature actually exists? And in the second place, this basic notion—that God is such that, as soon as he is thought of, he must be perceived by the mind as unquestionably existing—this notion, I say, must be proved to me by some unquestionable argument, but not by the one offered here, namely that this must be in my understanding because I understand what I'm hearing. For as far as I am concerned one might say the same thing about other things that are certain or even false, things about which I might be deceived (as I believe I often am).

Thus the example of the painter who already has in his mind the picture he is about to produce cannot be made to support this argument. For that picture, before it comes into being, exists in the art of the painter, and such a thing existing in the art of some painter is nothing other than a certain part of his understanding; for as Saint Augustine says, "If a craftsman is going to make a box, he first has it in his art. The box he actually produces is not life, but that in his art is life, because the artisan's soul, in which all such things exist before they are brought forth, is alive. And how are these things alive in the living soul of the artisan unless because [they] are nothing other than the knowledge or understanding of the soul itself? But leaving aside those things which are known to belong to the nature of the mind itself, in the case of those things which are perceived as true by the mind through hearing or thought, in this case there is a difference between the thing itself and the mind which grasps it. Thus even if it should be true that there is something greater than which cannot be thought, this thing, whether heard or understood, would not be like the as-yet-unmade picture in the painter's mind.

Moreover, there is the point already suggested earlier, namely that when [I] hear of something greater than all other things which can be thought of—and that something can be nothing other than God himself—I can no more entertain a thought of this being in terms of species or genera familiar to me than I can entertain such a thought of God himself, and for this

Aesop with Animals, 1476.

Source: Private library of Sharon Snyder and David Mitchell.

reason I am able to think he does not exist. For I have not known the thing itself and I cannot form a similitude of it from other things. For if I hear about some man completely unknown to me, whom I do not even know exists, I could at least think about him through that specific and generic knowledge by which I know what a man is or what men are like. Yet it could be true that, because the speaker was lying, the man I thought about actually did not exist at all, even though I had thought of him as an existing thing, my idea of him being based, not on knowledge of this particular man, but on knowledge of man in general. But when I hear someone say "God" or "something greater than everything else" I cannot think of it as I thought of that nonexistent man, for I was able to think of the latter in terms of some truly existing thing known to me, while in the former case I can think only of the bare words, and on this basis alone one can seldom or never gain any true knowledge. For when one thinks in this way, one thinks not so much of the word itself—which, insofar as it is the sound of letters or syllables is itself a real thing, but of what is signified by the sound heard. But a phrase like "that which is greater than everything else" is not thought of as one thinks about words when one knows what they mean. It is not thought of, that is, as one thinks about something he knows is true either in reality or in thought alone. It is thought of, instead, as one does when he does not really know what the words mean, but thinks of it only in terms of an affection produced by the words within his soul, yet tries to imagine what the words mean. On this basis, though, it would be amazing if he was ever able to penetrate to the truth of the thing. It is in this way and only in this way that this being is in my mind when I hear and understand someone saying there is something greater than everything else that can be thought of. So much for the claim that the supreme nature already exists in my mind.

Nevertheless, that this being must exist not only in my mind but in reality as well is proved to me by the following argument: If it did not, then whatever did exist in reality would be greater, and thus the thing which has already been proved to exist in my mind will not be greater than everything else. If it is said that this being, which cannot be conceived of in terms of any existing thing, exists in the mind, I do not deny that it exists in mine. But through this alone it can hardly be said to attain existence in reality. I will not concede that much to it unless convinced by some indubitable argument. For whoever says that it must exist because otherwise that which is greater than all other beings will not be greater than all other beings, that person isn't paying careful enough attention to what he says. For I do not yet grant, in fact I deny it or at least question it, that the thing existing in my mind is greater than any real thing. Nor do I concede that it exists in any way except this: the sort of existence (if you can call it such) a thing has when the mind attempts to form some image of a thing unknown to it on the basis of nothing more than some words the person has heard. How then is it demonstrated to me that the thing exists in reality merely because it is said to be greater than everything else? For I continue to deny and doubt that this is established, since I continue to question whether this greater thing is in my mind or thought even in the way that many doubtful or unreal things are. It would first have to be proved to me that this greater thing really exists somewhere. Only then will we be able to infer from the fact that is greater than everything else that it also subsists in itself.

For example, they say there is in the ocean somewhere an island which, due to the difficulty (or rather the impossibility) of finding what does not actually exist, is called "the lost island." And they say that this island has all manner of riches and delights, even more of them than the Isles of the Blest, and having no owner or inhabitant it is superior in the abundance of its riches to all other lands which are inhabited by men. If someone should tell me that such is the case, I will find it easy to understand what he says, since there is nothing difficult about it. But suppose he then adds, as if he were stating a logical consequence, "Well then, you can no longer doubt that this island more excellent than all other lands really exists somewhere, since you do not doubt that it is in your mind; and since it is more excellent to exist not only in the mind but in reality as well, this island must necessarily exist, because if it didn't, any other island really existing would be more excellent than it, and thus that island now thought of by you as more excellent will not be such." If, I say, someone tries to convince me though this argument that the island really exists and there should be no more doubt about it, I will either think he is joking or I will have a hard time deciding who is the bigger fool, me if I believe him or him if he thinks he has proved its existence without having first convinced me that this excellence is something undoubtedly existing in reality and not just something false or uncertain existing in my mind.

In the meantime, this is how the fool answers. If it is asserted in the first place that this being is so great that its nonbeing is logically inconceivable (this in turn being proved by nothing except that otherwise it would not be greater than all other beings), then the fool can answer, "When did I say that such a being, namely one greater than all others, actually exists, thus allowing you to proceed from there to argue that it so really exists that its very nonexistence is inconceivable?" It should first be proved conclusively that some being superior to (that is, greater and better than) all others exists, so that on this basis we can go on to prove the attributes such a greater and better being must possess. When, however, it is said that this highest being cannot be thought of as not existing, perhaps it would have been better to say that its nonbeing or the possibility of its nonbeing is unintelligible. For strictly speaking false things are unintelligible even though they can be thought of in the same way the fool thought God did not exist. I am absolutely certain that I exist, although I nevertheless know that my nonexistence is possible. And I understand without doubting it that the highest thing there is, namely God, exists and cannot not exist. I do not know, however, whether I can think of myself as nonexistent when I know for certain that I exist. If it turns out that I can do so in this case, why should I not be able to do the same concerning other things I know with equal certainty? If I cannot, though, the impossibility of doing so will not be something peculiar to thinking about God.

The other parts of that book are argued with such veracity, brilliance and splendor, and filled with such value, such an intimate fragrance of devout and holy feeling, that they should in no way be condemned because of those things which, at the beginning, . . . [though] rightly intuited, [are] less firmly argued. Rather those things should be argued more robustly and the entire work thus received with great respect and praise.

Anselm's Reply to Gaunilo

Since whoever wrote this reply to me is not the fool against whom I wrote in my treatise but instead one who, though speaking on behalf of the fool, is a catholic Christian and no fool himself, I can speak to him as a catholic Christian.

You say—whoever you are who claim that the fool can say these things—that something greater than which cannot be thought of is in the mind only as something that cannot be thought of in terms of some [existent thing known to us]. And you say that one can no more argue, "since a being greater than which cannot be thought of exists in my mind it must also exist in reality," than one can argue, "the lost island certainly exists in reality because when it is described in words the hearer has no doubt that it exists in his mind." I say in reply that if "a being greater than which cannot be thought of" is neither understood nor thought of, nor is it in our understanding or our thought, then God either is not that greater than which cannot be thought of or he is not understood or thought of, nor is he in the understanding or mind. In proving that this is false I appeal to your faith and conscience. Therefore "a being greater than which cannot be thought of" is really understood and thought of and it really is in our understanding and thought. And that is why the arguments by which you attempt to prove the contrary either are not true or what you think follows from them does not follow from them at all.

Moreover, you imagine that although "a being greater than which cannot be thought of" is understood, it does not follow that it exists in our understanding nor does it follow that, since it is in our understanding, it must exist in reality. I myself say with certainty that if such a being can even be thought of as existing, it must necessarily exist. For "a being greater than which cannot be thought of" cannot be thought of except as having no beginning; but whatever can be thought of as existing yet does not actually exist can be thought of as having a beginning. Therefore "a being greater than which cannot be thought of" cannot be thought of yet not actually exist. Therefore, if it can be thought of, it necessarily exists.

Furthermore, if it can be thought of at all, it must necessarily exist. For no one who denies or doubts the existence of "a being greater than which cannot be thought of" denies or doubts that, if it did exist, it would be impossible for it not to exist either in reality or in the mind. Otherwise it would not be "a being greater than which cannot be thought of." But whatever can be thought of yet does not actually exist, could, if it did come to exist, not exist again in reality and in the mind. That is why, if it can even be thought of, "a being greater than which cannot be thought of" cannot be nonexistent.

But let us suppose that it does not exist (if it is even possible to suppose as much). Whatever can be thought of yet does not exist, even if it should come into existence, would not be "a being greater than which cannot be thought of." Thus "a being greater than which cannot be thought of" would not be "a being greater than which cannot be thought of," which is absurd. Thus if "a being greater than which cannot be thought of" can even be thought of, it is false to say that it does not exist; and it is even more false if such can be understood and exist in the understanding.

I will go even farther. Without doubt whatever does not exist somewhere or at some time, even if it does exist somewhere or at some time, can be thought of as capable of existing never and nowhere, just as it does not exist somewhere or at some time. For what did not exist yesterday and exists today can be thought of as never existing, just as it is thought of as not having existed yesterday. And what does not exist here but does exist somewhere else can be thought of as not existing anywhere. And it is the same with something some parts of which are absent at times. If that is the case, then all of its parts and thus the thing in its entirety can be thought of as existing never and nowhere. For if it is said that time always exists and the world is everywhere, it is nevertheless true that time as a whole does not exist forever, nor does the entire world exist everywhere. And if individual parts of time exist when other parts do not, they can be thought of as never existing at all. And just as particular parts of the world do not exist where other parts do, so they can be thought of as never existing at all, anywhere. And what is composed of parts can be broken up in the mind and be nonexistent. Thus whatever does not exist as a whole sometime or somewhere can be thought of as not existing, even if it actually exists at the moment. But "a being greater than which cannot be thought of," if it exists, cannot be thought of as not existing. Otherwise it is not "a being greater than which cannot be thought of," which is absurd. Thus it cannot fail to exist in its totality always and everywhere.

Do you not believe that the being of which these things are understood can be thought about or understood or be in the thought or understanding to some extent? For if he is not, then we cannot understand these things about him. If you say that he is not understood or in the understanding because he is not fully understood, say as well that one who cannot look directly at the sun does not see the light of day, which is nothing other than the light of the sun. Certainly "a being greater than which cannot be thought of" is understood and exists in the understanding at least to the extent that these statements about it are understood. . . .

You often picture me as offering this argument: Because what is greater than all other things exists in the understanding, it must also exist in reality or else the being which is greater than all others would not be such. Never in my entire treatise do I say this. For there is a big difference between saying "greater than all other things" and "a being greater than which cannot be thought of." If someone says "a being greater than which cannot be thought of" is not something actually existing or is something which could possibly not exist or something which cannot even be understood, such assertions are easily refuted. For what does not exist is capable of not existing, and what is capable of not existing can be thought of as not existing. But whatever can be thought of as not existing, if it does actually exist, is not "a being greater than which cannot be thought of." . . .

It is not, it seems, so easy to prove the same thing of "that which is greater than all other things," for it is not all that obvious that something which can be thought of as not existing is not nevertheless greater than all things which actually exist.

Source: Burr, David, trans. n.d. *St. Anselm of Canterbury, Proslogion.* Available at http://dburr.hist.vt.edu/Anselm.html

Kai Kaus, *Qabus-nama*
(1082–1083 CE)

The Cabous Namè (in English: Qabus-nama or Kabusnama) is written as an instruction manual for princes. A passage in Chapter 7 asserts that a child who is not exposed to language during infancy will grow up unable to speak, providing as proof the example of congenitally deaf children. This assertion may have been the source of the Emperor Akbar's infamous experiment in which he had infants reared by deaf-mute nurses in a locked house, so that they would not be exposed to language. He was curious to discover what language, if any, they would produce.

Make an effort to be an attentive listener, for when one knows how to listen one may acquire wisdom and good expression, as may be shown from the case of children.

Suppose for example that a child were confined in a cellar from birth, and there were given its milk and food, but had never a word or caress from its mother or nursemaid. Clearly, as it grew, it would remain dumb and unable to produce a word, unless [or until] it chanced to have some opportunity to hear [speech] and so to learn to speak. A further proof is the fact that all who are born deaf are also mute. Isn't it the case that all dumb people are deaf?

Source: English translation of Querry, A., trans. 1886. Kai Kaus. *Le Cabous Namè ou livre de Cabous.* Paris: Leroux.

Ibn Khallikan, *Biographical Dictionary*

Ibn Khallikan produced this famous thirteenth-century collection of 865 biographies of well-known Muslims through six centuries, many also giving information on lesser-known persons. Over 100 entries mention some disability. A few among these were deaf people.

Thalab the Grammarian (Abu 'l-Abbas Ahmad Ibn Yahya Ibn Zaid Ibn Saiyar) (815–904), Vol. I: 85

[Thalab the Grammarian became deaf later in life, and lost his life in a traffic accident in Baghdad, apparently as a result of being unable to hear.]

The accident which caused his death happened in the following manner: he had left the mosque on Friday, when the afternoon-prayer was over; and some time before he had got a deafness, which prevented him from hearing unless with great difficulty; he was holding a book in his hand and reading it in the street, when a horse knocked against him and threw him into a deep pit, out of which he was taken nearly senseless. He was immediately borne to his house, complaining of his head, and he died the next day.

Imad ad-Dawlat (ca. 892–949), Vol. II: 333

[After capturing Shiraz, Imad ad-Dawlat found hidden wealth, which enabled him to consolidate his grip. He then had a further stroke of good luck, arising because a deaf tailor misunderstood the situation and thought that he had been betrayed.]

Imad ad-Dawlat . . . caused a dress to be cut out for his own use, and having inquired for a skilful tailor to make it up, they told him of a person who had served the former governor of the town in that capacity. In pursuance of his orders, this man was brought to him; and the fellow, happening to be deaf, imagined that secret information had been lodged against him for retaining in his possession some property which his former master had confided in his care. Impressed with this belief, he swore, when spoken to by the prince, that he had only twelve chests in his house, and did not know what they contained. Surprised at such an answer, Imad ad-Dawlat sent for the chests, which were discovered to be filled with money and dresses to an immense amount.

Dibil Ibn Ali'l-Khuzai (765–860/861), Vol. I: 507–511

It is stated also that he was deaf and had a scrofulous swelling on the back of his neck. —Dibil was a good poet, but scurrilous and addicted to satire; always ready to slander men of merit, and sparing none, not even the khalifs. He lived (however) to an advanced age, and he used to say: 'For fifty years I have gone about with my cross on my shoulder, but could find none to crucify me on it.' [Some examples are given of prominent men who would happily have crucified Dibil for his satirical verses about them.]

[Dibil's conduct was sometimes eccentric:] 'Dibil' means 'a tall camel.' He used to relate that one day as he was passing along, he saw a man in a fit of epilepsy; on which he went up and shouted in his ear, as loud as he could, the word 'Dibil,' and that the man rose up and walked away as if nothing had happened.

Muhammad Ibn Sirin (653/654–729), Vol. II: 586–589

[Muhammad Ibn Sirin was a highly esteemed law lecturer of Basra who was also valued as an accurate and early transmitter of sayings and incidents ("traditions," or *hadiths*) from the life of the prophet Muhammad. As the hadiths were to become the major source of rules for everyday conduct among Muslims, second only to the Quran, the accuracy of oral transmission was a subject of intensive study. Doubt could be cast on a tradition if anything detrimental was known about the conduct or probity of any link in the chain of transmission, as appears in some comments below. It might be anticipated that a known, significant hearing impairment would be considered a serious defect in a transmitter; but evidently this was not so in the case of Ibn Sirin.]

Abu Bakr Muhammad Ibn Sirin was a native of Basra. His father was slave to Anas Ibn Malik [footnote: "one of the most eminent among the Companions" (of the prophet Muhammad)] . . . Muhammad Ibn Sirin delivered Traditions on the authority of Abu Huraira, Abd Allah Ibn Omar, Abd Allah Ibn az-Zubair, Imran Ibn Husain, and Anas Ibn Malik;

[To students of law] "As-Shabi used to say 'Stick to that deaf man!' meaning thereby Ibn Sirin; because he was dull of hearing. . . . Al-Asmai used to say:

'Al-Hasan al-Basri [was, in furnishing Traditions] a generous prince; but when the deaf man (meaning Ibn Sirin) furnishes Traditions, retain them carefully; as for Ka-ada, [he was, as a collector of Traditions, like] one who gathers fire-wood in the dark, [picking up both bad and good].'

Abu'l-Abbas Muhammad Ibn Yakub al-Asamm, Vol. 4: 397

Abu'l-Abbas Muhammad Ibn Yakub al-Asamm ('the deaf'), a mawla to the Omaiyide family, a native of Naisapur and the chief Traditionist of that age in Khorasan, taught during seventy-six years the knowledge which he had acquired. His death took place in . . . 957. He lost his hearing after having travelled and made his studies.

Abu'l-Aswad ad-Duwali (d. 688/689), Vol. I: 662–667

[Eminent and learned grammarian and poet of Basra. His remark about the need to appear in public even though disabled, if he were not to risk disappearing from anyone's notice, seems to transcend history and geography.]

It is related that Abu'l-Aswad had an attack of the palsy, and that he used to go to the market himself, although scarcely able to draw his leg after him, and yet he was rich and possessed both male and female slaves: a person who knew this accosted him one day and said: 'God has dispensed you from the necessity of moving about on your own business; why do you not remain seated at home?' To which he replied: 'No; I go in and out, and the eunuch says: "He is coming," and the boy says: "He is coming," whereas, were I to continue sitting in the house, the sheep might [pass] urine upon me without any person's preventing them.'

Katada Ibn Diama As-Sadusi (679/680–735/736), Vol. II: 513–514

[A learned man who had been born blind, at Basra.]

"'Katada,' said Abu Amr, 'was the most learned genealogist of his time, and, in his youth he met Daghfal. He used to go from one end of Basra to the other without a guide."

Source: de Slane, M. G., trans. 1842. *Ibn Khallikan's Biographical Dictionary Translated from the Arabic.* 4 vols. Paris; Oriental Translation Fund.

▣ Legend of Saint Wilgefortis (1100s–1400s)

Saint Wilgefortis (traditionally thought to be derived from virgo, "virgin," and fortis, "strong"), supposedly a Portuguese virgin martyr, is a fictional saint whose story resulted from the combination of several popular legends. She is known by a variety of alternate names in different countries. The legend demonstrates the use of masculine attributes as chosen deformity by women to escape the imprisonment of marriage.

A fabulous female saint known also as UNCUMBER, KUMMERNIS, KOMINA, COMERA, CUMERANA, HULFE, ONTCOMMENE, ONTCOMMER, DIGNEFORTIS, EUTROPIA, REGINFLEDIS, LIVRADE, LIBERATA, etc.

The legend makes her a Christian daughter of a pagan King of Portugal. In order to keep her vow of chastity, she prayed God to disfigure her body, that she might evade the command of her father to marry a pagan prince. God caused a beard to grow on her chin, whereupon her father had her crucified. Connected with this legend is the story of a destitute fiddler to whom, when he played before her image (or before her crucified body), she gave one of her golden boots. Being condemned to death for the theft of the boot, he was granted his request to play before her a second time, and, in presence of all, she kicked off her other boot, thus establishing his innocence.

The legend is not a Christian adaptation of the Hermaphroditus of Greek mythology or of other androgynous myths of pagan antiquity, as it cannot be traced back further than the fifteenth century. It rather originated from a misinterpretation of the famous "Volto Santo" of Lucca, a representation of the crucified Saviour, clothed in a long tunic, His eyes wide open,

People on a Cart, *by Giacomo Jaquerio (fifteenth century). An example of medieval wheeled mobility for a man who cannot walk.*

Source: Castle, Manta, Italy. Photo credit: Scala/Art Resource, New York.

His long hair falling over His shoulders, and His head covered with a crown. This crucifix, popularly believed to be the work of Nicodemus, is preserved in the Basilica of Lucca and highly venerated by the people. In the early Middle Ages it was common to represent Christ on the cross clothed in a long tunic, and wearing a royal crown; but since the eleventh century this practice has been discontinued. Thus it happened that copies of the "Volto Santo" of Lucca, spread by pilgrims and merchants in various parts of Europe, were no longer recognized as representations of the crucified Saviour, but came to be looked upon as pictures of a woman who had suffered martyrdom.

The name Wilgefortis is usually derived from *Virgo fortis,* but recently Schnürer has shown that Wilgefortis is probably a corruption of *Hilge Vartz* (*Vartz, Fratz,* face), "Holy Face." This would corroborate the opinion that the legend originated in the "Volto Santo." The old English name *Uncumber,* as also the German *Oncommer* and their equivalents in other languages, rose from the popular belief that every one who invokes the saint in the hour of death will die *ohne Kummer,* without anxiety. When the cult of St. Wilgefortis began to spread in the fifteenth and sixteenth centuries, her name found its way into various breviaries and martyrologies. Thus a breviary, printed at Paris for the Diocese of Salisbury in 1533, has a beautiful metric antiphon and prayer in her honour. Her feast is celebrated on 20 July. She is usually represented nailed to a cross: as a girl of ten or twelve years, frequently with a beard, or as throwing her golden boot to a musician playing before her, sometimes also with one foot bare.

Source: Ott, Michael. 1913. "Wilgefortis." In *Catholic Encyclopedia.* Available at http://www.newadvent.org/cathen/ 15622a.htm

"Tomi" from *Samguk Sagi* (1145)

Samguk Sagi was put together by Kim Pusik in 1145; the work covers the history of the Three Kingdom period, roughly from the first century BCE *to the seventh century* CE*. Tomi's story shows that disablement was practiced as a form of punishment in ancient Korea. The story celebrates a wife's virtue in remaining faithful to her disabled husband.*

Tomi was a native of Paekche (B.C.18–A.D.678). He was a righteous man of humble birth, with a beautiful and chaste wife, and those who knew him spoke well of him. King Kaeru [128–166] heard of the couple and summoned Tomi. "Generally, women consider chastity and purity to be their foremost virtues," he said, "but if they are tempted with clever words in the dark when no one else is around, few will remain unmoved."

Tomi replied, "One cannot fathom another's mind, but your subject's wife would remain true even on pain of death."

Wishing to test the wife's virtue, the king detained Tomi on some pretext and sent a trusted attendant on horseback to Tomi's house to announce a royal visit. That night the king himself arrived and said to Tomi's wife, "I've long heard about your beauty and I like you. I won you from your husband in a wager. Tomorrow I'll make you my consort, so from now on you're mine."

"The king would not tell a lie, so how could I disobey you? Please enter the room first. I'll change my clothes and follow you," the wife said to the king. She then sent in a female slave disguised as herself.

Later, when the king realized that he had been deceived, he grew angry. On trumped-up charges the king had Tomi's eyes gouged out and had him dragged to a skiff and set adrift on the river. Then he had Tomi's wife sent in and tried to violate her. She declared, "Now that I've lost my husband, I cannot live alone. Still more, since I am to serve your majesty, how could I go against your will? But at the moment I am menstruating, and my body is unclean. Please allow me to wait another day, and then I'll be yours." The king believed her. The wife then seized the opportunity to escape and reached the shore, only to find that there was no boat. She cried to Heaven, and an empty skiff appeared. She jumped aboard and reached Ch'onso Island, where she found her husband. He was still alive, and the couple dug up tree roots to still their hunger. Eventually the couple boarded a boat that took them to the foot of Mount San in Koguryo. The people there took pity on them and provided them with clothes and food. They lived on, and eventually died far from home.

Source: *Samguk Sagi,* in the *Anthology of Korean Literature: From Early Times to the Nineteenth Century.* Compiled and edited by Peter H. Lee. Honolulu: The University Press of Hawaii, 1981, p. 25.

Snorri Sturluson, *Saga of Harald Hardrade* (1179–1241)

The Saga of Harald Hardrade is part of the series Heimskringla, which chronicled the histories of the kings of Norway. Harald (1015–1066) was given the epithet Hardrade (i.e., "severe counsellor," "tyrant") by the Norwegians, perhaps in response to cruelties such as those detailed in the first selection, which describes Harald blinding the Greek emperor. The second selection, not specifically about Harald, describes the miraculous cure of a disabled man.

14. King Olaf's Miracle and Blinding the Greek Emperor

When Harald drew near to the prison King Olaf the Saint stood before him and said he would assist him. On that spot of the street a chapel has since been built and consecrated to Saint Olaf and which chapel has stood there ever since. The prison was so constructed that there was a high tower open above, but a door below to go into it from the street. Through it Harald was thrust in, along with Haldor and Ulf. Next night a lady of distinction with two servants came, by the help of ladders, to the top of the tower, let down a rope into the prison and hauled them up. Saint Olaf had formerly cured this lady of a sickness and he had appeared to her in a vision and told her to deliver his brother. Harald went immediately to the Varings, who all rose from their seats when he came in and received him with joy. The men armed themselves forthwith and went to where the emperor slept. They took the emperor prisoner and put out both the eyes of him. So says Thorarin Skeggjason in his poem:

> "Of glowing gold that decks the hand
> The king got plenty in this land;
> But it's great emperor in the strife
> Was made stone-blind for all his life."

So says Thiodolf, the skald, also:—

> "He who the hungry wolf's wild yell
> Quiets with prey, the stern, the fell,
> Midst the uproar of shriek and shout
> Stung the Greek emperor's eyes both out:
> The Norse king's mark will not adorn,
> The Norse king's mark gives cause to mourn;
> His mark the Eastern king must bear,
> Groping his sightless way in fear."

In these two songs, and many others, it is told that Harald himself blinded the Greek emperor; and they would surely have named some duke, count, or other great man, if they had not known this to be the true account; and King Harald himself and other men who were with him spread the account.

59. King Olaf's Miracle on a Cripple

West in Valland, a man had such bad health that he became a cripple, and went on his knees and elbows. One day he was upon the road, and had fallen asleep. He dreamt that a gallant man came up to him and asked him where he was going. When he named the neighbouring town, the man said to him, "Go to Saint Olaf's church that stands in London, and there thou shalt be cured." There-upon he awoke, and went straightway to inquire the road to Olaf's church in London. At last he came to London Bridge, and asked the men of the castle if they could tell him where Olaf's church was; but they replied, there were so many churches that they could not tell to whom each of them was consecrated. Soon after a man came up and asked him where he wanted to go, and he answered to Olaf's church. Then said the man, "We shall both go together to Olaf's church, for I know the way to it." Thereupon they went over the bridge to the shrine where Olaf's church was; and when they came to the gates of the churchyard the man mounted over the half-door that was in the gate, but the cripple rolled himself in, and rose up immediately sound and strong: when he looked about him his conductor had vanished.

Source: Laing, Samuel, trans. 1844. Snorri Sturluson. Heimskringla. Online Medieval and Classical Library Release #15b. Available at http://sunsite.berkeley .edu/OMACL/Heimskringla/

▣ Saint Francis of Assisi

(1181–1226)

The excerpt below begins with Francis's recovery after being locked up by his father for throwing away the household fortune as an act of material renunciation. In the later excerpt, which details events from around 1208, St. Francis of Assisi firmly renounces his possession of all worldly belongings, and puts on a coarse woolen tunic (a dress worn by some of the poorest Umbrian peasants), and takes up a spiritual life among them. During one trip on horseback across the Umbrian plain he came upon an individual with leprosy. In order to conquer his repulsion, he embraced the man and gave him all his remaining money. This is a common story of saintly sacrifice toward disabled individuals as a sign of religious devotion to socially rejected bodies.

Chapter 1: The Convalescent

There awoke one morning in Assisi a young man who was just recovering from a severe illness. It was seven hundred years ago. The hour was an early one. The window blinds were not yet opened. Out of doors the day's business was in full blast; the bells for mass had long ago rung out from St. Maria del Vescovado, which lay almost under the windows. The strong morning light streamed in through the crack where the window blinds met.

The young man knew it all so well—one morning after another the long weeks of his convalescence had passed thus. Soon his mother would come in and would draw the shutters aside, and the light would enter in dazzling brightness. Then he would get his morning draught, and his bed would be made over; he used to lie on one side of the wide bed while the other was made up for him. And so he would lie there, tired, but at peace, and look out on the blue cloudless autumn sky, listening to the splashing on the stones of the street as the people of the neighbourhood threw their waste water out of the windows. As the forenoon advanced the rays of the sun began to come in—first along the high wall of the window alcove—then right across the brick floor of the room, and when they approached the bed, it was time to take the midday meal. After midday the blinds were again closed, and he took his siesta in the quiet comfortable obscurity of the room. Then he awoke and the blinds were again

tantum vite spatium saltem quo
ad mensuram dierum meorum
ut valeam peccata mea deplo
rare ut veniam ac gratiam
et misericordiam tuam conse
qui merear. Qui vivis et
regnas deus per omnia secu
la seculorum. Amen.
De sancto francisco. Antipho.
Salve sancte
pater pa
trie spes for
ma minorum.
Virtutis spe
culum recta
via regula
morum.
carnis ab exilio duc nos ad re
gna polorum. V. Ora pro nobis

"Saint Francis Receiving the Stigmata: Suffrage to Saint Francis." Two years before his death, Saint Francis received the stigmata (the wounds of Christ) in his hands, feet, and side. Such bodily markings were often represented as a testimony of one's religious faithfulness. From the Playfair Book of Hours (Ms. L.475-1918, Fol. 167r. French [Rouen], late fifteenth century [CT13091]).

Source: Victoria and Albert Museum, London. Photo credit: Victoria and Albert Museum, London/Art Resource, New York.

thrown open to admit the light; the sun had left the window—but if he raised himself up in the bed, he could see the mountains under a blue veil on the other side of the plain, and soon the crimson evening red of the late autumn day burned in the western sky. As the darkness quickly fell, he heard the noise of sheep, which were driven bleating into the stable, and of peasants and peasant girls, who sang on their way home from the fields. They were the wonderful heart-gripping folk-songs of Umbria which the invalid heard—the songs which even to-day are in the people's mouths and whose slow, wonderfully melancholy tones fill the soul with sadness till it is ready to burst with helpless longing and melancholy.

At last the songs ceased and it was night. Over the distant mountains gleamed a single bright star. When that showed itself, it was time to close the shutters and to light the night-lamp—the lamp which in the long nights of fever had constantly burned through the long hours of his uneasy dreams.

To-day there was to be a change—to-day at last he was to have permission to leave his bed. How glad he was to go into the other rooms, to see and touch all the things he had so long missed, and had been so near losing forever. He must even venture down into the business, see the clerks measure the good Tuscan cloth with their yardsticks, and draw in the bright ringing coins.

Just as the young man was busy with these dreams the door opened. As on every morning of his illness, it was his mother who entered. As she threw the shutters aside he saw that she carried, as she brought his morning meal, a suit of man's clothes over her arm.

"I have had a new suit of clothes made for you, my Francis," said she as she laid them down at the foot of the bed.

And as he finished his meal she sat down by the window while he dressed himself.

"What a lovely morning it is," said she, almost as if she were talking to herself. "How brightly the sun shines! I see all the houses over in Bettona so clearly, although there is the whole extent of the broad plain between us, and out in the middle of the green vineyards, Isola Romanesca lies like an island in a lake. And smoke is rising straight up from all the chimneys—as if from a censer in a church. Ah, it seems to me, my Francis, that on such a morning as this, heaven and earth are as beautiful as a church on a feast-day, and that all creatures praise, love and thank God."

To these words Francis gave no answer but silence.

But a moment later he broke out, as he ceased his dressing:

"How weak I am!"

His mother changed the current of her remarks and their tone.

"It is always so, when one has been sick," she said brightly. "As long as you lie in bed you think that you can do anything, but as soon as you get your feet from under the covers you find that it is different. I know this from my own experience, and therefore I had the foresight to bring a stick for you."

And she went to the door and brought in a beautiful polished stick with an ivory handle. Soon after the mother and son together left the sick-room.

But first of all the poor were in his thoughts. To see them, to hear their troubles, to help them in their necessities—there were hereafter his principal concerns. And little by little the desire was firmly established within his heart: "if I could only find by personal experience how it felt to be poor—how it is to be, not one of those who go by and throw down a shilling, but to be the one who stands in rags and dirt, and humbly bowing, stretches out his faded hat for alms!" Many a time, we may think, he stood among the beggars at some church door—stood among them while they pitifully asked for a mite. But it was not like him to do only this. He himself must do the begging in order to understand poverty, and this could not be done in Assisi where everyone knew him.

For the lepers occupied a very particular position among the sick and poor of the Middle Ages. Based on a passage in the Prophet Isaiah (liii.4) the lepers were looked upon as an image of the Redeemer, more than all other sufferers. As early as the days of Gregory the Great we find the story of the monk, Martyrius, who met a leper by the wayside, who from pain and weariness was fallen to the ground and could drag himself no further. Martyrius wrapped the sick man in his cloak and carried him to his convent. But the leper changed in his arms to Jesus himself, who rose to heaven as he blessed the monk, and said to him: "Martyrius, thou wert not ashamed of me on earth; I will not be ashamed of thee in heaven!" A similar legend is told of St. Julian, of St. Leo IX, and of the Blessed Colombini.

And so the lepers were more than any others an object for pious care during the Middle Ages. For them was founded a special order of knights—Knights of Lazarus—whose whole office was to take care of the lepers. So too there were erected all over Europe the numerous houses of St. George, [of which] lepers' homes there were 19,000 in the thirteenth century. But in spite of everything the life of the leper was sad enough, they were repulsed by the rest of humanity, and they were hedged in by severe laws isolating them and hemming them in on all sides.

As with all other cities, there was also in the vicinity of Assisi a lepers' hospital—the lepers were in fact the first real hospital patients and in some languages their name expresses this fact. The hospital lay midway between Assisi and Portiuncula, near where the words *Casa Gualdi* appear over the entrance to a large estate. It was called San Salvatore delle Pareti, and was owned by an order of Crucigers, founded under Alexander III for the care of the lepers.

On his walks in this place, Francis now and then passed by the hospital, but the mere sight of it had filled him with horror. He would not even give an alms to a leper unless some one else would take it for him. Especially when the wind blew from the hospital, and the weak, nauseating odor, peculiar to the leper, came across the road, he would hurry past with averted face and fingers in his nostrils.

It was in this that he felt his greatest weakness, and in it he was to win his greatest victory.

For one day, as he was as usual calling upon God, it happened that the answer came. And the answer was this: "the flesh it is your duty to despise and hate, if you wish to know my will. And when you have begun thus, all that which now seems to you sweet and lovely will become intolerable and bitter, but all which you used to avoid will turn itself to great sweetness and exceeding joy."

These were the words which at last gave Francis a definite programme, which showed him the way he was to follow. He certainly pondered over these words in his lonely rides over the Umbrian plain and, just as he one day woke out of reverie, he found the horse making a sudden movement, and saw on the road before him, only a few steps distant, *a leper,* in his familiar uniform.

Francis started, and even his horse shared in the movement, and his first impulse was to turn and flee as fast as he could. But there were the words he had heard within himself, so clearly before him—"what you used to abhor shall be to you joy and sweetness." . . . And *what* had he hated more than the lepers? Here was the time to take the Lord at His word—to show his good will. . . .

And with a mighty victory over himself, Francis sprang from his horse, approached the leper, from whose deformed countenance the awful odor of corruption issued forth, placed his alms in the outstretched wasted hand—bent down quickly and kissed the fingers of the sick man, covered with the awful disease, whilst his system was nauseated with the action. . . .

When he again sat upon his horse, he hardly knew how he had got there. He was overcome by excitement, his heart beat, he knew not whither he rode. But the Lord had kept his word. Sweetness, happiness, joy streamed into his soul—flowed and kept flowing, although his soul seemed full and more full—like the clear stream which, filling an earthen vessel, keeps on pouring and flows over its rim, with an ever clearer, purer stream. . . .

The next day Francis voluntarily wandered down the road he had hitherto always avoided—the road to San Salvatore delle Pareti. And when he reached the gate he knocked, and when it was opened to him he entered. From all the cells the sick came swarming out—came with their half-destroyed faces, blind inflamed eyes, with club-feet, with swollen, corrupted arms and fingerless hands. And all this dreadful crowd gathered around the young merchant, and the odor from their unclean swellings was so strong that Francis against his will for a moment had to hold his breath to save himself from sickness. But he soon recovered control of himself, he drew out the well-filled purse he had brought with him, and began to deal out his alms. And on every one of the dreadful hands that were reached out to take his gifts he imprinted a kiss, as he had done the day before.

Thus it was that Francis won the greatest victory man can win—the victory over oneself. From now on he was master of himself, and not like the most of us—his own slave.

But even the greatest victor in the spiritual field must be ever on the watch for his always vigilant enemy. Francis had conquered in great things—the tempter tried now to bring him to defeat in small things.

Francis continued as before to go everyday to his oratory in the cave outside the city to pray there. Now it often happened that on the way there he met a humpbacked old woman—one of the common deformed creatures who, in the south, so willingly betake themselves to the sheltering obscurity of the churches. They can be seen there all day long, rattling their rosaries, or dozing in a corner, but the instant a stranger approaches, they draw the kerchief around their heads, limp out from their corner, and mutter piteously with outstretched hand: *"Un soldo, signore! Un soldo, signorino mio!"* (A penny, sir! A penny, sir!)

Such a pitiful old beggar was it who now every day limped across the young man's path. And it happened that in the newly converted young soul there rose a repugnance and a resistance—a repugnance to the dirt and misery of the old woman, a resistance to her troublesome ways and to her persistency. And as he went on his way, and the sun shone, and the fields were green, and the distant mountains showed grey-blue, a voice whispered within him: "And are you willing to give up all this—are you willing to abandon it all? You will give up light and sun, life and joy, the cheerful open-air feasts—and will shut yourself up in a cave and waste your best years in useless prayers, and finally become an old fool, shaking with the palsy, who pitifully wanders about from church to church, and, perhaps in secret, sighs and mourns over his wasted life?"

Thus the wicked enemy whispered into the young man's soul, and this was the moment when Francis's youth and light-loving eyes and knightly soul weakened. But as he reached his cave he always succeeded in conquering himself—and the harder the struggle had been, the deeper was the peace which followed—the joy and the hope—all in converse with God.

Source: O'Connor Sloane, T., trans. 1955. Johannes Jorgensen. *St. Francis of Assisi: A Biography.* Garden City, NY: Doubleday.

▣ Zeami, *Semimaru*
(ca. 1300s)

This version of the story of the fictional character Semimaru was written in fourteenth-century Japan by Zeami. Although many versions of the story exist, all revolve around Semimaru, a blind musician who plays the biwa *(a type of lute). In this version, Semimaru is the son of Emperor Daigo. The play provides a glimpse of how the Japanese viewed disability at the time of its writing. This excerpt begins with Semimaru's banishment—his father has commanded that he be abandoned on Mount Osaka, because his blindness is interpreted as his having failed in his religious obligations in a former life. Semimaru's mentally ill sister Sakagami, who lives as a wanderer, visits him, and they commiserate on how they have fallen from their royal origins.*

Kiyotsura and Attendants
Like lame-wheeled carriages
We creep forth reluctantly
On the journey from the Capital;
How hard it is to say farewell
As dawn clouds streak the east!
Today he first departs the Capital
When again to return? His chances are as fragile
As unraveled threads too thin to intertwine.
Friendless, his destination is unknown.
Even without an affliction
Good fortune is elusive in this world,
Like the floating log the turtle gropes for

Once a century: The path is in darkness
And he, a blind turtle, must follow it.
Now as the clouds of delusion rise
We have reached Mount Osaka
We have reached Mount Osaka.

[*Semimaru sits on a stool before the Chorus. Kiyotsura kneels at the shite-pillar. The Bearers exit through the slit door.*]

Semimaru

Kiyotsura!

Kiyotsura

I am before you.

[*From his kneeling position, he bows deeply.*]

Semimaru

Are you to leave me on this mountain?

Kiyotsura

Yes, your highness. So the Emperor has commanded, and I have brought you this far. But I wonder just where I should leave you.

Since the days of the ancient sage kings
Our Emperors have ruled the country wisely,
Looking after its people with compassion—
But what can his Majesty have had in mind?
Nothing could have caught me so unprepared.

Semimaru

What a foolish thing to say, Kiyotsura. I was born blind because I was lax in my religious duties in a former life.

That is why the Emperor, my father,
Ordered you to leave me in the wilderness,
Heartless this would seem, but it's his plan
To purge in this world my burden from the past,
And spare me suffering in the world to come.
This is a father's true kindness.
You should not bewail his decree.

Kiyotsura

Now I shall shave your head.
His Majesty has so commanded.

Semimaru

What does this act signify?

Kiyotsura

It means you have become a priest,
A most joyous event.

[*Semimaru rises. The stage assistant removes his nobleman's outer robe and places a priest's hat on his head.*]

Semimaru

Surely Seishi's poem described such a scene:
"I have cut my fragrant scented hair
My head is pillowed half on sandalwood."

Kiyotsura

Such splendid clothes will summon thieves, I fear.
Allow me to take your robe and give you instead
This cloak of straw they call a *mino.*

[*Semimaru mimes receiving the mino.*]

Semimaru

Is this the *mino* mentioned in the lines.
"I went to Tamino Island when it rained"?

Kiyotsura

And I give you this *kasa* rainhat
To protect you also from the rain and dew.

[*He takes a kasa from the stage assistant and hands it to Semimaru.*]

Semimaru

Then this must be the *kasa* of the poem
"Samurai—take a kasa for your lord."

[*Semimaru puts down the kasa.*]

Kiyotsura

And this staff will guide you on your way.
Please take it in your hands.

[*He takes a staff from the stage assistant and hands it to Semimaru.*]

Semimaru

Is this the staff about which Henjo wrote:
"Since my staff was fashioned by the gods
I can cross the mountain of a thousand years"?

[*Kiyotsura kneels at the shite-pillar.*]

Kiyotsura

His staff brought a thousand prosperous years,

Semimaru

But here the place is Mount Osaka,

Kiyotsura

A straw-thatched hut by the barrier;

Semimaru

Bamboo pillars and staff, my sole support.

Kiyotsura

By your father, the Emperor,

Semimaru

Abandoned,

Chorus

I meet my unsure fate at Mount Osaka.
You who know me, you who know me not
Behold—this is how a prince, Daigo's son,
Has reached the last extremity of grief.

[*He lowers his head to give a sad expression to his mask.*]

Travelers and men on horses
Riding to and from the Capital,
Many people, dressed for their journeys,
Will drench their sleeves in sudden showers

How hard it is to abandon him,
To leave him all alone—
How hard it is to abandon him,
To tear ourselves away.
[*Kiyotsura bows to Semimaru.*]
But even farewells must have an end;
By the light of the daybreak moon
Stifling tears that have no end, they depart.
[*Weeping, Kiyotsura goes to the bridgeway.*]
Semimaru, the Prince, left behind alone,
Takes in his arms his lute, his one possession,
Clutches his staff and falls down weeping.

[*Semimaru picks up the staff and kasa, comes forward, and turns toward the departing Kiyotsura. Kiyotsura stops at the second pine and looks back at him, then exits. Semimaru retreats, kneels, drops his kasa and staff, and weeps. Hakuga no Sammi enters and stands at the naming-place.*]

Hakuga

I am Hakuga no Sammi. I have learned that Prince Semimaru has been abandoned on Mount Osaka and it pains me so much to think of him at the mercy of the rain and dew that I have decided to build a straw hut where he may live.

[*He opens the door of the hut, then goes to Semimaru at the shite-pillar.*]

The hut is ready at last, I shall inform him of this. [*He bows to Semimaru.*]

Pardon me, sir; Hakuga is before you. If you stay here in this way, you will be soaked by the rain. I have built you a straw hut and I hope you will live in it. Please, come with me.

[*He takes Semimaru's hand and leads him inside the hut, then steps back and bows.*]

If ever you need anything, you have only to summon me, Hakuga no Sammi. I shall always be ready to serve you. I take my leave of you for now.

[*He closes the door of the hut, then exits. Sakagami enters wearing the zo mask. Her robe is folded back from her right shoulder indicating that she is deranged. She stops at the first pine.*]

Sakagami

I am the third child of the Emperor Daigo,
The one called Sakagami, Unruly Hair.
Though born a princess, some deed of evil
From my unknown past in former lives
Causes my mind at times to act deranged.
And in my madness I wander distant ways.
My blueblack hair grows skywards;
Though I stroke it, it will not lie flat.
[*She smooths down her hair.*]

Those children over there—what are they laughing at?

[*She looks to the right as if watching passersby.*]

What? You find it funny that my hair stands on end? Yes,

I suppose hair that grows upside down is funny.
My hair is disordered, but much less than you—
Imagine, commoners laughing at me!

How extraordinary it is that so much before our eyes is upside down. Flower seeds buried in the ground rise up to grace the branches of a thousand trees. The moon hangs high in the heavens, but its light sinks to the bottom of countless waters.

[*She looks up and down.*]
I wonder which of all these should be said to go in the proper direction and which is upside down?
I am a princess, yet I have fallen,
And mingle with the ruck of common men;
[*She proceeds to the stage while chanting.*]
My hair, rising upward from my body,
Turns white with the touch of stars and frost:
The natural order or upside down?
How amazing that both should be within me!
[*She enters the stage.*]
The wind combs even the willows' hair
But neither can the wind untangle,
Nor my hand separate this hair.
[*She takes hold of her hair and looks at it.*]
Shall I rip it from my head? Throw it away?
I lift my sleeved hands—what is this?
The hair-tearing dance? How demeaning!
[*She begins to dance, in a deranged manner.*]

Chorus

As I set forth from the flowery Capital
From the flowery Capital,
At Kamo River what were those mournful cries?
The river ducks? Not knowing where I went
I crossed the river Shirakawa
And when I reached Awataguchi, I wondered,
"Whom shall I meet now at Matsuzaka?"
I thought I had yet to pass the barrier
But soon Mount Otowa fell behind me
How sad it was to leave the Capital!
Pine crickets, bell crickets, grasshoppers,
How they cried in the dusk at Yamashina!
I begged the villagers, "Don't scold me, too!"
I may be mad, but you should know
My heart is a pure rushing stream:
"When in the clear water
At Osaka Barrier
It sees its reflection

The tribute horse from Mochizuki
Will surely shy away."
Have my wanderings brought me to the same place?
In the running stream I see my reflection.
Though my own face, it horrifies me:
Hair like tangled briers crowns my head
Eyebrows blackly twist—yes, that is really
Sakagami's reflection in the water.
Water, they say, is a mirror,
But twilight ripples distort my face.

[*Sakagami sits at the stage assistant's position, indicating she has arrived at Mount Osaka. Semimaru, inside the hut, opens his fan and holds it in his left hand as if playing his lute.*]

Semimaru

The first string and the second wildly sound
The autumn wind brushes the pines and falls
With broken notes; the third string and the fourth
The fourth is myself, Semimaru,
And four are the strings of the lute I play
As sudden strings of rain drive down on me
How dreadful is this night!
"All things in life
In the end are alike;
Whether in a palace or a hovel
We cannot live forever."

[*While Semimaru is speaking Sakagami comes before the shite-pillar. Semimaru inclines his head toward her as she speaks.*]

Sakagami

How strange—I hear music from this straw-thatched hut,
The sounds of a *biwa,* elegantly plucked—
To think a hovel holds such melodies!
But why should the notes evoke this sharp nostalgia?
With steps silent, as the rain beating on the thatch
She stealthily approaches, stops and listens.

[*She silently comes to stage center. Semimaru folds his fan.*]

Semimaru

Who is there? Who's making that noise outside my hut?
Hakuga no Sammi, lately you've been coming
From time to time to visit me—is that you?

Sakagami

As I approach and listen carefully—that's the voice of my brother, the Prince!
It's Sakagami! I'm here!
Semimaru, is that you inside?

Semimaru

Can it be my sister, the Princess?
Amazed, he opens the door of his hut.

[*Taking his staff he rises and opens the door.*]

Sakagami

Oh—how wretched you look!

[*She comes up to Semimaru as he emerges from the hut.*]

Semimaru

They take each other hand in hand

[*They place their hands on each other's shoulders and kneel.*]

Sakagami

My royal brother,
is that indeed you?
Semimaru
My royal sister,
is that indeed you?

Chorus

They speak each other's names as in one voice.
Birds are also crying, here at Osaka,
Barrier of meeting—but no barrier
Holds back the tears that soak each other's sleeves.

[*Both weep. During the following passage Sakagami returns to the middle of the stage and kneels.*]

Chorus

They say that sandalwood reveals its fragrance
From the first two leaves—but how much closer still
Are we who sheltered beneath a single tree!
The wind rising in the orange blossoms
Awakens memories we shall preserve
We who flowered once on linking branches!
The love between brothers is told abroad:
Jozo and Jogen, Sori and Sokuri;
And nearer at hand, in Japan
The children of Emperor Ojin,
The princes Naniwa and Uji,
Who yielded the throne, each to the other:
All these were brothers and sisters
Bound in love, like us, like linking branches.

Sakagami

But did I imagine my brother
Would ever live in such a hovel?

Chorus

Had no music come from that straw-thatched hut
How should I have known? But I was drawn
By the music of those four strings,

Sakagami

Drawn like the water offered to the gods

Chorus

From deep wells of love and far-reaching ties.

The world may have reached its final phase
But the sun and moon have not dropped to the ground.
Things are still in their accustomed place, I thought,
But how can it be, then, that you and I
Should cast away our royalty and live like this,
Unable even to mingle with common men?
A mad woman, I have come wandering now
Far from the Capital girdled by clouds,
To these rustic scenes, a wretched beggar,
By the roads and forests, my only hope
The charity of rustics and travelers.
To think it was only yesterday you lived
In jeweled pavilions and golden halls;
You walked on polished floors and wore bright robes.
In less time than it takes to wave your sleeve,
Today a hovel is your sleeping-place.
Bamboo posts and bamboo fence, crudely fashioned
Eaves and door: straw your window, straw the roof,
And over your bed, the quilts are mats of straw:
Pretend they are your silken sheets of old.

Semimaru
My only visitors—how rarely they come—
Are monkeys on the peak, swinging in the trees;
Their doleful cries soak my sleeve with tears.
I tune my lute to the sound of the showers,
I play for solace, but tears obscure the sounds.
Even rain on the straw roof makes no noise.
Through breaks in the eaves moonlight seeps in.
But in my blindness, the moon and I are strangers.
In this hut I cannot even hear the rain—
How painful to contemplate life in this hut!
[*Both weep.*]

Sakagami
Now I must go; however long I stayed
The pain of parting never would diminish.
Farewell, Semimaru.
[*Both rise.*]

Semimaru
If sheltering under a single tree
Were our only tie, parting would still be sad;
How much sadder to let my sister go!
Imagine what it means to be alone!
[*Sakagami moves toward the shite-pillar.*]

Sakagami
Truly I pity you; even the pain
Of wandering may provide distraction,
But remaining here—how lonely it will be!
Even as I speak the evening clouds have risen,
I rise and hesitate; I stand in tears.
[*She weeps.*]

Semimaru
The evening crows call on the barrier road,
Their hearts unsettled

Sakagami
As my raven hair,
My longing unabated, I must go.

Semimaru
Barrier of Meeting, don't let her leave!

Sakagami
As I pass by the grove of cedars
[*She goes to the first pine.*]

Semimaru
Her voice grows distant . . .

Sakagami
By the eaves of the straw hut . . .

Semimaru
I stand hesitant.

Chorus
"Farewell," she calls to him, and he responds,
"Please visit me as often as you can."
[*Sakagami goes to the third pine and turns back to look at Semimaru.*]
Her voice grows faint but still he listens,
[*Sakagami starts to exit. Semimaru takes a few steps forward, stops and listens. His blind eyes gaze in her direction.*]
She turns a final time to look at him.
Weeping, weeping they have parted,
Weeping, weeping they have parted.
[*Sakagami exits, weeping. Semimaru also weeps.*]

Source: Matisoff, Susan, trans.; Keene, Donald, ed. 1970. *Semimaru: Twenty Plays of the No Theatre.* New York: Columbia University Press. Available at http://etext.lib.virginia.edu/japanese/noh/KeeSemi.html

Bernard de Gordon, from *Lilium Medicinae* (1307)

Bernard de Gordon, a Scottish physician, devoted a chapter of his medical text Lilium Medicinae ("Lilies of Medicine") to the origins and treatment of leprosy. He described 11 different types of treatment for the disease; while acknowledging that the advanced form of the disease is incurable, he believed in the value of life-prolonging and palliative care. His description in this excerpt of a female patient with leprosy who was under his care indicates that at least some medieval leprosy patients did have access to medical care.

Barthelemy l'Anglais, Livre des proprieté des choses (Ms. 22532. France, fifteenth century). Patient giving urine sample during a medical examination. Medieval depiction of medical scrutiny of bodily fluids as mode of diagnosis and scrutiny of health.

Source: Bibliothèque Nationale, Paris. Photo credit: D.Y./Art Resource, New York.

Leprosy is either introduced from within the uterus, or after birth. If from within the uterus, it is because of conception at the time of menstruation, or because it is the child of a leper, or because a leper has had intercourse with a pregnant woman and thus the baby will be leprous, for leprosy is generated out of these great corruptions that befall the conception. If it should happen after birth, this can be because the air is bad, corrupted and pestilential, or because of prolonged use of melancholic foods, such as lentils and other legumes, and from such melancholic meats as that of foxes, bears, wild boars, hares and other quadrupeds such as asses and the like, since in some regions all wild animals are eaten. Leprosy also arises from too much company with lepers, and from coitus with a leprous woman. And also in him who lies with a woman who has lain with a leper whose seed still remains in her womb. For, from coitus with a leper the woman is not infected unless she continues a long time, because of the density of the womb. But if a healthy man lies with a woman with whom a leper has lain, the leper's semen yet remaining in her womb, he will necessarily become leprous because the pores are loose in the male and the infection readily moves to the whole body. Therefore most extraordinary precaution is to be observed, and if some bad circumstance necessitates it, one should work to expel the seed from the womb by dancing, sneezing, bathing, and rinsing the womb with cleansing agents. Furthermore, such measures should be taken as far in advance as possible; and there are many other means, which need not be recited, of expelling the received semen. Without these, one should be prepared for the gourd [i.e., the beggar's cup], [life under] the stars, and everlasting disgrace. Everyone ought to guard against lying with a leprous woman, and I will tell what happened: a certain countess came leprous to Montpellier, and in the end she was under my treatment. A bachelor in medicine who attended to her, lay with her and impregnated her, and he was made completely leprous. Fortunate therefore is he who is made cautious by the dangers of others.

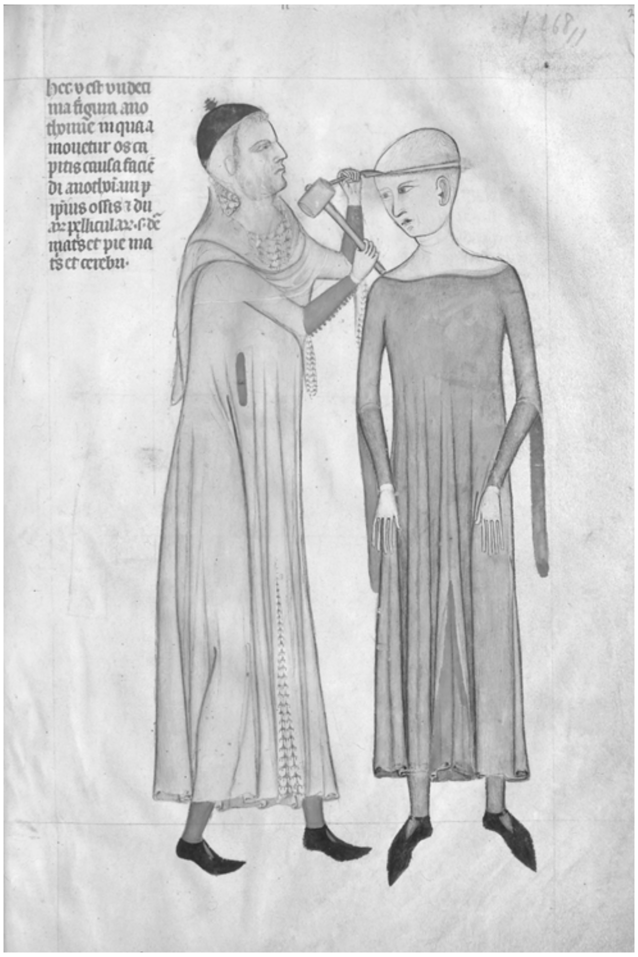
Source: Quoted in Holcomb, Richmond C. 1941. "The Antiquity of Congenital Syphilis." *Bulletin of the History of Medicine* 10:148–167.

Edward III, *Ordinance of Labourers* (1349)

In the Ordinance of Labourers, King Edward III attempted—unsuccessfully, as it turned out—to prevent wages from increasing because of the labor shortage caused by a recent outbreak of the bubonic plague. The ordinance is one of the first European poor laws that seeks to punish individuals for refusing to labor and return them to some form of work.

Because that many valiant beggars, as long as they may live of begging, do refuse to labor, giving themselves to idleness and vice, and sometime to theft and other abominations; none upon the said pain of imprisonment, shall under the color of pity or alms, give anything to such, which may labor, or presume to favor them towards their desires, so that thereby they may be compelled to labor for their necessary living.

Source: Edward III. 1349. *Ordinance of Labourers.* Available at http://www.britannia.com/history/ docs/ laborer1.html



Guy de Pavia (fourteenth century), Doctor Operating on a Man's Skull (Liber notabilium Philippi septimi, francorum regis, a libris Galieni extractus, by Guy de Pavia. Italian manuscript, 1345. Ms. 333/562, fol. 11). A fourteenth-century example of medical intervention through the skull.

Source: Musée Condé, Chantilly, France. Photo credit: Giraudon/ Art Resource, New York.

Saint Lidwina of Schiedam (1380–1433)

Saint Lidwina (Lydwine) lived in Schiedam (Holland). The text provides a glimpse of how illness and suffering provided a context for the experience of divine revelation. In particular, her story illustrates the strong tradition within Christianity of viewing suffering, if embraced willingly, as having the potential to lead to holiness and even to sensory experiences of God.

At the age of 15 Lidwina broke a rib while ice skating and remained bedridden for the rest of her life. She put her illness to a supernatural purpose. She was suffering voluntarily for the welfare of the Church. She fasted during this entire time when she was bedridden and was found often in ecstasy. It is interesting to note that the name Lidwina (a formalization of Lidie) comes from the Dutch word "lijden" which means to suffer. The aid of physicians were enlisted by Lidwina's parents to seek a cure for her disease. She was in intense pain, sobbed on her bed in a state of terrible abandonment, was given to constant vomiting, suffered burning fevers and could not hold down food of any kind. This situation lasted for three years . . .

Then followed a relatively blissful period but she was still confined to bed and could not get up. In the following years she still suffered greatly from abscesses, inflamed sores, and it was said she was near death twenty-two times. At the age of 28, the coldest winter ever experienced in Holland set in, when even the fish froze in the rivers, the tears she shed at night froze to her face. From the Third Order of Saint Francis in Schiedam she received a woolen shirt to wear, however she was not a member of that lay order.

Saint Lidwina . . . continued to suffer and the more she suffered, apparently, the more she was given God's Gift of contemplation and bilocation. She was given to be in two places at once, when Jesus asked her to be with him at Golgotha. In answer to His request, Lidwina replied: "O Saviour, I am ready to accompany you to that mountain and to suffer and die there with you!" (Huysmans, 1923)

"He took her with Him, and when she returned to her bed, which corporeally she had never left, they saw ulcers on her lips, wounds on her arms, the marks of thorns on her forehead and splinters on her limbs, which exhaled a very pronounced perfume of spices." A number of miraculous healings were reported. For example, Lidwina prayed for a woman, a friend of hers, who had a frightful toothache. The woman's pain ceased immediately. Also, another woman came to her to ask for her intercession for her child who was screaming with pain. When the child was placed on Lidwina's bed his troubles disappeared. When the child grew up, he became a priest in memory of Lidwina. Additional miracles continued after her death and she is not forgotten.

Source: Huysmans, J. K. 1979. *Saint Lidwina of Schiedam.* Hastings, Agnes, trans. Rockford, IL: Tan Books.

Distribution of Alms to Poor and Lame*, fifteenth century. Stained glass depiction of organized efforts to give charity to disabled people unable to work or refused employment. The figure distributing help is literally mobbed by those seeking food and drink. English (Coventry?), stained glass.*

Source: Victoria and Albert Museum, London. Photo credit: Victoria and Albert Museum, London/Art Resource, New York.

▣ *The Book of Margery Kempe,* Chapter 74 (ca. 1430)

Margery Kempe was a well-respected merchant-class wife and mother of 14 children in fifteenth-century England. Her comfortable position in the social hierarchy began to change, however, following the vision of Jesus she experienced after the birth of her first child. Thereafter, her increasing commitment to attaining holiness brought her into conflict with the hierarchy of her town, as her community tried to determine whether her holiness—which led her, for example, to succumb to fits of loud weeping during church services—was genuine. In the following excerpt, which echoes the selection about St. Francis of Assisi, Kempe is told by Jesus that if she truly loves him and his suffering, she must learn to overcome her revulsion from persons with leprosy. Accordingly, she visits two women with leprosy, kisses their sores, and tries to befriend and comfort them.

The sayd creatur on a day, heryng hir messe and revolvyng in hir mende the tyme of hir deth, sor syhyng and sorwyng for it was so long delayd, seyd on this maner, “Alasse, Lord, how long schal I thus wepyn and mornyn for thy lofe and for desyr of thy presens?” Owr Lord answeryd in hir sowle and seyd, “Al this fifteen yer.” Than seyd sche, “A, Lord, I schal thynkyn many thowsend yerys.” Owr Lord answeryd to hir, “Dowtyr, thu must bethynkyn the of my blissyd modyr that levyd aftyr me in erth fifteen yer, also Seynt John

Saint Lawrence Distributing Alms to the Poor, *by Fra Angelico (1387–1455). In order to thwart the greed of the prefect of Rome, who sought to raid the wealth of the church, St. Lawrence gathered up the poor and lame. On the appointed collection day he invited the prefect to accompany him to view the "wondrous riches of our God." Fresco.*

Source: Cappella Niccolina, Vatican Palace, Vatican State. Photo credit: Scala/Art Resource, New York.

the Evangelyst, and Mary Mawdelyn, the whech lovyd me rith hyly." "A, blysful Lord," seyd sche, "I wolde I wer as worthy to ben sekyr of thy lofe as Mary Mawdelyn was." Than seyd owr Lord, "Trewly, dowtyr, I love the as wel, and the same pes that I gaf to hir the same pes I geve to the. For, dowtyr, ther is no seynt in hevyn displesyd thow I love a creatur in erde as mech as I do hem. Therfor thei wil non otherwyse than I wil." Thus owr mercyful Lord Crist Jhesu drow hys creatur unto hys lofe and to mynde of hys passyon that sche myth not duryn to beheldyn a lazer er an other seke man, specialy yyf he had any wowndys aperyng on hym. So sche cryid and so sche wept as yyf sche had sen owr Lord Jhesu Crist wyth hys wowndys bledyng. And so sche dede in the syght of hir sowle, for thorw the beheldyng of the seke man hir mende was al takyn into owr Lord Jhesu Crist. Than had sche gret morning and sorwyng for sche myth not kyssyn the lazerys whan sche sey hem er met with hem in the stretys for the lofe of Jhesu. Now gan sche to lovyn that sche had most hatyd befor tyme, for ther was no thyng mor lothful ne mor abhomynabyl to hir whil sche was in the yerys of werldly prosperité than to seen er beheldyn a lazer, whom now thorw owr Lordys mercy sche desyryd to halsyn and kyssyn for the lofe of Jhesu whan sche had tyme and place convenyent. Than sche teld hir confessowr how gret desyre sche had to kyssyn lazerys, and he warnyd hir that sche schulde kyssyn no men, but, yyf sche wolde algatys kyssyn, sche schuld kyssyn women. Than was sche glad, for sche had leve to kyssyn the seke women and went to a place wher seke women dwellyd whech wer ryth ful of the sekenes and fel down on hir kneys beforn hem, preyng hem that sche myth kyssyn her mowth for the lofe of Jhesu. And so sche kyssyd ther two seke women with many an holy thowt and many a devowt teer, and, whan sche had kyssyd hem and telde hem ful many good wordys and steryd hem to mekenes and pacyens that thei schulde not grutchyn wyth her sekenes but hyly thankyn God therfor and thei schulde han gret blysse in hevyn thorw the mercy of owr Lord Jhesu Crist, than the oo woman had so many temptacyons that sche wist not how sche myth best be governyd. Sche was so labowryd wyth hir gostly enmy that sche durst not blissyn hir ne do no worschep to God for dreed that the devyl schuld a slayn hir. And sche was labowryd wyth many fowle and horibyl thowtys, many mo than sche cowde tellyn. And, as sche seyd, sche was a mayde. Therfor the sayd creatur went to hir many tymys to comfortyn hir and preyd for hir, also ful specialy that God schulde strength hir ageyn hir enmye, and it is to belevyn that he dede so, blissyd mote he ben.

Source: Staley, Lynn, ed. 1996. *The Booke of Margery Kempe.* Kalamazoo, MI: Medieval Institute Publications.

Sir Thomas Malory, *The Book of King Arthur and His Noble Knights of the Round Table* (ca. 1470)

In the following selection, clearly reminiscent of biblical healing accounts, we see Galahad performing two miraculous healings. This excerpt immediately follows the chapter in which Galahad and his followers were fed from the Sangreal (the Holy Grail) and thus is intended to illustrate the transmission of Jesus' healing power by means of the grail.

Book 17, Chapter 21

How Galahad Anointed with the Blood of the Spear the Maimed King, and Other Adventures

And Galahad went anon to the spear which lay upon the table, and touched the blood with his fingers, and came after to the maimed king and anointed his legs. And therewith he clothed him anon, and start upon his feet out of his bed as an whole man, and thanked Our Lord that He had healed him. And that was not to the world ward, for anon he yielded him to a place of religion of white monks, and was a full holy man. . . .

Truly, said Percivale, in the name of God, well hath my sister holden us covenant. Then took they out of the ship the table of silver, and he took it to Percivale and to Bors, to go to fore, and Galahad came behind. And right so they went to the city, and at the gate of the city they saw an old man crooked. Then Galahad called him and bade him help to bear this heavy thing. Truly, said the old man, it is ten year ago that I might not go but with crutches. Care thou not, said Galahad, and arise up and shew thy good will. And so he essayed, and found himself as whole as ever he was. Then ran he to the table, and took one part against Galahad. And anon arose there great noise in the city, that a cripple was made whole by knights marvellous that entered into the city.

Source: Eliot, Charles W., trans. 1909–1914. *The Holy Grail, by Sir Thomas Malory.* New York: P. F. Collier & Son, 1909–14.

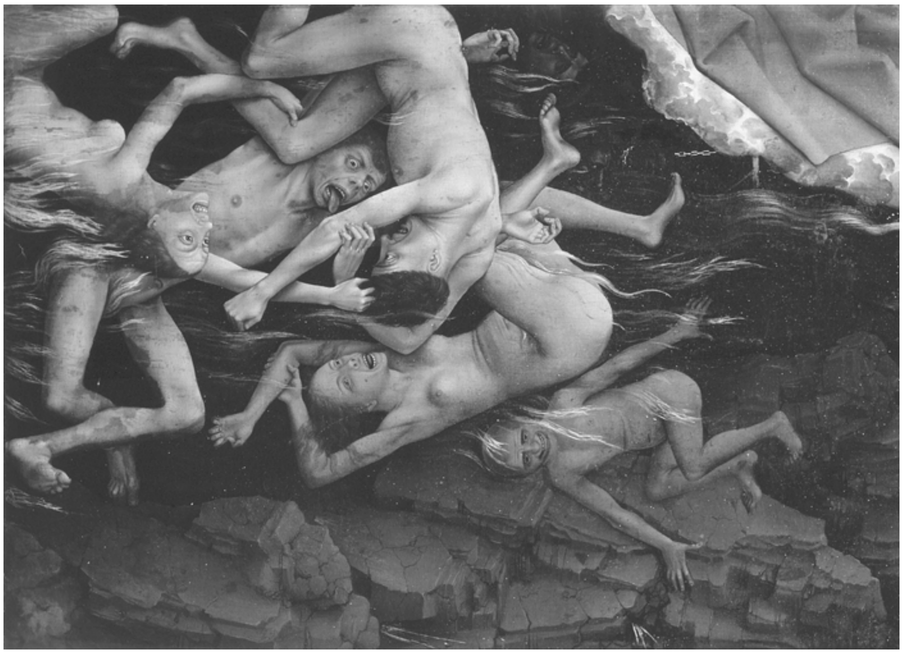
St. Wolfgang Heals the Possessed Woman Brought before Him, *by Michael Pacher (ca. 1434–1498) and Friedrich Pacher (1475–1481). In the background is the building of the church at St. Wolfgang. Closed Saint Wolfgang Altar (workday view). Examples of individuals with psychiatric disabilities were often treated as metaphysical signs of possession by the devil. In this illustration, some of the violence of exorcism is captured in the scene of restraint as the woman is dragged to the throne of St. Wolfgang.*

Source: St. Wolfgang Church, St. Wolfgang, Austria. Photo credit: Erich Lessing/Art Resource, New York.

Christopher Columbus, from a Letter to Ferdinand and Isabella (1493)

In this excerpt from one of the early announcements of the "discovery" of the New World, taken from a letter to King Ferdinand and Queen Isabella of Spain, Columbus uses the absence of disease or deformity to create a utopian vision of native life on the islands around Hispaniola. In doing so, he participates in a common characteristic of European travel narrative writing, which constructs racialized societies as locations unfamiliar with conditions that ravaged Europe at the time.

The inhabitants of both sexes in this island, and in all the others which I have seen, or of which I have received information, go always naked as they were



Last Judgment: Detail of the Damned in Hell, *by Rogier (Roger) van der Weyden (ca. 1399–1464). Representations of condemned individuals in the underworld often characterize them as having deformed bodies as a symbol of their torment and immorality.*

Source: Hotel-Dieu, Beaune, France. Photo credit: Giraudon/Art Resource, New York.

born, with the exception of some of the women, who use the covering of a leaf, or small bough, or an apron of cotton which they prepare for that purpose. None of them, as I have already said, are possessed of any iron, neither have they weapons, being unacquainted with, and indeed incompetent to use them, not from any deformity of body (for they are well-formed), but because they are timid and full of fear. They carry however in lieu of arms, canes dried in the sun, on the ends of which they fix heads of dried wood sharpened to a point, and even these they dare not use habitually; for it has often occurred when I have sent two or three of my men to any of the villages to speak with the natives, that they have come out in a disorderly troop, and have fled in such haste at the approach of our men, that the fathers forsook their children and the children their fathers. This timidity did not arise from any loss or injury that they had received from us; for, on the contrary, I gave to all I approached whatever articles I had about me, such as cloth and many other things, taking nothing of theirs in return: but they are naturally timid and fearful. As soon however as they see that they are safe, and have laid aside all fear, they are very simple and honest, and exceedingly liberal with all they have; none of them refusing any thing he may possess when he is asked for it, but on the contrary inviting us to ask them.

Source: From a letter to Ferdinand and Isabella, King and Queen of Spain, in which Christopher Columbus describes his first voyage to the New World (1493). In Jehlen, Myra and Michall Warner, eds. 1997. P. 13 in *The English Literatures of America 1500–1800.* New York: Routledge.

▣ Erasmus of Rotterdam, *The Praise of Folly* (1511)

In The Praise of Folly, the Renaissance humanist Erasmus of Rotterdam used Folly (a personification of foolishness or stupidity) as the speaker in order to level real criticisms at his society. The work takes the form of a classical encomium, with Folly speaking her praise of herself, especially with reference to the many people and institutions (including governments and churches) that depend on her so much. In the selection excerpted here, Folly speaks in praise of "fools" and "madmen," but readers should keep in mind that Erasmus's heavy irony suggests anything but true praise of cognitively disabled and mentally ill individuals.

But to return to the happiness of fools, who when they have passed over this life with a great deal of pleasantness and without so much as the least fear or sense of death, they go straight forth into the Elysian field, to recreate their pious and careless souls with such sports as they used here. Let's proceed then, and compare the condition of any of your wise men with that of this fool. Fancy to me now some example of wisdom you'd set up against him; one that had spent his childhood and youth in learning the sciences and lost the sweetest part of his life in watchings, cares, studies, and for the remaining part of it never so much as tasted the least of pleasure; ever sparing, poor, sad,

Minerva Chasing the Vices out of the Garden, *by Andreas Mantegna (1431–1506). The vices on exhibit in the lower left are identified with a variety of denigrated body types, including racialized and disability characteristics. Visual artists have often employed bodily difference as a sign of divine disfavor. Minerva, in full military regalia, dominates the scene by virtue of her own classical figure. Oil on canvas.*

Source: Louvre, Paris. Photo credit: Réunion des Musées Nationaux/Art Resource, New York.

sour, unjust, and rigorous to himself, and troublesome and hateful to others; broken with paleness, leanness, crassness, sore eyes, and an old age and death contracted before their time (though yet, what matter is it, when he die that never lived?); and such is the picture of this great wise man.

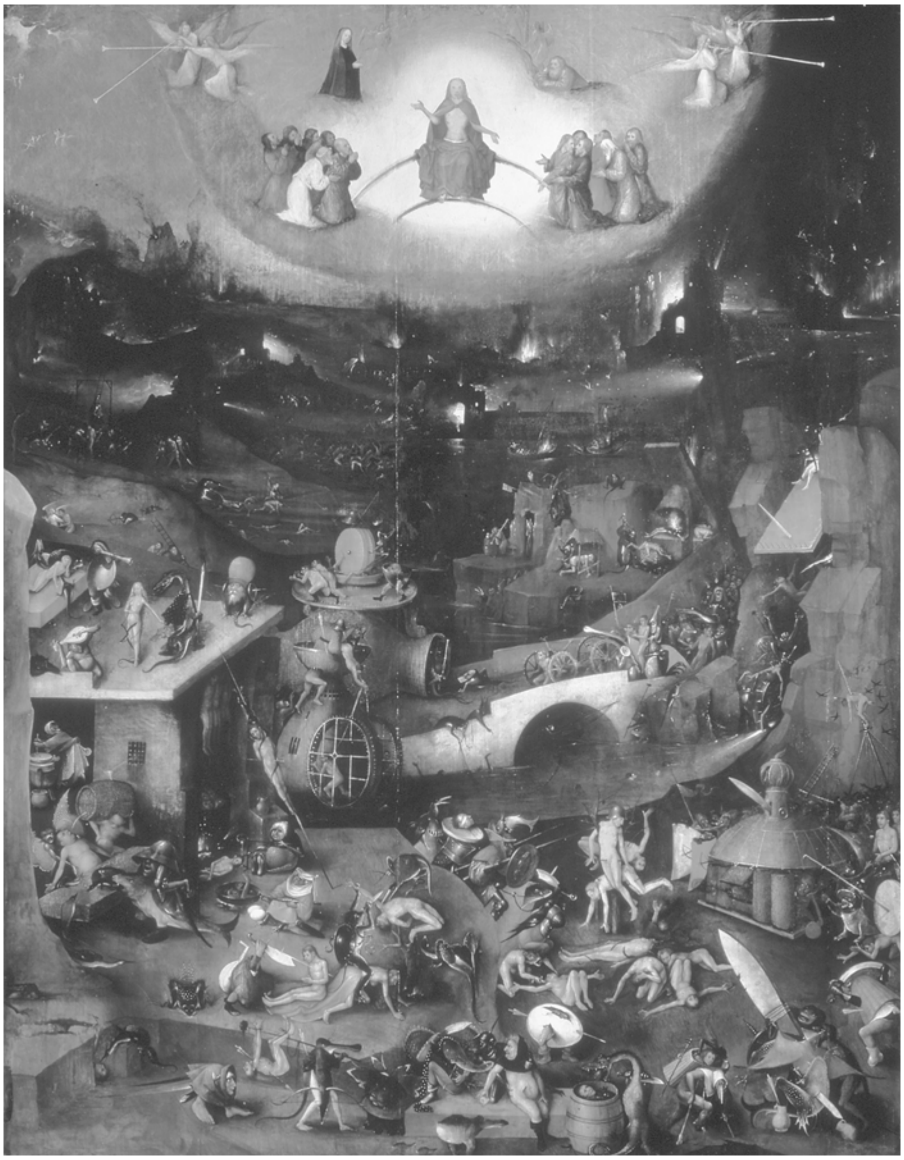
And here again do those frogs of the Stoics croak at me and say that nothing is more miserable than madness. But folly is the next degree, if not the very thing. For what else is madness than for a man to be out of his wits? But to let them see how they are clean out of the way, with the Muses' good favor we'll take this syllogism in pieces. Subtly argued, I must confess, but as Socrates in Plato teaches us how by splitting one Venus and one Cupid to make two of either, in like manner should those logicians have done and distinguished madness from madness, if at least they would be thought to be well in their wits themselves. For all madness is not miserable, or Horace had never called his poetical fury a beloved madness; nor Plato placed the raptures of poets, prophets, and lovers among the chiefest blessings of this life; nor that sibyl in Virgil called Aeneas' travels mad labors. But there are two sorts of madness, the one that which the revengeful Furies send privily from hell, as often as they let loose their snakes and put into men's breasts either the desire of war, or an insatiate thirst after gold, or some dishonest love, or parricide, or incest, or sacrilege, or the like plagues, or when they terrify some guilty soul with the conscience of his crimes; the other, but nothing like this, that which comes from me and is of all other things the most desirable; which happens as often as some pleasing dotage not only clears the mind of its troublesome cares but renders it more jocund. And this was that which, as a special blessing of the gods, Cicero, writing to his friend Atticus, wished to himself, that he might be the less sensible of those miseries that then hung over the commonwealth.

Nor was that Grecian in Horace much wide of it, who was so far made that he would sit by himself whole days in the theatre laughing and clapping his hands, as if he had seen some tragedy acting, whereas in truth there was nothing presented; yet in other things a man well enough, pleasant among his friends, kind to his wife, and so good a master to his servants that if they had broken the seal of his bottle, he would not have run mad for it. But at last, when by the care of his friends and physic he was freed from his distemper and become his own man again, he thus expostulates with them, "Now, by Pollux, my friends, you have rather killed than preserved me in thus forcing me from my pleasure." By which you see he liked it so well that he lost it against his will. And trust me, I think they were the madder of the two, and had the greater need of hellebore, that should offer to look upon so pleasant a madness as an evil to be removed by physic; though yet I have not determined whether every distemper of the sense or understanding be to be called madness.

For neither he that having weak eyes should take a mule for an ass, nor he that should admire an insipid poem as excellent would be presently thought mad; but he that not only errs in his senses but is deceived also in his judgment, and that too more than ordinary and upon all occasions— he, I must confess, would be thought to come very near to it. As if anyone hearing an ass bray should take it for excellent music, or a beggar conceive himself a king. And yet this kind of madness, if, as it commonly happens, it turn to pleasure, it brings a great delight not only to them that are possessed with it but to those also that behold it, though perhaps they may not be altogether so mad as the other, for the species of this madness is much larger than the people take it to

Saint Bernard Exorcising an Evil Spirit, *and* Death of Saint Bernard of Clairvaux, *by Joerg Breu, the Elder (1475–1537). Panel from the Altar of Saint Bernard. Tempera on wood. 1500, 74 × 74 cm. Another image in the long tradition of visual representations of the use of exorcism of evil spirits as an intervention for those with psychiatric conditions.*

Source: Sammlungen des Stiftes, Zwettl, Austria. Photo credit: Erich Lessing/Art Resource, New York.



The Last Judgement *(ca. 1500), by Hieronymous Bosch (1450–1516). Central panel of triptych. Oil on oakwood, 164 × 127 cm. One of Bosch's most famous paintings, depicting the scene of judgment day as a chaos. As in the van Leyden painting on the same theme, many of the figures receiving punishment have visibly twisted, stunted, or defaced bodies that indicate their immoralilty. Disability has served as a form of artistic shorthand for human degeneration.*

Source: Akademie der Bildenden Kuenste, Vienna, Austria. Photo credit: Erich Lessing/Art Resource, New York.

be. For one mad man laughs at another, and beget themselves a mutual pleasure. Nor does it seldom happen that he that is the more mad, laughs at him that is less mad. And in this every man is the more happy in how many respects the more he is mad; and if I were judge in the case, he should be ranged in that class of folly that is peculiarly mine, which in truth is so large and universal that I scarce know anyone in all mankind that is wise at all hours, or has not some tang or other of madness.

Source: Erasmus, Desiderius. 1668. *The Praise of Folly*. John Wilson, trans. Available at http://etext.library.adelaide.edu.au/e/erasmus/praise/e65p.html

Part Two

Modernity and Normalization

▣ 1500–1800 ▣ 1800–1945

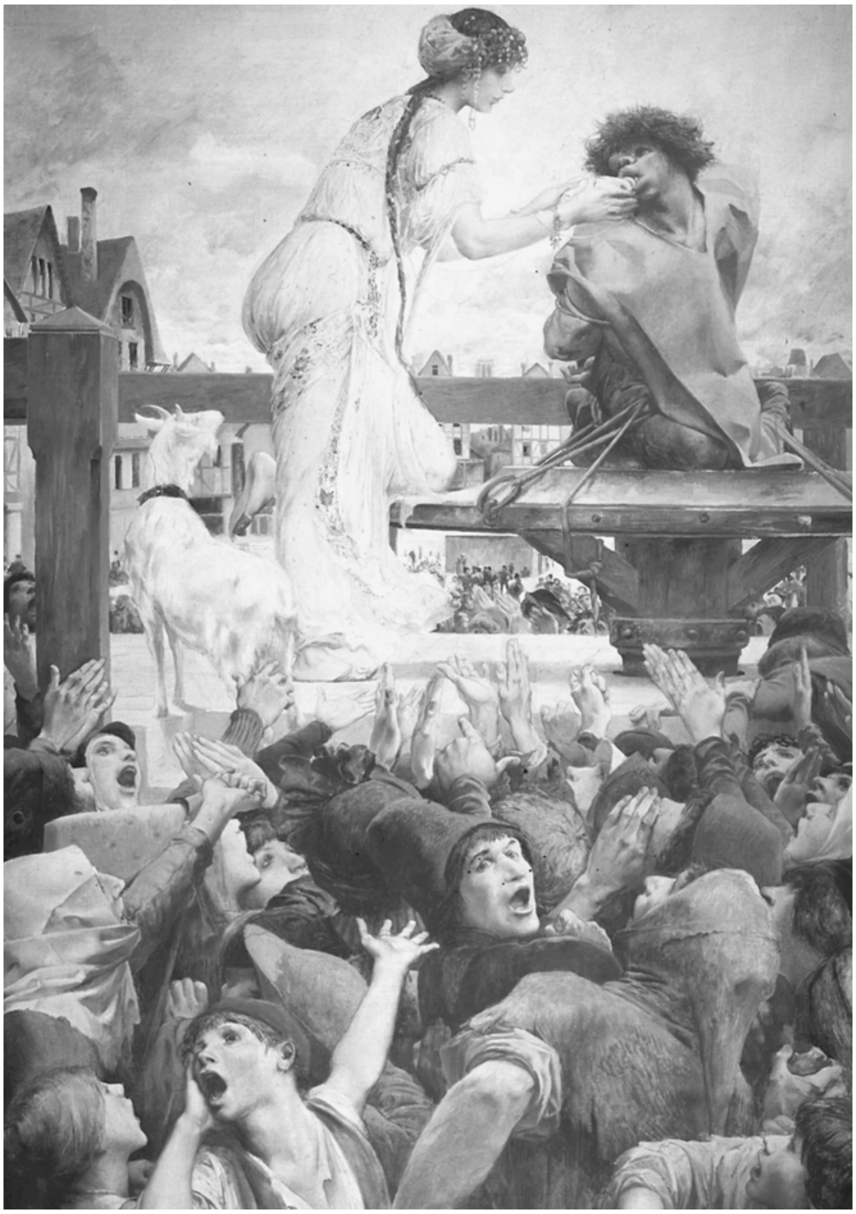


Illustration for The Hunchback of Notre Dame: *"Esmeralda Feeds Quasimodo," by Luc Olivier Merson (1846–1920). As the disabled Quasimodo is exhibited for public ridicule, the female protagonist, Esmeralda, experiences a moment of empathy and provides relief for his dehydration.*

Source: Art Resource, New York.

Modernity and Normalization: 1500–1800

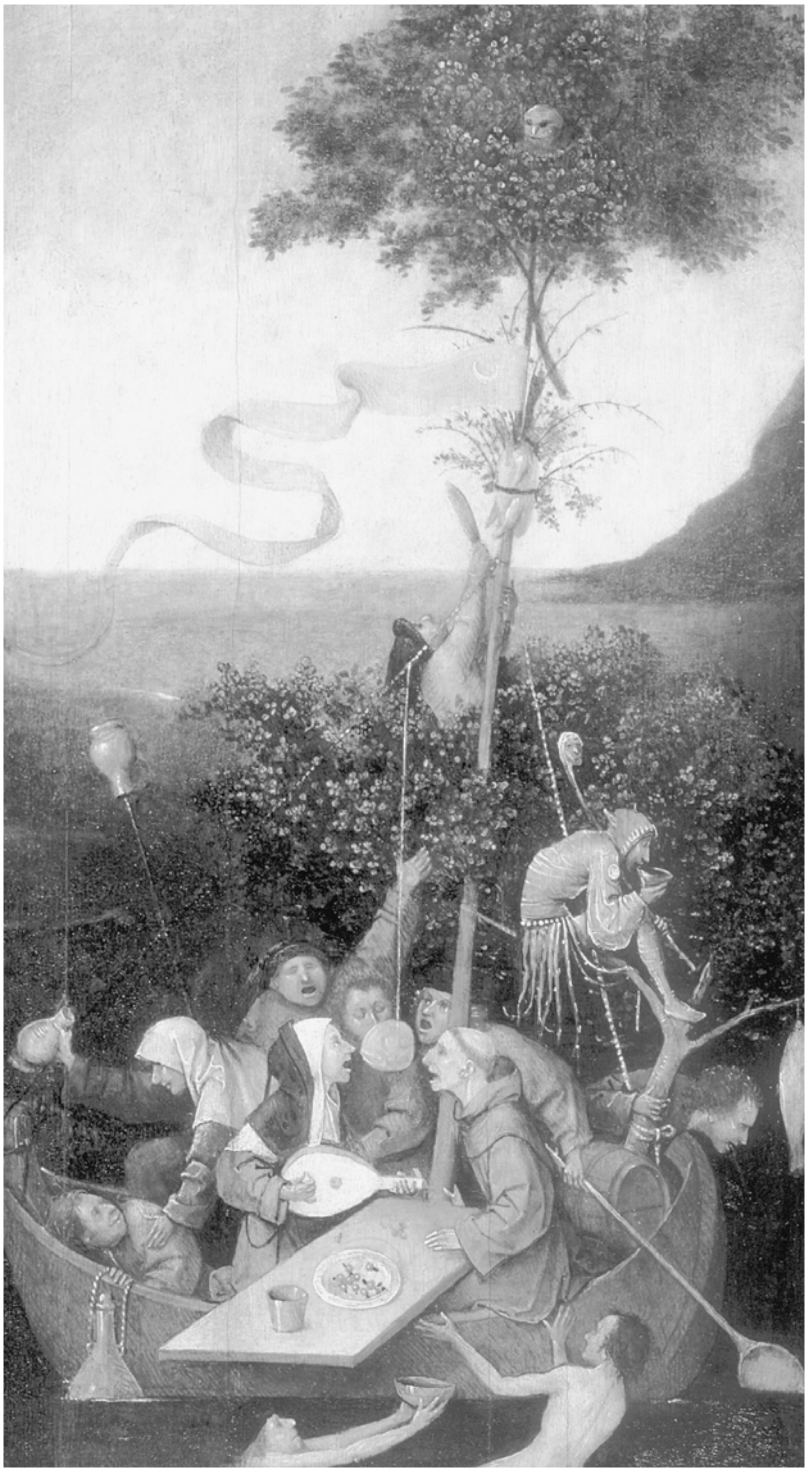
Busbecq on the Murder of Mustapha (1553)

The French diplomat Ogier Ghiselin de Busbecq was near at hand at the time, and soon after the event he weighed and sifted various accounts of the grim execution of Prince Mustapha and the subsequent death of Prince Jehangir to send a detailed and circumstantial report back to France. The excerpt provides a glimpse into the role played by mute servants in the sultan's court.

There was great uneasiness among the soldiers, when Mustapha arrived in the camp. He was brought to his father's tent, and there everything betokened peace. There was not a soldier on guard, no aide-de-camp, no policeman, nothing that could possibly alarm him and make him suspect treachery. But there were in the tent certain mutes—a favourite kind of servant among the Turks—strong and sturdy fellows, who had been appointed as his executioners. . . . As soon as he entered the inner tent, they threw themselves upon him, and endeavoured to put the fatal noose around his neck. Mustapha, being a man of considerable strength, made a stout defence, and fought. . . . Solyman felt how critical the matter was, being only separated by the linen hangings of his tent from the stage, on which this tragedy was being enacted. When he found that there was an unexpected delay in the execution of his scheme, he thrust out his head from the chamber of his tent, and glared on the mutes with fierce and threatening eyes; at the same time, with signs full of hideous meaning, he sternly rebuked their slackness. Hereon the mutes, gaining fresh strength from the terror he inspired, threw Mustapha down, got the bowstring round his neck, and strangled him. [Editors' note: M. Miles (2000. "Signing in the Seraglio: Mutes, Dwarfs and Jestures at the Ottoman Court 1500–1700." *Disability & Society* 15:115–134) notes that Busbecq's original Latin reads: "at erant muti aliquot, quos Turcae habent in deliciis, validi & robustii homines, ad caedem ejus destinati" and comments that "in the translation, the word 'servant' seems to be an insertion based on the known history of service by deaf-mutes at the Ottoman court."]

Jehangir, the youngest [of Sultan Suleiman's sons] is dead. . . . The news of Mustapha's death, when it arrived at Constantinople, overwhelmed the young prince with terror and dismay. The poor lad, whose person was disfigured by a hump, had no strength of mind or body to enable him to resist the shock. . . . So great was his misery that it brought on an illness which terminated in his death.

[Editors' note: Busbecq had a good eye for local color and detail, much beyond the diplomatic scene. He may have liked to place on record his own goodness of heart in ransoming a Spanish captive, as we see in the following excerpt, yet he seems almost to admire the finely calibrated microexploitation by which a "complete cripple" could be rendered financially productive in Turkey.]



Ship of Fools, *by Hieronymous Bosch (1450–1516). The ship of fools was a method of sending those who could not or would not work away from towns and into the countryside. Here, Bosch situates authority figures in his ship instead of those considered insane, cognitively or physically disabled, or socially derelict in some other way.*

Source: Art Resource, New York.

But the people who among us [i.e., in France] are beggars among them are slaves, for when a slave has lost the use of his limbs his master is still bound to maintain him; besides, however feeble a slave may be, they manage to get some service from him. I remember ransoming a Spanish gentleman, who had been an officer in his own army. Though he was completely crippled by his wounds, yet the Turk who had bought him managed to make some profit of him. He took him over to Asia, where flocks of geese are kept, and hired him out as goose-herd, by which he turned a nice little penny.

Source: Forster, C. T., and F. H. B. Daniell, ed. and trans. 1881. Vol. 1, pp. 117–118, 178–179, and 209–210 of *The Life and Letters of Ogier Ghiselin de Busbecq,* 2 Vols. London: Kegan Paul.

Albert Howe Lybyer on the Sultan Suleiman
(1913)

At the Ottoman court at Istanbul in the early 1550s, power struggles were in full swing among those of the Sultan's women who had borne him sons or who had other highly placed strings to pull. When the Sultan died, the losers in such struggles could face an early death or lifelong house arrest. Further, this excerpt from a twentieth-century historian's account suggests that disability did not disqualify sons from the sultan's favor.

Roxelana had triumphed completely over the mother of Mustapha; her son-in-law Rustem, married to Suleiman's well-beloved daughter Mihrmah, had held the supreme office of grand vizier for nine years; her hump-backed son Jehangir was Suleiman's favorite child.

Nevertheless, as late as the beginning of 1553 Suleiman seems to have intended still that Mustapha should occupy the throne.

Source: Lybyer, Albert Howe. 1913. P. 142 in *The Government of the Ottoman Empire in the Time of Suleiman the Magnificent.* Cambridge, MA: Harvard University Press.

Bartolomej Georgijevic on the Murder of Mustapha (1569)

This report, another of the many accounts by European travel writers of the murder of Mustapha, contains a description of the sultan's fourth son, who was disabled but also recognized for his intellectual gifts.

[Speaking of Suleiman's sons] The fourth was sirnamed langir of the bunches, wher with he was both deformed before, & behinde in his backe, notwithstanding of a sharpe prudent and politike will.

Source: Georgijevic, Bartolomej, 1569. Gough, Hugh, trans. *The ofspring of the house of Ottomanno, etc.* London: Thomas Marshe.

Descriptions of King James I of England (1566–1625)

King James I (he was James I of England, but James VI of Scotland), notorious persecutor of Puritans and Brownists in England, ruled with a condition similar to what would now be diagnosed as cerebral palsy. Many commentators have discussed the impact of his disability on private and public perceptions of his reign. The following excerpts demonstrate the wide range of commentary made upon his physical and psychological person by two of his contemporaries.

M. de Fontenoy, the envoy to James I's mother, reported to the secretary in 1584 that:

> His manners . . . are aggressive and very uncivil, both in speaking, eating, clothes, games . . . He never stays in one place, taking a singular pleasure in walking up and down, but his carriage is ungainly, his steps erratic and vagabond, even in his own chamber.

King James I of England *(c. 1619), by Paul van Somer I (c. 1576–1621). King James I, one of the persecutors of the Puritan and Brownist religious sects, had a disability akin to today's diagnosis of cerebral palsy. His disability was commonly referenced by his contemporaries—often to his detriment.*

In Anthony Weldon's book *The Court and Character of King James,* he describes James's demeanor and appearance in the following manner:

> The king's character is much easier to take than his picture, for he could never be brought to sit for the taking of that . . . He was of a middle stature, more corpulent through his cloathes than in his body, yet fat enough, his cloathes ever being made large and easie, the doublets quilted for steletto proofe, his breeches in great pleits and full stuffed: he was naturally

> of a timorous disposition, which was the reason of his quilted doublets; his eyes large, ever rowling after any stranger that came in his presence, inasmuch as many for shame have left the roome, as being out of countenance; his beard was very thin: his tongue too large for his mouth, which ever made his speak full in the mouth, and made him drink very uncomely, as if eating his drink, which came out into the cup of each side of his mouth . . . his legs were very weake, having had (as was thought) some foul play in his youth, that weaknesse made him ever leaning on other mans shoulders; his walk was ever circular, his fingers ever in that walke fiddling about his codpiece.

Sources: *De Fontenay on James VI, 1584 (Aged 18 Years).* n.d. Available at: http://faculty.history.wisc.edu/sommerville/123/PF011.htm

Weldon, Anthony. 1650. *The Court and Character of King James.* London: John Wright.

Ambroise Paré, from *Monsters and Marvels* (1575)

Ambroise Paré (1510–1590) was a well-recognized barber-surgeon in the courts of Charles IX, Henri III, and Catherine de Medici. In this excerpt from the opening of his work on human "monstrosity," the writer parses out distinctions between differences considered deviancy and those associated with the miraculous. In doing so, Paré created some early diagnostic categories that occupied the border between medical pathology and religious superstition.

Monsters are things that appear outside the course of Nature (and are usually signs of some forthcoming misfortune), such as a child who is born with one arm, another who will have two heads, and additional members over and above the ordinary.

Marvels are things which happen that are completely against Nature as when a woman will give birth to a serpent, or to a dog, or some other thing that is totally against Nature, as we shall show hereafter through several examples of said monsters and marvels which examples I have gathered along with the illustrations from several authors, such as the *Histories prodigieuses* of Pierre Boistuau, and from Claude Tiesserand, from Saint Paul, Saint Augustine, Esdras the Prophet, and from certain ancient philosophers, to wit from Hippocrates, Galen, Empedocles, Aristotle, Pliny, Lycosthenes, and others who will be quoted as deemed appropriate.

Michel de Montaigne (1533–1592) writing. Often referred to as the originator of the essay form, Montaigne wrote essays critical of the treatment of disabled people in France during the sixteenth century. He also inherited a painful gallbladder condition that resulted in a significant level of impairment.

Source: Art Resource, New York.

Maimed persons include the blind, the one-eyed, the hump-backed, those who limp or [have] arms too short, or the nose too sunken, as do the very flat-nosed; or those who have thick, inverted lips or a closure of the genitals in girls, because of the hymen; or because of a more than natural amount of flesh, or because they are hermaphrodites; or those having spots or warts or wens, or any other thing that is against Nature.

Source: Paré, Ambroise. 1982. Pallister, Janis L., trans. P. 3 in *Monsters and Marvels.* Chicago: University of Chicago Press. (Originally published 1575)

Michel de Montaigne, from *Essays* (1575)

The sixteenth-century French philosopher Michel de Montaigne originated the essay form; the two essays *excerpted here show a more open-minded attitude toward disability than was common at the time. In the first excerpt, Montaigne ironically describes the many myths surrounding the sexual capacities of disabled people. He argues for a recognition that our beliefs about human differences are largely imagined and then detrimentally imposed upon individuals who appear outside of our expectations. The argument may also be a direct response to Ambroise Paré's metaphysical readings of human anomalies in Monsters and Marvels. In the second excerpt, Montaigne argues against the practice of displaying disabled children for money. His argument explicitly addresses the nonmonstrous spectacle represented by even extreme human differences while including disability in the continuum of divinely appointed diversity.*

Chapter XI. Of Cripples

'Tis now two or three years ago that they made the year ten days shorter in France.—[By the adoption of the Gregorian calendar.]—How many changes may we expect should follow this reformation! it was really moving heaven and earth at once. Yet nothing for all that stirs from its place my neighbours still find their seasons of sowing and reaping, the opportunities of doing their business, the hurtful and propitious days, dust at the same time where they had, time out of mind, assigned them; there was no more error perceived in our old use, than there is amendment found in the alteration; so great an uncertainty there is throughout; so gross, obscure, and obtuse is our perception. 'Tis said that this regulation might have been carried on with less inconvenience, by subtracting for some years, according to the example of Augustus, the Bissextile, which is in some sort a day of impediment and trouble, till we had exactly satisfied this debt, the which itself is not done by this correction, and we yet remain some days in arrear: and yet, by this means, such order might be taken for the future, arranging that after the revolution of such or such a number of years, the supernumerary day might be always thrown out, so that we could not, henceforward, err above four-and-twenty hours in our computation. We have no other account of time but years; the world has for many ages made use of that only; and yet it is a measure that to this day we are not agreed upon, and one that we still doubt what form other nations have variously given to it, and what was the true use of it. What does this saying of some mean, that the heavens in growing old bow themselves down nearer towards us, and put us into an uncertainty even of hours and days? and that which Plutarch says of the months, that astrology had not in his time determined as to the motion of the moon; what a fine condition are we in to keep records of things past.

I was just now ruminating, as I often do, what a free and roving thing human reason is. I ordinarily see that men, in things propounded to them, more willingly study to find out reasons than to ascertain truth: they slip over presuppositions, but are curious in examination of consequences; they leave the things, and fly to the causes. Pleasant talkers! The knowledge of causes only concerns him who has the conduct of things; not us, who are merely to undergo them, and who have perfectly full and accomplished use of them, according to our need, without penetrating into the original and essence; wine is none the more pleasant to him who knows its first faculties. On the contrary, both the body and the soul interrupt and weaken the right they have of the use of the world and of themselves, by mixing with it the opinion of learning; effects concern us, but the means not at all. To determine and to distribute appertain to superiority and command; as it does to subjection to accept. Let me reprehend our custom. They commonly begin thus: "How is such a thing done?" Whereas they should say, "Is such a thing done?" Our reason is able to create a hundred other worlds, and to find out the beginnings and contexture; it needs neither matter nor foundation: let it but run on, it builds as well in the air as on the earth, and with inanity as well as with matter:

> "Dare pondus idonea fumo."
> ["Able to give weight to smoke."]
>
> —Persius, v. 20.

I find that almost throughout we should say, "there is no such thing," and should myself often make use of this answer, but I dare not: for they cry that it is an evasion produced from ignorance and weakness of understanding; and I am fain, for the most part, to juggle for company, and prate of frivolous subjects and tales that I believe not a word of; besides that, in truth, 'tis a little rude and quarrelsome flatly to deny a stated fact; and few people but will affirm, especially in things hard to be believed, that they have seen them, or at least will name witnesses whose authority will stop our mouths from contradiction. In this way, we know the foundations and means of things that never were; and the world scuffles about a thousand questions, of which both the Pro and the Con are false.

> "Ita finitima sunt falsa veris, ut in praecipitem locum non debeat se sapiens committere."
>
> ["False things are so near the true, that a wise man should not trust himself in a precipitous place."]
>
> —Cicero, *Acad*., ii. 21.

Truth and lies are faced alike; their port, taste, and proceedings are the same, and we look upon them with the same eye. I find that we are not only remiss in defending ourselves from deceit, but that we seek and offer ourselves to be gulled; we love to entangle ourselves in vanity, as a thing conformable to our being.

I have seen the birth of many miracles in my time; which, although they were abortive, yet have we not failed to foresee what they would have come to, had they lived their full age. 'Tis but finding the end of the clew, and a man may wind off as much as he will; and there is a greater distance betwixt nothing and the least thing in the world than there is betwixt this and the greatest. Now the first that are imbued with this beginning of novelty, when they set out with their tale, find, by the oppositions they meet with, where the difficulty of persuasion lies, and so caulk up that place with some false piece;

[Voltaire says of this passage, "He who would learn to doubt should read this whole chapter of Montaigne, the least methodical of all philosophers, but the wisest and most amiable."—*Melanges Historiques,* xvii. 694, ed. of Lefevre.]
besides that:

> "Insita hominibus libido alendi de industria rumores."
>
> ["Men having a natural desire to nourish reports."]
>
> —Livy, xxviii. 24.

we naturally make a conscience of restoring what has been lent us, without some usury and accession of our own. The particular error first makes the public error, and afterwards, in turn, the public error makes the particular one; and thus all this vast fabric goes forming and piling itself up from hand to hand, so that the remotest witness knows more about it than those who were nearest, and the last informed is better persuaded than the first.

'Tis a natural progress; for whoever believes anything, thinks it a work of charity to persuade another into the same opinion; which the better to do, he will make no difficulty of adding as much of his own invention as he conceives necessary to his tale to encounter the resistance or want of conception he meets with in others. I myself, who make a great conscience of lying, and am not very solicitous of giving credit and authority to what I say, yet find that in the arguments I have in hand, being heated with the opposition of another, or by the proper warmth of my own narration, I swell and puff up my subject by voice, motion, vigour, and force of words, and moreover, by extension and amplification, not without some prejudice to the naked truth; but I do it conditionally withal, that to the first who brings me to myself, and who asks me the plain and bare truth, I presently surrender my passion, and deliver the matter to him without exaggeration, without emphasis, or any painting of my own. A quick and earnest way of speaking, as mine is, is apt to run into hyperbole. There is nothing to which men commonly are more inclined than to make way for their own opinions; where the ordinary means fail us, we add command, force, fire, and sword. 'Tis a misfortune to be at such a pass, that the best test of truth is the multitude of believers in a crowd, where the number of fools so much exceeds the wise:

> "Quasi vero quidquam sit tam valde, quam nil sapere, vulgare."
>
> ["As if anything were so common as ignorance."]
>
> —Cicero, *De Divin*., ii.
>
> "Sanitatis patrocinium est, insanientium turba."
>
> ["The multitude of fools is a protection to the wise."]
>
> —St. Augustine, *De Civit. Dei*, vi. 10.

'Tis hard to resolve a man's judgment against the common opinions: the first persuasion, taken from the very subject itself, possesses the simple, and from them diffuses itself to the wise, under the authority of the number and antiquity of the witnesses. For my part, what I should not believe from one, I should not believe from a hundred and one: and I do not judge opinions by years.

'Tis not long since one of our princes, in whom the gout had spoiled an excellent nature and sprightly disposition, suffered himself to be so far persuaded with the report made to him of the marvellous operations of a certain priest who by words and gestures cured all sorts of diseases, as to go a long journey to seek him out, and by the force of his mere imagination, for some hours so persuaded and laid his legs asleep, as to obtain that service from them they had long time forgotten. Had fortune heaped up five or six such-like incidents, it had been enough to have brought this miracle into nature. There was afterwards discovered so much simplicity and so little art in the author of these performances, that he was thought too contemptible to be punished, as would be thought of most such things, were they well examined:

> "Miramur ex intervallo fallentia."
>
> ["We admire after an interval (or at a distance) things that deceive."]
>
> —Seneca, *Ep*., 118, 2.

So does our sight often represent to us strange images at a distance that vanish on approaching near:

> "Nunquam ad liquidum fama perducitur."
>
> ["Report is never fully substantiated."]
>
> —Quintus Curtius, ix. 2.

'Tis wonderful from how many idle beginnings and frivolous causes such famous impressions commonly, proceed. This it is that obstructs information; for whilst we seek out causes and solid and weighty ends, worthy of so great a name, we lose the true ones; they escape our sight by their littleness. And, in truth, a very prudent, diligent, and subtle inquisition is required in such searches, indifferent, and not prepossessed. To this very hour, all these miracles and strange events have concealed themselves from me: I have never seen greater monster or miracle in the world than myself: one grows familiar with all strange things by time and custom, but the more I frequent and the better I know myself, the more does my own deformity astonish me, the less I understand myself.

The principal right of advancing and producing such accidents is reserved to fortune. Passing the day before yesterday through a village two leagues from my house, I found the place yet warm with a miracle that had lately failed of success there, where with first the neighbourhood had been several months amused; then the neighbouring provinces began to take it up, and to run thither in great companies of all sorts of people. A young fellow of the place had one night in sport counterfeited the voice of a spirit in his own house, without any other design at present, but only for sport; but this having succeeded with him better than he expected, to extend his farce with more actors he associated with him a stupid silly country girl, and at last there were three of them of the same age and understanding, who from domestic, proceeded to public, preachings, hiding themselves under the altar of the church, never speaking but by night, and forbidding any light to be brought. From words which tended to the conversion of the world, and threats of the day of judgment (for these are subjects under the authority and reverence of which imposture most securely lurks), they proceeded to visions and gesticulations so simple and ridiculous that—nothing could hardly be so gross in the sports of little children. Yet had fortune never so little favoured the design, who knows to what height this juggling might have at last arrived? These poor devils are at present in prison, and are like shortly to pay for the common folly; and I know not whether some judge will not also make them smart for his. We see clearly into this, which is discovered; but in many things of the like nature that exceed our knowledge, I am of opinion that we ought to suspend our judgment, whether as to rejection or as to reception.

Great abuses in the world are begotten, or, to speak more boldly, all the abuses of the world are begotten, by our being taught to be afraid of professing our ignorance, and that we are bound to accept all things we are not able to refute: we speak of all things by precepts and decisions. The style at Rome was that even that which a witness deposed to having seen with his own eyes, and what a judge determined with his most certain knowledge, was couched in this form of speaking: "it seems to me." They make me hate things that are likely, when they would impose them upon me as infallible. I love these words which mollify and moderate the temerity of our propositions: "peradventure; in some sort; some; 'tis said, I think," and the like: and had I been set to train up children I had put this way of answering into their mouths, inquiring and not resolving: "What does this mean? I understand it not; it may be: is it true?" so that they should rather have retained the form of pupils at threescore years old than to go out doctors, as they do, at ten. Whoever will be cured of ignorance must confess it.

Iris is the daughter of Thaumas; [That is, of Admiration. She (Iris, the rainbow) is beautiful, and for that reason, because she has a face to be admired, she is said to have been "the daughter of Thamus."—Cicero, De Nat. Deor., iii. 20.] admiration is the foundation of all philosophy, inquisition the progress, ignorance the end. But there is a sort of ignorance, strong and generous, that yields nothing in honour and courage to knowledge; an ignorance which to conceive requires no less knowledge than to conceive knowledge itself. I read in my younger years a trial that Corras [a celebrated Calvinist lawyer, born at Toulouse; 1513, and assassinated there, 4th October 1572.], a councillor of Toulouse, printed, of a strange incident, of two men who presented themselves the one for the other. I remember (and I hardly remember anything else) that he seemed to have rendered the imposture of him whom he judged to be guilty, so wonderful and so far exceeding both our knowledge and his own, who was the judge, that I thought it a very bold sentence that condemned him to be hanged. Let us have some form of decree that says, "The court understands nothing of the matter" more freely and ingenuously than the Areopagites did, who, finding themselves perplexed with a cause they could not unravel, ordered the parties to appear again after a hundred years.

The witches of my neighbourhood run the hazard of their lives upon the report of every new author who seeks to give body to their dreams. To accommodate the examples that Holy Writ gives us of such things, most certain and irrefragable examples, and to tie them to our modern events, seeing that we neither see the causes nor the means, will require another sort-of wit than ours. It, peradventure, only appertains to that sole all-potent testimony to tell us. "This is, and that is, and not that other." God ought to be believed; and certainly with very good reason; but not one amongst us for all that who is astonished at his own narration (and he must of necessity be astonished if he be not out of his wits), whether he employ it about other men's affairs or against himself.

I am plain and heavy, and stick to the solid and the probable, avoiding those ancient reproaches:

> "Majorem fidem homines adhibent iis, quae
> non intelligunt;
> —Cupidine humani ingenii libentius obscura
> creduntur."

> ["Men are most apt to believe what they least understand: and from the acquisitiveness of the human intellect, obscure things are more easily credited." The second sentence is from Tacitus, *Hist*. 1. 22.]

I see very well that men get angry, and that I am forbidden to doubt upon pain of execrable injuries; a new way of persuading! Thank God, I am not to be cuffed into belief. Let them be angry with those who accuse their opinion of falsity; I only accuse it of difficulty and boldness, and condemn the opposite affirmation equally, if not so imperiously, with them. He who will establish this proposition by authority and huffing discovers his reason to be very weak. For a verbal and scholastic altercation let them have as much appearance as their contradictors;

> "Videantur sane, non affirmentur modo;"

> ["They may indeed appear to be; let them not be affirmed (Let them state the probabilities, but not affirm.)"]
>
> —Cicero, *Acad*., n. 27.

but in the real consequence they draw from it these have much the advantage. To kill men, a clear and strong light is required, and our life is too real and essential to warrant these supernatural and fantastic accidents.

As to drugs and poisons, I throw them out of my count, as being the worst sort of homicides: yet even in this, 'tis said, that men are not always to rely upon the personal confessions of these people; for they have sometimes been known to accuse themselves of the murder of persons who have afterwards been found living and well. In these other extravagant accusations, I should be apt to say, that it is sufficient a man, what recommendation soever he may have, be believed as to human things; but of what is beyond his conception, and of supernatural effect, he ought then only to be believed when authorised by a supernatural approbation. The privilege it has pleased Almighty God to give to some of our witnesses, ought not to be lightly communicated and made cheap. I have my ears battered with a thousand such tales as these: "Three persons saw him such a day in the east three, the next day in the west: at such an hour, in such a place, and in such habit"; assuredly I should not believe it myself. How much more natural and likely do I find it that two men should lie than that one man in twelve hours' time should fly with the wind from east to west? How much more natural that our understanding should be carried from its place by the volubility of our disordered minds, than that one of us should be carried by a strange spirit upon a broomstaff, flesh and bones as we are, up the shaft of a chimney? Let not us seek illusions from without and unknown, we who are perpetually agitated with illusions domestic and our own. Methinks one is pardonable in disbelieving a miracle, at least, at all events where one can elude its verification as such, by means not miraculous; and

I am of St. Augustine's opinion, that, "'tis better to lean towards doubt than assurance, in things hard to prove and dangerous to believe."

'Tis now some years ago that I travelled through the territories of a sovereign prince, who, in my favour, and to abate my incredulity, did me the honour to let me see, in his own presence, and in a private place, ten or twelve prisoners of this kind, and amongst others, an old woman, a real witch in foulness and deformity, who long had been famous in that profession. I saw both proofs and free confessions, and I know not what insensible mark upon the miserable creature: I examined and talked with her and the rest as much and as long as I would, and gave the best and soundest attention I could, and I am not a man to suffer my judgment to be made captive by prepossession. In the end, and in all conscience, I should rather have prescribed them hellebore than hemlock;

> "Captisque res magis mentibus, quam conscel-
> eratis similis visa;"
>
> ["The thing was rather to be attributed to madness, than malice." ("The thing seemed to resemble minds possessed rather than guilty.")]
>
> —Livy, viii, 18.

justice has its corrections proper for such maladies. As to the oppositions and arguments that worthy men have made to me, both there, and often in other places, I have met with none that have convinced me, and that have not admitted a more likely solution than their conclusions. It is true, indeed, that the proofs and reasons that are founded upon experience and fact, I do not go about to untie, neither have they any end; I often cut them, as Alexander did the Gordian knot. After all, 'tis setting a man's conjectures at a very high price upon them to cause a man to be roasted alive.

We are told by several examples, as Praestantius of his father, that being more profoundly, asleep than men usually are, he fancied himself to be a mare, and that he served the soldiers for a sumpter; and what he fancied himself to be, he really proved. If sorcerers dream so materially; if dreams can sometimes so incorporate themselves with effects, still I cannot believe that therefore our will should be accountable to justice; which I say as one who am neither judge nor privy councillor, and who think myself by many degrees unworthy so to be, but a man of the common sort, born and avowed to the obedience of the public reason, both in its words and acts. He who should record my idle talk as being to the prejudice of the pettiest law, opinion, or custom of his parish, would do himself a great deal of wrong, and me much more; for, in what I say, I warrant no other certainty, but that 'tis what I had then in my thought, a tumultuous and wavering thought. All I say is by way of discourse, and nothing by way of advice:

> "Nec me pudet, ut istos fateri nescire, quod
> nesciam;"
>
> ["Neither am I ashamed, as they are, to confess my ignorance of what I do not know."]
>
> —Cicero, *Tusc*. Quaes., i. 25.

I should not speak so boldly, if it were my due to be believed; and so I told a great man, who complained of the tartness and contentiousness of my exhortations. Perceiving you to be ready and prepared on one part, I propose to you the other, with all the diligence and care I can, to clear your judgment, not to compel it. God has your hearts in His hands, and will furnish you with the means of choice. I am not so presumptuous even as to desire that my opinions should bias you—in a thing of so great importance: my fortune has not trained them up to so potent and elevated conclusions. Truly, I have not only a great many humours, but also a great many opinions, that I would endeavour to make my son dislike, if I had one. What, if the truest are not always the most commodious to man, being of so wild a composition?

Whether it be to the purpose or not, 'tis no great matter: 'tis a common proverb in Italy, that he knows not Venus in her perfect sweetness who has never lain with a lame mistress. Fortune, or some particular incident, long ago put this saying into the mouths of the people; and the same is said of men as well as of women; for the queen of the Amazons answered the Scythian who courted her to love, "Lame men perform best." In this feminine republic, to evade the dominion of the males, they lamed them in their infancy—arms, legs, and other members that gave them advantage over them, and only made use of them in that wherein we, in these parts of the world, make use of them. I should have been apt to think; that the shuffling pace of the lame mistress added some new pleasure to the work, and some extraordinary titillation to those who were at the sport; but I have lately learnt that ancient philosophy has itself determined it, which says that the legs and thighs of lame women, not receiving, by reason of their imperfection, their due aliment, it falls out that the genital parts above are fuller and better supplied and much more vigorous; or else that this defect, hindering exercise, they who are troubled with it less dissipate their strength, and come more entire to the sports of Venus; which also is the reason why the Greeks decried the women-weavers as being more hot than other women by reason of their sedentary trade, which they carry on without any great exercise of the body. What is it we may not reason of at this rate? I might also say of these, that the jaggling about whilst so sitting at work, rouses and provokes their desire, as the swinging and jolting of coaches does that of our ladies.

Do not these examples serve to make good what I said at first: that our reasons often anticipate the effect, and have so infinite an extent of jurisdiction that they judge and exercise themselves even on inanity itself and non-existency? Besides the flexibility of our invention to forge reasons of all sorts of dreams, our imagination is equally facile to receive impressions of falsity by very frivolous appearances; for, by the sole authority of the ancient and common use of this proverb, I have formerly made myself believe that I have had more pleasure in a woman by reason she was not straight, and accordingly reckoned that deformity amongst her graces.

Torquato Tasso, in the comparison he makes betwixt France and Italy, says that he has observed that our legs are generally smaller than those of the Italian gentlemen, and attributes the cause of it to our being continually on horseback; which is the very same cause from which Suetonius draws a quite opposite conclusion; for he says, on the contrary, that Germanicus had made his legs bigger by the continuation of the same exercise.

Nothing is so supple and erratic as our understanding; it is the shoe of Theramenes, fit for all feet. It is double and diverse, and the matters are double and diverse too. "Give me a drachm of silver," said a Cynic philosopher to Antigonus. "That is not a present befitting a king," replied he. "Give me then a talent," said the other. "That is not a present befitting a Cynic."

> "Seu plures calor ille vias et caeca relaxat
> Spiramenta, novas veniat qua succus in herbas
> Seu durat magis, et venas astringit hiantes;
> Ne tenues pluviae, rapidive potentia colic
> Acrior, aut Boreae penetrabile frigus adurat."

> ["Whether the heat opens more passages and secret pores through which the sap may be derived into the new-born herbs; or whether it rather hardens and binds the gaping veins that the small showers and keen influence of the violent sun or penetrating cold of Boreas may not hurt them."]
>
> *—Virg., Georg., i. 89.*

> "Ogni medaglia ha il suo rovescio."
>
> ["Every medal has its reverse."—Italian Proverb.]

This is the reason why Clitomachus said of old that Carneades had outdone the labours of Hercules, in having eradicated consent from men, that is to say, opinion and the courage of judging. This so vigorous fancy of Carneades sprang, in my opinion, anciently from the impudence of those who made profession of knowledge and their immeasurable self-conceit. AEsop was set to sale with two other slaves; the buyer asked the first of these what he could do; he, to enhance his own value, promised mountains and marvels, saying he could do this and that, and I know not what; the second said as much of himself or more: when it came to AEsop's turn, and that he was also asked what he could do; "Nothing," said he, "for these two have taken up all before me; they know everything." So has it happened in the school of philosophy: the pride of those who attributed the capacity of all things to the human mind created in others, out of despite and emulation, this opinion, that it is capable of nothing: the one maintain the same extreme in ignorance that the others do in knowledge; to make it undeniably manifest that man is immoderate throughout, and can never stop but of necessity and the want of ability to proceed further.

Chapter XXX. Of a Monstrous Child

This story shall go by itself; for I will leave it to physicians to discourse of. Two days ago I saw a child that two men and a nurse, who said they were the father, the uncle, and the aunt of it, carried about to get money by showing it, by reason it was so strange a creature. It was, as to all the rest, of a common form, and could stand upon its feet; could go and gabble much like other children of the same age; it had never as yet taken any other nourishment but from the nurse's breasts, and what, in my presence, they tried to put into the mouth of it, it only chewed a little and spat it out again without swallowing; the cry of it seemed indeed a little odd and particular, and it was just fourteen months old. Under the breast it was joined to another child, but without a head, and which had the spine of the back without motion, the rest entire; for though it had one arm shorter than the other, it had been broken by accident at their birth; they were joined breast to breast, and as if a lesser child sought to throw its arms about the neck of one something bigger. The juncture and thickness of the place where they were conjoined was not above four fingers, or thereabouts, so that if you thrust up the imperfect child you might see the navel of the other below it, and the joining was betwixt the paps and the navel. The navel of the imperfect child could not be seen, but all the rest of the belly, so that all that was not joined of the imperfect one, as arms, buttocks, thighs, and legs, hung dangling upon the other, and might reach to the mid-leg. The nurse, moreover, told us that it urined at both bodies, and that the members of the other were nourished, sensible, and in the same plight with that she gave suck to, excepting that they were shorter and less. This double body and several limbs relating to one head might be interpreted a favourable prognostic to the king,—[Henry III.]—of maintaining these various parts of our state under the union of his laws; but lest the event should prove otherwise, 'tis better to let it alone, for in things already past there needs no divination,

> "Ut quum facts sunt, tum ad conjecturam aliqui interpretatione revocentur;"
>
> ["So as when they are come to pass, they may then by some interpretation be recalled to conjecture."]
>
> —Cicero, *De Divin*., ii. 31.

as 'tis said of Epimenides, that he always prophesied backward.

I have just seen a herdsman in Medoc, of about thirty years of age, who has no sign of any genital parts; he has three holes by which he incessantly voids his water; he is bearded, has desire, and seeks contact with women.

Those that we call monsters are not so to God, who sees in the immensity of His work the infinite forms that He has comprehended therein; and it is to be believed that this figure which astonishes us has relation to some other figure of the same kind unknown to man. From His all wisdom nothing but good, common; and regular proceeds; but we do not discern the disposition and relation:

> "Quod crebro videt, non miratur, etiamsi, cur fiat, nescit. Quod ante non vidit, id, si evenerit, ostentum esse censet."
>
> ["What he often sees he does not admire, though he be ignorant how it comes to pass. When a thing happens he never saw before, he thinks that it is a portent."]
>
> —Cicero, *De Divin*., ii. 22.

Whatever falls out contrary to custom we say is contrary to nature, but nothing, whatever it be, is contrary to her. Let, therefore, this universal and natural reason expel the error and astonishment that novelty brings along with it.

Source: Cotton, Charles, trans., and William Carew Hazlitt, ed. 1877. *The Essays of Montaigne.* Available at: http://www.gutenberg.org/files/3598/old/mn18v10.txt (Chapter XI) and http://www.gutenberg.org/files/3592/old/mn12v10.txt (Chapter XXX).

William Shakespeare, from *Richard III* (ca. 1591–1594)

Shakespeare's rendition of the story of King Richard III, often cited as the first "modern" protagonist, uses his torment by others on the basis of his disability as the impetus for courtly intrigue and brutal murder. The excerpt here is from his famous opening monologue, in which the future usurper of the throne of the two young heirs of King Edward IV contemplates his exclusion from peacetime merrymaking on the basis of his "deformities."

Act I, Scene i, Lines 1–40

London. A street. Enter Richard, Duke of Gloucester, solus

Gloucester:

Now is the winter of our discontent
Made glorious summer by this sun of York;
And all the clouds that lowered upon our house
In the deep bosom of the ocean buried.
Now are our brows bound with victorious wreaths,
Our bruised arms hung up for monuments,
Our stern alarums changed to merry meetings,
Our dreadful marches to delightful measures.
Grim-visaged war hath smoothed his wrinkled front,
And now, instead of mounting barbed steeds
To fright the souls of fearful adversaries,
He capers nimbly in a lady's chamber

Edmund Kean as Richard III, *by John James Halls (19th c.). The renowned early nineteenth-century actor here portrays Shakespeare's Richard III, the "hump-backed king," as a physically deformed usurper of the British throne. The performance of the disabled avenger became one of the most commonly staged plays in Shakespeare's repertoire, and generations of actors have approached the dramatic role as a question of "to limp or not to limp."*

Source: Art Resource, New York.

To the lascivious pleasing of a lute.
But I, that am not shaped for sportive tricks
Nor made to court an amorous looking-glass;
I, that am rudely stamped, and want love's majesty
To strut before a wanton ambling nymph;
I, that am curtailed of this fair proportion,
Cheated of feature by dissembling nature,
Deformed, unfinished, sent before my time
Into this breathing world scarce half made up,
And that so lamely and unfashionable
That dogs bark at me as I halt by them—
Why I, in this weak piping time of peace,
Have no delight to pass away the time,
Unless to spy my shadow in the sun
And descant on mine own deformity
And therefore, since I cannot prove a lover
To entertain these fair well-spoken days,
I am determined to prove a villain
And hate the idle pleasures of these days.
Plots have I laid, inductions dangerous,
By drunken prophecies, libels, and dreams,
To set my brother Clarence and the king
In deadly hate the one against the other;
And if King Edward be as true and just
As I am subtle, false, and treacherous,
This day should Clarence closely be mewed up
About a prophecy which says that G
Of Edward's heirs the murderer shall be.

▣ Richard Wragg on the Ottoman Court (1590s)

T*he following excerpts from Mayes's book are based on the reports of Richard Wragg, the secretary to Edward Barton. In the autumn of 1593, Edward Barton, the Ambassador of Queen Elizabeth to the Ottoman Court, had been insulted by the acting Grand Vizier Ferhad Pasha. To bring this to the attention of Sultan Murad III, Barton adopted the local expedient of standing up in a boat near the seaside mosque where the Sultan went to pray.*

1593 (Sept.) "Presently a dwarf who had helped Barton on other occasions beckoned to him to come to the shore" (P. 56). Later, when the Queen's presents to the Sultan were displayed, "The courtyard was crowded with dumb men and dwarfs," and Barton and his retinue "moved slowly through the exotic crowd of eunuchs, dwarfs and mutes till they came level with the kiosk" where the Sultan was seated (P. 58).

[Editors' note: After the death of Murad III and the accession of Sultan Mehmet III in 1595, there were great changes among the courtiers. To have any access to the Sultan, the European ambassadors were obliged to start again and make new contacts.]

1595 [After the death of Murad III and the accession of Sultan Mehmet III,] "There were changes among the pashas. Even the eunuchs, the dwarfs and the women of the harem he [Barton] had used in his diplomatic game were now swept away to the Old Seraglio like so much lumber" (P. 63).

Source: Mayes, Stanley. 1956. Pp. 54–63 in *An Organ for the Sultan.* London: Putnam.

The Mute Woman, *by Raphael (1483–1520). Raphael, who included disabled figures in many of his works, identifies this woman as "mute" to deepen her mystery.*

Source: Art Resource, New York.

John Sanderson's Travels in Constantinople (Late 16th c.)

In 1594, the year before Sultan Murad III died, the English traveler John Sanderson gleaned some statistics about people living in Constantinople (Istanbul). The total population was believed to be 1,231,207. The dwarfs and "dumb" men were listed among people offering various services:

1594 In Constantinople ar resident:

Solacks [*solaq*], his footemen 300

Falconers, dwarfs, and dome [i.e., dumb] men 300

Whores of all sorts, at least 1000

[Total] 1,231,207 (P. 82)

1595 (25 Jan.) Sultan Murad deceased the 7th of this moneth and was buryed the same day his sonne Sultan Mahemett arived, which was the 17th. That day his 19 sonns weare strangoled in thier brothers presence. . . . The 4 muti (thoughe by commandement) which murtherd them weare also strangoled. (P. 141)

1600 [After describing executions by impaling.] They strangle with a bowestring thier bretherin, bassaies, and other great men. (P. 87) [Footnote text: "Meaning the Sultan's brethren."]

[Editors' note: Sanderson remarked on the Grand Signior (the Sultan), the Bustanji bashi (Chief Gardener), and the Sultan's use of water transport on State barges (*qayiq* or caike).]

This Bustangiebassi is a man of accompt about the Turke, and the great (but not the common) executioner; for the Turke imploy{s} him in strangling viceroyes, throwing by night rebelliouse soldiers into the sea, and sutchlike. Chefe gardner is his office, havinge thowsands [of] jamoglaines and thier governors at his commaund. He kepethe the caikes, and always steereth when the Great Turke goeth uppon the water. . . . His [the Sultan's] court of dwarfs and dum men always folowe (except the very principall, who ar with him) in another caike; and many times also his women. (P. 89)

Source: Sanderson, John. 1931. Foster, William, ed. *The Travels of John Sanderson in the Levant 1584-1602 with His Autobiography and Selections from His Correspondence.* London: Hakluyt Society.

Thomas Dallam, Account of an Organ Carryed to the Grand Seignor (1599)

Visiting the court of the Emperor Mehmet III at Constantinople, Thomas Dallam recorded a dazzling scene at the Sultan's court on September 25, 1599. An organ with chiming clock and mobile figures, designed and assembled by Dallam and his team on *the orders of Queen Elizabeth, had been shipped to Constantinople and shown to the Sultan, with Dallam waiting outside. The organ was set to chime and play automatically, and the mobile figures had been through their motions, including a bush with birds that sang and opened their wings. The Sultan was pleased. He asked why the organ keys moved though nobody was playing them, and learned that the organ could be played using these keys. Dallam was brought in to demonstrate. He spent some minutes dazzled by the array of courtiers, among whom were 100 "dumb" men and 100 dwarfs, extremely short but thickset. Dallam was most impressed by the "dumb" men's sign language.*

The Grand Sinyor satt still, behouldinge the presente which was befor him, and I stood daslinge my eyes with loukinge upon his people that stood behinde him, the which was four hundrethe persons in number.

Tow hundrethe of them weare his princepall padgis, the yongest of them 16 yeares of age, som 20, and som 30. They weare apparled in ritche clothe of goulde made in gowns to the mydlegge; . . . Those 200 weare all verrie proper men, and Christians borne. [They were slaves taken from Christian families of the empire. Some had become Muslims.]

The thirde hundrethe weare Dum men, that could nether heare nore speake, and theye weare likwyse in gouns of riche Clothe of gould and Cordivan buskins; . . . Som of them had haukes in theire fistes.

The fourthe hundrethe weare all dwarffs, bige-bodied men, but verrie low of stature. Everie Dwarfe did weare a simmeterrie (scimitar) by his side, and they weare also apareled in gowns of Clothe of gould.

I did moste of all wonder at those dumb men, for they lett me understande by theire perfitt sins (signs) all thinges that they had sene the presente dow by its motions.

Source: Bent, J. Theodore, ed. 1893. *Early Voyages and Travels in the Levant I. The Diary of Master Thomas Dallam 1599–1600.* London: Hakluyt Society.

Stories from the *Ebisu Mandara* (ca. 1600–1950s)

The excerpts below represent brief biographies of notable Japanese disabled people, with some discussion of the occupations traditionally assigned to disabled people. They are intended as a beginning effort to construct a history of disabled people in Japan. The majority of these materials derive from the mythological figure Hiruko to the 1950s. Stories suggest that the disabled and rejected Hiruko was "rehabilitated" in popular imagination as Ebisu, the Japanese god of good fortune and fishermen. The texts are by a well-known writer, himself disabled.

6. Foster Parents of Iwakura

There is a piece of Haiku poem by famous poet Buson Yosano in the middle of the Edo period (1600–1868): "In Iwakura, Fall in Love Mad Women, Little Cuckoo." [It is] a fantastic work matching impending voice of little cuckoo and passionate love of women. There might be many cuckoos in villages of northern Kyoto in mountains leading to Mt. Kurama. There was a special relation between the place Iwakura and mad women, that is to say, those who became insane, suffered neurosis, or dementia. It went back some hundreds years, from the time the poem was composed in the Heian period (794–1185). Once a noble woman had a nervous breakdown but completely recovered by standing under the waterfall of Iwakura. The rumor spread out. More nobles visited Iwakura. Some brought children who were mentally retarded. However, they could not expect prompt recovery. The nobles asked nearby families to take care of these children for a long period, then some of them finally arranged adoption for lifelong care taking. Such a custom continued for more than one thousand years. Those families who adopted the children could expect good protection by the aristocracy.

8. Throng!! Japanese Gypsy

The gypsy is famous in Europe. In Japan also there were supposedly people who lived like them. [These were] aborigines who were subjugated, relatives of a ruling clan that had been defeated, driven away from their homeland, started a wandering life. Among them, it seems there were singers and players of flutes, drums, Chinese fiddles, biwa (lute) to earn the daily food; also Prologue Speaker for the drama, clowns to crack jokes, acrobats of tight-rope walking. It could be a lively group. Such a group was named Kugutsu. There is evidence that blind people and so-called midgets and hunchbacks showed their unique arts in the group. They might be original members, others might join asking protection after leaving villages due to difficulties to engage in agriculture or fishery with physical disability. According to legend, Yoshitsune Minamoto hid among the throng of Kugutsu when he went from Mount Kurama to Oshu by stealth.

9. Founder of Biwa by the Blind Semimaru

Oosaka no seki is the first checkpoint from Kyoto (capital city in those days) to eastern cities, going down from Higashiyama (East Mount) to Omi, [a] famous place from ancient days. Its name 'Oosaka' has connotation of 'hope to meet again', along with sorrow of parting. In the mount Oosaka near the checkpoint, word had spread that [an] exquisite melody was heard every night, nobody knew from what time. Whether it was the pastime of a Tengu (long-nosed goblin) or god of the mount, once people listened they were fascinated with the music. One full moon night it turned out who it was. A master hand of cross flute from the capital encountered a blind person playing biwa (lute) sitting on a rock facing [the] river. He gave only the name Semimaru, supposed to be [a] court servant or the fourth prince of the Emperor Daigo. The flute musician visited Mount Oosaka every night afterwards, [and] eventually was initiated the secret tune of biwa Ryusen Takuboku according to the record. The story was disseminated all over the country, reportedly, and many blind people [and] aspiring musicians came to ask lectures. Biwa, once monopolized by the aristocracy, was thus popularized by the blind.

10. Caretaking and Camping Car

The Kamakura period (1185–1333) was one of the periods when religion in Japan was most prosperous. New schools not only for the nobles but for general public appeared one after another. Nichirenshu school and Jodoshinshu school were among them, [and] Jishu school by Ippen shonin (a holy priest) was representative one. At this school was performed Odori Nenbutsu (dance and chant Buddhist prayer), which may have had power to induce people into religious ecstasy. He advocated Buddhist prayer throughout Japan, and was accompanied by [a] good many people. Ippen shonin hijiri-e (holy pictures of Ippen shonin) and Ippen shonin e-den (picture of life of Ippen shonin) are scrolls with paintings describing his life and we can see such scenes in them. Among various people there were persons with different impairments. Some seem to be on boards with small wooden wheels, some use wooden getas (clogs) on their hands. . . . Moreover there was also a person whose female caretaker provided him with foods. It is interesting that a hut with wheels appeared also. In modern terms it is camping car. We can only guess how it was used but it is probable that the wheeled hut is for the sick and the disabled.

11. Foundation of Kengyo System—Akashi Kengyo

The Conflict of South and North Courts was the turbulent period when warriors and people throughout the country were split between the South Court of Yoshino and the North Court of Kyoto and battled in many regions. However, everybody alike wished the union of Japan, peace as the result of victory of one's own side. The Taiheiki (Record of Peace) is a full-length piece dealing with the riotous time, whose title seems to express such a wish better than its content. In those days, there was a man who unified the world regardless of military power, authority, hatred and betrayal, then firmly built up his position. It was Kengyo AKASHI (the Kengyo was a blind official responsible for welfare of blind people). He was an excellent player of Heike biwa (chanting of Heike warrior tales, with elements of courtly and religious music, which blind monks played on the lute), and began Ichikata School after unifying several schools existing in each region. He also put various narrations of Heike monogatari (Stories of Taira Clan) together. His reputation spread irrespective of South and North Courts, and his followers increased. He played at both courts when invited. Finally he was awarded a purple [permit?] [bowl?] as proof that he could go to the courts whenever he liked. Thus he founded the basis of Kengyo system for all blind people.

12. Prominent Activity of Biwa Hoshi (Lute-Playing Buddhist Friar)

There are magnificent dramas of prosperity and vicissitudes between Genji (Minamoto Clan) and Heik (Taira Clan), as almost all Japanese people know. They include episodes of Yoshitsune and Benkei at Gojo bridge, a folding fun target of Yoichi Nasu, a flute of Aoba and the death Atsumori, sincere loves of Tomoe Gogen, Heike Clan submerged themselves into the sea of Dannoura. Heroic battles and beautiful love stories scattered among them. It was blind biwa hoshi who popularized and let the original work Heike

Monogatari (Stories of Heike Clan) sink deeply into people's minds. They earned their daily food by narrating each paragraph of stories accompanied with the much-loved biwa at cities or on occasion of festive days of shrines and temples in front of many people. Without such activities of wandering from place to place and reciting them, the melancholic stories might not have been so widely known all over Japan. It was also those biwa hoshi that added flavour and made them more sophisticated while chanting. Those biwa hoshi appear often in literature of [the] Muromachi period (1333–1568), [and] also in well-known Choju Giga (Comic of birds and animals).

13. Strategists in the Age of Wars

Kansuke Yamamoto, the brains of the invincible Takeda army, reportedly was in reality a man who dragged his shorter leg, missing one of [his] eyes, with innumerable wounds on body, small and ugly. As he made himself the tactician of a feudal lord, after he had come adrift from another region, we can infer how intelligent he must have been. By the way, Hideyoshi Toyotomi who later obtained the ruling power of Japan, had the No. 1 strategist of the age, Hanbei Takenaka beside him. He was said to be worthy of aiming at the whole country. He suffered from a disease in the chest and planned recuperative life, then changed his mind, moved by passion of Hideyoshi even [if] it might shorten his lifespan. These two passed away accomplishing their purpose of life; on the other hand, Josui Kuroda (Kanbei) lived long and left a prosperous family behind him. Once [when] he was confined in the Itami Castle when he visited there as messenger of Hideyoshi, one of his knees became unstretchable. They say that he took the command of battles at the front line on a palanquin carried on [the] shoulders of subjects. There were other men, Kiyomasa Kato and Ukon Takayama, some say that they had suffered Hansen's disease (leprosy). The age of wars produced many disabled people, sacrificed their lives, but on other hand, even disabled people were given some importance depending on their ability.

15. The Blind with Shamisen at Hand

Now [the] shamisen is regarded as one of the most popular music instrument[s] but it was originally jabisen (lute using skin of snake) of Ryukyu (now Okinawa) that was introduced at the end of Muromachi period (1333–1568). Like various commodities brought from overseas, jabisen must have arrived at the Sakai port, [the] most flourishing town of the day, and awaited buyers (and players). Those who became interested in such a new foreign music culture at first were feudal lords becoming wealthy and men of culture protected by lords, besides blind persons [who] also got in touch with it fairly soon. As Sakai town prospered, many biwa hoshi probably came in there. They knew how to play stringed instruments using bachi (plectrum) so it would be easier for them to get used to jabisen. The atmosphere of seeking something new in port town would be suitable for them to cast off attachment for biwa without much ado. The choice of the blind changed drastically the course of mainstream . . . popular Japanese music afterwards.

16. Patron of Basho—Sanpu Sugiyama

It is well known that Basho Matsuo, one of the most representative literary men of [the] Genroku period, enhanced the Haikai from a sort of word game to an art form. He had many pupils all over the country. Sanpu Sugiyama was among them, the most reliable person throughout his life, starting from [the] days before Basho had become famous. Sanpu was a powerful merchant named Koiya (house of camps), [and] was patron for Basho during his stay in Edo. Bashoan (hermitage of Basho) in Fukagawa was the source of his pseudonym as there was a big Basho (Japanese banana) in the garden, which was believed to be a watch house of fish reserve of Koiya to keep fish alive temporarily. Sanpu's life seems without any trouble, but in truth, he had [a] heavy hearing impairment. Reportedly Basho never composed Haiku poem about hearing troubles, showing consideration for Sanpu.

17. Koto (Japanese Harp) and Yatsuhashi Kengyo (The Highest Rank of Court Musician)

Shamisen and Koto were the most popular instruments played among [the] general public during the Edo era. These instruments were introduced by blind people who played them to earn their living. It was blind persons called Biwahoshi (blind religious minstrel) who Japanized [the] Jabisen (a snake-skin shamisen) of Ryukyu (now Okinawa prefecture). We cannot forget the fact of how the blind supported the music of Joruri (including Gidayubushi) accompanied with shamisen, although the reciter Takemoto Gidayu is the only well-known character of Gidayubushi, (Gidayu is a form of ballad-drama, Gidayubushi is its music accompaniment), which played on stage. It was written by Monzaemon Chikamatsu, one of the three most famous literati of [the] Genroku period. Even now, players of shamisen have names like Tsurusawa, Takesawa. These -sawa endings are derived from the founder Sawaoh Kengyo. [The] koto has long history, [being] originally played as musical instruments of Gagaku (ancient imperial court music). It is certain that Biwahoshi themselves, looking for new instruments other than biwa, improved koto and the way of performance so that ordinary people could enjoy it. We may say that Yatsuhashi Kengyo was the most important person who tried to spread koto. We can still enjoy his music nowadays, for example, instrumental music like Melody of 6-dan, Melody of 8-dan and vocal music of Kumiuta (included several pieces of Japanese poems of Kokinshu, etc.), accompanied by koto.

19. Sugiyama Kengyo, Worshipped at Shrine

It is said that Ieyasu Tokugawa, the founder of Edo Government who laid the basis of about 200 years of peaceful period, especially tried to protect the blind as there was a blind person among his own relatives. Kengyo Waich Sugiyama, kept close with the fifth Shogun (generalissimo) Tsuneyoshi, consolidated the system of Kengyo, placed chief kengyo not only in Kyoto but in Edo (now called Tokyo) to heighten the status of Edo. He also installed seminar house of acupuncture. He generalized acupuncture as a job of the blind, and initiated the Sugiyama school. In the beginning of Edo era, [the] Heike biwa was outdated, but neither [the] koto nor [the] shamisen had yet become popular, so the blind were looking for new types of work. Moreover, not all blind people could play music. Then acupuncture and massage became their important job. Sugiyama himself was once turned out by the first teacher of acupuncture because he showed little talent for it. On such an occasion, he supposedly devised [a] new method. It was to put a needle in a thin tube, different from [the] traditional way of tapping the end of needles or screwing the needles in. For his virtuous achievements, he is worshipped in the Sugiyama Shrine located in Chitose of the Sumida ward in Tokyo.

21. Akinari Ueda, with Cancroid Hands

We cannot forget the name of Akinari Ueda, author of Ugetsu Monogatari (Story of rain and moon), which is full of noble romantic scent and fantastic atmosphere, [a] rare masterpiece in Japanese literature before [the] modern ages. His grave is located in the garden of a subordinate temple in the precinct of Nanzenji Temple in Kyoto. The tomb stone was engraved with [a] crab, showing the epitaph “Tomb of Mucho” (without intestines). Mucho is the alias of crabs as they seem to have no bowels. He often used it as his pen name of Haiku poems, etc. Why did Akinari particularly stick to crabs? The reason was his fingers. He suffered smallpox and lost or shortened some fingers by the effects of the disease. When he wrote, he had to hold a pen with the remaining two fingers like a crab. A scholar of Akinari once wrote that a person with disability of legs may forget it while writing something even if he cannot walk. In the case of Akinari, however, he had to face up to his hands whenever he wrote. Using hands with disability, he created incomparable masterpieces.

22. Bakin Takizawa, Struggled Against

In the later half of the Edo period, the center of culture moved from the Kyoto-Osaka area to Edo, [and] publishing became active. Printing was done by carving a board for one entire page, not [a] word. They could print both pictures and phrases mixed with Chinese characters and Japanese letters without much trouble. To popularize printed matters, illustrations were very useful. Nanso Satomi Hakkenden, whose dramatis personae were 8 swordsmen that have the letter of Inu (dog) respective in their name, show various gallantry in the story. Chinsetsu Yumiharizuki is about the brave life of Tametomo Minamoto. Both works were written by Bakin Takizawa, published with the rise of printing culture. It took him more than 10 years to complete the works though, as they were very long stories of about tens of volumes. Encouragement by the readers might have renewed the source of energy for him. Suddenly a tragedy assaulted him. It was weakening eyesight by disease. Finally he totally lost sight, couldn’t write a word. Ideas occurred to him, but he couldn’t put them down. How vexatious it must be for an author! When he asked help from [his] daughter-in-law to dictate it, she was at a loss because phrases were mixed with difficult Chinese words and expressions.

24. Seibi Natsume, Suffered Gout

The Haiku poems, inspired artistic value by Basho Matsuo and rich poetic value by poets like Buson Yosa, were becoming popular as time went by. In modern terms, it can be described as [a] remarkable increase of [the] haiku population. Persons of excellent creativity of haiku with trustworthy personality were respected as leading figures of the field. Seibi Natsume was one of those reputable authorities. He possessed [a] tranquil, elegant style of haiku, commented on others' poems accurately, so he was adored by people. He wrote essays and studied senior haiku poets, too. It is said that he also took care of haiku poets from local cities or who were poor and relied upon him as *he* ran one of the biggest Fudasashi, which is equivalent to [a] pawnshop nowadays in Edo (now Tokyo). Issa Kobayashi, famous for the unique popular style of his works was also his guest while he was in Edo. He suffered severe gout throughout the life though. Not only [was he] unable to walk but also he was constantly agonized by intense pains. Once he retired from the business, but when his younger brother died early, he had to resume the responsibility of business again. He found relief only in composing haiku poems.

25. Origin of Wheel Chairs

We don't know when appeared Izariguruma, [the] prototype of wheelchairs. Supposedly it began to be used fairly early, in accordance with people's necessity. It was depicted in two different scenes in Hokusai Comic by Hokusai Katsushika in [the] Edo period. [The] lower picture shows [a] wheelchair with two levels, on which one can sit down. [The] upper picture shows a plain board with wheels made of wood. To move, they pushed with long poles against the ground, probably because it had smaller wheels than nowadays. The one man looks like a beggar, while the other seems to be an intelligent person with social status like master of haiku, etc., as he wears [a] special cap and respectable clothes. It is a good contrast that one uses only one pole, while the other uses two poles. It appeared, however, [that] the speed and operational technique of the wheelchair with one pole could be much superior to the other. Relaxed flexibility and shrewd toughness. It splendidly well expresses [the] difference of characters derived from respective lives.

26. Bokushi Suzuki of Hokuetsu Seppu

When the Tokugawa rule began to decay one of the most popular writers of the highly matured Edo Culture, Kyoden Santo, received a letter asking his assistance for . . . publishing a book. [The] sender's name was Bokushi Suzuki of Echigo (Niigata Prefecture now). Although Kyoden was a little acquainted with Bokushi as [a] haiku poet, the manuscript sent to him was not original haiku poem nor ordinary selected poems, nor a novel following the style of Kyoden to be famous like him. What was described scrupulously in it was the rural district of Echigo where Bokushi lived, snowbound almost half the year, and the life of people in heavy snow. The book 'Hokuetsu Seppu' was published by enthusiasm of Bokushi, and unexpectedly won so much popularity that a sequel to it was requested. In those days, there was boom of travel, so it might be regarded as variation of the travel guides introducing noted places and specialities of locality that were much published following the boom. The book, however, was the first scientific essay in Japan and work of ethnography in fact. The continuation was never written though. The author had serious problem of hearing and devoted himself to keeping diary which served as vent for his frustration and troubles among his family and family business (pawnshop) caused by the disability.

27. Famous Scholar, Hokiichi Hanawa

A boy who lost his eyesight at the age of six came up to Edo from [the] local town of Musashino with great hope, but he could not make progress in music with koto nor shamisen, nor was he good at acupuncture nor massage. He despaired of life, [and] thought to commit suicide by jumping into [the] Chidorigafuchi moat of Yotsuya; but his master encouraged him and said that he was allowed to do anything he was interested in for three years. Then if he couldn't succeed at anything, he must go back home. Following the advice, he decided to start studying. Fortunately a volunteer of so-called man-to-man tutor appeared next door to his house, his good luck bloomed all of a sudden. He became a pupil of Kamo no Mabuchi when he was 17, showed genius and finished 6 Japanese history books includ[ing] Nihon Shoki in short period. This is the famous episode of how Hokiichi Hanawa (1746–1821) made of himself a great scholar. Two years after he was promoted to be

Kengyo through his study, he assisted proofreading of Dai-Nihon Shi and received salary of 10 nin-buchi (amount on which 10 people could live for a year) by Mito-han (feudal clan). On the other hand, he gave periodical open lecture of Genji monogatari at his home. There was a senryu at that time who asked for directions to 'the blind man who can see' at Bancho. It might show how active was the private school held at his house in Bancho of Kojimachi town. He then initiated the great work of publishing Gunsho Ruiju (Collected Classics of Japanese Literature).

28. Terakoya (Private School) and Children with Disabilities

During [the] Edo period, almost all Han (feudal clans) installed schools to teach children of vassals. On the other hand, the number of Terakoya (private school at the local temple) for children of ordinary people increased rapidly as time went by. [There were] public schools for elites and private schools for general public. More precisely, we can think of the Terakoya as a private school with easygoing atmosphere, not aiming at higher education. The popularity of such terakoya in big cities like Edo and Osaka was surprisingly high near the end of [the] Edo shogunate. We can guess that it served as [the] basis of [the] rapid growth of [the] school system in [the] Meiji period. They taught mainly elementary Japanese, Chinese characters and calligraphy, mathematics with abacus as often said "reading, writing and abacus" without much formalities. There are records that among the pupils at Terakoya were some children with disability. It reveals the wish of parents for those children to learn writing so that they could earn money. Children with hearing problem[s] were, however, not accepted.

29. Kuzuhara Koto (Rank of Blind Court Musicians, Below Kengyo in Ancient Times), Folding Paper, and Wooden Printing

The wonder of art of Japanese paper folding that produces three-dimensional crane, tortoise and goldfish from a piece of paper became the topic in New York recently. The fact that a blind person demonstrated it caught further attention from people. One hundred and ten years ago, there was a blind man well known as an expert of paper folding, who lived in Yatsuhira village in Bingo (Kaminobe town, Aki-gun Hiroshima Prefecture now). Some exquisite masterpieces like a crane with little chicks at the end of both wings were devised by him. His name was Kuzuhara Koto. He was a skilled player of the Japanese koto, became Koto when he was still young but couldn't achieve the rank of Kengyo until he died. It seemed he didn't need the position of Kengyo because he was born in [a] rich family in [a] local city where the life was not so busy as big city life. Besides, the authority of Kengyo decreased as people tended to buy the position with money more and more. To add to our surprise, Kuzuhara kept a diary for 33 years from [the] Edo period to [the] Meiji and it is still in existence. He wrote it using homemade block print. He set up types in a frame, recognising each different type [of] block by touch.

32. "Are You Going to Massage a Pine Tree?"

He lost eyesight when he was halfway through studies in school. Once he decided to die, but did not succeed. Then he awoke to the love of God and started the career as theologian. He went England to study, supported by good assistance and encouragement of his sister, then his name Takeo Iwahashi became better known abroad than in Japan. After returning to Japan, he dedicated himself to disseminate braille as he believed that study was necessary for blind people while advocating the love of God. It is a famous episode that he angrily said to those who were reluctant to acknowledge the need of study, "The day will come when you should have at least physical knowledge of human body to massage it. If not, you won't be admitted to massage anyone. It'll be too late to start studying. Are you going to massage a pine tree then?" He opened Light House in Osaka, issued newspapers and books in braille, [and] devoted himself to give assistance and improve [the] social status of the blind. He invited Ms. Helen Keller to Japan before and after the Second World War, [and] gave lectures throughout the country. It met with big response not only from the disabled but also from general public.

33. Hand Boy, Seisaku Noguchi

There was a boy teased with the nickname "Pole-hand". When he was a crawling baby, he fell in a fireplace and burnt one hand, eventually all fingers of the hand stuck together. It was a poor village at the lakeside of Inawashiro Lake in Aizu (Fukuoka prefecture now). His name was Seisaku Noguchi. As his family was strictly poor, he had to catch loaches and sell them in towns. Other children looked down on him and made fun of it. He had particularly strong competitive spirit with bright head. "Some day I'll pay it back to them!" His fighting spirit flared up in vexation and anger. After he graduated from elementary school, he worked as a substitute teacher. People around collected a fund for him to get operation of hand. Among them were those who had made fun of him. The operation succeeded and restored his fingers. Such a joy led him to medical science, then he changed his name to Hideyo Noguchi. This is the story of Dr. Noguchi, who was the first Japanese nominated [for] the candidacy of the Nobel Peace Prize.

34. 6-Shaku Sick Bed, Shiki Masaoka

"If I could stand up, I would eat snow on Mount Everest in the Himalayas in North India." This is one of eight series of poems with the phrase "If I could stand up". There are other pieces he composed as the inspiration hit him. For instance, I'd like to bath in the hot spring of Hakone, I'd like to float in a boat on a lake in the moonshine, etc. It is interesting that there exist comparable poems of traditional haiku and ones reflecting the thrust of the period Meiji when Japan opened the door to [the] world. The poet Shiki Matsuoka went to battlefield as journalist during Japan-China War (Nisshin War). On his coming back to Japan, he bled severely on the ship. Afterwards his illness worsened in the stomach, waist and hip and he was kept on a sick bed. As his disease was developing, needing medical treatment, we should call it sickness rather than disability. But we might classify him as one of disabled persons because he lived disabled daily life, not able to walk for a long time. Confined in sick bed of 6-shaku (about 2 square metres), he took his pen, facing the ceiling of his room, to infuse a new spirit into the traditional Japanese literature by accomplishing great works such as Renovation of haiku poems and then Renovation of tanka poems.

35. Cherry Blossoms, Japanese Harp (Koto) and Michio Miyagi

There might not be any Japanese who does not know melodies of koto like Variation of Sakura (Cherry blossom) known as 'Sakura Sakura', and the serenely delightful tune Spring Sea. Moreover, they are some of the most popular tunes abroad as music representing Japan and also symbolizing it. For that reason, the composer Michio Miyagi is regarded as a world famous musician. He was brought up in Korea, but had lost eyesight in his childhood. He returned to Japan alone and started professional training of koto. There might have been some hardships until he distinguished himself. But once his talent was approved and given adequate chances, his life became like a smooth sailing with favorable wind. As composer, he created several famous pieces including [the] formerly mentioned two tunes. As player, he contributed [to] the development of koto performance, tried to play ten koto in concert or play with other orchestral music, changed the instrument from merely [a] Japanese party accessory to the one that fits [a] large scale stage in the world. He fell from [a] night train and died, it was a mysterious accident. Only on that occasion do we notice that he was one of the disabled.

37. King of Joshu (Tochigi Prefecture)—Kijo Murakami

There lived a man in Takasaki city in Gunma prefecture who was moved by 'Papers for Poem Composers' by Shiki Masaoka and he found his real meaning of life in literature. He worked as Daisho (judicial scrivener now) and spent frustrated days due to disappointment he had met several times. It was caused by the disability of hearing. He failed [the] medical exam for entry to the Army officer school because of [his] hearing impairment, of which he had not been aware. Then he went to Tokyo by himself to study in [the] university aiming to be a lawyer, but the door was also shut because of the hearing problem. The condition worsened so much that even he himself realized at heart that he couldn't easily understand what others said. He found new life in literature facing the reality as it is, so he changed the course of [his] life and devoted himself to haiku poems. He made poems of mountains and rivers of the hometown Joshu with pride, and reflected the image of himself on wounded or disabled little animals. His name was Kijo Murakami (1870–1938), one of the representative haiku poets of [the] Taisho period.

Cool Spring Day,
A Blind Dog Goes Stumbling Under Moon,
There Lives the King in a Potato Field

38. New Age Woman with Crutch

It was just before the fascism [?] of the Showa period swallowed everything, when people sought for freedom, it was the so-called Taisho Democracy period in the early 20th century. The women's movement developed excitedly, women of various characteristics called New Age Women appeared spectacularly. Shizu Shiraki (1895–1918) was a new type woman representing the disabled. She was born in Sapporo, unhealthy from birth. Moreover, she suffered tubercular rheumatism after she fell down while climbing [a] mountain, it caused her to have the right leg amputated when she graduated from women's school. She enjoyed making Tanka poems and verses or trying to make occidental movies as [a] pastime in the hospital, then she made up her mind to be a writer making good use of her tragedy as fertilizer [for her imagination]. Her virgin work 'Woman with Crutch' and the second piece 'Death at the age thirty-three', both dealing with the agony of having one's limb cut off, received favorable assessment from the literary world. In real life, she got married with a painter Mr. Kiyotsugu Uenoyama in spite of objections by her relatives, [and] even . . . gave birth to a baby. She fulfilled the life with strong will to accomplish it, [and] died young at ten years earlier than predicted thirty-three. Her name is scarcely mentioned nowadays but she was a writer to set beside Ms. Yuriko Nakajo (called Miyamoto today).

39. Haiku Poet Moppo Tomita and His Best Friend Seifu

The great earthquake of Kanto in 1923 (Taisho 12) brought deaths to many people by earthquakes and the following fires. The poet Moppo Tomita was one of them, burnt to death at riverside of Higashi-Mukojima of Sumida River. He was born in Ele restaurant, and could not walk due to sickness suffered in infant days. People rumored that this came from a grudge of eels and he could not stay at the restaurant any more. He worked in Yuzenzome dyeing craftsman's, to be an in-house disciple overcoming the disability. Living together with mother and other brothers in a poor compound flat, he earned money by making dolls or cheap confectionery goods, doing his best to sustain living. [The] only relief he found in those days was haiku poems [which] he liked from . . . childhood. Then Seifu Arai appeared as real Messiah for his life. He was a rich man [a] running movie theater in Aaskusa town, [a] university student (Moppo didn't go to it) who had [a] robust body. Those two had contrary characters but they made very close friends. Mr. Arai not only introduced Moppo's works to the literature world as a new wave but also took care of his living. Both in name and in real terms he was an excellent volunteer. Here is one of Moppo's masterpieces:

On Autumn Sunset,
a Spider Extends String on my Shoulder

40. First Night and Spring at Sanatorium

It was in 1936 (Showa 11) all judges of Literature World Award experienced deep shock. They encountered a devastatingly compassionate work. Its title was "The First Night of Life", depicting without reserve the agony of a person suffering Hansen's disease (leprosy). He had been driven to the extreme to live in a sanatorium shut out from outer world, completely away from his past, from the society he had lived in. In those days, there was no adequate medical treatment for Hansen's disease. Once caught, it led to a miserable death. Generally, people believed that it could be infected anywhere, anytime, so they extraordinarily feared the sickness. Anyone who caught it [had to] move to live separately in sanatoria compulsorily. The literary work was recommended for the Award not through fear or compassion but because it showed the keen critical eyes of the writer and his steady writing ability. His pen name was Tamio Hojo, his real name unknown. His past must have been so completely erased. "Spring of Little Bird" dealt similarly with the tragedy of separated life through [the] eyes and mind of a woman. It was once made into a movie and became well known. The author, Masako Ogawa, treated those sick people as nurse and is believed to have caught the disease later and died in a sanatorium in a small island in the Inland Sea.

41. Naked Wandering Painter, Kiyoshi Yamashita

In 1937 Children's shred drawing [i.e., collage] exhibition of Yawata Gakuen, institution for mentally disabled was held at Waseda University and became a hot topic. Especially [the] works of Kiyoshi Yamashita were remarkable in terms of quality and volume. In the exhibition at Seijusha Publishing Co. Ltd., 'Ginza ward' attracted the attention of many painters and Kiyoshi obtained [a] good reputation as [a] unique painter. Without seeing the original picture it can hardly be imagined how elaborately two or three mili colored papers were stuck and created vivid and delicate touch. Some praised his works as like Van Gogh's painting style in his Paris age. [The] following year, however, he had left the institution and started on wanderings. It may be true that the fear of a physical examination for conscription motivated him to wander but he was rather born to be a wanderer. Since then he repeatedly wandered around for several months or years and returned to the institution unexpectedly. The distance reached to the extent of travelling almost [the] whole [of] Japan. He expressed what he had seen and learned during his journeys in the form of shred drawing and wrote down his experience of wandering. The movie Hadaka no Taisho Hourouki (Story of Naked Big-Shot) describes his world in those days. Speaking of planned journeys, there was only once when he went to Europe accompanied by his teacher Ryuzaburo Sikiba. He truly encountered Van Gogh's world through this trip.

Source: Hanaka, Syuncho. 1998. *Ebisu Mandara* (Japanese and English texts). Available at the Japan Council on Disability website: http://www.jdnet.gr.jp/Ebisu/Index.en.html. Used by permission of the author.

▣ Wolfgang Büttner on the Fool Claus Narr (1572)

The author of this story, Wolfgang Büttner, uses the fool Claus Narr as a tool for his Protestant teachings. According to Protestant ethics, work and leisure should follow each other. Fun and joy are permissible, but neither should last too long.

XV, 32: Gemahlter Vogel [Painted Bird]

Er sahe einen gemahlten Vogel an der Wand stehen
den schewet vnd jechet er mit seinem Hute
daß er abflüge.
Als er aber nit auffliegen wolt
sprach er: Wolan der Vogel sitzt gewiß
er were recht gut zu schiessen
wenn der Wildtschütze hie were mit seinem zeuge.

Lehre.
Es taug noch wol wenn man kurtzweilt
Mit schimpfferey die zeit vertreibt
Doch wenn man sitzt zu lang vnd fest
So seynds nicht angeneme Gäst.
Von dem man sagen solt diß wort
Jhr sitzet gwiß an einem orth
Man möcht euch schiessen wie ein Wandt
An der ein gmahlter Vogel stand
Ein stetten Gast vnd nächtig Fisch
Wündscht ich mir nicht an meinem Tisch.

Account of the Source

Claus Narr saw a painted bird on the wall and attempted to shoo it away with his hat. When that did not succeed, he regretted that there was no hunter nearby who could shoot down the bird. In the paragraph entitled, "Lehre" (lesson), a reference is made to the fact that it is good when one can converse with jokes and fun. But it is not pleasant when guests have this opportunity and overstay their welcome. In this situation, these guests are like the painted bird on the wall, which one might gladly shoot. One does not desire to share his table with either a permanent guest or yesterday's fish.

Comments on the Lesson

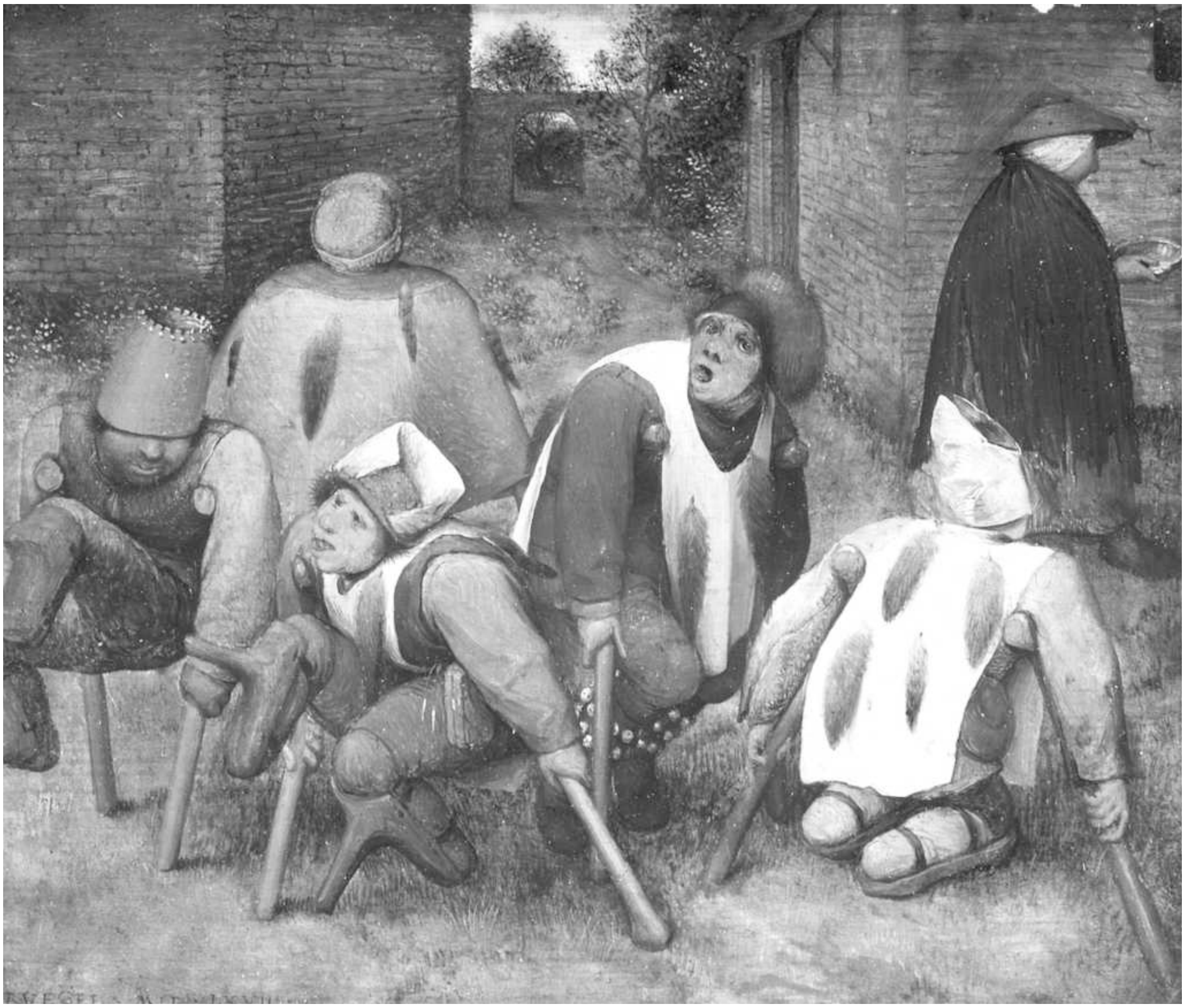
The author of this story, Wolfgang Buettner, uses the fool as tool for the Protestant teachings. According to Protestant ethics, work and leisure should follow each other. Fun and joy are permissible, but neither should last too long. The painted bird, which the "natural" fool mistakes for a live bird, at first tries to chase away, and wishes to have shot, serves as an illustration of the unpleasantness that ensues when guests stay too long.

Source: Büttner, Wolfgang. 1572. Pp. 462–463 in *Von Claus Narren. Sechs hundert sieben vnd zwantzig Historien, etc.* Erstdruck: Eisleben.

▣ Richard Knolles, from *The Turkish History* (1603)

The 1553 murder of Mustapha inspired numerous accounts by Western observers, many of which mentioned the numerous disabled people at the court of the Emperor Suleiman, Mustapha's father. This account by Richard Knolles drew heavily on Hugh Gough's English translation of the account by Bartolomej Georgijevic. This excerpt begins after the Sultan's eldest son and heir apparent, Mustapha, having been summoned, arrives unarmed at an outer chamber of the tent of his father, the Emperor Suleiman.

So when he was come into the more inward roomes of the tent, he was with such honour as belonged to his state cheerfully received by his fathers Eunuchs. But



The Cripples, *by Pieter Brueghel the Elder (1525–1569). In this work, Brueghel captures a group of disabled alms seekers preparing to head out to their street posts. The artist sardonically scribbled on the back of the painting: "Cripples go and be prosperous."*

Source: Art Resource, New York.

seeing nothing else provided but one Seat whereon to sit himself alone, he perplexed in mind, stood still a while musing; at length asked where the Emperor his Father was? Whereunto they answered, That he should by and by see him; and with that casting his Eye aside, he saw seven Mutes (these are strong Men bereft of their Speech, whom the Turkish Tyrants have always in readiness, the more secretly to execute their bloody Butchery) coming from the other side of the Tent towards him; at whose sight strucken with a sudden terrour, said no more, but *Lo my death*; and with that, arising, was about to have fled; but in vain, for he was caught hold on by the Eunuch and Mutes, and by force drawn to the place appointed for his death; where without further stay, the Mutes cast a Bow-string about his Neck, he poor Wretch still striving, and requesting that he might speak but two words to his Father before he died. [Suleiman in fact urged on the executioners with angry shouts.]

He [Suleiman] sent for *Tzihanger* the Crooked . . . in sporting wise . . . bid him go meet his Brother *Mustapha*. [Suleiman omitted to say that Jehangir would find only a corpse. He sent servants offering Mustapha's wealth and position to Jehangir. The latter refused, and died shortly afterwards. Knolles says that he stabbed himself.]

[Editors' note: Sultan Murad III (sometimes Murath, or Amurath), who reigned from 1574 to 1595, also had "mutes" among his servants, and engaged in vigorous and hazardous exercises with them, though he was subject to epileptic fits. In the following excerpt, Knolles quotes from a contemporary report by Johannes Leunclavius.]

This summer also, Amurath disporting himself with his Mutes, was almost dead. These Mutes are lusty strong Fellows, deprived of their Speech; who nevertheless certain by signs can both aptly express their own Conceits; and understand the meaning of others: these men for their Secrecie are the cruel Ministers of the Turkish Tyrants most horrible commands; and therefore of them had in great regard. With these Mutes mounted upon fair and fat, but heavy and unready Horses, was Amurath, upon a light and ready Horse, sporting himself (as the manner of the Turkish Emperours is) riding sometime about one, sometime about another; and striking now the Horse, now the Man, at his Pleasure, when suddenly he was taken with a fit of the falling Sickness, his old Disease; and so falling from his Horse, was taken up for dead. . . . Nevertheless, Amurath shortly after recovered again, and to appease that Rumor of his Death (openly upon their Sabbath, which is the Friday) rid from his Palace to the Temple of Sophia; where I with many others saw him (saith Leunclavius) his Countenance yet all pale and discoloured.

Source: Knolles, Richard. 1603. *The Turkish History, etc.* London: Adam Islip.

▣ Ottaviano Bon's Description of the Ottoman Court (1607)

The Italian diplomat Ottaviano Bon lived at Istanbul from 1604 to 1607, and some of his observations of the Ottoman Court were translated into English and published at various times in the seventeenth century. Of primary interest here are his descriptions of the signing system used by the many deaf individuals connected with the court.

[By cultivating a senior court official, Bon was able to tour some interior parts of the seraglio, when the Sultan was absent.] And in the Lake there was a little Boat, the which (as I was enformed) the Grand Signior did oftentimes goe into with his Mutes and Buffones, to make them row up and downe, and to sport with them, making them leape into the water; and many times as he walked with them above the sides of the Lake, he would throw them downe into it, and plunge them over head and eares. [p. 328]

[Bon made detailed notes about the education of pages for court service, and about other court servants.] Now, for the most part, they all stay at the least six yeeres in this Schoole, and such as are dull and hard of apprehension stay longer. [p. 355] Moreover, every one of them (according to his inclination and disposition) shall learne a Trade, necessary for the Service of the Kings person, to make up a Terbent, to shave, to paire nayles, to fold up Apparell handsomely, to keepe Landspaniels, to keepe Hawkes, to be Sewers, to be Quiries of the Stable, to be Targetbearers, and to waite at the Grand Signiors Table, and the like Services, as it is also used in the Courts of other Kings and Emperours. [p. 356]

Besides the Women, and Ajamoglans of this Seraglio, and the aforesaid Youths last spoken of; there are many and divers Ministers for all manner of necessarie services, and particular functions: there are also Buffons of all sorts, and such as shew trickes, Musicians, Wrestlers, many dumbe men both old and young, who have libertie to goe in and out with leave of the Capee Agha; And this is worthie the observation, that in the Serraglio, both the King and others can reason and discourse of any thing as well and as distinctly, alla mutesca, by nods and signes, as they can with words: a thing well befitting the gravitie of the better sort of Turkes, who care not for much babling. The same is also used amongst the Sultanaes, and other the Kings Women: for with them likewise there are divers dumbe women, both old and young. And this hath beene an ancient custome in the Serraglio: wherefore they get as many Mutes as they can possibly find: and chiefly for this one reason; that they hold it not a thing befitting the Grand Signior. Neither stands it with his greatnesse, to speake to any about him familiarly: but he may in that manner more tractably and domestically jest and sport with the Mutes, then with other that are about him. [pp. 362–363]

The Black-moore Girls, are no sooner brought into the Serraglio after their arrivall at Constantinople, (for they come by Ship from Cairo and from thereabouts) but they are carryed to the Womens lodgings, where they are brought up and made fit for all services; and by how much the more uglie and deformed they are, by so much the more they are esteemed of, by the Sultanaes; wherefore the Bashaw of Cairo (who for the most part sends them all) is alwayes diligent to get the most ill-favoured, cole-blacke, flat-nosed Girles that may bee had throughout all Egypt. [p. 369]

All the while that he [the Sultan] is at Table, he very seldome or never speakes to any man, albeit there stand afore him divers Mutes and Jesters, to make him merrie, playing trickes and sporting one with another Alla Mutescha, which the King understands very well, for by signes their meaning is easily conceived. Now whilst the Agha's are eating, the King passeth away the time with his Mutes and Buffones, not speaking (as I said) at all with his Tongue, but only by signes: and now and then he kicks and buffeteth them in sport, but forth-with makes them amends by giving them Money; for which purpose his pockets are aiwayes furnished. [pp. 374–375]

[Bon remarks on the sale of fruit from the Royal gardens. The gardeners] bring the money weekely to the Bustangee Bashee who afterwards gives it to his Majestie, and it is called the Kings Pocket-money; for he gives it away by handfuls, as he sees occasion, to his Mutes and Buffons. [p. 380]

[While the Sultan was being conveyed by boat,] Now the Bustangee Bashee, by reason the King talkes much with him in the Barge, (at which time, least any one should heare what they say, the Mutes fall a howling like little Dogs) may benefit or prejudice whom he pleaseth. [p. 385]

Source: Purchas, Samuel. 1607. Pp. 322–406 in *Hakluytus Posthumus or Purchas His Pilgrimes,* Vol. IX. Republished 1905. Glasgow, Scotland: MacLehose.

▣ George Sandys, from *A Relation of a Journey . . .* (1615)

George Sandys, an English gentleman and a shrewd observer, visited Istanbul in 1610 and recorded what he saw and heard at the court of Sultan Ahmed I, who reigned from 1603 to 1617. Like many earlier observers, he remarked with wonder on the sign language used within the court.

[Of the Sultan] Yet he is an unrelenting punisher of offences, even in his owne houshold: having caused eight of his Pages, at my being there, to be throwne into the Sea for Sodomy (an ordinary crime, if esteemed a crime, in that nation) in the night time. [p. 73]

Fifty Mutes he [the Sultan] hath borne deafe and dumbe, whereof some few be his daily companions; the rest are his Pages. It is a wonderfull thing to see how readily they can apprehend, and relate by signes, even matters of great difficultie. [p. 74]

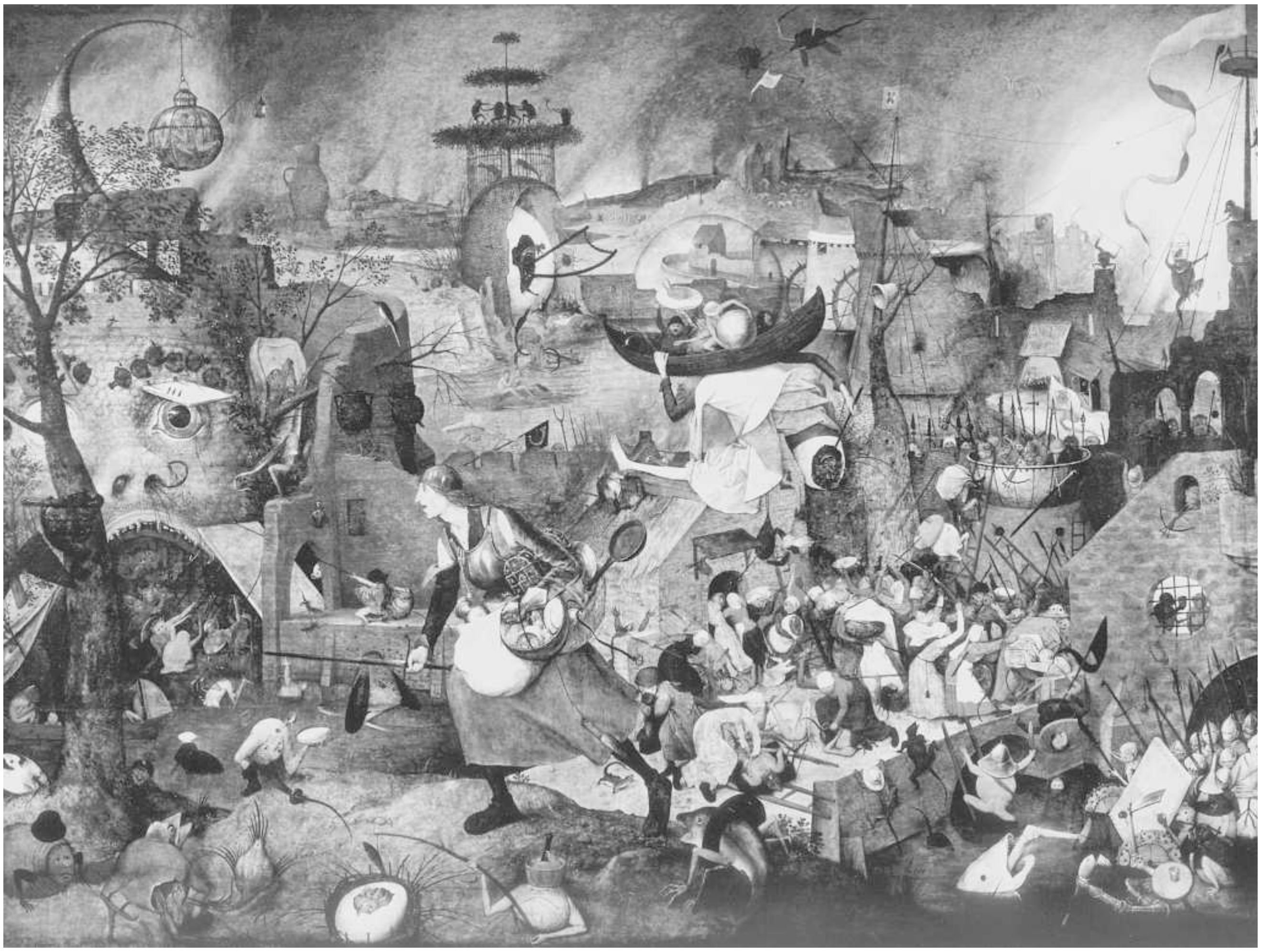
Source: Sandys, George. 1615. *A Relation of a Iourney . . . Containing a Description of the Turkish Empire, etc.* London: W. Barrett.

▣ Michel Baudier on the Ottoman Empire (1624)

Michel Baudier's work draws heavily on other writers and summarizes some aspects of Ottoman court life under Sultan Ahmed I. When Ahmed I died in 1617, his brother Mustafa I briefly acceded to the throne. But Mustafa seems to have been weak-minded and unable to assert any grip on the court. He earned the courtiers' contempt by speaking to people just as any ordinary person would do, rather than maintaining the distance, dignity, and mystique expected of the Sultan.

c. 1600–1620: Other men which are of his Family, speake not unto him but by signes, and this dumbe language is practised, and understood as readily in the Serrail, as a distinct and articulate voice among us. For which cause they use the service of as many dumbe men as they can find; who having accustomed others to their signes and gestures make them to learne their Language. The Sultana's doe the like. The gravitie of his person, and the custome of the Empire forbids him to speake to any. The Sultana's his women practise it, they have many dumbe slaves in their serrail. Sultan Mustapha Uncle to Osman, who in the end of the yeare 1617 held the scepter of the Turkish Empire, for that he could not accustome himselfe to this silent gravitie, gave occasion to the Councell of State to complaine of him, and to say that to speake freely unto his people as Mustapha did, was more fit for a lanizarie or a Turkish Merchant did, then for their Emperour. They contemned him, and held his freedome and familiaritie unworthy of the Empire.

[Baudier gleaned the following report of the demise in 1606 of Dernier, the Chief Gardener, which suggests that ad hoc executions did not always proceed smoothly.] He will defend his life couragiously, and



Dulle Griet [Mad Meg] *(1562–1566), by Pieter Brueghel the Elder (1525–1569). In this painting, Brueghel portrays an image of psychiatric disability at the heart of chaos and social destruction. The image foregrounds longstanding associations of cognitive difference with immorality.*

Source: Art Resource, New York.

let them see that a man, which hath long time handled a Spade and a Mattocke, is not soe easily mastered. *Achmat* sends for *Dernier* to the *Serrail*; he comes and is scarce entred when he suspects the partie which was made against him; he goes into the *Grand Seigneurs* quarter, being there, this troupe of *Capigis* fall upon him to seaze on him, and to put the Halter about his necke; he frees himself from them, and stands upon his defence although he had nothing in his hands, and with his fists scatters them bravely; hee beats one of their Noses flat, puts out the eye of another, and strikes out his teeth that held the Halter, and puts him out of breath which had taken hold of his Arme, and remaines free in the midst of al them which did inviron him, and durst not take him. [Eventually, more fearful of the Sultan's wrath than of Dernier's fist, they overpower and strangle him.] This thing happened at Constantinople in the year 1606. [pp. 178–180]

Source: Baudier, Michel. 1635. Grimeston, Edward, trans. *The history of the imperiall estate of the grand seigneurs their habitations, liues, titles . . . gouernment and tyranny.* London: Richard Meighen.

Francis Bacon, from *Essayes or Counsels* (1625)

In this analysis of deformity, Francis Bacon, often referred to as the "father of empiricism," argues that the ridicule heaped upon deformed members of the *court causes them to seek revenge against those who would malign them. Further, Bacon also counsels suspicion toward these seemingly "helpless" individuals, for their differences may serve as a disguise for loftier political ambitions. Rather than referring to living persons, the analysis could serve as a pointed piece of literary criticism about the ruses of Shakespeare's Richard III.*

XLIV. Of Deformity

Deformed persons are commonly even with nature, for as nature hath done ill by them, so do they by nature, being for the most part (as the Scripture saith) *void of natural affection*; and so they have their revenge of nature. Certainly there is a consent between the body and the mind, and where nature erreth in the one, she ventureth in the other. *Ubi peccat in uno, periclitatur in altero*. But because there is in man an election touching the frame of his mind and a necessity in the frame of his body, the stars of natural inclination are sometimes obscured by the sun of discipline and virtue. Therefore it is good to consider of deformity, not as a sign, which is more deceivable, but as a cause, which seldom faileth of the effect. Whosoever hath anything fixed in his person that doth induce contempt hath also a perpetual spur in himself to rescue and deliver himself from scorn. Therefore all deformed persons are extreme bold. First, as in their own defence, as being exposed to scorn, but in process of time by a general habit. Also it stirreth in them industry, and especially of this kind, to watch and observe the weakness of others, that they may have somewhat to repay. Again, in their superiors it quencheth jealousy towards them, as persons that they think they may at pleasure despise; and it layeth their competitors and emulators asleep, as never believing they should be in possibility of advancement, till they see them in possession. So that upon the matter, in a great wit deformity is an advantage to rising. Kings in ancient times (and at this present in some countries) were wont to put great trust in eunuchs, because they that are envious towards all are more obnoxious and officious towards one. But yet their trust towards them hath rather been as to good spials and good whisperers than good magistrates and officers. And much like is the reason of deformed persons. Still the ground is, they will, if they be of spirit, seek to free themselves from scorn, which must be either by virtue or malice; and therefore let it not be marveled if sometimes they prove excellent persons, as was Agesilaus, Aanger the son of Solyman, Aesop, Gasca, President of Peru; and Socrates may go likewise amongst them, with others.

Source: Bacon, Francis. 1625. T*he essayes or counsels, ciuill and morall, of Francis Lo. Verulam, Viscount St. Alban*. London: Hanna Barret. Available at: http://www.classicallibrary.org/bacon/essays/45.htm

Witch Trial of Jane Hawkins (1638–1641)

The New England magistrates restricted and then expelled Jane Hawkins for her cultivation of the medical arts and religious authority as a woman. Women's efforts to occupy public positions of authority reserved for men prompted severe punishments from the Puritan patriarchy. These transgressions of gendered social roles often prompted accusations of witchcraft.

Jane Hawkins, the wife of Richard Hawkins, had liberty till the beginning of the third month, called May, and the magistrates (if she did not depart before) to dispose of her; and in the meantime she is not to meddle in surgery, or physic, drinks, plasters, or oils, nor to question matters of religion, except with the elders for satisfaction. March 12, 1638.

Jane Hawkins is enjoined to depart away tomorrow morning, and not to return again hither, upon pain of severe whipping and such other punishment as the court shall think meet; and her sons bound . . . to carry her away, according to order: June 2, 1641.

Source: Hall, David. 1991. *Witch-Hunting in Seventeenth Century New England: A Documentary History: 1638–1692.* Boston: Northwestern University Press.

Evliya Efendi, from *Narrative of Travels in Europe, Asia, and Africa* (1635)

Evliya Efendi (also known as Evliya Celebi) served in the Seraglio under the Sultan Murad IV, who reigned from 1623 to 1640. Evliya is best known for his highly descriptive travel writing, but as a young man he spent a year as a page under Murad IV. He first met the Sultan in 1635. His account includes *descriptions of fools, dwarfs, and mutes; discussion of female circumcision; and an analysis of the thoughts of the father of a hydrocephalic child.*

On the day I was dressed as above related, with the splendid turban, two mutes came, and with many curious motions led me into the Khás oda (inner chamber), to Melek Ahmed Aghá and his predecessor Mustafá. [Vol. 1 (1) 133]

[In 1640 Evliya noted how Sultan Ibrahim (who reigned 1640–1648 and became known as Ibrahim the Mad) exchanged a man who would have given him good counsel for a pack of wolves who would lead him to his doom.] Kara Mustafá Páshá, the brave and sagacious vezir, being put to death, the Sultan [Ibrahim] fell into the hands of all the favourites and associates of the harem, the dwarfs, the mutes, the eunuchs, the women, particularly Jinjí Khoájeh. [Vol. 1 (1) 149]

[In a list of buildings in Constantinople, Evliya states that he has "preferred assigning each of the principal baths to a certain class of men in the following amusing way." Towards the end of a long list, there appear:] for the infirm (Maatúh), that of Koja Mohammed Páshá; for buffoons, that of Shengel; . . . for dwarfs, that of Little Aghá. [p. 180; *Ma'tuh* is a term historically used in Islamic Civil Law in Turkey to mean a person of unsound mind, sometimes "feebleminded."]

[In a list of baths in suburbs of Constantinople:] The bath of Kúlákis with good servants, nice waiters, who however are deaf as is implied by the name (Kúlákis, no ears). [Vol. 1 (ii) 45]

[Evliya gave a hugely detailed description of the vast and colourful procession of the guilds or fraternities of Constantinople:] (48) The Sheikhs of the beggars (Dilenjí), number seven thousand . . . some blind, some lame, some paralytic, some epileptic, some having lost a hand or foot, some naked and bare-foot, and some mounted on asses. [Vol. 1 (ii) 115] (254) The Sword-cutlers. . . . The most celebrated sword cutler is deaf David. Sultan Murád IV., who so well understood the worth and use of the sword, never used any but blades of Isfahán, or of deaf David. He made him by an Imperial rescript Chief of the sword-cutlers. [Vol. 1 (ii) 178]

Source: Efendi, Evliya. 1834. Ritter, Joseph von Hammer, trans. *Narrative of Travels in Europe, Asia, and Africa.* London: Oriental Translation Fund. (Originally published 1635)

▣ Henry Blount, from *A Voyage into the Levant* (1636)

Sir Henry Blount, who travelled through the Levant in the early 1630s, provided a few comments on the welfare of poor and disabled people in Turkey. He also wrote of some who pretended to be mad in order to eat without the need to work.

[On the Sultan's Janissaries in the 1630s:] They are never cast off for when old or maimed, they are kept in Garrison. [p. 116]

There are very few beggars in Turkey, by reason of the great plenty of Victuals; only one sort I wondered at, that is, their Santones who are able cunning Rogues much like our Tom of Bedlams; ever with some such disguise to pretend a crazed Brain. [p. 195]

Source: Blount, Henry. 1664. *A Voyage into the Levant,* 5th ed. London: Andrew Crooke. (Originally published 1636)

▣ John Milton, from *Paradise Lost* (1674)

In his invocation of the Muse at the beginning of the third book of his epic, the blind poet John Milton equates light with God and dark with formlessness. His blindness seems to become a metaphor when he likens his earlier description of night to being "Taught by the Heavenly Muse to venture down / The dark descent, and up to re-ascend." Although he can feel the "lamp," his eyes will never see again, because "so thick a drop serene hath quenched their orbs." He asks for an implanted inner eye, mentions and invokes predecessors, and asks for inner vision of report, imagining "things invisible to mortal sight" that can turn deprivation into a value.

Hail, holy Light, offspring of Heaven first-born!
Or of the Eternal coeternal beam
May I express thee unblamed? since God is light,
And never but in unapproached light
Dwelt from eternity, dwelt then in thee,
Bright effluence of bright essence increate!
Or hear'st thou rather pure Ethereal Stream,
Whose fountain who shall tell? Before the Sun,
Before the Heavens, thou wert, and at the voice
Of God, as with a mantle, didst invest
The rising World of waters dark and deep,
Won from the void and formless Infinite!

Parable of the Blind Leading the Blind, *by Pieter Brueghel the Elder (1525–1569). As with his paintings* The Cripples *and* Mad Meg, *Brueghel uses blindness as a metaphor for ineptitude. Ironically, the theme has become one of the most reproduced themes in visual artistic traditions.*

Source: Scala/Art Resource, New York.

Thee I revisit now with bolder wing,
Escaped the Stygian Pool, though long detained
In that obscure sojourn, while in my flight,
Through utter and through middle Darkness borne,
With other notes than to the Orphean lyre
I sung of Chaos and eternal Night,
Taught by the Heavenly Muse to venture down
The dark descent, and up to re-ascend,
Though hard and rare. Thee I revisit safe,
And feel thy sovran vital lamp; but thou
Revisit'st not these eyes, that rowl in vain
To find thy piercing ray, and find no dawn;
So thick a drop serene hath quenched their orbs,
Or dim suffusion veiled. Yet not the more
Cease I to wander where the Muses haunt
Clear spring, or shady grove, or sunny hill,
Smit with the love of sacred song; but chief
Thee, Sion, and the flowery brooks beneath,
That wash thy hallowed feet, and warbling flow,
Nightly I visit: nor sometimes forget
Those other two equalled with me in fate,
(So were I equalled with them in renown!)
Blind Thamyris and blind Maeonides,
And Tiresias and Phineus, prophets old:
Then feed on thoughts that voluntary move
Harmonious numbers; as the wakeful bird
Sings darkling, and, in shadiest covert hid,
Tunes her nocturnal note. Thus with the year
Seasons return; but not to me returns
Day, or the sweet approach of even or morn,
Or sight of vernal bloom, or summer's rose,
Or flocks, or herds, or human face divine;
But cloud instead and ever—during dark
Surrounds me, from the cheerful ways of men
Cut off, and, for the book of knowledge fair,
Presented with a universal blank
Of Nature's works, to me expunged and rased,
And wisdom at one entrance quite shut out.
So much the rather thou, Celestial Light,
Shine inward, and the mind through all her powers
Irradiate; there plant eyes; all mist from thence
Purge and disperse, that I may see and tell
Of things invisible to mortal sight.

Source: Milton, John. 1674. *Paradise Lost,* III.1–55. Available at: http://eir.library.utoronto.ca/rpo/display/poem2652.html

▣ Anne Bradstreet, "The Author to Her Book" (1678)

Bradstreet's book The Tenth Muse *was published in London in 1650. It is thought that she wrote this poem in 1666, when a second edition seemed to have been considered, although the poem was not published until 1678, after Bradstreet's death. In this prefatory poem, Bradstreet likens her presumed diminished skill as a woman writer to the birth of a deformed child. One may witness its various deficiencies and yet embrace the child as one's own.*

Thou ill-form'd offspring of my feeble brain,
Who after birth did'st by my side remain,
Till snatcht from thence by friends, less wise than true,
Who thee abroad, expos'd to publick view,
Made thee in rags halting to th' press to trudge,
Where errors were not lessened (all may judge).
At thy return my blushing was not small,
My rambling brat (in print) should mother call,
I cast thee by as one unfit for light,
They visage was so irksome in my sight;
Yet being mine own, at length affection would
Thy blemishes amend, if so I could:
I wash'd thy face, but more defects I saw,
And rubbing off a spot, still made a flaw.
I stretch thy joints to make thee even feet,
Yet still thou run'st more hobbling than is meet;
In better dress to trim thee was my mind,
But nought save homespun cloth i' th' house I find;
In this array, 'mongst vulgars may'st thou roam,
In critics hands, beware thou dost not come;
And take thy way where yet thou art not known,
If for thy father askt, say thou had'st none:
And for thy mother, she alas is poor,
Which caus'd her thus to send thee out of door.

Source: Bradstreet, Anne. 1678. "The Author to Her Book." Available at: http://www.vcu.edu/engweb/webtexts/Bradstreet/bradpoems.htm

▣ Sir Paul Rycaut, from *The History of the Present State of the Ottoman Empire* (1686)

The English diplomat Sir Paul Rycaut served at the Ottoman Court from 1661 to 1665, during the long reign of Sultan Mehmed IV (1648–1687). Among many people who left an account of their time in Istanbul and at the Ottoman court in the seventeenth century, Rycaut was one of very few who stated his sources for matters of which he was not personally a witness.

[Under Sultan Mehmet IV, reigned 1648–1687] Chap. VIII of the Mutes and Dwarfs. Besides the Pages, there is a sort of Attendants to make up the Ottoman Court, called *Bizebani*, or *Mutes*, men naturally born deaf, and so consequently for want of receiving the sound of words are dumb: These are in number about 40, who by night are lodged amongst the Pages in the two Chambers, but in the day time have their stations before the *Mosque* belonging to the Pages, where they learn and perfect themselves in the language of the *Mutes*, which is made up of several signs, in which by custome they can discourse and fully express themselves; not onely to signifie their sense in familiar questions, but to recount Stories, understand the Fables of their own Religion, the Laws and Precepts of the *Alchoran*, the name of *Mahomet*, and what else may be capable of being expressed by the Tongue. The most ancient amongst them, to the number of about eight or nine, are called the Favourite Mutes, and are admitted to attendance in the *Haz Oda*; who onely serve in the place of *Buffons* for the Grand Signior to sport with, whom he sometimes kicks, sometimes throws in the Cisterns of Water, sometimes makes fight together like the combat of *Clineas* and *Dametas*. But this language of the *Mutes* is so much in fashion in the *Ottoman* Court, that none almost but can deliver his sense in it, and is of much use to those who attend the Presence of the Grand Signior, before whom it is not reverent or seemly so much as to whisper. The Dwarfs are called *Giuge*; these also have their quarters amongst the Pages of the two Chambers, untill they have learned with due reverence and humility to stand in the Presence of the Grand Signior. And if one of these have that benefit, as by Natures fortunate error to be both a Dwarf, and an Eunuch, he is much more esteemed, than if Nature and Art had concurred together to make him the perfectest creature in the World; one of this sort was presented by a certain *Pasha*, to the Grand Signior, who was so acceptable to him and the Queen Mother, that he attired him immediately in clothe of Gold, and gave him liberty through all the Gates of the *Seraglio*. [pp. 62–64]

[Editors' note: This book includes an engraving showing a mute and a dwarf. They are full-figure, standing, adult males, dressed in full-length gowns, slippers, and hats, the dwarf being depicted as perhaps half height. The dwarf is not directly comparable with the mute, because he is shown standing behind and to one side of the mute.]

Source: Rycaut, Paul. 1686. *The history of the present state of the Ottoman Empire, etc.,* 6th ed. London: Clavell, Robinson, and Churchill. (Originally published 1666)

Bobovi's Description of the Ottoman Court (1686)

The following excerpt describes the mute people who lived at the court of the Ottoman Empire during the seventeenth century. These observations, taken from Bobovius (Ali Bey), a senior interpreter at the court, briefly describe the use of sign language by the mute people. The work was translated into English from a French translation of 1686 (manuscript in the Bibliothèque Nationale, Paris), based on an Italian manuscript by Bobovius.

La Monstrua *(1680), by Juan Carreno de Miranda (1614–1685). The title of this painting of Eugenia Martinez Valleji means "the monster" and suggests a derogatory reading of the subject's size. Carreno de Miranda also objectified her sexual power by painting the same figure as a nude.*

Source: Art Resource, New York.

In the palace environs there are also fifty or sixty *dilsiz* or *zebani*. These are the mutes who sleep in the Great and Little Chambers, but sit before the Mosque of the pages of the Great Hall during the day, or are visited by other mutes who have left the Palace with pay and recompense of the sultan. They are expert in sign language and know the significance of everything by sign. They visit and converse with the young and help them to perfect their sign language by telling fables and histories, sayings and scriptures in sign. They teach them the names of the prophets and all sorts of other words. The eight or nine oldest mutes are housed in the *has oda* and are called *musahib* because they play and frolic with the sultan. He entertains himself by their fencing and somersaults in the water of the fountain and, when he is satisfied with their badinage, he throws them *akçes* or *sequins* and enjoys watching them pilfer and battle among themselves. When he wishes to have more diversity, he sometimes has both the dwarfs and the mutes come . . . . The dwarfs are called *cüce* and are lodged in the Great and the Little Hall of the pages until they are instructed and have perfected all of the requirements for living in the presence of the sultan with respect and charity. Truely, there are few things more highly valued than mutes, dwarfs and eunuchs altogether. The rarest present that one could give the sultan is a personage endowed with these three beautiful qualities. Once found, he lacked for nothing. He was dressed in precius vests and was extended the favor of the sultan and the Queen Mother. He passed freely in all quarters of the Palace. [p. 23]

While he [the sultan] eats, the mutes and dwarfs perform. He throws them morsels of the food served to him and watches the ensuing scuffle. [p. 63]

[Referring to a map of *Topkapi Sarayi*] 'C' is the *meşcit* in which the pages of the Great Hall pray five times a day. 'D' is the corner nook of the mutes, where they remain during the day with their elders. This is where one may come to learn the beauties of their language. [p. 75]

Pages of one chamber don't dare to mix with pages of another chamber. Indeed, they can communicate with those of other chambers only by speaking with the signs of the mutes. Those in the has oda are always forced to communicate by signs and gestures, maintaining a complete silence at all times in the sultan's presence. [p. 80]

Source: Fisher, C. G., & A. W. Fisher. 1987. *Topkapi Sarayi* in the Mid-Seventeenth Century: Bobovi's Description. *Archivum Ottomanicum* 10:5–81.

Cotton Mather, from "The Wonders of the Invisible World" (1693)

Condemning testimony provided during the Salem witch trials often cited bodily torment as the sign of torture by women accused of witchcraft. Inexplicable pain and suffering of the afflicted, along with revelations of the accused person's own bodily differences, provided the proof of evildoing. The Puritan minister Cotton Mather provided this description of the trial of Bridget Bishop, the first woman to be tried and executed as a witch during the Salem witch trials.

I. She was indicted for bewitching of several persons in the neighborhood, the indictment being drawn up, according to the form in such cases usual. And pleading, not guilty, there were brought in several persons, who had undergone many kinds of miseries, which were preternaturally inflicted, and generally ascribed unto a horrible witchcraft. There was little occasion to prove the witchcraft; it being evident and notorious to all beholders. Now to fix the witchcraft on the prisoner at the bar; the first thing used was, the testimony of the bewitched; whereof, several testified, that the shape of the prisoner did oftentimes very grieviously pinch them, choke them, bite them, and afflict them; urging them to write their names in a book, which the said specter called, ours. One of them did further testify, that it was the shape of the prisoner, with another, which one day took her from her wheel, and carrying her towards the riverside, threatened there to drown her; if she did not sign to the book mentioned; which yet she refused. Others of them did testify, that the said shape, did in her threats, brag to them, that she had been the death of sundry persons, then by her named; that she had ridden a man, then likewise named. Another testified, the apparition of ghosts under the specter of Bishop, crying out, you murdered us! About the truth whereof, there was in the matter of fact, but too much suspicion.

II. It was testified, that at the examination of the prisoner, before the magistrates, the bewitched were extremely tortured. If she did but cast her eyes on them, they were presently struck down; and this in such a manner as there could be no collusion in the business. But upon the touch of her hand upon them, when they lay in their swoons, they would immediacy revive; and not upon the touch of anyone's else. Moreover, upon some special actions of her body, as the shaking of her head, or the turning of her eyes, they precisely and painfully felt into the like postures. And many of the like accidents now fell out, while she was at the bar. One at the same time testifying, that she said, she could not be troubled to see the afflicted thus tormented.

III. There was testimony likewise brought in, that a man striking once at the place, where a bewitched person said, the shape of this Bishop stood, the bewitched cried out, that he had tore her coat, in the place then particularly specified; and the woman's coat, was found to be torn in that very place.

IV. One Deliverance Hobbs, who had confessed her being a witch, was now tormented by the specters, for her confession. And she now testified, that this bishop, tempted her to sign the book again, and to deny what she had confessed. She affirmed, that it was the shape of this prisoner, which whipped her with iron rods, to compel her thereunto. She affirmed, that this Bishop was at a general meeting of the witches, in a field at Salem Village, and there partook of a diabolical sacrament, in bread and wine then administered.

V. To render it further unquestionable, that the prisoner at the bar, was the person truly charged in *this* witchcraft, there were produced many evidences of *other* witchcrafts, by her perpetrated. For instance, John Cook testified, that about five or six years ago, one morning, about sunrise, he was in his chamber, assaulted by the shape of this prisoner: which looked on him, grinned at him, and very much hurt him, with a blow on the side of the head: and that on the same day, about noon, the same shape walked in the room where he was, and an apple strangely flew out of his hand, into the lap of his mother, six or eight foot from him.

VI. Samuel Gray, testified, that about fourteen years ago, he waked on a night, and saw the room where he lay, full of light; and that he then saw plainly a woman between the cradle, and the bedside, which looked upon him. He rose, and it vanished; though he found the doors all fast. Looking out at the entry door, he saw the same woman, in the same garb again; and said, *In God's name, what do you come for?* He went to bed, and had the same woman again assaulting him. The child in the cradle gave a great screech, and the woman disappeared. It was long before the child could be quieted; and though it were a very likely thriving child, yet from this time it pined away, and after divers months died in a sad condition. He knew not Bishop, nor her name; but when he saw her after this, he knew by her countenance, and apparel, and all circumstances, that it was the apparition of this Bishop, which had troubled him.

Source: Mather, Cotton. 1693. "The Wonders of the Invisible World." Available at: http://etext.lib.virginia.edu/etcbin/toccer-new2?id=Bur4Nar.sgm&images=images/modeng&data=/texts/english/modeng/parsed&tag=public&part=all

▣ Begging Laws (1697)

This excerpt provides an example of an early badging law used to identity "legitimate" disabled people, who were eligible to receive alms and permitted to beg within parishes.

Parliament directed that *all* people legitimately on relief . . . shall upon the shoulder of the right sleeve of the uppermost garment . . . in an open and visible manner, wear such badge or mark as is herein-after mentioned and expressed, that is to say, a large Roman P, together with the first letter of the name of the parish or place whereof such poor person is an inhabitant, cut either in red or blue cloth.

Source: "8 & 9 William 3, ch. 30." 1697. Reprinted in de Schweinitz, Karl. 1943. P. 87 in *England's Road to Social Security*. Philadelphia: University of Pennsylvania Press.

▣ John Dryden, from the Preface to *Fables, Ancient and Modern* (1700)

In this preface, John Dryden admits to some physical effects of his advancing age, but he declares that his mental acuity and "judgment" have persisted—indeed, have increased. His "faculties of soul" remain, even if his memory is fading slightly. He could "lawfully plead some part of the old gentleman's excuse" for any imperfections in the book, but he will not in this case, asking instead for a general allowance for mere human frailty.

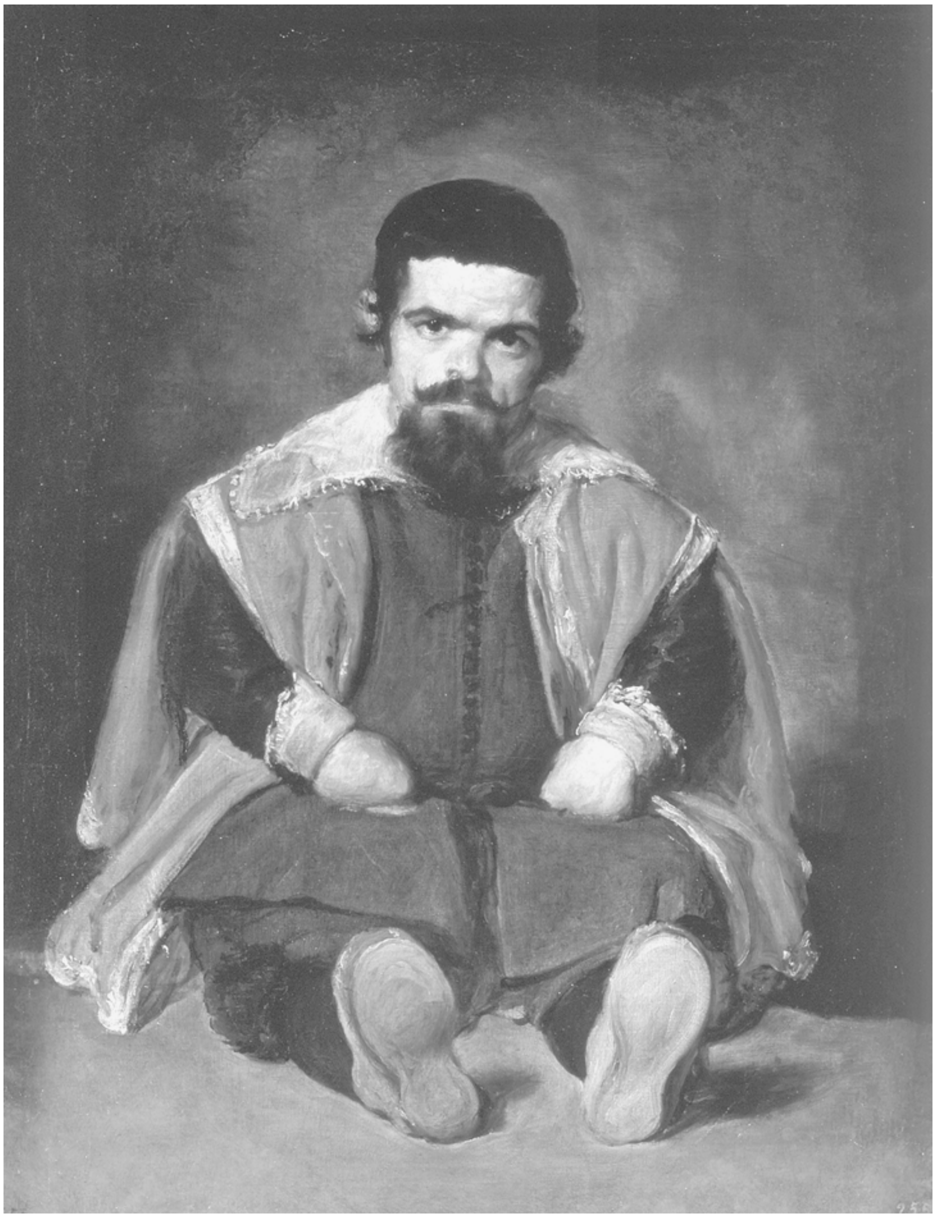
By the mercy of God, I am already come within twenty years of his number, a cripple in my limbs; but what decays are in my mind, the reader must determine. I think myself as vigorous as ever in the faculties of my soul, excepting only my memory, which is not impair'd to any great degree; and if I lose not more of it, I have no great reason to complain. What judgment I had, increases rather than diminishes; and thoughts, such as they are, come crowding in so fast upon me, that my only difficulty is to choose or to reject; to run them into verse, or to give them the other harmony of prose. I have so long studied and practic'd both, that they are grown into a habit, and become familiar to me. In short, tho' I may lawfully plead some part of the old gentleman's excuse, yet I will reserve it till I think I have greater need, and ask no grains of allowance for the faults of this my present work, but those which are given of course to human frailty.

Source: Dryden, John. 1700. "Preface." F*ables, Ancient and Modern*. Available at: http://bartleby.school.aol.com/39/25.html

▣ "March's Ears" (1700)

This Welsh folktale touches upon a number of important themes, including the perceived importance of concealment to the disabled person as well as the fear of exposure and exhibition of the disability. This story emphasizes that disability affects the well-born and the low-born equally: no matter how many riches one possesses, a disability can ruin one's life.

March ab Meirchion was lord of Castellmarch, in Lleyn. He ruled over leagues of rich land, tilled by hundreds of willing and obedient vassals. He had great possessions, fleet horses, greyhounds, hawks; countless black cattle and sheep, and a great herd of swine. (But few possessed pigs at that time, and their flesh was esteemed better than the flesh of oxen. Arthur himself sought to have one of March's sows.) In his palace he had much treasure of gold, silver, and Conway pearls, and all men envied him. But March was not happy: he had a secret, and day and night he was torn with dread lest it should be discovered. *He had horse's ears!*



Portrait of the Jester Sebastian de Morra, *by Diego Rodriguez Velázquez (1599–1660). One of Spain's most famous painters, Velázquez dedicated himself to painting the "common things" in his environment. When not pursuing his livelihood as a portraitist of the upper classes, Velázquez shirked the classical tradition's emphasis on symmetry and conventional beauty by painting many of his acquaintances who were people with disabilities.*

Source: Art Resource, New York.

To no one was the secret known except his barber. This man he compelled to take a solemn oath that he would not reveal his deformity to any living soul. If he wittingly or unwittingly should let anyone know that March's ears were other than human, March swore that he would cut his head off.

The barber became as unhappy as March: indeed his wretchedness was greater, because his fate would be worse if the secret were revealed. March would undergo ridicule, which is certainly a serious thing : but the barber would undergo decapitation, which is much more serious. The secret disagreed with his constitution so violently that he lost his appetite and his colour, and began to fall into a decline. So ill did he become that he had to call in a physician. This man was skilled in his craft, and he said to the barber, "You are being killed by a suppressed secret: unless you communicate it to someone you will soon be in your grave."

This announcement did not give the barber much consolation. He explained to the physician that if he did as he was directed he would lose his head. If in any event he had to come to the end of his earthly career, he preferred being interred with his head joined to, rather than separated from, his trunk. The physician then suggested that he should tell his secret to the ground. The barber thought there was not much danger to his cervical vertebrae (this is the learned name for neck bones) if he did this, and adopted the suggestion. He was at once relieved. His colour and appetite gradually came back, and before long he was as strong and well as he had ever been.

Now it happened that a fine crop of reeds grew on the spot where the barber whispered his secret to the ground. March prepared a great feast, and sent for one of Maelgwn Gwynedd's pipers, who was the best piper in the world, to make music for his guests. On his way to Castellmarch, the piper observed these fine reeds, and as his old pipe was getting worn out, he cut them and made an excellent new pipe. When his guests had eaten and drunk, March ordered the piper to play. What was the surprise of all when the pipe gave out no music, but only the words, "Horse's ears for March ab Meirchion, horse's ears for March ab Meirchion," over and over again. March drew his sword and would have slain the piper, but the hapless musician begged for mercy. He was not to blame, he said: he had tried to play his wonted music, but the pipe was charmed, and do what he would, he could get nothing out of it but the words, "Horse's ears for March ab Meirchion." March tried the pipe himself, but even he could not elicit any strains from it, but only the words, "Horse's ears for March ab Meirchion." So he forgave the piper and made no further effort to conceal his deformity.

Source: V. Wales. n.d. "March's Ears." In *Welsh Fairy Stories.* Available at: http://www.red4.co.uk/Folklore/fairytales/marchsears.htm

"The Story of the Barber's Sixth Brother" from *Arabian Nights* (1704–1717)

The plot of this tale from the Arabian Nights depends in part on the cultural ideas of difference regarding disabled people. The hunchback's body becomes not just an object of entertainment and merriment, but a literal object, as his apparently dead body is passed around, propped up, and examined before the discovery that his amazing "constitution" has made him only appear to be dead.

"This,"—continued the barber,—"is the tale I related to the Caliph, who, when I had finished, burst into fits of laughter."

"Well were you called 'the Silent,'" said he; "no name was ever better deserved. But for reasons of my own, which it is not necessary to mention, I desire you to leave the town, and never to come back."

"I had of course no choice but to obey, and travelled about for several years until I heard of the death of the Caliph, when I hastily returned to Bagdad, only to find that all my brothers were dead. It was at this time that I rendered to the young cripple the important service of which you have heard, and for which, as you know, he showed such profound ingratitude, that he preferred rather to leave Bagdad than to run the risk of seeing me. I sought him long from place to place, but it was only to-day, when I expected it least, that I came across him, as much irritated with me as ever"—So saying the tailor went on to relate the story of the lame man and the barber, which has already been told.

"When the barber," he continued, "had finished his tale, we came to the conclusion that the young man had been right, when he had accused him of being a great chatter-box. However, we wished to keep him with us, and share our feast, and we remained at table till the hour of afternoon prayer. Then the company broke up, and I went back to work in my shop."

"It was during this interval that the little hunchback, half drunk already, presented himself before me, singing and playing on his drum. I took him home, to amuse my wife, and she invited him to supper. While eating some fish, a bone got into his throat, and in spite of all we could do, he died shortly. It was all so sudden that we lost our heads, and in order to divert suspicion from ourselves, we carried the body to the house of a Jewish physician. He placed it in the chamber of the purveyor, and the purveyor propped it up in the street, where it was thought to have been killed by the merchant."

"This, Sire, is the story which I was obliged to tell to satisfy your highness. It is now for you to say if we deserve mercy or punishment; life or death?"

The Sultan of Kashgar listened with an air of pleasure that filled the tailor and his friends with hope. "I must confess," he exclaimed, "that I am much more interested in the stories of the barber and his brothers, and of the lame man, than in that of my own jester. But before I allow you all four to return to your own homes, and have the corpse of the hunchback properly buried, I should like to see this barber who has earned your pardon. And as he is in this town, let an usher go with you at once in search of him."

The usher and the tailor soon returned, bringing with them an old man who must have been at least ninety years of age. "O Silent One," said the Sultan, "I am told that you know many strange stories. Will you tell some of them to me?"

"Never mind my stories for the present," replied the barber, "but will your Highness graciously be pleased to explain why this Jew, this Christian, and this Mussulman, as well as this dead body, are all here?"

"What business is that of yours?" asked the Sultan with a smile; but seeing that the barber had some reasons for his question, he commanded that the tale of the hunch-back should be told him.

"It is certainly most surprising," cried he, when he had heard it all, "but I should like to examine the body." He then knelt down, and took the head on his knees, looking at it attentively. Suddenly he burst into such loud laughter that he fell right backwards, and when he had recovered himself enough to speak, he turned to the Sultan. "The man is no more dead than I am," he said; "watch me." As he spoke he drew a small case of medicines from his pocket and rubbed the neck of the hunchback with some ointment made of balsam. Next he opened the dead man's mouth, and by the help of a pair of pincers drew the bone from his throat. At this the hunch-back sneezed, stretched himself and opened his eyes.

The Sultan and all those who saw this operation did not know which to admire most, the constitution of the hunchback who had apparently been dead for a whole night and most of one day, or the skill of the barber, whom everyone now began to look upon as a great man. His Highness desired that the history of the hunchback should be written down, and placed in the archives beside that of the barber, so that they might be associated in people's minds to the end of time. And he did not stop there; for in order to wipe out the memory of what they had undergone, he commanded that the tailor, the doctor, the purveyor and the merchant, should each be clothed in his presence with a robe from his own wardrobe before they returned home. As for the barber, he bestowed on him a large pension, and kept him near his own person.

Source: Lang, Andrew, trans. 1898. "The Story of the Barber's Sixth Brother." *Arabian Nights.* Available at: http://www.wollamshram.ca/1001/Lang/lang.htm

Joseph Addison, from *The Spectator* (1711)

The Spectator, a daily periodical issued by Joseph Addison and Richard Steele in 1711–1712 and by Addison alone in 1714, offered witty observations on manners and literature for a primarily middle-class audience. The excerpt from No. 58 provides a portion of Addison's invective against the many forms of what he calls "false wit" in literature. In the excerpt from No. 63, Addison draws on these examples to create a dream vision in which disabled human bodies serve as metaphors for false wit.

From No. 58

Ut pictura poesis erit

—Horace

Nothing is so much admired and so little understood as Wit. No Author that I know of has written professedly upon it; and as for those who make any Mention of it, they only treat on the Subject as it has accidentally fallen inn their Way, and that too in little short Reflections, or in general declamatory Flourishes, without entering into the Bottom of the Matter. I hope therefore I shall perform an acceptable Work to my Countrymen if I treat at large upon this Subject; which I shall endeavor to do in a Manner suitable to it, that I may not incur the Censure which a famous Critick bestows upon one who had written a Treatise upon *the Sublime* in a low groveling Stile. I intend to lay aside a whole Week for this Undertaking, that the Scheme of my Thoughts may not be broken and interrupted; and I dare promise my self, if my Readers will give me a Week's Attention, that this great City will be very much changed for the better by next *Saturday* Night. I shall endeavor to make what I say intelligible to ordinary Capacities; but if my Readers meet with any Paper that in some Parts of it may be a little out of their Reach, I would not have them discouraged, for they may assure themselves the next shall be much clearer.

As the great and only End of these my Speculations is to banish Vice and Ignorance out of the Territories of *Great Britain*, I shall endeavor as much as possible to establish among us a Taste of polite Writing. It is with this View that I have endeavored to set my Readers right in several Points relating to Operas and Tragedies; and shall from Time to Time impart my Notions of Comedy, as I think they may tend to its Refinement and Perfection. I find by my Bookseller that these Papers of Criticism, with that upon Humour, have met with a more kind Reception that indeed I could have hoped for from such Subjects; for which Reason I shall enter upon my present Undertaking with greater Cheerfulness.

In this and one or two following Papers I shall trace out the History of false Wit, and distinguish the several Kinds of it as they have prevailed in different Ages of the World. This I think the more necessary at present, because I observed there were Attempts on foot last Winter to revive some of those antiquated Modes of Wit that have been long exploded out of the Commonwealth of Letters. There were several Satyrs and Panegyricks handed about in Acrostick, by which Means some of the most arrant undisputed Blockheads about the Town began to entertain ambitious Thoughts, and to set up for polite Authors. I shall therefore describe at length those many Arts of false Wit, in which a Writer does not shew himself a Man of a beautiful Genius, but of great Industry.

The first Species of false Wit which I have met with is very venerable for its Antiquity, and has produced several Pieces which have lived very near as long as the *Iliad* itself: I mean those short Poems printed among the minor *Greek* Poets, which resemble the Figure of an Egg, a Pair of Wings, an Ax, a Shepherd's Pipe, and an Altar.

As for the first, it is a little oval Poem, and may not improperly be called a Scholar's Egg. I would endeavor to hatch it, or, in more intelligible Language, to translate it into *English*, did not I find the Interpretation of it very difficult; for the Author seems to have been more intent upon the Figure of his Poem, than upon the Sense of it.

The Pair of Wings consist of twelve Verses, or rather Feathers, every Verse decreasing gradually in its Measure according to its Situation in the Wing. The Subject of it (as in the rest of the Poems which follow) bears some remote Affinity with the Figure, for it describes a God of Love, who is always painted with Wings.

The Ax methinks would have been a good Figure for a Lampoon, had the Edge of it consisted of the most satirical Parts of the Work; but as it is in the Original, I take it to have been nothing else but the Posy of an Ax which was consecrated to *Minerva,* and was thought to have been the same . . .

From No. 63

> *Humano Capiti cervicem pictor Equinam*
> *Jungere si velit et varias inducere plumas*
> *Undique collatis membris, ut turpiter atrum*
> *Desinat in piscem mulier Formosa superne;*
> *Spectatum admissi risum teatis, amici?*
> *Credite, Pisones, isti tabulae fore librum*
> *Persimilen, cujus, velut aegri somnia, vanae*
> *Finguntur species*
>
> —Horace

It is very hard for the Mind to disengage it self from a Subject in which it has been long employed. The Thoughts will be rising of themselves from time to time, tho' we give them no Encouragement; as the Tossings and Fluctuations of the Sea continue several hours after the Winds are laid.

It is to this that I impute my last Night's Dream or Vision which formed into one Continued Allegory the several Schemes of Wit, whether False, Mixed, or true, that have been the Subject of my late Papers.

Methoughts I was transported into a Country that was filled with Prodigies and Enchantments, Governed by the Goddess of Falsehood, and entitled the *Region of false Wit*. There was nothing in the Fields, the Woods, and the Rivers, that appeared natural. Several of the Trees blossom'd in Leaf-Gold, some of them produced Bone Lace, and some of them precious Stones, the Fountains bubbled in an Opera Tune, and were filled with Stags, Wild-Boars, and Mermaids, that lived among the Waters, at the same time that Dolphins and several kinds of Fish played upon the Banks, or took their Pastime in the Meadows. The Birds had many of them Golden beaks, and human Voices. The Flowers perfumed the Air with Smells of Incense, Amber-Greese and Pulvillios, and were so interwoven with one another, that they grew up in Pieces of Embroidery. The Winds were fill'd with Sighs and Messages of distant Lovers. As I was walking to and fro in this enchanted Wilderness, I could not forbear breaking out into Soliloquies upon the several Wonders which lay before me, when to my great Surprise I found there were artificial Ecchoes in every Walk, that by Repetitions of certain Words which I spoke, agreed with me, or contradicted me, in everything I said. In the midst of my Conversation with these invisible Companions, I discover'd in the Center of a very dark Grove a Monstrous Fabrick built after the Gothick manner, and covered with innumerable Devices in that barbarous kind of Sculpture. I immediately went up to it, and found it to be a kind of Heathen Temple consecrated to the God of Dullness. Upon my Entrance I saw the Deity of the Place dressed in the Habit of a Monk, with a Book in one Hand and a Rattle in the other. Upon his right Hand was Industry, with a Lamp burning before Her; and on his left Caprice, with a Monkey sitting on her Shoulder. Before his Feet there was shaped in that manner, to comply with the Inscription that surrounded it. Upon the Altar there lay several Offerings of Axes, Wings, and Eggs, cut in Paper, and inscribed with Verses. The Temple was filled with Votaries, who applied themselves to different Diversions, as their Fancies directed them. In one Part of it I saw a Regiment of Anagrams, who were continually in motion, turning to the Right or to the Left, facing about, doubling their Ranks, shifting their Stations, and throwing themselves into all the Figures and Counter-marches of the most changeable and perplexed Exercise.

Not far from these was a body of *Acrosticks*, made up of very disproportioned Persons. It was disposed into three Columns, the Officers planting themselves in a Line on the left Hand of each Column. The Officers were all of them at least Six Foot high, and made three Rows of very proper Men; but the Common Soldiers, who filled up the spaces between the Officers, were such Dwarfs, Cripples, and Scare-Crows, that one could hardly look upon them without laughing. There were behind the *Acrosticks* two or three files of *Chronograms*, which differed only from the former, as their Officers were equipped (like the Figure of Time) with an Hourglass in one Hand, and a Scythe in the other, and took their Posts promiscuously among the private Men whom they commanded.

In the Body of the Temple, and before the very Face of the Deity methoughts I saw the Phantom of *Tryphiodorus* the *Lipo-grammatist*, engaged in a Ball with four and twenty Persons, who pursued him by turns through all the Intricacies and Labyrinths of a Country Dance, without being able to overtake him.

Observing several to be very busie at the Western End of the *Temple*, I inquired into what they were doing, and found there was in that Quarter the great Magazine of *Rebus'*s. These were several things of the most different Natures tied up in Bundles. . . . One of the Workmen seeing me very much surprized, told me, there was an infinite deal of Wit in several of those Bundles, and that he would explain them to me if I pleased: I thanked him for his Civility, but told him I was in very great haste at that time. As I was going out of the Temple, I observed in one Corner of it a Cluster of Men and Women laughing very heartily, and diverting themselves at a Game of *Crambo*. I heard several *double Rhymes* as I passed by them, which raised a great deal of Mirth.

Not far from these was another Set of Merry People engaged at a Diversion, in which the whole Jest was to mistake one Person for another. To give occasion for these ludicrous Mistakes, they were divided into Pairs, every Pair being covered from Head to Foot with the same kind of Dress, though, perhaps, there was not the least Resemblance in their Faces. By this means an old Man was sometimes mistaken for a Boy, a Woman for a Man, and a Black-a-moor for an *European*, which very often produced great Peals of Laughter. These I guess'd to be a Party of *Punns*. But being very desirous to get out of the World of Magick, which had almost turned my Brain, I left the Temple, and crossed over the Fields that lay about it with all the speed I could make. I was not gone far before I heard the Sound of Trumpets and Alarms, which seemed to proclaim the March of an Enemy; and, as I afterwards found, was in reality what I apprehended it. There appear'd at a great distance a very shining Light, and in the midst of it a Person of a most beautiful Aspect; her Name was TRUTH. On her Right Hand there marched a Male Deity, who bore several Quivers on his Shoulders, and grasped several Arrows in his Hand. His Name was *Wit*. The Approach of these two Enemies filled all the Territories of *False Wit* with an unspeakable Consternation, insomuch that the Goddess of those Regions Appear'd inn Person upon her Frontiers with the several inferior Deities, and the different Bodies of Forces which I had before seen in the Temple, who were now drawn up in Array, and prepared to give their Foes a warm Reception. As the March of the Enemy was very slow, it gave time to the several Inhabitants who border'd upon the *Regions of* FALSEHOOD to draw their Forces into a Body, with a Design to stand upon their Guard as Neuters, and attend the Issue of the Combat.

I must here inform my Reader, that the Frontiers of the Enchanted Region, which I have before described, were inhabited by the Species of MIXED WIT, who made a very odd Appearance when they were Mustered together in an Army. There were Men whose Bodies were stuck full of Darts, and Women whose eyes were burning Glasses: Men that had Hearts of Fire, and Women that had Breasts of Snow. It would be endless to describe several Monsters of the like Nature, that composed this great Army; which immediately fell asunder, and divided it self into two Parts; the one half throwing themselves behind the Banners of TRUTH, and the others behind those of FALSEHOOD.

The Goddess of FALSEHOOD was of a Gigantick Stature, and advanced some Paces before the front of her Army; but as the dazzling Light, which flowed from TRUTH, began to shine upon her, she faded insensibly; insomuch that inn a little space she looked rather like an huge Phantom, than a real Substance. At length, as the Goddess of TRUTH approached still nearer to her, she fell away entirely, and vanish'd amidst the Brightness of Place where she had been seen.

As at the rising of the Sun the Constellations grow thin, and the Stars go out one after another, 'till the whole Hemisphere is extinguish'd; such was the vanishing of the Goddess; and not only of the Goddess her self, but of the whole Army that attended her, which sympathized with their Leader, and shrunk into Nothing, in Proportion as the Goddess disappeared. At the same time the whole Temple sunk, the Fish betook themselves to the Streams, and thee wild Beasts to the Woods: The Fountains recover'd their Murmurs, the Birds their Voices, the Trees their Leaves, the Flowers their Scents, and the whole Face of Nature its true and genuine Appearance. Tho' I still continued asleep, I fancy'd my self as it were awaken'd out of a Dream, when I saw this Region of Prodigies restor'd to Woods and Rivers, Fields and Meadows.

Source: Addison, Joseph, and Richard Steele. 1711, May 7. *The Spectator,* 58. Available at: http://www.fullbooks.com/The-Spectator-Volume-17.html

Addison, Joseph, and Richard Steele. 1711, May 12. *The Spectator,* 63. Available at: http://www.fullbooks.com/The-Spectator-Volume-18.html

Lady Mary Wortley Montagu, Poems (18th c.)

In 1716, Lady Mary Wortley Montagu accompanied her husband, Edward Wortley Montagu, when he was sent as ambassador to Constantinople. She had contracted smallpox the year before and had been left badly scarred. In Constantinople, she learned of the practice of inoculating people against smallpox, and she introduced the method upon her return to England. The first poem included here suggests the horror felt by women at this time at "losing their beauty" as a result of the scarring of smallpox. In the second poem, the speaker mourns her lost beauty most painfully at the moment when she finds someone she hopes can look beyond it. In the final poem, interestingly, we find that Wortley Montagu's experience of smallpox did not render her sympathetic to the disability of another; she uses Alexander Pope's body, deformed by tuberculosis of the spine, as the basis for some of her satire against him.

Satturday: The Small Pox. Flavia

The wretched Flavia, on her couch reclined,
Thus breath'd the anguish of a wounded mind,
A glass revers'd in her right hand she bore,
For now she shunn'd the face she sought before.
"How am I chang'd! alas! how am I grown
A frightful spectre to myself unknown!
Where's my complexion? where my radiant bloom,
That promis'd happiness for years to come?
Then with what pleasure I this face survey'd!
To look once more, my visits oft delay'd!
Charm'd with the view, a fresher red would rise,
And a new life shot sparkling from my eyes!
"Ah! faithless glass, my wonted bloom restore;
Alas! I rave, that bloom is now no more!
The greatest good the gods on men bestow,
Ev'n youth itself, to me is useless now.
There was a time (oh! that I could forget!)
When opera-tickets pour'd before my feet;
And at the Ring, where brightest beauties shine,
The earliest cherries of the spring were mine.
Witness, O Lilly; and thou, Motteux, tell,
How much japan these eyes have made ye sell.
With what contempt ye saw me oft despise
The humble offer of the raffled prize;
For at each raffle still each prize I bore,
With scorn rejected, or with triumph wore!
Now beauty's fled, and presents are no more!
"For me the patriot has the House forsook,
And left debates to catch a passing look:
For me the soldier has soft verses writ:
For me the beau has aim'd to be a wit.
For me the wit to nonsense was betray'd;
The gamester has for me his dun delay'd,
And overseen the card he would have play'd.
The bold and haughty, by success made vain,
Aw'd by my eyes have trembled to complain:
The bashful 'squire, touch'd by a wish unknown,
Has dar'd to speak with spirit not his own:
Fir'd by one wish, all did alike adore;
Now beauty's fled, and lovers are no more!
"As round the room I turn my weeping eyes,
New unaffected scenes of sorrow rise.
Far from my sight that killing picture bear,
The face disfigure, and the canvas tear:
That picture which with pride I us'd to show,
The lost resemblance that upbraids me now.
And thou, my toilette! where I oft have sat,

Las Meninas, or the Family of Phillip IV, *by Diego Rodriguez Velázquez (1599–1660). Building upon the role of individuals of short stature or with cognitive disabilities as those who were allowed to critique power openly, Velázquez allows the gaze of the disabled attendant in this work to meet that of the viewer. In doing so, the figure calls attention to the act of looking upon bodies as objects without self-awareness.*

Source: Art Resource, New York.

While hours unheeded pass'd in deep debate
How curls should fall, or where a patch to place;
If blue on scarlet best became my face:
Now on some happier nymph your aid bestow;
On fairer heads, ye useless jewels, glow!
No borrow'd lustre can my charms restore;
Beauty is fled, and dress is now no more!
"Ye meaner beauties, I permit ye shine;
Go, triumph in the hearts that once were mine:
But, 'midst your triumphs with confusion know,
'Tis to my ruin all your charms ye owe.
Would pitying Heav'n restore my wonted mien,
Ye still might move unthought of and unseen:
But oh, how vain, how wretched is the boast
Of beauty faded, and of empire lost!
What now is left but, weeping, to deplore
My beauty fled, and empire now no more!
"Ye cruel chemists, what withheld your aid?
Could no pomatum save a trembling maid?
How false and trifling is that art ye boast!
No art can give me back my beauty lost.
In tears, surrounded by my friends, I lay
Mask'd o'er, and trembled at the sight of day;
Mirmillio came my fortune to deplore
(A golden-headed cane well carv'd he bore),
Cordials, he cried, my spirits must restore!
Beauty is fled, and spirit is no more!
"Galen, the grave officious Squirt was there.
With fruitless grief and unavailing care;
Machaon too, the great Machaon, known
By his red cloak and his superior frown;
And why, he cried, this grief and this despair?
You shall again be well, again be fair;
Believe my oath (with that an oath he swore);
False was his oath; my beauty was no more!
"Cease, hapless maid, no more thy tale pursue,
Forsake mankind, and bid the world adieu!
Monarchs and beauties rule with equal sway:
All strive to serve, and glory to obey:
Alike unpitied when depos'd they grow,
Men mock the idol of their former vow.
"Adieu! ye parks—in some obscure recess,

Where gentle streams will weep at my distress,
Where no false friend will in my grief take part,
And mourn my ruin with a joyful heart;
There let me live in some deserted place,
There hide in shades this lost inglorious face.
Plays, operas, circles, I no more must view!
My toilette, patches, all the world adieu!"

This Once Was Me

This once was me, thus my complexion fair,
My cheek thus blooming, and thus curl'd my Hair,
This picture which with pride I us'd to show
The lost resemblance but upbraids me now,
Yet all these charms I only would renew
To make a mistrisse less unworthy you.
'Tis said, the Gods by ardent Bows are gain'd,
Iphis her wish (however wild) obtain'd,
Pygmalion warm'd to Life his Ivory maid,
Will no kind power restore my charms decaid?
With useless Beauty my first Youth was crown'd,
In all my Conquests I no pleasure found,
The croud I shunn'd, nor of Applause was vain
And Felt no pity for a Lover's pain.
The pangs of passion coldly I despised
And view'd with scorn the ravage of my Eyes.
Now that contempt too dearly is repaid,
Th'impetuous Fire does my whole Soul invade.
O more than Madness!—with compassion View
A Heart could only be enflam'd by You.
In that Lov'd Form there does at once unite
All that can raise Esteem, or give delight,
A Heart like mine is not below your care,
Artless and Honest, tender and sincere,
Where no mean thought has ever found a place
Look on my Heart, and you'll forget my Face.

Verses: Addresed to the Imitator of the First Satire of the Second Book of Horace

In two large columns on thy motley page
Where Roman wit is strip'd with English rage;
Where ribaldry to satire makes pretence,
And modern scandal rolls with ancient sense:
Whilst on one side we see how Horace thought,
And on the other how he never wrote;
Who can believe, who view the bad, the good
That the dull copyist better understood
That spirit he pretends to imitate,
Than heretofore that Greek he did translate?
Thine is just such an image of *his* pen,
As thou thyself art of the sons of men,
Where our own species in burlesque we trace,
A sign-post likeness of the human race,
That is at once resemblance and disgrace.
Horace can laugh, is delicate, is clear,
You only coarsely rail, or darkly sneer;
His style is elegant, his diction pure,
Whilst none thy crabbed numbers can endure;
Hard as thy heart, and as thy birth obscure.
If *he* has thorns, they all on roses grow;
Thine like thistles, and mean brambles show;
With this exception, that, though rank the soil,
Weeds as they are, they seem produc'd by toil.
Satire should, like a polish'd razor, keen,
Wound with a touch, that's scarcely felt or seen:
Thine is an oyster-knife, that hacks and hews;
The rage, but not the talent to abuse;
And is in *hate*, what *love* is in the stews.
'Tis the gross *lust* of hate, that still annoys,
Without distinction, as gross love enjoys:
Neither to folly, nor to vice confin'd,
The object of thy spleen is humankind:
It preys on all who yield, or who resist:
To thee 'tis provocation to exist.
But if thou seest a great and generous heart,
Thy bow is doubly bent to force a dart.
Nor dignity nor innocence is spar'd,
Nor age, nor sex, nor thrones, nor graves, rever'd.
Nor only justice vainly we demand,
But even benefits can't rein thy hand;
To this or that alike in vain we trust,
Nor find thee less ungrateful than unjust.
Not even youth and beauty can control
The universal rancour of thy soul;
Charms that might soften superstition's rage,
Might humble pride, or thaw the ice of age.
But how should'st thou by beauty's force be mov'd,
No more for loving made than to be lov'd?
It was the equity of righteous Heav'n,
That such a soul to such a form was giv'n;
And shows the uniformity of fate,
That one so odious should be born to hate.
When God created thee, one would believe
He said the same as to the snake of Eve;
To human race antipathy declare,
'Twixt them and thee be everlasting war.
But oh! the sequel of the sentence dread,
And whilst you *bruise their heel*, beware your head.
Nor think thy weakness shall be thy defence,
The female scold's protection in offence.
Sure 'tis as fair to beat who cannot fight,

As ‘tis to libel those who cannot write.
And if thou draw’st thy pen to aid the law,
Others a cudgel, or a rod, may draw.
If none with vengeance yet thy crimes pursue,
Or give thy manifold affronts their due;
If limbs unbroken, skin without a stain,
Unwhipt, unblanketed, unkick’d, unslain,
That wretched little carcase you retain,
The reason is, not that the world wants eyes,
But thou’rt so mean, they see, and they despise:
When fretful *porcupine*, with ranc’rous will,
From mounted back shoots forth a harmless quill,
Cool the spectators stand; and all the while
Upon the angry little monster smile.
Thus ‘tis with thee:—while impotently safe,
You strike unwounding, we unhurt can laugh.
Who but must laugh, this bully when he sees,
A puny insect shiv’ring at a breeze?
One over-match’d by every blast of wind,
Insulting and provoking all mankind.
Is this the *thing* to keep mankind in awe,
To make those tremble who escape the law?
Is this *the ridicule* to live so long,
The deathless satire and *immortal song?*
No: like the self-blown praise, thy scandal flies;
And, as we’re told of wasps, it stings and dies.
If none do yet return th’intended blow,
You all your safety to your dulness owe:
But whilst that armour thy poor corse defends,
‘Twill make thy readers few, as are thy friends:
Those, who thy nature loath’d, yet lov’d thy art,
Who lik’d thy head, and yet abhorr’d thy heart:
Chose thee to read, but never to converse,
And scorn’d in prose him whom they priz’d in verse
Ev’n they shall now their partial error see,
Shall shun thy writings like thy company;
And to thy books shall ope their eyes no more
Than to thy person they would do their door.
Nor thou the justice of the world disown,
That leaves thee thus an outcast and alone;
For though in law to murder be to kill,
In equity the murder’s in the will:
Then whilst with coward-hand you stab a name,
And try at least t’assassinate our fame,
Like the first bold assassin’s be thy lot,
Ne’er be thy guilt forgiven, or forgot;
But, as thou hat’st be hated by mankind,
And with the emblem of thy crooked mind
Mark’d on thy back, like Cain by God’s own hand,
Wander, like him, accursed through the land.

Source: Montagu, Lady Mary Wortley. 1993. Halsband, Robert, ed. *Essays and Poems and “Simplicity,” a Comedy*. New York: Oxford University Press.

[Editors’ note: This poem was probably written jointly by Lady Mary and Lord Hervey in 1733, in response to Alexander Pope’s satire of Lady Mary.]

Joseph Pitton de Tournefort, from *A Voyage into the Levant* (1717)

By the time Joseph Pitton de Tournefort was writing, in the early eighteenth century, an anti-Orientalist critique (that is, that Tournefort’s treatment objectifies as exotic and radically different the people he describes) may be justified. Tournefort may have been reliable for some things, but often he gives signs of incorporating into his account material from earlier writers about things that he had not himself seen (and that quite possibly were no longer there to see). He also gives signs of embroidering and inflating events or practices.

The Pavilion which is toward the *Bosphorus*, is higher than that of the Port, and built on Arches which support three Salons terminated by gilded Domes. The Prince comes thither to sport with his Women and Mutes. [Vol. II, P. 185]

. . . the Palace therefore is fill’d only with a Train of Creatures intirely consecrated to him. They may be divided into five Classes; the *Eunuchs*, the *Ichoglans*, the *Azamoglans*, the *Women*, and the *Mutes*; to whom may be added the *Dwarfs* and the *Buffoons*, who deserve not to be accounted a distinct Class by themselves.

Besides the Officers already mention’d, the Sultans have also in their Palace two sorts of People, who serve to divert them; namely, the *Mutes*, and the *Dwarfs*. The Mutes of the Seraglio are a Species of rational Creatures by themselves: for, not to disturb the Prince’s Repose, they have invented a Language among themselves, the Characters of which are express’d by Signs alone; and these Signs are understood by Night as well as by Day, by touching certain Parts of their Body. This Language is so much in fashion in the Seraglio, that they who would please there, and are oblig'd to be in the Prince's Presence, learn it very carefully: for it would be a want of the deep Respect they owe him, to whisper one another in the Ear before him. [Vol. II, P. 235]

Source: Tournefort, Joseph Pitton de. 1741. Ozell, J., trans. *A Voyage into the Levant, etc.* 3 Vols. London: Midwinter et al. (Originally published in French 1717)

▣ David Hume, "Of National Characters" (1748)

In the following excerpt, the Scottish philosopher David Hume comments on the innate biological and cognitive inferiority of "negroes." His writing participated in a late-eighteenth-century discourse of racial stigmatization based on the idea of inbuilt characteristics that could not be overcome.

I am apt to suspect the negroes and in general all other species of men (for there are four or five different kinds) to be naturally inferior to the whites. There never was a civilized nation of any other complexion than white, nor even any individual eminent either in action or speculation. No ingenious manufactures amongst them, no arts, no sciences. On the other hand, the most rude and barbarous of the whites, such as the ancient GERMANS, the present TARTARS, have still something eminent about them in their valour, form of government, or some other particular. Such a uniform and constant differences could not happen in so many countries and ages, if nature had not made an original distinction betwixt these breeds of men. Not to mention our colonies, there are Negroe slaves dispersed all over Europe, of which none ever discovered any symptoms of ingenuity, tho' low people, without education, will start up amongst us, and distinguish themselves in every profession. In JAMAICA indeed they talk of one negroe as a man of parts and learning; but 'tis likely he is admired for very slender accomplishments like a parrot, who speaks a few words plainly.

Source: Hume, David. 1748. "Of National Characters." In *Three Essays, Moral and Political.* Available at: http://www.engl.virginia.edu/enec981/dictionary/03humeK1.html

▣ David Hume, "Of the Standard of Taste" (1757)

In this discussion, Hume essentializes (and implicitly racializes) the idea of taste, the faculty of appreciating beauty and quality in its many forms, by connecting taste to superior health of sensory organs and a lack of taste to some defect therein. For Hume, therefore, taste results not from the superior education afforded to the few whose class, race, and gender status makes them eligible for it, but from inborn fineness of sensibility.

#12. It appears then, that, amidst all the variety and caprice of taste, there are certain general principles of approbation or blame, whose influence a careful eye may trace in all operations of the mind. Some particular forms or qualities, from the original structure of the internal fabric, are calculated to please, and others to displease; and if they fail of their effect in any particular instance, it is from some apparent defect or imperfection in the organ. A man in a fever would not insist on his palate as able to decide concerning flavours; nor would one, affected with the jaundice, pretend to give a verdict with regard to colours. In each creature, there is a sound and a defective state; and the former alone can be supposed to afford us a true standard of a taste and sentiment. If, in the sound state of the organ, there be an entire or considerable uniformity of sentiment among men, we may thence derive an idea of the perfect beauty; in like manner as the appearance of objects in daylight, to the eye of a man in health, is denominated their true and real colour, even while colour is allowed to be merely a phantasm of the senses.

#13. Many and frequent are the defects in the internal organs, which prevent or weaken the influence of those general principles, on which depends our sentiment of beauty or deformity. Though some objects, by the structure of the mind, be naturally calculated to give pleasure, it is not to be expected, that in every individual the pleasure will be equally felt. Particular incidents and situations occur, which either throw a false light on the objects, or hinder the true from conveying to the imagination the proper sentiment and perception.

#23. Thus, though the principles of taste be universal, and, nearly, if not entirely the same in all men; yet few are qualified to give judgment on any work of art, or establish their own sentiment as the standard of beauty. The organs of internal sensation are seldom so perfect as to allow the general principles their full play, and produce a feeling correspondent to those principles. They either labour under some defect, or are vitiated by some disorder; and by that means, excite a sentiment, which may be pronounced erroneous. When the critic has no delicacy, he judges without any distinction, and is only affected by the grosser and more palpable qualities of the object: The finer touches pass unnoticed and disregarded. Where he is not aided by practice, his verdict is attended with confusion and hesitation. Where no comparison has been employed, the most frivolous beauties, such as rather merit the name of defects, are the object of his admiration. Where he lies under the influence of prejudice, all his natural sentiments are perverted. Where good sense is wanting, he is not qualified to discern the beauties of design and reasoning, which are the highest and most excellent. Under some or other of these imperfections, the generality of men labour; and hence a true judge in the finer arts is observed, even during the most polished ages, to be so rare a character; Strong sense, united to delicate sentiment, improved by practice, perfected by comparison, and cleared of all prejudice, can alone entitle critics to this valuable character; and the joint verdict of such, wherever they are to be found, is the true standard of taste and beauty.

Source: Hume, David. 1757. "Of the Standard of Taste." In *Four Dissertations*. Available at: http://www.csulb.edu/~jvancamp/361r15.html

Sarah Scott, from A *Description of Millenium Hall* (1762)

In this feminist utopia, bluestocking novelist Sarah Scott promulgates female separatism and self-sufficiency along with middle-class economic and moral virtue. Disability figures in this text as evidence of the pastoral charity of Scott's heroines, while also functioning as the novel's attempt at humane display of the kind of physical difference exploited at Bartholomew Fair.

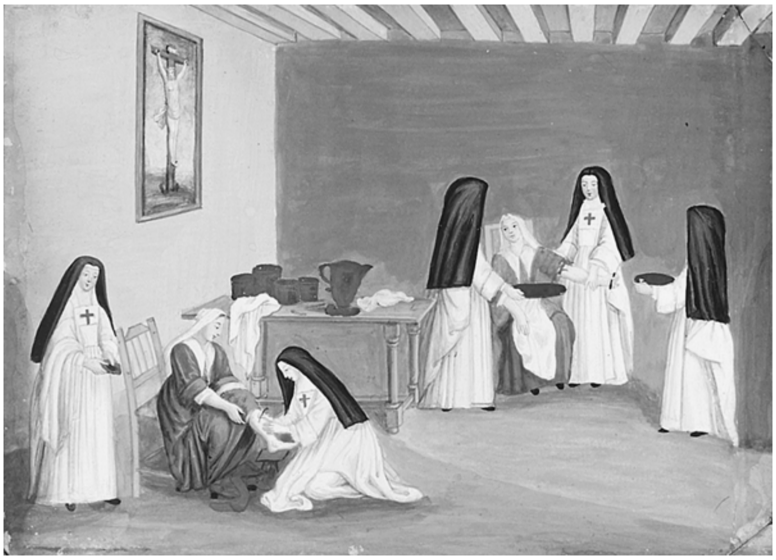
Dear Sir,

Though, when I left London, I promised to write to you as soon as I had reached my northern retreat, yet, I believe, you little expected instead of a letter to receive a volume; but I should not stand excused to myself, were I to fail communicating to you the pleasure I received in my road hither, from the sight of a society, whose acquaintance I owe to one of those fortunate, though in appearance trifling, accidents, from which sometimes arise the most pleasing circumstances of our lives for as such I must ever esteem the acquaintance of that amiable family, who have fixed their abode at a place which I shall nominate Millenium Hall, as the best adapted to the lives of the inhabitants, and to avoid giving the real name, fearing to offend that modesty which has induced them to conceal their virtues in retirement.

In giving you a very circumstantial account of this society, I confess I have a view beyond the pleasure, which a mind like yours must receive from the contemplations of so much virtue. Your constant endeavours have been to inculcate the best principles into youthful minds, the only probable means of mending mankind; for the foundation of most of our virtues, or our vices, are laid in that season of life when we are most susceptible of impression, and when on our minds, as on a sheet of white paper, any characters may be engraven; these laudable endeavours, by which we may reasonably expect the rising generation will be greatly improved, render particularly due to you, any examples which may teach those virtues that are not easily learnt by precept, and shew the facility of what, in mere speculation, might appear surrounded with a discouraging impracticability; you are the best judge, whether , by being made public, they may be conducive to your great end of benefiting the world. I therefore submit the future fate of the following sheets entirely to you, and shall not think any prefatory apology for the publication at all requisite; for though a man who supposes his own life and actions deserve universal notice, or can be of general use, may be liable to the imputation of vanity, yet as I have no other share than that of a spectator, and auditor, in what I purpose to relate, I presume no apology can be required; for my vanity must rather be mortified than flattered in the description of such virtues as will continually accuse me of my own deficiencies, and lead me to make an humiliating comparison between these excellent ladies and myself.

You may remember, Sir, that when I took leave of you with a design of retiring to my native country, there to enjoy the plenty and leisure for which a few years labour had furnished me with the necessary requisites, I was advised by an eminent physician to make a very extensive tour through the western part of this kingdom, in order, by frequent change of air, and continued exercise, to cure the ill effects of my long abode in the hot and unwholesome climate of Jamaica, where, while I increased my fortune, I gradually impaired my constitution; and though one, who like me, had dedicated all his application to mercantile gain, will not allow that he has given up the substance for the shadow, yet perhaps it would be difficult to deny, that I thus sacrificed the greater good in pursuit of the less.

The eagerness with which I longed to fix in my wished for retirement, made me imagine, that when I had once reached it, even the pursuit of health would be insufficient inducement to determine me to leave my retreat, I therefore chose to make the advised tour before I went into the north. As the pleasure arising from a variety of beautiful objects is but half enjoyed, when we have no one to share it with us, I accepted the offer Mr. Lamont (the son of my old friend) made of accompanying me in my journey. As this young gentleman has not the good fortune to be known to you, it may not be amiss, as will appear in the sequel, to let you into his character.



Nuns Attending at the Infirmary, *Anonymous (18th c.). This work depicts an example of an early hospital for the sick that catered primarily to those who were homeless or disabled. The bulk of the care sought to minister to the spiritual needs of patients.*

Source: Art Resource, New York.

Mr. Lamont is a young man of about twenty-five years of age, of an agreeable person, and lively understanding; both perhaps have concurred to render him a coxcomb. The vivacity of his parts soon gained him such a degree of encouragement as excited his vanity, and raised in him an high opinion of himself. A very generous father enabled him to partake of every fashionable amusement, and the natural bent of his mind soon led him into all the dissipation which the gay world affords. Useful and improving studies were laid aside for such desultory reading, as he found most proper to furnish him with topics for conversation, in the idle societies he frequented. Thus that vivacity, which, properly qualified, might have become true wit, degenerated into pertness and impertinence. A consciousness of an understanding, which he never exerted, rendered him conceited; those talents which nature kindly bestowed upon him, by being perverted, gave rise to his greatest faults. His reasoning faculty, by a partial and superficial use, led him to infidelity, and the desire of being thought superiorly distinguishing, established him an infidel. Fashion, not reason, has been the guide of all his thoughts and actions. But with these faults he is good-natured, and not unentertaining, especially in a tete a tete, where he does not desire to shine, and therefore his vanity lies dormant, and suffers the best qualifications of his mind to break forth. This induced me to accept of him as a fellow traveller.

We proceded on our journey as far as Cornwall, without meeting with any other than the usual incidents of the road, till one afternoon, when our chaise broke down. The worst circumstance attending this accident was our being several miles from a town, and so ignorant of the country, that we knew not whether there was any village within a moderate distance. We sent the postilion on my man’s horse to the next town to fetch a smith, and leaving my servant to guard the chaise, Mr. Lamont and I walked towards an avenue of oaks, which we observed at a small distance. The thick shade they afforded us, the fragrance wafted from the woodbines with which they were encircled, was so delightful, and the beauty of the grounds so very attracting, that we strolled on, desirous of approaching the house to which this avenue led. It is a mile and a half in length, but the eye is so charmed with the remarkable verdure and neatness of the fields, with the beauty of the flowers which are planted all round them, and seem to mix with the quickest hedges, that time steals away insensibly.

When we had walked about half a mile in a scene truly pastoral, we began to think ourselves in the days of Theocritus, so sweetly did the sound of a flute come wafted through the air. Never did pastoral swain make sweeter melody on his oaten reed. Our ears now afforded us fresh attraction, and with quicker steps we proceeded, till we came within sight of the musician that had charmed us. Our pleasure was not a little heightened, to see, as the scene promised, in reality a shepherd, watching a large flock of sheep. We continued motionless, listening to his music, till a lamb straying from its fold demanded his care, and he laid aside his instrument, to guide home the little wanderer.

Curiosity now prompted us to walk on; the nearer we came to the house, the greater we found the profusion of flowers which ornamented every field. Some had no other defence than hedges of rose trees and sweet-briars, so artfully planted, that they made a very thick hedge, while at the lower part, pinks, jonquils, hyacinths, and various other flowers, seemed to grow under their protection. Primroses, violets, lilies of the valley, and polyanthuses enriched such shady spots, as, for want of sun, were not well calculated for the production of other flowers. The mixture of perfumes which exhaled from this profusion composed the highest fragrance, and sometimes the different scents regaled the senses alternately, and filled us with reflections on the infinite variety of nature.

When we were within about a quarter of a mile of the house, the scene became still more animated. On one side was the greatest variety of cattle, the most beautiful of their kinds, grazing in fields whose verdure equaled that of the finest turf, nor were they destitute of their ornaments, only the woodbines and Jessamine, and such flowers, as might have tempted the inhabitants of these pastures to crop them, were defended with roses and sweet-briars, whose thorns preserved them from all attacks.

Though Lamont had hitherto been little accustomed to admire nature, yet was he much captivated with this scene, and with his usual levity cried out, 'If Nebuchadnezzar had such pastures as these to range in, his seven years expulsion from human society might now be the most agreeable part of his life.' My attention was too much engaged to criticize the light turn of Lamont's mind, nor did his thoughts continue long on the same subject, for our observation was soon called off, by a company of hay-makers in the fields on the other side of the avenue. The cleanliness and neatness of the young women thus employed, rendered them a more pleasing subject for Lamont's contemplation than any thing we had yet seen; in them we beheld rural simplicity, without any of those marks of poverty and boorish rusticity, which would have spoilt the pastoral air of the scene around us; but not even the happy amiable innocence, which their figures and countenances expressed, gave me so much satisfaction as the sight of the number of children, who were all exerting the utmost of their strength, with an air of delighted emulation between themselves, to contribute their share to the general undertaking. Their eyes sparkled with that spirit which health and activity can only give, and the rosy cheeks shewed the benefits of youthful labour. Curiosity is one of those insatiable passions that grow by gratification; it still prompted us to proceed, not unsatisfied with what we had seen, but desirous to see still more of this earthly paradise. We approached the house, wherein, as it was the only human habitation in view, we imagined must reside the Primum Mobile of all we had yet beheld. We were admiring the magnificence of the ancient structure and inclined to believe it the abode of the genius which presided over this fairy land, when we were surprised by a storm, which had been for some time gathering over our heads, though our thoughts had been too agreeably engaged to pay much attention to it. We took shelter under the thick shade of a large oak, but the violence of the thunder and lightening made our situation rather uncomfortable. All those whom we had a little before seen so busy, left their work on hearing the first clap of thunder, and ran with the utmost speed to Millenium Hall, so I shall call the noble mansion of which I am speaking, as to an assured asylum against every evil.

Some of these persons, I imagine, perceived us; for immediately after they entered, came out a woman, who, by her air and manner of address, we guessed to be the house-keeper, and desired us to walk into the house till the storm was over. We made some difficulties about taking that liberty, but she still persisting in her invitation, had my curiosity to see the inhabitants of this hospitable mansion been less, I could not have refused to comply, as by prolonging these ceremonious altercations I was detaining her in the storm, we therefore agreed to follow her.

If we had been inclined before to fancy ourselves on enchanted ground, when after being led through a large hall, we were introduced to the ladies, who knew nothing of what had passed, I could scarcely forbear believing myself in the Attick school.

The room where they sat was about forty-five feet long, of a proportionable breadth, with three windows on one side, which looked into a garden, and a large bow at the upper end. Over against the windows were three large book-cases, upon the top of the middle one stood an orrery, and a globe on each of the others. In the bow sat two ladies reading, with pen, ink, and paper on a table before them, at which was a young girl translating out of French. At the lower end of the room was a lady painting, with exquisite art indeed, a beautiful Madona; near her another, drawing a landscape out of her own imagination; a third, carving a picture-frame in wood, in the finest manner; a fourth, engraving; and a young girl reading aloud to them; the distance from the ladies in the bow-window being such, that they could receive no disturbance from her. At the next window were placed a group of girls, from the age of ten years old to fourteen. Of these, one was drawing figures, another a landscape, a third a perspective view, a fourth engraving, a fifth carving, a sixth turning in wood, a seventh writing, an eighth cutting out linen, another making a gown, and by them an empty chair and a tent, with embroidery, finely fancied, before it, which we afterwards found had been left by a young girl who was gone to practise on the harpsicord.

As soon as we entered they all rose up, and the house-keeper introduced us, by saying, she saw us standing under a tree to avoid the storm, and so had desired us to walk in. The ladies received us with the greatest politeness, and expressed concern, that when their house was so near, we should have recourse to so insufficient a shelter. Our surprise at the sight of so uncommon a society, occasioned our making but an awkward return to their obligating reception; nor when we observed how many arts we had interrupted, could we avoid being ashamed that we had then intruded upon them.

But before I proceed farther, I shall endeavour to give you some idea of the persons of the ladies, whose minds I shall afterwards best describe by their actions. The two who sat in the bow window were called Mrs. Maynard and Mrs. Selvyn. Mrs. Maynard is between forty and fifty years of age, a little woman, well made, with a lively and genteel air, her hair black, and her eyes of the same colour, bright and piercing, her features good, and complexion agreeable, though brown. Her countenance expresses all the vivacity of youth, tempered with a serenity which becomes her age.

Mrs. Selvyn can scarcely be called tall, though she approaches that standard. Her features are too irregular to be handsome, but there is a sensibility and delicacy in her countenance which render her extremely engaging; and her person is elegant.

Mrs. Mancel, whom we had disturbed from her painting, is tall and finely formed, has great elegance of figure, and is graceful in every motion. Her hair is of a fine brown, her eyes blue, with all that sensible sweetness which is peculiar to that colour. In short, she excels in every beauty but the bloom, which is so soon faded, and so impossible to be imitated by the utmost efforts of art, nor has she suffered any farther by years than the loss of that radiance, which renders beauty rather more resplendent than more pleasing.

Mrs. Trentham, who was carving by her, was the tallest of the company, and in dignity of air particularly excels, but her features and complexion have been so injured by the small pox, that one can but just guess they were once uncommonly fine; a sweetness of countenance, and a very sensible look, indeed, still remain, and have baffled all the most cruel ravages of that distemper.

Lady Mary Jones, whom we found engraving, seems to have been rather pleasing than beautiful. She is thin, and pale, but a pair of the finest black eyes I ever saw, animate, to a great degree, a countenance, which sickness has done its utmost to render languid, but has, perhaps only made more delicate and amiable. Her person is exquisitely genteel, and her voice, in common speech, enchantingly melodious.

Mrs. Morgan, the lady who was drawing, appears to be upwards of fifty, tall, rather plump, and extremely majestic, an air of dignity distinguishes her person, and every virtue is engraven in indelible characters on her countenance. There is a benignity in every look, which renders the decline of life, if possible, more amiable than the bloom of youth. One would almost think nature had formed her for a common parent, such universal and tender benevolence beams from every glance she casts around her.

The dress of the ladies was thus far uniform, the same neatness, the same simplicity and cleanliness appeared in each, and they were all in lutestring night-gowns, though of different colours, nor was there anything unfashionable in their appearance, except that they were free from any trumpery ornaments. The girls were all clothed in camblet coats, but not uniform in colour, their linen extremely white and clean though coarse.

Some of them were pretty, and none had any defect in person, to take off from that general pleasingness which attends youth and innocence.

They had been taught such an habit of attention, that they seemed not at all disturbed by our conversation, which was of that general kind, as might naturally be expected on such an occasion, though supported by the ladies with more sensible vivacity and politeness, than is usual, where part of the company are such total strangers to the rest; till by chance one of the ladies called Mrs. Maynard by her name.

From the moment I saw her, I thought her face not unknown to me, but could not recollect where, or when I had been acquainted with her, but her name brought to my recollection, that she was not only an old acquaintance, but a near relation. I observed, that she had looked on me with particular attention, and I begged her to give me leave to ask her, of what family of Maynards she was? Her answer confirmed my supposition, and as she told me, that she believed she had some remembrance of my face, I soon made her recollect our affinity and former intimacy, though my twenty years abode in Jamaica, the alteration the climate had wrought in me, and time had made in us both, had almost effaced us from each other's memory.

There is great pleasure in renewing the acquaintance of our youth; a thousand pleasing ideas accompany it; many mirthful scenes and juvenile amusements return to the remembrance, and make us, as it were, live over again what is generally the most pleasing part of life. Mrs. Maynard seemed no less sensible of the satisfaction arising from this train of thoughts than myself, and the rest of the company were so indulgently good-natured, as in appearance, to share them with us. The tea table by no means interrupted our conversation, and I believe I should have forgot that our journey was not at an end, if a servant had not brought in word, that my man, who had observed our motions, was come to inform us, that our chaise could not be repaired that night.

The ladies immediately declared, that though their equipage was in order, they would not suffer it to put an end to a pleasure they owed to the accident which had happened to ours, and insisted we should give them our company till the smith had made all necessary reparations, adding, that I could not be obstinately bent on depriving Mrs. Maynard so soon of the satisfaction she received, from having recovered so long lost a relation. I was little inclined to reject this invitation: pleasure was the chief design of my journey, and I saw not how I could receive more, than by remaining in a family so extraordinary, and so perfectly agreeable. When both parties are well agreed, the necessary ceremonies previous to a compliance are soon over, and it was settled that we should not think of departing before the next day at soonest.

The continuance of the rain rendered it impossible to stir out of the house; my cousin, who seemed to think variety necessary to amuse, asked if we loved music? Which being answered in the affirmative, she begged the other ladies to entertain us with one of their family concerts, and we joining in the petition, proper orders were given, and we adjourned into another room, which was well furnished with musical instruments. Over the door was a beautiful Saint Cecilia, painted in crayons by Mrs. Mancel, and a fine piece of carved work over the chimney, done by Mrs. Trentham, which was a very artificial representation of every sort of musical instruments.

While we were admiring these performances, the company took their respective places. Mrs. Mancel seated herself at the harpsichord, Lady Mary Jones played on the arch lute, Mrs. Morgan on the organ, Mrs. Selvyn and Mrs. Trentham each on the six-stringed bass; the shepherd who had charmed us in the field was there with his German flute; a venerable looking man, who is their steward, played on the violincello, a lame youth on the French horn, another, who seemed very near blind, on the bassoon, and two on the fiddle. My cousin had no share in the performance except singing agreeably, wherein she was joined by some of the ladies, and where the music could bear it, by ten of the young girls, with two or three others whom we had not seen, and whose voices and manner were equally pleasing. They performed several of the finest pieces of the Messiah and Judas Maccabeus, with exquisite taste, and the most exact time. There was a sufficient number of performers to give the choruses all their pomp and fullness, and the songs were sung in a manner so touching and pathetic, as could be equaled by none, whose hearts were not as much affected by the words, as their senses were by the music. The sight of so many little innocents joining in the most sublime harmony, made me almost think myself already amongst the heavenly choir, and it was a great mortification to me to be brought back to this sensual world, by so gross an attraction as a call to supper, which put an end to our concert, and carried us to another room, where we found a repast more elegant than expensive.

The evening certainly is the most social part of the day, without any of those excesses which so often turn it into senseless revelry. The conversation after supper was particularly animated, and left us still more charmed with the society into which chance had introduced us; the sprightliness of their wit, the justness of their reflexions, the dignity which accompanied their vivacity, plainly evinced with how much greater strength the mind can exert itself in a regular and rational way of life, than in a course of dissipation. At this house every change came too soon, time seemed to wear a double portion of wings, eleven o'clock struck, and the ladies ordered a servant to shew us our rooms, themselves retiring to theirs.

It was impossible for Lamont and I to part till we had spent an hour in talking over this amiable family, with whom he could not help being much delighted, though he observed, 'they were very deficient in the bon ton, there was too much solidity in all they said, they would trifle with trifles indeed, but had not the art of treating more weighty subjects with the same lightness, which gave them an air of rusticity; and he did not doubt, but on a more intimate acquaintance we should find their manners much rusticated, and their heads filled with antiquated notions, by having lived so long out of the great world.'

I rose the next morning very early, desirous to make the day, which I purposed for the last of my abode in this mansion, as long as I could. I went directly into the garden, which, by what I saw from the house was extremely pretty. As I passed by the windows of the saloon, I perceived the ladies and their little pupils were earlier risers than myself, for they were all at their various employments. I first went into the gayest flower garden I ever beheld. The rainbow exhibits not half the variety of tints, and they are so artfully mingled, and ranged to make such a harmony of colours, as taught me how much the most beautiful objects may be improved by a judicious disposition of them. Beyond these beds of flowers rises a shrubbery, where every thing sweet and pleasing is collected. As these ladies have no taste but what is directed by good sense, nothing found a place here from being only uncommon, for they think few things are very rare but because they are little desirable; and indeed it is plain they are free from that littleness of mind, which makes people value a thing the more for its being possessed by no one but themselves. Behind the shrubbery is a little wood, which affords a gloom, rendered more agreeable by its contrast with the dazzling beauty of that part of the garden that leads to it. In the high pale which encloses this wood I observed a little door; curiosity induced me to pass through it; I found it opened on a row of the neatest cottages I ever saw, which the wood had concealed from my view. They were new and uniform, and therefore I imagined all dedicated to the same purpose. Seeing a very old woman spinning at one of the doors, I accosted her, by admiring the neatness of her habitation.

'Ay, indeed, said she, it is a most comfortable place, God bless the good ladies! I and my neighbours are as happy as princesses, we have every thing we want and wish, and who can say more?' 'Very few so much, answered I, but pray what share have the ladies in procuring the happiness you seem so sensible of.'

'Why Sir, continued the old woman, it is all owing to them. I was almost starved when they put me into this house, and no shame of mine, for so were my neighbours too; perhaps we were not so painstaking as we might have been; but that was not our faults, you know, as we had not things to work with, nor any body to set us to work, poor folks cannot know every thing as these good ladies do; we were half dead for want of victuals, and then people have not courage to set about any thing. Nay, all the parish were so when they came into it, young and old, there was not much to chuse, few of us had rags to cover us, or a morsel of bread to eat, except the two Squires; they indeed grew rich, because they had our work, and paid us not enough to keep life and soul together; they live above a mile off, so perhaps they did not know how poor we were, I must say that for them; the ladies tell me I ought not to speak against them, for every one has faults, only we see other peoples, and are blind to our own; and certainly it is true enough, for they are very wise ladies as well as good, and must know such things.'

As my new acquaintance seemed as loquacious as her age promised, I hoped for full satisfaction, and asked her, 'How she and her neighbours employed themselves?' 'Not all alike, replied the good woman, I will tell you, all about it. There are twelve of us that live here. We have every one a house of two rooms, as you may see, beside other conveniences, and each a little garden, but though we are separated, we agree as well, perhaps better, than if few lived together, and all help one another. Now, there is neighbour Susan, and neighbour Rachel; Susan is lame, so she spins cloaths for Rachel; and Rachel cleans Susan's house, and does such things for her as she cannot do for herself. The ladies settled all these matters at first, and told us, that as they, to please God, assisted us, we must in order to please him serve others; and that to make us happy they would have a melancholy life if she was to be always spinning and knitting, seeing other people around her talking, and not be able to hear a word they said, so the ladies busy her in making broths and caudles, and such things, for all the sick poor in this and the next parish, and two of us are fixed upon to carry what she has made to those that want them; to visit them often, and spend more or less time with them every day according as they have, or have not relations to take care of them; for though the ladies always hire nurses for those who are very ill, yet they will not trust quite to them, but make us overlook them, so that in a sickly time we shall be all day going from one to another.'

'But, said I, there are I perceive many children amongst you, how happens that? your ages shew they are not your own.'

'Oh! as for that, replied my intelligencer, I will tell you how that is. You must know these good ladies, heaven preserve them! take every child after the fifth of every poor person, as soon as it can walk, till when they pay the mother for nursing it; these children they send to us to keep out of harm, and as soon as they can hold a knitting-needle to teach them to knit, and to spin, as much as they can be taught before they are four or five years old, when they are removed into one of the schools. They are pretty company for us, and make us mothers again, as it were, in our old age; then the childrens relations are all so fond of us for our care of them, that it makes us a power of friends, which you know is very pleasant, though we want nothing from them but their good wills.'

Here I interrupted her by observing, that it must take up a great deal of time, and stop their work, consequently lessen their profits.

'There is nothing in that, continued the good woman, the ladies steward sends us in all we want in the way of meat, drink, and firing; and our spinning we carry to the ladies; they employ a poor old weaver, who before they came broke for want of work, to weave it for us, and when there is not enough they put more to it, so we are sure to have our cloathing; if we are not idle that is all over our houses, which they tell us, and certainly with truth, for it is a great deal of trouble to them, is all for our good, for that we cannot be healthy if we are not clean and neat. Then every saint's day, and every Sunday after church, we all go down to the hall, and the ladies read prayers, and a sermon to us, and their own family; nor do they ever come here without giving us some good advice. We used to quarrel, to be sure, sometimes when we first came to these houses, but the ladies condescended to make it up amongst us, and shewed us so kindly how much it was our duty to agree together, and to forgive every body their faults, or else we could not hope to be forgiven by God, against whom we so often sinned, that now we love one another like sisters, or indeed better, for I often see such quarrel. Beside, they have taught us when we are as much to blame, which we may be sure enough will happen, let us try ever so much to the contrary. Then the ladies seem so pleased when we do any kindness to one another, as to be sure is a great encouragement; and if any of us are sick they are so careful and so good, that it would be a shame if we did not do all we can for one another, who have been always neighbours and acquaintance, when such great ladies, who never knew us, as I may say, but to make us happy, and have no reason to take care of us but that we are poor, are so kind and condescending to us.'

I was so pleased with the good effect which the charity of her benefactors had on the mind, as well as the situation of this old woman, whose neighbours by her own account were equally benefited by the blessings they received, that I should have stayed longer with her, if a bell had not rang at Millenium Hall, which she informed me was a summons to breakfast. I obeyed its call, and after thanking her for her conversation, returned with a heart warmed and enlarged, to the amiable society. My mind was so filled with exalted reflections on their virtues, that I was less attentive to the charms of inanimate nature than when I first passed through the gardens.

After breakfast the ladies proposed a walk, and as they had seen the course I took when I first went out, they led us a contrary way, lest, they said, I should be tired with the repetition of the same scene. I told them with great truth, that 'what I had beheld could never weary, for virtue is a subject we must ever contemplate with fresh delight, and as such examples could not fail of improving every witness of them, the pleasure of reflection would encrease, as one daily grew more capable of enjoying it, by cultivating kindred sensations.' By some more explicit hints they found out to what I alluded, and thereby knew where I had been, but turning the conversation to present objects, they conducted us to a very fine wood, which is laid out with so much taste, that Lamont observed the artist's hand was never more distinguishable, and perceived in various spots the direction of the person at present most famous for that sort of improvement.

The ladies smiled, and one of them answered, 'He did their wood great honour, in thinking art had lent her assistance to nature, but that there was little in that place for which they were not solely obliged to the latter.' Mrs. Trentham interrupted her who was speaking, and told us, that, 'As she had no share in the improvements which had been made, she might with the better grace assure Mr. Lamont, that Lady Mary Jones, Mrs. Mancel, and Mrs. Morgan, were the only persons who had laid out that wood, and the commonest labourers in the country had executed their orders.' Lamont was much surprised at this piece of information, and though he would have thought it still more exquisitely beautiful had it been the design of the person he imagined, yet truth is so powerful, that he could not suppress his admiration and surprise. Every cut in it is terminated by some noble object. In several places are seats formed with such rustic simplicity, as have more real grandeur in them, than can be found in the most expensive buildings. On an eminence, 'bosomed high in tufted trees,' is a temple dedicated to solitude. The structure is an exquisite piece of architecture, the prospect from it noble and extensive, and the windows so placed, that one sees no house but at so considerable a distance, as not to take off from the solitary air, which is perfectly agreeable to a temple declaredly dedicated to solitude. The most beautiful object in the view is a very large river, in reality an arm of the sea, little more than a quarter of a mile distant from the building; about three miles beyond it lies the sea, on which the sun then shone, and made it dazzlingly bright. In the temple is a picture of Contemplation, another of Silence, two of various birds and animals, and a couple of moon-light pieces, the workmanship of ladies.

Close by the temple runs a gentle murmuring rivulet, which flows in meanders through the rest of the wood, sometimes concealed from view, and then appearing at the next turning of the walk. The wood is well peopled with pheasants, wild turkies, squirrels and hares, who live so unmolested, that they seem to have forgot all fear, and rather to welcome than fly those who come amongst them. Man never appears there as a merciless destroyer; but the preserver, instead of the tyrant of the inferior part of the creation. While they continue in that wood, none but natural evil can approach them, and from that they are defended as much as possible. We there 'walked joint tenant of the shade,' with the animal race; and a perfect equality in nature's bounty seems enjoyed by the whole creation. One could scarcely forbear thinking those happy times were come, when 'The wolf shall dwell with the lamb, and the leopard shall lye down with the kid; and the calf, and the young lion, and the fatling together, and a young child shall lead them. The wilderness and the solitary place shall be glad for them, and the desart shall rejoice, and blossom as the rose.'

At the verge of this wood, which extends to the river I have mentioned, without perceiving we were entering a building, so well is the outside of it concealed by trees, we found ourselves in a most beautiful grotto, made of fossils, spars, coral, and such shells, as are at once both fine and rustic; all of the glaring, tawdry kind are excluded, and by the gloom and simplicity preserved, one would imagine it the habitation of some devout anchoret. Ivy and moss in some places cover, while they seem to unite, the several materials of the variegated walls. The rivulet which runs through the wood, falls down one side of the grotto with great rapidity, broken into various streams by the spar and coral, and passing through, forms a fine cascade just at the foot of the grotto, from whence it flows into the river. Great care is taken to prevent the place from growing damp, so that we sat some time in it with safety, admiring the smooth surface of the river, to which it lies very open.

As the ladies had some daily business on their hands which they never neglect, we were obliged to leave this lovely scene, where I think I could have passed my life with pleasure, and to return towards the house, though by a different way from that we came, traversing the other side of the wood. In one spot where we went near the verge, I observed a pale, which, upon examination, I found was continued for some acres, though it was remarkable only in one place. It is painted green, and on the inside a hedge of yews, laurel, and other thick evergreens, rises to about seven or eight feet high. I could not forbear asking what was thus so carefully enclosed? The ladies smiled on each other, but evaded answering my question, which only encreased my curiosity. Lamont, not less curious, and more importunate, observed, that 'the inclosure bore some resemblance to one of Lord Lamore's, where he kept lions, tigers, leopards, and such foreign animals, and he would be hanged, if the ladies had not made some such collection, intreating that he might be admitted to see them; for nothing gave him greater entertainment than to behold those beautiful wild beasts, brought out of their native woods, where they had reigned as kings, and here tamed and subjected by the superior art of man. It was a triumph of human reason, which could not fail to afford great pleasure.'

'Not to us, I assure you, Sir, replied Mrs. Mancel, when reason appears only in the exertion of cruelty and tyrannical oppression, it is surely not a gift to be boasted of. When a man forces the furious steed to endure the bit, or breaks oxen to the yoke, the great benefits he receives from, and communicates to the animals, excuses the forcible methods by which it is accomplished. But to see a man, from a vain desire to have in his possession the native of another climate and another country, reduce a fine and noble creature to misery, and confine him within narrow inclosures whose happiness consisted in unbounded liberty, shocks my nature. There is I confess something so amiable in gentleness, that I could be pleased with seeing a tyger caress its keeper, if the cruel means by which the fiercest of beasts is taught all the servility of a fawning spaniel, did not recur every instant to my mind; and it is not much less abhorrent to my nature, to see a venerable lion jumping over a stick, than it would be to behold a hoary philosopher forced by some cruel tyrant to spend his days in whipping a top, or playing with a rattle. Every thing to me loses its charm when it is put out of that station wherein nature, or to speak more properly, the all-wise Creator has placed it. I imagine man has a right to use the animal race for his own preservation, perhaps for his convenience, but certainly not to treat them with wanton cruelty, and as it is not in his power to give them any thing so valuable as their liberty, it is, in my opinion, criminal to enslave them, in order to procure ourselves a vain amusement, if we have so little feeling as to find any while others suffer.'

'I believe madam, replied Lamont, it is most advisable for me not to attempt to defend what I have said; should I have reason on my side, while you have humanity on yours, I should make but a bad figure in the argument. What advantage could I expect from applying to the understanding, while your amiable disposition would captivate even reason itself? But still I am puzzled; what we behold is certainly an inclosure, how can that be without a confinement to those that are within it?'

'After having spoken so much against tyranny, said Mrs. Mancel smiling, I do not know whether I should be excusable, if I left you to be tyrannized by curiosity, which I believe can inflict very severe pains, at least, if I may be allowed to judge by the means people often take to satisfy it. I will therefore gratify you with the knowledge of what is within this inclosure, which makes so extraordinary an impression upon you. It is, then, an asylum for those poor creatures who are rendered miserable from some natural deficiency or redundancy.

'Here they find refuge from tyranny of those wretches, who seem to think that being two or three feet taller gives them a right to make them a property, and expose their unhappy forms to the contemptuous curiosity of the unthinking multitude. Procrustes has been branded through all ages with the name of tyrant; and principally, as it appears, from fitting the body of every stranger to a bed which he kept as the necessary standard, cutting off the legs of those whose height exceeded the length of it, and stretching on the rack such as fell short of that measure, till they attained the requisite proportion. But is not almost every man a Procrustes? We have not the power of shewing our cruelty exactly in the same method, but actuated by the like spirit, we abridge of their liberty, and torment by scorn, all who either fall short, or exceed the usual standard, if they happen to have the additional misfortune of poverty. Perhaps we are in no part more susceptible than in our vanity, how much then must those poor wretches suffer, whose deformity would lead them to wish to be secluded from human view, in being exposed to the public, whose observations are no better than expressions of scorn, and who are surprised to find that any thing less than themselves can speak, or appear like intelligent beings. But this is only part of what they have to endure. As if their deficiency in height deprived them of the natural right to air and sunshine, they are kept confined in small rooms, and because they fill less space than common, are stuffed into chairs so little, that they are squeezed as close as a pair of gloves in a walnut-shell.

'This miserable treatment of persons, to whom compassion should secure more than common indulgence, determined us to purchase these worst sort of slaves, and in this place we have five who owed their wretchedness to being only three foot high, one grey-headed toothless old man of sixteen years of age, a woman of about seven feet in height, and a man who would be still taller, if the weakness of his body, and the wretched life he for some time led, in the hands of one of these monster-mongers, did not make him bend almost double, and oblige him to walk almost on crutches; with which infirmities he is well pleased, as they reduce him near the common standard.'

We were very desirous of seeing this enfranchised [Editors' note: Here, set free, rather than endowed with the right to vote.] company; but Mrs. Morgan told us it was what they seldom granted, for fear of inflicting some of the pains from which they had endeavoured to rescue those poor creatures, but she would step in, and ask if they had no objection to our admission, and if that appeared really the case she would gratify us.

This tenderness to persons who were under such high obligations, charmed me. She soon returned with the permission we wished, but intreated us to pay all our attention to the house and the garden, and to take no more than a civil notice of its inhabitants. We promised obedience, and followed her. Her advice was almost unnecessary, for the place could not have failed of attracting our particular observation. It was a quadrangle of about six acres, and the inward part was divided by nets into eight parts, four of which were filled with poultry of all sorts, which were fed here for the use of the hall, and kept with the most exact cleanliness. The other four parts were filled with shrubs and flowers, which were cultivated with great delight by these once unfortunate, but now happy beings. A little stream ran across the quadrangle, which served for drink to the poultry, and facilitated the watering of the flowers. I have already said, that at the inward edge of the pale was a row of ever-greens; at their feet were beds of flowers, and a little gravel walk went around the whole. At each corner was an arbour made with woodbines and jessamine, in one or two of which there was always an agreeable shade.

At one side of the quadrangle was a very neat habitation, into which a dwarf invited us to enter, to rest ourselves after our walk; they were all passing backwards and forwards, and thus gave us a full view of them, which would have been a shocking sight, but for the reflexions we could not avoid making on their happy condition, and the very extraordinary humanity of the ladies to whom they owed it; so that instead of feeling the pain one might naturally receive from seeing the human form so disgraced, we were filled with admiration for the human mind, when so nobly exalted by virtue, as it is in the patronesses of these poor creatures, who wore an air of cheerfulness, which shewed they thought the churlishness wherewith they had been treated by nature sufficiently compensated. The tender enquiries the ladies made after their healths, and the kind notice they took of each of them, could not be exceeded by anything but the affection, I might almost say adoration, with which these people beheld their benefactresses.

This scene had made too deep an impression on our minds, not to be the subject of our discourse all the way home, and in the course of conversation, I learnt, that when these people were first rescued out of their misery, their healths were much impaired, and their tempers more so: to restore the first, all medicinal care was taken, and air and exercise assisted greatly in their recovery; but to cure the malady of the mind, and conquer that internal source of unhappiness, was a work of longer time. Even these poor wretches had their vanity, and would contend for superior merit, of which, the argument was the money their keepers had gained in exhibiting them. To put an end to this contention, the ladies made them understand, that what they thought a subject of boasting, was only a proof of their being so much farther from the usual standard of the human form, and therefore a more extraordinary spectacle. But it was long before one of them could be persuaded to lay aside her pretensions to superiority, which she claimed on account of an extraordinary honour she had received from a great princess, who had made her a present of a sedan chair.

At length, however, much reasoning and persuasion, a conviction of principles, of which they had before no knowledge, the happiness of their situation, and the improvements of their healths, concurred to sweeten their tempers, and they now live in great harmony. They are entirely mistresses of their house, have two maids to wait on them, over whom they have sole command, and a person to do such little things in their garden as they cannot themselves perform; but the cultivation of it is one of their great pleasures; and by their extraordinary care, they have the satisfaction of presenting the finest flowers of the spring to their benefactresses, before they are blown in any other place.

When they first came, the ladies told us, that the horror they had conceived of being exhibited as public spectacles, had fixed in them such a fear of being seen by any stranger, that the sound of a voice, with which they were not acquainted at the outside of the paling, or the trampling of feet, would set them all a running behind the bushes to hide themselves, like so many timorous partridges in a mew, hurrying behind sheaves of corn for shelter; they even found a convenience in their size, which, though it rendered them unwilling to be seen, enabled them so easily to find places for concealment.

By degrees the ladies brought them to consent to see their head servants, and some of the best people in the parish; desiring, that to render it more agreeable to their visitors, they would entertain them with fruit and wine; advising them to assist their neighbours in plain work; thus to endear themselves to them, and procure more frequent visits, which as they chose to confine themselves within so narrow a compass, and enjoyed but precarious health, their benefactresses thought a necessary amusement. These recommendations, and the incidents wherewith their former lives had furnished them to amuse their company, and which they now could relate with pleasure, from the happy sense that all mortifications were past, rendered their conversation much courted among that rank of people.

It occurred to me, that their dislike to being seen by numbers, must prevent their attendance on public worship, but my cousin informed me that was thus avoided. There was in the church an old gallery, which from disuse was grown out of repair; this the ladies caused to be mended, and the front of it so heightened, that these little folks when in it could not be seen; the tall one contrived by stooping when they were there, not to appear of any extraordinary height: To this they were conveyed in the ladies coach, and set down close to covered stairs, which led up to the gallery.

This subject employed our conversation till we approached the hall; the ladies then, after insisting that we should not think of going from thence that day, all left us except Mrs. Maynard. It may seem strange that I was not sorry for their departure; but, in truth, I was so filled with astonishment, at characters so new, and so curious to know by what steps women thus qualified both by nature and by fortune to have the world almost at command, were brought thus to seclude themselves from it, and make as it were a new one for themselves, constituted on such very different principles from that I had hitherto lived in, that I longed to be alone with my cousin, in hopes that I might from her receive some account of this wonder. I soon made my curiosity known, and beseeched her to gratify it.

'I see no good reason, said she, why I should not comply with your request, as my friends are above wishing to conceal any part of their lives, though themselves are never the subject of their own conversation. If they have had any follies they do not desire to hide them; they have not pride enough to hurt with candid criticisms, and have too much innocence to fear any very severe censures. But as we did not all reach this paradise at the same time, I shall begin with the first inhabitants of, and indeed the founders of this society, Mrs. Mancel and Mrs. Morgan, who from their childhood have been so connected, that I could not, if I would, disunite them in my relation; and it would almost be a sin to endeavour to separate them even in idea.'

We sat down in an arbour, whose shade invited us to seek there a defence against the sun, which was then in its meridian, and shone with uncommon heat. The woodbines, the roses, the jessamines, the pinks, and above all, the minionette with which it was surrounded, made the air one general perfume; every breeze came loaded with fragrance, stealing and giving odour. A rivulet ran bubbling by the side of the arbour, whose gentle murmurs soothed the mind into composure, and seemed to hush us to attention, when Mrs. Maynard thus began, to shew her readiness to comply with my request.

Source: Scott, Sarah. 1762. *A Description of Millenium Hall.* London: J. Newbery.

▣ Immanuel Kant, from *Observations on the Feeling of the Beautiful and the Sublime* (1764)

In this excerpt the renowned Enlightenment philosopher, Immanuel Kant, discusses the "savages" of Africa, North America, and "the Orient." Kant argues for the innate inferiority of African peoples based upon inferior physical and mental characteristics.

"Of National Characteristics, so far as they Depend upon the Distinct Feeling of the Beautiful and Sublime"

The Negroes of Africa have by nature no feeling that rises above the trifling. Mr. Hume challenges anyone to cite a single example in which a Negro has shown talents, and asserts that among the hundreds of thousands of black who are transported elsewhere from their countries, although many of them have even been set free, still not a single one was ever found who presented anything great in art or science or any other praiseworthy quality, even though among the whites some continually rise aloft from the lowest rabble, and through superior gifts earn respect in the world. So fundamental is the difference between these two races of man, and it appears to be as great in regard to mental capacities as in color. The religion of fetishes so widespread among them is perhaps a sort of idolatry that sinks as deeply into the trifling as appears to be possible to human nature. A bird's feather, a cow's horn, a conch shell, or any other common object, as soon as it becomes consecrated by a few words, is an object of veneration and of invocation in swearing oaths. The blacks are very vain but in the Negro's way, and so talkative that they must be driven apart from each other with thrashings.

Among all savages there is no nation that displays so sublime a mental character as those of North America. They have a strong feeling for honor, and as in quest of it they seek wild adventures hundreds of miles abroad, they are still extremely careful to avert the least injury to it when their equally harsh enemy, upon capturing them, seeks by cruel pain to extort cowardly groans from them. The Canadian savage, moreover, is truthful and honest. The friendship he establishes is just as adventurous and enthusiastic as anything of that kind reported from the most ancient and fabled times. He is extremely proud, feels the whole worth of freedom, and even in his education suffers no encounter that would let him feel a low subservience. Lycurgus probably gave statutes to just such savages; and if a lawgiver arose among those Six Nations, one would see a Spartan republic rise in the New World; for the undertaking of the Argonauts is little different from the war parties of these Indians, and Jason excels Attakakullakulla in nothing but the honor of a Greek name. All these savages have little feeling for the beautiful in moral understanding, and the generous forgiveness of an injury, which is at once noble and beautiful, is completely unknown as a virtue among the savages, but rather is disdained as a miserable cowardice. Valor is the greatest merit of the savage and revenge his sweetest bliss. The remaining natives of this part of the world show few traces of a mental character disposed to the finer feelings, and an extraordinary apathy constitutes the mark of this type of race.

If we examine the relation of the sexes in these parts of the world, we find that the European alone has found the secret of decorating with so many flowers the sensual charm of a mighty inclination and of interlacing it with so much morality that he has not only extremely elevated its agreeableness but also made it very decorous. The inhabitant of the Orient is of a very false taste in this respect. Since he has no concept of the morally beautiful which can be united with this impulse, he loses even the worth of the sensuous enjoyment, and his harem is a constant source of unrest. He thrives on all sorts of amorous grotesqueries, among which the imaginary jewel is only the foremost, which he seeks to safeguard above all else, whose whole worth consists only in smashing it, and of which one in our part of the world generally entertains much malicious doubt—and yet to whose preservation he makes use of very unjust and often loathsome means. Hence there a woman is always in a prison, whether she may be a maid, or have a barbaric, good-for-nothing and always suspicious husband. In the lands of the black, what better can one expect than what is found prevailing, namely the feminine sex in the deepest slavery? A despairing man is always a strict master over anyone weaker, just as with us that man is always a tyrant in the kitchen who outside his own house hardly dares to look anyone in the face. Of course, Father Labat reports that a Negro carpenter, whome he reproached for haughty treatment toward his wives, answered: "You whites are indeed fools, for first you make great concessions to your wives, and afterward you complain when they drive you mad." And it might be that there were something in this which perhaps deserved to be considered; but in short, this fellow was quite black from head to foot, a clear proof that what he said was stupid.

Source: Kant, Immanuel. 2004. Goldthwait, John T., trans. *Observations on the Feeling of the Beautiful and Sublime,* 2nd ed. Berkeley: University of California Press. (Originally published 1764)

Anna Laetitia Barbauld (1743–1825), from "An Inquiry into Those Types of Distress That Excite Agreeable Sensations"

Theorizing aesthetics in terms of natural impulses, Anna Laetitia Barbauld (1743–1825) comments on the undesirability of having characters, such as Henry Fielding's Amelia, endowed with blemishes and imperfections. In contending that deformity is innately repulsive *to the imagination, Barbauld (in the rest of the text) contrasts "disgusting" physical imperfection with more pleasing kinds of "distress," which instead produce sympathy, admiration, or fascination in readers.*

Deformity is always disgusting, and the imagination cannot reconcile it with the idea of a favourite character; therefore the poet and romance-writer are fully justified in giving a larger share of beauty to their principal figures than is usually met with in common life. A late genius, indeed, in a whimsical mood, gave us a lady with her nose crushed for the heroine of his story: but the circumstance spoils the picture; and though in the course of the story it is kept a good deal out of sight, whenever it does recur to the imagination we are hurt and disgusted. It was an heroic instance of virtue in the nuns of a certain abbey, who cut off their noses and lips to avoid violation; yet this would make a very bad subject for a poem or a play. Something akin to this is the representation of any thing unnatural; of which kind is the famous story of the Roman charity, and for this reason I cannot but think it an unpleasing subject for either the pen or the pencil.

Source: Barbauld, Anna Laetitia. 1825. "An Inquiry into Those Types of Distress That Excite Agreeable Sensations." T*he Works of Anna Laetitia Barbauld, with a Memoir by Lucy Aikin.* London: Longman et al.

The Madwoman, *by Théodore Géricault (1791–1824). The French neo-Baroque painter Géricault was fascinated with topics of disability and death. He based a number of his works on common beliefs about appearances as manifesting otherwise interior disorders of the mind.*

Source: Art Resource, New York.

Johann Wolfgang von Goethe, from T*he Sorrows of Young Werther* (1774)

The Sorrows of Young Werther (Die Leiden des jungen Werther*) by Johann Wolfgang von Goethe is an account of a young man's intense and overwhelming attachment to the object of his affections. The fictional epistolary account, which ends notoriously with the desperate suicide of the emotionally overwrought narrator, caused a sensation upon its publication and thereafter. Napoleon is said to have read it seven times; it was banned in some locales for provoking obsessive youth to suicide, though it can more likely be seen as a cautionary tale of emotional trauma.*

AUGUST 12

Certainly Albert is the best fellow in the world. I had a strange scene with him yesterday. I went to take leave of him; for I took it into my head to spend a few days in these mountains, from where I now write to you. As I was walking up and down his room, my eye fell upon his pistols. "Lend me those pistols," said I, "for my journey." "By all means," he replied, "if you will take the trouble to load them; for they only hang there for form." I took down one of them; and he continued, "Ever since I was near suffering for my extreme caution, I will have nothing to do with such things." I was curious to hear the story. "I was staying," said he, "some three months ago, at a friend's house in the country. I had a brace of pistols with me, unloaded; and I slept without any anxiety. One rainy afternoon I was sitting by myself, doing nothing, when it occurred to me I do not know how that the house might be attacked, that we might require the pistols, that we might in short, you know how we go on fancying, when we have nothing better to do. I gave the pistols to the servant, to clean and load. He was playing with the maid, and trying to frighten her, when the pistol went off—God knows how!—the ramrod was in the barrel; and it went straight through her right hand, and shattered the thumb. I had to endure all the lamentation, and to pay the surgeon's bill; so, since that time, I have kept all my weapons unloaded. But, my dear friend, what is the use of prudence? We can never be on our guard against all possible dangers. However,"—now, you must know I can tolerate all men till they come to "however;"—for it is self-evident that every universal rule must have its exceptions. But he is so exceedingly accurate, that, if he only fancies he has said a word too precipitate, or too general, or only half true, he never ceases to qualify, to modify, and extenuate, till at last he appears to have said nothing at all. Upon this occasion, Albert was deeply immersed in his subject: I ceased to listen to him, and became lost in reverie. With a sudden motion, I pointed the mouth of the pistol to my forehead, over the right eye. "What do you mean?" cried Albert, turning back the pistol. "It is not loaded," said I. "And even if not," he answered with impatience, "what can you mean? I cannot comprehend how a man can be so mad as to shoot himself, and the bare idea of it shocks me."

"But why should any one," said I, "in speaking of an action, venture to pronounce it mad or wise, or good or bad? What is the meaning of all this? Have you carefully studied the secret motives of our actions? Do you understand—can you explain the causes which occasion them, and make them inevitable? If you can, you will be less hasty with your decision."

"But you will allow," said Albert; "that some actions are criminal, let them spring from whatever motives they may." I granted it, and shrugged my shoulders.

"But still, my good friend," I continued, "there are some exceptions here too. Theft is a crime; but the man who commits it from extreme poverty, with no design but to save his family from perishing, is he an object of pity, or of punishment? Who shall throw the first stone at a husband, who, in the heat of just resentment, sacrifices his faithless wife and her perfidious seducer? or at the young maiden, who, in her weak hour of rapture, forgets herself in the impetuous joys of love? Even our laws, cold and cruel as they are, relent in such cases, and withhold their punishment."

"That is quite another thing," said Albert; "because a man under the influence of violent passion loses all power of reflection, and is regarded as intoxicated or insane."

"Oh! you people of sound understandings," I replied, smiling, "are ever ready to exclaim 'Extravagance, and madness, and intoxication!' You moral men are so calm and so subdued! You abhor the drunken man, and detest the extravagant; you pass by, like the Levite, and thank God, like the Pharisee, that you are not like one of them. I have been more than once intoxicated, my passions have always bordered on extravagance: I am not ashamed to confess it; for I have learned, by my own experience, that all extraordinary men, who have accomplished great and astonishing actions, have ever been decried by the world as drunken or insane. And in private life, too, is it not intolerable that no one can undertake the execution of a noble or generous deed, without giving rise to the exclamation that the doer is intoxicated or mad? Shame upon you, ye sages!"

"This is another of your extravagant humours," said Albert: "you always exaggerate a case, and in this matter you are undoubtedly wrong; for we were speaking of suicide, which you compare with great actions, when it is impossible to regard it as anything but a weakness. It is much easier to die than to bear a life of misery with fortitude."

I was on the point of breaking off the conversation, for nothing puts me so completely out of patience as the utterance of a wretched commonplace when I am talking from my inmost heart. However, I composed myself, for I had often heard the same observation with sufficient vexation; and I answered him, therefore, with a little warmth, "You call this a weakness—beware of being led astray by appearances. When a nation, which has long groaned under the intolerable yoke of a tyrant, rises at last and throws off its chains, do you call that weakness? The man who, to rescue his house from the flames, finds his physical strength redoubled, so that he lifts burdens with ease, which, in the absence of excitement, he could scarcely move; he who, under the rage of an insult, attacks and puts to flight half a score of his enemies, are such persons to be called weak? My good friend, if resistance be strength, how can the highest degree of resistance be a weakness?"

Albert looked steadfastly at me, and said, "Pray forgive me, but I do not see that the examples you have adduced bear any relation to the question." "Very likely," I answered; "for I have often been told that my style of illustration borders a little on the absurd. But let us see if we cannot place the matter in another point of view, by inquiring what can be a man's state of mind who resolves to free himself from the burden of life,—a burden often so pleasant to bear,—for we cannot otherwise reason fairly upon the subject.

"Human nature," I continued, "has its limits. It is able to endure a certain degree of joy, sorrow, and pain, but becomes annihilated as soon as this measure is exceeded. The question, therefore, is, not whether a man is strong or weak, but whether he is able to endure the measure of his sufferings. The suffering may be moral or physical; and in my opinion it is just as absurd to call a man a coward who destroys himself, as to call a man a coward who dies of a malignant fever."

Source: Goethe, Johann Wolfgang von. 1917. Carlyle, Thomas, trans. *The Sorrows of Young Werther.* New York: Collier. (Originally published 1774)

Jean-Jacques Rousseau, from *Reveries of the Solitary Walker* (1778)

As one architect of the Romantic cult of individuality, Rousseau outlaws obligation to others as an unfair restriction by society on the individual. Here, Rousseau demonstrates that his sense of obligation toward a crippled beggar boy erodes his freedom to act while producing at the same time an unhealthy dependency in the boy. Charity hobbles the individuality of both the giver and receiver by producing dependency where, apparently, independence should reign.

In one corner of the boulevard, just by the Porte d'Enfer, a woman sets up stall every day in the summer to sell fruit, rolls and tisane. This woman has a little boy who is very sweet, but a cripple, and he hobbles about on his crutches begging from passers-by in a not unpleasant way. I had struck up a sort of acquaintance with the little fellow, and every time I went past he came up without fail to make me a little compliment, which was always followed by a little gift from me. The first few times I was delighted to see him and gave him money very willingly, and I continued doing so for some time with the same pleasure, usually even giving myself the added satisfaction of engaging him in conversation and listening to his pleasant chatter. This pleasure gradually became a habit, and this was somehow transformed into a sort of duty which I soon began to find irksome, particularly on account of the preamble I was obliged to listen to, in which he never failed to address me as Monsieur Rousseau so as to show that he knew me well, thus making it quite clear to me on the contrary that he knew no more of me than those who had taught him. From that time on I felt less inclined to go that way, and in the end I unthinkingly adopted the habit of making a detour when I approached this obstacle.

Source: Rousseau, Jean-Jacques. 1979. Butterworth, Charles E. trans. "Sixth Walk." In *Reveries of the Solitary Walker.* Harmondsworth, UK: Penguin.

James Forbes, The Blind Diver of Dhuboy (1781)

James Forbes reported a civil case from Dhuboy (now Dabhoi), Gujarat, North India, in 1781. The story focuses on a broken contract by a goldsmith whose wife had thrown herself and a treasure of jewels into a well in order to deprive him of the chance to take up with another woman. The goldsmith promised to reward a blind man with one third of the treasure if he located it during a dive, but then he reneged on the agreement.

A certain blind man, well known in Dhuboy, died during my residence there. Although deprived of one sense, he seemed to enjoy the others in greater perfection: among various talents he could generally discover hidden treasure, whether buried in the earth, or concealed under water, and possessed the faculty of diving and continuing a long time in that element without inconvenience. As he never commenced a search without stipulating for one third of the value restored, he had, by this occupation, maintained an aged father, a wife, and several children. The old man complained, that several persons for whom his son had found money, refused to make good their promise; and particularly a goldsmith, who on being summoned before the court, acknowledged the truth of the story, but thought a third part of the amount too large a proportion. The goldsmith had reprimanded his wife for misconduct: being a woman of spirit, she took the first opportunity of his absence to collect as much of his money and valuables as possible, and threw them, together with herself and her own jewels and ornaments, into a well. As they had not lived very happily together, the goldsmith on his return, was not much concerned about his wife, but regretting the loss of his treasure he made diligent search for her body, which was found in an adjoining well, divested of all her ornaments. Surprized and disappointed, he knew not what further to do, when a confidential friend of his wife told him the deceased had taken off her gold chains and jewels, and tying them up in a bag with his own valuables, threw them into another well, but where it was she knew not; having alleged two reasons for her conduct, that he might lose his property, and be deprived of the means of procuring another wife, which he would find difficult without the jewels. The blind man was sent for, and after a long search, found the bag in a distant well, but could not prevail on the goldsmith to give him his share; and since his decease his father had been unsuccessful. The court of adawlat decreed him one third of the property.

Source: Forbes, James. 1813. Vol. II:362–364 in *Oriental Memoirs . . . Written During Seventeen Years Residence in India.* London: White, Cochrane.

▣ Samuel Johnson, from "The Life of Pope" (1781)

In Johnson's "Life of Pope," the excruciating details of Pope's physical impairment serve to disempower the "King of Parnassus," allowing Johnson to question—by a standard juxtaposition of what he called the "character" of the author with the appraisal of his work in each of the Lives of the Poets—the polished perfection of Pope's eminently "prudent" art.

The person of Pope is well known not to have been formed by the nicest model. He has, in his account of the 'Little Club,' compared himself to a spider, and by another is described as protuberant behind and before. He is said to have been beautiful in his infancy; but he was of a constitution originally feeble and weak, and as bodies of a tender frame are easily distorted his deformity was probably in part the effect of his application. His stature was so low that, to bring him to a level with common tables, it was necessary to raise his seat. But his face was not displeasing, and his eyes were animated and vivid.

By natural deformity or accidental distortion his vital functions were so much disordered that his life was a 'long disease.' His most frequent assailant was the headache, which he used to relieve by inhaling the steam of coffee, which he very frequently required.

Most of what can be told concerning his petty peculiarities was communicated by a female domestic of the Earl of Oxford, who knew him perhaps after the middle of life. He was then so weak as to stand in perpetual need of female attendance; extremely sensible of cold, so that he wore a kind of fur doublet under a shirt of very coarse warm linen with fine sleeves. When he rose he was invested in bodice made of stiff canvas, being scarce able to hold himself erect till they were laced, and he then put on a flannel waistcoat. One side was contracted. His legs were so slender that he enlarged their bulk with three pair of stockings, which were drawn on and off by the maid; for he was not able to dress or undress himself, and neither went to bed nor rose without help. His weakness made it very difficult for him to be clean.

His hair had fallen almost all away, and he used to dine sometimes with Lord Oxford, privately, in a velvet cap. His dress of ceremony was black, with a tie-wig and a little sword.

The indulgence and accommodation which his sickness required had taught him all the unpleasing and unsocial qualities of a valetudinary man. He expected that every thing should give way to his ease or humor, as a child whose parents will not hear her cry has an unresisted dominion in the nursery.

Source: Johnson, Samuel. 1905. Hill, G. B., ed. "The Life of Pope." In *The Lives of the English Poets.* Oxford, UK: Clarendon Press. (Originally published 1781)

▣ Benjamin Rush, from Two Essays on the Mind (1786)

The American physician Benjamin Rush was ahead of his time in believing that mentally ill people deserved to be treated with respect. He sharply criticized the inhumane treatment he saw mental patients receive and was able to win public support for state funding for a ward for the insane. In this excerpt, Rush considers the connections between physical health and moral and mental characteristics.

It was probably a state of the human mind such, as has been described, that our Saviour alluded to in the disciple, who was about to betray him, when he called him "a devil." Perhaps the essence of depravity in infernal spirits, consists in their being wholly devoid of a moral faculty. In them the will has probably lost

King Lear Weeping over the Body of Cordelia *(1786–1788), by James Barry (1741–1806). In this recreation of a scene from Shakespeare's King Lear, Barry captures the protagonist's desperate mourning over the death of his daughter as a tragedy caused by his own descent into madness.*

Source: Art Resource, New York.

the power of choosing, as well as the inclination of enjoying moral good. It is true, we read of their trembling in a belief of the existence of God, and of anticipating future punishment by asking, whether they were to be tormented before their time: but this is the effect of coincidence, and hence arises another argument in favor of this judicial power of the mind, being distinct from the moral faculty. It would seem as if the Supreme Being had preserved the moral faculty in man from the ruins of his fall, on purpose to guide him back again to Paradise, and at the same time had constituted the conscience, both in men and in fallen spirits, a kind of royalty in his moral empire, on purpose to shew his property in all intelligent creatures, and their original resemblance to himself. Perhaps the essence of moral depravity in man consists in a total, but temporary, suspension of the power of conscience. Perhaps in this situation are emphatically said in the scriptures to be a "past feeling"—and to have their consciences seared, with a "hot iron"—they are likewise said to be "twice dead"—that is, the same torpor or moral insensibility, has seized both the moral faculty and the conscience.

I remarked in the beginning of this discourse, that persons who were deprived of the just exercise of memory—imagination—or judgment, were proper subjects of medicine; and that there are many cases upon record which prove, that the diseases from the derangement of these faculties, have yielded to the healing art.

It is perhaps only because the disorders of the moral faculty, have not been traced to a connection with physical causes, that medical writers have neglected to give them a place in their systems of nosology, and that so few attempts have been hitherto made, to lessen or remove them by physical as well as rational and moral remedies.

I hinted formerly, in proving the analogy between the effects of DISEASES upon the intellects, and upon the moral faculty, that the latter was frequently impaired by fevers and madness. I beg to add further upon this head, that not only fevers and madness, but the hysteria and hypochondriasis, as well as all those states of the body, whether idiopathic or symptomatic, which are accompanied with preternatural irritability—sensibility—topor—stupor—or morbidity of the nervous system, dispose to vice, either of the body or of the mind. It is in vain to attack these vices with lectures upon morality. They are only to be cured by medicine,—particularly by exercise,—the cold bath,—and by a cold or a warm atmosphere. The young woman, whose case I mentioned earlier, that lost her habit of veracity by a nervous fever, recovered this virtue, as soon as her system recovered its natural tone from this cold weather which happily succeeded her fever.

Weakness, disease, and pain, have many instances, given to a preternatural excitement to the human intellects. Cicero, Erasmus, Pascal, and Boilieu, were all well known to their contemporaries, as much by the feebleness of their constitutions, as by the strength of their minds. The great mental vigour, which has been observed in persons who are hump-backed, of which, the celebrated Roman orator Galba, and Mr. Pope, furnished memorable instances, is probably occasioned by the bodily weakness that is connected with deformity. But the effects of disease, whether occasioned or chronic, in an evolving mind, are still more remarkable. How often do we hear our patients discover, upon a sick or death-bed, marks of reflection, and even eloquence, to which they were strangers to in health! It has been remarked, that abortive and sickly children make sensible men and women. Disease, in this case, acts in various ways. It imposes a restraint upon their appetites, it confines them to the company of their parents, and of persons who are capable of improving them, and it certainly keeps up an action in the brain, in common with other parts of the body, which tends to impart vigour to the intellectual faculties.

But further. There are several well-attested instances, upon record, of persons speaking long forgotten languages in the delirium of a fever, and one, related by Dr. Frank, of a man, who spoke a language in a diseased state of his brain, which he had never learned. If this be true, he must have heard the words of it, without understanding, for it is impossible to conceive of the knowledge of even a single sound existing in the mind, unless it has been previously conveyed there through the medium of the ears.

In support of the influence of diseases in exciting the faculties of the mind, let us attend to the phenomena of diseases, which are produced by a morbid state of the brain. The intellects act here without order, but they act with uncommon celerity and force. Of this, every man must be convinced, who has paid the least attention to those operations in his own mind. The business of a day is often transacted in a dream, in the course of a single minute, and the perceptions of supposed impressions upon the imagination, are far more vivid than in the waking state. Even madness discovers the connection between morbid excitement in the body, and an increase of vigour and activity in certain intellectual operations. Who has not heard preternatural and brilliant effusions of eloquence, and wit in the cell of a hospital? The disease, in this instance, resembles an earthquake, which, in rending the ground, now and then throws upon its surface, with many offensive matters, certain precious fossils, which surprise and delight us by their novelty or splendour.

The effects of pain, in generating new ideas, or exciting old ones in a rapid succession, have been taken notice of in my account of the influence of the physical causes of the moral faculty. To the facts I have there mentioned, I shall add two more. The famous pedestrian traveler, Mr. Stewart, informed me, that he had seen torture produce short intervals of reason in some idiots in Italy. I have known the pain of a large abscess upon the back, produce the same effect upon a man, who had been confined for madness, which ended in fatuity, above twenty years in the Pennsylvania hospital.

Source: Rush, Benjamin. 1972. Carlson, Eric T., ed. T*wo Essays on the Mind: An Enquiry into the Influence of Physical Causes upon the Moral Faculty, and on the Influence of Physical Causes in Promoting an Increase of the Strength and Activity of the Intellectual Faculties of Man*. New York: Brunner/Mazel. (Originally published 1786)

James Boswell, from *The Life of Samuel Johnson* (1791)

Suspended between an early modern reading of disability as divine mark and a modern reading of disability as obstacle to be overcome by exceptional heroism, Boswell's Life of Johnson makes a hero of a writer considered in his own day to be both a physical oddity and a social monster. Samuel Johnson's many disabilities (partial deafness and blindness, obsessive-compulsive behaviors, crippling depression, and facial disfigurement among them) sometimes serve as markers of Johnson's painful progress as exemplary Christian hero, but at other times, Boswell's mentions of Johnson's disability fail to signify at all beyond the self-evident significance of anecdotal detail.

Samuel Johnson was born at Lichfield, in Staffordshire, on the 18th of September, N.S. 1709; and his initiation into the Christian Church was not delayed; for his baptism is recorded in the register of St. Mary's parish in that city, to have been performed on the day of his birth. His father is there stiled *Gentleman,* a circumstance of which an ignorant panegyrist has praised him for not being proud; when the truth is, that the appellation of Gentleman, though now lost in the indiscriminate assumption of *Esquire,* was commonly taken by those who could not boast of gentility. His father was Michael Johnson, a native of Derbyshire, of obscure extraction, who settled in Lichfield as a bookseller and stationer. His mother was Sarah Ford, descended of an ancient race of substantial yeomanry in Warwickshire. They were well advanced in years when they married, and never had more than two children, both sons; Samuel, their first born, who lived to be the illustrious character whose various excellence I am to endeavor to record, and Nathanael, who died in his twenty-fifty year.

Mr. Michael Johnson was a man of a large and robust body, and of a strong and active mind; yet, as in the most solid rocks veins of unsound substance are often discovered, there was in him a mixture of that disease, the nature of which eludes the most minute enquiry, though the effects are well known to be a weariness of life, an unconcern about those things which agitate the greater part of mankind, and a general sensation of gloomy wretchedness. From him then his son inherited, with some other qualities, 'a vile melancholy,' which in his too strong expression of any disturbance of the mind, 'made him mad all his life, at least not sober.' Michael was, however, forced by the narrowness of his circumstances to be very diligent in business, not only in his shop, but by occasionally resorting to several towns in the neighborhood, some of which were at a considerable distance from Lichfield. At that time booksellers' shops in the provincial towns of England were very rare, so that there was not one even in Birmingham, in which town old Mr. Johnson used to open a shop every market-day. He was a pretty good Latin scholar, and a citizen so creditable as to be made one of the magistrates of Lichfield; and, being a man of good sense, and skill in his trade, he acquired a reasonable share of wealth, of which however he afterwards lost the greatest part, by engaging unsuccessfully in a manufacture of parchment. He was a zealous high-churchman and royalist, and retained his attachment to the unfortunate house of Stuart, though he reconciled himself, by casuistical arguments of expediency and necessity, to take the oaths imposed by the prevailing power. . . .

Young Johnson had the misfortune to be much afflicted with the scrophula, or king's-evil, which disfigured a countenance naturally well formed, and hurt his visual nerves so much, that he did not see at all with one of his eyes, though its appearance was little different from that of the other. There is amongst his prayers, one inscribed *"When my EYE was restored to its use,"* which ascertains a defect that many of his friends knew he had, though I never perceived it. I supposed him to be only near-sighted; and indeed I must observe, that in no other respect, could I discern any defect in his vision; on the contrary, the force of his attention and perceptive quickness made him see and distinguish all manner of objects, whether of nature or of art, with a nicety that is rarely to be found. When he and I were travelling in the Highlands of Scotland, and I pointed out to him a mountain which I observed resembled a cone, he corrected my inaccuracy, by shewing me, that it was indeed pointed at the top, but that one side of it was larger than the other. And the ladies with whom he was acquainted agree, that no man was more nicely and minutely critical in the elegance of female dress. When I found that he saw the romantick beauties of Islam, in Derbyshire, much better than I did, I told him that he resembled an able performer upon a bad instrument. How false and contemptible then are all the remarks which have been made to the prejudice either of his candour or of his philosophy, founded upon a supposition that he was almost blind. It has been said, that he contracted this grievous malady from his nurse. His mother, yielding to the superstitious notion, which, it is wonderful to think, prevailed so long in this country, as to the virtue of the regal touch; a notion, which our kings encouraged, and to which a man of such enquiry and such judgement as Carte could give credit; carried him to London, where he was actually touched by Queen Anne. Mrs. Johnson indeed, as Mr. Hector informed me, acted by the advice of the celebrated Sir John Floyer, then a physician in Lichfield. Johnson used to talk of this very frankly; and Mrs. Piozzi has preserved his very picturesque description of the scene, as it remained upon his fancy. Being asked if he could remember Queen Anne,—"He had (he said) a confused, but somehow a sort of solemn recollection of a lady in diamonds, and a long black hood." This touch, however, was without any effect. I ventured to say to him, in allusion to the political principles in which he was educated, and of which he ever retained some odour, that "his mother had not carried him far enough; she should have taken him to ROME."

▣ William Wordsworth, from "The Idiot Boy" (1798)

"The Idiot Boy" was one of the key odes published in the Romantic manifesto Lyrical Ballads*, a series of poems by Wordsworth and Samuel Taylor Coleridge*

The Sleep of Reason Produces Monsters, *by Francisco Goya (1746–1828). Goya's illustration captures his belief that excessive confidence in Reason's ability to conquer nature results in the repression of phenomena less easy to explain through empirical observation. Here, the sleeping scientific observer finds himself assaulted by occult imaginings that have been sidelined by his rational inquiry during the period of the Enlightenment.*

Source: Art Resource, New York.

that paid homage to the life of the folk as worthy of literary treatment. In this excerpt, the Idiot Boy is charged with the responsibility of setting out on the family horse to retrieve a doctor for an ill neighbor. By the end of the journey the boy has failed to return with the physician but has experienced a sublime journey into Nature that sustains himself and the poet.

'Tis eight o'clock,—a clear March night,
The moon is up,—the sky is blue,
The owlet, in the moonlight air,
Shouts from nobody knows where;
He lengthens out his lonely shout,
Halloo! halloo! a long halloo!

—Why bustle thus about your door,
What means this bustle, Betty Foy?
Why are you in this mighty fret?
And why on horseback have you set
Him whom you love, your Idiot Boy? . . .

. . . And Betty o'er and o'er has told
The Boy, who is her best delight,
Both what to follow, what to shun,
What do, and what to leave undone,
How turn to left, and how to right.

And Betty's most especial charge,
Was, "Johnny! Johnny! mind that you
Come home again, nor stop at all,—
Come home again, whate'er befall,
My Johnny, do, I pray you do." . . .

. . . But when the Pony moved his legs,
Oh! then for the poor Idiot Boy!
For joy he cannot hold the bridle,
For joy his head and heels are idle,
He's idle all for very joy.

And while the Pony moves his legs,
In Johnny's left hand you may see
The green bough motionless and dead:
The Moon that shines above his head
Is not more still and mute than he. . . .

. . . The clock is on the stroke of one;
But neither Doctor nor his Guide
Appears along the moonlight road;
There's neither horse nor man abroad,
And Betty's still at Susan's side.

And Susan now begins to fear
Of sad mischances not a few,
That Johnny may perhaps be drowned;
Or lost, perhaps, and never found;
Which they must both for ever rue. . . .

. . . Poor Betty now has lost all hope,
Her thoughts are bent on deadly sin,

A green-grown pond she just has past,
And from the brink she hurries fast,
Lest she should drown herself therein.

And now she sits her down and weeps;
Such tears she never shed before;
"Oh dear, dear Pony! my sweet joy!
Oh carry back my Idiot Boy!
And we will ne'er o'erload thee more." . . .

. . . Your Pony's worth his weight in gold:
Then calm your terrors, Betty Foy!
She's coming from among the trees,
And now all full in view she sees
Him whom she loves, her Idiot Boy.

And Betty sees the Pony too:
Why stand you thus, good Betty Foy?
It is no goblin, 'tis no ghost,
'Tis he whom you so long have lost,
He whom you love, your Idiot Boy.

She looks again—her arms are up—
She screams—she cannot move for joy;
She darts, as with a torrent's force,
She almost has o'erturned the Horse,
And fast she holds her Idiot Boy. . . .

. . . For while they all were travelling home,
Cried Betty, "Tell us, Johnny, do,
Where all this long night you have been,
What you have heard, what you have seen:
And, Johnny, mind you tell us true."

Now Johnny all night long had heard
The owls in tuneful concert strive;
No doubt too he the moon had seen;
For in the moonlight he had been
From eight o'clock till five.

And thus, to Betty's question, he
Made answer, like a traveller bold,
(His very words I give to you,)
"The cocks did crow to-whoo, to-whoo,
And the sun did shine so cold!"
—Thus answered Johnny in his glory,
And that was all his travel's story.

Source: Wordsworth, William. 1798. "The Idiot Boy." In Wordsworth, William, and Samuel Taylor Coleridge, *Lyrical Ballads.* Bristol, UK: T. N. Longman.

Modernity and Normalization: 1800–1945

▣ Samuel Taylor Coleridge, from "Dejection: An Ode" (1802)

This poem is a study in the feelings of melancholy often found in Romantic poetry, but with the essential difference that Coleridge questions the capacity of the natural world to raise one's spirits. Rather, affliction remains the responsibility of each person, and one can find a cure only through inner resources.

My genial spirits fail;
And what can these avail
To lift the smothering weight from off my breast?
It were a vain endeavour,
Though I should gaze for ever
On that green light that lingers in the west:
I may not hope from outward forms to win
The passion and the life, whose fountains are within.

Source: Coleridge, Samuel Taylor. 1802. Lines 39–46 in "Dejection: An Ode." Available at: http://etext.lib.virginia.edu/stc/Coleridge/poems/Dejection_An_Ode.html

▣ John Keats, "This Living Hand" (1816)

John Keats died at the age of 25 following many years of poor health from tuberculosis. Thought to address Keats's fiancée, Fanny Brawne, this poem describes the complex emotions felt at the bedside of the dying or disabled person. The hand of death invites us to sacrifice ourselves to save those who are dying or disabled at the same time that it excites the fear that death and disability may be contagious.

This Living Hand

This living hand, now warm and capable
Of earnest grasping, would, if it were cold
And in the icy silence of the tomb,
So haunt thy days and chill thy dreaming nights
That thou wouldst wish thine own heart dry of blood
So in my veins red life might stream again,
And thou be conscience-calmed—see here it is—
I hold it towards you.

Source: Keats, John. 1816. "This Living Hand." Available at: http://www.portablepoetry.com/poems/john_keats/this_living_hand.html

▣ Mary Shelley, from *Frankenstein* (1818)

Shelley explores the isolation of the monster, who cannot show his face in the light of day or buy redemption through good deeds. Shelley's use of physical difference to explore the marginal status of her protagonist is a familiar device among Romantic writers, as is her suggestion that the monster's loneliness may be cured only by finding a soul mate. In this excerpt, the monster is recounting some of his history to his creator, Victor Frankenstein.

"Cursed, cursed creator! Why did I live? Why, in that instant, did I not extinguish the spark of existence, which you had so wantonly bestowed? I know not;

Laennec at the Necker Hospital Ausculting a Tuberculosis Patient in Front of His Students *(1816), by Theobold Chartran (1849–1907). A common way for physicians to diagnose the presence of tuberculosis was through auscultation of the chest with a stethoscope while listening for crackles during breathing.*

Source: Art Resource, New York.

despair had not yet taken possession of me; my feelings were those of rage and revenge. I could with pleasure have destroyed the cottage and its inhabitants, and have glutted myself with their shrieks and misery.

“When night came, I quitted my retreat, and wandered in the wood; and now, no longer restrained by the fear of discovery, I gave vent to my anguish in fearful howlings. I was like a wild beast that had broken the toils; destroying the objects that obstructed me, and ranging through the wood with a stag like swiftness. O! what a miserable night I passed! the cold stars shone in mockery, and the bare trees waved their branches above me: now and then the sweet voice of a bird burst forth amidst the universal stillness. All, save I, were at rest or in enjoyment: I, like the arch-fiend, bore a hell within me; and, finding myself unsympathised with, wished to tear up the trees, spread havoc and destruction around me, and then to have sat down and enjoyed the ruin.

“But this was a luxury of sensation that could not endure; I became fatigued with excess of bodily exertion, and sank on the damp grass in the sick impotence of despair. There was none among the myriads of men that existed who would pity or assist me; and should I feel kindness towards my enemies? No: from that moment I declared everlasting war against the species, and, more than all, against him who had formed me, and sent me forth to this insupportable misery.

“The sun rose; I heard the voices of men, and knew that it was impossible to return to my retreat during that day. Accordingly I hid myself in some thick underwood, determining to devote the ensuing hours to reflection on my situation.

“The pleasant sunshine, and the pure air of day, restored me to some degree of tranquility; and when I considered what had passed at the cottage, I could not help believing that I had been too hasty in my conclusions. I had certainly acted imprudently. It was apparent that my conversation had interested the father in my behalf, and I was a fool in having exposed my person to the horror of his children. I ought to have familiarized the old De Lacey to me, and by degrees to have discovered myself to the rest of his family, when they should have been prepared for my approach. But I did not believe my errors to be irretrievable; and, after much consideration, I resolved to return to the cottage, seek the old man, and by my representations win him to my party.

“These thoughts calmed me, and in the afternoon I sank into a profound sleep; but the fever of my blood did not allow me to be visited by peaceful dreams. The horrible scene of the preceding day was for ever acting before my eyes; the females were flying, and the enraged Felix tearing me from his father's feet. I awoke exhausted; and, finding that it was already night, I crept forth from my hiding-place, and went in search of food.

"When my hunger was appeased, I directed my steps towards the well known path that conducted to the cottage. All there was at peace. I crept into my hovel, and remained in silent expectation of the accustomed hour when the family arose. That hour passed, the sun mounted high in the heavens, but the cottagers did not appear. I trembled violently, apprehending some dreadful misfortune. The inside of the cottage was dark, and I heard no motion; I cannot describe the agony of this suspense.

"Presently two countrymen passed by; but, pausing near the cottage, they entered into conversation, using violent gesticulations; but I did not understand what they said, as they spoke the language of the country, which differed from that of my protectors. Soon after, however, Felix approached with another man: I was surprised, as I knew that he had not quitted the cottage that morning, and waited anxiously to discover, from his discourse, the meaning of these unusual appearances.

In Frankenstein *(1931), one of the earliest feature-length sound films, James Whale brought Mary Shelley's nineteenth-century story of deviant creation to the screen. In this movie still, a dual disability interchange occurs between the "lumbering" monster and a blind man. The social stigma applied to both individuals is mitigated through their momentary friendship.*

Source: Frankenstein (1931), directed by James Whale. B&W, 90 minutes. Reprinted by permission of Paul Darke.

"'Do you consider,' said his companion to him, 'that you will be obliged to pay three months' rent, and to lose the produce of your garden? I do not wish to take any unfair advantage, and I beg therefore that you will take some days to consider of your determination.'

"'It is utterly useless,' replied Felix; 'we can never again inhabit your cottage. The life of my father is in the greatest danger, owing to the dreadful circumstance that I have related. My wife and my sister will never recover their horror. I entreat you not to reason with me any more. Take possession of your tenement, and let me fly from this place.'

"Felix trembled violently as he said this. He and his companion entered the cottage, in which they remained for a few minutes, and then departed. I never saw any of the family of De Lacey more.

"I continued for the remainder of the day in my hovel in a state of utter and stupid despair. My protectors had departed, and had broken the only link that held me to the world. For the first time the feelings of revenge and hatred filled my bosom, and I did not strive to control them; but, allowing myself to be borne away by the stream, I bent my mind towards injury and death. When I thought of my friends, of the mild voice of De Lacey, the gentle eyes of Agatha, and the exquisite beauty of the Arabian, these thoughts vanished, and a gush of tears somewhat soothed me. But again, when I reflected that they had spurned and deserted me, anger returned, a rage of anger; and, unable to injure anything human, I turned my fury towards inanimate objects. As night advanced, I placed a variety of combustibles around the cottage;

and, after having destroyed every vestige of cultivation in the garden, I waited with forced impatience until the moon had sunk to commence my operations.

"As the night advanced, a fierce wind arose from the woods, and quickly dispersed the clouds that had loitered in the heavens: the blast tore along like a mighty avalanche, and produced a kind of insanity in my spirits that burst all bounds of reason and reflection. I lighted the dry branch of a tree, and danced with fury around the devoted cottage, my eyes still fixed on the western horizon, the edge of which the moon nearly touched. A part of its orb was at length hid, and I waved my brand; it sunk, and, with a loud scream, I fired the straw, and heath, and bushes, which I had collected. The wind fanned the fire, and the cottage was quickly enveloped by the flames, which clung to it, and licked it with their forked and destroying tongues.

"As soon as I was convinced that no assistance could save any part of the habitation, I quitted the scene and sought for refuge in the woods.

"And now, with the world before me, whither should I bend my steps? I resolved to fly far from the scene of my misfortunes; but to me, hated and despised, every country must be equally horrible. At length the thought of you crossed my mind. I learned from your papers that you were my father, my creator; and to whom could I apply with more fitness than to him who had given me life? Among the lessons that Felix had bestowed upon Safie, geography had not been omitted. I had learned from these the relative situations of the different countries of the earth. You had mentioned Geneva as the name of your native town; and towards this place I resolved to proceed.

"But how was I to direct myself? I knew that I must travel in a south westerly direction to reach my destination; but the sun was my only guide. I did not know the names of the towns that I was to pass through, nor could I ask information from a single human being; but I did not despair. From you only could I hope for succour, although towards you I felt no sentiment but that of hatred. Unfeeling, heartless creator! you had endowed me with perceptions and passions, and then cast me abroad an object for the scorn and horror of mankind. But on you only had I any claim for pity and redress, and from you I determined to seek that justice which I vainly attempted to gain from any other being that wore the human form.

"My travels were long, and the sufferings I endured intense. It was late in autumn when I quitted the district where I had so long resided. I travelled only at night, fearful of encountering the visage of a human being. Nature decayed around me, and the sun became heatless; rain and snow poured around me; mighty rivers were frozen; the surface of the earth was hard, and chill, and bare, and I found no shelter. Oh, earth! how often did I imprecate curses on the cause of my being! The mildness of my nature had fled, and all within me was turned to gall and bitterness. The nearer I approached to your habitation, the more deeply did I feel the spirit of revenge enkindled in my heart. Snow fell, and the waters were hardened; but I rested not. A few incidents now and then directed me, and I possessed a map of the country; but I often wandered wide from my path. The agony of my feelings allowed me no respite: no incident occurred from which my rage and misery could not extract its food; but a circumstance that happened when I arrived on the confines of Switzerland, when the sun had recovered its warmth, and the earth again began to look green, confirmed in an especial manner the bitterness and horror of my feelings.

"I generally rested during the day, and travelled only when I was secured by night from the view of man. One morning, however, finding that my path lay through a deep wood, I ventured to continue my journey after the sun had risen; the day, which was one of the first of spring, cheered even me by the loveliness of its sunshine and the balminess of the air. I felt emotions of gentleness and pleasure, that had long appeared dead, revive within me. Half surprised by the novelty of these sensations, I allowed myself to be borne away by them; and, forgetting my solitude and deformity, dared to be happy. Soft tears again bedewed my cheeks, and I even raised my humid eyes with thankfulness towards the blessed sun which bestowed such joy upon me.

"I continued to wind among the paths of the wood, until I came to its boundary, which was skirted by a deep and rapid river, into which many of the trees bent their branches, now budding with the fresh spring. Here I paused, not exactly knowing what path to pursue, when I heard the sound of voices that induced me to conceal myself under the shade of a cypress. I was scarcely hid, when a young girl came running towards the spot where I was concealed, laughing, as if she ran from some one in sport. She continued her course along the precipitous sides of the river, when suddenly her foot slipt, and she fell into the rapid stream. I rushed from my hiding place; and, with extreme labour from the force of the current, saved her, and dragged her to shore. She was senseless; and I endeavoured by every means in my power to restore animation, when I was suddenly interrupted by the approach of a rustic, who was probably the person from whom she had playfully fled. On seeing me, he darted towards me, and tearing the girl from my arms, hastened towards the deeper parts of the wood. I followed speedily, I hardly knew why; but when the man saw me draw near, he aimed a gun, which he carried, at my body, and fired. I sunk to the ground, and my injurer, with increased swiftness, escaped into the wood.

"This was then the reward of my benevolence! I had saved a human being from destruction, and, as a recompense, I now writhed under the miserable pain of a wound, which shattered the flesh and bone. The feelings of kindness and gentleness which I had entertained but a few moments before gave place to hellish rage and gnashing of teeth. Inflamed by pain, I vowed eternal hatred and vengeance to all mankind. But the agony of my wound overcame me; my pulses paused, and I fainted.

"For some weeks I led a miserable life in the woods, endeavouring to cure the wound which I had received. The ball had entered my shoulder, and I knew not whether it had remained there or passed through; at any rate I had no means of extracting it. My sufferings were augmented also by the oppressive sense of the injustice and ingratitude of their infliction. My daily vows rose for revenge—a deep and deadly revenge, such as would alone compensate for the outrages and anguish I had endured.

"After some weeks my wound healed, and I continued my journey. The labours I endured were no longer to be alleviated by the bright sun or gentle breezes of spring; all joy was but a mockery, which insulted my desolate state, and made me feel more painfully that I was not made for the enjoyment of pleasure.

"But my toils now drew near a close; and in two months from this time I reached the environs of Geneva.

"It was evening when I arrived, and I retired to a hiding-place among the fields that surround it, to meditate in what manner I should apply to you. I was oppressed by fatigue and hunger, and far too unhappy to enjoy the gentle breezes of evening, or the prospect of the sun setting behind the stupendous mountains of Jura.

"At this time a slight sleep relieved me from the pain of reflection, which was disturbed by the approach of a beautiful child, who came running into the recess I had chosen, with all the sportiveness of infancy. Suddenly, as I gazed on him, an idea seized me, that this little creature was unprejudiced, and had lived too short a time to have imbibed a horror of deformity. If, therefore, I could seize him, and educate him as my companion and friend, I should not be so desolate in this peopled earth.

"Urged by this impulse, I seized on the boy as he passed and drew him towards me. As soon as he beheld my form, he placed his hands before his eyes and uttered a shrill scream: I drew his hand forcibly from his face, and said, 'Child, what is the meaning of this? I do not intend to hurt you; listen to me.'

"He struggled violently. 'Let me go,' he cried; 'monster! ugly wretch! you wish to eat me, and tear me to pieces—You are an ogre—Let me go, or I will tell my papa.'

"'Boy, you will never see your father again; you must come with me.'

"'Hideous monster! let me go. My papa is a Syndic—he is M. Frankenstein—he will punish you. You dare not keep me.'

"'Frankenstein! you belong then to my enemy—to him towards whom I have sworn eternal revenge; you shall be my first victim.'

"The child still struggled, and loaded me with epithets which carried despair to my heart; I grasped his throat to silence him, and in a moment he lay dead at my feet.

"I gazed on my victim, and my heart swelled with exultation and hellish triumph: clapping my hands, I exclaimed, 'I, too, can create desolation; my enemy is not invulnerable; this death will carry despair to him, and a thousand other miseries shall torment and destroy him.'

"As I fixed my eyes on the child, I saw something glittering on his breast. I took it; it was a portrait of a most lovely woman. In spite of my malignity, it softened and attracted me. For a few moments I gazed with delight on her dark eyes, fringed by deep lashes, and her lovely lips; but presently my rage returned: I remembered that I was for ever deprived of the delights that such beautiful creatures could bestow; and that she whose resemblance I contemplated would, in regarding me, have changed that air of divine benignity to one expressive of disgust and affright.

"Can you wonder that such thoughts transported me with rage? I only wonder that at that moment, instead of venting my sensations in exclamations and agony, I did not rush among mankind and perish in the attempt to destroy them.

"While I was overcome by these feelings, I left the spot where I had committed the murder, and seeking a more secluded hiding-place, I entered a barn which had appeared to me to be empty. A woman was sleeping on some straw; she was young: not indeed so beautiful as her whose portrait I held; but of an agreeable aspect, and blooming in the loveliness of youth and health. Here, I thought, is one of those whose joy-imparting smiles are bestowed on all but me. And then I bent over her, and whispered, 'Awake, fairest, thy lover is near—he who would give his life but to obtain one look of affection from thine eyes: my beloved, awake!'

"The sleeper stirred; a thrill of terror ran through me. Should she indeed awake, and see me, and curse me, and denounce the murderer? Thus would she assuredly act, if her darkened eyes opened and she beheld me. The thought was madness; it stirred the fiend within me—not I, but she shall suffer: the murder I have committed because I am for ever robbed of all that she could give me, she shall atone. The crime had its source in her: be hers the punishment! Thanks to the lessons of Felix and the sanguinary laws of man, I had learned now to work mischief. I bent over her, and placed the portrait securely in one of the folds of her dress. She moved again, and I fled.

"For some days I haunted the spot where these scenes had taken place; sometimes wishing to see you, sometimes resolved to quit the world and its miseries for ever. At length I wandered towards these mountains, and have ranged through their immense recesses, consumed by a burning passion which you alone can gratify. We may not part until you have promised to comply with my requisition. I am alone, and miserable; man will not associate with me; but one as deformed and horrible as myself would not deny herself to me. My companion must be of the same species, and have the same defects. This being you must create."

Source: Shelley, Mary. 1981. Pp. 121–129 in *Frankenstein*. New York: Bantam. (Originally published 1818)

George Gordon, Lord Byron, from *The Deformed Transformed* (1822)

Upon Byron's death, this unfinished manuscript for a drama, based on Goethe's Faust and a popular novel of the times entitled The Three Brothers, *was discovered in his drawer. In the work the hunchbacked protagonist, Arnold, is given the opportunity to trade in his "deformed" body for that of the Greek warrior Achilles. The stranger who makes this offer sets out to demonstrate that a disabled body does not hinder one from social accomplishments by taking up Arnold's discarded exterior himself. It should be noted that Byron was born with a physical impairment and so lived with disability his entire life.*

Lord Byron, English Poet*, by Thomas Lawrence (1769–1830). Lord Byron, who was diagnosed with a clubfoot at birth (his condition is now thought to have been Little's disease), wrote about experiences of social ostracization in his last, unfinished play,* The Deformed Transformed. *In the work, the hunchbacked protagonist, Arnold, makes a Faustian deal with a stranger to exchange his disabled body for the more able body of the Greek hero Achilles. The result is Byron's ironic commentary on masculine militarization and the unacknowledged capacities of those who occupy socially rejected physicalities.*

Source: Art Resource, New York.

Part I.

Scene I: A Forest.
Enter Arnold and his mother Bertha.
Bert.
Out, Hunchback!
Arn.
I was born so, Mother!

Bert.
Out,
Thou incubus! Thou nightmare! Of seven sons,
The sole abortion!
Arn.
Would that I had been so,
And never seen the light!
Bert.
I would so, too!
But as thou hast—hence, hence—and do thy best!
That back of thine may bear its burthen; 'tis
More high, if not so broad as that of others.
Arn.
It bears its burthen;—but, my heart! Will it
Sustain that which you lay upon it, Mother?
I love, or, at the least, I loved you: nothing
Save You, in nature, can love aught like me.
You nursed me—do not kill me!
Bert.
Yes—I nursed thee,
Because thou wert my first-born, and I knew not
If there would be another unlike thee,
That monstrous sport of Nature. But get hence,
And gather wood!
Arn.
I will: but when I bring it,
Speak to me kindly. Though my brothers are
So beautiful and lusty, and as free
As the free chase they follow, do not spurn me:
Our milk has been the same.
Bert.
As is the hedgehog's,
Which sucks at midnight from the wholesome dam
Of the young bull, until the milkmaid finds
The nipple, next day, sore, and udder dry.
Call not thy brothers brethren! Call me not
Mother; for if I brought thee forth, it was
As foolish hens at times hatch vipers, by
Sitting upon strange eggs. Out, urchin, out!
[Exit Bertha.]
Arn. *(solus).*
Oh, mother!—She is gone, and I must do
Her bidding;—wearily but willingly
I would fulfil it, could I only hope
A kind word in return. What shall I do?
[Arnold begins to cut wood: in doing this he wounds one of his hands.]
My labour for the day is over now.
Accursèd be this blood that flows so fast;
For double curses will be my meed now
At home—What home? I have no home, no kin,
No kind—not made like other creatures, or
To share their sports or pleasures. Must I bleed, too,
Like them? Oh, that each drop which falls to earth
Would rise a snake to sting them, as they have stung me!
Or that the Devil, to whom they liken me,
Would aid his likeness! If I must partake
His form, why not his power? Is it because
I have not his will too? For one kind word
From her who bore me would still reconcile me
Even to this hateful aspect. Let me wash
The wound.
[Arnold goes to a spring, and stoops to wash his hand: he starts back.]
They are right; and Nature's mirror shows me,
What she hath made me. I will not look on it
Again, and scarce dare think on't. Hideous wretch
That I am! The very waters mock me with
My horrid shadow—like a demon placed
Deep in the fountain to scare back the cattle
From drinking therein.
[He pauses.]
And shall I live on,
A burden to the earth, myself, and shame
Unto what brought me into life? Thou blood,
Which flowest so freely from a scratch, let me
Try if thou wilt not, in a fuller stream,
Pour forth my woes for ever with thyself
On earth, to which I will restore, at once,
This hateful compound of her atoms, and
Resolve back to her elements, and take
The shape of any reptile save myself,
And make a world for myriads of new worms!
This knife! now let me prove if it will sever
This withered slip of Nature's nightshade—my
Vile form—from the creation, as it hath
The green bough from the forest.
[Arnold places the knife in the ground, with the point upwards.]
Now 'tis set,
And I can fall upon it. Yet one glance
On the fair day, which sees no foul thing like
Myself, and the sweet sun which warmed me, but
In vain. The birds—how joyously they sing!
So let them, for I would not be lamented:
But let their merriest notes be Arnold's knell;
The fallen leaves my monument; the murmur
Of the near fountain my sole elegy.
Now, knife, stand firmly, as I fain would fall!
[As he rushes to throw himself upon the knife, his eye is suddenly caught by the fountain, which seems in motion.]

The fountain moves without a wind: but shall
The ripple of a spring change my resolve?
No. Yet it moves again! The waters stir,
Not as with air, but by some subterrane
And rocking Power of the internal world.
What's here? A mist! No more?—

[A cloud comes from the fountain. He stands gazing upon it: it is dispelled, and a tall black man comes towards him.]

Arn.
What would you? Speak!
Spirit or man?
Stran.
As man is both, why not
Say both in one?
Arn.
Your form is man's, and yet
You may be devil.
Stran.
So many men are that
Which is so called or thought, that you may add me
To which you please, without much wrong to either.
But come: you wish to kill yourself;—pursue
Your purpose.
Arn.
You have interrupted me.
Stran.
What is that resolution which can e'er
Be interrupted? If I be the devil
You deem, a single moment would have made you
Mine, and for ever, by your suicide;
And yet my coming saves you.
Arn.
I said not
You were the Demon, but that your approach
Was like one.
Stran.
Unless you keep company
With him (and you seem scarce used to such high
Society) you can't tell how he approaches;
And for his aspect, look upon the fountain,
And then on me, and judge which of us twain
Looks likest what the boors believe to be
Their cloven-footed terror.
Arn.
Do you—dare you
To taunt me with my born deformity?
Stran.
Were I to taunt a buffalo with this
Cloven foot of thine, or the swift dromedary
With thy Sublime of Humps, the animals
Would revel in the compliment. And yet
Both beings are more swift, more strong, more mighty
In action and endurance than thyself,
And all the fierce and fair of the same kind
With thee. Thy form is natural: 'twas only
Nature's mistaken largess to bestow
The gifts which are of others upon man.
Arn.
Give me the strength then of the buffalo's foot,
When he spurns high the dust, beholding his
Near enemy; or let me have the long
And patient swiftness of the desert-ship,
The helmless dromedary!—and I'll bear
Thy fiendish sarcasm with a saintly patience.
Stran.
I will.
Arn. *(with surprise).*
Thou *canst*?
Stran.
Perhaps. Would you aught else?
Arn.
Thou mockest me.
Stran.
Not I. Why should I mock
What all are mocking? That's poor sport, methinks.
To talk to thee in human language (for
Thou canst not yet speak mine), the forester
Hunts not the wretched coney, but the boar,
Or wolf, or lion—leaving paltry game
To petty burghers, who leave once a year
Their walls, to fill their household cauldrons with
Such scullion prey. The meanest gibe at thee,—
Now I can mock the mightiest.
Arn.
Then waste not
Thy time on me: I seek thee not.
Stran.
Your thoughts
Are not far from me. Do not send me back:
I'm not so easily recalled to do
Good service.
Arn.
What wilt thou do for me?
Stran.
Change
Shapes with you, if you will, since yours so irks you;
Or form you to your wish in any shape.
Arn.
Oh! then you are indeed the Demon, for
Nought else would wittingly wear mine.

Stran.
I'll show thee
The brightest which the world e'er bore, and give thee
Thy choice.
Arn.
On what condition?
Stran.
There's a question!
An hour ago you would have given your soul
To look like other men, and now you pause
To wear the form of heroes.
Arn.
No; I will not.
I must not compromise my soul.
Stran.
What soul,
Worth naming so, would dwell in such a carcase?
Arn.
'Tis an aspiring one, whate'er the tenement
In which it is mislodged. But name your compact:
Must it be signed in blood?
Stran.
Not in your own.
Arn.
Whose blood then?
Stran.
We will talk of that hereafter.
But I'll be moderate with you, for I see
Great things within you. You shall have no bond
But your own will, no contract save your deeds.
Are you content?
Arn.
I take thee at thy word.
Stran.
Now then!—
[The Stranger approaches the fountain, and turns to Arnold.]
A little of your blood.
Arn.
For what?
Stran.
To mingle with the magic of the waters,
And make the charm effective.
Arn. *(holding out his wounded arm).*
Take it all.
Stran.
Not now. A few drops will suffice for this.
[The Stranger takes some of Arnold's blood in his hand, and casts it into the fountain.]
Shadows of Beauty!
Shadows of Power!
Rise to your duty—
This is the hour!
Walk lovely and pliant
From the depth of this fountain,
As the cloud-shapen giant
Bestrides the Hartz Mountain.
Come as ye were,
That our eyes may behold
The model in air
Of the form I will mould,
Bright as the Iris
When ether is spanned;—
Such *his* desire is,
[Pointing to Arnold.]
Such *my* command!
Demons heroic—
Demons who wore
The form of the Stoic
Or sophist of yore—

Or the shape of each victor—
From Macedon's boy,
To each high Roman's picture,
Who breathed to destroy—
Shadows of Beauty!
Shadows of Power!
Up to your duty—
This is the hour!
[Various phantoms arise from the waters, and pass in succession before the Stranger and Arnold.]
Arn.
What do I see?
Stran.
The black-eyed Roman, with
The eagle's beak between those eyes which ne'er
Beheld a conqueror, or looked along
The land he made not Rome's, while Rome became
His, and all theirs who heired his very name.
Arn.
The phantom's bald; my quest is beauty. Could I
Inherit but his fame with his defects!
Stran.
His brow was girt with laurels more than hairs.
You see his aspect—choose it, or reject.
I can but promise you his form; his fame
Must be long sought and fought for.
Arn.
I will fight, too,
But not as a mock Cæsar. Let him pass:
His aspect may be fair, but suits me not.

Stran.
Then you are far more difficult to please
Than Cato's sister, or than Brutus's mother,
Or Cleopatra at sixteen—an age
When love is not less in the eye than heart.
But be it so! Shadow, pass on!
[The phantom of Julius Cæsar disappears.]
Arn.
And can it
Be, that the man who shook the earth is gone,
And left no footstep?
Stran.
There you err. His substance
Left graves enough, and woes enough, and fame
More than enough to track his memory;
But for his shadow—'tis no more than yours,
Except a little longer and less crooked
I' the sun. Behold another!
[A second phantom passes].
Arn.
Who is he?
Stran.
He was the fairest and the bravest of
Athenians. Look upon him well.
Arn.
He is
More lovely than the last. How beautiful!
Stran.
Such was the curled son of Clinias;—wouldst thou
Invest thee with his form?
Arn.
Would that I had
Been born with it! But since I may choose further,
I will *look* further.
[The shade of Alcibiades disappears.]
Stran.
Lo! behold again!
Arn.
What! that low, swarthy, short-nosed, round-eyed satyr,
With the wide nostrils and Silenus' aspect,
The splay feet and low stature! I had better
Remain that which I am.
Stran.
And yet he was
The earth's perfection of all mental beauty,
And personification of all virtue.
But you reject him?
Arn.
If his form could bring me
That which redeemed it—no.
Stran.
I have no power
To promise that; but you may try, and find it
Easier in such a form—or in your own.
Arn.
No. I was not born for philosophy,
Though I have that about me which has need on't.
Let him fleet on.
Stran.
Be air, thou Hemlock-drinker!
[The shadow of Socrates disappears: another rises.]
Arn.
What's here? whose broad brow and whose curly beard
And manly aspect look like Hercules,
Save that his jocund eye hath more of Bacchus
Than the sad purger of the infernal world,
Leaning dejected on his club of conquest,
As if he knew the worthlessness of those
For whom he had fought.
Stran.
It was the man who lost
The ancient world for love.
Arn.
I cannot blame him,
Since I have risked my soul because I find not
That which he exchanged the earth for.
Stran.
Since so far
You seem congenial, will you wear his features?
Arn.
No. As you leave me choice, I am difficult.
If but to see the heroes I should ne'er
Have seen else, on this side of the dim shore,
Whence they float back before us.
Stran.
Hence, Triumvir,
Thy Cleopatra's waiting.
[The shade of Antony disappears: another rises.]
Arn.
Who is this?
Who truly looketh like a demigod,
Blooming and bright, with golden hair, and stature,
If not more high than mortal, yet immortal
In all that nameless bearing of his limbs,
Which he wears as the Sun his rays—a something
Which shines from him, and yet is but the flashing
Emanation of a thing more glorious still.
Was he e'er human only?

Stran.
Let the earth speak,
If there be atoms of him left, or even
Of the more solid gold that formed his urn.
Arn.
Who was this glory of mankind?
Stran.
The shame
Of Greece in peace, her thunderbolt in war—
Demetrius the Macedonian, and
Taker of cities.
Arn.
Yet one shadow more.
Stran. *(addressing the shadow).*
Get thee to Lamia's lap!
[The shade of Demetrius Poliorcetes vanishes: another rises.]
I'll fit you still,
Fear not, my Hunchback: if the shadows of
That which existed please not your nice taste,
I'll animate the ideal marble, till
Your soul be reconciled to her new garment.
Arn.
Content! I will fix here.
Stran.
I must commend
Your choice. The godlike son of the sea-goddess,
The unshorn boy of Peleus, with his locks
As beautiful and clear as the amber waves
Of rich Pactolus, rolled o'er sands of gold,
Softened by intervening crystal, and
Rippled like flowing waters by the wind,
All vowed to Sperchius as they were—behold them!
And him—as he stood by Polixena,
With sanctioned and with softened love, before
The altar, gazing on his Trojan bride,
With some remorse within for Hector slain
And Priam weeping, mingled with deep passion
For the sweet downcast virgin, whose young hand
Trembled in his who slew her brother. So
He stood i' the temple! Look upon him as
Greece looked her last upon her best, the instant
Ere Paris' arrow flew.
Arn.
I gaze upon him
As if I were his soul, whose form shall soon
Envelope mine.
Stran.
You have done well. The greatest
Deformity should only barter with
The extremest beauty—if the proverb's true
Of mortals, that Extremes meet.
Arn.
Come! Be quick!
I am impatient.
Stran.
As a youthful beauty
Before her glass. You both see what is not,
But dream it is what must be.
Arn.
Must I wait?
Stran.
No; that were a pity. But a word or two:
His stature is twelve cubits; would you so far
Outstep these times, and be a Titan? Or
(To talk canonically) wax a son
Of Anak?
Arn.
Why not?
Stran.
Glorious ambition!
I love thee most in dwarfs! A mortal of
Philistine stature would have gladly pared
His own Goliath down to a slight David:
But thou, my manikin, wouldst soar a show
Rather than hero. Thou shalt be indulged,
If such be thy desire; and, yet, by being
A little less removed from present men
In figure, thou canst sway them more; for all
Would rise against thee now, as if to hunt
A new-found Mammoth; and their cursèd engines,
Their culverins, and so forth, would find way
Through our friend's armour there, with greater ease
Than the Adulterer's arrow through his heel
Which Thetis had forgotten to baptize
In Styx.
Arn.
Then let it be as thou deem'st best.
Stran.
Thou shalt be beauteous as the thing thou seest,
And strong as what it was, and—
Arn.
I ask not
For Valour, since Deformity is daring.
It is its essence to o'ertake mankind
By heart and soul, and make itself the equal—
Aye, the superior of the rest. There is
A spur in its halt movements, to become
All that the others cannot, in such things

As still are free to both, to compensate
For stepdame Nature's avarice at first.
They woo with fearless deeds the smiles of fortune,
And oft, like Timour the lame Tartar, win them.
Stran.
Well spoken! And thou doubtless wilt remain
Formed as thou art. I may dismiss the mould
Of shadow, which must turn to flesh, to incase
This daring soul, which could achieve no less
Without it.
Arn.
Had no power presented me
The possibility of change, I would
Have done the best which spirit may to make
Its way with all Deformity's dull, deadly,
Discouraging weight upon me, like a mountain,
In feeling, on my heart as on my shoulders—
A hateful and unsightly molehill to
The eyes of happier men. I would have looked
On Beauty in that sex which is the type
Of all we know or dream of beautiful,
Beyond the world they brighten, with a sigh—
Not of love, but despair; nor sought to win,
Though to a heart all love, what could not love me
In turn, because of this vile crookèd clog,
Which makes me lonely. Nay, I could have borne
It all, had not my mother spurned me from her.
The she-bear licks her cubs into a sort
Of shape;—my Dam beheld my shape was hopeless.
Had she exposed me, like the Spartan, ere
I knew the passionate part of life, I had
Been a clod of the valley,—happier nothing
Than what I am. But even thus—the lowest,
Ugliest, and meanest of mankind—what courage
And perseverance could have done, perchance
Had made me something—as it has made heroes
Of the same mould as mine. You lately saw me
Master of my own life, and quick to quit it;
And he who is so is the master of
Whatever dreads to die.
Stran.
Decide between
What you have been, or will be.
Arn.
I have done so.
You have opened brighter prospects to my eyes,
And sweeter to my heart. As I am now,
I might be feared—admired—respected—loved
Of all save those next to me, of whom I
Would be belovèd. As thou showest me
A choice of forms, I take the one I view.
Haste! haste!
Stran.
And what shall *I* wear?
Arn.
Surely, he
Who can command all forms will choose the highest,
Something superior even to that which was
Pelides now before us. Perhaps his
Who slew him, that of Paris: or—still higher—
The Poet's God, clothed in such limbs as are
Themselves a poetry.
Stran.
Less will content me;
For I, too, love a change.
Arn.
Your aspect is
Dusky, but not uncomely.
Stran.
If I chose,
I might be whiter; but I have a *penchant*
For black—it is so honest, and, besides,
Can neither blush with shame nor pale with fear;
But I have worn it long enough of late,
And now I'll take your figure.
Arn.
Mine!
Stran.
Yes. You
Shall change with Thetis' son, and I with Bertha,
Your mother's offspring. People have their tastes;
You have yours—I mine.
Arn.
Despatch! despatch!
Stran.
Even so.

[The Stranger takes some earth and moulds it along the turf, and then addresses the phantom of Achilles.]

Beautiful shadow
Of Thetis's boy!
Who sleeps in the meadow
Whose grass grows o'er Troy:
From the red earth, like Adam,
Thy likeness I shape,
As the Being who made him,
Whose actions I ape.
Thou Clay, be all glowing,
Till the Rose in his cheek

Be as fair as, when blowing,
It wears its first streak!

Ye Violets, I scatter,
Now turn into eyes!
And thou, sunshiny Water,
Of blood take the guise!
Let these Hyacinth boughs
Be his long flowing hair,
And wave o'er his brows,
As thou wavest in air!
Let his heart be this marble
I tear from the rock!
But his voice as the warble
Of birds on yon oak!
Let his flesh be the purest
Of mould, in which grew
The Lily-root surest,
And drank the best dew!
Let his limbs be the lightest
Which clay can compound,
And his aspect the brightest
On earth to be found!
Elements, near me,
Be mingled and stirred,
Know me, and hear me,
And leap to my word!
Sunbeams, awaken
This earth's animation
'Tis done! He hath taken
His stand in creation!

[Arnold falls senseless; his soul passes into the shape of Achilles, which rises from the ground; while the phantom has disappeared, part by part, as the figure was formed from the earth.]

Source: Gordon, George, Lord Byron. 1822. *The Deformed Transformed*. Available at: http://www.blackmask.com/books64c/deftrans.htm

Victor Hugo, from *The Hunchback of Notre Dame* (1831)

Here Hugo introduces his main character, Quasimodo the hunchback, who alone can save but not win the beautiful Esmeralda. Every grotesque person in Paris is invited by the rabble-rouser Coppenole to compete in a grimacing contest for the title of the Pope of Fools, but the winner, Quasimodo, is the one who incorporates more disabilities than anyone else. The introduction of Quasimodo to readers in this crowd scene allows Hugo to catalog the many superstitions and fears surrounding disability at the same time that he presents readers with one of the most memorable heroes in French literature, the Romantic outcast par excellence. This excerpt begins with the crowd shouting "Noel! Noel! Noel!" (the old French word for hurrah) to signify their overwhelming vote for Quasimodo as Pope of Fools.

From Chapter V. "Quasimodo"

"Noel! Noel! Noel!" shouted the people on all sides. That was, in fact, a marvellous grimace which was beaming at that moment through the aperture in the rose window. After all the pentagonal, hexagonal, and whimsical faces, which had succeeded each other at that hole without realizing the ideal of the grotesque which their imaginations, excited by the orgy, had constructed, nothing less was needed to win their suffrages than the sublime grimace which had just dazzled the assembly. Master Coppenole himself applauded, and Clopin Trouillefou, who had been among the competitors (and God knows what intensity of ugliness his visage could attain), confessed himself conquered: We will do the same. We shall not try to give the reader an idea of that tetrahedral nose, that horseshoe mouth; that little left eye obstructed with a red, bushy, bristling eyebrow, while the right eye disappeared entirely beneath an enormous wart; of those teeth in disarray, broken here and there, like the embattled parapet of a fortress; of that callous lip, upon which one of these teeth encroached, like the tusk of an elephant; of that forked chin; and above all, of the expression spread over the whole; of that mixture of malice, amazement, and sadness. Let the reader dream of this whole, if he can.

The acclamation was unanimous; people rushed towards the chapel. They made the lucky Pope of the Fools come forth in triumph. But it was then that surprise and admiration attained their highest pitch; the grimace was his face.

Or rather, his whole person was a grimace. A huge head, bristling with red hair; between his shoulders an enormous hump, a counterpart perceptible in front; a system of thighs and legs so strangely astray that they could touch each other only at the knees, and, viewed

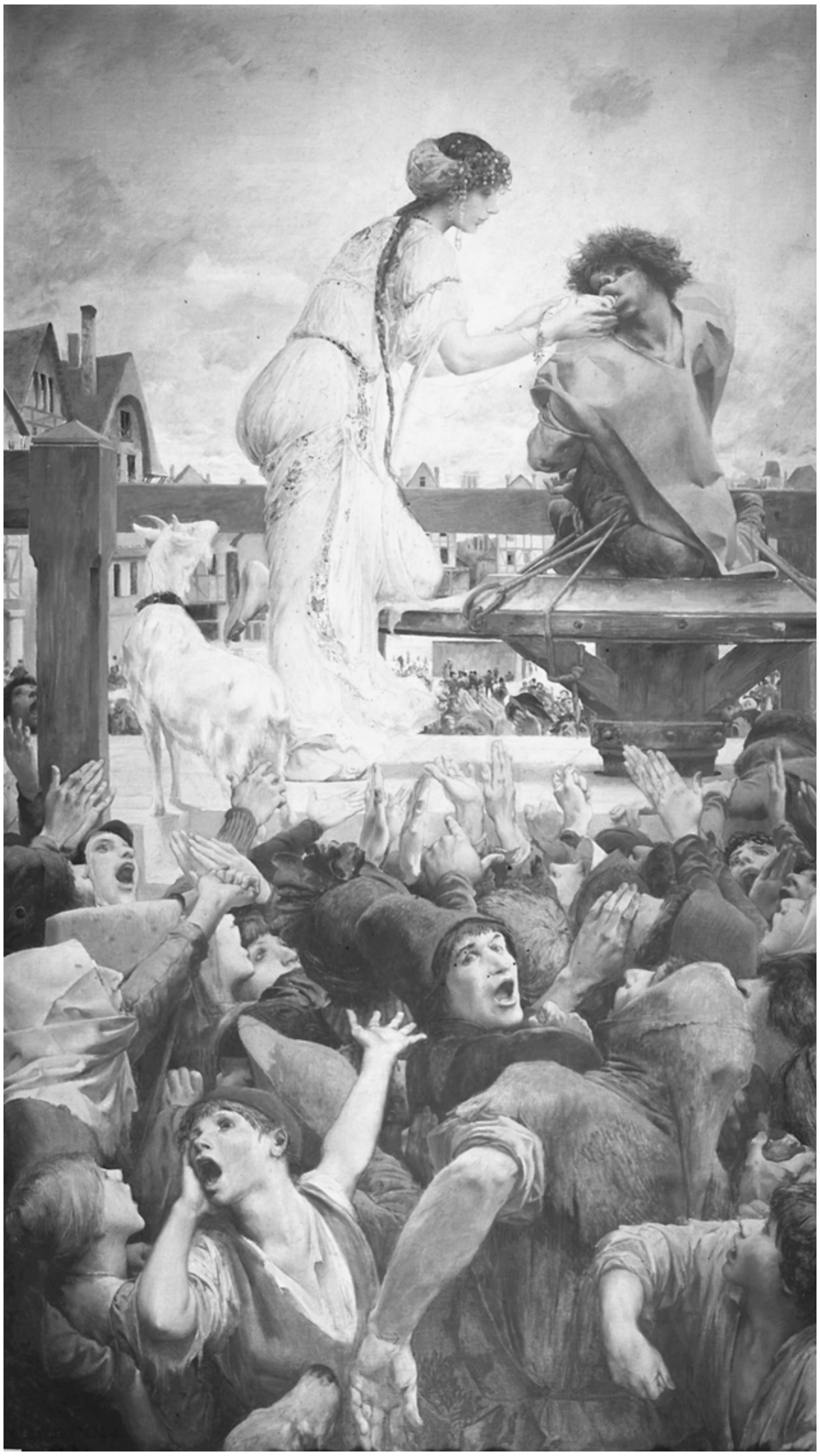


Illustration for The Hunchback of Notre Dame: *“Esmeralda Feeds Quasimodo,” by Luc Olivier Merson (1846–1920). As the disabled Quasimodo is exhibited for public ridicule, the female protagonist, Esmeralda, experiences a moment of empathy and provides relief for his dehydration. The scene recalls the biblical passage when Christ is offered water while carrying his cross. This also recalls the common practice of the public display of people with disabilities for profit. While cultivating sympathy for rejected bodies, Hugo leaves them largely outside of the sphere of meaningful human relationships.*

Source: Art Resource, New York.

from the front, resembled the crescents of two scythes joined by the handles; large feet, monstrous hands; and, with all this deformity, an indescribable and redoubtable air of vigor, agility, and courage,—strange exception to the eternal rule which wills that force as well as beauty shall be the result of harmony. Such was the pope whom the fools had just chosen for themselves.

One would have pronounced him a giant who had been broken and badly put together again.

When this species of cyclops appeared on the threshold of the chapel, motionless, squat, and almost as broad as he was tall; squared on the base, as a great man says; with his doublet half red, half violet, sown with silver bells, and, above all, in the perfection of his ugliness, the populace recognized him on the instant, and shouted with one voice,—

“’Tis Quasimodo, the bellringer! ’tis Quasimodo, the hunchback of Notre-Dame! Quasimodo, the one-eyed! Quasimodo, the bandy-legged! Noel! Noel!”

It will be seen that the poor fellow had a choice of surnames.

“Let the women with child beware!” shouted the scholars.

“Or those who wish to be,” resumed Joannes.

The women did, in fact, hide their faces.

“Oh! the horrible monkey!” said one of them.

“As wicked as he is ugly,” retorted another.

“He’s the devil,” added a third.

“I have the misfortune to live near Notre-Dame; I hear him prowling round the eaves by night.”

“With the cats.”

“He’s always on our roofs.”

“He throws spells down our chimneys.”

“The other evening, he came and made a grimace at me through my attic window. I thought that it was a man. Such a fright as I had!"

"I'm sure that he goes to the witches' sabbath. Once he left a broom on my leads."

"Oh! what a displeasing hunchback's face!"

"Oh! what an ill-favored soul!"

"Whew!"

The men, on the contrary, were delighted and applauded. Quasimodo, the object of the tumult, still stood on the threshold of the chapel, sombre and grave, and allowed them to admire him.

One scholar (Robin Poussepain, I think), came and laughed in his face, and too close. Quasimodo contented himself with taking him by the girdle, and hurling him ten paces off amid the crowd; all without uttering a word.

Master Coppenole, in amazement, approached him.

"Cross of God! Holy Father! you possess the handsomest ugliness that I have ever beheld in my life. You would deserve to be pope at Rome, as well as at Paris."

So saying, he placed his hand gayly on his shoulder. Quasimodo did not stir.

Coppenole went on,—"You are a rogue with whom I have a fancy for carousing, were it to cost me a new dozen of twelve livres of Tours. How does it strike you?"

Quasimodo made no reply.

"Cross of God!" said the hosier, "are you deaf?"

He was, in truth, deaf.

Nevertheless, he began to grow impatient with Coppenole's behavior, and suddenly turned towards him with so formidable a gnashing of teeth, that the Flemish giant recoiled, like a bull-dog before a cat.

Then there was created around that strange personage, a circle of terror and respect, whose radius was at least fifteen geometrical feet. An old woman explained to Coppenole that Quasimodo was deaf.

"Deaf!" said the hosier, with his great Flemish laugh.

"Cross of God! He's a perfect pope!"

"He! I recognize him," exclaimed Jehan, who had, at last, descended from his capital, in order to see Quasimodo at closer quarters, "he's the bellringer of my brother, the archdeacon. Good-day, Quasimodo!"

"What a devil of a man!" said Robin Poussepain still all bruised with his fall. "He shows himself; he's a hunchback. He walks; he's bandy-legged. He looks at you; he's one-eyed. You speak to him; he's deaf. And what does this Polyphemus do with his tongue?"

"He speaks when he chooses," said the old woman; "he became deaf through ringing the bells. He is not dumb."

"That he lacks," remarks Jehan.

"And he has one eye too many," added Robin Poussepain.

"Not at all," said Jehan wisely. "A one-eyed man is far less complete than a blind man. He knows what he lacks."

In the meantime, all the beggars, all the lackeys, all the cutpurses, joined with the scholars, had gone in procession to seek, in the cupboard of the law clerks' company, the cardboard tiara, and the derisive robe of the Pope of the Fools. Quasimodo allowed them to array him in them without wincing, and with a sort of proud docility. Then they made him seat himself on a motley litter. Twelve officers of the fraternity of fools raised him on their shoulders; and a sort of bitter and disdainful joy lighted up the morose face of the cyclops, when he beheld beneath his deformed feet all those heads of handsome, straight, well-made men. Then the ragged and howling procession set out on its march, according to custom, around the inner galleries of the Courts, before making the circuit of the streets and squares.

Source: Hugo, Victor. 1831. *The Hunchback of Notre Dame.* Available at: http://www.online-literature.com/victor_hugo/hunchback_notre_dame/

▣ Comments on Lord Byron's Medical Care (19th c.)

This excerpt from Abt's work, which includes important quotations from Jeaffreson's biography of Lord Byron, inveighs against the "carelessness" with which disabled children were treated in Byron's time, arguing that Byron could have lived a long and healthy life if ignorant doctors had not interfered with his condition. Most contemporary biographers now refer to Byron's impairment as Little's disease (an early designation for cerebral palsy).

The world has undoubtedly suffered greatly from this carelessness [for the welfare of disabled children]. Hundreds, who might otherwise have contributed to the beauty of civilization, or have led their fellow men to new accomplishments, have been deprived of their birthright. In the past, only the wealthy cripples have had any opportunity for education. And even they have been handicapped by lack of orthopedic knowledge on the part of the medical profession. It is commonly believed that Lord Byron had a clubfoot. As a matter of fact, the great poet might have lived to an advanced age and produced volumes of additional poetry, had he not received the attention of a "quack doctor." As a young boy, Byron was afflicted with "lameness due to a contraction of the tendon Achilles which compelled him to walk on the balls and toes of his feet. The foot (later) was considerably distorted so as to turn inward, a malformation which may have been caused altogether by the violence with which it was treated." "The lad at Nottingham suffered much at the hands of a bone setter, Lavenden. . . . Blind to the nature of the case, the man did precisely as any other pretender of his kind would have done. . . . He rubbed the foot with oil, twisted it about with violence screwing and torturing bone and muscle into better behavior." In the opinion of medical men, had Byron been given the proper care, his deformity might have been entirely cured. As walking was always painful for him because of his obesity, he continually dieted. The dieting reduced his resistance, which, had it been stronger, might have successfully combated the fever which carried him away on the battle fields of Greece at the age of thirty-six years. Thus was the world deprived of one great man through carelessness.

Sources: Abt, Henry Edward. 1924. *The Care, Cure, and Education of the Crippled Child.* International Society for Crippled Children. Available at: http://www.disabilitymuseum.org/lib/docs/1449.htm

Jeaffreson, John Cordy. 1833. Vol. 1 of *The Real Lord Byron: New Views of the Poet's Life.* London: Hurst and Blackett.

Harriet Martineau, from *Society in America* (1837)

Asylum tourism was popular with both domestic and foreign travelers in antebellum America. Harriet Martineau, a deaf English writer, visited the United States and wrote of her experiences. Her report on the American means of treating people with various disabilities is found in the context of descriptions of American prisons, poor relief, temperance, abolition, and other varied and energetic approaches to dependency and reform.

The idea of travelling in America was first suggested to me by a philanthropist's saying to me, "Whatever else may be true about the Americans, it is certain that they have got at principles of justice and mercy in the treatment of the least happy classes of society which we may be glad to learn from them. I wish you would go and see what they are." I did so; and the results of my investigation have not been reserved for this short chapter, but are spread over the whole of my book. The fundamental democratic principles on which American society is organised, are those "principles of justice and mercy" by which the guilty, the ignorant, the needy, and the infirm, are saved and blessed. The charity of a democratic society is heart-reviving to witness; for there is a security that no wholesale oppression is bearing down the million in one direction, while charity is lifting up, the hundred in another. Generally speaking, the misery that is seen is all that exists: there is no paralysing sense of the hopelessness of setting up individual benevolence against social injustice. If the community has not yet arrived at the point at which all communities are destined to arrive, of perceiving guilt to be infirmity, of obviating punishment, ignorance, and want, still the Americans are more blessed than others, in the certainty that they have far less superinduced misery than societies abroad, and are using wiser methods than others for its alleviation. In a country where social equality is the great principle in which all acquiesce, and where, consequently, the golden rule is suggested by every collision between man and man, neglect of misery is almost as much out of the question as the oppression from which most misery springs. . . .

The pauperism of the United States is, to the observation of a stranger, nothing at all. To residents, it is an occasion for the exercise of their ever-ready charity. It is confined to the ports, emigrants making their way back into the country, the families of intemperate or disabled men; and unconnected women, who depend on their own exertions. The amount altogether is far from commensurate with the charity of the community; and it is to be hoped that the curse of a legal charity, at least to the able-bodied, will be avoided in a country where it certainly cannot become necessary within any assignable time. I was grieved to see the magnificent pauper asylum near Philadelphia, made to accommodate luxuriously 1200 persons; and to have its arrangements pointed out to me, as yielding far more comfort to the inmates than the labourer can secure at home by any degree of industry and prudence. There are so many persons in the city, however, who see the badness of the principle, and regret the erection, that I trust a watch will be maintained over the establishment, and its corridors kept as empty as possible. In Boston, the principles of true charity have been better acted upon. There, many of the clergymen,—among the rest, Father Taylor, the seaman's friend,—are in possession of wisdom, derived from the mournful experience of England; and seem likely to save the city from the misery of a debasing pauperism among any class of its inhabitants. I know no large city where there is so much mutual helpfulness, so little neglect and ignorance of the concerns of other classes, as in Boston: and I cannot but anticipate that from thence the world may derive the brightest lesson that has yet been offered it, in the duties of the rich towards the poor. If the agents of the benevolence of the wealthy will but be scrupulously careful to avoid all that mental encroachment and moral interference, which have but too generally ruined the efficacy of charity, and go on to exhibit the devotion of the philanthropist, without the inquisitiveness and authoritativeness of the priest, they may deserve the thanks of the whole of society, as well as the attachment of those whom they befriend.

In Boston, an excellent plan has been adopted for the prevention of fraud on the part of paupers, and the mutual enlightenment and guidance of the agents of charity. A weekly meeting is held of delegates, from all societies engaged in the relief of the poor. The delegates compare lists of the persons relieved, so as to ascertain that none are fraudulently receiving from more than one society: they discuss and investigate doubtful cases; extend indulgence to those of peculiar hardship; and, in short, secure all the advantages of cooperation. Perhaps there are no cities in England but London too large for a somewhat similar organisation: and its adoption would be an act of great wisdom.

In the south, I was rather amused at a boast which was made to me of the small amount of pauperism. As the plague distances all lesser diseases, so does slavery obviate pauperism. In a society of two classes, where the one class are all capitalists, and the other property, there can be no pauperism but through the vice or accidental disability of members of the first. But I was beset by many an anxious thought about the fate of disabled slaves. Masters are, of course, bound to take care of their slaves for life. There are doubtless many masters who guard the comfort of their helpless negroes all the more carefully from the sense of the

From the Black Paintings, by Francisco de Goya (1746–1828). In this work, one monk, deaf, listens to the other, who shout in the deaf monk's ear. This work, from Goya's Black Paintings series, was created on the wall of his house, the Quinta del Sordo. The Black Paintings were all made during the latter part of the artist's life. Goya experienced deafness as he grew older, and this work depicts his feelings of alienation from the hearing world by having those in the background yelling into the ears of the caped figure with a walking stick in the foreground.

Source: Art Resource, New York.

entire dependence of the poor creatures upon their mercy: but, there are few human beings fit to be trusted with absolute power: and while there are many who abuse the authority they have over slaves who are not helpless, it is fearful to think what may be the fate of those who are purely burdensome. I observed, here and there, an idiot slave. Those whom I saw were kindly treated, humoured, and indulged. These were the only cases of natural infirmity that I witnessed among the negroes; and the absence of others struck me. At Columbia, South Carolina, I was taken by a benevolent physician to see the State Lunatic Asylum, which might be considered his work; so diligent had he been in obtaining appropriations for the object from the legislature, and afterwards in organising its plans, with great wisdom and humanity. When we were looking out from the top of this building, watching the patients in their airing grounds, I observed that no people of colour were visible in any part of the establishment. I inquired whether negroes were as subject to insanity as whites. Probably; but no means were known to have been taken to ascertain the fact. From the violence of their passions, there could be no doubt that insanity must exist among them. Were such insane negroes ever seen?—No one present had ever seen any.—Where were they then?—It was some time before I could get a clear answer to this: but my friend the physician said, at length, that he had no doubt they were kept in out-houses, chained to logs, to prevent their doing harm. No member of society is charged with the duty of investigating cases of disease and suffering among slaves who cannot make their own state known. They are wholly at the mercy of their owners. The physician told me that it was his intension, now he had accomplished his object of establishing a lunatic asylum for the whites, to persevere no less strenuously till he obtained one for the blacks. He will probably not find this a very difficult object to effect; for the interest of masters, as well as their humanity, is concerned in having an asylum provided by the State for the useless or mischievous negroes.

The Lunatic Asylums of the United States [are] an honour to the country, to judge by those which I saw. The insane in Pennsylvania hospital, Philadelphia, should be removed to some more light and cheerful abode, and be much more fully supplied with employment, and with stimulus to engage in it. I was less pleased with their conditions than with that of any other insane patients whom I saw. The institution at Worcester, Massachusetts, is admirably managed under Dr. Woodward. So was that at Charlestown, near Boston, by Dr. Lee; a young physician who has since died, mourned by his grateful patients, and by all who had their welfare at heart. The establishment at Bloomingdale; near New York, is of similar excellence. The only great deficiency that I am aware of is one which belongs to most lunatic asylums, and which it does not rest with the superintendent to supply;—a want of sufficient employment. Every exertion is made to provide a variety of amusements, and to encourage all little undertakings that may be suggested: but regular, important business is what is wanted. It is to be hoped that in the establishment of all such institutions, the provision of an ample quantity of land will be one of the prime considerations. Watchful and ingenious kindness may do much to alleviate the miseries of the insane; but if cure is sought, I believe it is agreed by those who know best that regular employment, with a reasonable object, is indispensable.

The Asylum for the Blind at Philadelphia was a young institution at the time I saw it; but it pleased me more than any I ever visited: more than the larger one at Boston; whose institution and conduct are, however, honourable to all concerned in it. The reason of my preference of the Philadelphia one is that the pupils there were more active and cheerful than those of Boston. The spirits of the inmates are the one infallible test of the management of an institution for the blind. The fault of such in general is that mirth is not sufficiently cultivated, and religion too exclusively so. It should ever be remembered that religion comes out of the mind, and not in at the eye or ear; and that the truest way of cultivating religion is to exercise the faculties, and enlarge the stock of ideas to the utmost. The method of printing for the blind, introduced with such admirable ingenuity and success into the American institutions, I should like to see employed to bring within the reach of the blind the most amusing works that can be found. I should like to see it made an object with benevolent persons to go and give the pupils a hearty laugh occasionally, by reading droll books, and telling amusing stories. The one thing which the born blind want most is to have their cheerlessness removed, to be drawn out of their abstractions, and exercised in play on the greatest possible variety of familiar objects and events. They should hear no condolence: their friends should keep their sympathetic sorrow to themselves; and explain, cheerfully and fully, the allusions to visual objects which must occur in all reading and conversation. It grieves me to hear the hymns and other compositions put into the mouths of blind pupils, all full of lamentation and resignation about not seeing the stars and the face of nature. Such sorrow is for those who see to feel on their behalf; or for those who have lost sight: not for those who never saw. Put into their mouths, it becomes cant. When a roving sea-captain tells his children of the glories of oriental scenery which they are destined never to behold, does he teach them to sigh, and struggle to submit patiently to their destiny of staying at home? Does he not rather make them take pleasure in mirthfully and eagerly learning what he can teach? The face of nature is a foreign land to the born blind. Let them be taught all that can possibly be conveyed to them, and in the most spirited manner that they can bear. There is a nearer approach to the realisation of this principle of teaching the blind in the Philadelphia house than I ever saw elsewhere. It would be enough to cheer a misanthrope to see a little German boy there, picked up out of the streets, dull, neglected, and depressed; but within a few months, standing in the centre of the group of musicians, fiddling and stamping time with all his might, and quite ready to obey every instigation to laugh. Mr. Friedlander, the tutor, is much to be congratulated on what he has already done.

It may be worth suggesting here that while some of the thinkers of America, like many of the same classes in England, are mourning over the low state of the Philosophy of Mind in their country, society is neglecting a most important means of obtaining the knowledge requisite for the acquisition of such philosophy. Scholars are embracing alternately the systems of Kant, of Fichte, of Spurzheim, of the Scotch school; or abusing or eulogising Locke, asking who Hartley was, or weaving a rainbow arch of transcendentalism, which is to comprehend the whole that lies within human vision, but sadly liable to be puffed away in dark vapour with the first breeze of reality; scholars are thus labouring at a system of mental philosophy on any but the experimental method, while the materials for experiment lie all around and within them. If they object, as is common, the difficulty of experimenting on their conscious selves, there is the mental pathology of their blind schools, and the asylums for the deaf and dumb. I am aware that they put away the phenomena of insanity as irrelevant; but the same objections do not pertain to the other two classes. Let the closet speculations be pursued with all vigour; but if there were joined with these a close and unwearied study of the phenomena of the minds of persons deficient in a sense, and especially of those precluded from the full use of language, the world might fairly look for an advance in the science of Mind equal to that which medical science owes to pathology. It will not probably lodge us in any final and total result, any more than medicine and anatomy promise to ascertain the vital principle: but it will doubtless yield us some points of certainty, in aid of the fluctuating speculations amidst which we are now tossed, while few can be found to agree even upon matters of so-called universal consciousness. I should like to see a few philosophers interested in ascertaining and recording the manifestations of some progressive minds, peculiar from infirmity, for a series of years. If any such in America, worthy to undertake the task, from having strength enough to put away theory and prejudice, and record only what is really manifested to them, should be disposed to take my hint, I hope they will not wait for a philosophical "class to fall into."

Source: Martineau, Harriet. 1837. Chapter 4, "Sufferers," in *Society in America.* Available at: http://www2.pfeiffer.edu/~lridener/DSS/Martineau/v3p3c4.html

▣ English Poor Law Amendment (1841)

This nineteenth-century amendment act introduced significant changes in the policy management of poor and disabled people in England. It sought to narrow eligibility requirements for workhouses in order to make that institution less preferable than even jobs garnering the lowest paid wages. Further, the policy prohibited outdoor relief (support for those living in the community) and mandated public support in workhouse settings alone.

The superiority of the condition of the pauper . . . as regards medical aid will, on the one hand, encourage a resort to the poor rates for medical relief, so far as it is given out of the workhouse, and will thus tempt the industrious labourer into pauperism; and on the other hand, it will discourage sick clubs and friendly societies and other similar institutions, which are not only valuable in reference to the contingencies against which they provide, but as creating and fostering a spirit of frugality and forethought amongst the labouring classes.

Source: English Poor Law Commission. 1841. [Amendment to *An Act for the Amendment and Better Administration of the Laws Relating to the Poor in England and Wales.* 4 & 5 Will. IV cap. 76.]

William Dodd, from *A Narrative of William Dodd: Factory Cripple* (1841)

William Dodd began working in an English textile factory at the age of five, working up to 18 hours a day at times. Within a few years, the work had rendered him severely disabled. He continued to work in the textile factories but was able to learn to read and write by attending school at night, which enabled him to leave factory work. Eventually, Lord Ashley, a member of parliament interested in protecting child laborers, commissioned him to write of his experiences. With Lord Ashley's support, Dodd was able to publish a number of books. His descriptions of the experiences of child laborers were so compelling that reform opponents in the House of Commons launched attacks on his character and credibility (a brief excerpt from a speech attacking Dodd is included after the excerpts from Dodd's book). Dodd eventually decided to move to the United States, where he continued to write against the child labor system.

At the age of six I became a piecer. The duties of the piecer will not be clearly understood by the reader, unless he is acquainted with the machine for spinning woollen yarn, called a billy. A billy is a machine somewhat similar in form to the letter H, one side being stationary, and the other moveable, and capable of being pushed close in under the stationary part, almost like the drawer of a side table; the moveable part, or carriage, runs backwards and forwards, by means of six iron wheels, upon three iron rails, as a carriage on a railroad. In this carriage are the spindles, from 70 to 100 in number, all turned by one wheel, which is in the care of the spinner. When the spinner brings the carriage close up under the fixed part of the machine, he is able, to obtain a certain length of carding for each spindle, say 10 or 12 inches, which he draws back, and spins into yarn; this done, he winds the yarn round the spindles, brings the carriage close up as before, and again obtains a fresh supply of cardings.

These cardings are taken up by the piecer in the left hand, about twenty at a time. He holds them about four inches from one end, the other end hanging down; these he takes, with the right hand, one at a time, for the purpose of piecing, and laying the ends of the cardings about 2 inches over each other, he rubs them together on the canvas cloth with his flat hand. He is obliged to be very expert, in order to keep the spinner well supplied. A good piecer will supply from 30 to 40 spindles with cardings.

The number of cardings a piecer has through his fingers in a day is very great; each piecing requires three or four rubs, over a space of three or four inches; and the continual friction of the hand in rubbing the piecing upon the coarse wrapper wears off the skin, and causes the finger to bleed. The position in which the piecer stands to his work is with the right foot forward, and his right side facing the frame: the motion he makes in going along in front of the frame, for the purpose of piecing, is neither forwards or backwards, but in a sliding direction, constantly keeping his right side towards the frame. In this position he continues during the day, with his hands, feet, and eyes constantly in motion. It will be easily seen, that the chief weight of his body rests upon his right knee, which is almost always the first joint to give way.

I have frequently worked at the frame till I could scarcely get home, and in this state have been stopped by people in the streets who noticed me shuffling along, and advised me to work no more in the factories; but I was not my own master. During the day, I frequently counted the clock, and calculated how many hours I had still to remain at work; my evenings were spent in preparing for the following day—in rubbing my knees, ankles, elbows, and wrists with oil, etc. I went to bed, to cry myself to sleep, and pray that the Lord would take me to himself before morning. . . .

My legs became distorted. Standing in the easiest position, when the feet are about 14 inches apart, the knees and thighs are then pressing close together, so that the legs form a sort of arch for the support of the body. One evil arising from the bending and curving of the legs is the blood-vessels must go wrong. One serious evil resulting from the imperfect circulation of the blood, is the drying up of the marrow in the bones. The bones then decay.

In the spring of 1840, I began to feel some painful symptoms in my right wrist, arising from the general weakness of my joints, brought on in the factories. The swelling and pain increased; and although I had the advice of medical practitioners, it was all to no purpose; and, having been off work for a length of time, and my resources failing, I was under the necessity of entering St. Thomas's Hospital where every care and attention was paid to me. It soon became evident to all who saw me, that I must, very soon, lose either my hand or my life. A consultation was held by the surgeons of the hospital, who came to the conclusion, that amputation was absolutely necessary. On the 18th of July, I underwent the operation. The hand being taken off a little below the elbow. Thus, another plan to raise myself above want, and keep myself out of the workhouse, was frustrated and dashed.

John Bright's Speech in the House of Commons (March 1844)

I have in my hand two publications; one is *The Adventures of William Dodd the Factory Cripple* and the other is entitled *The Factory System*—both books have gone forth to the public under the sanction of the noble Lord Ashley. I do not wish to go into the particulars of the character of this man, for it is not necessary to my case, but I can demonstrate, that his books and statements are wholly unworthy of credit. Dodd states that from the hardships he endured in a factory, he was "done up" at the age of thirty-two, whereas I can prove that he was treated with uniform kindness, which he repaid by gross immorality of conduct, and for which he was discharged from his employment.

Source: Dodd, William. 1841. *A Narrative of William Dodd: Factory Cripple,* 2nd ed. London: L & G Seeley.

Charles Dickens, from *A Christmas Carol* (1843)

With the aid of the Spirit of Christmas Present, Scrooge witnesses the family life of the impoverished Cratchits, at the heart of which is their son, Tiny Tim. Dickens focuses all emotions on the disabled but angelic child, with the moral measure of the other characters being taken by the degree of their sympathy for him.

Then up rose Mrs. Cratchit, Cratchit's wife, dressed out but poorly in a twice-turned gown, but brave in ribbons, which are cheap and make a goodly show for sixpence; and she laid the cloth, assisted by Belinda Cratchit, second of her daughters, also brave in ribbons; while Master Peter Cratchit plunged a fork into the saucepan of potatoes, and getting the corners of his monstrous shirt-collar (Bob's private property, conferred upon his son and heir in honour of the day) into his mouth, rejoiced to find himself so gallantly attired, and yearned to show his linen in the fashionable Parks. And now two smaller Cratchits, boy and girl, came tearing in, screaming that outside the baker's they had smelt the goose, and known it for their own; and basking in luxurious thoughts of sage-and-onion, these young Cratchits danced about the table, and exalted Master Peter Cratchit to the skies, while he (not proud, although his collars nearly choked him) blew the fire, until the slow potatoes bubbling up, knocked loudly at the saucepan-lid to be let out and peeled.

"What has ever got your precious father then," said Mrs. Cratchit. "And your brother, Tiny Tim; and Martha warn't as late last Christmas Day by half-an-hour!"

"Here's Martha, mother!" said a girl, appearing as she spoke.

"Here's Martha, mother!" cried the two young Cratchits. "Hurrah! There's such a goose, Martha!"

"Why, bless your heart alive, my dear, how late you are!" said Mrs. Cratchit, kissing her a dozen times, and taking off her shawl and bonnet for her, with officious zeal.

"We'd a deal of work to finish up last night," replied the girl, "and had to clear away this morning, mother!"

"Well! Never mind so long as you are come," said Mrs. Cratchit. "Sit ye down before the fire, my dear, and have a warm, Lord bless ye!"

"No no! There's father coming," cried the two young Cratchits, who were everywhere at once. "Hide Martha, hide!"

So Martha hid herself, and in came little Bob, the father, with at least three feet of comforter exclusive of the fringe, hanging down before him; and his thread-bare clothes darned up and brushed, to look seasonable; and Tiny Tim upon his shoulder. Alas for Tiny Tim, he bore a little crutch, and had his limbs supported by an iron frame!

"Why, where's our Martha?" cried Bob Cratchit looking round.

"Not coming," said Mrs. Cratchit.

"Not coming!" said Bob, with a sudden declension in his high spirits; for he had been Tim's blood horse all the way from church, and had come home rampant. "Not coming upon Christmas Day!"

Martha didn't like to see him disappointed, if it were only in joke; so she came out prematurely from behind the closet door, and ran into his arms, while the two young Cratchits hustled Tiny Tim, and bore him off into the wash-house, that he might hear the pudding singing in the copper.

"And how did little Tim behave?" asked Mrs. Cratchit, when she had rallied Bob on his credulity and Bob had hugged his daughter to his heart's content.

"As good as gold," said Bob, "and better. Somehow he gets thoughtful sitting by himself so much, and thinks the strangest things you ever heard. He told me, coming home, that he hoped the people saw him in the church, because he was a cripple, and it might be pleasant to them to remember upon Christmas Day, who made lame beggars walk and blind men see."

Bob's voice was tremulous when he told them this, and trembled more when he said that Tiny Tim was growing strong and hearty.

His active little crutch was heard upon the floor, and back came Tiny Tim before another word was spoken, escorted by his brother and sister to his stool beside the fire; and while Bob, turning up his cuffs—as if, poor fellow, they were capable of being made more shabby—compounded some hot mixture in a jug with gin and lemons, and stirred it round and round and put it on the hob to simmer; Master Peter and the two ubiquitous young Cratchits went to fetch the goose, with which they soon returned in high procession.

Such a bustle ensued that you might have thought a goose the rarest of all birds; a feathered phenomenon, to which a black swan was a matter of course: and in truth it was something very like it in that house. Mrs. Cratchit made the gravy (ready beforehand in a little saucepan) hissing hot; Master Peter mashed the potatoes with incredible vigour; Miss Belinda sweetened up the apple-sauce; Martha dusted the hot plates; Bob took Tiny Tim beside him in a tiny corner at the table; the two young Cratchits set chairs for everybody, not forgetting themselves, and mounting guard upon their posts, crammed spoons into their mouths, lest they should shriek for goose before their turn came to be helped. At last the dishes were set on, and grace was said. It was succeeded by a breathless pause, as Mrs. Cratchit, looking slowly all along the carving-knife, prepared to plunge it in the breast; but when she did, and when the long expected gush of stuffing issued forth, one murmur of delight arose all round the board, and even Tiny Tim, excited by the two young Cratchits, beat on the table with the handle of his knife, and feebly cried Hurrah!

There never was such a goose. Bob said he didn't believe there ever was such a goose cooked. Its tenderness and flavour, size and cheapness, were the themes of universal admiration. Eked out by the apple-sauce and mashed potatoes, it was a sufficient dinner for the whole family; indeed, as Mrs. Cratchit said with great delight (surveying one small atom of a bone upon the dish), they hadn't ate it all at last! Yet every one had had enough, and the youngest Cratchits in particular, were steeped in sage and onion to the eyebrows! But now, the plates being changed by Miss Belinda, Mrs. Cratchit left the room alone—too nervous to bear witnesses—to take the pudding up, and bring it in.

Suppose it should not be done enough! Suppose it should break in turning out! Suppose somebody should have got over the wall of the back-yard, and stolen it, while they were merry with the goose: a supposition at which the two young Cratchits became livid! All sorts of horrors were supposed.

Hallo! A great deal of steam! The pudding was out of the copper. A smell like a washing-day! That was the cloth. A smell like an eating-house, and a pastry cook's next door to each other, with a laundress's next door to that! That was the pudding. In half a minute Mrs. Cratchit entered: flushed, but smiling proudly: with the pudding, like a speckled cannon-ball, so hard and firm, blazing in half of half-a-quarter of ignited brandy, and bedight with Christmas holly stuck into the top.

Oh, a wonderful pudding! Bob Cratchit said, and calmly too, that he regarded it as the greatest success achieved by Mrs. Cratchit since their marriage. Mrs. Cratchit said that now the weight was off her mind, she would confess she had had her doubts about the quantity of flour. Everybody had something to say about it, but nobody said or thought it was at all a small pudding for a large family. It would have been flat heresy to do so. Any Cratchit would have blushed to hint at such a thing.

At last the dinner was all done, the cloth was cleared, the hearth swept, and the fire made up. The compound in the jug being tasted and considered perfect, apples and oranges were put upon the table, and a shovel-full of chesnuts on the fire. Then all the Cratchit family drew round the hearth, in what Bob Cratchit called a circle, meaning half a one; and at Bob

Cratchit's elbow stood the family display of glass; two tumblers, and a custard-cup without a handle.

These held the hot stuff from the jug, however, as well as golden goblets would have done; and Bob served it out with beaming looks, while the chesnuts on the fire sputtered and crackled noisily. Then Bob proposed:

"A Merry Christmas to us all, my dears. God bless us!"

Which all the family re-echoed.

"God bless us every one!" said Tiny Tim, the last of all.

He sat very close to his father's side, upon his little stool. Bob held his withered little hand in his, as if he loved the child, and wished to keep him by his side, and dreaded that he might be taken from him.

"Spirit," said Scrooge, with an interest he had never felt before, "tell me if Tiny Tim will live."

"I see a vacant seat," replied the Ghost, "in the poor chimney corner, and a crutch without an owner, carefully preserved. If these shadows remain unaltered by the Future, the child will die."

"No, no," said Scrooge. "Oh no, kind Spirit! say he will be spared."

"If these shadows remain unaltered by the Future, none other of my race," returned the Ghost, "will find him here. What then? If he be like to die, he had better do it, and decrease the surplus population."

Scrooge hung his head to hear his own words quoted by the Spirit, and was overcome with penitence and grief.

"Man," said the Ghost, "if man you be in heart, not adamant, forbear that wicked cant until you have discovered What the surplus is, and Where it is. Will you decide what men shall live, what men shall die? It may be, that in the sight of Heaven, you are more worthless and less fit to live than millions like this poor man's child. Oh God! to hear the Insect on the leaf pronouncing on the too much life among his hungry brothers in the dust!"

Scrooge bent before the Ghost's rebuke, and trembling cast his eyes upon the ground. But he raised them speedily, on hearing his own name.

"Mr. Scrooge!" said Bob; "I'll give you Mr. Scrooge, the Founder of the Feast!"

"The Founder of the Feast indeed!" cried Mrs. Cratchit, reddening. "I wish I had him here. I'd give him a piece of my mind to feast upon, and I hope he'd have a good appetite for it."

"My dear," said Bob, "the children; Christmas Day."

"It should be Christmas Day, I am sure," said she, "on which one drinks the health of such an odious, stingy, hard, unfeeling man as Mr. Scrooge. You know he is, Robert! Nobody knows it better than you do, poor fellow!"

"My dear," was Bob's mild answer, "Christmas Day."

"I'll drink his health for your sake and the Day's," said Mrs. Cratchit, "not for his. Long life to him! A merry Christmas and a happy new year!—he'll be very merry and very happy, I have no doubt!"

The children drank the toast after her. It was the first of their proceedings which had no heartiness in it. Tiny Tim drank it last of all, but he didn't care twopence for it. Scrooge was the Ogre of the family. The mention of his name cast a dark shadow on the party, which was not dispelled for full five minutes.

Source: Dickens, Charles. 1843. *A Christmas Carol.* Available at: http://www.literature.org/authors/dickens-charles/christmas-carol/index.html

Nathaniel Hawthorne, from "The Birthmark" (1846)

Georgiana is beautiful but flawed by a small, hand-shaped birthmark on her face. Her scientist husband, Aylmer, wants to make her perfect at any cost. Hawthorne's story asks readers to contemplate whether we need to be perfect to be loved and whether our flaws are an essential part of who we are. The excerpt here begins with Aylmer's presentation of the potion he has created to erase Georgina's birthmark.

"Drink, then, thou lofty creature!" exclaimed Aylmer, with fervid admiration. "There is no taint of imperfection on thy spirit. Thy sensible frame, too, shall soon be all perfect!"

She quaffed the liquid, and returned the goblet to his hand.

"It is grateful," said she, with a placid smile. "Methinks it is like water from a heavenly fountain; for it contains I know not what of unobtrusive fragrance and deliciousness. It allays a feverish thirst, that had parched me for many days. Now, dearest, let me sleep. My earthly senses are closing over my spirit, like the leaves around the heart of a rose, at sunset."

She spoke the last words with a gentle reluctance, as if it required almost more energy than she could command to pronounce the faint and lingering syllables. Scarcely had they loitered through her lips, ere she was lost in slumber. Aylmer sat by her side, watching her aspect with the emotions proper to a man, the whole value of whose existence was involved in the process now to be tested. Mingled with this mood, however, was the philosophic investigation, characteristic of the man of science. Not the minutest symptom escaped him. A heightened flush of the cheek—a slight irregularity of breath—a quiver of the eyelid—a hardly perceptible tremor through the frame—such were the details which, as the moments passed, he wrote down in his folio volume. Intense thought had set its stamp upon every previous page of that volume; but the thoughts of years were all concentrated upon the last.

While thus employed, he failed not to gaze often at the fatal Hand, and not without a shudder. Yet once, by a strange and unaccountable impulse, he pressed it with his lips. His spirit recoiled, however, in the very act, and Georgiana, out of the midst of her deep sleep, moved uneasily and murmured, as if in remonstrance. Again, Aylmer resumed his watch. Nor was it without avail. The Crimson Hand, which at first had been strongly visible upon the marble paleness of Georgiana's cheek now grew more faintly outlined. She remained not less pale than ever; but the birthmark, with every breath that came and went, lost somewhat of its former distinctness. Its presence had been awful; its departure was more awful still. Watch the stain of the rainbow fading out of the sky; and you will know how that mysterious symbol passed away.

"By Heaven, it is well nigh gone!" said Aylmer to himself, in almost irrepressible ecstasy. "I can scarcely trace it now. Success! Success! And now it is like the faintest rose-color. The slightest flush of blood across her cheek would overcome it. But she is so pale!"

He drew aside the window-curtain, and suffered the light of natural day to fall into the room, and rest upon her cheek. At the same time, he heard a gross, hoarse chuckle, which he had long known as his servant Aminadab's expression of delight.

"Ah, clod! Ah, earthly mass!" cried Aylmer, laughing in a sort of frenzy. "You have served me well! Master and Spirit—Earth and Heaven—have both done their part in this! Laugh, thing of the senses! You have earned the right to laugh."

These exclamations broke Georgiana's sleep. She slowly unclosed her eyes, and gazed into the mirror, which her husband had arranged for that purpose. A faint smile flitted over her lips, when she recognized how barely perceptible was now that Crimson Hand, which had once blazed forth with such disastrous brilliancy as to scare away all their happiness. But then her eyes sought Aylmer's face, with a trouble and anxiety that he could by no means account for.

"My poor Aylmer!" murmured she.

"Poor? Nay, richest! Happiest! Most favored!" exclaimed he. "My peerless bride, it is successful! You are perfect!"

"My poor Aylmer!" she repeated, with a more than human tenderness. "You have aimed loftily!—you have done nobly! Do not repent, that, with so high and pure a feeling, you have rejected the best the earth could offer. Aylmer—dearest Aylmer—I am dying!"

Alas, it was too true! The fatal Hand had grappled with the mystery of life, and was the bond by which an angelic spirit kept itself in union with a mortal frame. As the last crimson tint of the birth-mark—that sole token of human imperfection—faded from her cheek, the parting breath of the now perfect woman passed into the atmosphere, and her soul, lingering a moment near her husband, took its heavenward flight. Then a hoarse, chuckling laugh was heard again! Thus ever does the gross Fatality of Earth exult in its invariable triumph over the immortal essence, which, in this dim sphere of half-development, demands the completeness of a higher state. Yet, had Aylmer reached a profounder wisdom, he need not thus have flung away the happiness, which would have woven his mortal life of the self-same texture with the celestial. The momentary circumstance was too strong for him; he failed to look beyond the shadowy scope of Time, and living once for all in Eternity, to find the perfect Future in the present.

Source: Hawthorne, Nathaniel. 1937. "The Birthmark." Pearson, Norman Holmes, ed. *The Complete Novels and Selected Tales of Nathaniel Hawthorne.* New York: Random House. (Originally published 1846)

▣ Abraham Lincoln, "My Childhood's Home I See Again" (1846)

In this poem, Lincoln acknowledges his own struggle with severe depression and draws an analogy between his experience of emotional duress and that of a childhood friend, Matthew, who has now become a "madman." Following his imprisonment for threatening harm to his parents, Matthew expresses his isolation *by howling, which solidifies the poet's identification with this outlaw figure.*

My Childhood's Home I See Again

I

My childhood's home I see again,
And sadden with the view;
And still, as memory crowds my brain,
There's pleasure in it too.

O Memory! thou midway world
'Twixt earth and paradise,
Where things decayed and loved ones lost
In dreamy shadows rise,

And, freed from all that's earthly vile,
Seem hallowed, pure, and bright,
Like scenes in some enchanted isle
All bathed in liquid light.

As dusky mountains please the eye
When twilight chases day;
As bugle-tones that, passing by,
In distance die away;

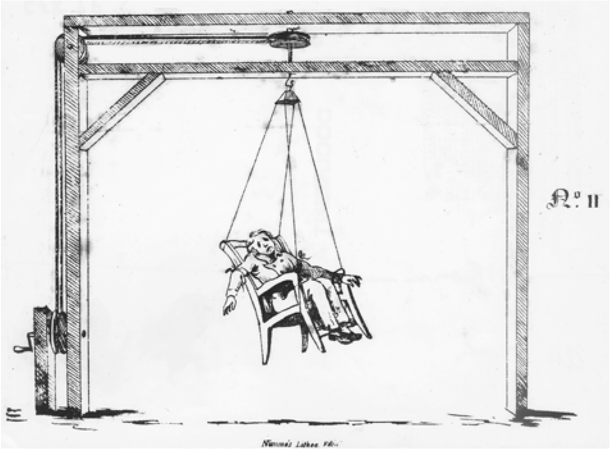
As leaving some grand waterfall,
We, lingering, list its roar—
So memory will hallow all
We've known, but know no more.

Near twenty years have passed away
Since here I bid farewell
To woods and fields, and scenes of play,
And playmates loved so well.

Where many were, but few remain
Of old familiar things;
But seeing them, to mind again
The lost and absent brings.

The friends I left that parting day,
How changed, as time has sped!
Young childhood grown, strong manhood gray,
And half of all are dead.

I hear the loved survivors tell
How nought from death could save,
Till every sound appears a knell,
And every spot a grave.



Rotary Machine for the Treatment of Moral Sufferers. This rotary machine was used in the early nineteenth century for the treatment of those diagnosed as emotionally unbalanced or insane.

Source: Art Resource, New York.

I range the fields with pensive tread,
And pace the hollow rooms,
And feel (companion of the dead)
I'm living in the tombs.

II

But here's an object more of dread
Than ought the grave contains—
A human form with reason fled,
While wretched life remains.

Poor Matthew! Once of genius bright,
A fortune-favored child—
Now locked for aye, in mental night,
A haggard mad-man wild.

Poor Matthew! I have ne'er forgot,
When first, with maddened will,
Yourself you maimed, your father fought,
And mother strove to kill;

When terror spread, and neighbors ran,
Your dange'rous strength to bind;
And soon, a howling crazy man
Your limbs were fast confined.

How then you strove and shrieked aloud,
Your bones and sinews bared;
And fiendish on the gazing crowd,
With burning eye-balls glared—

And begged, and swore, and wept and prayed
With maniac laughter joined—
How fearful were those signs displayed
By pangs that killed thy mind!

And when at length, tho' drear and long,
Time smoothed thy fiercer woes,
How plaintively thy mournful song
Upon the still night rose.

I've heard it oft, as if I dreamed,
Far distant, sweet, and lone—
The funeral dirge, it ever seemed
Of reason dead and gone.

To drink its strains, I've stole away,
All stealthily and still,
Ere yet the rising God of day
Had streaked the Eastern hill.

Air held his breath; trees, with the spell,
Seemed sorrowing angels round,
Whose swelling tears in dew-drops fell
Upon the listening ground.

But this is past; and nought remains,
That raised thee o'er the brute.
Thy piercing shrieks, and soothing strains,
Are like, forever mute.

Now fare thee well—more thou the cause,
Than subject now of woe.
All mental pangs, by time's kind laws,
Hast lost the power to know.

O death! Thou awe-inspiring prince,
That keepst the world in fear;
Why dost thou tear more blest ones hence,
And leave him ling'ring here?

Source: Lincoln, Abraham. 1953. "My Childhood's Home I See Again." Basler, Roy P., Marion Dolores Pratt, and Lloyd A. Dunlap, eds. *The Collected Works of Abraham Lincoln:* Vol. 1. New Brunswick, NJ: Rutgers University Press. (Originally written 1846)

"Phrenology of Tom Thumb" (1846)

In keeping with the nineteenth century's penchant for medical curiosity closets and freak show exhibition as entertainment, the following excerpt discusses the phrenological examination of General Tom Thumb (phrenologists purported to be able to "read" a person's mental abilities and character by means of the shape of the skull). Tom Thumb, who was born Charles S. Stratton in 1838, became one of P. T. Barnum's main exhibits at the age of four and was named after a character in a Grimm's fairy tale "who was in all his limbs, but no longer than a thumb."

The head of General Tom Thumb has been examined by Mr. Straton, who reports of it that the size of the brain is the smallest recorded of one capable of sane and somewhat vigorous mental manifestation.

"As regards the balance of the different parts of the head, 'General Tom Thumb' is a very favorable specimen in most particulars. The anterior and coronal regions are slightly below an equal balance, the posterior is slightly above. Some of the individual organs present slight deviations from the equal balance. In the anterior region, individuality, form, size, weight, locality, and eventuality, especially the last, are the largest organs. Cautiousness is conspicuous in the lateral aspect. The cerebellum seems to be very small, as defective indeed as I have ever seen it in an infant of six months. In this particular the 'general' is a very remarkable case against the doctrine held by some, that the cerebellum is connected with the regulation of muscular action; for, if there be any one thing more than another, for which he can be said to be remarkable, apart from his diminutive size and fine proportions, it is his control over muscular action. In his representations of the Grecian statues, Napoleon, Frederick the Great, the English gentleman, the Highland chieftain, &c., the rapidity with which he can change his posture, and the accuracy with which he can imitate the actions and attitudes—so far as mere muscular action is concerned—of the objects represented, are regarded as very remarkable. His intellectual acquirements are said to be *very* limited as yet. It will be extremely important to note his progress in this particular. It is to be hoped that phrenologists who happen to meet with the 'general' will endeavor to inform themselves as *accurately* as possible regarding his progress and proficiency in intellectual pursuits, and report from time to time. His muscular system has attained a degree of firmness, strength, and maturity, quite equal to, or rather beyond, the average of his age. It is legitimate to presume that the brain is matured in a corresponding degree. His health is said to be excellent. 'General Tom Thumb' is, then, I repeat, a case of unusual interest to the phrenological world. He affords the extremely rare opportunity of solving one question in the great problem: What amount of manifestation is a well-balanced and healthy head of a given size capable of? The 'general' is certainly very near, if he does not actually touch, the extreme lowest point on the scale of size. What, then, is a head of 66 or a brain of 40 cubic inches capable of attaining in his circumstances!"—*Critic.*

Source: "Phrenology of Tom Thumb." 1846. *Littell's Living Age,* October 31. Available at: http://www.disabilitymuseum.org/lib/docs/2004.htm?page=print

Charlotte Brontë, from *Jane Eyre* (1847)

In Brontë's novel, Jane Eyre and Edward Rochester are in love, but Rochester is not free to marry because he is already married to Bertha, a madwoman he keeps locked in the attic of his manor; upon learning of the situation, Jane leaves. In this excerpt from late in the novel, she is reunited with Rochester only to find that he has been blinded in the fire started by his suicidal wife. Now that Bertha is dead, Jane and Rochester may live together, but the impediment of madness has been replaced by that of blindness.

From Chapter 36

"Poor Mr. Edward!" he ejaculated, "I little thought ever to have seen it! Some say it was a just judgment on him for keeping his first marriage secret, and wanting to take another wife while he had one living: but I pity him, for my part."

"You said he was alive?" I exclaimed.

"Yes, yes: he is alive; but many think he had better be dead."

"Why? How?" My blood was again running cold. "Where is he?" I demanded. "Is he in England?"

"Ay—ay—he's in England; he can't get out of England, I fancy—he's a fixture now."

What agony was this! And the man seemed resolved to protract it.

"He is stone-blind," he said at last. "Yes, he is stone-blind, is Mr. Edward."

I had dreaded worse. I had dreaded he was mad. I summoned strength to ask what had caused this calamity.

"It was all his own courage, and a body may say, his kindness, in a way, ma'am: he wouldn't leave the house till every one else was out before him. As he came down the great staircase at last, after Mrs. Rochester had flung herself from the battlements, there was a great crash—all fell. He was taken out from under the ruins, alive, but sadly hurt: a beam had fallen in such a way as to protect him partly; but one eye was knocked out, and one hand so crushed that Mr. Carter, the surgeon, had to amputate it directly. The other eye inflamed: he lost the sight of that also. He is now helpless, indeed—blind and a cripple."

"Where is he? Where does he now live?"

"At Ferndean, a manor-house on a farm he has, about thirty miles off: quite a desolate spot."

"Who is with him?"

"Old John and his wife: he would have none else. He is quite broken down, they say."

"Have you any sort of conveyance?"

"We have a chaise, ma'am, a very handsome chaise."

"Let it be got ready instantly; and if your post-boy can drive me to Ferndean before dark this day, I'll pay both you and him twice the hire you usually demand."

From Chapter 37

The manor-house of Ferndean was a building of considerable antiquity, moderate size, and no architectural pretensions, deep buried in a wood. I had heard of it before. Mr. Rochester often spoke of it, and sometimes went there. His father had purchased the estate for the sake of the game covers. He would have let the house, but could find no tenant, in consequence of its ineligible and insalubrious site. Ferndean then remained uninhabited and unfurnished, with the exception of some two or three rooms fitted up for the accommodation of the squire when he went there in the season to shoot.

To this house I came just ere dark on an evening marked by the characteristics of sad sky, cold gale, and continued small penetrating rain. The last mile I performed on foot, having dismissed the chaise and driver with the double remuneration I had promised. Even when within a very short distance of the manor-house, you could see nothing of it, so thick and dark grew the timber of the gloomy wood about it. Iron gates between granite pillars showed me where to enter, and passing through them, I found myself at once in the twilight of close-ranked trees. There was a grass-grown track descending the forest aisle between hoar and knotty shafts and under branched arches. I followed it, expecting soon to reach the dwelling; but it stretched on and on, it wound far and farther: no sign of habitation or grounds was visible.

I thought I had taken a wrong direction and lost my way. The darkness of natural as well as of sylvan dusk gathered over me. I looked round in search of another road. There was none: all was interwoven stem, columnar trunk, dense summer foliage—no opening anywhere.

I proceeded: at last my way opened, the trees thinned a little; presently I beheld a railing, then the house—scarce, by this dim light, distinguishable from the trees; so dank and green were its decaying walls. Entering a portal, fastened only by a latch, I stood amidst a space of enclosed ground, from which the wood swept away in a semicircle. There were no flowers, no garden-beds; only a broad gravel-walk girdling a grass-plat, and this set in the heavy frame of the forest. The house presented two pointed gables in its front; the windows were latticed and narrow: the front door was narrow too, one step led up to it. The whole looked, as the host of the Rochester Arms had said, "quite a desolate spot." It was as still as a church on a week-day: the pattering rain on the forest leaves was the only sound audible in its vicinage.

"Can there be life here?" I asked.

Yes, life of some kind there was; for I heard a movement—that narrow front-door was unclosing, and some shape was about to issue from the grange.

It opened slowly: a figure came out into the twilight and stood on the step; a man without a hat: he stretched forth his hand as if to feel whether it rained. Dusk as it was, I had recognised him—it was my master, Edward Fairfax Rochester, and no other.

I stayed my step, almost my breath, and stood to watch him—to examine him, myself unseen, and alas! to him invisible. It was a sudden meeting, and one in which rapture was kept well in check by pain. I had no difficulty in restraining my voice from exclamation, my step from hasty advance.

His form was of the same strong and stalwart contour as ever: his port was still erect, his hair was still raven black; nor were his features altered or sunk: not in one year's space, by any sorrow, could his athletic strength be quelled or his vigorous prime blighted. But in his countenance I saw a change: that looked desperate and brooding—that reminded me of some wronged and fettered wild beast or bird, dangerous to approach in his sullen woe. The caged eagle, whose gold-ringed eyes cruelty has extinguished, might look as looked that sightless Samson.

And, reader, do you think I feared him in his blind ferocity?—if you do, you little know me. A soft hope blest with my sorrow that soon I should dare to drop a kiss on that brow of rock, and on those lips so sternly sealed beneath it: but not yet. I would not accost him yet.

He descended the one step, and advanced slowly and gropingly towards the grass-plat. Where was his daring stride now? Then he paused, as if he knew not which way to turn. He lifted his hand and opened his eyelids; gazed blank, and with a straining effort, on the sky, and toward the amphitheatre of trees: one saw that all to him was void darkness. He stretched his right hand (the left arm, the mutilated one, he kept hidden in his bosom); he seemed to wish by touch to gain an idea of what lay around him: he met but vacancy still; for the trees were some yards off where he stood. He relinquished the endeavour, folded his arms, and stood quiet and mute in the rain, now falling fast on his uncovered head. At this moment John approached him from some quarter.

"Will you take my arm, sir?" he said; "there is a heavy shower coming on: had you not better go in?"

"Let me alone," was the answer.

John withdrew without having observed me. Mr. Rochester now tried to walk about: vainly,—all was too uncertain. He groped his way back to the house, and, re-entering it, closed the door.

I now drew near and knocked: John's wife opened for me. "Mary," I said, "how are you?"

She started as if she had seen a ghost: I calmed her. To her hurried "Is it really you, miss, come at this late hour to this lonely place?" I answered by taking her hand; and then I followed her into the kitchen, where John now sat by a good fire. I explained to them, in few words, that I had heard all which had happened since I left Thornfield, and that I was come to see Mr. Rochester. I asked John to go down to the turnpike-house, where I had dismissed the chaise, and bring my trunk, which I had left there: and then, while I removed my bonnet and shawl, I questioned Mary as to whether I could be accommodated at the Manor House for the night; and finding that arrangements to that effect, though difficult, would not be impossible, I informed her I should stay. Just at this moment the parlour-bell rang.

"When you go in," said I, "tell your master that a person wishes to speak to him, but do not give my name."

"I don't think he will see you," she answered; "he refuses everybody."

When she returned, I inquired what he had said. "You are to send in your name and your business," she replied. She then proceeded to fill a glass with water, and place it on a tray, together with candles.

"Is that what he rang for?" I asked.

"Yes: he always has candles brought in at dark, though he is blind."

"Give the tray to me; I will carry it in."

I took it from her hand: she pointed me out the parlour door. The tray shook as I held it; the water spilt from the glass; my heart struck my ribs loud and fast. Mary opened the door for me, and shut it behind me.

This parlour looked gloomy: a neglected handful of fire burnt low in the grate; and, leaning over it, with his head supported against the high, old-fashioned mantelpiece, appeared the blind tenant of the room. His old dog, Pilot, lay on one side, removed out of the way, and coiled up as if afraid of being inadvertently trodden upon. Pilot pricked up his ears when I came in: then he jumped up with a yelp and a whine, and bounded towards me: he almost knocked the tray from my hands. I set it on the table; then patted him, and said softly, "Lie down!" Mr. Rochester turned mechanically to SEE what the commotion was: but as he SAW nothing, he returned and sighed.

"Give me the water, Mary," he said.

I approached him with the now only half-filled glass; Pilot followed me, still excited.

"What is the matter?" he inquired.

"Down, Pilot!" I again said. He checked the water on its way to his lips, and seemed to listen: he drank, and put the glass down. "This is you, Mary, is it not?"

"Mary is in the kitchen," I answered.

He put out his hand with a quick gesture, but not seeing where I stood, he did not touch me. "Who is this? Who is this?" he demanded, trying, as it seemed, to SEE with those sightless eyes—unavailing and distressing attempt! "Answer me—speak again!" he ordered, imperiously and aloud.

"Will you have a little more water, sir? I spilt half of what was in the glass," I said.

"WHO is it? WHAT is it? Who speaks?"

"Pilot knows me, and John and Mary know I am here. I came only this evening," I answered.

"Great God!—what delusion has come over me? What sweet madness has seized me?"

"No delusion—no madness: your mind, sir, is too strong for delusion, your health too sound for frenzy."

"And where is the speaker? Is it only a voice? Oh! I CANNOT see, but I must feel, or my heart will stop and my brain burst. Whatever—whoever you are—be perceptible to the touch or I cannot live!"

He groped; I arrested his wandering hand, and prisoned it in both mine.

"Her very fingers!" he cried; "her small, slight fingers! If so there must be more of her."

The muscular hand broke from my custody; my arm was seized, my shoulder—neck—waist—I was entwined and gathered to him.

"Is it Jane? WHAT is it? This is her shape—this is her size—"

"And this her voice," I added. "She is all here: her heart, too. God bless you, sir! I am glad to be so near you again."

"Jane Eyre!—Jane Eyre," was all he said.

"My dear master," I answered, "I am Jane Eyre: I have found you out—I am come back to you."

"In truth?—in the flesh? My living Jane?"

"You touch me, sir,—you hold me, and fast enough: I am not cold like a corpse, nor vacant like air, am I?"

"My living darling! These are certainly her limbs, and these her features; but I cannot be so blest, after all my misery. It is a dream; such dreams as I have had at night when I have clasped her once more to my heart, as I do now; and kissed her, as thus—and felt that she loved me, and trusted that she would not leave me."

"Which I never will, sir, from this day."

"Never will, says the vision? But I always woke and found it an empty mockery; and I was desolate and abandoned—my life dark, lonely, hopeless—my soul athirst and forbidden to drink—my heart famished and never to be fed. Gentle, soft dream, nestling in my arms now, you will fly, too, as your sisters have all fled before you: but kiss me before you go—embrace me, Jane."

"There, sir—and there!"

I pressed my lips to his once brilliant and now rayless eyes—I swept his hair from his brow, and kissed that too. He suddenly seemed to arouse himself: the conviction of the reality of all this seized him.

"It is you—is it, Jane? You are come back to me then?"

"I am."

"And you do not lie dead in some ditch under some stream? And you are not a pining outcast amongst strangers?"

"No, sir! I am an independent woman now."

"Independent! What do you mean, Jane?"

"My uncle in Madeira is dead, and he left me five thousand pounds."

"Ah! this is practical—this is real!" he cried: "I should never dream that. Besides, there is that peculiar voice of hers, so animating and piquant, as well as soft: it cheers my withered heart; it puts life into it.—What, Janet! Are you an independent woman? A rich woman?"

"If you won't let me live with you, I can build a house of my own close up to your door, and you may come and sit in my parlour when you want company of an evening."

"But as you are rich, Jane, you have now, no doubt, friends who will look after you, and not suffer you to devote yourself to a blind lamenter like me?"

"I told you I am independent, sir, as well as rich: I am my own mistress."

Source: Brontë, Charlotte. 1847. *Jane Eyre.* Available at: http://www.online-literature.com/brontec/janeeyre/

▣ Samuel Gridley Howe, "Report Made to the Legislature of Massachusetts upon Idiocy" (1848)

Howe's report to the Massachusetts legislature on the prevalence and condition of those labeled "idiots" led to the establishment of the first U.S. training school for the feebleminded. The training school was attached to the Perkins Institute for the Blind on a grant of $2,500 per annum for three years. In the narrative, Howe relies on the theory of idiocy advanced by Edouard Seguin, which views idiocy as based on a failed or severely diminished will (self-control).

To His Excellency, GEORGE N. BRIGGS, *Governor of the Commonwealth of Massachusetts:*

SIR: The undersigned, commissioners appointed by your excellency, under the act of April 11, 1846, "to inquire into the condition of the Idiots of the Commonwealth, to ascertain their number, and whether anything can be done in their behalf," respectfully as follows:—

REPORT:

When we accepted the task assigned to us, it was not without a sense of its importance. We did not look upon idiocy as a thing which concerned only the hundred or thousand unfortunate creatures in this generation who are stunted or blighted by it; for even if means could be found of raising all the idiots now within our borders from their brutishness, and alleviating their suffering, the work would have to be done over again, because the next generation would be burdened with an equal number of them. Such means would only cut off the outward cancer, and leave the vicious sources of it in the system. We regarded idiocy as a diseased excrescence of society; as an outward sign of an inward malady. It was hard to believe it to be in the order of Providence that the earth should always be encumbered with so many creatures in the human shape, but without the light of human reason. It seemed impious to attribute to the Creator any such glaring imperfection in his handiwork. It appeared to us certain that the existence of so many idiots in every generation *must* be the consequence of some violation of the *natural laws;*—that where there was so much suffering, there must have been sin. We resolved, therefore, to seek for the *sources* of the evil, as well as to gauge the depth and extent of the misery. It was to be expected that the search would oblige us to witness painful scenes, not only of misfortunes and sufferings, but of deformities and infirmities, the consequences of ignorance, vice, and depravity. The subjects of them, however, were brethren of the human family; the end proposed was not only to relieve their sufferings, and improve their condition; but, if possible, to lessen such evils in coming generations; the task, therefore, was not to be shrunk from, however repulsive and painful was its contemplation.

It is to be confessed, however, that we have been painfully disappointed by the sad reality, for the numbers of beings originally made in God's image, but now sunk in utter brutishness, is fearfully great, even beyond anything that had been anticipated.

The examination of their physical condition forces one into scenes, from the contemplation of which the mind and the senses instinctively revolt.

In searching for the causes of this wretchedness in the condition and habits of the progenitors of the sufferers, there is found a degree of physical deterioration, and of mental and moral darkness, which will hardly be credited.

We would fain be spared any relation of what has been witnessed, as well for our own sake, as for the tastes and feelings of others, which must be shocked by the recital of it. It would be pleasanter simply to recommend such measures as would tend to remove the present evils, and prevent their recurrence. But this may not be. Evils cannot be grappled with, and overcome, unless their nature and extent are fully known.

Besides, our duty was not only to examine into, but to report upon, the *condition* of the idiots in our Commonwealth; and that duty must be done.

During the year 1846, we endeavored, by means of circular letters addressed to the town clerks, and to other persons in every town of the Commonwealth, to ascertain the number, and, as far as could be, the condition of the idiots in their respective neighborhoods.

The answers obtained to most of these inquiries were, in many cases, very vague and unsatisfactory. It was soon seen that little dependence could be placed upon information so obtained, even as to numbers, much less, as to the condition and wants of the idiots. We, therefore, visited as many towns as possible, and endeavored, by personal observation and by inquiries, to gather all the information in our power, respecting the numbers, condition, and treatment of the unfortunate objects of our inquiry, whether they were in the public almshouses or at private charge.

It was not possible, however, to obtain all the desired information, because the researches were begun too late in the season, and because the subject grew in importance and in dreadful interest, the more closely it was examined.

The imperfect results of these inquiries were embodied in a report, made March 13th, 1847, and printed by order of the legislature.

Being directed to continue these labors, the painful inquiry was resumed during the last summer.

By diligent and careful inquiries in nearly one hundred towns in different parts of the State, we have ascertained the existence, and examined the condition, of *five hundred and seventy-four* human beings who are condemned to hopeless idiocy, who are considered and treated as idiots by their neighbors, and left to their own brutishness. They are also idiotic in a legal sense; that is, they are regarded as incapable of entering into contracts, and are irresponsible for their actions, although some of them would not be considered as idiots according to the definition of idiocy by medical writers. There are a few cases where insanity has terminated in total *dementia.* There are others where the sufferers seemed to have had all their faculties in youth, and to have gradually lost them, not by insanity but by unknown causes. Excluding such cases, there are four hundred and twenty persons who are to be regarded as truly idiots.

These are found in 77 towns. But of these towns only 63 were thoroughly examined. These contain an aggregate population of 183,942; among which were found 361 idiots, exclusive of insane persons. Now if the other parts of the State contain the same proportion of idiots to their whole population, the total number in the Commonwealth is *between twelve and fifteen hundred!*

This is a fearful number, and it may seem to others, as it did at first to us, to be incredible. It is far greater than any calculation based upon previous returns to the legislature by commissions appointed to ascertain the number of lunatics and idiots, or that number of idiots set down in the pauper abstract, published by the secretary of state, as supported or relieved by the towns. That document makes the number to be only 377; whereas, if our observations are correct, and the other towns in the State furnish a proportionate number of pauper idiots, then the whole number in the State of that class should be over 500. It is probable, however, that the overseers of the poor, in making their return, gave only the number of idiots in almshouses, and overlooked many who receive aid from the towns at their own houses. When a poor woman applies for aid, they do not go to inquire whether any of her children are idiotic or not; whereas we pursued our inquiries into the families, and found many idiots there. However, without any reference to the manner in which other returns have been made, or any question about the degree of care which was observed, by those who made them, to distinguish between idiots and lunatics, it seems certain that our own return is a very near approach to the truth. Indeed, if there be any material error, it must be of omission, for our calculation is not based upon vague reports or answers returned to circulars. We have examined almost every case personally or by an agent on whom dependence could be placed, and in a few only have relied upon other sources of information which seemed unquestionable.

There is yet another mode by which to try the correctness of these conclusions. The returns made to us in 1846, by the town clerks in 119 towns, containing an aggregate population of 213,993 inhabitants, give the names of 394 persons who are considered by them as idiots. If to these are added 361 idiots proper, found in 1847, in 63 other towns, containing an aggregate population of 178,693,—they make a total of 182 towns, and an aggregate of 392,586 inhabitants, among whom are found 755 idiots. In this ratio, the number in the State would be over 1300, even considering the population as no greater than it was in 1840, and supposing that the number in the towns that give imperfect returns, is even as great as in those that were thoroughly examined.

We make our report, therefore, of the number of idiots in the towns examined, with entire confidence that it is not too high; and conclude, moreover, that if the other parts of the Commonwealth furnish an equal number, there are over twelve hundred persons within the State who are considered and treated as idiots. This, it will be observed, is even a greater number than was supposed to exist, when the partial report of last year was made.

The same thing has been experienced, in estimates made of the number of the insane. When attention was first turned to the subject, the number reported was supposed to be altogether an exaggeration; yet every succeeding examination has shown that the number is greater than that given by the preceding ones.

Over four hundred idiots have been minutely inspected by us personally, or by an agent upon whom we can rely. Upon the bodily and mental condition of these will be based our remarks and conclusions.

In an appendix will be found their names, ages, physical condition, and mental and moral character. It may seem to some, who inspect the tables, that they contain many trivial details with regard to the physical condition of the persons named; but it is hard to be too minute in these statements. The whole subject of idiocy is new. Science has not yet thrown her certain light upon its remote, or even its proximate causes. There is little doubt, however, that they are to be found in the CONDITION OF THE BODILY ORGANIZATION. The size and shape of the head, therefore; the proportionate development of its different parts; the condition of the nervous system; the temperament; the activity of the various functions; the development of the great cavities;—the chest and abdomen; the stature,—the weight,—every peculiarity, in short, that can be noted in a great number of individuals, may be valuable to future observers. We contribute our own observations to the store of facts, out of which science may, by and by, deduce general laws. If any bodily peculiarities, however minute, always accompany peculiar mental conditions, they become important; they are the finger-marks of the Creator, by which we learn to read his works.

There are yet more subtle causes of idiocy existing in the bodily organization, and derived from the action of that mysterious, but inevitable law, by which Nature, outraged in the persons of the parents, exacts her penalty from the persons of their children. We have endeavored to throw some light upon this also; or rather, to give a number of detached luminous points; trusting that more accurate observers will furnish many others, until all the dark surface shall be made bright, and the whole subject become clear.

The tables have been made with great care; and though they cannot pretend to perfect accuracy, they are recommended to the physiologist and student of nature, as furnishing humble, but important data.

With these introductory remarks, we proceed with our report.

Definition of Terms. Idiots. Idiocy

A difficulty is met, at the very outset, in the want of terms which clearly explain and define themselves.

Our commission is to examine into the condition of idiots. What is an idiot?—*A being in the human form, but utterly devoid of sense and understanding?* If so, then our report would be brief. Very few such have been found. Creatures are sometimes born of women, who are utterly wanting in the corporeal instruments by which understanding is most immediately manifested,—monsters without heads; but Nature lets none such cumber the earth; they come into life only to die; they take one short step from birth to death. A few seem to possess a brain and nervous system, but in such an abnormal condition as will not suffice even for command of muscular motion. Such creatures have only organic life. All other beings in human shape, manifest *some* sense and understanding.

Source: Howe, Samuel Gridley. 1848. "Report Made to the Legislature of Massachusetts upon Idiocy." Available at: http://www.personal.dundee.ac.uk/~mksimpso/howe3.htm

Nathaniel Hawthorne, from *The Scarlet Letter* (1850)

In this description of Roger Chillingworth, the vengeful estranged husband of Hester Prynne, Hawthorne draws a twisted, asymmetrical body. The man's internal emotional turmoil, Hawthorne implies, may not be expressed as outright rage, but its effect appears nonetheless, inevitably, as physical deformity. The reader is meant to perceive menace in the man's tics and uneven stance.

He was small in stature, with a furrowed visage which, as yet, could hardly be termed aged. There was a remarkable intelligence in his features, as of a person who had so cultivated his mental part that it could not fail to mould the physical to itself, and become manifest by unmistakable tokens. Although, by a seemingly careless arrangement of his heterogeneous garb, he had endeavored to conceal or abate the peculiarity, it was sufficiently evident to Hester Prynne that one of this man's shoulders rose higher than the other. Again, at this first instant of perceiving that thin visage and the slight deformity of the figure, she pressed her infant to her bosom with so compulsive a force that the poor babe uttered another cry of pain. But the mother did not seem to hear it.

At his arrival in the marketplace, and some time before she saw him, the stranger had bent his eyes on Hester Prynne. It was carelessly, at first, like a man chiefly accustomed to look inward, and to whom external matters are of little value and import unless they bear relation to something within his mind. Very soon, however, his look became keen and penetrative. A writhing horror twisted itself across his features, like a snake gliding swiftly over them, and making one little pause, with all its wreathed intervolutions in open sight. His face darkened with some powerful emotion, which, nevertheless, he so instantaneously controlled by an effort of his will, that, save a single moment, its expression might have passed for calmness. After a brief space, the convulsion grew almost imperceptible, and finally subsided into the depths of nature. When he found the eyes of Hester Prynne fastened on his own, and saw that she appeared to recognize him, he slowly and calmly raised his finger, made a gesture with it in the air, and laid it on his lips.

Source: Hawthorne, Nathaniel. 1850. *The Scarlet Letter.* Available at: www.online-literature.com/ hawthorne/scarletletter/

King Lear and the Fool in the Storm *(1836), by Louis Boulanger (1806–1867). In Shakespeare's* King Lear, *the fool functions as the one character in the play allowed to critique the king's decisions openly. His challenge to authority is allowed because he is viewed as mentally unstable and therefore does not pose a threat to traditional lines of authority. However, in the scene depicted here, Lear joins in the fool's fun-making at his own expense for a time before threatening to whip the fool for his audacity.*

Source: Art Resource, New York.

Edgar Allan Poe, "Hop-Frog" (1850)

Poe's tale creates such sympathy for the disabled jester that readers may forgive the act of revenge directed against the mean-spirited monarch he serves. Poe uses the jester's point of view to criticize society but also exposes the violence often underlying jokes, in particular the ridicule directed toward people who are different.

I never knew anyone so keenly alive to a joke as the king was. He seemed to live only for joking. To tell a good story of the joke kind, and to tell it well, was the surest road to his favor. Thus it happened that his seven ministers were all noted for their accomplishments as jokers. They all took after the king, too, in being large, corpulent, oily men, as well as inimitable jokers. Whether people grow fat by joking, or whether there is something in fat itself which predisposes to a joke, I have never been quite able to determine; but certain it is that a lean joker is a rara avis in terris.

About the refinements, or, as he called them, the 'ghost' of wit, the king troubled himself very little. He had an especial admiration for breadth in a jest, and would often put up with length, for the sake of it. Over-niceties wearied him. He would have preferred Rabelais' 'Gargantua' to the 'Zadig' of Voltaire: and, upon the whole, practical jokes suited his taste far better than verbal ones.

At the date of my narrative, professing jesters had not altogether gone out of fashion at court. Several of the great continental 'powers' still retain their 'fools,' who wore motley, with caps and bells, and who were expected to be always ready with sharp witticisms, at a moment's notice, in consideration of the crumbs that fell from the royal table.

Our king, as a matter of course, retained his 'fool.' The fact is, he required something in the way of folly—if only to counterbalance the heavy wisdom of the seven wise men who were his ministers—not to mention himself.

His fool, or professional jester, was not only a fool, however. His value was trebled in the eyes of the king, by the fact of his being also a dwarf and a cripple. Dwarfs were as common at court, in those days, as fools; and many monarchs would have found it difficult to get through their days (days are rather longer at court than elsewhere) without both a jester to laugh with, and a dwarf to laugh at. But, as I have already observed, your jesters, in ninety-nine cases out of a hundred, are fat, round, and unwieldy—so that it was no small source of self-gratulation with our king that, in Hop-Frog (this was the fool's name), he possessed a triplicate treasure in one person.

I believe the name 'Hop-Frog' was not that given to the dwarf by his sponsors at baptism, but it was conferred upon him, by general consent of the several ministers, on account of his inability to walk as other men do. In fact, Hop-Frog could only get along by a sort of interjectional gait—something between a leap and a wriggle—a movement that afforded illimitable amusement, and of course consolation, to the king, for (notwithstanding the protuberance of his stomach and a constitutional swelling of the head) the king, by his whole court, was accounted a capital figure.

But although Hop-Frog, through the distortion of his legs, could move only with great pain and difficulty along a road or floor, the prodigious muscular power which nature seemed to have bestowed upon his arms, by way of compensation for deficiency in the lower limbs, enabled him to perform many feats of wonderful dexterity, where trees or ropes were in question, or any thing else to climb. At such exercises he certainly much more resembled a squirrel, or a small monkey, than a frog.

I am not able to say, with precision, from what country Hop-Frog originally came. It was from some barbarous region, however, that no person ever heard of—a vast distance from the court of our king. Hop-Frog, and a young girl very little less dwarfish than himself (although of exquisite proportions, and a marvellous dancer), had been forcibly carried off from their respective homes in adjoining provinces, and sent as presents to the king, by one of his ever-victorious generals.

Under these circumstances, it is not to be wondered at that a close intimacy arose between the two little captives. Indeed, they soon became sworn friends. Hop-Frog, who, although he made a great deal of sport, was by no means popular, had it not in his power to render Trippetta many services; but she, on account of her grace and exquisite beauty (although a dwarf), was universally admired and petted; so she possessed much influence; and never failed to use it, whenever she could, for the benefit of Hop-Frog.

On some grand state occasion—I forgot what—the king determined to have a masquerade, and whenever a masquerade or any thing of that kind, occurred at our court, then the talents, both of Hop-Frog and Trippetta were sure to be called into play. Hop-Frog, in especial, was so inventive in the way of getting up pageants, suggesting novel characters, and arranging costumes, for masked balls, that nothing could be done, it seems, without his assistance.

The night appointed for the fete had arrived. A gorgeous hall had been fitted up, under Trippetta's eye, with every kind of device which could possibly give eclat to a masquerade. The whole court was in a fever of expectation. As for costumes and characters, it might well be supposed that everybody had come to a decision on such points. Many had made up their minds (as to what roles they should assume) a week, or even a month, in advance; and, in fact, there was not a particle of indecision anywhere—except in the case of the king and his seven ministers. Why they hesitated I never could tell, unless they did it by way of a joke. More probably, they found it difficult, on account of being so fat, to make up their minds. At all events, time flew; and, as a last resort they sent for Trippetta and Hop-Frog.

When the two little friends obeyed the summons of the king they found him sitting at his wine with the seven members of his cabinet council; but the monarch appeared to be in a very ill humor. He knew that Hop-Frog was not fond of wine, for it excited the poor cripple almost to madness; and madness is no comfortable feeling. But the king loved his practical jokes, and took pleasure in forcing Hop-Frog to drink and (as the king called it) 'to be merry.'

"Come here, Hop-Frog," said he, as the jester and his friend entered the room; "swallow this bumper to the health of your absent friends, (here Hop-Frog sighed,) and then let us have the benefit of your invention. We want characters—characters, man—something novel—out of the way. We are wearied with this everlasting sameness. Come, drink! the wine will brighten your wits."

Hop-Frog endeavored, as usual, to get up a jest in reply to these advances from the king; but the effort was too much. It happened to be the poor dwarf's birthday, and the command to drink to his 'absent friends' forced the tears to his eyes. Many large, bitter drops fell into the goblet as he took it, humbly, from the hand of the tyrant.

"Ah! ha! ha!" roared the latter, as the dwarf reluctantly drained the beaker.—"See what a glass of good wine can do! Why, your eyes are shining already!"

Poor fellow! his large eyes gleamed, rather than shone; for the effect of wine on his excitable brain was not more powerful than instantaneous. He placed the goblet nervously on the table, and looked round upon the company with a half-insane stare. They all seemed highly amused at the success of the king's 'joke.'

"And now to business," said the prime minister, a very fat man.

"Yes," said the King; "Come lend us your assistance. Characters, my fine fellow; we stand in need of characters—all of us—ha! ha! ha!" and as this was seriously meant for a joke, his laugh was chorused by the seven.

Hop-Frog also laughed although feebly and somewhat vacantly.

"Come, come," said the king, impatiently, "have you nothing to suggest?"

"I am endeavoring to think of something novel," replied the dwarf, abstractedly, for he was quite bewildered by the wine.

"Endeavoring!" cried the tyrant, fiercely; "what do you mean by that? Ah, I perceive. You are Sulky, and want more wine. Here, drink this!" and he poured out another goblet full and offered it to the cripple, who merely gazed at it, gasping for breath.

"Drink, I say!" shouted the monster, "or by the fiends—"

The dwarf hesitated. The king grew purple with rage. The courtiers smirked. Trippetta, pale as a corpse, advanced to the monarch's seat, and, falling on her knees before him, implored him to spare her friend.

The tyrant regarded her, for some moments, in evident wonder at her audacity. He seemed quite at a loss what to do or say—how most becomingly to express his indignation. At last, without uttering a syllable, he pushed her violently from him, and threw the contents of the brimming goblet in her face.

The poor girl got up the best she could, and, not daring even to sigh, resumed her position at the foot of the table.

There was a dead silence for about half a minute, during which the falling of a leaf, or of a feather, might have been heard. It was interrupted by a low, but harsh and protracted grating sound which seemed to come at once from every corner of the room.

"What—what—what are you making that noise for?" demanded the king, turning furiously to the dwarf.

The latter seemed to have recovered, in great measure, from his intoxication, and looking fixedly but quietly into the tyrant's face, merely ejaculated:

"I—I? How could it have been me?"

"The sound appeared to come from without," observed one of the courtiers. "I fancy it was the parrot at the window, whetting his bill upon his cage-wires."

"True," replied the monarch, as if much relieved by the suggestion; "but, on the honor of a knight, I could have sworn that it was the gritting of this vagabond's teeth."

Hereupon the dwarf laughed (the king was too confirmed a joker to object to any one's laughing), and displayed a set of large, powerful, and very repulsive teeth. Moreover, he avowed his perfect willingness to swallow as much wine as desired. The monarch was pacified; and having drained another bumper with no very perceptible ill effect, Hop-Frog entered at once, and with spirit, into the plans for the masquerade.

"I cannot tell what was the association of idea," observed he, very tranquilly, and as if he had never tasted wine in his life, "but just after your majesty, had struck the girl and thrown the wine in her face—just after your majesty had done this, and while the parrot was making that odd noise outside the window, there came into my mind a capital diversion—one of my own country frolics—often enacted among us, at our masquerades: but here it will be new altogether. Unfortunately, however, it requires a company of eight persons and—"

"Here we are!" cried the king, laughing at his acute discovery of the coincidence; "eight to a fraction—I and my seven ministers. Come! what is the diversion?"

"We call it," replied the cripple, "the Eight Chained Ourang-Outangs, and it really is excellent sport if well enacted."

"We will enact it," remarked the king, drawing himself up, and lowering his eyelids.

"The beauty of the game," continued Hop-Frog, "lies in the fright it occasions among the women."

"Capital!" roared in chorus the monarch and his ministry.

"I will equip you as ourang-outangs," proceeded the dwarf; "leave all that to me. The resemblance shall be so striking, that the company of masqueraders will take you for real beasts—and of course, they will be as much terrified as astonished."

"Oh, this is exquisite!" exclaimed the king. "Hop-Frog! I will make a man of you."

"The chains are for the purpose of increasing the confusion by their jangling. You are supposed to have escaped, en masse, from your keepers. Your majesty cannot conceive the effect produced, at a masquerade, by eight chained ourang-outangs, imagined to be real ones by most of the company; and rushing in with savage cries, among the crowd of delicately and gorgeously habited men and women. The contrast is inimitable!"

"It must be," said the king: and the council arose hurriedly (as it was growing late), to put in execution the scheme of Hop-Frog.

His mode of equipping the party as ourang-outangs was very simple, but effective enough for his purposes. The animals in question had, at the epoch of my story, very rarely been seen in any part of the civilized world; and as the imitations made by the dwarf were sufficiently beast-like and more than sufficiently hideous, their truthfulness to nature was thus thought to be secured.

The king and his ministers were first encased in tight-fitting stockinet shirts and drawers. They were then saturated with tar. At this stage of the process, some one of the party suggested feathers; but the suggestion was at once overruled by the dwarf, who soon convinced the eight, by ocular demonstration, that the hair of such a brute as the ourang-outang was much more efficiently represented by flax. A thick coating of the latter was accordingly plastered upon the coating of tar. A long chain was now procured. First, it was passed about the waist of the king, and tied, then about another of the party, and also tied; then about all successively, in the same manner. When this chaining arrangement was complete, and the party stood as far apart from each other as possible, they formed a circle; and to make all things appear natural, Hop-Frog passed the residue of the chain in two diameters, at right angles, across the circle, after the fashion adopted, at the present day, by those who capture Chimpanzees, or other large apes, in Borneo.

The grand saloon in which the masquerade was to take place, was a circular room, very lofty, and receiving the light of the sun only through a single window at top. At night (the season for which the apartment was especially designed) it was illuminated principally by a large chandelier, depending by a chain from the centre of the sky-light, and lowered, or elevated, by means of a counter-balance as usual; but (in order not to look unsightly) this latter passed outside the cupola and over the roof.

The arrangements of the room had been left to Trippetta's superintendence; but, in some particulars, it seems, she had been guided by the calmer judgment of her friend the dwarf. At his suggestion it was that, on this occasion, the chandelier was removed. Its waxen drippings (which, in weather so warm, it was quite impossible to prevent) would have been seriously detrimental to the rich dresses of the guests, who, on account of the crowded state of the saloon, could not all be expected to keep from out its centre; that is to say, from under the chandelier. Additional sconces were set in various parts of the hall, out of the way, and a flambeau, emitting sweet odor, was placed in the right hand of each of the Caryaides [Caryatides] that stood against the wall—some fifty or sixty altogether.

The eight ourang-outangs, taking Hop-Frog's advice, waited patiently until midnight (when the room was thoroughly filled with masqueraders) before making their appearance. No sooner had the clock ceased striking, however, than they rushed, or rather rolled in, all together—for the impediments of their chains caused most of the party to fall, and all to stumble as they entered.

The excitement among the masqueraders was prodigious, and filled the heart of the king with glee. As had been anticipated, there were not a few of the guests who supposed the ferocious-looking creatures to be beasts of some kind in reality, if not precisely ourang-outangs. Many of the women swooned with affright; and had not the king taken the precaution to exclude all weapons from the saloon, his party might soon have expiated their frolic in their blood. As it was, a general rush was made for the doors; but the king had ordered them to be locked immediately upon his entrance; and, at the dwarf's suggestion, the keys had been deposited with him.

While the tumult was at its height, and each masquerader attentive only to his own safety (for, in fact, there was much real danger from the pressure of the excited crowd), the chain by which the chandelier ordinarily hung, and which had been drawn up on its removal, might have been seen very gradually to descend, until its hooked extremity came within three feet of the floor.

Soon after this, the king and his seven friends having reeled about the hall in all directions, found themselves, at length, in its centre, and, of course, in immediate contact with the chain. While they were thus situated, the dwarf, who had followed noiselessly at their heels, inciting them to keep up the commotion, took hold of their own chain at the intersection of the two portions which crossed the circle diametrically and at right angles. Here, with the rapidity of thought, he inserted the hook from which the chandelier had been wont to depend; and, in an instant, by some unseen agency, the chandelier-chain was drawn so far upward as to take the hook out of reach, and, as an inevitable consequence, to drag the ourang-outangs together in close connection, and face to face.

The masqueraders, by this time, had recovered, in some measure, from their alarm; and, beginning to regard the whole matter as a well-contrived pleasantry, set up a loud shout of laughter at the predicament of the apes.

"Leave them to me!" now screamed Hop-Frog, his shrill voice making itself easily heard through all the din. "Leave them to me. I fancy I know them. If I can only get a good look at them, I can soon tell who they are."

Here, scrambling over the heads of the crowd, he managed to get to the wall; when, seizing a flambeau from one of the Caryaides [Caryatides], he returned, as he went, to the centre of the room—leaping, with the agility of a monkey, upon the kings head, and thence clambered a few feet up the chain; holding down the torch to examine the group of ourang-outangs, and still screaming: "I shall soon find out who they are!"

And now, while the whole assembly (the apes included) were convulsed with laughter, the jester suddenly uttered a shrill whistle; when the chain flew violently up for about thirty feet—dragging with it the dismayed and struggling ourang-outangs, and leaving them suspended in mid-air between the sky-light and the floor. Hop-Frog, clinging to the chain as it rose, still maintained his relative position in respect to the eight maskers, and still (as if nothing were the matter) continued to thrust his torch down toward them, as though endeavoring to discover who they were.

So thoroughly astonished was the whole company at this ascent, that a dead silence, of about a minute's duration, ensued. It was broken by just such a low, harsh, grating sound, as had before attracted the attention of the king and his councillors when the former threw the wine in the face of Trippetta. But, on the present occasion, there could be no question as to whence the sound issued. It came from the fang-like teeth of the dwarf, who ground them and gnashed them as he foamed at the mouth, and glared, with an expression of maniacal rage, into the upturned countenances of the king and his seven companions.

"Ah, ha!" said at length the infuriated jester. "Ah, ha! I begin to see who these people are now!" Here, pretending to scrutinize the king more closely, he held the flambeau to the flaxen coat which enveloped him, and which instantly burst into a sheet of vivid flame. In less than half a minute the whole eight ourang-outangs were blazing fiercely, amid the shrieks of the multitude who gazed at them from below, horror-stricken, and without the power to render them the slightest assistance.

At length the flames, suddenly increasing in virulence, forced the jester to climb higher up the chain, to be out of their reach; and, as he made this movement, the crowd again sank, for a brief instant, into silence. The dwarf seized his opportunity, and once more spoke:

"I now see distinctly." he said, "what manner of people these maskers are. They are a great king and his seven privy-councillors,—a king who does not scruple to strike a defenceless girl and his seven councillors who abet him in the outrage. As for myself, I am simply Hop-Frog, the jester—and this is my last jest."

Owing to the high combustibility of both the flax and the tar to which it adhered, the dwarf had scarcely made an end of his brief speech before the work of vengeance was complete. The eight corpses swung in their chains, a fetid, blackened, hideous, and indistinguishable mass. The cripple hurled his torch at them, clambered leisurely to the ceiling, and disappeared through the sky-light.

It is supposed that Trippetta, stationed on the roof of the saloon, had been the accomplice of her friend in his fiery revenge, and that, together, they effected their escape to their own country: for neither was seen again.

Source: Poe, Edgar Allan. 1850. "Hop-Frog." In Vol. 5 of *The Works of Edgar Allan Poe.* Available at: http://whitewolf.newcastle.edu.au/words/authors/P/PoeEdgarAllan/prose/raven_5/hopfrog.html

Herman Melville, from *Moby Dick: or The Whale* (1851)

As the "monomaniacal" captain of the Pequod, Melville's one-legged Ahab storms about the ship with great ferocity. His personal and metaphysical anger over his "dismasting" leads him into a vengeful and ill-fated quest to hunt down and kill the white whale, Moby-Dick, as his singular life objective. In making this Ahab's life's goal, the novel supplies one of the most influential portraits of disability as a quest narrative of revenge.

Chapter 28: Ahab

For several days after leaving Nantucket, nothing above hatches was seen of Captain Ahab. The mates regularly relieved each other at the watches, and for aught that could be seen to the contrary, they seemed to be the only commanders of the ship; only they sometimes issued from the cabin with orders so sudden and peremptory, that after all it was plain they but commanded vicariously. Yes, their supreme lord and dictator was there, though hitherto unseen by any eyes not permitted to penetrate into the now sacred retreat of the cabin.

Every time I ascended to the deck from my watches below, I instantly gazed aft to mark if any strange face were visible; for my first vague disquietude touching the unknown captain, now in the seclusion of the sea, became almost a perturbation. This was strangely heightened at times by the ragged Elijah's diabolical incoherences uninvitedly recurring to me, with a subtle energy I could not have before conceived of. But poorly could I withstand them, much as in other moods I was almost ready to smile at the solemn whimsicalities of that outlandish prophet of the wharves. But whatever it was of apprehensiveness or uneasiness—to call it so—which I felt, yet whenever I came to look about me in the ship, it seemed against all warranty to cherish such emotions. For though the harpooneers, with the great body of the crew, were a far more barbaric, heathenish, and motley set than any of the tame merchant-ship companies which my previous experiences had made me acquainted with, still I ascribed this—and rightly ascribed it—to the fierce uniqueness of the very nature of that wild Scandinavian vocation in which I had so abandonedly embarked. But it was especially the aspect of the three chief officers of the ship, the mates, which was most forcibly calculated to allay these colourless misgivings, and induce confidence and cheerfulness in every presentment of the voyage. Three better, more likely sea-officers and men, each in his own different way, could not readily be found, and they were every one of them Americans; a Nantucketer, a Vineyarder, a Cape man. Now, it being Christmas when the ship shot from out her harbor, for a space we had biting Polar weather, though all the time running away from it to the southward; and by every degree and minute of latitude which we sailed, gradually leaving that merciless winter, and all its intolerable weather behind us. It was one of those less lowering, but still grey and gloomy enough mornings of the transition, when with a fair wind the ship was rushing through the water with a vindictive sort of leaping and melancholy rapidity, that as I mounted to the deck at the call of the forenoon watch, so soon as I levelled my glance towards the taffrail, foreboding shivers ran over me. Reality outran apprehension; Captain Ahab stood upon his quarter-deck.

There seemed no sign of common bodily illness about him, nor of the recovery from any. He looked like a man cut away from the stake, when the fire has overrunningly wasted all the limbs without consuming them, or taking away one particle from their compacted aged robustness. His whole high, broad form, seemed made of solid bronze, and shaped in an unalterable mould, like Cellini's cast Perseus. Threading its way out from among his grey hairs, and continuing right down one side of his tawny scorched face and neck, till it disappeared in his clothing, you saw a slender rod-like mark, lividly whitish. It resembled that perpendicular seam sometimes made in the straight, lofty trunk of a great tree, when the upper lightning tearingly darts down it, and without wrenching a single twig, peels and grooves out the bark from top to bottom, ere running off into the soil, leaving the tree still greenly alive, but branded. Whether that mark was born with him, or whether it was the scar left by some desperate wound, no one could certainly say. By some tacit consent, throughout the voyage little or no allusion was made to it, especially by the mates. But once Tashtego's senior, an old Gay-Head Indian among the crew, superstitiously asserted that not till he was full forty years old did Ahab become that way branded, and then it came upon him, not in the fury of any mortal fray, but in an elemental strife at sea. Yet, this wild hint seemed inferentially negatived, by what a grey Manxman insinuated, an old sepulchral man, who, having never before sailed out of Nantucket, had never ere this laid eye upon wild Ahab. Nevertheless, the old sea-traditions, the immemorial credulities, popularly invested this old Manxman with preternatural powers of discernment. So that no white sailor seriously contradicted him when he said that if ever Captain Ahab should be tranquilly laid out—which might hardly come to pass, so he muttered—then, whoever should do that last office for the dead, would find a birth-mark on him from crown to sole.

So powerfully did the whole grim aspect of Ahab affect me, and the livid brand which streaked it, that for the first few moments I hardly noted that not a little of this overbearing grimness was owing to the barbaric white leg upon which he partly stood. It had previously come to me that this ivory leg had at sea been fashioned from the polished bone of the sperm whale's jaw. "Aye, he was dismasted off Japan," said the old Gay-Head Indian once; "but like his dismasted craft, he shipped another mast without coming home for it. He has a quiver of 'em."

I was struck with the singular posture he maintained. Upon each side of the Pequod's quarter deck, and pretty close to the mizzen shrouds, there was an auger hole, bored about half an inch or so, into the plank. His bone leg steadied in that hole; one arm elevated, and holding by a shroud; Captain Ahab stood erect, looking straight out beyond the ship's ever-pitching prow. There was an infinity of firmest fortitude, a determinate, unsurrenderable wilfulness, in the fixed and fearless, forward dedication of that glance. Not a word he spoke; nor did his officers say aught to him; though by all their minutest gestures and expressions, they plainly showed the uneasy, if not painful, consciousness of being under a troubled master-eye. And not only that, but moody stricken Ahab stood before them with a crucifixion in his face; in all the nameless regal overbearing dignity of some mighty woe.

Ere long, from his first visit in the air, he withdrew into his cabin. But after that morning, he was every day visible to the crew; either standing in his pivot-hole, or seated upon an ivory stool he had; or heavily walking the deck. As the sky grew less gloomy; indeed, began to grow a little genial, he became still less and less a recluse; as if, when the ship had sailed from home, nothing but the dead wintry bleakness of the sea had then kept him so secluded. And, by and by, it came to pass, that he was almost continually in the air; but, as yet, for all that he said, or perceptibly did, on the at last sunny deck, he seemed as unnecessary there as another mast. But the Pequod was only making a passage now; not regularly cruising; nearly all whaling preparatives needing supervision the mates were fully competent to, so that there was little or nothing, out of himself, to employ or excite Ahab, now; and thus chase away, for that one interval, the clouds that layer upon layer were piled upon his brow, as ever all clouds choose the loftiest peaks to pile themselves upon.

Nevertheless, ere long, the warm, warbling persuasiveness of the pleasant, holiday weather we came to, seemed gradually to charm him from his mood. For, as when the red-cheeked, dancing girls, April and May, trip home to the wintry, misanthropic woods; even the barest, ruggedest, most thunder-cloven old oak will at least send forth some few green sprouts, to welcome such glad-hearted visitants; so Ahab did, in the end, a little respond to the playful allurings of that girlish air. More than once did he put forth the faint blossom of a look, which, in any other man, would have soon flowered out in a smile.

Chapter 106: Ahab's Leg

The precipitating manner in which Captain Ahab had quitted the Samuel Enderby of London, had not been unattended with some small violence to his own person. He had lighted with such energy upon a thwart of his boat that his ivory leg had received a half-splintering shock. And when after gaining his own deck, and his own pivot-hole there, he so vehemently wheeled round with an urgent command to the steersman (it was as ever, something about his not steering inflexibly enough); then, the already shaken ivory received such an additional twist and wrench, that though it still remained entire, and to all appearances lusty, yet Ahab did not deem it entirely trustworthy.

And, indeed, it seemed small matter for wonder, that for all his pervading, mad recklessness, Ahab did at times give careful heed to the condition of that dead bone upon which he partly stood. For it had not been very long prior to the Pequod's sailing from Nantucket, that he had been found one night lying prone upon the ground, and insensible; by some unknown, and seemingly inexplicable, unimaginable casualty, his ivory limb having been so violently displaced, that it had stake-wise smitten, and all but pierced his groin; nor was it without extreme difficulty that the agonizing wound was entirely cured.

Nor, at the time, had it failed to enter his monomaniac mind, that all the anguish of that then present suffering was but the direct issue of a former woe; and he too plainly seemed to see, that as the most poisonous reptile of the marsh perpetuates his kind as inevitably as the sweetest songster of the grove; so, equally with every felicity, all miserable events do naturally beget their like. Yea, more than equally, thought Ahab; since both the ancestry and posterity of Grief go further than the ancestry and posterity of Joy. For, not to hint of this: that it is an inference from certain canonic teachings, that while some natural enjoyments here shall have no children born to them for the other world, but, on the contrary, shall be followed by the joy-childlessness of all hell's despair; whereas, some guilty mortal miseries shall still fertilely beget to themselves an eternally progressive progeny of griefs beyond the grave; not at all to hint of this, there still seems an inequality in the deeper analysis of the thing. For, thought Ahab, while even the highest earthly felicities ever have a certain unsignifying pettiness lurking in them, but, at bottom, all heart-woes, a mystic significance, and, in some men, an archangelic grandeur; so do their diligent tracings-out not belie the obvious deduction. To trail the genealogies of these high mortal miseries, carries us at last among the sourceless primogenitures of the gods; so that, in the face of all the glad, hay-making suns, and soft-cymballing, round harvest-moons, we must needs give in to this: that the gods themselves are not for ever glad. The ineffaceable, sad birth-mark in the brow of man, is but the stamp of sorrow in the signers.

Unwittingly here a secret has been divulged, which perhaps might more properly, in set way, have been disclosed before. With many other particulars concerning Ahab, always had it remained a mystery to some, why it was, that for a certain period, both before and after the sailing of the Pequod, he had hidden himself away with such Grand-Lama-like exclusiveness; and, for that one interval, sought speechless refuge, as it were, among the marble senate of the dead. Captain Peleg's rooted reason for this thing appeared by no means adequate; though, indeed, as touching all Ahab's deeper part, every revelation partook more of significant darkness than of explanatory light. But, in the end, it all came out; this one matter did, at least. That direful mishap was at the bottom of his temporary recluseness. And not only this, but to that ever-contracting, dropping circle ashore, who, for any reason, possessed the privilege of a less banned approach to him; to that timid circle the above hinted casualty—remaining, as it did, moodily unaccounted for by Ahab—invested itself with terrors, not entirely underived from the land of spirits and of wails. So that, through their zeal for him, they had all conspired, so far as in them lay, to muffle up the knowledge of this thing from others; and hence it was, that not till a considerable interval had elapsed, did it transpire upon Pequod's decks.

But be all this as it may; let the unseen, ambiguous synod in the air, or the vindictive princes and potentates of fire, have to do or not with earthly Ahab, yet, in this present matter of his leg, he took plain practical procedures;—he called the carpenter.

And when that functionary appeared before him, he bade him without delay set about making a new leg, and directed the mates to see him supplied with all the studs and joists of jaw-ivory (Sperm Whale) which had thus far been accumulated on the voyage, in order that a careful selection of the stoutest, clearest-grained stuff might be secured. This done, the carpenter received orders to have the leg completed that night; and to provide all the fittings for it, independent of those pertaining to the distrusted one in use. Moreover, the ship's forge was ordered to be hoisted out of its contemporary idleness in the hold; and, to accelerate the affair, the blacksmith was commanded to proceed at once to the forging of whatever iron contrivances might be needed.

Source: Melville, Herman. 1851. *Moby Dick: or The Whale.* Available at: http://www.americanliterature.com/MD/MDINDEX.HTML

Herbert Spencer, from *Social Statics or Order* (1851)

Herbert Spencer (1820–1903) was a British-born biologist and social philosopher whose theory of evolution was toppled by that of Charles Darwin in The Origins of Species. However, Spencer is credited with *condensing (many might claim simplifying) Darwin's argument into the adage "survival of the fittest." Although Darwin resisted this designation for years, he finally accepted this shorthand way of capturing his theory of adaptation. The idea of "survival of the fittest" was often used during the eugenics period and beyond to explain why disabled people were the "weak links" in a hierarchy of valued human capacities.*

The Evanescence of Evil

All evil results from the non-adaptation of constitution to conditions. Does a shrub dwindle in poor soil, or become sickly when deprived of light, or die outright if removed to a cold climate? It is because the harmony between its organization and its circumstances has been destroyed. Those experiences of the farm-yard and the menagerie which show that pain, disease, and death, are entailed upon animals by certain kinds of treatment, may be similarly generalized. Every suffering incident to the human body, from a headache up to a fatal illness, from a burn or a sprain up to accidental loss of life, is similarly traceable to the having placed that body in a situation for which its powers did not fit it. Nor is the expression confined in its application to physical evil. Is the bachelor unhappy because his means will not permit him to marry? Does the mother mourn over her lost child? Does the emigrant lament leaving his fatherland? The explanation is still the same. No matter what the special nature of the evil, it is invariably referable to one generic cause—want of congruity between the faculties and their spheres of action.

Equally true is that evil perpetually tends to disappear. In virtue of an essential principle of life, this non-adaptation of an organism to its condition is ever being rectified; and modification of one or both, continues until the adaptation is complete. Whatever possesses vitality, from the elementary cell up to man himself, inclusive, obeys this law. We see it illustrated in the acclimatization of plants, in the altered habits of domesticated animals, in the varying characteristics of our own race. Accustomed to the brief arctic summer, the Siberian herbs and shrubs spring up, flower, and ripen their seeds, in the space of a few weeks. If exposed to the rigour of northern winters, animals of the temperate zone get thicker coats and become white. The greyhound which, when first transported to the high plateaus of the Andes, fails in the chase from want of breath, acquires, in the course of generations, a more efficient pair of lungs.

Man exhibits the same adaptability. He alters in colour according to habitat—lives here upon rice and there upon whale oil—gets larger digestive organs if he habitually eats innutritious food—acquires the power of long fasting if his mode of life is irregular, and loses it when the supply of food is certain—attains acute vision, hearing, and scent, when his habits of life call for them, and gets these senses blunted when they are less needful. That such changes are towards fitness for surrounding circumstances no one can question. When he sees that the dweller in marshes lives in an atmosphere which is certain death to a stranger—when he sees that the Hindoo can lie down and sleep under a tropical sun, while his white master with closed blinds, and water sprinklings, and punkah, can hardly get a doze—when he sees that the Greenlander and the Neapolitan subsist comfortably on their respective foods—blubber and macaroni, but would be made miserable by an interchange of them—when he sees that in other cases there is still this fitness to diet, to climate, and to modes of life, even the most skeptical must admit that some law of adaptation is at work. In the drunkard who needs an increasing quantity of spirits to intoxicate him, and in the opium eater who has to keep taking a larger dose to produce the usual effect, he may mark how the system gradually acquires power to resist what is noxious. Those who smoke, who take snuff, or who habitually use medicines, can furnish like illustrations. This universal law of physical modification, is the law of mental modification also. The multitudinous differences of capacity and disposition which have, in course of time, grown up between the Indian, African, Mongolian, and Caucasian races, and between the various subdivisions of them, must all be ascribed to the acquirement in each case of fitness for surrounding circumstances. Why all this divergence from the one original type? If adaptation of constitution to conditions is not the cause, what is the cause?

There are none however, who can with anything like consistency combat this doctrine; for all use arguments that presuppose its truth. They do this when they attribute differences of national character to differences in social customs and arrangements; and again when they comment on the force of habit; and again when they discuss the probable influence of a proposed measure upon public morality; and again when they recommend practice as a means of acquiring increased aptitude; and again when they describe certain pursuits as elevating and others as degrading;

and again when they talk of getting used to anything; and again when they teach that virtuous conduct eventually becomes pleasurable, or when they warn against the power of a long-encouraged vice.

We must adopt one of three propositions. We must either affirm that the human being is unaltered by the influences brought to bear on him—his circumstances; or that he tends to become *un*fitted to those circumstances; or that he tends to become fitted to them. If the first be true, then all schemes of education, of government, of social reform are useless. If the second be true, then the way to make a man virtuous is to accustom him to vicious practices, and *vice versa.* Both of which propositions being absurd, we are impelled to admit the remaining one.

Keeping in mind these truths, that all evil results from the non-adaptation of constitution to conditions; and that where this non-adaptation exists it is continually being diminished by the changing of constitution to suit conditions; we shall be prepared for comprehending the present position of the human race.

By the increase of population the state of existence we call social has been necessitated. Men living in this state suffer under numerous evils. By the hypothesis it follows that their characters are not completely adapted to such a state.

In what respects are they not so adapted? What is the special qualification which the social state requires?

It requires that each individual shall have such desires only, as may be fully satisfied without trenching upon the ability of other individuals to obtain like satisfactions. If the desires of each are not thus limited, then either all must have certain of their desires ungratified; or some must get gratification for them at the expense of others. Both of which alternatives, necessitating pain, imply non-adaptation.

But why is not man adapted to the social state?

Simply because he yet partially retains characteristics appropriate to an antecedent state. The respects in which he is not fitted to society, are the respects in which he is fitted for his original predatory life. His primitive circumstances required that he should sacrifice the welfare of other beings to his own; his present circumstances require that he shall not do so; and in so far as his old attribute still clings to him, he is unfit for the social state. All sins of men against one another, from the cannibalism of the Fijian to the crimes and venalities we see around us; the felonies which fill our prisons, the trickeries of trade, the quarrellings of class with class and of nation with nation, have their causes comprehended under this generalization.

Men needed one moral constitution to fit him for his original state; he needs another to fit him for his present state; and he has been, is, and will long continue to be, in process of adaptation. And the belief in human perfectibility merely amounts to the belief that, in virtue of this process, man will eventually become completely suited to his mode of life.

Progress, therefore, is not an accident, but a necessity. Instead of civilization being artificial it is a part of nature; all of a piece of development of an embryo or the unfolding of a flower. The modifications mankind have undergone, and are still undergoing, result from a law underlying the whole organic creation; and provided the human race continues, and the constitution of things remains the same, those modifications must end in completeness. As surely as the tree becomes bulky when it stands alone, and slender if one of a group; as surely as a blacksmiths arm grows large, and the skin of a laborer's hand thick; as surely as the eye tends to become long-sighted in the sailor, and short-sighted in the student; as surely as a clerk acquires rapidity in writing and calculation; as surely as the musician learns to detect an error of a semitone amidst what seems to others a very babel of sounds; as surely as a passion grows by indulgence and diminishes when restrained; as surely as a disregarded conscience becomes inert, and one that is obeyed active; as surely as there is any meaning in such terms as habit, custom, practice;—so surely must the human faculties be moulded into complete fitness for the social state; so surely must evil and immorality disappear; so surely must man become perfect.

[Editors' note: Spencer later added the following qualifications to the foregoing argument.] With the exception of small verbal improvements, I have let this chapter stand unaltered, though it is now clear to me that the conclusions drawn in it should be largely qualified. 1. Various races of mankind, inhabiting bad habitats, and obliged to lead miserable lives, cannot by any amount of adaptation be moulded into satisfactory types. 2. Astronomical and geological changes must continue hereafter to cause such changes of surface and climate as must entail migrations from habitats rendered unfit to fitter habitats; and such migrations must entail modified modes of life, with consequent re-adaptations. 3. The rate of progress towards any adapted form must diminish with the approach to complete adaptation, since the force producing it must diminish; so that, other causes apart, perfect adaptation can be reached only in infinite time.

Source: Spencer, Herbert. 1915. Pp. 28–32 in *Social Statics or Order: Together with Man versus the State.* New York: D. Appleton. (Originally published 1851)

Phineas T. Barnum, from *The Life of P. T. Barnum* (1855)

Barnum was an extraordinary entrepreneur, an impresario, and a self-made man. He remade himself several times during his long career as a showman. The following is an excerpt from Barnum's first autobiography, published at the height of his antebellum success and fame. Barnum relates how he pulled himself out of financial danger with his purchase of the American Museum and how he achieved his first profits there with the Fejee Mermaid. Moses Kimball of the Boston Museum was his friend, and he was the means by which Barnum obtained the Fejee Mermaid. Barnum was a master of promotion—notice how he promoted the Fejee Mermaid. When he obtained the services of the four-year-old Charles Stratton, Barnum would use similar approaches in promoting the boy he called Tom Thumb.

The American Museum, at the date of my purchase, was little more than the nucleus of what it is now. During the thirteen years of my proprietorship, I have considerably more than doubled the value of the permanent attractions and curiosities of the establishment. The additions were derived, partly from Peale's Museum, (which I bought and transferred to my former collection in the fall of 1842;) partly from the large and rare collection known as the Chinese Museum, (which I removed to the American Museum in 1848;) and partly by purchases wherever I could find curiosities, in both America and Europe.

The space now occupied for my Museum purposes is more than double what it was in 1841. The Lecture Room, which was originally narrow, ill-contrived and uncomfortable, has been several times enlarged and improved, and at present may be pronounced one of the most commodious and beautiful halls of entertainment in New-York.

There have been enlargement and improvement in other respects. At first, the Museum was merely a collection of curiosities by day, and in the evening there was a performance, consisting of disjointed and disconnected amusements, such as are still to be found at many of the inferior shows. Saturday *afternoon* was soon appropriated to performances, and shortly afterwards the *afternoon* of Wednesday was added. The programme has for years included the afternoon and evening of every day in the week, (of course excepting the Sabbath,) and on great holidays, we have sometimes given as many as twelve performances.

Harriet Tubman, *by Jacob Lawrence (1917–2000). Harriet Tubman, a leader of the Underground Railroad for escaped slaves from the American South, experienced a head injury as a teenager when an angry overseer hit her with a weight intended for another slave. Her efforts assisted more than 300 individuals to remove themselves from status as human chattel.*

Source: Art Resource, New York.

There has been a gradual change in these, and the transient attractions of the Museum have been greatly diversified. Industrious fleas, educated dogs, jugglers, automatons, ventriloquists, living statuary, tableaux, gipsies, albinoes, fat boys, giants, dwarfs, rope-dancers, caricatures of phrenology, and "live Yankees," pantomime, instrumental music, singing and dancing in great variety, (including Ethiopians,) etc. Dioramas, panoramas, models of Dublin, Paris, Niagara, Jerusalem, etc., mechanical figures, fancy glass-blowing, knitting machines and other triumphs in the mechanical arts, dissolving views, American Indians, including their warlike and religious ceremonies enacted on the stage, etc., etc.

I need not specify the order of time in which these varieties were presented to the public. In one respect there has been a thorough though gradual change in the general plan, for the *moral drama* is now, and has been for several years, the principal feature of the Lecture Room of the American Museum.

Apart from the merit and interest of these performances, and apart from every thing connected with the stage, my permanent collection of curiosities is, without doubt, abundantly worth the uniform charge of admission to all the entertainments of the establishment, and I can therefore afford to be accused of "humbug" when I add such transient novelties as increase its attractions. If I have exhibited a questionable dead mermaid in my Museum, it should not be overlooked that I have also exhibited cameleopards, a rhinoceros, grisly bears, orang-outangs, great serpents, etc., about which there could be no mistake because they were alive; and I should hope that a little "clap-trap" occasionally, in the way of transparencies, flags, exaggerated pictures, and puffing advertisements, might find an offset in a wilderness of wonderful, instructive, and amusing realities. Indeed I cannot doubt that the sort of "clap-trap" here referred to, is allowable, and that the public like a little of it mixed up with the great realities which I provide. The titles of "humbug," and the "prince of humbugs," were first applied to me by myself. I made these titles a part of my "stock in trade," and may here quote a passage from the "Fortunes of the Scattergood Family," a work by the popular English writer, Albert Smith:

"'It's a great thing to be a humbug,' said Mr. Rossett. 'I've been called so often. It means hitting the public in reality. Anybody who can do so, is sure to be called a humbug by somebody who can't.'"

Among my first extra exhibitions produced at the American Museum, was a model of the Falls of Niagara, belonging to Grain the artist. It was undoubtedly a fine model, giving the mathematical proportions of that great cataract, and the trees, rocks, buildings, etc., in its vicinity. But the absurdity of the thing consisted in introducing water, thus pretending to present a *facsimile* of that great wonder of nature. The falls were about eighteen inches high, every thing else being in due proportion!

I confess I felt somewhat ashamed of this myself, yet it made a good line in the bill, and I bought the model for $200.

Source: Barnum, Phineas T. 1855. *The Life of P. T. Barnum.* New York: Redfield. .

Lizzie Jones's Letter Home from the Orthopaedic Institution for the Cure of Deformities (1855)

Eliza Adam "Lizzie" Jones (1839–1911) of Orange County, North Carolina, wrote this and several subsequent letters to relatives during her stay at a clinic in Brooklyn, New York. The letter demonstrates some of the paradoxical intersections between gender and disability in antebellum Southern culture. Marriageability was important and required a sound physique, but for planter-class daughters with "deformities," a winter of confinement in Brooklyn might also be a release from restrictive dresses and rural monotony.

I suppose you think me not very true to my promises—if I had known when I left Raleigh, how hard it is to write away from home I don't think I would have made any positive promises about writing, however now that I am beginning to be settled, I can write much more easily. You cannot think how strange it seemed to me to have to take up my abode at this 'Orthopaedic Institution for the Cure of Deformities'—that is the sign in *great big* letters! Aunt Sal and Fan are staying with me, and I tell them that they will be called deformed too. I hope, dear cousin, you won't wait for me to get cured, before you come on because though it may take a good while, yet every one is quite certain that I *will* be straitened up, and it will be *so* nice to have you here. You asked me to tell you the mode of treatment—that I received—it is very simple indeed; at present I do nothing more than take gymnastic exercises every day, which are very pleasant, and drink some kind of wine. I have been over to New York very often, and seen as many fine sights as Aunt Sally or Fanny. But this state of things is not to last long—the Dr. has already expressed a desire that I should stay more at *home,* and in about half an hour, he is going to apply electricity to me; they have been laughing at me all the morning about being so anxious for the time to come; although I know it will be disagreeable, I am just as anxious about it as if it were some delightful sensation I were going to experience. . . . I will put on a brace in two or three days which will prevent me from wearing anything but a loose wrapper, then of course I cannot go out, so I am going to try to make up for leaving school by reading a great deal. I am sure I ought to improve myself in that respect, for it will be the principal means I have of entertaining myself.

Source: Jones, Lizzie. 1855. Letter. Cameron Family Papers, Southern Historical Collection, University of North Carolina at Chapel Hill.

John J. Flournoy to William Turner, "A Mighty Change" (1856)

The following excerpts are from correspondence debating the value and need for a separate deaf commonwealth/state. Flournoy argues that a separate state would be an empowering project for the deaf community and would not involve the entire deaf community but rather a select group. It would prove that deaf people had the same capabilities as nondeaf people. Booth responds by discussing the impossibility of Flournoy's proposal, citing educational and economic problems and the paucity of fit land. Much of the debate reveals social attitudes about and barriers to the capabilities of the deaf.

John J. Flournoy to William Turner

After William Turner, the principal of the American Asylum, gently rejected Flournoy's proposal for a deaf commonwealth, Flournoy sent him the following response. The letter was published in the American Annals of the Deaf and Dumb *in 1856.*

Rev. W. W. Turner;

Rev. and Dear Friend: I am in receipt of your kind favor of the 6th inst., replying to my inquiry of last summer, concerning the feasibility and propriety, in your view, of colonizing some small territory in our country with a population of mutes. Your objections I have duly considered and weighed: and although I accord to them that respect and that deference due from me to your sentiments, still I might confess my want of conviction as yet, unless you would do away with the force of the following observations, predicated as an answer to your remarks. . . .

You will observe that my appeal, circulated among my class of our people, and sent to Europe, did not have intention of persuading the migration of the *entire* deaf population of those regions—but only a portion of them! And it is presumable that there are among them a sufficient number who would agree to emigrate, provided the General Government would do what I clearly laid down, I believe, in those papers: *secure the government and offices of small territory or State, to the mute community!* Neither home, nor parents, nor friends, would or ought to deter a body of enterprising and resolute deaf men from moving to such a possession! We do not ask it as a grant, boon or charity from the government—the ruling powers and legislature have too much grudged us any pittance they have seen their predecessors give in its infancy to the American Asylum at Hartford—but we will pay our pre-emptive right money for the acres, if only guaranteed the control of the commonwealth. That government will give us *such* a prerogative to a State about the size of Rhode Island or Connecticut, I confess I do not feel sanguine enough to hope! But there is nothing like trying. . . .

The old cry about the incapacity of men's minds from physical disabilities, I think it were time, now in this intelligent age, to *explode!* You asked, how could a deaf man legislate and govern among the hearing, any more than a blind man lead an army? (I use your ideas—not your language. The matter is just as I give it.) Did you ever believe lame men, and blind men, and deaf men, when usefulness was in view, were as useless as dumb beasts? Certainly not. Then where does your reasoning limit their capacity? You use a military figure: and I will dwell a little on one. Have you ever heard how Muley Molech had himself borne in a litter, when lamed by wounds, to the head of his legions, and how he vanquished the foe? So much for a *lame* man. Then, as for a *blind* one, such a one as the beggared Belisarius of declining Rome or Byzantium; was such a man of no military moment because sightless? I would myself, if I were contemporary with himself, suggest the Romans that he be provided with a military academy to teach the strategy of war—or be kept on a hill near a battle to direct emergencies, while the seeing faithfully inform him of events. Here then, literally meeting you with your own weapons, is a great blind general made consummate leader, if experienced. But the application of such views to the deaf is not legitimate. We do not claim *all* offices, nor to do *every* thing. But we do attest that we are capable of many of which the prejudice, and sometimes even

Mementos of soldiers who fought in the U.S. Civil War and surgeon's kit. The surgeon's instrument kit was used by Dr. Charles Stein during the Civil War. Stein served as assistant surgeon to the 57th New York Infantry, known as the "Polish Legion."

Source: Art Resource, New York.

malignance of our hearing brethren deprive us!! It were better that Congress had the presence of some blind philosophers to lead the way in legislation, than to have only seeing men without wisdom. The court of the Areopagus, at ancient Athens, blindfolded the judges to prevent prejudice against unprepossessing suitors. And so long as this was the custom, no judicial decision was so faultless as that of these people. So much for your simile in disparagement of the *blind.*

So of the deaf. Many of us have hearts, of an integrity superior to the *mad* hearing partisans that go to Congress and to legislatures, and fill presidential and gubernatorial seats; and when the fact is that some of us are sages, so far as rational views and Christian principles be taken into consideration;—you can not observe that the loss is greatly the country's, in not being able to avail of our supervision, from the prejudices and disparagements of the world about a sense or two!

Advocating, therefore, a formation out West, of a deaf State, I wish to preserve in urging a measure by which alone our class of people can attain to the dignity and honor of Human Nature. Else our course is (under the idea that a deaf and dumb man is of little consequence) within the circle of diffident humility. I spurn this imputation of thousands of my hearing *inferiors*—who give the fatness of power and office to their own class—and keep me, like Lazarus, out at the gate of splendid and munificent patronage without sending me a solitary crumb from the table.

Place *me* for an example in any Capitol with Legislative sanctity, and I will move for an *aid,* a hearer and amanuensis, to reveal to me what is said, what to be done, what to do, and to read my speeches. And by this way I can get along supremely well, as Legislator. The gist and gravamen being that my intelligence and judgement may prove better and superior to the hearing majority. So your object about deaf incapacity is answered . . .

Can I then concede that hearing men "are the ones and wisdom shall die with them?" No sir—No. I am to lead—and can only lead where deaf capacity be widely acknowledged. I am not in your estimation, I hope, descending to "fanaticism," or to "peculiarity." *Evasions like these will not do!* Men must think. They must investigate before they feel warranted to traduce sterling persons who are not made to sit down and acquiesce in perfidy to self and to mankind.

That deaf men have not my feelings and ambition, is no reason that they should not find a habitation of their own.

If only in such a State forty deaf men, or even twelve, were found, the constitution guarantying power to them alone, they may rule all the hearing owning continents, encroach on the deaf there. If our children hear, let them go to other States. *This Government is to be sacred to the Deaf alone.* In hearing communities how many children stay with their parents? Do brothers and sisters continue together? How then expect deaf-mutes to be such perpetual children as to claim and assert nothing appertaining to the dignity and grandeur of humanity, but to stick to home.

The idea, therefore, of acquiring a commonwealth for themselves ought not to be abandoned.

You say that deaf persons have privileges among the hearing and can amass wealth. But how tardily, where competition by the auricular is such that no isolated deaf person is able to break through a single web of its massive Free Masonry? The auricular are not satisfied with hearing, nor with the usual mutual sympathies of their own class, but are banded and combined together in associations, open, and societies, secret, until they form a compact moral mechanism, that fairly by their majority, puts us in the shade. I know not how at this day the people of your section comport towards the deaf. But when I was at Hartford, I saw that a tailor (A.S.B.) *disdainfully* repelled away a mute applicant for the post of *foreman* (D.A.S.). Even if it be better for our class *now* in New England, it is far from one-ninety-ninth so, in Georgia, whose Legislature, after my prayer in 1834, granting a deaf education to the mutes here, a few years thereafter, became chagrined at having *honored me,* and though they dared not revoke their education, still they made a law to "*make deaf and dumb persons idiots in law and to provide them guardians.*" Thus in the South we are contemned, spurned, degraded and abhorred, and I see no redemption but in forming a powerful oligarchy of our own to control a State at the West—a Deaf-mute Republic.

We constitutionally allow no foreigner to be President—nationally. We would in that small State allow no hearing man to have any lucrative office. This is all I care about. Its Legislature, Judiciary, &c., all mutes.

A deaf community, once established, to whom only offices are open to Congress and at home, as none others should be eligible—would easily draw mute recipients for the bounty from all sections. Once fixed, I see nothing deterrent.

I fear my letter is quite annoyingly lengthy, and will now close. I have said all I believe necessary to convince you of the propriety of our plan, which will only fail because the deaf and dumb are not worthy of a better destiny, or are as unlike as possible,

Your affectionate and obliged humble servant,
John J. Flournoy

Edmund Booth to John J. Flournoy, 1858

Edmund Booth wrote this response to Flournoy. Although it was not intended for publication, Booth agreed to allow the Annals *to publish it in January 1858, along with a number of other letters on the subject of a deaf commonwealth.*

Dear Sir,
In regard to a community of deaf-mutes in the West, or anywhere—supposing you mean a community exclusively or mainly of mutes—let me say candidly that I hold it to be an impossibility, save in the commencement, and that on a very small scale. Just consider a moment. A community of this class would be a mixture of a few well and many half-educated; and among them must be many non-readers and frivolous. And then the general equality claimed with all by the latter, would operate to keep the more sensible from joining such community; for we all know that gossip, scandal, backbiting and other diabolisms are as common among mutes as among hearing persons.

Again: They will need to work at a variety of trades, and a commonwealth of mutes could never exceed 10,000, supposing all in the U.S. were brought in. A sparsely settled state would make nobody rich, and would satisfy few; and no law could be made effectual to prevent their selling their lands, buildings, &c., to hearing persons. Thus the distinct nature of the community would soon be lost. And it would so happen in any event, for their children being mostly of the hearing order, it would become a hearing community faster than the fathers and mothers died out.

I think the wiser course is to let the mutes remain as they are—scattered and in one sense lost—among their hearing associates. In such situations they are compelled to read and write, and thus keep their minds under the educational process through life.

In reply to your other questions: the country *will* suit them. But in Iowa there is no land unsold or in market, save the railroad lands, which are withdrawn, and they are narrow strips and cannot be obtained save at $2.50 per acre or more, and that at cash down the moment they are brought into market. Speculators have drained Iowa completely of her government lands, with the exceptions as above. Government lands can be obtained in Minnesota, where they are not yet in market, especially in the western part of that territory; but it is too far north and too cold to suit my ideas of a residence. The cold in the West is less than in the same latitude East. For a community of mutes, Nebraska is almost out of the question. It is mostly a barren country. I speak from observation, having traveled through it from the Missouri river to the South Pass. Iowa is a prairie country. Perhaps one-tenth of it timber. One-twentieth would be nearer the truth. The guide books say one-third or one-fourth. My own observations say one-tenth.

I see no country that would suit your ideas so well as Kansas. But to me the whole scheme looks much like those of other communities formed on the exclusive system, like those of Mons. Cabet, Rapp, &c. They had the incentive of religion and friendship and community of goods, labor and profit. With us it would be otherwise; and we should break through before we had made half a trial.

Yours truly,
E. Booth

Flournoy to Turner, 1858

Flournoy's response appeared with Booth's letter in the same issue of the Annals.

Rev. Mr. Turner:

My dear Friend—This being a free country, where every "smart" man, and his name is legion, has his opinion whether crude or vulgar, or refined and intellectual, the American community are very unquiet and debatable, subject to a thousand though not very learned of profound sentiments, political and social. The deaf and dumb have taken a color of character from this disputatious habit, a specimen of which is evinced in the enclosed letter from Edmund Booth, Esq. Instead of meeting my project with a philosophical view, I am met by objections, some of which, like yours and Mr. Booth's, are truly formidable! It would seem then, that without intending to be the great leader and original mind, I am the chief in this cause, and that if I carry it not forward, the idea of a deaf community may prove abortive as to any practical result.

There is always some objection to every project under the sun, and often very cogent ones. What is a man then to do? Abandon every scheme because impeded by natural and conventional obstacles? Certainly not. Many of the greatest nations have been founded in time by defiance of the untoward predictions of impractible visionaries. Many a costly experiment has been forsaken on no better hypothesis. The invention of the daguerreotype—the photogenic art—was not accidental, but by a design; and persistent, philosophical chemists began and followed out the plan, until Daguerre, in the final series of the successive experimenters, perfected the science by which our features are in exact copies transmitted to posterity. Resolution and perseverance will accomplish wonders. And I pray God that the deaf and dumb may prove worthy of the name of men.

Mr. Booth thinks the West will not suit the mutes. From his description of the North-west I agree with him in that opinion. His other views have been answered before in the annals and elsewhere.

I do not know what kind of a constitution the mutes may superstruct, whether to make real estate inherent only in the deaf, by that organic law all have to respect and defer to; or in case of default, to escheat to the estate. This, however, is certain, that the *control* of our community over the commonwealth would be strict and universal. This is what we want and for what we may emigrate. *The government of a piece of Territory.* Nothing more or less.

Mr. Booth believes we can do better, and will read more, scattered as we are and "lost" among the hearing. I challenge him to show me twenty deaf-mutes in a hundred, that are constant readers, adequate to comprehending either literature or science, as they now are dispersed among hearing people, who do not read any or much themselves, and who have a sense (auricular) by which they gather in their knowledge, a privilege debarred the deaf, who therefore are the more ignorant *for being thus scattered.* Whereas if convened in a land peculiarly their own, the concentration of reading intellects would set a beneficial example; and preaching and lectures in the sign language, and libraries of suitable books, may improve their minds and hearts, beyond what is attainable in their scattered condition. For this, as a principal cause and source of improvement, this colony is a desideratum.

But the difficulty that meets me on all sides is, how can you keep up the mute population? The children of deaf parents are mostly hearing. These will inherit property and the community will not endure. This reasoning seems to take it that our society is to be organized like that of the hearing, and to be modeled upon the same principles. Now there is no such thing. I acknowledge that the hearing children of deaf parents may not inherit land in that anomalous and contracted community—neither power nor patronage. But the other States are so near, and their parents may supply them with the means to buy real estate in them. When they have a good location, the mutes would come in from all parts of the world. An Asylum for their education may be founded there, as well as other Institutions, so that there will be no lacking of the deaf *materiel.* What then of this visionary difficulty! We will allow such hearing persons as come for trade or residence, to vote with us. *We would give woman that right.* Hence we may always possess sufficient population to be a State. But even if this be futile, we can remain a Territory of the Federal Government and enjoy its powerful protection under Omnipotence; the General Government guaranteeing to us the peculiar Constitution we may devise: "Republical in form."

If mutes *cannot* do this they are justly held as inferior and *useless* in the world. For they ought not to pretend to be "any body" among hearing men, who do what deaf "dogs" shrink from achieving *alone.* But we are men, and have under god only to try, and the thing is a finished work!

After this argument, which if published I hope may satisfy the overscrupulous, I would approach the great point that is before us. I think we can acquire territory enough from the Cherokees or other red men, West of Arkansas, and *very cheaply,* on which to make our experiment, or else from the State of Maine. Perhaps some one of the New England, Northern or Middle States may grant space enough for this purpose. I myself prefer the Indian Territory, if the U.S. government would sanction and aid a cession. Hence, no fear about trade and business. Capital will accumulate in our hands when our skill and industry are concentrated, and our ruling prerogative unimpeachable. Whereas now, in their scattered condition, especially in the Middle and Southern States, few deaf men have employment of respectability, and their ignorance is "stereotyped," as I have shown, by their unfortunate and dispersed situation, without preaching or any instruction whatsoever. When combined, competition and a sense of high duty and responsibility will cause them to study books, documents, and men and things, and like other communities we shall produce men of intellectual predominance.

Even should the contemplated colony fail, as Mr. Booth predicts, one great utility to ourselves will have been derived from a practical experience. We shall have proved to the other nations and our own, that a deaf and dumb people are capable of many things; and to our successors in misfortune, offices and employment may be opened. They may be treated as men and women of *some use* to society and to the country, and respected accordingly. And this will to us be no inconsiderable triumph; and the victory sure, as the deaf now continues to prove this competency and fidelity in lands and other trusts. And this, we, as accountable beings, who may not bury our talent in a napkin, owe to the long and harmless line of the "pantomimic generations" that are to come after us!

I have now fully, I hope, in attempting something like a reply to Mr. Booth, given what refutation I am able, to the many objects that are ever starting up to confound this project. I hope the Annals will embrace both Mr. Booth's letter and mine. I presume that invaluable periodical will devote some space to this discussion, as relating so closely to the welfare and interests of the community, to whose benefit it is so inseparately devoted.

I am, dear sir, truly and respectfully,
your most obliged, obedient, humble servant,
J. J. Flournoy

Source: Krentz, Christopher, ed. 2002. *An Anthology of Deaf American Writing, 1816–1864.* Washington, DC: Gallaudet University Press.

Rebecca Davis, from "Life in the Iron Mills" (1861)

Davis's stories of immigrant workers' lives in hellish industrial settings highlighted the harsh physical toll of mill work and unrelenting poverty. In this scene, the ever-weary Deborah's eyes are emphasized as pale, watery, bleared, and glazed. "Stupor and vacancy" have made her face seem older and more apathetic; elsewhere in the narrative, we see her twisted spine and ghostly pale complexion as well. Hugh Wolfe, also mentioned in this extract, is another Davis character whose body and artistic talents are wasted by deprivation and overexertion.

She watched him eat with a painful eagerness. With a woman's quick instinct, she saw that he was not hungry,—was eating to please her. Her pale, watery eyes began to gather a strange light.

"Is't good, Hugh? T'ale was a bit sour, I feared."

"No, good enough." He hesitated a moment. "Ye're tired, poor lass! Bide here till I go. Lay down on that heap of ash, and go to sleep."

He threw her an old coat for a pillow, and turned to his work. The heap was the refuse of the burnt iron, and was not a hard bed; the half-smothered warmth, too, penetrated her limbs, dulling their pain and cold shiver.

Miserable enough she looked, lying there on the ashes like a limp, dirty rag,—yet not an unfitting figure to crown the scene of hopeless discomfort and veiled crime: more fitting, if one looked deeper into the heart of things,—at her thwarted woman's form, her colorless life, her walking stupor that smothered pain and hunger,—even more fit to be a type of her class. Deeper yet if one could look, was there nothing worth reading in this wet, faded thing, half-covered with ashes? no story of a soul filled with groping passionate love, heroic unselfishness, fierce jealousy? of years of weary trying to please the one human being whom she loved, to gain one look of real heart-kindness from him? If anything like this were hidden beneath the pale, bleared eyes, and dull, washed-out-looking face, no one had ever taken the time to read their signs: not the half-clothed furnace-tender, Wolfe, certainly. Yet he was kind to her; it was his nature to be kind, even to the very rats that swarmed in the cellar; kind to her in just the same way. She knew that. And it might be that very knowledge that had given to her face its apathy and vacancy more than her low, torpid life. One sees that dead, vacant look steal sometimes over the rarest, finest of the women's faces,—in the very midst, it may be, of their warmest summer's day; and then one can guess at the secret of intolerable solitude that lies hidden beneath the delicate laces and brilliant smile. There was no warmth, no brilliancy, no summer for this woman; so the stupor and vacancy had time to gnaw into her face perpetually. She was young, too, though no one guessed it; so the gnawing was the fiercer.

She lay quiet in the dark corner, listening, through the monotonous din and uncertain glare of the works, to the dull plash of the rain in the far distance,—shrinking back whenever the man Wolfe happened to look towards her. She knew, in spite of all his kindness, that there was that in her face and form which made him loathe the sight of her. She felt by instinct, although she could not comprehend it, the finer nature of the man, which made him among his fellow-workmen something unique, set apart. She knew, that, down under all the vileness and coarseness of his life, there was a groping passion for whatever was beautiful and pure,—that his soul sickened with disgust for her deformity, even when his words were kindest. Through this dull consciousness, which never left her, came, like a sting, the recollection of the little Irish girl she had left in the cellar. The recollection struck through even her stupid intellect with a vivid glow of beauty and of grace. Little Janey, timid, helpless, clinging to Hugh as her only friend: that was the sharp thought, the bitter thought, that drove into the glazed eyes a fierce light of pain. You laugh at it? Are pain and jealousy less savage realities down here in this place I am taking you to than in your own house, or your own heart, your heart, which they clutch at sometimes? The note is the same, I fancy, be the octave high or low.

If you could go into this mill where Deborah lay, and drag out from the hearts of these men the terrible tragedy of their lives, taking it as a symptom of the disease of their class, no ghost Horror would terrify you more. A reality of soul starvation, of living death, that meets you every day under the besotted faces on the street—I can paint nothing of this, only give you the outside outlines of a night, a crisis in the life of one man: whatever muddy depth of a soul-history lies beneath you can read according to the eyes God has given you.

Source: Davis, Rebecca. 1861. "Life in the Iron Mills." *Atlantic Monthly.* Available at: http://www.worldwideschool.org/library/books/lit/socialcommentary/LifeintheIron-Mills/Chap1.html

Edouard Séguin, *Idiocy: And Its Treatment by the Physiological Method* (1866)

After his successful work in France developing training programs for those diagnosed as idiots, Séguin moved to the United States. He became an influential figure in the institutionalization movement of the nineteenth century and developed a theory that idiocy resulted from a lack of control over the will. In order to counter this "deficiency," Séguin advocated physical exercise and concentration-based tasks that asked individuals to master their bodies through programs of self-hygiene.

Synonyms.—Named by Savage, *Amentia;* by Segar, *Imbecillitas ingenii;* by Vogel, *Fatuitas ingenii;* by Linnaeus, *Morosis;* by Cullen and Fodéré, *Demence innée;* by Willis, *Stupiditas;* by Pinel, *Idiotism;* by some English writers, *Idiotcy;* by Esquirol and the majority of Encyclopædias and dictionaries, *Idiocy.*

We shall use this latter term to express the physiological infirmity; and would like to see the name given to it by Pinel, Idiotism, preserved to express the specific condition of mind pertaining to idiocy.

Its definitions have been so numerous, they are so different one from the other, and they have so little bearing on the treatment, that their omission cannot be much felt in a practical treatise. Our own, if objectionable, will be found at least to correspond to a plan of treatment, both supporting each other; and may suffice until a better definition and a better treatment can be devised.

Idiocy is a specific infirmity of the cranio-spinal axis, produced by deficiency of nutrition in utero and neo-nati. It incapacitates mostly the functions which give rise to the reflex, instinctive, and conscious phenomena of life; consequently, the idiot moves, feels, understands, wills, but imperfectly; does nothing, thinks of nothing, cares for nothing (extreme cases), he is a minor legally irresponsible; isolated, without associations; a soul shut up in imperfect organs, an innocent.

The *modus operandi* of deficiency of nutrition in the first period of life has not yet been fully investigated; it may bear upon all the tissues, but we are concerned here mostly with its actions on the nervous system.

At the time when deficiency of nutrition takes place it stops the foetal progress, and gives permanency to the transitory type through which the foetus was passing; these transient types being to some extent analogous to the persistent forms of the lower animals. For instance, *atresia palpebrarum* testifies to the presence of the cause of arrest of development as far back as the third month of gestation; arrest of development of the inter-auricular septum leaves the human heart homologous with the heart of fishes; similar early arrest of nutrition of the encephalon leaves its circumvolutions unfinished at the low types of the orang-outang, the calf, or even lower. After the time at which deficiency of nutrition has stopped the ascending evolution of the embryo at one of its low types, it sometimes continues its deleterious action of altering, or entirely destroying the foetus also. For instance, it may destroy one of two foetuses for the nutrition of the other, leaving next to the spared one an acephalus, or only a few fragments of an organized being; or it may partially destroy an encephalon at any stage of development, even after birth, by the intervening of hydrocephalus; or it may give rise to some embryonic malady, destructive of a set of organs or of functions. Though the deficiency of nutrition may affect the whole being, it strikes by preference one set of organs, such as those of speech, of hearing, of local contractility. Deficiency of nutrition happens in two ways; slowly, when induced by depressing influences; or at once, when brought on by a shock. Hence, the first leaves the child a prey to maladies of embryonic origin, or at best at a low point of vitality; the other leaves him well provided for by anterior nutrition, but torpid, or prey to automatism, epilepsy, etc.

Nothing hinders us now from entering into the study of the physiological symptoms after having taken a rapid survey of the infant born idiotic, or predisposed to idiocy.

The only thing which could tempt us to form a diagnosis when the child is just born, is the often monstrous shape exhibited by the head. But it is so difficult to appreciate what part of it is due to deficiency of nutrition or to transitory compressions from maneuvres or instruments; and the head is endowed with such a power of reaction and self-modulation against these transient deformities, that we had better let it receive its own finishing touch before venturing on the expression of a judgement upon its unfinished state. But after the first cries, the child shuts himself up into a chrysalid life. He is rosy and rather puffy, or greyish and shrivelled in his loose integuments, according to his general health. For a time nothing more of him may be foreseen than is seen. Even a few months later, if the mother, feeling her baby without reaction in her embrace, seized with a secret presentiment, seeks for advice, the physician rarely happens to see him otherwise than nursing and sleeping. He has scarcely the chance to notice the head hanging back, or rolled on the pillow automatically, the eyes unlighted and playing the pendulum in their sockets, fixed, or upward or sideways; the difficulty of swallowing the milk once drawn in the mouth; the absence of voice or its animal sounds; the inability of the spine to support the body; the flaccidity of the legs; the hands closed, thumbs inward, by the side instead of coming out from the cradle to take with a firm grasp their share of this world.

In the midst of this uncertainty, profuse salivation, involuntary excretions, imperfect sensations or disordered movements appear daily more settled, instead of the opposite abilities vainly expected. Or after a fall, a blow, exposure to cold, isolation, prolonged successions, fright, or in the period of teething, coma sets in or convulsions appear. After which some function of the reflex or voluntary order, motor or sensitive, is impaired. But the commotion of the cerebro-spinal axis may be temporary or prolonged, producing more convulsions, deeper coma, other incapacitations; throwing the little sufferer far behind his fellows, or leaving him a confirmed idiot. Between these two extremes the majority of young idiots do not differ very sensibly from common babies; because the power of both may be expressed by the same verb, they cannot. But tomorrow the well infant will use his hands, the idiot will allow his to hang in half flexion; the first will move his head at will, the second will toss it about; the look of the former penetrates every day farther than the domain of the touch, that of the latter has no straight dart, and wanders from the inner to the outer canthus; the one will set erect on his spine, the other shall remain recumbent where left, the first will laugh in your face with a contagious will, the second shall not be moved into an intellectual or social expression by any provocation whatever. And each day carves more deeply the differential characters of both; not by making the idiot worse, unless from bad habits gotten by neglect, but by the hourly progress of the other. Idiocy so viewed from its origin is a continuance of the isolation and helplessness of babyhood under ampler forms and obsolete proportions. Compared unavoidably with children of his age, the idiot seems to grow worse every day; his tardy improvement looking like backward steps. With his incapacity of action, of expression, of feeling, he makes a sickening sight indeed by the side of a bright child entering into the intricacies of life as on an open play-ground.

At this stage there can be no mistake; we see plainly what he is, and we can describe what we see. This is the time when the study of the physiological symptoms will make up for the deficiency of the anatomo-pathological ones.

The functions of organic life are generally below the normal standard. The respiration is not deep; the pulse is without resistance. The appetite is sometimes quite anormal in its objects or limited to a few things, rarely voracious, though it looks so, owing to the unconventional or decidedly animal modes of eating and drinking of these children. The swallowing of the food without being masticated, only rolled up in saliva, resumes many of these imperfections which are to be attributed in variable proportions to absence of intelligence, want of action of the will on the organs of mastication and deglutition, deformity of and want of relation between the same. As might be expected, imperfect chewing produces on them, as on other children, unpleasant effects, but no more. Their excretions cannot be said to present any dissimilarity from those of others which our senses can discriminate; only their sebaceous matters are as different from ours as ours are from those of the variously colored races, or from those emitted in most diseases.

The functions of animal life, or of relation, are generally affected in idiocy; either by perversion, diminution, or suppression. We shall begin the study of these anomalies in the organs whose contractility has for object the movement of displacement and prehension.

The incapacity of walking, and of prehending objects, to whatever degree it exists, gives the measure of the isolation of the idiot. He is isolated because he cannot possess himself of those which come in the range of his imperfect grasp; he is double immured in his muscular infirmity. The same motor function may exist, but escaping the control of the will, it produces movements more or less disordered, mechanical, spasmodic, or automatic. Disordered, when their want of harmony prevents the accomplishment of their object; mechanical, when their recurrence, in the course of other normal movements, cannot be otherwise produced or prevented, but can hardly be postponed by a superior influence; spasmodic, when they proceed from an accessory condition of the nerves congener to chorea or epilepsy; automatic, when they consist in the continuity or frequent recurrence of a single unavoidable gesture, without object or meaning. The simple disorder of movements involves a waste of nervous power, disabling, more or less, the child for useful activity, but not depriving him of it entirely. The mechanism throws, unexpectedly, some instinctive jerk or motion in the midst of well-regulated actions. The spasmodism accompanies all actions, as in chorea, or substitutes itself at times for all the normal acts, as in epileptic seizures. The automatism acts as a substitute for all, or nearly all other modes of contractility; it incapacitates more and more the child's muscular power for any useful purposes; and, as a sorry compensation, furnishes him with a supply of involuntary instead of voluntary exercise. Of the four anormal ways of expending uselessly and unwillingly the contractile force allotted to the muscular system, automatism is the most tenacious, when, for years past, no physiological action has been induced by proper training in its stead.

Idiocy affects the body in its general habits, as bending forward, throwing the head backward, moving it in a rotatory manner which seems impossible, swinging the body to and fro, or in a sort of sideway roll.

The following are examples of another kind of hyperæsthesia: some of our children will be unable to touch anything, but with the delicacy of the humming-bird, and seem to suffer greatly from any other mode of contact imposed upon the hands. The feet of others are so much affected with similar exaltation of sensibility, that the thinnest shoes pain them, and the contact of the softest carpet or floor makes them recoil or advance, as if they could not help it, and as if walking on live coals. The hands of one child will move with prestidigitative briskness without apparent object, single or interlaced, to intercept some rays of light falling obliquely into their vacant eyes. Other hands, affected with disorder of the touch, without obvious complication, are caressed, sucked, bitten, till the blood starts, or a heavy callus is formed to protect them; others are constantly bathed in saliva, and their skin nearly resembles that of the washer-woman; these hands feel, out of the mouth like fish out of water. We could multiply these examples of anomalies of sensation, single or double, merely tactile or altogether tactile and contractile, by which the hand is robbed of its powers as an instrument of touch, as well as of prehension.

Setting aside these localized tactile disorders, general sensibility proper is dull in idiots, who are soon benumbed by cold and less affected by heat, but much prostrated by the atmospheric modifications of a thunder-storm.

With them the Taste and Smell are oftener indifferent than anormal. Rarely we see them have a taste for non-alimentary substances, or an exclusive appetence for one kind of food. Some of them, without swallowing, chew beads, suck pieces of broken china, etc., with apparent relish. The smell may take possession of the same articles and scent them for hours, or delight in the fragrance of two pieces of silex, stricken one against the other; or, this sense may substitute itself for any other, as a means of discrimination and knowledge; or, on the contrary, be dead-like to all intent and appearance. But the difference between the errors of function of these two senses is, that the taste is oftener depraved, and the smell is more frequently exalted.

The Hearing is sometimes so passive and limited, and the intellectual wants so disinterested to the noises transmitted to the ear, that the idiot, though possessed of perfect organs of audition, is practically deaf, and, of course, mute; no deafness, and yet no hearing. Therefore, it is prudent to remember that next to the deafness from birth, or from infantile diseases, there is an intellectual deafness from idiocy; the only one which we shall specially consider. In this interesting condition the child may hear, and even audit the sound of objects that he knows and wishes for, and none other. For instance, he hears music, and no articulated voices; or he may retain and repeat tunes, and not be able to hear or repeat a single word. He may even, in extreme cases, be absolutely indifferent, and, consequently, appear really insensible to sounds; and then the diagnosis has to be postponed till the state of the organ and function is thoroughly ascertained by an experimental training of that sense. So far, he is practically deaf and mute, but is not so organically. This difficult point in diagnosis has caused many mistakes.

The Sight may be as badly and more ostentatiously impaired than the hearing. Be it fixed in one canthus, be it wandering and unfixable, be it glossy, laughing, like a picture moving behind a motionless varnish, be it dull and immured to images, its meanings are not doubtful; it means idiocy. Our expressions here would be very incorrect if they conveyed the idea that these defects of vision prevent the child from seeing. The images being printed on their passing into the ocular chamber, as the river-side scenery is on the passing current, the child, when he pays an accidental attention, gets a notion of some of them, but the transitory perception produced thereby can hardly serve him for educational purposes. The principal characters of this infirmity are, the repugnance of the child to look and the incapacity of his will to control the organs of vision; he sees by chance, but never looks. These defects of the sight, when grave, are always connected with automatic motions, and both oppose serious obstacles to progress; one by the ease with which the child can use his negative will to prevent the training of his eyes, the other by depriving him of all knowledge to be acquired farther than the touch can reach. This complication makes a child look very unfavorably indeed, and increases much the task of his teacher.

Some idiots are deprived of speech, that is to say, do not pronounce a word. Some, speaking a few words more or less connected in sentences, have yet no language; for the word language conveys with it the meaning of interchange of ideas. In this acceptation, language does not belong to idiots before they are educated, nor to those who are but imperfectly so, and consequently, they have a speech more or less limited, but no language: strictly speaking, speech represents the function, language the faculty.

When we come to examine the anomalies of the speech, as here defined, it is well to exclude, previously, the many organic disorders which may interfere with it as a function, and which have nothing to do with idiocy but as an external impediment and exogenous aggravation. For, because a child is idiotic, it does not necessarily follow that his organs of perceiving speech and of expressing language may not be impaired by some independent affection. Idiotic or intelligent, a child may be deprived of hearing, or of the movements necessary to form the speech, directly by malformation or paralysis, or indirectly by the many causes producing deafness. These are the causes of the organic mutism which must never be attributed to idiocy, but which too often aggravates it.

To substantiate in a few words the causes of the functional mutism derived from idiocy, we point out, first, the incapacity of the will to move the organs; second, the long silence in which idiots have confirmed their mutism, like prisoners have gotten theirs in protracted confinement; third, the absence of persevering and intelligent efforts of their friends to make them speak; fourth, the want of desire to exercise that function, and the want of understanding of the power of speech as a faculty.

In this wreck of powers, one human, irresistible tendency or impulse is left him; for as low as we find him, lower than the brute in regard to activity and intelligence, he has, as the great, the lowly, the privileged, the millions, his hobby or amulet that no animal has: the external thing toward which his human, centrifugal power gravitates; if it be only a broken piece of china, a thread, a rag, an unseizable ray of the sun, he shall spend his life in admiring, kissing, catching, polishing, sucking it, according to what it may be. Till we take away that amulet, as Moses took it from his people, we must have something to substitute for it. This worship or occupation shows that if the idiot can form, of himself, no other connexion with the world, he is ready to do so if we only know how to help him.

That the idiot is endowed with a moral nature, no one who has had the happiness of ministering to him will deny. Epileptic, paralytic, choreic, or imbecile children will often strike or bite their mother or affectionate attendant. If any idiot is found doing the same (and we never found any) he must have been taught it by some cruel treatment imposed upon him. In general, as soon as his mind is opened to reflection, the tender family feelings are so deep in him that they often interfere with his successful transplantation into the broader and richer ground of our public institutions. It is true that his habits are sad, droll, or repulsive; that his doings are often worse than none; but these manifestations exhibit as much the carelessness and want of intelligence of the parents or keepers as they do the primary character of the infirmity. Does not the idiot, in making his silly gestures, tacitly say, “See what I am doing; if you knew how to teach me better and more I would do it.” It is true, that previous to being educated, the slightest work is too much for him, and makes him recoil; but if we succeed in making him believe that he has accomplished a real object, emulation will appear and shed a ray of satisfaction over his face. He is sensible to eulogy, reproach, command, menace, even to imaginary punishment; he sympathizes with the pains he can understand; he loves those who love him; he tries to please those who please him; his sense of duty and propriety is limited, but perfect in its kind; his egotism is moderate; his possessive and retentive propensities sufficient; his courage, if not Samsonian, is not aggressive, and may easily be cultivated. As a collective body, idiotic children are, in their institutions, equal in order and decency, in true lovingness, if not in loveliness, to any collection of children in the land. Their moral powers are influenced by isolation, company, multitude, silence, turmoil, music, human eloquence, as they are in all masses of mankind. If we are asked how we pretend to see all these good and promising dispositions in the unfortunate subject whom we have depicted as more or less motionless, speechless and repulsive, we can affirm that the idiot, even when neglected in his lowest conditions, does not manifest any character contrary to the one here described; a character which we have seen him assume, steadily and uniformly, under the influence of a proper training, and, as we firmly believe, in virtue of his own moral nature: he is one of us in mankind, but shut up in an imperfect envelope.

Therefore, we must not confound with imbeciles, insanes, epileptics, etc., the harmless idiot, sitting awkwardly, bashful, or at least reserved on our approach. He will answer us if he can, rarely mistaking, never deceiving, but often times failing to understand. His mind is extremely limited but not deranged and with no special tendency to final insanity. He has been hurt often, but he never assailed anybody; he loves quiet places and arrangements; repeated monotonous sounds, or stillness, and above all plain and familiar faces; he has a look, not of envy at things and persons, but of abstraction, gazing far out of this world into a something which neither we nor he can discern.

How could any child, subject to other disease or infirmity, be mistaken for him? Nevertheless this confusion takes place. Practically and legally, the idiot has been assimilated to unfortunate beings whose rights upon society are different from his; and he has suffered deeply by the mistake.

The child nearest akin to an idiot is called simply backward, in French *enfant arrièrè,* his character may be better delineated by comparison with the idiot, who presents even in superficial cases, an arrest of development, whilst the feeble-minded child is only retarded in his. The idiot has disordinate movements, cannot use his hands, swings his body in walking, presents some sensorial vices or incapacity; on the other hand, the backward child is free from any disordered activity, uses his hands naturally but with very little effectiveness, walks without defect, but without firmness or elasticity, presents no sensorial anomaly but does not much use his senses to quicken his sluggish comprehension; when the idiot does not seem to make any progress, and when the ordinary child improves in the ratio of ten, the backward child improves only in that of one, two, three, or five. This child may be, and is in fact, actually educated with the confirmed idiot; and there is no inconvenience, but advantage, in their being treated alike.

The same could not be said of the following case which is now as rarely met among idiots, as it frequently was thirty years ago in the *"hospices"* and poor-houses. He looks dignified, sad, depressed, wistful, immovable, idiotic—but worse than an idiot, he is a dement. There does not seem to be a sensible difference between them, but idiocy is accompanied by some sensorial disorders, begins young, by its worst symptoms, and generally ends quite early; whilst dementia commences in later life, is accompanied by an insidious touch of paralysis, especially of the sphincters; it soon alters the alæ nasi and the external auditory apparatus, and eventually may continue to a great age, ending by its worst symptoms.

A young lad who looks and stands like an idiot, with deep, dull eyes, hollow cheeks, thin hanging hands, flesh gone from his long, lank limbs, and empty frame; a prey to fever, languor, inappetence; tired of everything, forgetting instead of learning, avoiding company and light, sleepless yet never wide awake, speech embarrassed, mind absent, hope, gayety, cheerfulness, friendship, love future, all given up for the worship of one's self, and of a few apparitions evoked by the mania of self-destruction; his tendency is toward early death, through imbecility or dementia.

Source: Seguin, Edouard. 1866. Pp. 39–77 in *Idiocy: And Its Treatment by the Physiological Method.* New York: William Wood and Company.

▣ Karl Marx, from *Capital* (1867)

In Marx's famous analysis of capitalism, he uses disability both to impugn the character of the typical capitalist and also to demonstrate the degree to which unchecked manufacturing practices produce disability in the worker's body.

Part 4, Chapter 14, Section 5.
The Capitalistic Character of Manufacture

An increased number of labourers under the control of one capitalist is the natural starting-point, as well of co-operation generally, as of manufacture in particular. But the division of labour in manufacture makes this increase in the number of workmen a technical necessity. The minimum number that any given capitalist is bound to employ is here prescribed by the previously established division of labour. On the other hand, the advantages of further division are obtainable only by adding to the number of workmen, and this can be done only by adding multiples of the various detail groups. But an increase in the variable component of the capital employed necessitates an increase in its constant component, too, in the workshops, implements, &c., and, in particular, in the raw material, the call for which grows quicker than the number of workmen. The quantity of it consumed in a given time, by a given amount of labour, increases in the same ratio as does the productive power of that labour in consequence of its division. Hence, it is a law, based on the very nature of manufacture, that the minimum amount of capital, which is bound to be in the hands of each capitalist, must keep increasing; in other words, that the transformation into capital of the social means of production and subsistence must keep extending.

In manufacture, as well as in simple co-operation, the collective working organism is a form of existence of capital. The mechanism that is made up of numerous individual detail labourers belongs to the capitalist. Hence, the productive power resulting from a combination of labours appears to be the productive power of capital. Manufacture proper not only subjects the previously independent workman to the discipline and command of capital, but, in addition, creates a hierarchic gradation of the workmen themselves. While simple co-operation leaves the mode of working by the individual for the most part unchanged, manufacture thoroughly revolutionises it, and seizes labour-power by its very roots. It converts the labourer into a crippled monstrosity, by forcing his detail dexterity at the expense of a world of productive capabilities and instincts; just as in the States of La Plata they butcher a whole beast for the sake of his hide or his tallow. Not only is the detail work distributed to the different individuals, but the individual himself is made the automatic motor of a fractional operation, and the absurd fable of Menenius Agrippa, which makes man a mere fragment of his own body, becomes realised. If, at first, the workman sells his labour-power to capital, because the material means of producing a commodity fail him, now his very labour-power refuses its services unless it has been sold to capital. Its functions can be exercised only in an environment that exists in the workshop of the capitalist after the sale. By nature unfitted to make anything independently, the manufacturing labourer develops productive activity as a mere appendage of the capitalist's workshop. As the chosen people bore in their features the sign manual of Jehovah, so division of labour brands the manufacturing workman as the property of capital.

The knowledge, the judgement, and the will, which, though in ever so small a degree, are practised by the independent peasant or handicraftsman, in the same way as the savage makes the whole art of war consist in the exercise of his personal cunning these faculties are now required only for the workshop as a whole. Intelligence in production expands in one direction, because it vanishes in many others. What is lost by the detail labourers, is concentrated in the capital that employs them. It is a result of the division of labour in manufactures, that the labourer is brought face to face with the intellectual potencies of the material process of production, as the property of another, and as a ruling power. This separation begins in simple co-operation, where the capitalist represents to the single workman, the oneness and the will of the associated labour. It is developed in manufacture which cuts down the labourer into a detail labourer. It is completed in modern industry, which makes science a productive force distinct from labour and presses it into the service of capital.

In manufacture, in order to make the collective labourer, and through him capital, rich in social productive power, each labourer must be made poor in individual productive powers. "Ignorance is the mother of industry as well as of superstition. Reflection and fancy are subject to err; but a habit of moving the hand or the foot is independent of either. Manufactures, accordingly, prosper most where the mind is least consulted, and where the workshop may . . . be considered as an engine, the parts of which are men." As a matter of fact, some few manufacturers in the middle of the 18th century preferred, for certain operations that were trade secrets, to employ half-idiotic persons.

"The understandings of the greater part of men," says Adam Smith, "are necessarily formed by their ordinary employments. The man whose whole life is spent in performing a few simple operations . . . has no occasion to exert his understanding. . . . He generally becomes as stupid and ignorant as it is possible for a human creature to become." After describing the stupidity of the detail labourer he goes on: "The uniformity of his stationary life naturally corrupts the courage of his mind. . . . It corrupts even the activity of his body and renders him incapable of exerting his strength with vigour and perseverance in any other employments than that to which he has been bred. His dexterity at his own particular trade seems in this manner to be acquired at the expense of his intellectual, social, and martial virtues. But in every improved and civilised society, this is the state into which the labouring poor, that is, the great body of the people, must necessarily fall." For preventing the complete deterioration of the great mass of the people by division of labour, A. Smith recommends education of the people by the State, but prudently, and in homeopathic doses. G. Garnier, his French translator and commentator, who, under the first French Empire, quite naturally developed into a senator, quite as naturally opposes him on this point. Education of the masses, he urges, violates the first law of the division of labour, and with it "our whole social system would be proscribed." "Like all other divisions of labour," he says, "that between hand labour and head labour is more pronounced and decided in proportion as society (he rightly uses this word, for capital, landed property and their State) becomes richer. This division of labour, like every other, is an effect of past, and a cause of future progress . . . ought the government then to work in opposition to this division of labour, and to hinder its natural course? Ought it to expend a part of the public money in the attempt to confound and blend together two classes of labour, which are striving after division and separation?"

Some crippling of body and mind is inseparable even from division of labour in society as a whole. Since, however, manufacture carries this social separation of branches of labour much further, and also, by its peculiar division, attacks the individual at the very roots of his life, it is the first to afford the materials for, and to give a start to, industrial pathology.

"To subdivide a man is to execute him, if he deserves the sentence, to assassinate him if he does not. . . . The subdivision of labour is the assassination of a people."

Part 4, Chapter 15, Section 9. The Factory Acts. Sanitary and Educational Clauses of the Same. Their General Extension in England

Factory legislation, that first conscious and methodical reaction of society against the spontaneously developed form of the process of production, is, as we have seen, just as much the necessary product of modern industry as cotton yarn, self-actors, and the electric telegraph. Before passing to the consideration of the extension of that legislation in England, we shall shortly notice certain clauses contained in the Factory Acts, and not relating to the hours of work.

Apart from their wording, which makes it easy for the capitalist to evade them, the sanitary clauses are extremely meagre, and, in fact, limited to provisions for whitewashing the walls, for insuring cleanliness in some other matters, for ventilation, and for protection against dangerous machinery. In the third book we shall return again to the fanatical opposition of the masters to those clauses which imposed upon them a slight expenditure on appliances for protecting the limbs of their workpeople, an opposition that throws a fresh and glaring light on the Free-trade dogma, according to which, in a society with conflicting interests, each individual necessarily furthers the common weal by seeking nothing but his own personal advantage! One example is enough. The reader knows that during the last 20 years, the flax industry has very much extended, and that, with that extension, the number of scutching mills in Ireland has increased. In 1864 there were in that country 1,800 of these mills. Regularly in autumn and winter women and "young persons," the wives, sons, and daughters of the neighbouring small farmers, a class of people totally unaccustomed to machinery, are taken from field labour to feed the rollers of the scutching mills with flax. The accidents, both as regards number and kind, are wholly unexampled in the history of machinery. In one scutching mill, at Kildinan, near Cork, there occurred between 1852 and 1856, six fatal accidents and sixty mutilations; every one of which might have been prevented by the simplest appliances, at the cost of a few shillings. Dr. W. White, the certifying surgeon for factories at Downpatrick, states in his official report, dated the 15th December, 1865: "The serious accidents at the scutching mills are of the most fearful nature. In many cases a quarter of the body is torn from the trunk, and either involves death, or a future of wretched incapacity and suffering. The increase of mills in the country will, of course, extend these dreadful results, and it will be a great boon if they are brought under the legislature. I am convinced that by proper supervision of scutching mills a vast sacrifice of life and limb would be averted."

What could possibly show better the character of the capitalist mode of production, than the necessity that exists for forcing upon it, by Acts of Parliament, the simplest appliances for maintaining cleanliness and health? In the potteries the Factory Act of 1864 "has whitewashed and cleansed upwards of 200 workshops, after a period of abstinence from any such cleaning, in many cases of 20 years, and in some, entirely," (this is the "abstinence" of the capitalist!) "in which were employed 27,800 artisans, hitherto breathing through protracted days and often nights of labour, a mephitic atmosphere, and which rendered an otherwise comparatively innocuous occupation, pregnant with disease and death. The Act has improved the ventilation very much." At the same time, this portion of the Act strikingly shows that the capitalist mode of production, owing to its very nature, excludes all rational improvement beyond a certain point. It has been stated over and over again that the English doctors are unanimous in declaring that where the work is continuous, 500 cubic feet is the very least space that should be allowed for each person. Now, if the Factory Acts, owing to their compulsory provisions, indirectly hasten on the conversion of small workshops into factories, thus indirectly attacking the proprietary rights of the smaller capitalists, and assuring a monopoly to the great ones, so, if it were made obligatory to provide the proper space for each workman in every workshop, thousands of small employers would, at one full swoop, be expropriated directly! The very root of the capitalist mode of production, i.e., the self-expansion of all capital, large or small, by means of the "free" purchase and consumption of labour-power, would be attacked. Factory legislation is therefore brought to a deadlock before these 500 cubic feet of breathing space. The sanitary officers, the industrial inquiry commissioners, the factory inspectors, all harp, over and over again, upon the necessity for those 500 cubic feet, and upon the impossibility of wringing them out of capital. They thus, in fact, declare that consumption and other lung diseases among the workpeople are necessary conditions to the existence of capital.

Paltry as the education clauses of the Act appear on the whole, yet they proclaim elementary education to be an indispensable condition to the employment of children. The success of those clauses proved for the first time the possibility of combining education and gymnastics with manual labour, and, consequently, of combining manual labour with education and gymnastics. The factory inspectors soon found out by questioning the schoolmasters, that the factory children, although receiving only one half the education of the regular day scholars, yet learnt quite as much and often more. "This can be accounted for by the simple fact that, with only being at school for one half of the day, they are always fresh, and nearly always ready and willing to receive instruction. The system on which they work, half manual labour, and half school, renders each employment a rest and a relief to the other; consequently, both are far more congenial to the child, than would be the case were he kept constantly at one. It is quite clear that a boy who has been at school all the morning, cannot (in hot weather particularly) cope with one who comes fresh and bright from his work." Further information on this point will be found in Senior's speech at the Social Science Congress at Edinburgh in 1863. He there shows, amongst other things, how the monotonous and uselessly long school hours of the children of the upper and middle classes, uselessly add to the labour of the teacher, "while he not only fruitlessly but absolutely injuriously, wastes the time, health, and energy of the children." From the Factory system budded, as Robert Owen has shown us in detail, the germ of the education of the future, an education that will, in the case of every child over a given age, combine productive labour with instruction and gymnastics, not only as one of the methods of adding to the efficiency of production, but as the only method of producing fully developed human beings.

Modern Industry, as we have seen, sweeps away by technical means the manufacturing division of labour, under which each man is bound hand and foot for life to a single detail-operation. At the same time, the capitalistic form of that industry reproduces this same division of labour in a still more monstrous shape; in the factory proper, by converting the workman into a living appendage of the machine; and everywhere outside the Factory, partly by the sporadic use of machinery and machine workers, partly by re-establishing the division of labour on a fresh basis by the general introduction of the labour of women and children, and of cheap unskilled labour.

The antagonism between the manufacturing division of labour and the methods of Modern Industry makes itself forcibly felt. It manifests itself, amongst other ways, in the frightful fact that a great part of the children employed in modern factories and manufactures, are from their earliest years riveted to the most simple manipulations, and exploited for years, without being taught a single sort of work that would afterwards make them of use, even in the same manufactory or factory. In the English letter-press printing trade, for example, there existed formerly a system, corresponding to that in the old manufactures and handicrafts, of advancing the apprentices from easy to more and more difficult work. They went through a course of teaching till they were finished printers. To be able to read and write was for every one of them a requirement of their trade. All this was changed by the printing machine. It employs two sorts of labourers, one grown up, renters, the other, boys mostly from 11 to 17 years of age whose sole business is either to spread the sheets of paper under the machine, or to take from it the printed sheets. They perform this weary task, in London especially, for 14, 15, and 16 hours at a stretch, during several days in the week, and frequently for 36 hours, with only 2 hours' rest for meals and sleep. A great part of them cannot read, and they are, as a rule, utter savages and very extraordinary creatures. "To qualify them for the work which they have to do, they require no intellectual training; there is little room in it for skill, and less for judgment; their wages, though rather high for boys, do not increase proportionately as they grow up, and the majority of them cannot look for advancement to the better paid and more responsible post of machine minder, because while each machine has but one minder, it has at least two, and often four boys attached to it." As soon as they get too old for such child's work, that is about 17 at the latest, they are discharged from the printing establishments. They become recruits of crime. Several attempts to procure them employment elsewhere, were rendered of no avail by their ignorance and brutality, and by their mental and bodily degradation.

Source: Marx, Karl. 1887. Moore, Samuel, and Edward Aveling, trans. *Capital: A Critique of Political Economy, Vol. I. The Process of Capitalist Production*. London: S. Sonnenschein, Lowrey.

▣ Francis Galton, from *Hereditary Genius* (1869)

Sir Francis Galton, who coined the term eugenics, used statistics to determine average and exceptional characteristics of human bodies. In this excerpt, he sets out to argue that genius and intelligence are passed down according to the laws of basic heredity that govern common qualities such as eye and hair color. In doing so, Galton set out to demonstrate that control over breeding practices could artificially engineer a more superior national race endowed with the qualities he most admired.

Introductory Chapter

I propose to show in this book that a man's natural abilities are derived by inheritance, under exactly the same limitations as are the form and physical features of the whole organic world. Consequently, as it is easy, notwithstanding those limitations, to obtain by careful selection a permanent breed of dogs or horses gifted with peculiar powers of running, or of doing anything else, so it would be quite practicable to produce a highly-gifted race of men by judicious marriages during several consecutive generations. I shall show that social agencies of an ordinary character, whose influences are little suspected, are at this moment working towards the degradation of human nature, and that others are working towards its improvement. I conclude that each generation has enormous power over the natural gifts of those that follow, and maintain that it is a duty we owe to humanity to investigate the range of that power, and to exercise it in a way that, without being unwise towards ourselves, shall be most advantageous to future inhabitants of the earth.

I am aware that my views, which were first published four years ago in *Macmillan's Magazine* (in June and August 1865), are in contradiction to general opinion; but the arguments I then used have been since accepted, to my great gratification, by many of the highest authorities on heredity. In reproducing them, as I now do, in a much more elaborate form, and on a greatly enlarged basis of induction, I feel assured that, inasmuch as what I then wrote was sufficient to earn the acceptance of Mr. Darwin (*Domestication of Plants and Animals, ii 7),* the increased amount of evidence submitted in the present volume is not likely to be gainsaid.

The general plan of my argument is to show that high reputation is a pretty accurate test of high ability; next to discuss the relationships of a large body of fairly eminent men—namely, the Judges of England from 1660 to 1868, the Statesmen of the time of George III, and the Premiers during the last 100 years—and to obtain from these a general survey of the laws of heredity in respect to genius. Then I shall examine, in order, the kindred of the most illustrious Commanders, men of Literature and of Science, Poets, painters, and Musicians, of whom history speaks. I shall also discuss the kindred of a certain selection of Divines and of modern Scholars. Then will follow a short chapter, by way of comparison, on the hereditary transmission of physical gifts, as deduced from the relationships of certain classes of Oarsmen and Wrestlers. Lastly, I shall collate my results, and draw conclusions.

It will be observed that I deal with more than one grade of ability. Those upon whom the greater part of my volume is occupied, and on whose kinships my argument is most securely based, have been generally reputed as endowed by nature with extraordinary genius. There are so few of these men that, although they are scattered throughout the whole historical period of human existence, their number does not amount to more than 400, and yet a considerable proportion of them will be found to be interrelated.

Another grade of ability with which I deal is that which includes numerous highly eminent, and all the illustrious names of modern English history, whose immediate descendants are living among us, whose histories are popularly known, and whose relationships may readily be traced by the help of biographical dictionaries, peerages, and similar books of reference.

A third and lower grade is that of the English Judges, massed together as a whole, for the purpose of the prefatory statistical inquiry of which I have already spoken. No one doubts that many of the ablest intellects of our race are to be found among the Judges; nevertheless the *average* ability of a Judge cannot be rated as equal to that of the lower of the two grades I have described.

I trust the reader will make allowance for a large and somewhat important class of omissions I have felt myself compelled to make when treating of the eminent men of modern days. I am prevented by a sense of decorum from quoting names of their relations in contemporary life who are not recognized as public characters, although their abilities may be highly appreciated in private life. Still less consistent with decorum would it have been, to introduce the names of female relatives that stand in the same category. My case is so overpoweringly strong, that I am perfectly able to prove my point without having recourse to this class of evidence. Nevertheless, the reader should bear in mind that it exists; and I beg he will do me the justice of allowing that I have not overlooked the whole of the evidence that does not appear in my pages. I am deeply conscious of the imperfection of my work, but my sins are those of omission, not of commission. Such errors as I may and must have made, which give a fictitious support to my arguments, are, I am confident, out of all proportion fewer than such omissions of facts as would have helped to establish them.

I have taken little notice in this book of modern men of eminence who are not English, or at least well known to Englishmen. I feared, if I included large classes of foreigners, that I should make glaring errors. It requires a very great deal of labour to hunt out relationships, even with the facilities afforded to a countryman having access to persons acquainted with the various families; much more would it have been difficult to hunt out the kindred of foreigners. I should have especially liked to investigate the biographies of Italians and Jews, both of whom appear to be rich in families of high intellectual breeds. Germany and America are also full of interest. It is little less so with respect to France, where the Revolution and the guillotine made sad havoc among the progeny of her abler races.

There is one advantage to a candid critic in my having left so large a field untouched; it enables me to propose a test that any well-informed reader may easily adopt who doubts the fairness of my examples. He may most reasonably suspect that I have been unconsciously influenced by my theories to select men whose kindred were most favourable to their support. If so, I beg he will test my impartiality as follows:—Let him take a dozen names of his own selection, as the most eminent in whatever profession and in whatever country he knows most about, and let him trace out for himself their relations. It is necessary, as I find by experience, to take some pains to be sure that none, even of the immediate relatives, on either the male or female side, have been overlooked. If he does what I propose, I am confident he will be astonished at the completeness with which the results will confirm my theory. I venture to speak with assurance, because it has often occurred to me to propose this very test to incredulous friends, and invariably, so far as my memory serves me, as large a proportion of the men who were named were discovered to have eminent relations, as the nature of my views on heredity would have led us to expect.

From "Classification of Men According to their Natural Gifts"

In whatever way we may test ability, we arrive at equally enormous intellectual differences. Lord Macaulay (*see* under LITERATURE for his remarkable kinships) had one of the most tenacious of memories. He was able to recall many pages of hundreds of volumes by various authors, which he had acquired by simply reading them over. An average man could not certainly carry in his memory one thirty-second—ay, or one hundredth—part as much as Lord Macaulay. The father of Seneca had one of the greatest memories on record in ancient times (*see* under LITERATURE for his kinships). Porson, the Greek scholar, was remarkable for this gift, and, I may add, the "Porson memory" was hereditary in that family. In statesmanship, generalship, literature, science, poetry, art, just the same enormous differences are found between man and man; and numerous instances recorded in this book, will show in how small degree, eminence, either in these or any other class of intellectual powers, can be considered as due to purely special powers. They are rather to be considered in those instances as the result of concentrated efforts, made by men who are widely gifted. People lay too much stress on apparent specialities, thinking over-rashly that, because a man is devoted to some particular pursuit, he could not possibly have succeeded in anything else. They might just as well say that, because a youth had fallen desperately in love with a brunette, he could not possibly have fallen in love with a blonde. He may or may not have more natural liking for the former type of beauty than the latter, but it is as probable as not that the affair was mainly or wholly due to a general amorousness of disposition. It is just the same with special pursuits. A gifted man is often capricious and fickle before he selects his occupation, but when it has been chosen, he devotes himself to it with a truly passionate ardour. After a man of genius has selected his hobby, and so adapted himself to it as to seem unfitted for any other occupation in life, and to be possessed of but one special aptitude, I often notice, with admiration, how well he bears himself when circumstances suddenly thrust him into a strange position. He will display an insight into new conditions, and a power of dealing with them, with which even his most intimate friends were unprepared to accredit him. Many a presumptuous fool has mistaken indifference and neglect for incapacity; and in trying to throw a man of genius on ground where he was unprepared for attack, has himself received a most severe and unexpected fall. I am sure that no one who has had the privilege of mixing in the society of the abler men of any great capital, or who is acquainted with the biographies of the heroes of history, can doubt the existence of grand human animals, of natures pre-eminently noble, of individuals born to be kings of men. I have been conscious of no slight misgiving that I was committing a kind of sacrilege whenever, in the preparation of materials for this book, I had occasion to take the measurement of modern intellects vastly superior to my own, or to criticize the genius of the most magnificent historical specimens of our race. It was a process that constantly recalled to me a once familiar sentiment in bygone days of African travel, when I used to take altitudes of the huge cliffs that domineered above me as I traveled along their bases, or to map the mountainous landmarks of unvisited tribes, that loomed in faint grandeur beyond my actual horizon.

I have not cared to occupy myself much with people whose gifts are below the average, but they would be an interesting study. The number of idiots and imbeciles among the twenty million inhabitants of England and Wales is approximately estimated at 50,000, or as 1 in 400. Dr. Seguin, a great French authority on these matters, states that more than thirty per cent. of idiots and imbeciles, put under suitable instruction, have been taught to conform to social and moral law, and rendered capable of order, of good feeling, and of working like *the third* of an average man. He says that more than forty per cent. have become capable of the ordinary transactions of life, under friendly control; of understanding moral and social abstractions, and of working like *two-thirds* of a man. And, lastly, that from twenty-five to thirty per cent. come nearer and nearer to the standard of manhood, till some of them will defy the scrutiny of good judges, when compared with ordinary young men and women. In the order next above idiots and imbeciles are a large number of milder cases scattered among private families and kept out of sight, the existence of whom is, however, well known to relatives and friends; they are too silly to take a part in general society, but are easily amused with some trivial, harmless occupation. Then comes a class of whom the Lord Dundreary of the famous play may be considered a representative; and so, proceeding through successive grades, we gradually ascend to mediocrity. I know two good instances of hereditary silliness short of imbecility, and have reason to believe I could easily obtain a large number of similar facts.

To conclude, the range of mental power between—I will not say the highest Caucasian and the lowest savage—but between the greatest and least of English intellects, is enormous. There is a continuity of natural ability reaching from one knows not what height, and descending to one can hardly say what depth. I propose in this chapter to range men according to their natural abilities, putting them into classes separated by equal degrees of merit, and to show the relative number of individuals included in the several classes. Perhaps some person might be inclined to make an offhand guess that the number of men included in the several classes would be pretty equal. If he thinks so, I can assure him he is most egregiously mistaken.

The method I shall employ for discovering all this is an application of the very curious theoretical law of "deviation from an average." First, I will explain the law, and then I will show that the production of natural intellectual gifts comes justly within its scope.

The law is an exceedingly general one. M. Quetelet, the Astronomer-Royal of Belgium, and the greatest authority on vital and social statistics, has largely used it in his inquiries. He has also constructed numerical tables, by which the necessary calculations can be easily made, whenever it is desired to have recourse to the law. Those who wish to learn more than I have space to relate, should consult his work, which is a very readable octavo volume, and deserves to be far better known to statisticians than it appears to be. Its title is *Letters on Probabilities,* translated by Downes. Layton and Co. London: 1849.

Source: Galton, Francis. 1869. *Hereditary Genius.* Available at: http://www.mugu.com/galton/books/hereditary-genius/

Mark Twain, from *Innocents Abroad: Or, The New Pilgrim's Progress* (1869)

One of Twain's most popular books, this travel odyssey explores his experiences in the Middle East, Crimea, Greece, and Egypt. In this excerpt, Twain discusses the impact of the presence of a doctor in his party on "diseased" populations seeking medical assistance in their conditions.

From Chapter 45

This morning, during breakfast, the usual assemblage of squalid humanity sat patiently without the charmed circle of the camp and waited for such crumbs as pity might bestow upon their misery. There were old and young, brown-skinned and yellow. Some of the men were tall and stalwart, (for one hardly sees any where such splendid-looking men as here in the East,) but all the women and children looked worn and sad, and distressed with hunger. They reminded me much of Indians, did these people. They had but little clothing, but such as they had was fanciful in character and fantastic in its arrangement. Any little absurd gewgaw or gimcrack they had they disposed in such a way as to make it attract attention most readily. They sat in silence, and with tireless patience watched our every motion with that vile, uncomplaining impoliteness which is so truly Indian, and which makes a white man so nervous and uncomfortable and savage that he wants to exterminate the whole tribe.

These people about us had other peculiarities, which I have noticed in the noble red man, too: they were infested with vermin, and the dirt had caked on them till it amounted to bark.

The little children were in a pitiable condition—they all had sore eyes, and were otherwise afflicted in various ways. They say that hardly a native child in all the East is free from sore eyes, and that thousands of them go blind of one eye or both every year. I think this must be so, for I see plenty of blind people every day, and I do not remember seeing any children that hadn't sore eyes. And, would you suppose that an American mother could sit for an hour, with her child in her arms, and let a hundred flies roost upon its eyes all that time undisturbed? I see that every day. It makes my flesh creep. Yesterday we met a woman riding on a little jackass, and she had a little child in her arms—honestly, I thought the child had goggles on as we approached, and I wondered how its mother could afford so much style. But when we drew near, we saw that the goggles were nothing but a camp meeting of flies assembled around each of the child's eyes, and at the same time there was a detachment prospecting its nose. The flies were happy, the child was contented, and so the mother did not interfere.

As soon as the tribe found out that we had a doctor in our party, they began to flock in from all quarters. Dr. B., in the charity of his nature, had taken a child from a woman who sat near by, and put some sort of a wash upon its diseased eyes. That woman went off and started the whole nation, and it was a sight to see them swarm! The lame, the halt, the blind, the leprous—all the distempers that are bred of indolence, dirt, and iniquity—were represented in the Congress in ten minutes, and still they came! Every woman that had a sick baby brought it along, and every woman that hadn't, borrowed one. What reverent and what worshiping looks they bent upon that dread, mysterious power, the Doctor! They watched him take his phials out; they watched him measure the particles of white powder; they watched him add drops of one precious liquid, and drops of another; they lost not the slightest movement; their eyes were riveted upon him with a fascination that nothing could distract. I believe they thought he was gifted like a god. When each individual got his portion of medicine, his eyes were radiant with joy—notwithstanding by nature they are a thankless and impassive race—and upon his face was written the unquestioning faith that nothing on earth could prevent the patient from getting well now.

Christ knew how to preach to these simple, superstitious, disease-tortured creatures: He healed the sick. They flocked to our poor human doctor this morning when the fame of what he had done to the sick child went abroad in the land, and they worshiped him with their eyes while they did not know as yet whether there was virtue in his simples or not. The ancestors of these—people precisely like them in color, dress, manners, customs, simplicity—flocked in vast multitudes after Christ, and when they saw Him make the afflicted whole with a word, it is no wonder they worshiped Him. No wonder His deeds were the talk of the nation. No wonder the multitude that followed Him was so great that at one time—thirty miles from here—they had to let a sick man down through the roof because no approach could be made to the door; no wonder His audiences were so great at Galilee that He had to preach from a ship removed a little distance from the shore; no wonder that even in the desert places about Bethsaida, five thousand invaded His solitude, and He had to feed them by a miracle or else see them suffer for their confiding faith and devotion; no wonder when there was a great commotion in a city in those days, one neighbor explained it to another in words to this effect: "They say that Jesus of Nazareth is come!"

Well, as I was saying, the doctor distributed medicine as long as he had any to distribute, and his reputation is mighty in Galilee this day. Among his patients was the child of the Shiek's daughter—for even this poor, ragged handful of sores and sin has its royal Shiek—a poor old mummy that looked as if he would be more at home in a poor-house than in the Chief Magistracy of this tribe of hopeless, shirtless savages. The princess—I mean the Shiek's daughter—was only thirteen or fourteen years old, and had a very sweet face and a pretty one. She was the only Syrian female we have seen yet who was not so sinfully ugly that she couldn't smile after ten o'clock Saturday night without breaking the Sabbath. Her child was a hard specimen, though—there wasn't enough of it to make a pie, and the poor little thing looked so pleadingly up at all who came near it (as if it had an idea that now was its chance or never,) that we were filled with compassion which was genuine and not put on.

Source: Twain, Mark. 1869. *Innocents Abroad: Or, The New Pilgrim's Progress.* Available at: http://www.mtwain.com/Innocents_Abroad/0.html

▣ Deaf and Deaf-Mute Servants in the Sultan's Court (1870–1909)

The following excerpts all pertain to populations identified as deaf and deaf-mute. They were all written during the reign of Sultan Abdel Hamid II (reigned 1876–1909). Those by the German physician and traveler Nachtigal and the French colonial governor Henri Gaden indicate that deaf servants were still much required by the Sultan, who sent his requisition as far as the slave-trading center at Darfur.

G. Nachtigal

From Nachtigal, G. 1971–1987. Fisher, A. G. B., & H. J. Fisher, trans. *Sahara and Sudan.* London: Hurst.

1870s In 1872, Nachtigal learned that the leading men of Bornu had given gifts, including "ordinary slaves, eunuchs, deaf-mutes and dwarfs," to an emissary of the Ottoman Sultan (Vol. IV: P. 4). At Kuka (capital of Bornu), west of Lake Chad, he remarked that "deaf and dumb slave girls" were sold for high prices to serve the wives of businessmen in some Islamic countries (Vol. II: P. 218).

Henri Gaden

Gaden, Henri. 1907. Etats musulmans de l'Afrique centrale et leurs rapports avec la Mecque et Constantinople. *Questions diplomatiques et coloniales* 24: 436–447.

1870s Gaden (P. 444) noted the long reign (1874–1898) of Sultan Yusuf at Ouadai (now in Chad), who "sent eunuchs to Constantinople almost yearly. Once, when the Ottoman Sultan Abd el-Hamid asked him particularly for deaf-mutes, he searched his kingdom and sent all whom he could find."

J. Sibree

Sibree, J. 1884. Notes on relics of the sign and gesture language among the Malagasy. *Journal of the Anthropological Institute of Great Britain and Ireland* 13:174–183. [Note that Pp. 179–182 include a "Postscript," with contributions from authors Houlder, Price, Peill, and Thorne, and on Pp. 182–183 there are "Discussion" notes, from Mr. Hyde Clark.]

1884 In reported discussion after Sibree's paper, Mr. Hyde Clarke gave more detail of the sign language used in the Ottoman Seraglio, which he had witnessed (Pp. 182–183). Both Sibree and Hyde Clarke were interested in tracing back their observations of gesture language in the 1880s to earlier sources, as far back as the historical texts with which they were familiar, that is, from ancient Rome and Palestine.

Daguerreotype (1849) of Dorothea Lynde Dix (1802–1887). In the United States during the Progressive Era, Dorothea Lynde Dix was a social reformer and advocate for those diagnosed as feebleminded and mentally ill. Dix demanded an end to the neglect of individuals deemed valueless and lobbied for the creation of humane, state-supported institutions in the United States.

Source: Art Resource, New York.

Ludger Busse

Busse, Ludger. 1994. Ferdi Garati und seine Schule für Gehörlose und Blinde in Istanbul—Die Ursprünge des türkischen Sonderschulwesens. *Hörgeschädigten Pädagogik* 48:227–235.

1889 Describes the opening by F. Garati of a formal deaf school at Istanbul in 1889 and its functioning until it closed in 1926. A blind school was added in 1890, but it closed seven years later.

▣ Charles Darwin, from *The Descent of Man* (1871)

In this excerpt, Darwin argues in favor of his evolutionary theory based on beliefs about the inferior bodies/capacities of racialized and disabled populations. The existence of "lesser" forms of humanity and monstrous abnormalities serves to anchor proofs about the continuity of human and animal forms.

Chapter II. On the Manner of Development of Man from Some Lower Form

I have elsewhere so fully discussed the subject of Inheritance, that I need here add hardly anything. A greater number of facts have been collected with respect to the transmission of the most trifling, as well as of the most important characters in man, than in any of the lower animals; though the facts are copious enough with respect to the latter. So in regard to mental qualities, their transmission is manifest in our dogs, horses, and other domestic animals. Besides special tastes and habits, general intelligence, courage, bad and good temper, &c., are certainly transmitted. With man we see similar facts in almost every family; and we now know, through the admirable labours of Mr. Galton, that genius which implies a wonderfully complex combination of high faculties, tends to be inherited; and, on the other hand, it is too certain that insanity and deteriorated mental powers likewise run in families.

With respect to the causes of variability, we are in all cases very ignorant; but we can see that in man as in the lower animals, they stand in some relation to the conditions to which each species has been exposed, during several generations. Domesticated animals vary more than those in a state of nature; and this is apparently due to the diversified and changing nature of the conditions to which they have been subjected. In this respect the different races of man resemble domesticated animals, and so do the individuals of the same race, when inhabiting a very wide area, like that of America. We see the influence of diversified conditions in the more civilised nations; for the members belonging to different grades of rank, and following different occupations, present a greater range of character than do the members of barbarous nations. But the uniformity of savages has often been exaggerated, and in some cases can hardly be said to exist. It is, nevertheless, an error to speak of man, even if we look only to the conditions to which he has been exposed, as "far more domesticated" than any other animal. Some savage races, such as the Australians, are not exposed to more diversified conditions than are many species which have a wide range. In another and much more important respect, man differs widely from any strictly domesticated animal; for his breeding has never long been controlled, either by methodical or unconscious selection. No race or body of men has been so completely subjugated by other men, as that certain individuals should be preserved, and thus unconsciously selected, from somehow excelling in utility to their masters. Nor have certain male and female individuals been intentionally picked out and matched, except in the well-known case of the Prussian grenadiers; and in this case man obeyed, as might have been expected, the law of methodical selection; for it is asserted that many tall men were reared in the villages inhabited by the grenadiers and their tall wives. In Sparta, also, a form of selection was followed, for it was enacted that all children should be examined shortly after birth; the well-formed and vigorous being preserved, the others left to perish.

If we consider all the races of man as forming a single species, his range is enormous; but some separate races, as the Americans and Polynesians, have very wide ranges. It is a well-known law that widely-ranging species are much more variable than species with restricted ranges; and the variability of man may with more truth be compared with that of widely-ranging species, than with that of domesticated animals.

Not only does variability appear to be induced in man and the lower animals by the same general causes, but in both the same parts of the body are effected in a closely analogous manner. This has been proved in such full detail by Godron and Quatrefages, that I need here only refer to their works. Monstrosities, which graduate into slight variations, are likewise so similar in man and the lower animals, that the same classification and the same terms can be used for both, as has been shewn by Isidore Geoffroy St.-Hilaire. In my work on the variation of domestic animals, I have attempted to arrange in a rude fashion the laws of variation under the following heads:—The direct and definite action of changed conditions, as exhibited by all or nearly all the individuals of the same species, varying in the same manner under the same circumstances. The effects of the long-continued use or disuse of parts. The cohesion of homologous parts. The variability of multiple parts. Compensation of growth; but of this law I have found no good instance in the case of man. The effects of the mechanical pressure of one part on another; as of the pelvis on the cranium of the infant in the womb. Arrests of development, leading to the diminution or suppression of parts. The reappearance of long-lost characters through reversion. And lastly, correlated variation. All these so-called laws apply equally to man and the lower animals; and most of them even to plants. It would be superfluous here to discuss all of them; but several are so important, that they must be treated at considerable length. . . .

Effects of the Increased Use and Disuse of Parts

It is well known that use strengthens the muscles in the individual, and complete disuse, or the destruction of the proper nerve, weakens them. When the eye is destroyed, the optic nerve often becomes atrophied. When an artery is tied, the lateral channels increase not only in diameter, but in the thickness and strength of their coats. When one kidney ceases to act from disease, the other increases in size, and does double work. Bones increase not only in thickness, but in length, from carrying a greater weight. Different occupations, habitually followed, lead to changed proportions in various parts of the body. Thus it was ascertained by the United States Commission that the legs of the sailors employed in the late war were longer by 0.217 of an inch than those of the soldiers, though the sailors were on an average shorter men; whilst their arms were shorter by 1.09 of an inch, and therefore, out of proportion, shorter in relation to their lesser height. This shortness of the arms is apparently due to their greater use, and is an unexpected result: but sailors chiefly use their arms in pulling, and not in supporting weights. With sailors, the girth of the neck and the depth of the instep are greater, whilst the circumference of the chest, waist, and hips is less, than in soldiers.

Whether the several foregoing modifications would become hereditary, if the same habits of life were followed during many generations, is not known, but it is probable. Rengger attributes the thin legs and thick arms of the Payaguas Indians to successive generations having passed nearly their whole lives in canoes, with their lower extremities motionless. Other writers have come to a similar conclusion in analogous cases. According to Cranz, who lived for a long time with the Esquimaux, “The natives believe that ingenuity and dexterity in seal-catching (their highest art and virtue) is hereditary; there is really something in it, for the son of a celebrated seal-catcher will distinguish himself, though he lost his father in childhood.” But in this case it is mental aptitude, quite as much as bodily structure, which appears to be inherited. It is asserted that the hands of English labourers are at birth larger than those of the gentry. From the correlation which exists, at least in some cases, between the development of the extremities and of the jaws, it is possible that in those classes which do not labour much with their hands and feet, the jaws would be reduced in size from this cause. That they are generally smaller in refined and civilized men than in hard-working men or savages, is certain. But with savages, as Mr. Herbert Spencer has remarked, the greater use of the jaws in chewing coarse, uncooked food, would act in a direct manner on the masticatory muscles, and on the bones to which they are attached. In infants, long before birth, the skin on the soles of the feet is thicker than on any other part of the body; and it can hardly be doubted that this is due to the inherited effects of pressure during a long series of generations.

It is familiar to every one that watchmakers and engravers are liable to be short-sighted, whilst men living much out of doors, and especially savages, are generally long-sighted. Short-sight and long-sight certainly tend to be inherited. The inferiority of Europeans, in comparison with savages, in eyesight and in the other senses, is no doubt the accumulated and transmitted effect of lessened use during many generations; for Rengger states that he has repeatedly observed Europeans, who had been brought up and spent their whole lives with the wild Indians, who nevertheless did not equal them in the sharpness of their senses. The same naturalist observes that the cavities in the skull for the reception of the several sense-organs are larger in the American aborigines than in Europeans; and this probably indicates a corresponding difference in the dimensions of the organs themselves. Blumenbach has also remarked on the large size of the nasal cavities in the skulls of the American aborigines, and connects this fact with their remarkably acute power of smell. The Mongolians of the plains of northern Asia, according to Pallas, have wonderfully perfect senses; and Prichard believes that the great breadth of their skulls across the zygomas follows from their highly-developed sense organs.

The Quechua Indians inhabit the lofty plateaux of Peru; and Alcide d'Orbigny states that, from continually breathing a highly rarefied atmosphere, they have acquired chests and lungs of extraordinary dimensions. The cells, also, of the lungs are larger and more numerous than in Europeans. These observations have been doubted, but Mr. D. Forbes carefully measured many Aymaras, an allied race, living at the height of between 10,000 and 15,000 feet; and he informs me that they differ conspicuously from the men of all other races seen by him in the circumference and length of their bodies. In his table of measurements, the stature of each man is taken at 1000, and the other measurements are reduced to this standard. It is here seen that the extended arms of the Aymaras are shorter than those of Europeans, and much shorter than those of Negroes. The legs are likewise shorter; and they present this remarkable peculiarity, that in every Aymara measured, the femur is actually shorter than the tibia. On an average, the length of the femur to that of the tibia is as 211 to 252; whilst in two Europeans, measured at the same time, the femora to the tibiae were as 244 to 230; and in three Negroes as 258 to 241. The humerus is likewise shorter relatively to the forearm. This shortening of that part of the limb which is nearest to the body, appears to be, as suggested to me by Mr. Forbes, a case of compensation in relation with the greatly increased length of the trunk. The Aymaras present some other singular points of structure, for instance, the very small projection of the heel.

These men are so thoroughly acclimatised to their cold and lofty abode, that when formerly carried down by Spaniards to the low eastern plains, and when now tempted down by high wages to the gold-washings, they suffer a frightful rate of mortality. Nevertheless Mr. Forbes found a few pure families which had survived during two generations: and he observed that they still inherited their characteristic peculiarities. But it was manifest, even without measurement, that these peculiarities had all decreased; and on measurement, their bodies were found not to be so much elongated as those of the men on the high plateau; whilst their femora had become somewhat lengthened, as had their tibiae, although in a less degree. The actual measurements may be seen by consulting Mr. Forbes's memoir. From these observations, there can, I think, be no doubt that residence during many generations at a great elevation tends, both directly and indirectly, to induce inherited modifications in the proportions of the body.

Although man may not have been much modified during the latter stages of his existence through the increased or decreased use of parts, the facts now given shew that his liability in this respect has not been lost; and we positively know that the same law holds good with the lower animals. Consequently we may infer that when at a remote epoch the progenitors of man were in a transitional state, and were changing from quadrupeds into bipeds, natural selection would probably have been greatly aided by the inherited effects of the increased or diminished use of the different parts of the body.

Arrests of Development

There is a difference between arrested development and arrested growth, for parts in the former state continue to grow whilst still retaining their early condition. Various monstrosities come under this head; and some, as a cleft palate, are known to be occasionally inherited. It will suffice for our purpose to refer to the arrested brain-development of microcephalous idiots, as described in Vogt's memoir. Their skulls are smaller, and the convolutions of the brain are less complex than in normal men. The frontal sinus, or the projection over the eyebrows, is largely developed, and the jaws are prognathous to an "effrayant" degree; so that these idiots somewhat resemble the lower types of mankind. Their intelligence, and most of their mental faculties, are extremely feeble. They cannot acquire the power of speech, and are wholly incapable of prolonged attention, but are much given to imitation. They are strong and remarkably active, continually gambolling and jumping about, and making grimaces. They often ascend stairs on all-fours; and are curiously fond of climbing up furniture or trees. We are thus reminded of the delight shewn by almost all boys in climbing trees; and this again reminds us how lambs and kids, originally alpine animals, delight to frisk on any hillock, however small. Idiots also resemble the lower animals in some other respects; thus several cases are recorded of their carefully smelling every mouthful of food before eating it. One idiot is described as often using his mouth in aid of his hands, whilst hunting for lice. They are often filthy in their habits, and have no sense of decency; and several cases have been published of their bodies being remarkably hairy.

Reversion

Many of the cases to be here given, might have been introduced under the last heading. When a structure is arrested in its development, but still continues growing, until it closely resembles a corresponding structure in some lower and adult member of the same group, it may in one sense be considered as a case of reversion. The lower members in a group give us some idea how the common progenitor was probably constructed; and it is hardly credible that a complex part, arrested at an early phase of embryonic development, should go on growing so as ultimately to perform its proper function, unless it had acquired such power during some earlier state of existence, when the present exceptional or arrested structure was normal. The simple brain of a microcephalous idiot, in as far as it resembles that of an ape, may in this sense be said to offer a case of reversion. There are other cases which come more strictly under our present head of reversion. Certain structures, regularly occurring in the lower members of the group to which man belongs, occasionally make their appearance in him, though not found in the normal human embryo; or, if normally present in the human embryo, they become abnormally developed, although in a manner which is normal in the lower members of the group. These remarks will be rendered clearer by the following illustrations.

In the above work (vol. ii., p. 12), I also attributed, though with much hesitation, the frequent cases of polydactylism in men and various animals to reversion. I was partly led to this through Prof. Owen's statement, that some of the Ichthyopterygia possess more than five digits, and therefore, as I supposed, had retained a primordial condition; but Prof. Gegenbaur (*Jenaische Zeitschrift*, B. v., Heft 3, s. 341), disputes Owen's conclusion. On the other hand, according to the opinion lately advanced by Dr. Gunther, on the paddle of Ceratodus, which is provided with articulated bony rays on both sides of a central chain of bones, there seems no great difficulty in admitting that six or more digits on one side, or on both sides, might reappear through reversion. I am informed by Dr. Zouteveen that there is a case on record of a man having twenty-four fingers and twenty-four toes! I was chiefly led to the conclusion that the presence of supernumerary digits might be due to reversion from the fact that such digits, not only are strongly inherited, but, as I then believed, had the power of regrowth after amputation, like the normal digits of the lower Vertebrata. But I have explained in the second edition of my Variation under Domestication why I now place little reliance on the recorded cases of such regrowth. Nevertheless it deserves notice, inasmuch as arrested development and reversion are intimately related processes; that various structures in an embryonic or arrested condition, such as a cleft palate, bifid uterus, &c., are frequently accompanied by polydactylism.

This has been strongly insisted on by Meckel and Isidore Geoffroy St.-Hilaire. But at present it is the safest course to give up altogether the idea that there is any relation between the development of supernumerary digits and reversion to some lowly organized progenitor of man.

In various mammals the uterus graduates from a double organ with two distinct orifices and two passages, as in the marsupials, into a single organ, which is in no way double except from having a slight internal fold, as in the higher apes and man. The rodents exhibit a perfect series of gradations between these two extreme states. In all mammals the uterus is developed from two simple primitive tubes, the inferior portions of which form the cornua; and it is in the words of Dr. Farre, "by the coalescence of the two cornua at their lower extremities that the body of the uterus is formed in man; while in those animals in which no middle portion or body exists, the cornua remain ununited. As the development of the uterus proceeds, the two cornua become gradually shorter, until at length they are lost, or, as it were, absorbed into the body of the uterus." The angles of the uterus are still produced into cornua, even in animals as high up in the scale as the lower apes and lemurs.

Now in women, anomalous cases are not very infrequent, in which the mature uterus is furnished with cornua, or is partially divided into two organs; and such cases, according to Owen, repeat "the grade of concentrative development," attained by certain rodents. Here perhaps we have an instance of a simple arrest of embryonic development, with subsequent growth and perfect functional development; for either side of the partially double uterus is capable of performing the proper office of gestation. In other and rarer cases, two distinct uterine cavities are formed, each having its proper orifice and passage. No such stage is passed through during the ordinary development of the embryo; and it is difficult to believe, though perhaps not impossible, that the two simple, minute, primitive tubes should know how (if such an expression may be used) to grow into two distinct uteri, each with a well-constructed orifice and passage, and each furnished with numerous muscles, nerves, glands and vessels, if they had not formerly passed through a similar course of development, as in the case of existing marsupials. No one will pretend that so perfect a structure as the abnormal double uterus in woman could be the result of mere chance. But the principle of reversion, by which a long-lost structure is called back into existence, might serve as the guide for its full development, even after the lapse of an enormous interval of time.

Professor Canestrini, after discussing the foregoing and various analogous cases, arrives at the same conclusion as that just given. He adduces another instance, in the case of the malar bone, which, in some of the Quadrumana and other mammals, normally consists of two portions. This is its condition in the human foetus when two months old; and through arrested development, it sometimes remains thus in man when adult, more especially in the lower prognathous races. Hence Canestrini concludes that some ancient progenitor of man must have had this bone normally divided into two portions, which afterwards became fused together. In man the frontal bone consists of a single piece, but in the embryo, and in children, and in almost all the lower mammals, it consists of two pieces separated by a distinct suture. This suture occasionally persists more or less distinctly in man after maturity; and more frequently in ancient than in recent crania, especially, as Canestrini has observed, in those exhumed from the Drift, and belonging to the brachycephalic type. Here again he comes to the same conclusion as in the analogous case of the malar bones. In this, and other instances presently to be given, the cause of ancient races approaching the lower animals in certain characters more frequently than do the modern races, appears to be, that the latter stand at a somewhat greater distance in the long line of descent from their early semi-human progenitors.

Various other anomalies in man, more or less analogous to the foregoing, have been advanced by different authors, as cases of reversion; but these seem not a little doubtful, for we have to descend extremely low in the mammalian series, before we find such structures normally present.

In man, the canine teeth are perfectly efficient instruments for mastication. But their true canine character, as Owen remarks, "is indicated by the conical form of the crown, which terminates in an obtuse point, is convex outward and flat or sub-concave within, at the base of which surface there is a feeble prominence. The conical form is best expressed in the Melanian races, especially the Australian. The canine is more deeply implanted, and by a stronger fang than the incisors." Nevertheless, this tooth no longer serves man as a special weapon for tearing his enemies or prey; it may, therefore, as far as its proper function is concerned, be considered as rudimentary. In every large collection of human skulls some may be found, as Haeckel observes, with the canine teeth projecting considerably beyond the others in the same manner as in the anthropomorphous apes, but in a less degree. In these cases, open spaces between the teeth in the one jaw are left for the reception of the canines of the opposite jaw. An inter-space of this kind in a Kaffir skull, figured by Wagner, is surprisingly wide. Considering how few are the ancient skulls which have been examined, compared to recent skulls, it is an interesting fact that in at least three cases the canines project largely; and in the Naulette jaw they are spoken of as enormous.

Of the anthropomorphous apes the males alone have their canines fully developed; but in the female gorilla, and in a less degree in the female orang, these teeth project considerably beyond the others; therefore the fact, of which I have been assured, that women sometimes have considerably projecting canines, is no serious objection to the belief that their occasional great development in man is a case of reversion to an ape-like progenitor. He who rejects with scorn the belief that the shape of his own canines, and their occasional great development in other men, are due to our early forefathers having been provided with these formidable weapons, will probably reveal, by sneering, the line of his descent. For though he no longer intends, nor has the power, to use these teeth as weapons, he will unconsciously retract his "snarling muscles" (thus named by Sir C. Bell), so as to expose them ready for action, like a dog prepared to fight.

Many muscles are occasionally developed in man, which are proper to the Quadrumana or other mammals. Professor Vlacovich examined forty male subjects, and found a muscle, called by him the ischio-pubic, in nineteen of them; in three others there was a ligament which represented this muscle; and in the remaining eighteen no trace of it. In only two out of thirty female subjects was this muscle developed on both sides, but in three others the rudimentary ligament was present. This muscle, therefore, appears to be much more common in the male than in the female sex; and on the belief in the descent of man from some lower form, the fact is intelligible; for it has been detected in several of the lower animals, and in all of these it serves exclusively to aid the male in the act of reproduction. . . .

That this unknown factor is reversion to a former state of existence may be admitted as in the highest degree probable. It is quite incredible that a man should through mere accident abnormally resemble certain apes in no less than seven of his muscles, if there had been no genetic connection between them. On the other hand, if man is descended from some ape-like creature, no valid reason can be assigned why certain muscles should not suddenly reappear after an interval of many thousand generations, in the same manner as with horses, asses, and mules, dark-coloured stripes suddenly reappear on the legs, and shoulders, after an interval of hundreds, or more probably of thousands of generations.

These various cases of reversion are so closely related to those of rudimentary organs given in the first chapter, that many of them might have been indifferently introduced either there or here. Thus a human uterus furnished with cornua may be said to represent, in a rudimentary condition, the same organ in its normal state in certain mammals. Some parts which are rudimentary in man, as the os coccyx in both sexes, and the mammae in the male sex, are always present; whilst others, such as the supracondyloid foramen, only occasionally appear, and therefore might have been introduced under the head of reversion. These several reversionary structures, as well as the strictly rudimentary ones, reveal the descent of man from some lower form in an unmistakable manner.

Correlated Variation

In man, as in the lower animals, many structures are so intimately related, that when one part varies so does another, without our being able, in most cases, to assign any reason. We cannot say whether the one part governs the other, or whether both are governed by some earlier developed part. Various monstrosities, as I. Geoffroy repeatedly insists, are thus intimately connected. Homologous structures are particularly liable to change together, as we see on the opposite sides of the body, and in the upper and lower extremities. Meckel long ago remarked, that when the muscles of the arm depart from their proper type, they almost always imitate those of the leg; and so, conversely, with the muscles of the legs. The organs of sight and hearing, the teeth and hair, the colour of the skin and of the hair, colour and constitution, are more or less correlated. Professor Schaaffhausen first drew attention to the relation apparently existing between a muscular frame and the strongly-pronounced supra-orbital ridges, which are so characteristic of the lower races of man.

Besides the variations which can be grouped with more or less probability under the foregoing heads, there is a large class of variations which may be provisionally called spontaneous, for to our ignorance they appear to arise without any exciting cause. It can, however, be shewn that such variations, whether consisting of slight individual differences, or of strongly-marked and abrupt deviations of structure, depend much more on the constitution of the organism than on the nature of the conditions to which it has been subjected.

Rate of Increase

. . . If we look back to an extremely remote epoch, before man had arrived at the dignity of manhood, he would have been guided more by instinct and less by reason than are the lowest savages at the present time. Our early semi-human progenitors would not have practised infanticide or polyandry; for the instincts of the lower animals are never so perverted as to lead them regularly to destroy their own offspring, or to be quite devoid of jealousy. There would have been no prudential restraint from marriage, and the sexes would have freely united at an early age. Hence the progenitors of man would have tended to increase rapidly; but checks of some kind, either periodical or constant, must have kept down their numbers, even more severely than with existing savages. What the precise nature of these checks were, we cannot say, any more than with most other animals. We know that horses and cattle, which are not extremely prolific animals, when first turned loose in South America, increased at an enormous rate. The elephant, the slowest breeder of all known animals, would in a few thousand years stock the whole world. The increase of every species of monkey must be checked by some means; but not, as Brehm remarks, by the attacks of beasts of prey. No one will assume that the actual power of reproduction in the wild horses and cattle of America, was at first in any sensible degree increased; or that, as each district became fully stocked, this same power was diminished. No doubt, in this case, and in all others, many checks concur, and different checks under different circumstances; periodical dearths, depending on unfavourable seasons, being probably the most important of all. So it will have been with the early progenitors of man.

Natural Selection

We have now seen that man is variable in body and mind; and that the variations are induced, either directly or indirectly, by the same general causes, and obey the same general laws, as with the lower animals. Man has spread widely over the face of the earth, and must have been exposed, during his incessant migration, to the most diversified conditions. The inhabitants of Tierra del Fuego, the Cape of Good Hope, and Tasmania in the one hemisphere, and of the arctic regions in the other, must have passed through many climates, and changed their habits many times, before they reached their present homes. The early progenitors of man must also have tended, like all other animals, to have increased beyond their means of subsistence; they must, therefore, occasionally have been exposed to a struggle for existence, and consequently to the rigid law of natural selection. Beneficial variations of all kinds will thus, either occasionally or habitually, have been preserved and injurious ones eliminated. I do not refer to strongly-marked deviations of structure, which occur only at long intervals of time, but to mere individual differences. We know, for instance, that the muscles of our hands and feet, which determine our powers of movement, are liable, like those of the lower animals, to incessant variability. If then the progenitors of man inhabiting any district, especially one undergoing some change in its conditions, were divided into two equal bodies, the one half which included all the individuals best adapted by their powers of movement for gaining subsistence, or for defending themselves, would on an average survive in greater numbers, and procreate more offspring than the other and less well endowed half.

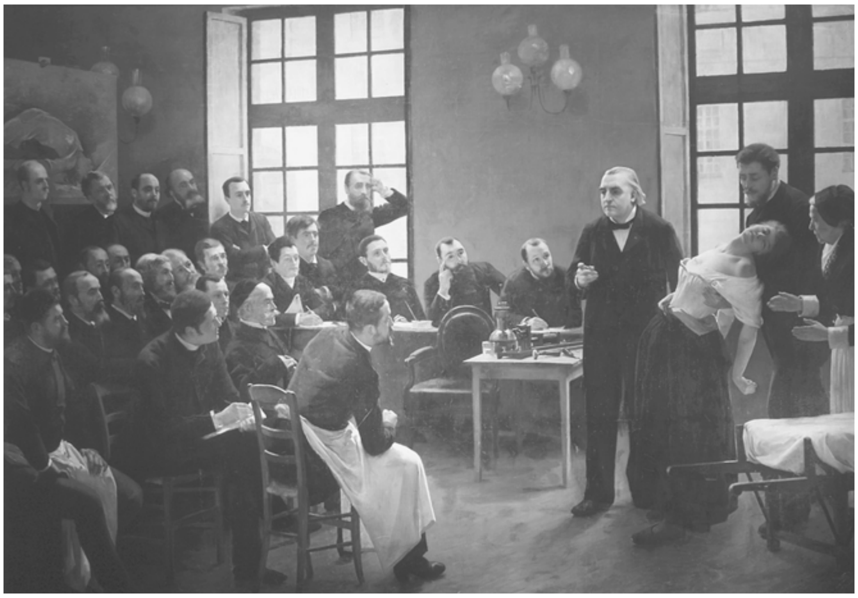
Source: Darwin, Charles. 1871. *The Descent of Man.* London: John Murray.

Victoria Woodhull, "Tried as by Fire" (1871)

Victoria Woodhull gave her speech "Tried as by Fire" on a tour of 150 appearances around the United States, to audiences totaling over a quarter of a million people, by her own estimate. In the speech, she dramatically and explicitly connects feminism and eugenics. Woodhull's is an early expression of the idea *that, if only women had sexual freedom and knowledge, their children would necessarily be free of deformity and defects. As evidence of this connection, in this passage Woodhull offers her personal experience, a rare public, firsthand narrative about raising a disabled son in the nineteenth century.*

Go home with me and see desolation and devastation in another form. The cold, iron bolt has entered my heart and left my life a blank, in ashes upon my lips. Wherever I go I carry a living corpse in my breast, the vacant stare of whose living counterpart meets me at the door of my home. My boy, now nineteen years of age, who should have been my pride and my joy, has never been blessed by the dawning of reasoning. I was married at fourteen, ignorant of everything that related to my maternal functions. For this ignorance, and because I knew no better than to surrender my maternal functions to a drunken man, I am cursed with this living death. Do you think my mother's heart does not yearn for the love of my boy? Do you think I do not realize the awful condition to which I have consigned him? Do you think that I would not willingly give my life to make him what he has a right to be? Do you think his face is not ever before me pressing me on to declare these terrible social laws to the world? Do you think with this sorrow seated on my soul I can ever sit quietly down and permit women to go on ignorantly, repeating my crime? Do you think I can ever cease to hurl the bitterest imprecations at the accursed thing that has made my life one long misery? Do you think I can ever hesitate to warn the young maidens against my fate, or advise them never to surrender the control of their maternal functions to any man! Ah! if you do, you do not know the agony that rests here. Not to do less than I am doing were madness; it were worse than crime; it were the essence of ten thousand crimes concentrated in one soul to sing it in eternal infamy.

Source: Woodhull, Victoria. 1871, April 29. "Tried as by Fire." *Woodhull & Claflin's Weekly,* 2(24):10.



A Lesson on Hysteria by Dr. Jean Martin Charcot *(1823–1890), by André Brouillet (1857–1920). A French physician and neurologist, Charcot was well known for being able to induce female patients diagnosed with hysteria to have hypnotic fainting spells in front of his medical students, professional colleagues, and visitors. He believed that hysteria was hereditary and that hypnosis could be used to simulate the symptoms to facilitate the study of his patients.*

Source: Art Resource, New York.

Victoria Woodhull on Women's Suffrage (1871)

Suffrage rhetoric in the 1870s frequently referred to disability issues in regard to voting. Disabled men vote, the argument ran, so why are women categorically excluded on the basis of "weakness"? In the second extract below, the issue is individuality. In a discussion of the well-known conjoined twins Millie and Christine McKoy, Woodhull argues that they should get two votes "as their mother gave them two names," analogous to the most famous such twins, Chang and Eng Bunker (who were also North Carolinians by this time).

A Woman's Thoughts on the Human Question

[The weaker physique of the average woman] is a curious reason for the subordination of the woman; since in a just application it would defeat itself, in depriving every physically feeble or ailing or crippled man—no matter what his moral or intellectual status—of the vote, and placing the same in the hand of every amazon, virago, termagant—no matter how coarse or ignorant—if they could but muscularly grasp it.

Source: Buddington, Zadel Barnes. "A Woman's Thoughts on the Human Question." Originally published in the *National Standard* (n.d.); reprinted on April 15, 1871, in *Woodhull & Clafin's Weekly*, 2(23):2.

A Question Answered

A correspondent asks us whether, if woman suffrage is established, the North Carolina two-headed girl, so called, will have two votes or one? We think, for the purpose of answering the question, we can give the monstrosity a plural position and call them girls, as their mother gave them two names—Milly and Christiana. They have two hearts and two heads, and would be as much entitled to two votes as Chang and Eng, the Siamese twins.

Source: Woodhull, Victoria. 1871, April 22. "A Question Answered." *Woodhull & Claflin's Weekly* 2(24):10.

▣ Hindu Testimony Acts (1872–1922)

This series of excerpts provides a sense of the range of British colonial policies in India regarding the legal status of mentally ill and mentally disabled people, including the admissibility of testimony by those deemed lunatic, weak-minded, and so forth.

Competence to Testify

The Indian Evidence Act, 1872, Section 118, provided that "all persons shall be competent to testify unless the Court considers that they are prevented from understanding the questions put to them, or from giving rational answers to those questions, by tender years, extreme old age, disease, whether of body of mind, or any other cause of the same kind."

Explanation: "A lunatic is not incompetent to testify, unless he is prevented by his lunacy from understanding the questions put to him and giving rational answers to them."

Incapacity Due to Mental Infirmity

John Mayne's *Treatise on Hindu Law and Usage* goes into detail of particular cases and decisions. Mayne remarks, "As to mental infirmity, it has been held that the degree of incapacity which amounts to idiocy is not utter mental darkness. It is sufficient if the person is, and has been from his birth, of such an unsound and imbecile mind as to be incapable of instruction or discrimination between right and wrong. He must, in short, be one whom it would be impossible to describe as a reasoning being. Mere want of sound, or even ordinary, intelligence is not sufficient." In short, there is an area of opinion in which experts might well disagree.

Source: Stephen, James F. 1872. P. 200 in *The Indian Evidence Act (1. of 1872) with an Introduction on the Principles of Judicial Evidence.* London: Macmillan.

Source: Mayne, John D. 1922. Coutts Trotter, V. M., ed. *A Treatise on Hindu Law and Usage,* 9th ed. Madras, India: Higginbothams.

▣ Johanna Spyri, from *Heidi* (1880–1881)

In Clara, Swiss author Spyri created one of the classic disabled child characters in children's literature. Clara, a city child visiting in the mountains, is sweet and uncomplaining, but lonely and pampered at home. Fresh air, Alpine scenery, and friendship restore more than her spirits: In this climactic scene, Clara is suddenly able to walk, with the encouragement of Heidi and the grudging support of Peter (a boy who earlier had destroyed Clara's wheelchair in a fit of jealousy).

"Would you think me unkind, Clara," she said rather hesitatingly, "if I left you for a few minutes? I should run there and back very quickly. I want so to see how the flowers are looking—but wait—" for an idea had come into Heidi's head. She ran and picked a bunch or two of green leaves, and then took hold of Snowflake and led her up to Clara.

"There, now you will not be alone," said Heidi, giving the goat a little push to show her she was to lie down near Clara, which the animal quite understood. Heidi threw the leaves into Clara's lap, and the latter told her friend to go at once to look at the flowers as she was quite happy to be left with the goat; she liked this new experience. Heidi ran off, and Clara began to hold out the leaves one by one to Snowflake, who snoozled up to her new friend in a confiding manner and slowly ate the leaves from her hand. It was easy to see that Snowflake enjoyed this peaceful and sheltered way of feeding, for when with the other goats she had much persecution to endure from the larger and stronger ones of the flock. And Clara found a strange new pleasure in sitting all alone like this on the mountain side, her only companion a little goat that looked to her for protection. She suddenly felt a great desire to be her own mistress and to be able to help others, instead of herself being always dependent as she was now. Many thoughts, unknown to her before, came crowding into her mind, and a longing to go on living in the sunshine, and to be doing something that would bring happiness to another, as now she was helping to make the goat happy. An unaccustomed feeling of joy took possession of her, as if everything she had ever known or felt became all at once more beautiful, and she seemed to see all things in a new light, and so strong was the sense of this new beauty and happiness that she threw her arms round the little goat's neck, and exclaimed, "O Snowflake, how delightful it is up here! if only I could stay on for ever with you beside me!"

Heidi had meanwhile reached her field of flowers, and as she caught sight of it she uttered a cry of joy. The whole ground in front of her was a mass of shimmering gold, where the cistus flowers spread their yellow blossoms. Above them waved whole bushes of the deep blue bell-flowers; while the fragrance that arose from the whole sunlit expanse was as if the rarest balsam had been flung over it. The scent, however, came from the small brown flowers, the little round heads of which rose modestly here and there among the yellow blossoms. Heidi stood and gazed and drew in the delicious air. Suddenly she turned round and reached Clara's side out of breath with running and excitement. "Oh, you must come," she called out as soon as she came in sight, "it is more beautiful than you can imagine, and perhaps this evening it may not be so lovely. I believe I could carry you, don't you think I could?" Clara looked at her and shook her head. "Why, Heidi, what can you be thinking of! you are smaller than I am. Oh, if only I could walk!"

Heidi looked round as if in search of something, some new idea had evidently come into her head. Peter was sitting up above looking down on the two children. He had been sitting and staring before him in the same way for hours, as if he could not make out what he saw. He had destroyed the chair so that the friend might not be able to move anywhere and that her visit might come to an end, and then a little while after she had appeared right up here under his very nose with Heidi beside her. He thought his eyes must deceive him, and yet there she was and no mistake about it.

Heidi now looked up to where he was sitting and called out in a peremptory voice, "Peter, come down here!"

"I don't wish to come," he called in reply.

"But you are to, you must; I cannot do it alone, and you must come here and help me; make haste and come down," she called again in an urgent voice.

"I shall do nothing of the kind," was the answer.

Heidi ran some way up the slope towards him, and then pausing called again, her eyes ablaze with anger, "If you don't come at once, Peter, I will do something to you that you won't like; I mean what I say."

Peter felt an inward throe at these words, and a great fear seized him. He had done something wicked which he wanted no one to know about, and so far he had thought himself safe. But now Heidi spoke exactly as if she knew everything, and whatever she did know she would tell her grandfather, and there was no one he feared so much as this latter person. Supposing he were to suspect what had happened about the chair! Peter's anguish of mind grew more acute. He stood up and went down to where Heidi was awaiting him.

"I am coming and you won't do what you said."

Peter appeared now so submissive with fear that Heidi felt quite sorry for him and answered assuringly, "No, no, of course not; come along with me, there is nothing to be afraid of in what I want you to do."

As soon as they got to Clara, Heidi gave her orders: Peter was to take hold of her under the arms on one side and she on the other, and together they were to lift her up. This first movement was successfully carried through, but then came the difficulty. As Clara could not even stand, how were they to support her and get her along? Heidi was too small for her arm to serve Clara to lean upon.

"You must put one arm well around my neck so, and put the other through Peter's and lean firmly upon it, then we shall be able to carry you."

Peter, however, had never given his arm to any one in his life. Clara put hers in his, but he kept his own hanging down straight beside him like a stick.

"That's not the way, Peter," said Heidi in an authoritative voice. "You must put your arm out in the shape of a ring, and Clara must put hers through it and lean her weight upon you, and whatever you do, don't let your arm give way; like that. I am sure we shall be able to manage."

Peter did as he was told, but still they did not get on very well. Clara was not such a light weight, and the team did not match very well in size; it was up one side and down the other, so that the supports were rather wobbly.

Clara tried to use her own feet a little, but each time drew them quickly back.

"Put your foot down firmly once," suggested Heidi, "I am sure it will hurt you less after that."

"Do you think so?" said Clara hesitatingly, but she followed Heidi's advice and ventured one firm step on the ground and then another; she called out a little as she did it; then she lifted her foot again and went on, "Oh, that was less painful already," she exclaimed joyfully.

"Try again," said Heidi encouragingly.

And Clara went on putting one foot out after another until all at once she called out, "I can do it, Heidi! look! look! I can make proper steps!" And Heidi cried out with even greater delight, "Can you really make steps, can you really walk? really walk by yourself? Oh, if only grandfather were here!" and she continued gleefully to exclaim, "You can walk now, Clara, you can walk!"

Source: Spyri, Johanna. 1918. *Heidi.* Philadelphia: David McKay. (Originally published 1880–1881)

Emperor Wilhelm of Germany, Speech before Parliament (1881)

In this speech, delivered in support of a bill to establish accident insurance for workers, Emperor Wilhelm makes it clear that the bill is motivated as much by political as by humanitarian ends: Guaranteeing assistance to those disabled in workplace accidents will make socialism less attractive to the working classes.

Past institutions intended to insure working people against the danger of falling into a condition of helplessness owing to the incapacity resulting from accident or age have proved inadequate, and their insufficiency has to no small extent contributed to cause the working classes to seek help by participating in Social Democratic movements.

Source: Dawson, William. 1912. P. 111 in *Social Insurance in Germany, 1883–1911.* London: Scribner's.

Robert Louis Stevenson, from *Treasure Island* (1883)

This scene from Robert Louis Stevenson's Treasure Island *introduces one of the most memorable and complicated characters in the history of literature, the pirate Long John Silver, as seen through the eyes of young Jim Hawkins. Disloyal and friendly, murderous and loving, Long John appears as a crippled, yet dexterous, acrobat and consummate talker, at once winning and despicable, physically powerful and impaired. Long John Silver emerges from a gallery of the eyeless, fingerless, and stupid not as the sailor outlaw with an eye patch or hook but as the peg-legged criminal of the sea who will be from this moment on fixed for all time in the Western imagination as the essence of what a pirate is: an enigma made vivid through the embodiment of disability.*

As I was waiting, a man came out of a side room, and, at a glance, I was sure he must be Long John. His left leg was cut off close by the hip, and under the left shoulder he carried a crutch, which he managed with wonderful dexterity, hopping about upon it like a bird. He was very tall and strong, with a face as big as a ham—plain and pale, but intelligent and smiling. Indeed, he seemed in the most cheerful spirits, whistling as he moved about among the tables, with a merry word or a slap on the shoulder for the more favoured of his guests.

Now, to tell you the truth, from the very first mention of Long John in Squire Trelawney's letter, I had taken a fear in my mind that he might prove to be the very one-legged sailor whom I had watched for so long at the old 'Benbow.' But one look at the man before me was enough. I had seen the captain, and Black Dog, and the blind man Pew, and I thought I knew what a buccaneer was like—a very different creature, according to me, from this clean and pleasant-tempered landlord.

I plucked up courage at once, crossed the threshold, and walked right up to the man where he stood, propped on his crutch, talking to a customer.

'Mr Silver, sir?' I asked, holding out the note.

'Yes, my lad,' said he; 'such is my name, to be sure. And who may you be?' And then as he saw the squire's letter, he seemed to me to give something almost like a start.

'Oh!' said he, quite loud, and offering his hand, 'I see. You are our new cabin-boy; pleased I am to see you.'

And he took my hand in his large firm grasp.

Doctor Philippe Pinel Orders the Removal of the Chains at the Lunatic Asylum, *by Tony Robert-Fleury (1838–1911). This painting captures Pinel's now-mythic effort to free the inmates from their chains at the all-female asylum of Salpetriere. He made the decision following his appointment as superintendent at the institution in 1794 after viewing conditions in the wards. The action is widely recognized as a transition in inmate care from punitive to psychoanalytic—what is now referred to as "moral treatment." In some cases, straightjackets replaced the chains; therefore, in* Madness and Civilization, *Michel Foucault treats this "liberation" as merely the substitution of one disciplinary system with another.*

Source: Art Resource, New York.

Just then one of the customers at the far side rose suddenly and made for the door. It was close by him, and he was out in the street in a moment. But his hurry had attracted my notice, and I recognised him at a glance. It was the tallow-faced man, wanting two fingers, who had come first to the 'Admiral Benbow.'

'Oh,' I cried, 'stop him! it's Black Dog!'

'I don't care two coppers who he is,' cried Silver. 'But he hasn't paid his score. Harry, run and catch him.'

One of the others who was nearest the door leaped up, and started in pursuit.

'If he were Admiral Hawke he shall pay his score,' cried Silver; and then, relinquishing my hand—'Who did you say he was?' he asked. 'Black what?'

'Dog, sir,' said I. 'Has Mr Trelawney not told you of the buccaneers? He was one of them.'

'So?' cried Silver. 'In my house! Ben, run and help Harry. One of those swabs, was he? Was that you drinking with him, Morgan? Step up here.'

The man whom he called Morgan—an old, grey-haired, mahogany-faced sailor—came forward pretty sheepishly, rolling his quid.

'Now, Morgan,' said Long John, very sternly; 'you never clapped your eyes on that Black—Black Dog before, did you, now?'

'Not I, sir,' said Morgan, with a salute.

'You didn't know his name, did you?'

'No, sir.'

'By the powers, Tom Morgan, it's as good for you!' exclaimed the landlord. 'If you had been mixed up with the like of that, you would never have put another foot in my house, you may lay to that. And what was he saying to you?'

'I don't rightly know, sir,' answered Morgan.

'Do you call that a head on your shoulders, or a blessed dead-eye?' cried Long John. 'Don't rightly know, don't you! Perhaps you don't happen to rightly know who you were speaking to, perhaps? Come, now, what was he jawing—v'yages, cap'ns, ships? Pipe up! What was it?'

'We was a-talkin' of keel-hauling,' answered Morgan.

'Keel-hauling, was you? and a mighty suitable thing, too and you may lay to that. Get back to your place for a lubber Tom.'

And then, as Morgan rolled back to his seat, Silver added to me in a confidential whisper, that was very flattering, as I thought:—

'He's quite an honest man, Tom Morgan, on'y stupid. An now,' he ran on again, aloud, 'let's see—Black Dog? No, don't know the name, not I. Yet I kind of think I've—yes, I've seen the swab. He used to come here with a blind beggar he used.'

'That he did, you may be sure,' said I. 'I knew that blind man, too. His name was Pew.'

'It was!' cried Silver, now quite excited. 'Pew! That were his name for certain. Ah, he looked a shark, he did! If we run down this Black Dog, now, there’ll be news for Captain Trelawney! Ben’s a good runner; few seamen run better than Ben. He should run him down, hand over hand, by the powers! He talked o’ keel-hauling, did he? I’ll keel-haul him!’

All the time he was jerking out these phrases he was stumping up and down the tavern on his crutch, slapping tables with his hand, and giving such a show of excitement as would have convinced an Old Bailey judge or a Bow Street runner. My suspicions had been thoroughly re-awakened on finding Black Dog at the ‘Spy-glass,’ and I watched the cook narrowly. But he was too deep, and too ready, and too clever for me, and by the time the two men had come back out of breath, and confessed that they had lost the track in a crowd, and been scolded like thieves, I would have gone bail for the innocence of Long John Silver.

‘See here, now, Hawkins,’ said he, ‘here’s a blessed hard thing on a man like me, now, aint it? There’s Cap’n Trelawney—what’s he to think? Here I have this confounded son of a Dutchman sitting in my own house, drinking of my own rum! Here you comes and tells me of it plain; and here I let him give us all the slip before my blessed dead-lights! Now, Hawkins, you do me justice with the cap’n. You’re a lad, you are, but you’re as smart as paint. I see that when you first came in. Now, here it is: What could I do, with this old timber I hobble on? When I was an A B master mariner I’d have come up alongside of him, hand over hand, and broached him to in a brace of old shakes, I would; but now—’

And then, all of a sudden, he stopped, and his jaw drooped as though he had remembered something.

‘The score!’ he burst out. ‘Three goes o’ rum! Why, shiver my timbers, if I hadn’t forgotten my score!’

And, falling on a bench, he laughed until the tears ran down his cheeks. I could not help joining; and we laughed together, peal after peal, until the tavern rang again.

Source: Stevenson, Robert Louis. 1883. Ch. 8 in *Treasure Island.* London: Cassell.

Mary E. Wilkins Freeman, from “A Mistaken Charity” (1887)

The U.S. regional northeastern writer Mary E. Wilkins Freeman wrote numerous short stories about women’s efforts to free themselves of domestic and public constraints about femininity. In the story excerpted here, two aging sisters—one of whom is blind—develop an interdependency with each other while living in a ramshackle house. Their relationship revolves around their mutual needs rather than more traditional values of male self-sufficiency. Their efforts to live alone on their own terms violates their neighbors’ belief that dependency is a failing, and thus a movement takes shape to have them institutionalized against their will.

There were in a green field a little, low, weather-stained cottage, with a foot-path leading to it from the highway several rods distant, and two old women—one with a tin pan and old knife searching for dandelion greens among the short young grass, and the other sitting on the door-step watching her, or, rather, having the appearance of watching her.

“Air there enough for a mess, Harriét?” asked the old woman on the door-step. She accented oddly the last syllable of the Harriet, and there was a curious quality in her feeble, cracked old voice. Besides the question denoted by the arrangement of her words and the rising inflection, there was another, broader and subtler, the very essence of all questioning, in the tone of her voice itself; the cracked, quavering notes that she used reached out of themselves, and asked, and groped like fingers in the dark. One would have known by the voice that the old woman was blind.

The old woman on her knees in the grass searching for dandelions did not reply; she evidently had not heard the question. So the old woman on the door-step, after waiting a few minutes with her head turned expectantly, asked again, varying her question slightly, and speaking louder:

“Air there enough for a mess, do ye s’pose, Harriét?”

The old woman in the grass heard this time. She rose slowly and laboriously; the effort of straightening out the rheumatic old muscles was evidently a painful one; then she eyed the greens heaped up in the tin pan, and pressed them down with her hand.

“Wa’al, I don’t know, Charlotte,” she replied, hoarsely. “There’s plenty on ‘em here, but I ain’t got near enough for a mess; they do bile down so when you get ‘em in the pot; an’ it’s all I can do to bend my j’ints enough to dig ‘em.”

“I’d give consider’ble to help ye, Harriét,” said the old woman on the door-step.

But the other did not hear her; she was down on her knees in the grass again, anxiously spying out the dandelions.

So the old woman on the door-step crossed her little shrivelled hands over her calico knees, and sat quite still, with the soft spring wind blowing over her.

The old wooden door-step was sunk low down among the grasses, and the whole house to which it belonged had an air of settling down and mouldering into the grass as into its own grave.

When Harriet Shattuck grew deaf and rheumatic, and had to give up her work as tailoress, and Charlotte Shattuck lost her eyesight, and was unable to do any more sewing for her livelihood, it was a small and trifling charity for the rich man who held a mortgage on the little house in which they had been born and lived all their lives to give them the use of it, rent and interest free. He might as well have taken credit to himself for not charging a squirrel for his tenement in some old decaying tree in his woods.

So ancient was the little habitation, so wavering and mouldering, the hands that had fashioned it had lain still so long in their graves, that it almost seemed to have fallen below its distinctive rank as a house. Rain and snow had filtered through its roof, mosses had grown over it, worms had eaten it, and birds built their nests under its eaves; nature had almost completely overrun and obliterated the work of man, and taken her own to herself again, till the house seemed as much a natural ruin as an old tree-stump.

The Shattucks had always been poor people and common people; no especial grace and refinement or fine ambition had ever characterized any of them; they had always been poor and coarse and common. The father and his father before him had simply lived in the poor little house, grubbed for their living, and then unquestioningly died. The mother had been of no rarer stamp, and the two daughters were cast in the same mould.

After their parents' death Harriet and Charlotte had lived along in the old place from youth to old age, with the one hope of ability to keep a roof over their heads, covering on their backs, and victuals in their mouths—an all-sufficient one with them.

Neither of them had ever had a lover; they had always seemed to repel rather than attract the opposite sex. It was not merely because they were poor, ordinary, and homely; there were plenty of men in the place who would have matched them well in that respect; the fault lay deeper—in their characters. Harriet, even in her girlhood, had a blunt, defiant manner that almost amounted to surliness, and was well calculated to alarm timid adorers, and Charlotte had always had the reputation of not being any too strong in her mind.

Harriet had gone about from house to house doing tailor-work after the primitive country fashion, and Charlotte had done plain sewing and mending for the neighbors. They had been, in the main, except when pressed by some temporary anxiety about their work or the payment thereof, happy and contented, with that negative kind of happiness and contentment which comes not from gratified ambition, but a lack of ambition itself. All that they cared for they had had in tolerable abundance, for Harriet at least had been swift and capable about her work. The patched, mossy old roof had been kept over their heads, the coarse, hearty food that they loved had been set on their table, and their cheap clothes had been warm and strong.

After Charlotte's eyes failed her, and Harriet had the rheumatic fever, and the little hoard of earnings went to the doctors, times were harder with them, though still it could not be said that they actually suffered.

When they could not pay the interest on the mortgage they were allowed to keep the place interest free; there was as much fitness in a mortgage on the little house, anyway, as there would have been on a rotten old apple-tree; and the people about, who were mostly farmers, and good friendly folk, helped them out with their living. One would donate a barrel of apples from his abundant harvest to the two poor old women, one a barrel of potatoes, another a load of wood for the winter fuel, and many a farmer's wife had bustled up the narrow foot-path with a pound of butter, or a dozen fresh eggs, or a nice bit of pork. Besides all this, there was a tiny garden patch behind the house, with a straggling row of currant bushes in it, and one of gooseberries, where Harriet contrived every year to raise a few pumpkins, which were the pride of her life. On the right of the garden were two old apple-trees, a Baldwin and a Porter, both yet in a tolerably good fruit-bearing state. . . .

When the two old women sat down complacently to their meal of pork and dandelion greens in their little kitchen they did not dream how destiny slowly and surely was introducing some new colors into their web of life, even when it was almost completed, and that this was one of the last meals they would eat in their old home for many a day. In about a week from that day they were established in the "Old Ladies' Home" in a neighboring city. It came about in this wise: Mrs. Simonds, the woman who had brought the gift of hot doughnuts, was a smart, energetic person, bent on doing good, and she did a great deal. To be sure, she always did it in her own way. If she chose to give hot doughnuts, she gave hot doughnuts; it made not the slightest difference to her if the recipients of her charity would infinitely have preferred ginger cookies. Still, a great many would like hot doughnuts, and she did unquestionably a great deal of good.

She had a worthy coadjutor in the person of a rich and childless elderly widow in the place. They had fairly entered into a partnership in good works, with about an equal capital on both sides, the widow furnishing the money, and Mrs. Simonds, who had much the better head of the two, furnishing the active schemes of benevolence.

The afternoon after the doughnut episode she had gone to the widow with a new project, and the result was that entrance fees had been paid, and old Harriet and Charlotte made sure of a comfortable home for the rest of their lives. The widow was hand in glove with officers of missionary boards and trustees of charitable institutions. There had been an unusual mortality among the inmates of the "Home" this spring, there were several vacancies, and the matter of the admission of Harriet and Charlotte was very quickly and easily arranged. But the matter which would have seemed the least difficult—inducing the two old women to accept the bounty which Providence, the widow, and Mrs. Simonds were ready to bestow on them—proved the most so. The struggle to persuade them to abandon their tottering old home for a better was a terrible one. The widow had pleaded with mild surprise, and Mrs. Simonds with benevolent determination; the counsel and reverend eloquence of the minister had been called in; and when they yielded at last it was with a sad grace for the recipients of a worthy charity.

It had been hard to convince them that the "Home" was not an almshouse under another name, and their yielding at length to anything short of actual force was only due probably to the plea, which was advanced most eloquently to Harriet, that Charlotte would be so much more comfortable.

The morning they came away, Charlotte cried pitifully, and trembled all over her little shrivelled body. Harriet did not cry. But when her sister had passed out the low, sagging door she turned the key in the lock, then took it out and thrust it slyly into her pocket, shaking her head to herself with an air of fierce determination.

Mrs. Simonds's husband, who was to take them to the depot, said to himself, with disloyal defiance of his wife's active charity, that it was a shame, as he helped the two distressed old souls into his light wagon, and put the poor little box, with their homely clothes in it, in behind.

Mrs. Simonds, the widow, the minister, and the gentleman from the "Home" who was to take charge of them, were all at the depot, their faces beaming with the delight of successful benevolence. But the two poor old women looked like two forlorn prisoners in their midst. It was an impressive illustration of the truth of the saying "that it is more blessed to give than to receive."

Well, Harriet and Charlotte Shattuck went to the "Old Ladies' Home" with reluctance and distress. They stayed two months, and then—they ran away.

The "Home" was comfortable, and in some respects even luxurious; but nothing suited those two unhappy, unreasonable old women.

The fare was of a finer, more delicately served variety than they had been accustomed to; those finely flavored nourishing soups for which the "Home" took great credit to itself failed to please palates used to common, coarser food.

"O Lord, Harriét, when I set down to the table here there ain't no chinks," Charlotte used to say. "If we could hev some cabbage, or some pork an' greens, how the light would stream in!"

Then they had to be more particular about their dress. They had always been tidy enough, but now it had to be something more; the widow, in the kindness of her heart, had made it possible, and the good folks in charge of the "Home," in the kindness of their hearts, tried to carry out the widow's designs.

But nothing could transform these two unpolished old women into two nice old ladies. They did not take kindly to white lace caps and delicate neckerchiefs. They liked their new black cashmere dresses well enough, but they felt as if they broke a commandment when they put them on every afternoon. They had always worn calico with long aprons at home, and they wanted to now; and they wanted to twist up their scanty gray locks into little knots at the back of their heads, and go without caps, just as they always had done.

Charlotte in a dainty white cap was pitiful, but Harriet was both pitiful and comical. They were totally at variance with their surroundings, and they felt it keenly, as people of their stamp always do. No amount of kindness and attention—and they had enough of both—sufficed to reconcile them to their new abode. Charlotte pleaded continually with her sister to go back to their old home.

"O Lord, Harriét," she would exclaim (by the way, Charlotte's "O Lord," which, as she used it, was innocent enough, had been heard with much disfavor in the "Home," and she, not knowing at all why, had been remonstrated with concerning it), "let us go home. I can't stay here no ways in this world. I don't like their vittles, an' I don't like to wear a cap; I want to go home and do different. The currants will be ripe, Harriét. O Lord, thar was almost a chink, thinking about 'em. I want some of 'em; an' the Porter apples will be gittin' ripe, an' we could have some apple-pie. This here ain't good; I want merlasses fur sweeting. Can't we get back no ways, Harriét? It ain't far, an' we could walk, an' they don't lock us in, nor nothin.' I don't want to die here; it ain't so straight up to heaven from here. O Lord, I've felt as if I was slantendicular from heaven ever since I've been here, an' it's been so awful dark. I ain't had any chinks. I want to go home, Harriét."

"We'll go to-morrow mornin,'" said Harriet, finally; "we'll pack up our things an' go; we'll put on our old dresses, an' we'll do up the new ones in bundles, an' we'll jest shy out the back way to-morrow mornin'; an' we'll go. I kin find the way, an' I reckon we kin git thar, if it is fourteen mile. Mebbe somebody will give us a lift."

And they went. With a grim humor Harriet hung the new white lace caps with which she and Charlotte had been so pestered, one on each post at the head of the bedstead, so they would meet the eyes of the first person who opened the door. Then they took their bundles, stole slyly out, and were soon on the high-road, hobbling along, holding each other's hands, as jubilant as two children, and chuckling to themselves over their escape, and the probable astonishment there would be in the "Home" over it.

"O Lord, Harriét, what do you s'pose they will say to them caps?" cried Charlotte, with a gleeful cackle.

"I guess they'll see as folks ain't goin' to be made to wear caps agin their will in a free kentry," returned Harriet, with an echoing cackle, as they sped feebly and bravely along.

The "Home" stood on the very outskirts of the city, luckily for them. They would have found it a difficult undertaking to traverse the crowded streets. As it was, a short walk brought them into the free country road—free comparatively, for even here at ten o'clock in the morning there was considerable travelling to and from the city on business or pleasure.

People whom they met on the road did not stare at them as curiously as might have been expected. Harriet held her bristling chin high in air, and hobbled along with an appearance of being well aware of what she was about, that led folks to doubt their own first opinion that there was something unusual about the two old women.

Still their evident feebleness now and then occasioned from one and another more particular scrutiny. When they had been on the road a half-hour or so, a man in a covered wagon drove up behind them. After he had passed them, he poked his head around the front of the vehicle and looked back. Finally he stopped, and waited for them to come up to him.

"Like a ride, ma'am?" said he, looking at once bewildered and compassionate.

"Thankee," said Harriet, "we'd be much obleeged."

After the man had lifted the old women into the wagon, and established them on the back seat, he turned around, as he drove slowly along, and gazed at them curiously.

"Seems to me you look pretty feeble to be walking far," said he. "Where were you going?"

Harriet told him with an air of defiance.

"Why," he exclaimed, "it is fourteen miles out. You could never walk it in the world. Well, I am going within three miles of there, and I can go on a little farther as well as not. But I don't see—Have you been in the city?"

"I have been visitin' my married darter in the city," said Harriet, calmly.

Charlotte started, and swallowed convulsively.

Harriet had never told a deliberate falsehood before in her life, but this seemed to her one of the tremendous exigencies of life which justify a lie. She felt desperate. If she could not contrive to deceive him in some way, the man might turn directly around and carry Charlotte and her back to the "Home" and the white caps.

"I should not have thought your daughter would have let you start for such a walk as that," said the man. "Is this lady your sister? She is blind, isn't she? She does not look fit to walk a mile."

"Yes, she's my sister," replied Harriet, stubbornly: "an' she's blind; an' my darter didn't want us to walk. She felt reel bad about it. But she couldn't help it. She's poor, and her husband's dead, an' she's got four leetle children."

Harriet recounted the hardships of her imaginary daughter with a glibness that was astonishing. Charlotte swallowed again.

"Well," said the man, "I am glad I overtook you, for I don't think you would ever have reached home alive."

About six miles from the city an open buggy passed them swiftly. In it were seated the matron and one of the gentlemen in charge of the "Home." They never thought of looking into the covered wagon—and indeed one can travel in one of those vehicles, so popular in some parts of New England, with as much privacy as he could in his tomb. The two in the buggy were seriously alarmed, and anxious for the safety of the old women, who were chuckling maliciously in the wagon they soon left far behind. Harriet had watched them breathlessly until they disappeared on a curve of the road; then she whispered to Charlotte.

A little after noon the two old women crept slowly up the foot-path across the field to their old home.

"The clover is up to our knees," said Harriet; "an' the sorrel and the white-weed; an' there's lots of yaller butterflies."

"O Lord, Harriét, thar's a chink, an' I do believe I saw one of them yaller butterflies go past it," cried Charlotte, trembling all over, and nodding her gray head violently.

Harriet stood on the old sunken door-step and fitted the key, which she drew triumphantly from her pocket, in the lock, while Charlotte stood waiting and shaking behind her.

Then they went in. Everything was there just as they had left it. Charlotte sank down on a chair and began to cry. Harriet hurried across to the window that looked out on the garden.

"The currants air ripe," said she; "*an*' them pumpkins hev run all over everything."

"O Lord, Harriét," sobbed Charlotte, "thar is so many chinks that they air all runnin' together!"

Source: Freeman, Mary E. Wilkins. 1887. "A Mistaken Charity." In *A Humble Romance and Other Stories.* New York: Harper and Brothers.

Oscar Wilde, from "The Happy Prince" (1888)

In this short story, the Happy Prince, who didn't learn compassion during his life, becomes a statue. His experience as a statue teaches him compassion, and he enlists the help of a swallow to give his ruby, sapphire, and golden ornaments to the poor of the city. Wilde satirizes those who see only external qualities and who believe that things that are "no longer beautiful [are] no longer useful" rather than examining the true natures of things.

Early the next morning the Mayor was walking in the square below in the company of the Town councillors. As they passed the column he looked up at the statue: "Dear me! How shabby the Happy Prince looks!" he said.

"How shabby indeed!" cried the Town Councillors, who always agreed with the Mayor; and they went up to look at it.

"The ruby has fallen out of his sword, his eyes are gone, and he is golden no longer," said the Mayor; "in fact, he is little better than a beggar!"

"Little better than a beggar," said the Town Councillors.

"And here is actually a dead bird at his feet!" continued the Mayor. "We must really issue a proclamation that birds are not to be allowed to die here." And the Town Clerk made a note of the suggestion.

So they pulled down the statue of the Happy Prince. "As he is no longer beautiful he is no longer useful," said the Art Professor at the University.

Source: Wilde, Oscar. 1888. "The Happy Prince." Available at: http://www.online-literature.com/wilde/177/

"Sim Chung Jeon" ("The Dutiful Daughter") (1889)

This Korean folktale, which exists in hundreds of version, is one of the Pansori 12 Madang, a type of musical storytelling performance that originated during the late seventeenth century and continued to be popular during the eighteenth century. In the story of this pansori, "Sim Chung Jeon," Sim Chung sacrifices herself for the cure of her father Sim Hyun's blindness. The tale combines the cultural practice of human sacrifice, the Confucian value of filial piety, and the Buddhist idea of karma.

Sim Hyun, or Mr. Sim was highly esteemed in the Korean village in which he resided. He belonged to the yangban, or gentleman class, and when he walked forth it was with the stately swinging stride of the gentleman, while if he bestrode his favorite donkey, or was carried in his chair, a runner went ahead calling to the commoners to clear the road. His rank was not high, and though greatly esteemed as a scholar, his income would scarcely allow of his taking the position he was fitted to occupy. . . .

His parents had been very fortunate in betrothing him to a remarkably beautiful and accomplished maiden, daughter of a neighboring gentleman. . . . It was an exceptionally happy union, the pair being intellectually suited to each other, and apparently possessing the bodily attributes necessary to charm the other. . . .

Heaven had kindly prepared the way for the little visitor, however; for after fifteen years weary waiting, they were not going to look with serious disfavor upon a girl, however much their hopes had been placed upon the advent of a son. The child grew, and the parents were united as they only could be by such a precious bond. . . .

Just as their joy seemed too great to be lasting, it was suddenly checked by the death of the mother, which plunged them into a deep grief from which the father emerged totally blind. It soon became a question as to where the daily food was to come from; little by little household trinkets were given to the brokers to dispose of, and in ten years they had used up the homestead, and all it contained.

The father was now compelled to ask alms, and as his daughter was grown to womanhood, she could no longer direct his footsteps as he wandered out in the darkness of the blind. One day in his journeying he fell into a deep ditch, from which he could not extricate himself. After remaining in this deplorable condition for some time he heard a step, and called out for assistance, saying: “I am blind, not drunk,” whereupon the passing stranger said: “I know full well you are not drunk. True, you are blind, yet not incurably so.”

“Why, who are you that you know so much about me?” asked the blind man.

“I am the old priest of the temple in the mountain fortress.”

“Well, what is this that you say about my not being permanently blind?”

“I am a prophet, and I have had a vision concerning you. In case you make an offering of three hundred bags of rice to the Buddha of our temple, you will be restored to sight, you will be given rank and dignity, while your daughter will become the first woman in all Korea.”

“But I am poor, as well as blind,” was the reply. “How can I promise such a princely offering?”

“You may give me your order for it, and pay it along as you are able,” said the priest.

“Very well, give me pencil and paper,” whereupon they retired to a house, and the blind man gave his order for the costly price of his sight. Returning home weary, bruised, and hungry, he smiled to himself, in spite of his ill condition, at the thought of this giving an order for so much rice when he had not a grain of it to eat.

He obtained, finally, a little work in pounding rice in the stone mortars. It was hard labor for one who had lived as he had done; but it kept them from starving, and his daughter prepared his food for him as nicely as she knew how. One night, as the dinner was spread on the little, low table before him, sitting on the floor, the priest came and demanded his pay; the old blind man lost his appetite for his dinner, and refused to eat. He had to explain to his daughter the compact he had made with the priest, and, while she was filled with grief, and dismayed at the enormity of the price, she yet seemed to have some hope that it might be accomplished and his sight restored.

That night, after her midnight bath, she lay down on a mat in the open air, and gazed up to heaven, to which she prayed that her poor father might be restored to health and sight. While thus engaged, she feel asleep and dreamed that her mother came down from heaven to comfort her, and told her not to worry, that a means would be found for the payment of the rice, and that soon all would be happy again in the little family.

The next day she chanced to hear of the wants of a great merchant who sailed in his large boats to China for trade, but was greatly distressed by an evil spirit that lived in the water through which he must pass. For some time, it was stated, he had not been able to take his boats over this dangerous place, and his loss therefrom was very great. At last it was reported that he was willing and anxious to appease the spirit by making the offering the wise men had deemed necessary. Priests had told him that the sacrifice of a young maiden to the spirit would quiet it and remove the trouble. He was, therefore, anxious to find the proper person, and had offered a great sum to obtain such an one.

Sim Chung, hearing of this, decided that it must be the fulfillment of her dream, and having determined to go and offer herself, she put on old clothes and fasted while journeying, that she might look wan and haggard, like one in mourning. She had previously prepared food for her father, and explained to him that she wished to go and bow at her mother's grave, in return to her for having appeared to her in a dream.

When the merchant saw the applicant, he was at once struck with her beauty and dignity of carriage, in spite of her attempt to disguise herself. He said that it was not in his heart to kill people, especially maidens of such worth as she seemed to be. He advised her not to apply; but she told her story and said she would give herself for the three hundred bags of rice. "Ah! Now I see the true nobility of your character. I did not know that such filial piety existed outside the works of the ancients. I will send to my master and secure the rice," said the man, who happened to be but an overseer for a greater merchant.

She got the rice and took it to the priest in a long procession of one hundred and fifty ponies, each laboring under two heavy bags; the debt cancelled and her doom fixed, she felt the relaxation and grief necessarily consequent upon such a condition. She could not explain to her father, she mourned over the loneliness that would come to him after she was gone, and wondered how he would support himself after she was removed and until his sight should be restored. She lay down and prayed to heaven, saying: "I am only fourteen years old, and have but four more hours to live. What will become of my poor father? Oh! Who will care for him? Kind heaven, protect him when I am gone." Wild with grief she went and sat on her father's knee, but could not control her sobs and tears; whereupon he asked her what the trouble could be. Having made up her mind that the time had come, and that the deed was done and could not be remedied, she decided to tell him, and tried to break it gently; but when the whole truth dawned upon the poor old man it nearly killed him. He clasped her close to his bosom, and crying: "My child, my daughter, my only comfort, I will not let you go. What will eyes to be me if I can no longer look upon your lovely face?" They mingled their tears and sobs, and the neighbors, hearing the commotion in the usually quiet hut, came to see what was the trouble. Upon ascertaining the reason of the old man's grief, they united in the general wailing. Sim Chung begged them to come and care for the old man when she could look after him no more, and they agreed to do so. While the wailing and heart breaking was going on, a stranger rode up on a donkey and asked for the Sim family. He came just in time to see what the act was costing the poor people. He comforted the girl by giving her a cheque for fifty bags of rice for the support of the father when his daughter should be no more. She took it gratefully and gave it to the neighbors to keep in trust; she then prepared herself, took a last farewell, and left her fainting father to go to her bed in the sea.

In due time the boat that bore Sim Chung, at the head of a procession of boats, arrived at the place where the evil spirit reigned. She was dressed in bridal garments furnished by the merchant. On her arrival at the place, the kind merchant tried once more to appease the spirit by an offering of eatables, but it was useless, whereupon Sim Chung prayed to heaven, bade them all good-by[e] and leaped into the sea. Above, all was quiet, the waves subsided, the sea became like a lake, and the boats passed on their way unmolested.

When Sim Chung regained her consciousness she was seated in a little boat drawn by fishes, and pretty maidens were giving her to drink from a carved jade bottle. She asked them who they were, and where she was going. They answered: "We are servants of the King of the Sea, and we are taking you to his palace." . . .

Sim Chung wondered if this was death, and thought it very pleasant if it were. They passed through forests of waving plants, and saw great lazy fish feeding about in the water, till at last they reached the confines of the palace. Her amazement was then unbounded, for the massive walls were composed of precious stones, such as she had only heretofore seen used as ornaments. Pearls were used to cover the heads of nails in the great doors through which they passed, and everywhere there seemed a most costly and lavish display of the precious gems and metals, while the walks were made of polished black marble that shone in the water. . . .

The King treated her with great respect, and all the maidens and eunuchs bowed before her. She protested that she was not worthy of such attention. "I am," she said, "but the daughter of a beggar, for whom I thought I was giving my life when rescued by these maidens. I am in no way worthy of your respect." . . .

The King smiled a little, and said: Ah! I know more of you than you know of yourself. You must know that I am the Sea King, and that we know full well the doings of the stars which shine in the heaven above, for they continually visit us on light evenings. Well, you were once a star. Many say a beautiful one. [There was another star you loved] more than the others, and, in your attentions to him, you abused your office as cup-bearer to the King of Heaven, and let your lover have free access to all of the choice wines of the palace. In this way, before you were aware of it, the peculiar and choice brands that the King especially liked were consumed, and, upon examination, your fault became known. As punishment, the King decided to banish you to earth, but fearing to send you both at once, lest you might be drawn together there, he sent your lover first, and after keeping you in prison for a long time, you were sent as daughter to your former lover. He is the man you claim as father. Heaven has seen your filial piety, however, and repents. You will be hereafter most highly favored, as a reward for your dutiful conduct. He then sent her to fine apartments prepared for her, where she was to rest and recuperate before going back to earth. . . .

After a due period of waiting and feasting on royal food, Sim Chung's beauty was more than restored. She had developed into a complete woman, and her beauty was dazzling; her cheeks seemed colored by the beautiful tints of the waters through which she moved with ease and comfort, while her mind blossomed forth like a flower in the rare society of the Sea King and his peculiarly gifted people. . . .

At night, when all was quiet, Sim Chung was wont to come forth and rest herself by walking in the moonlight. But, on one occasion, the King, being indisposed and restless, thought he would go to breathe the rich perfume of the strange flower and rest himself. In this way he chanced to see Sim Chung before she could conceal herself, and, of course, his surprise was unbounded. He accosted her, not without fear demanding who she might be. She, being also afraid, took refuge in her flower, when, to the amazement of both, the flower vanished, leaving her standing alone where it had been but a moment before. . . .

His Majesty very reluctantly went to see what it all meant. An officer versed in astronomy stated that they had, on the previous night, observed a brilliant star descend from heaven and alight upon the palace, and that they believed it boded good to the royal family. . . . It so happened that the queen was deceased, and it was soon decided that the King should take this remarkable maiden for his wife. . . .

After some time spent in such luxury, Sim Chung became lonely and mourned for her poor father, but despaired of being able to see him. She knew not if he were alive or dead, and the more she thought of it the more she mourned, till tears were in her heart continually, and not infrequently overflowed from her beautiful eyes. The King chanced to see her weeping, and was solicitous to know the cause of her sorrow, whereupon she answered that she was oppressed by a strange dream concerning a poor blind man, and was desirous of alleviating in some way the suffering of the many blind men in the country. Together they agreed that they would summon all the blind men of the country to a great feast, at which they should be properly clothed, amply fed, and treated each to a present of cash. . . .

When sufficient time had elapsed for the satisfying of his hunger, he was ordered brought to the Queen's pavilion, where Her Majesty scrutinized him closely for a few moments, and then, to the surprise and dismay of all her attendants, she screamed: "My father! My father!" and fell at his feet senseless. . . .

[T]he poor old blind man could barely collect his senses sufficiently to grasp the situation. As the full truth began to dawn upon him, he cried: "Oh! My child, can the dead come back to us? I hear your voice; I feel your form; but how can I know it is you, for I have no eyes? Away with these sightless orbs!" And he tore at his eyes with his nails, when to his utter amazement and joy, the scales fell away, and he stood rejoicing in his sight once more. . . .

His Majesty was overjoyed to have his lovely Queen restored to her wonted happy frame of mind. He made the old man an officer of high rank, appointed him a fine house, and had him married to the accomplished daughter of an officer of suitable rank, thereby fulfilling the last of the prophecy of both the aged priest and the King of the Sea.

Source: Allen, H. N. 1889. Pp. 152–169 in *Korean Tales: Being a Collection of Stories Translated from the Korean Folk Lore.* New York: Knickerbocher Press.

Emily Dickinson, "Much Madness Is Divinest Sense" (1890)

With her usual economy of words and a confiding tone, Dickinson sketches the contextual nature of sanity and madness—what fits into the majority view is deemed fit, and the unusual is not only labeled but "handled with a Chain." Emily Dickinson, whose reclusive New England life remains the subject of much speculation, surely understood this harsh suspicion of difference from firsthand experience.

Much Madness is divinest Sense
To a discerning Eye;
Much Sense the starkest Madness.

The Bedroom at Arles *(1889), by Vincent Van Gogh (1853–1890). Oil on canvas. Van Gogh's painting shows a bedroom in the Arles "Yellow House" that he decorated in preparation for visits from fellow artists and relatives. The rendition of the room is vivid in the artist's characteristic manner.*

Source: Musée d'Orsay, Paris, France.

'Tis the Majority
In this, as All, prevails.
Assent, and you are sane;
Demur—you're straightway dangerous,
And handled with a Chain.

Source: Dickinson, Emily. 1890. "Much Madness Is Divinest Sense." Available at: http://www.bartleby.com/113/1011.html

John Harvey Kellogg, from *Plain Facts* (1890)

John Harvey Kellogg is best known for his connection with the sanatorium in Battle Creek, Michigan, and the cereals he invented for his patients there. Kellogg's book Plain Facts *was one of hundreds of books about eugenics produced during the late nineteenth and early twentieth centuries. The author, like many eugenicists of his era, counsels against the freedom of disabled people to procreate. The argument participates in longstanding fallacies about the prevention of "defects" as a duty of American citizens.*

Persons having serious congenital deformities should not marry. The reason for this rule is obvious. Persons suffering with serious congenital defects, as natural blindness, deafness, deformity of the limbs, or defective development of any part, will be more or less likely to transmit the same deformities or deficiencies to their children. There are, of course, cases of natural blindness, as well as of disability in other respects, to which this rule does not apply, the natural process of development not being seriously defective. It has even been observed that there is a slight tendency to the reproduction in the offspring, of deformity which has been artificially produced in the parents, and has existed for a long time. Many ancient nations observe this rule. Infants born cripples were strangled at birth or left to die. A Spartan king was once required by his people to pay a heavy fine for taking a wife who was inferior in size.

Source: Kellogg, John Harvey. 1890. *Plain Facts for Old and Young: Embracing the Natural History and Hygiene of Organic Life.* Burlington, IA: I. F. Segner.

Walt Whitman, from *Collected Prose* (1891)

The poet's bravura inventory of his own physical and mental states touches on both the mundane and the spiritual aspects of his everyday experience. The housekeeper and nurse are mentioned by way of explaining the supports he depends upon to keep up his writing, his "buoyant spirits," and his "unmitigated faith."

But physical disability and the war-paralysis above alluded to have settled upon me more and more, the last year or so. Am now (1891) domicil'd, and have been, for some years, in this little old cottage and lot in Mickle Street, Camden, with a house-keeper and man nurse. Bodily I am completely disabled, but still write for publication. I keep generally buoyant spirits, write often as there comes any lull in physical sufferings, get in the sun and down to the river whenever I can, retain fair appetite, assimilation and digestion, sensibilities acute as ever, the strength and volition of my right arm good, eyesight dimming, but brain normal, and retain my heart's and soul's unmitigated faith not only in their own original literary plans, but in the essential bulk of American humanity east and west, north and south, city and country, through thick and thin, to the last.

Source: Whitman, Walt. 1982. Kaplan, Justin, ed. *Complete Poetry and Collected Prose.* New York: Library of America.

Friedrich Nietzsche, from *Thus Spoke Zarathustra* (1891)

In this excerpt from one of the German philosopher's most influential works, Nietzsche inverts the common biblical scenario of a prophet proving his powers by curing disabilities. Instead, when the group of disabled characters invites Zarathustra to show the legitimacy of his philosophy by healing them, he launches into a discussion about the centrality of disability to those who experience such conditions. Also in this section, Zarathustra evolves his theory of eternal return—the belief that one would willingly choose to repeat one's life in every detail again. The key to this radical proposal is the idea that those with disabilities would presumably do anything to avoid their conditions, and therefore Zarathustra's formulation is held out as the challenge to the cripples as a test for the ultimate claim of value made for even the most devalued lives.

From "On Redemption"

When Zarathustra went one day over the great bridge, then did the cripples and beggars surround him, and a hunchback spoke thus to him:

"Behold, Zarathustra! Even the people learn from you, and acquire faith in your teaching: but for them to believe fully in you, one thing is still needful—you must first of all convince us cripples! Here have you now a fine selection, and verily, an opportunity with more than one forelock! The blind can you heal, and make the lame run; and from him who has too much behind, could you well, also, take away a little;—that, I think, would be the right method to make the cripples believe in Zarathustra!"

Zarathustra, however, answered thus to him who so spoke: When one takes his hump from the hunchback, then does one take from him his spirit—so do the people teach. And when one gives the blind man eyes, then does he see too many bad things on the earth: so that he curses him who healed him. He, however, who makes the lame man run, inflicts upon him the greatest injury; for hardly can he run, when his vices run away with him—so do the people teach concerning cripples. And why should not Zarathustra also learn from the people, when the people learn from Zarathustra?

It is, however, the small thing to me since I have been amongst men, to see one person lacking an eye, another an ear, and a third a leg, and that others have lost the tongue, or the nose, or the head.

I see and have seen worse things, and divers things so hideous, that I should neither like to speak of all matters, nor even keep silent about some of them: namely, men who lack everything, except that they have too much of one thing—men who are nothing more than a big eye, or a big mouth, or a big belly, or something else big,—reversed cripples, I call such men.

And when I came out of my solitude, and for the first time passed over this bridge, then I could not trust my eyes, but looked again and again, and said at last: "That is an ear! An ear as big as a man!" I looked still more attentively—and actually there did move under the ear something that was pitiably small and poor and slim. And in truth this immense ear was perched on a small thin stalk—the stalk, however, was a man! A person putting a glass to his eyes, could even recognize further a small envious countenance, and also that a bloated little soul dangled at the stalk. The people told me, however, that the big ear was not only a man, but a great man, a genius. But I never believed in the people when they spoke of great men—and I hold to my belief that it was a reversed cripple, who had too little of everything, and too much of one thing.

When Zarathustra had spoken thus to the hunchback, and to those of whom the hunchback was the mouthpiece and advocate, then did he turn to his disciples in profound dejection, and said:

My friends, I walk amongst men as amongst the fragments and limbs of human beings!

This is the terrible thing to my eye, that I find man broken up, and scattered about, as on a battle—and butcher—ground.

And when my eye flees from the present to the bygone, it finds ever the same: fragments and limbs and fearful chances—but no men!

The present and the bygone upon earth—ah! my friends—that is my most unbearable trouble; and I should not know how to live, if I were not a seer of what is to come.

A seer, a purposer, a creator, a future itself, and a bridge to the future—and alas! also as it were a cripple on this bridge: all that is Zarathustra.

Source: Nietzsche, Friedrich. 1891. Common, Thomas, trans. *Thus Spoke Zarathustra.* Available at: http://morrandir.philosophyforums.com/e-books/Nietzsche/TSZ.txt

▣ "The Legend of Knockgrafton" (1892)

This Celtic fairy tale discusses disabled people who are appropriately deserving of cure in that they have taken up the proper attitude toward their bodily afflictions.

There was once a poor man who lived in the fertile glen of Aherlow, at the foot of the gloomy Galtee mountains, and he had a great hump on his back: he looked just as if his body had been rolled up and placed upon his shoulders; and his head was pressed down with the weight so much that his chin, when he was sitting, used to rest upon his knees for support. The country people were rather shy of meeting him in any lonesome place, for though, poor creature, he was as harm-less and as inoffensive as a new-born infant, yet his deformity was so great that he scarcely appeared to be a human creature, and some ill-minded persons had set strange stories about him afloat. He was said to have a great knowledge of herbs and charms; but certain it was that he had a mighty skilful hand in plaiting straw and rushes into hats and baskets, which was the way he made his livelihood.

Lusmore, for that was the nickname put upon him by reason of his always wearing a sprig of the fairy cap, or lusmore (the foxglove), in his little Straw hat, would ever get a higher penny for his plaited work than any one else, and perhaps that was the reason why some one, out of envy, had circulated the strange stories about him. Be that as it may, it happened that he was returning one evening from the pretty town of Cahir towards Cappagh, and as little Lusmore walked very slowly, on account of the great hump upon his back, it was quite dark when he came to the old moat of Knockgrafton, which stood on the right-band side of his road. Tired and weary was he, and noways comfortable in his own mind at thinking how much farther he had to travel, and that he should be walking all the night; so he sat down under the moat to rest himself and began looking mournfully enough upon the moon.

Presently there rose a wild strain of unearthly melody upon the ear of little Lusmore; he listened, and he thought that he had never heard such ravishing music before. It was like the sound of many voices, each mingling and blending with the other so strangely that they seemed to be one, though all singing different strains, and the words of the song were these—

> *Da Luan, Da Mort* ["Monday, Tuesday"], *Da Luan,*
> *Da Mort, Da Luan, Da Mort;*

when there would be a moment's pause, and then the round of melody went on again.

Lusmore listened attentively, scarcely drawing his breath lest he might lose the slightest note. He now plainly perceived that the singing was within the moat; and though at first it had charmed him so much, he began to get tired of hearing the same round sung over and over so often without any change; so availing himself of the pause when the *Da Luan, Da Mort,* had been sung three times, he took up the tune, and raised it with the words *augus Da Cadine* ["and Wednesday"], and then went on singing with the voices in side of the moat, *Da Luan, Da Mort,* finishing the melody, when the pause again came, with *augus Da Cadine.*

The fairies within Knockgrafton, for the song was a fairy melody, when they heard this addition to the tune, were so much delighted that, with instant resolve, it was determined to bring the mortal among them, whose musical skill so far exceeded theirs, and little Lusmore was conveyed into their company with the eddying speed of a whirlwind.

Glorious to behold was the sight that burst upon him as he came down through the moat, twirling round and round, with the lightness of a straw, to the sweetest music that kept time to his motion. The greatest honour was then paid him, for he was put above all the musicians, and he had servants tending upon him, and everything to his heart's content, and a hearty welcome to all; and, in short, he was made as much of as if he had been the first man in the land.

Presently Lusmore saw a great consultation going forward among the fairies, and, notwithstanding all their civility, he felt very much frightened, until one stepping out from the rest came up to him and said,

"Lusmore Lusmore!
Doubt not, nor deplore,
For the hump which you bore
On your back is no more;
Look down on the floor,
And view it, Lusmore !"

When these words were said, poor little Lusmore felt himself so light, and so happy, that he thought he could have bounded at one jump over the moon, like the cow in the history of the cat and the fiddle; and he saw, with inexpressible pleasure, his hump tumble down upon the ground from his shoulders. He then tried to lift up his head, and he did so with becoming caution, fearing that he might knock it against the ceiling of the grand hall, where he was; he looked round and round again with greatest wonder and delight upon everything, which appeared more and more beautiful; and, overpowered at beholding such a resplendent scene, his head grew dizzy, and his eyesight became dim. At last he fell into a sound sleep, and when he awoke he found that it was broad daylight, the sun shining brightly, and the birds singing sweetly; and that he was lying just at the foot of the moat of Knockgrafton, with the cows and sheep grazing peacefully round about him. The first thing Lusmore did, after saying his prayers, was to put his hand behind to feel for his hump, but no sign of one was there on his back, and he looked at himself with great pride, for he had now become a well-shaped dapper little fellow, and more than that, found himself in a full suit of new clothes, which he concluded the fairies had made for him.

Towards Cappagh he went, stepping out as lightly, and springing up at every step as if he had been all his life a dancing-master. Not a creature who met Lusmore knew him without his hump, and he had a great work to persuade every one that he was the same man—in truth he was not, so far as outward appearance went.

Of course it was not long before the story of Lusmore's hump got about, and a great wonder was made of it. Through the country, for miles round, it was the talk of every one, high and low.

One morning, as Lusmore was sitting contented enough, at his cabin door, up came an old woman to him, and asked him if he could direct her to Cappagh.

"I need give you no directions, my good woman," said Lusmore, "for this is Cappagh; and whom may you want here?"

Portrait of Dr. Felix Rey, *by Vincent Van Gogh (1853–1890). After severing the lower half of his ear, Van Gogh was placed in a hospital in Arles, France, for medical and psychiatric care. His attending physician while at the hospital Hotel-Dieu was the physician portrayed here, Dr. Felix Rey. Rey remained Vincent's doctor for nearly a year, until the artist voluntarily admitted himself to the Saint-Paul-de-Mausole asylum.*

Source: Art Resource, New York.

"I have come," said the woman, "out of Decie's country, in the county of Waterford looking after one Lusmore, who, I have heard tell, had his hump taken off by the fairies for there is a son of a gossip of mine who has got a hump on him that will be his death; and maybe if he could use the same charm as Lusmore, the hump may be taken off him. And now I have told you the reason of my coming so far 'tis to find out about this charm, if I can."

Lusmore, who was ever a good-natured little fellow, told the woman all the particulars, how he had raised the tune for the fairies at Knockgrafton, how his hump had been removed from his shoulders, and how he had got a new suit of clothes into the bargain.

The woman thanked him very much, and then went away quite happy and easy in her own mind. When she came back to her gossip's house, in the county of Waterford, she told her everything that Lusmore had said, and they put the little hump-backed man, who was a peevish and cunning creature from his birth, upon a car, and took him all the way across the country. It was a long journey, but they did not care for that, so the hump was taken from off him; and they brought him, just at nightfall, and left him under the old moat of Knockgrafton.

Jack Madden, for that was the humpy man's name, had not been sitting there long when he heard the tune going on within the moat much sweeter than before; for the fairies were singing it the way Lusmore had settled their music for them, and the song was going on; *Da Luan, Da Mort, Da Luan, Da Mort, Da Luan, Da Mort, augus Da Cadine,* without ever stopping. Jack Madden, who was in a great hurry to get quit of his hump, never thought of waiting until the fairies had done, or watching for a fit opportunity to raise the tune higher again than Lusmore had; so having heard them sing it over seven times without stopping, out he bawls, never minding the time or the humour of the tune, or how he could bring his words in properly, *augus Da Cadine, augus Da Hena* ["and Wednesday and Thursday"], thinking that if one day was good, two were better; and that if Lusmore had one new suit of clothes given him, he should have two.

No sooner had the words passed his lips than he was taken up and whisked into the moat with prodigious force; and the fairies came crowding round about him with great anger, screeching, and screaming, and roaring out, "Who spoiled our tune? who spoiled our tune?" and one stepped up to him, above all the rest and said:

"Jack Madden! Jack Madden
Your words came so bad in
The tune we felt glad in;
This castle you're had in,
That your life we may sadden
Here's two humps for Jack Madden!"

And twenty of the strongest fairies brought Lusmore's hump and put it down upon poor Jack's back, over his own, where it became fixed as firmly as if it was nailed on with twelve-penny nails, by the best carpenter that ever drove one. Out of their castle they then kicked him; and, in the morning, when Jack Madden's mother and her gossip came to look after their little man, they found him half dead, lying at the foot of the moat, with the other hump upon his back. Well to be sure, how they did look at each other! but they were afraid to say anything, lest a hump might be put upon their own shoulders. Home they brought the unlucky Jack Madden with them, as downcast in their hearts and their looks as ever two gossips were; and what through the weight of his other hump, and the long journey, he died soon after, leaving they say his heavy curse to any one who would go to listen to fairy tunes again.

Source: Jacobs, Joseph, trans. 1892. "The Legend of Knock grafton." Available at: http://www.public-domaincontent.com/books/legends_and_sagas/celt/flat/flat03.shtml

Walter E. Fernald, from *The History of the Treatment of the Feeble-Minded* (1893)

Walter Fernald, MD, director of the Waltham Institution for Feeblemindedness in Massachusetts, wrote one of the first U.S. histories on the topic of treatment methods. The essay promotes the need to continue institutionalization practices at a time when public unrest about their utility escalated. Fernald argues that the old objective of returning institutionalized residents to the community was a failure and that training has now largely transformed into permanent custodianship on behalf of the state.

The first recorded attempt to educate an idiot was made about the year 1800, by Itard, the celebrated physician-in-chief to the National Institution for the Deaf and Dumb at Paris, upon a boy found wild in a forest in the center of France, and known as the "savage of Aveyron." "This boy could not speak any human tongue, and was devoid of all understanding and knowledge." Believing him to be a savage, for five years Itard endeavored with great skill and perseverance to develop at the same time the intelligence of his pupil and the theories of the materialistic school of philosophy. Itard finally became convinced that this boy was an idiot, and abandoned the attempt to educate him. In the year 1818 and for a few years afterward, several idiotic children were received and given instruction at the American Asylum for the Deaf and Dumb at Hartford, and a fair degree of improvement in physical condition, habits, and speech was obtained.

In the year 1828 Dr. Ferret, physician at the Bicêtre in Paris, attempted to teach a few of the more intelligent idiots who were confined in this hospital to read and write and to train them to habits of cleanliness and order. In 1831 Dr. Fabret attempted the same work at the Salpêtrière; and in 1833 Dr. Voisin opened his private school for idiots in Paris. None of these attempts was successful enough to insure its continuance.

In 1837 Dr. E. Séguin, a pupil of Itard and Esquirol, began the private instruction of idiots at his own expense. In 1842 he was made the instructor of the school at the Biçêtre, which had been reopened by Dr. Voisin in 1839. Dr. Séguin remained at the Biçêtre only one year, retiring to continue the work in his private school in the Hospice des Incurables. After seven years of patient work and experiments and the publication of two or three pamphlets describing the work, a committee from the Academy of Sciences at Paris in 1844 examined critically and thoroughly his methods of training and educating idiot children, and reported to the Academy, giving it the highest commendation and declaring that, up to the time he commenced his labors in 1837, idiots could not be educated by any means previously known or practiced, but that he had solved the problem. His work thus approved by the highest authority, Dr. Séguin continued his private school in Paris until the Revolution in 1848, when he came to America, where he was instrumental in establishing schools for idiots in various States.

In 1846 Dr. Séguin published his classical and comprehensive "Treatise on Idiocy," which was crowned by the Academy and has continued to be the standard text-book for all interested in the education of idiots up to the present time. His elaborate system of teaching and training idiots consisted in the careful "adaptation of the principles of physiology, through physiological means and instruments, to the development of the dynamic, perceptive, reflective, and spontaneous functions of youth." This physiological education of defective brains as a result of systematic training of the special senses, the functions, and the muscular system, was looked upon as a visionary theory, but has been verified and confirmed by modem experiments and researches in physiological psychology.

Dr. Séguin's school was visited by scientists and philanthropists from nearly every part of the civilized world, and, his methods bearing the test of experience, other schools were soon established in other countries, based upon these methods.

In 1842 Dr. Guggenbühl established a school upon the slope of the Abendenberg in Switzerland, for the care and training of cretins, so many of whom are found in the dark, damp valleys of the Alps. This school was very successful in its results, and attracted much attention throughout Europe. At Berlin, in 1842, a school for the instruction of idiots was opened by Dr. Saegert. In England the publication of the results of the work of Drs. Séguin, Guggenbühl, and Saegert, and the efforts of Drs. Connolly and Reed, led to the establishment of a private school at Bath in 1846, and later to the finely appointed establishments at Colchester and Earlswood.

The published description of the methods and results of these European schools attracted much interest and attention in America. In this country the necessity and humanity of caring for and scientifically treating the insane, the deaf and dumb, and the blind had become the policy of many of our most progressive States. The class of helpless and neglected idiots who had no homes, as a rule were cared for in jails and poorhouses. A few idiots who had been received at the special schools for the deaf and dumb and the blind showed considerable improvement after a period of training. Other cases who were especially troublesome had been sent to the insane hospitals, where it was shown that the habits and behavior of this class could be changed very much for the better. In their reports for 1845 Drs. Woodward and Brigham, superintendents of the State Insane Hospitals in Massachusetts and New York respectively, urged the necessity of making public provision for the education of idiots in those States. . . .

It was hoped and believed that a large proportion of this higher-grade or "improvable" class of idiots could be so developed and educated that they would be capable of supporting themselves and of creditably maintaining an independent position in the community. It was maintained that the State should not assume the permanent care of these defectives, but that they should be returned to their homes after they had been trained and educated. It was the belief of the managers that only a relatively small number of inmates could be successfully cared for in one institution. It was deemed unwise to congregate a large number of persons suffering under any common infirmity.

Nearly every one of these early institutions was opened at or near the capitals of their various States, in order that the members of the legislature might closely watch their operations and personally see their need and the results of the instruction and training of these idiots. No institution was ever abandoned or given up after having been established. In all of the institutions the applications for admission were far in excess of their capacity.

In the course of a few years, in the annual reports of these institutions we find the superintendents regretting that it was not expedient to return to the community a certain number of the cases who had received all the instruction the school had to offer. When the limit of age was reached, it was a serious problem to decide what should be done with the trained boy or girl. It was found that only a small proportion, even of these selected pupils, could be so developed and improved that they could go out into the world and support themselves independently. A larger number, as a result of the school discipline and training, could be taken home where they became comparatively harmless and unobjectionable members of the family, capable, under the loving and watchful care of their friends, of earning by their labor as much as it cost to maintain them. But in many cases the guardians of these children were unwilling to remove them from the institution, and begged that they might be allowed to remain where they could be made happy and kept from harm. Many of these cases were homeless and friendless, and, if sent away from the school, could only be transferred to almshouses where they became depraved and demoralized by association with adult paupers and vagrants of both sexes. It was neither wise nor humane to turn these boys and girls out to shift for themselves. The placing out of these feeble-minded persons always proved unsatisfactory. Even those who had suitable homes and friends able and willing to become responsible for them, by the death of these relatives were thrown on their own resources and drifted into pauperism and crime. It gradually became evident that a certain number of these higher-grade cases needed lifelong care and supervision, and that there was no suitable provision for this permanent custody outside these special institutions.

Once it was admitted that our full duty toward this class must include the retention and guardianship of some of these cases who had been trained in the schools, the wisdom and necessity of still further broadening the work became apparent. It was found that more than one-half of the applications for admission, and those by far the most insistent, were in behalf of the "unimprovables," as Dr. Howe described them. This lower class of idiots, many of them with untidy, disgusting, and disagreeable habits, feeble physically, perhaps deformed and misshapen, often partially paralyzed or subject to epilepsy, cannot be given suitable care at home. There is no greater burden possible in a home or a neighborhood. It has been well said that by institution care, for every five idiots cared for we restore four productive persons to the community; for, whereas at home the care of each of these children practically requires the time and energies of one person, in an institution the proportion of paid employees is not over one to each five inmates. The home care of a low-grade idiot consumes so much of the working capacity of the wage-earner of the household that often the entire family become pauperized. Humanity and public policy demanded that these families should be relieved of the burden of these helpless idiots. From the nature of their infirmities it is evident that the care of this class must last as long as they live. As nearly every one of these low-grade idiots eventually becomes a public burden, it is better to assume this care when they are young and susceptible of a certain amount of training than to receive them later on, undisciplined, helpless, destructive, adult idiots.

The brighter class of the feeble-minded, with their weak will power and deficient judgment, are easily influenced for evil, and are prone to become vagrants, drunkards, and thieves. The modern scientific study of the deficient and delinquent classes as a whole has demonstrated that a large proportion of our criminals, inebriates, and prostitutes are really congenital imbeciles, who have been allowed to grow up without any attempt being made to improve or discipline them. Society suffers the penalty of this neglect in an increase of pauperism and vice, and finally, at a greatly increased cost, is compelled to take charge of adult idiots in almshouses and hospitals, and of imbecile criminals in jails and prisons, generally during the remainder of their natural lives. As a matter of mere economy, it is now believed that it is better and cheaper for the community to assume the permanent care of this class before they have carried out a long career of expensive crime. . . .

The tendency to lead dissolute lives is especially noticeable in the females. A feeble-minded girl is exposed as no other girl in the world is exposed. She has not sense enough to protect herself from the perils to which women are subjected. Often bright and attractive, if at large they either marry and bring forth in geometrical ratio a new generation of defectives and dependants, or become irresponsible sources of corruption and debauchery in the communities where they live. There is hardly a poorhouse in this land where there are not two or more feeble-minded women with from one to four illegitimate children each. There is every reason in morality, humanity, and public policy that these feeble-minded women should be under permanent and watchful guardianship, especially during the child-bearing age. A feeble-minded girl of the higher grade was accepted as a pupil at the Massachusetts School for the Feeble-minded when she was fifteen years of age. At the last moment the mother refused to send her to the school, as she "could not bear the disgrace of publicly admitting that she had a feeble-minded child." Ten years later the girl was committed to the institution by the court, after she had given birth to six illegitimate children, four of whom were still living and all feeble-minded. The city where she lived had supported her at the almshouse for a period of several months at each confinement, had been compelled to assume the burden of the life-long support of her progeny, and finally decided to place her in permanent custody. Her mother had died broken-hearted several years previously.

Modern usage has sanctioned the use of the term "feeble-minded" to include all degrees and types of congenital defect, from that of the simply backward boy or girl but little below the normal standard of intelligence to the profound idiot, a helpless, speechless, disgusting burden, with every degree of deficiency between these extremes. The lack may be so slight as to involve only the ability to properly decide questions of social propriety or conduct, or simply questions of morality, or it may profoundly affect every faculty. In theory, the differences between these various degrees of deficiency are marked and distinct, while in practice the lines of separation are entirely indefinite, and individuals as they grow to adult life may be successively classed in different grades. "Idiocy," generically used, covers the whole range referred to, but is now specifically used to denote only the lowest grades. "Imbecility" has reference to the higher grades. "Feeble-Minded" is a less harsh expression, and satisfactorily covers the whole ground.

We have learned from the researches of modern pathology that in many cases the arrested or perverted development is not merely functional or a delayed infantile condition, but is directly due to the results of actual organic disease, or injury to the brain or nervous system, occurring either before birth or in early infancy.

The work of caring for this class in this country has been greatly aided by the active influence of the Association of Medical Officers of American Institutions for Idiotic and Feeble-minded Persons. This society was organized in 1876, during the Centennial Exposition at Philadelphia, and held its first meeting at the Pennsylvania Training School at Elwyn. The object of the Association is the consideration and discussion of all questions relating to the management, training, and education of idiots and feeble-minded persons. It also lends its influence to the establishment and fostering of institutions for this purpose. The Association meets annually for the reading of papers and the discussion of the various phases of this work. . . .

Source: Fernald, Walter E. 1893. *The History of the Treatment of the Feeble-Minded.* Boston: G. H. Ellis.

▣ Florence Kelley, "Injurious Employments" (1894)

In her first annual report as an Illinois factory inspector, Kelley focused on child labor as a practice that both disabled poor immigrant minors and exploited those who were already disabled. The story of Jaroslav Huptuk is especially revealing of its era; we see the various Progressive experts taking a hand in moving Huptuk from the community and unsafe work to the state institution (a resolution Kelley finds proper, in this instance).

The reckless employment of children in injurious occupations also is shown in the record of these medical examinations. A glaring example of this is Jaroslav Huptuk, a feeble-minded dwarf, whose affidavit shows him to be nearly sixteen years of age. This child weighs and measures almost exactly the same as a normal boy aged eight years and three months. Jaroslav Huptuk cannot read nor write in any language, not speak a consecutive sentence. Besides being dwarfed, he is so deformed as to be a monstrosity. Yet, with all these disqualifications for any kind of work, he has been employed for several years at an emery wheel, in a cutlery works, finishing knife-blades and bone handles, until, in addition to his other misfortunes, he is now suffering from [tuberculosis]. Dr. Holmes, having examined this boy, pronounced him unfit for work of any kind. His mother appealed from this to a medical college, where, however, the examining physician not only refused the lad a medical certificate, but exhibited him to the students as a monstrosity worthy of careful observation. He was finally taken in charge by an [orthopedist], and after careful treatment will be placed in a school for the feeble-minded. The kind of grinding at which this boy was employed has been prohibited in England for minors since 1883, by reason of the prevalence of "grinders' pthisis" among those who begin this work young.

Another occupation conspicuously injurious to children is the running of button-hole machines by foot-power. As a typical case: Joseph Poderovsky, aged fourteen years, was found by a deputy inspector running a heavy button-holer at 204 West Taylor street, in the shop of Michael Freeman. The child was required to report for medical examination, and pronounced by the examining physician rachitic and afflicted with a double lateral curvature of the spine. He was ordered discharged, and prohibited from working in any tailor shop. A few days later he was found at work at the same machine. A warrant was sworn out for the arrest of the employer, under Section Four of the law, but before it could be served the man left the State. This boy has a father in comfortable circumstances, and two adult able-bodied brothers.

Bennie Kelman, Russian Jew, four years in Chicago, fifteen years and four months old, father a glazier, found running a heavy sewing machine in a knee-pants shop. A health certificate was required, and the examination revealed a severe rupture. Careful questioning of the boy and his mother elicited the fact that he had been put to work in a boiler factory, two years before, when just thirteen years old, and had injured himself by lifting heavy masses of iron. Nothing had been done for the case, no one in the family spoke any English, or knew how help could be obtained. The sight test showed that he did not know his letters in English, though he claimed that he can read Jewish jargon. He was sent to the College of Physicians and Surgeons for treatment, and forbidden work until cured.

When the law went into operation, every tin-can and stamping works in Illinois was employing minors under sixteen years of age, at machines known to be liable to destroy the fingers, hands, and even the whole arm of the operator. The requirement of a medical certificate for all minors so employed has materially reduced their number, but the law should be so amended as to give the inspector power to prohibit the employment of minors at this and all kindred occupations. Until such power is conferred, the mutilation of children will continue to be a matter of daily [occurrence].

The working of the law, even in its present inadequate form, is exemplified in its application to the tin-can industry by Norton's tin-can factory at Maywood. Here a very large number of boys are employed, a score having been found under fourteen years of age. In one part of the factory twenty to thirty boys work upon a shelf suspended between the first and second floors of the building. These unfortunate lads crouch, lie on their sides, sit on their feet, kneel, in short, assume every possible attitude except the normal, straight, sitting or standing posture of healthful employment. Their work consists in receiving pieces of tin sent to them by boys on the second floor, sorting them and poking them into slits in the shelf, whence the pieces of tin are conveyed to the machines on the ground floor for which they are destined. The atmosphere of the room at the height of the shelf is such that the inspector could endure it but a few minutes at a time. The noise of the machinery was so overpowering that it was impossible to make the boys hear questions until after two or three repetitions. The pieces of tin being sharp, the lad's fingers were bound up in cloths to prevent cutting, but in many cases these cloths were found to be saturated with blood. Altogether, the situation of these tin can boys was among the most deplorable discovered. Four inspections were made, and literal compliance with the wording of the law in all respects required. When the season ended, it was with the assurance upon the part of the Norton Bros. that they will open next year with no minors employed on their Maywood premises under sixteen years of age.

Source: Kelley, Florence. 1894. "Injurious Employments." Pp. 10–13 in *First Annual Report of the Factory Inspectors of Illinois.* Springfield, IL: H. W. Rokker.

Cesare Lombroso and William Ferrero, from *The Female Offender* (1895)

In keeping with the late-nineteenth-century interest in "social Darwinism," which looks at societal phenomena from the perspective of Darwinian theory, this work examines criminality, prostitution, and lesbianism *in women with reference to inborn or physical characteristics.*

Although I argue that the female equivalent of the male born criminal is the prostitute and that she shares the same atavistic origin, I certainly need to state, very clearly, that she is less perverse and less harmful to society. While every crime involves calamity, prostitution can be a moral safety valve. In any case, it would not exist without male vice, for which it is a useful, if shameful, outlet. One might say that the more women degrade themselves, and the more they sin, the more they are helping society.

Thus, if I must show that in mind and body, woman is a male of arrested development, the fact that she is somewhat less criminal than he, and a little more pitiful, can compensate a thousandfold for her deficiency in the realm of intellect. Just as musical harmony and beauty conquer all social classes, the respect that all people have for women's intensity of feeling and maternal sentiment more than makes up for women's deficiency of intellect. A scientist will have a hundred admirers who quickly disappear, but women are saints who have a million admirers, forever.

Not one line of work justifies the great tyranny that continues to victimize women, from the taboo which forbids them to eat meat or touch a coconut, to that which impedes them from studying, and worse, from practicing a profession once they are educated. These ridiculous and cruel constraints, still widely accepted, are used to maintain or (sadder still) increase women's inferiority, exploiting them to our advantage. The same happens when we shower a docile victim with hypocritical elegies and, while pretending that she is an ornament, ready her for new sacrifices. (P. 37)

While these accumulated findings do not amount to much, this result is only natural. For if external differences between male criminals and normal men are few, they must be fewer still between female criminals and normal women. We noted earlier that stability of type is much greater in woman and differentiation much less, even when her skull is anomalous.

The following are our most important conclusions:

- Female criminals are shorter than normal women; and in proportion to their stature, prostitutes and female murderers weigh more than honest women
- Prostitutes have bigger calves than honest women
- Female thieves and above all prostitutes are inferior to honest women in cranial capacity and cranial circumference
- Criminals have darker hair than normal women, and this also holds good to a certain extent for prostitutes. Several studies have found that in these women rates of fair and red hair equal and sometimes exceed those of normal women.
- Grey hair, which is rare in the normal woman, is more than twice as frequent in the criminal woman. On the other hand, in both young and mature criminal women, baldness is less common than in normal women. Wrinkles are markedly more frequent in criminals of ripe years. Little of all this can be positively affirmed for prostitutes, who are painted and made up when not (as is usual) very young; but so far as it is possible to judge, prostitutes are as little subject to precocious greynes and baldness as are congenital male criminals. (Pp. 125–126)

The Nature and Causes of Lesbianism

Parent-Duchatelet, who is not always as correct in his analysis as he is precise in his information, explains lesbianism in terms of forced abstinence from men and residing with other women in prisons and brothels. But he does not take into consideration the fact that lesbianism also occurs in the broader world, which has little in common with prisons and brothels. To show this point, we have only to point out, as Sighele has sensibly noted, that a great many novels allude to this vice.

Lesbianism has various causes, the first and most significant of which is an excessive lustfulness, which seeks outlets in all directions, even in the most unnatural. In prisons, some women, being unable to satisfy themselves with a man, throw themselves on other women and become a center of corruption that spreads from the prisoners all the way to the nuns. This is why the majority of prisoners, even though they are only criminaloids and thus not oversexed, will become lesbians under the influence of extremely lascivious born criminals. As Parent-Duchatelet noted, prison is the great school for lesbianism. There even the most reluctant women, if they remain for eighteen or twenty months, end up giving in to the vice. In this respect women prisoners resemble animals; when unable to satisfy their sexual needs with the opposite sex, they attempt to do so with their own. The same thing occurs in madhouses, in which the appearance of a single lesbian is sufficient to infect all the other inmates, even if none of them earlier showed signs of this tendency (Lombroso, *Il tribadismo nei manicomi,* 1888).

A third cause of lesbianism is the way in which the gathering of many women, especially if the group includes prostitutes or lascivious women, provokes imitative behavior, intensifying the vices of each individual and increasing collective vice. Prostitutes often pass their days in the nude, in constant contact with another and often sleeping two or three in one bed. In the outer world, too, gatherings of women occur in boarding schools, during carnival orgies, and even during religious festivals. In brothels women hold competitions, betting on who has the most beautiful sexual organs; naturally this ends up in lesbianism. There are girls who at first resist, disgusted by this vice; they are therefore not born lesbians. Yet they succumb in a state of intoxication, or else they familiarize themselves with the practice little by little, eventually becoming occasional lesbians.

Fourth, maturity and old age tend to invert sexual characteristics, which further encourages sexual inversions among women. Natural history (as we saw earlier) demonstrates that among animals there is a tendency for elderly females to adopt masculine sexual habits. In fact, aging itself is a form of degeneration. While it is true that lesbianism can be found among many young women, most of them live in brothels, where they succumb when tempted by provocative companions.

Fifth, among prostitutes and also some women of easy morals, another cause of lesbianism is apathy and disgust for men produced by physical and sexual mistreatment. Abused by men, they may turn to women when they feel sexual passion (fishermen do not eat fish, as the saying goes). Then, too, women who truly love their paramours may from time to time experience male mistreatment, at which point they give themselves to women, hoping for more faithfulness and certainly kinder treatment. Thus did Nana throw herself at women out of disgust for men's filthy lusts and the way fickle lovers abandoned her.

"One of the causes of lesbianism," Sighle writes in "Coppia criminale" (Archivio di psichiatria, XII, P. 53), "is doubtless men's sexual perversions. Sadists (a term under which Sighele includes all men who practice sex unnaturally) force prostitutes into repugnant acts that exhaust and nauseate them. These women, even though they hardly seem feminine, can feel only disgust for men who are not completely masculine. And thus is born lesbianism—a logical and natural outcome. To escape one dreadful situation, prostitutes fall on one another." The same thing happens with women who are not prostitutes. (Pp. 176–178)

Source: Lombroso, Cesare, and William Ferrero. 1895. *The Female Offender.* New York: D. Appleton.

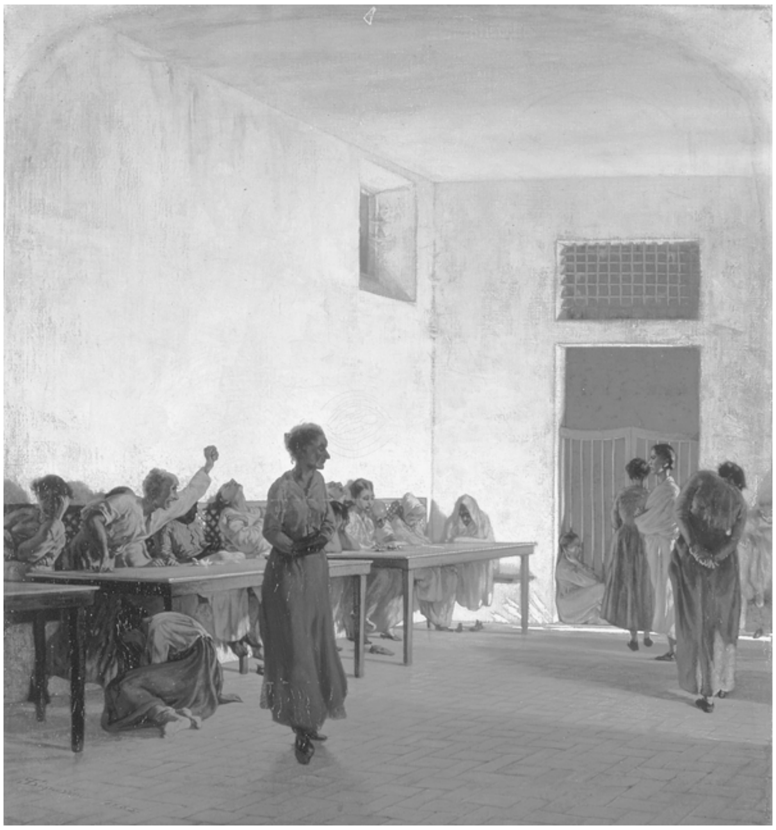
Max Nordau, from *Degeneration* (1895)

Nordau argues that the frenzied and crowded conditions of modern life, especially in urban centers, produce a degeneration of the human mind and body that may be transmitted genetically to subsequent generations. Among the symptoms of this degeneration are moral insanity, nervous disorders, and susceptibility to false beliefs. Nordau's theories were later embraced by the Nazis to attack racially undesirable groups, especially urban Jews.

The clearest notion we can form of degeneracy is to regard it as a *morbid deviation from an original type.* This deviation, even if, at the outset, it was ever so slight, contained transmissible elements of such a nature that anyone bearing in him the germs becomes more and more incapable of fulfilling his functions in the world; and mental progress, already checked in his own person, finds itself menaced also in its descendants.

When under any kind of noxious influence an organism becomes debilitated, its successors will not resemble the healthy, normal type of the species, with capacities for development, but will form a new subspecies, which, like all others, possesses the capacity of transmitting to its offspring, in a continuously increasing degree, its peculiarities, these being morbid deviations from the normal form—gaps in development, malformations, and infirmities. That which distinguishes degeneracy from the formation of new species (phylogeny) is, that the morbid variation does not continually subsist and propagate itself, like one that is healthy, but, fortunately, is soon rendered sterile, and after a few generations often dies out before it reaches the lowest grade of organic degradation.

Degeneracy betrays itself among men in certain physical characteristics, which are denominated 'stigmata,' or brandmarks—an unfortunate term derived from a false idea, as if [degeneracy] were necessarily the consequences of a fault, and the indication of it a punishment. Such stigmata consist of deformities, multiple and stunted growths in the first line of asymmetry, the unequal development of the two halves of the face and cranium; then imperfections in the development of the external ear, which is conspicuous for its enormous size, or protrudes from the head, like a handle, and the lobe of which is either lacking or adhering to the head, and the helix of which is not involuted; further, squint-eyes, haire lips, irregularities in the form and position of the teeth; pointed or flat palates, webbed or supernumerary fingers (syn- and poly-dactylia), etc. In this book from which I have quoted, Morel gives a list of the anatomic phenomena of degeneracy, which later observers have largely extended. In particular, Lombroso has conspicuously broadened our knowledge of stigmata, but he apportions them merely to his 'born criminals'—a limitation which from the very scientific standpoint of Lombroso himself cannot be justified, his 'born criminals' being nothing but a subdivision of degenerates. Fere expresses this very emphatically when he says 'Vice, crime and madness are only distinguished from each other by social prejudices.'



Department for Violent Female Mental Patients at San Bonafacio in Florence, Italy, *by Telemaco Signorini (1835–1901). This image portrays a locked ward for women diagnosed as "mental patients" within the Italian justice system. Nineteenth-century legal historians have discussed the ways in which psychiatry legitimated its professional necessity by providing expert professional opinions on the competency of those standing trial within the judicial system.*

Source: Art Resource, New York.

There might be a sure means of proving that the application of the term 'degenerates' to the origination of all the *fin-de-siecle* movements in art and literature is not arbitrary, that is no baseless conceit, but a fact; and that would be a careful physical examination of the persons concerned and an inquiry into their pedigree. In almost all cases, relatives would be met with who were undoubtedly degenerate, and one or more stigmata discovered which would indisputably establish the 'Degeneration.' Of course, from human consideration, the result of such an inquiry could often not be made public; and he alone would be convinced who should be able to undertake it himself.

Science, however, has found, together with these physical stigmata, others of a mental order, which betoken degeneracy quite as clearly as the former; and they allow of an easy demonstration from all the works of degenerates, so that it is not necessary to measure the cranium of an author, or to see the lobe of a painter's ear, in order to recognize the fact that he belongs to the class of degenerates.

Quite a number of different designations have been found for these persons. Maudsley and Ball call them 'borderland dwellers'—that is to say, dwellers on the borderland between reason and pronounced madness. Magnan gives to them the name of 'higher degenerates' (*degeneres de superieurs),* and Lombroso speaks of '*mattoids*' (from *matto,* the Italian for insane), and 'graphomaniacs,' under which he classifies those semi insane persons who feel a strong impulse to write. In spite, however, of this variety of nomenclature, it is a question simply of one single species of individuals, who betray their fellowship by the similarity of their mental physiognomy.

In the mental development of degenerates, we meet with the same irregularity that we have observed in their physical growth. The asymmetry of face and cranium finds, as it were, its counterpart in their mental faculties. Some of the latter are completely stunted, others morbidly exaggerated. That which nearly all degenerates lack is the sense of morality and of right and wrong. For them there exists no law, no decency, no modesty. In order to satisfy any momentary impulse, or inclination, or caprice, they commit crimes and trespasses with the greatest calmness and self-complacency, and do not comprehend that other persons take offense thereat. When this phenomenon is present in a high degree, we speak of 'moral insanity' with Maudsley; there are, nevertheless, lower stages in which the degenerate does not, perhaps, himself commit any act which will bring him into conflict with the criminal code, but at least asserts the theoretical legitimacy of crime; seeks, with philosophically sounding fustian, to prove that 'good' and 'evil,' virtue and vice, are arbitrary distinctions; goes into raptures over evildoers and their deeds; professes to discover beauties in the lowest and most repulsive things; and tries to awaken interest in and so-called 'comprehension' of every bestiality. The two psychological roots of moral insanity, in all its degrees of development, are firstly unbounded egoism, and, secondly, impulsiveness—i.e., inability to resist a sudden impulse to any deed; and these characteristics also constitute the chief intellectual stigmata of degenerates. In the following sections of this work, I shall find occasion on which to show on what organic grounds, and in consequence of what peculiarities of their brain and nervous system, degenerates are necessarily egotistical and impulsive. In these introductory remarks, I would wish only to point out the stigma itself.

Another mental stigma of degenerates is their emotionalism. Morel has even wished to make this peculiarity their chief characteristic—erroneously, it seems to me, for it is present in the same degree among hysterics, and, indeed, is to be found in perfectly healthy persons, who, from any transient cause, such as illness, exhaustion, or from any mental shock, have been temporarily weakened. Nevertheless, it is a phenomenon rarely absent in a degenerate. He laughs until he sheds tears, or weeps copiously without adequate occasion; a commonplace line of poetry or of prose sends a shudder down his back; he falls into raptures before indifferent pictures or statues; and music especially, even the most insipid and least commendable, arouses in him the most vehement emotions. He is quite proud of being so vibrant a musical instrument, and boasts that where the Philistine remains completely cold, he feels his inner self confounded, the depths of his being broken up, and the bliss of the Beautiful pressing him to the tips of his fingers. His excitability appears to him a mark of superiority; he believes himself to be possessed by a peculiar insight lacking in other mortals, and he is fain to despise the vulgar herd for the dullness and narrowness of their minds. The unhappy creature does not suspect that he is conceited about a disease and boasting about a derangement of the mind; and silly critics, when, through fear of being pronounced deficient in comprehension, they make desperate efforts to share the emotions of a degenerate in regard to some insipid or ridiculous production, or when they praise in exaggerated expressions the beauties which the degenerate asserts he finds therein, are unconsciously simulating one of the stigmata of semi-insanity.

Besides moral realm and emotionalism, there is to be observed in the degenerate a condition of mental weakness and dependency, which according to the circumstances of his life, assumes the form of pessimism, a vague fear of all men, and of the entire phenomenon of the universe, or self-abhorrence. 'These patients,' says Morel, 'feel perpetually compelled . . . to commiserate themselves, to sob, to repeat with the most desperate monotony the same questions and words. They have delirious presentations of ruin and damnation, and all sorts of imaginary fears.' 'Ennui never quits me' said a patient of this kind, whose case Roubinovitch describes, 'ennui of myself.' 'Among moral stigmata,' says the same author 'there are also to be specified those undefinable apprehensions manifested by degenerates when they see, smell, or touch any object.' And he further calls to notice 'their unconscious fear of everything and everyone.' In this picture of the sufferer from melancholia; downcast, somber, despairing of himself and the world, tortured by fear of the Unknown, menaced by undefined but dreadful dangers, we recognise in every detail the man of the Dusk of the Nations and the *fin-de-siecle* frame of mind, described in the first chapter.

With this characteristic dejectedness of the degenerate, there is combined, as a rule, a disinclination to action of any kind, attaining possibly to abhorrence of activity and powerlessness to will (*aboulia*). Now, it is a peculiarity of the human mind, known to every psychologist, that, inasmuch as the law of causality governs a man's whole thought, he imputes a rational basis to all his own decisions. This was prettily expressed by Spinoza when he said : 'If a stone flung by a human hand could think, it would certainly imagine that it flew because it wished to fly.' Many mental conditions and operations of which we become conscious are the result of causes which do not reach our consciousness. In this case we fabricate causes *a posteriori* for them, satisfying our mental need of distinct causality, and we have no trouble in persuading ourselves that we have truly explained them. The degenerate who shuns action is a consequence of his inherited deficiency of brain. He deceives himself into believing that he despises action from free determination, and takes pleasure in inactivity; and, in order to justify himself in his own eyes, he constructs a philosophy of renunciation and of contempt for the world and men, asserts that he has convinced himself of the excellence of Quietism, calls himself with consummate self-consciousness a Buddhist, and praises Nirvana in poetically eloquent phrases as the highest and worthiest ideal of the human mind. The degenerate and insane are the predestined disciples of Schopenhauer and Hartmann, and need only to acquire a knowledge of Buddhism to become converts to it.

With the incapacity for action there is connected the predilection for insane reverie. The degenerate is not in a condition to fix his attention long, or indeed at all, on any subject, and is equally incapable of correctly grasping, ordering, or elaborating into ideas and judgments the impressions of the internal world conveyed to his distracted consciousness by his defectively operating senses. It is easier and more convenient for him to allow his brain-centres to produce semi-lucid, nebulously blurred ideas and inchoate embryonic thoughts, and to surrender himself to the perpetual obfuscation of a boundless, aimless, and shoreless stream of fugitive ideas; and he rarely rouses himself to the painful attempt to check or counteract the capricious, and, as a rule, purely mechanical associations of ideas and succession of images, and bring under discipline the extraordinary tumult of his fluid presentations. On the contrary, he rejoices in his faculty of imagination, which he contrasts with the insipidity of the Philistine, and devotes himself with predilection to all sorts of unlicensed pursuits permitted by the unshackled vagabond of his mind; while he cannot endure well-ordered civil occupations, requiring attention and constant heed to reality. He calls this 'having an idealist temperament,' ascribes to himself irresistible aesthetic propinquities, and proudly styles himself an artist.

We will briefly mention some peculiarities frequently manifested by a degenerate. He is tormented by doubts, seeks for the basis of all phenomena, especially those whose first causes are completely inaccessible to us, and he is unhappy when his inquiries and ruminations lead, as is natural, to no result. He is ever supplying new recruits to the army of system-inventing metaphysicians, profound expositors of the riddle of the universe, seekers for the philosopher's stone, the squaring of the circle and perpetual motion. These last three subjects have such a special attraction for him, that the Patent Office at Washington is forced to keep on hand printed replies to the numberless memorials in which patents are constantly demanded for the solution of these chimerical problems. In view of Lombroso's researches, it can scarcely be doubted that the writings and acts of revolutionists and anarchists are also attributable to degeneracy. The degenerate is incapable of adapting himself to existing circumstances. This incapacity, indeed, is an indication of morbid variation in every species, and probably a primary cause of their sudden extinction. He therefore rebels against conditions and views of things which he necessarily feels to be painful, chiefly because they impose upon him the duty of self-control, of which he is incapable on account of his organic weakness of will. Thus he becomes an improver of the world, and devises plans for making mankind happy, which, without exception are conspicuous quite as much by their fervent philanthropy, and often pathetic insincerity, as by their absurdity and monstrous ignorance of all real relations.

Finally, a cardinal mark of degenerates which I have reserved to the last, is mysticism. Colin says 'Of all the delirious manifestations peculiar to the hereditarily-afflicted, none indicates the condition more clearly, we think, than mystical delirium, or, when the malady has not reached this point, the being constantly occupied with mystical and religious questions, and exaggerated piety, etc.' In the following books, where the art and poetry of the times are treated of, I shall find occasion to show the reader that no difference exists between these tendencies and the religious manias observed in nearly all degenerates and sufferers from hereditary mental taint.

I have enumerated the most important features characterizing the mental condition of the degenerate. The reader can now judge for himself whether or not the diagnosis 'degeneration' is applicable to the originators of the new aesthetic tendencies. It must not for that matter be supposed that degeneration is synonymous with absence of talent. Nearly all the inquirers who have had degenerates under their observation expressly establish the contrary. A badly balanced mind is susceptible of the highest conceptions, while, on the other hand, one meets in the same mind with traits of meanness and pettiness all the more striking from the fact that they co-exist with the most brilliant qualities.' We shall find this reservation in all authors who have contributed to the natural history of the degenerate. 'As regards their intellect, they can,' says Roubinovitch, 'attain to a high degree of development, but from a moral point of view their existence is completely deranged. . . . A degenerate will employ his brilliant faculties as well in the service of some grand object as in the satisfaction of the basest propensities.' Lombroso has cited a large number of undoubted geniuses who were equally undoubted mattoids, graphomaniacs, or pronounced lunatics; and the utterance of a French savant, Guerinsen, 'Genius is a disease of the nerves,' has become a 'winged word.' This expression was imprudent, for it gave ignorant babblers a pretext, and apparently a right, to talk of exaggeration, and to contemn experts in nervous and mental diseases, because they professedly saw a lunatic in everyone who ventured to be something more than the most characterless, average being. Science does not assert that every genius is a lunatic; there are some geniuses of superabundant power whose high privilege consists in the possession of one or other extraordinarily developed faculty, without the rest of their faculties falling short of the average standard. Just as little, naturally, is every lunatic a genius; most of them, even if we disregard idiots of different degrees, are much rather pitiably stupid and incapable; but in many, nay, in abundant cases, the 'higher degenerate' of Magnan, just as he occasionally exhibits gigantic bodily stature or the disproportionate growth of particular parts, has some mental gift exceptionally developed at the cost, it is true, of the remaining faculties, which are wholly or partially atrophied. It is this which enables the well-informed to distinguish at the first glance between the sane genius, and the highly, or even the most highly, gifted degenerate. Take from the former the special capacity through which he becomes a genius, and there still remains a capable, often conspicuously intelligent, clever, moral, and judicious man, who will hold his ground with propriety in our social mechanism. Let the same be tried with the case of a degenerate, and there remains only a criminal or madman, for whom healthy humanity can find no use. If Goethe had never written a line of verse, he would, all the same, have still remained a man of the world, of good principles, a fine art connoisseur, a judicious collector, a keen observer of nature. Let us on the contrary, imagine a Schopenhauer who had written no [astounding] books, and we should have before us only a repulsive *lusus naturae,* whose morals would necessarily exclude him from all respectable society, and whose fixed idea that he was a victim of persecution would point him out as a subject for a madhouse. The lack of harmony, the absence of balance, the singular incapacity of useful applying, or deriving satisfaction from, their own special faculty among highly gifted degenerates, strikes every healthy censor who does not allow himself to be prejudiced by the noisy admiration of critics, themselves degenerates: and will always prevent his mistaking the mattoid for the same exceptional man who opens out new paths for humanity and leads it to higher developments. I do not share Lombroso's opinion that highly-gifted degenerates are an active force in the progress of mankind. They corrupt and delude; they do, alas! frequently exercise deep influence, but this is always a baneful one. It may not be at once remarked, but it will reveal itself subsequently. If contemporaries do not recognise it, the historian of morals will point it out *a posteriori.* They, likewise, are leading men along the paths they themselves have found to new goals; but these goals are abysses or waste places. They are guides to swamps like will-o'-the-wisps, or to ruin like the ratcatcher of Hammelin. Observers lay stress on their unnatural sterility. 'They are,' says Tarabund, 'cranks; wrongheaded, unbalanced, incapable creatures; they belong to the class of whom it may not be said that they have no mind, but whose mind produces nothing.' 'A common type' writes Legrain, 'unites them:—weakness of judgment and unequal development of mental powers. . . . Their conceptions are never of a high order. They are incapable of great thoughts and prolific ideas. This fact forms a peculiar contrast to the frequently excessive development of their powers of imagination.' 'If they are painters,' we read in Lombroso, 'then their predominant attribute will be their colour-sense; they will be decorative. If they are poets, they will be rich in rhyme, brilliant in style, but barren of thought; sometimes they will be "decadents."

Such are the qualities of the most gifted of those who are discovering new paths, and are proclaimed by enthusiastic followers as the guides to the promised land of the future. Among them degenerates and mattoids predominate. The second of the above-mentioned diagnoses, on the contrary, applies for the most part to the multitude who admire these individuals and swear by them, who imitate the fashions they design, and take delight in the extravagances described in the previous chapter. In their case we have to deal chiefly with hysteria, or neurasthenia.

For reasons which will be elucidated in the next chapter, hysteria has hitherto been less studied in Germany than in France, where, more than elsewhere, it has formed a subject of earnest inquiry. We owe what we know of it almost exclusively to French investigators. The copious treatises of Axenfield, Richer, and in particular Gilles de la Tourette, adequately comprise our present knowledge of this malady; and I shall refer to these works when I enumerate the symptoms chiefly indicative of hysteria.

Among the hysterical—and it must not be thought that these are met with exclusively, or even preponderantly, among females, for they are quite as often, perhaps oftener, found among males—among the hysterical, as among the degenerate, the first thing which strikes us is an extraordinary emotionalism. 'The leading characteristic of the hysterical,' says Colin, 'is the disproportionate impressionability of their psychic centres. . . . They are, above all things, impressionable.' From this primary peculiarity proceeds a second quite as remarkable and important—the exceeding ease with which they can be made to yield to suggestion. The earlier observers always mentioned the boundless mendacity of the hysterical; growing, indeed, quite indignant at it, and making it the most prominent mark of the mental condition of such patients. They were mistaken. The hysterical subject does not consciously lie. He believes in the truth of his craziest inventions. The morbid mobility of his mind, the excessive excitability of his imagination, conveys to his consciousness all sorts of queer and senseless ideas. He suggests to himself that these ideas are founded on true perceptions, and believes in the truth of his foolish inventions until a new suggestion—perhaps his own, perhaps that of another person—has ejected the earlier one. A result of the susceptibility of the hysterical subject to suggestion is his irresistible passion for imitation, and the eagerness with which he yields to all the suggestions of writers and artists. When he sees a picture, he wants to become like it in attitude and dress; when he reads a book, he adopts its views blindly. He takes as a pattern the heroes of the novels which he has in his hand at the moment, and infuses himself into the characters moving before him on stage.

Added to this emotionalism and susceptibility to suggestion is a love of self never met in a sane person in anything like the same degree. The hysterical person's own 'I' towers up before his inner vision, and so completely fills his mental horizon that it conceals the whole of the remaining universe. He cannot endure that others should ignore him. He desires to be as important to his fellow-men as he is to himself. 'An incessant need pursues and governs the hysterical—to busy those about them with themselves. A means of satisfying this need is the fabrication of stories by which they become interesting. Hence come the adventurous occurrences which often enough occupy the police and the reports of the daily press. In the busiest thoroughfare the hysterical person is set upon, robbed, maltreated and wounded, dragged to a distant place, and left to die. He picks himself up painfully, and informs the police. He can show the wounds on his body. He gives all the details. And there is not a single word of truth in the whole story; it is all dreamt and imagined. He has himself inflicted his wounds in order for a short time to become the centre of public attention. In the lower stages of hysteria this need of making a sensation sometimes assumes more harmless forms. It displays itself in eccentricities of dress and behaviour. 'Other hysterical subjects are passionately fond of glaring colours and extravagant forms; they wish to attract attention and make themselves talked about.'

Source: Nordau, Max. 1895. Pp. 16–26 in *Degeneration*. New York: D. Appleton and Company.

▣ Charlotte Perkins Gilman, from *Women and Economics* (1898)

Charlotte Perkins Gilman was an accomplished writer and a feminist theorist. Although she was not widely recognized in her day as a sociologist, she also contributed to the field of sociology through her analysis of gender inequality. The intersection of eugenic thought and Progressive Era feminism is seen here in an excerpt from Gilman's best-known work of nonfiction. According to Gilman, Western women as a group are disabled by the culture, which overemphasizes their sexual appeal and maternal functions, to the detriment of their strength, coordination, and intelligence. This culturally produced weakness is in turn transmitted to their children, according to Gilman, and thus a feminism that restores and celebrates women's "natural" physical and mental gifts is also in the best interests of the race.

In this, in a certain over-coarseness and hardness, a too great belligerence and pride, a too great subservience to the power of sex-attraction, we find the main marks of excessive sex-distinction in men. It has been always checked and offset in them by the healthful activities of racial life. Their energies have been called out and their faculties developed along the lines of human progress. In the growth of industry, commerce, science, manufacture, government, art, religion, the male of our species has become human, far more than male. Strong as this passion is in him, inordinate as is his indulgence, he is a far more normal animal than the female of his species,—far less over-sexed. To him this field of special activity is but part of life,—an incident. The whole world remains besides. To her it is the world.

To make clear by an instance the difference between normal and abnormal sex-distinction, look at the relative condition of a wild cow and a "milch cow" such as we have made. The wild cow is a female. She has healthy calves, and milk enough for them; and that is all the femininity she needs. Otherwise than that she is bovine rather than feminine. She is a light, strong, swift, sinewy creature, able to run, jump and fight if necessary. We, for economic uses, have artificially developed the cow's capacity for producing milk. She has become a walking milk machine, bred and tended to that express end, her value measured in quarts. The secretion of milk is a maternal function—a sex function. The cow is oversexed. Turn her loose in natural conditions and, if she survives the change, she would revert in a very few generations to the plain cow, with her energies used in the general activities of her race, and not all running to milk.

Physically, woman belongs to a tall, vigorous, beautiful animal species, capable of great and varied exertion. In every race and time when she has opportunity for racial activity, she develops accordingly and is no less a woman for being a healthy human creature. In every race and time when she is denied this opportunity,—and few indeed, have been her years of freedom,—she has developed in the lines of action to which she was confined; and those were always the lines of sex-activity. In consequence the body of woman, speaking in the largest generalization, manifests sex-distinction predominantly.

Woman's femininity—and the "eternal feminine" means simply the eternal sexual—is more apparent in proportion to her humanity than the femininity of other animals in proportion to their caninity or felinity or equinity. "A feminine hand" or "a feminine foot" is distinguishable anywhere. We do not hear of " a feminine paw" or a "feminine hoof." A hand is an organ of prehension, a foot an organ of locomotion: they are not secondary sexual characteristics. The comparative smallness and feebleness of woman is a sex distinction. We have carried it to such an excess that women are commonly known as "the weaker sex." There is no such glaring difference between male and female in other advanced species. In the long migration of birds, in the careless motion of the grazing herds that used to swing up and down over the continent each year, in the wild steep journeys of the breeding salmon, nothing is heard of the weaker sex. And among the higher carnivore, where longer maintenance of the younger brings their condition nearer ours, the hunter dreads the attack of the female more than that of the male. The disproportionate weakness is an excessive sex-distinction. Its injurious effect may be broadly shown in Oriental nations, where the female in curtained harems is confined most exclusively to sex-functions and denied most fully the exercise of race-functions. In such peoples the weakness, the tendency to small bones and adipose tissue of the over-sexed female, is transmitted to the male with a retarding effect on the development of the race. Conversely in early Germanic tribes, the comparatively free and humanly developed women—tall, strong and brave—transmitted to their sons a greater proportion of human power and much less of morbid sex-tendency.

The degree of feebleness and clumsiness common to women, the comparative inability to stand, walk, run, jump, climb and perform other race-functions common to both sexes, is an excessive sex distinction; and the ensuing transmission of this relative feebleness to their children, boys and girls alike, retards human development. Strong, free, active women, the sturdy, field-working peasant, the burden-bearing savage, are no less good mothers for their human strength. But our civilized "feminine delicacy," which appears somewhat less delicate when recognized as an expression of sexuality in excess,—makes us no better mothers, but worse. The relative weakness of women is a sex-distinction. It is apparent in her to a degree that injures motherhood, that injures wifehood, that injures the individual. The sex-usefulness and the human usefulness of women, their general duty to their kind, are greatly injured by this degree of distinction. In every way the over-sexed condition of the human female reacts unfavorably upon herself, her husband, her children, and the race.

Source: Gilman, Charlotte Perkins. 1966. Pp. 43–47 in *Women and Economics.* New York: Harper & Row. (Originally published 1898)

Charlotte Perkins Gilman, from "The Yellow Wallpaper" (1899)

Charlotte Perkins Gilman was herself prescribed the "rest cure" by its greatest proponent, Dr. Samuel Weir Mitchell. The oppressive gender assumptions implicit in the treatment of "invalid women"—with near-complete confinement to the home and bed, alone, without reading or other activity—were not lost on Gilman. "The Yellow Wallpaper," widely read as a feminist classic, is a semiautobiographical account of a woman's descent into madness.

John laughs at me, of course, but one expects that in marriage.

John is practical in the extreme. He has no patience with faith, an intense horror of superstition, and he scoffs openly at any talk of things not to be felt and seen and put down in figures.

John is a physician, and *perhaps*—(I would not say it to a living soul, of course, but this is dead paper and a great relief to my mind)—*perhaps* that is one reason I do not get well faster.

You see he does not believe I am sick!

And what can one do?

If a physician of high standing, and one's own husband, assures friends and relatives that there is really nothing the matter with one but temporary nervous depression—a slight hysterical tendency—what is one to do?

My brother is also a physician, and also of high standing, and he says the same thing.

So I take phosphates or phosphites—whichever it is, and tonics, and journeys, and air, and exercise, and am absolutely forbidden to "work" until I am well again. . . .

So I walk a little in the garden or down that lovely lane, sit on the porch under the roses, and lie down up here a good deal.

I'm getting really fond of the room in spite of the wall-paper. Perhaps *because* of the wall-paper.

It dwells in my mind so!

I lie here on this great immovable bed—it is nailed down, I believe—and follow that pattern about by the hour. It is as good as gymnastics, I assure you. I start, we'll say, at the bottom, down in the corner over there where it has not been touched, and I determine for the thousandth time that I *will* follow that pointless pattern to some sort of a conclusion. . . .

There is one end of the room where it is almost intact, and there, when the crosslights fade and the low sun shines directly upon it, I can almost fancy radiation after all,—the interminable grotesques seem to form around a common centre and rush off in headlong plunges of equal distraction.

It makes me tired to follow it. I will take a nap I guess.

I don't know why I should write this.

I don't want to.

I don't feel able. And I know John would think it absurd. But I must say what I feel and think in some way—it is such a relief!

But the effort is getting to be greater than the relief.

Half the time now I am awfully lazy, and lie down ever so much.

John says I mustn't lose my strength, and has me take cod liver oil and lots of tonics and things, to say nothing of ale and wine and rare meat.

Dear John! He loves me very dearly, and hates to have me sick. I tried to have a real earnest reasonable talk with him the other day, and tell him how I wish he would let me go and make a visit to Cousin Henry and Julia.

But he said I wasn't able to go, nor able to stand it after I got there; and I did not make out a very good case for myself, for I was crying before I had finished.

It is getting to be a great effort for me to think straight. Just this nervous weakness I suppose.

And dear John gathered me up in his arms, and just carried me upstairs and laid me on the bed, and sat by me and read to me till it tired my head.

He said I was his darling and his comfort and all he had, and that I must take care of myself for his sake, and keep well.

He says no one but myself can help me out of it, that I must use my will and self-control and not let any silly fancies run away with me.

There's one comfort, the baby is well and happy, and does not have to occupy this nursery with the horrid wall-paper.

If we had not used it, that blessed child would have! What a fortunate escape! Why, I wouldn't have a child of mine, an impressionable little thing, live in such a room for worlds.

I never thought of it before, but it is lucky that John kept me here after all, I can stand it so much easier than a baby, you see.

Of course I never mention it to them any more—I am too wise,—but I keep watch of it all the same.

There are things in that paper that nobody knows but me, or ever will.

Behind that outside pattern the dim shapes get clearer every day.

It is always the same shape, only very numerous.

And it is like a woman stooping down and creeping about behind that pattern. I don't like it a bit. I wonder—I begin to think—I wish John would take me away from here!

Source: Gilman, Charlotte Perkins. 1899. "The Yellow Wallpaper." Available at: http://www.pagebypagebooks.com/ Charlotte_Perkins_ Gilman/The_Yellow_Wallpaper/

Stephen Crane, from *The Monster* (1899)

Levi Hume, a resident of Port Jervis, New York, became the model for Henry Johnson, the main character in Crane's novel The Monster*, about a black man who must face the ridicule of the townspeople. In real life, Hume was a physically disabled man who was employed as an ash man. Hume's physical imperfections, coupled with the layers of black soot he wore as a result of his labors, caused the townspeople to be less than kind. Furthermore, The Monster is said to have parallels to one of the town's most shameful historic events, the only public lynching in New York State. Interestingly enough, the lynching is said to have occurred in Orange Square—the very same square in which Crane used to sit with the orange blossoms. In the novel, a small-town doctor's son is saved from a burning house by Henry Johnson, a black man. In gratitude, the doctor takes it upon himself to salvage the life of the badly burned and disfigured hero. Others warn him that he is doing no service to the patient, but the physician cannot let go of one to whom he owes such a profound debt. The town begins to fear the newly created "monster." The burned man's life becomes a nightmare of rejection; the physician and his family are progressively rejected by the community.*

V.

Jake Rogers was the first man to reach the home of Tuscarora Hose Company Number Six. He had wrenched his key from his pocket as he tore down the street, and he jumped at the spring-lock like a demon. As the doors flew back before his hands he leaped and kicked the wedges from a pair of wheels, loosened a tongue from its clasp, and in the glare of the electric light which the town placed before each of his hose-houses the next comers beheld the spectacle of Jake Rogers bent like hickory in the manfulness of his pulling, and the heavy cart was moving slowly towards the doors. Four men joined him at the time, and as they swung with the cart out into the street, dark figures sped towards them from the ponderous shadows back of the electric lamps. Some set up the inevitable question, "What district?"

"Second," was replied to them in a compact howl. Tuscarora Hose Company Number Six swept on a perilous wheel into Niagara Avenue, and as the men, attached to the cart by the rope which had been paid out from the windlass under the tongue, pulled madly in their fervor and abandon, the gong under the axle clanged incitingly. And sometimes the same cry was heard, "What district?"

"Second."

On a grade Johnnie Thorpe fell, and exercising a singular muscular ability, rolled out in time from the track of the on-coming wheel, and arose, dishevelled and aggrieved, casting a look of mournful disenchantment upon the black crowd that poured after the machine. The cart seemed to be the apex of a dark wave that was whirling as if it had been a broken dam. Back of the lad were stretches of lawn, and in that direction front doors were banged by men who hoarsely shouted out into the clamorous avenue, "What district?"

At one of these houses a woman came to the door bearing a lamp, shielding her face from its rays with her hands. Across the cropped grass the avenue represented to her a kind of black torrent, upon which, nevertheless, fled numerous miraculous figures upon bicycles. She did not know that the towering light at the corner was continuing its nightly whine.

Suddenly a little boy somersaulted around the corner of the house as if he had been projected down a flight of stairs by a catapultian boot. He halted himself in front of the house by dint of a rather extraordinary evolution with his legs. "Oh, ma," he gasped, "can I go? Can I, ma?"

She straightened with the coldness of the exterior mother-judgment, although the hand that held the lamp trembled slightly. "No, Willie; you had better come to bed."

Instantly he began to buck and fume like a mustang. "Oh, ma," he cried, contorting himself—"oh, ma, can't I go? Please, ma, can't I go? Can't I go, ma?"

"It's half past nine now, Willie."

He ended by wailing out a compromise: "Well, just down to the corner, ma? Just down to the corner?"

From the avenue came the sound of rushing men who wildly shouted. Somebody had grappled the bell-rope in the Methodist church, and now over the town rang this solemn and terrible voice, speaking from the clouds. Moved from its peaceful business, this bell gained a new spirit in the portentous night, and it swung the heart to and fro, up and down, with each peal of it.

"Just down to the corner, ma?"

"Willie, it's half past nine now."

VI.

The outlines of the house of Dr. Trescott had faded quietly into the evening, hiding a shape such as we call Queen Anne against the pall of the blackened sky. The neighborhood was at this time so quiet, and seemed so devoid of obstructions, that Hannigan's dog thought it a good opportunity to prowl in forbidden precincts, and so came and pawed Trescott's lawn, growling, and considering himself a formidable beast. Later, Peter Washington strolled past the house and whistled, but there was no dim light shining from Henry's loft, and presently Peter went his way. The rays from the street, creeping in silvery waves over the grass, caused the row of shrubs along the drive to throw a clear, bold shade.

A wisp of smoke came from one of the windows at the end of the house and drifted quietly into the branches of a cherry-tree. Its companions followed it in slowly increasing numbers, and finally there was a current controlled by invisible banks which poured into the fruit-laden boughs of the cherry-tree. It was no more to be noted than if a troop of dim and silent gray monkeys had been climbing a grape-vine into the clouds.

After a moment the window brightened as if the four panes of it had been stained with blood, and a quick ear might have been led to imagine the fire-imps calling and calling, clan joining clan, gathering to the colors. From the street, however, the house maintained its dark quiet, insisting to a passer-by that it was the safe dwelling of people who chose to retire early to tranquil dreams. No one could have heard this low droning of the gathering clans.

Suddenly the panes of the red window tinkled and crashed to the ground, and at other windows there suddenly reared other flames, like bloody spectres at the apertures of a haunted house. This outbreak had been well planned, as if by professional revolutionists.

A man's voice suddenly shouted: "Fire! Fire! Fire!" Hannigan had flung his pipe frenziedly from him because his lungs demanded room. He tumbled down from his perch, swung over the fence, and ran shouting towards the front door of the Trescotts.' Then he hammered on the door, using his fists as if they were mallets. Mrs. Trescott instantly came to one of the windows on the second floor. Afterwards she knew she had been about to say, "The doctor is not at home, but if you will leave your name, I will let him know as soon as he comes."

Hannigan's bawling was for a minute incoherent, but she understood that it was not about croup.

"What?" she said, raising the window swiftly.

"Your house is on fire! You're all ablaze! Move quick if—" His cries were resounding in the street as if it were a cave of echoes. Many feet pattered swiftly on the stones. There was one man who ran with an almost fabulous speed. He wore lavender trousers. A straw hat with a bright silk band was held half crumpled in his hand.

As Henry reached the front door, Hannigan had just broken the lock with a kick. A thick cloud of smoke poured over them, and Henry, ducking his head, rushed into it. From Hannigan's clamor he knew only one thing, but it turned him blue with horror. In the hall a lick of flame had found the cord that supported "Signing the Declaration." The engraving slumped suddenly down at one end, and then dropped to the floor, where it burst with the sound of a bomb. The fire was already roaring like a winter wind among the pines.

At the head of the stairs Mrs. Trescott was waving her arms as if they were two reeds. "Jimmie! Save Jimmie!" she screamed in Henry's face. He plunged past her and disappeared, taking the long-familiar routes among these upper chambers, where he had once held office as a sort of second assistant house-maid.

Hannigan had followed him up the stairs, and grappled the arm of the maniacal woman there. His face was black with rage. "You must come down," he bellowed.

She would only scream at him in reply: "Jimmie! Jimmie! Save Jimmie!" But he dragged her forth while she babbled at him.

As they swung out into the open air a man ran across the lawn, and seizing a shutter, pulled it from its hinges and flung it far out upon the grass. Then he frantically attacked the other shutters one by one. It was a kind of temporary insanity.

"Here, you," howled Hannigan, "hold Mrs. Trescott—And stop—"

The news had been telegraphed by a twist of the wrist of a neighbor who had gone to the fire-box at the corner, and the time when Hannigan and his charge struggled out of the house was the time when the whistle roared its hoarse night call, smiting the crowd in the park, causing the leader of the band, who was about to order the first triumphal clang of a military march, to let his hand drop slowly to his knees.

VII.

Henry pawed awkwardly through the smoke in the upper halls. He had attempted to guide himself by the walls, but they were too hot. The paper was crimpling, and he expected at any moment to have a flame burst from under his hands.

"Jimmie!"

He did not call very loud, as if in fear that the humming flames below would overhear him.

"Jimmie! Oh, Jimmie!"

Stumbling and panting, he speedily reached the entrance to Jimmie's room and flung open the door. The little chamber had no smoke in it at all. It was faintly illumined by a beautiful rosy light reflected circuitously from the flames that were consuming the house. The boy had apparently just been aroused by the noise. He sat in his bed, his lips apart, his eyes wide, while upon his little white-robed figure played caressingly the light from the fire. As the door flew open he had before him this apparition of his pal, a terror-stricken negro, all tousled and with wool scorching, who leaped upon him and bore him up in a blanket as if the whole affair were a case of kidnapping by a dreadful robber chief. Without waiting to go through the usual short but complete process of wrinkling up his face, Jimmie let out a gorgeous bawl, which resembled the expression of a calf's deepest terror. As Johnson, bearing him, reeled into the smoke of the hall, he flung his arms about his neck and buried his face in the blanket. He called twice in muffled tones: "Mam-ma! Mam-ma!"

When Johnson came to the top of the stairs with his burden, he took a quick step backwards. Through the smoke that rolled to him he could see that the lower hall was all ablaze. He cried out then in a howl that resembled Jimmie's former achievement. His legs gained a frightful faculty of bending sideways. Swinging about precariously on these reedy legs, he made his way back slowly, back along the upper hall. From the way of him then, he had given up almost all idea of escaping from the burning house, and with it the desire. He was submitting, submitting because of his fathers, bending his mind in a most perfect slavery to this conflagration.

He now clutched Jimmie as unconsciously as when, running toward the house, he had clutched the hat with the bright silk band.

Suddenly he remembered a little private staircase which led from a bedroom to an apartment which the doctor had fitted up as a laboratory and work-house, where he used some of his leisure, and also hours when he might have been sleeping, in devoting himself to experiments which came in the way of his study and interest.

When Johnson recalled this stairway the submission to the blaze departed instantly. He had been perfectly familiar with it, but his confusion had destroyed the memory of it.

In his sudden momentary apathy there had been little that resembled fear, but now, as a way of safety came to him, the old frantic terror caught him. He was no longer creature to the flames, and he was afraid of the battle with them. It was a singular and swift set of alternations in which he feared twice without submission, and submitted once without fear.

"Jimmie!" he wailed, as he staggered on his way. He wished this little inanimate body at his breast to participate in his tremblings. But the child had lain limp and still during these headlong charges and countercharges, and no sign came from him.

Johnson passed through two rooms and came to the head of the stairs. As he opened the door great billows of smoke poured out, but gripping Jimmie closer, he plunged down through them. All manner of odors assailed him during this flight. They seemed to be alive with envy, hatred, and malice. At the entrance to the laboratory he confronted a strange spectacle. The room was like a garden in the region where might be burning flowers. Flames of violet, crimson, green, blue, orange, and purple were blooming everywhere. There was one blaze that was precisely the hue of a delicate coral. In another place was a mass that lay merely in phosphorescent inaction like a pile of emeralds. But all these marvels were to be seen dimly through clouds of heaving, turning, deadly smoke.

Johnson halted for a moment on the threshold. He cried out again in the negro wail that had in it the sadness of the swamps. Then he rushed across the room. An orange-colored flame leaped like a panther at the lavender trousers. This animal bit deeply into Johnson. There was an explosion at one side, and suddenly before him there reared a delicate, trembling sapphire shape like a fairy lady. With a quiet smile she blocked his path and doomed him and Jimmie. Johnson shrieked, and then ducked in the manner of his race in fights. He aimed to pass under the left guard of the sapphire lady. But she was swifter than eagles, and her talons caught in him as he plunged past her. Bowing his head as if his neck had been struck, Johnson lurched forward, twisting this way and that way. He fell on his back. The still form in the blanket flung from his arms, rolled to the edge of the floor and beneath the window.

Johnson had fallen with his head at the base of an old-fashioned desk. There was a row of jars upon the top of this desk. For the most part, they were silent amid this rioting, but there was one which seemed to hold a scintillant and writhing serpent.

Suddenly the glass splintered, and a ruby-red snakelike thing poured its thick length out upon the top of the old desk. It coiled and hesitated, and then began to swim a languorous way down the mahogany slant. At the angle it waved its sizzling molten head to and fro over the closed eyes of the man beneath it. Then, in a moment, with mystic impulse, it moved again, and the red snake flowed directly down into Johnson's upturned face.

Afterwards the trail of this creature seemed to reek, and amid flames and low explosions drops like red-hot jewels pattered softly down it at leisurely intervals.

VIII.

Suddenly all roads led to Dr. Trescott's. The whole town flowed toward one point. Chippeway Hose Company Number One toiled desperately up Bridge Street Hill even as the Tuscaroras came in an impetuous sweep down Niagara Avenue. Meanwhile the machine of the hook-and-ladder experts from across the creek was spinning on its way. The chief of the fire department had been playing poker in the rear room of Whiteley's cigar-store, but at the first breath of the alarm he sprang through the door like a man escaping with the kitty.

In Whilomville, on these occasions, there was always a number of people who instantly turned their attention to the bells in the churches and schoolhouses. The bells not only emphasized the alarm, but it was the habit to send these sounds rolling across the sky in a stirring brazen uproar until the flames were practically vanquished. There was also a kind of rivalry as to which bell should be made to produce the greatest din. Even the Valley Church, four miles away among the farms, had heard the voices of its brethren, and immediately added a quaint little yelp.

Doctor Trescott had been driving homeward, slowly smoking a cigar, and feeling glad that this last case was now in complete obedience to him, like a wild animal that he had subdued, when he heard the long whistle, and chirped to his horse under the unlicensed but perfectly distinct impression that a fire had broken out in Oakhurst, a new and rather high-flying suburb of the town which was at least two miles from his own home. But in the second blast and in the ensuing silence he read the designation of his own district. He was then only a few blocks from his house. He took out the whip and laid it lightly on the mare. Surprised and frightened at this extraordinary action, she leaped forward, and as the reins straightened like steel bands, the doctor leaned backward a trifle. When the mare whirled him up to the closed gate he was wondering whose house could be afire. The man who had rung the signal-box yelled something at him, but he already knew. He left the mare to her will.

In front of his door was a maniacal woman in a wrapper. "Ned!" she screamed at sight of him. "Jimmie! Save Jimmie!"

Trescott had grown hard and chill.

"Where?" he said. "Where?"

Mrs. Trescott's voice began to bubble. "Up—up—up—" She pointed at the second-story windows.

Hannigan was already shouting: "Don't go in that way! You can't go in that way!"

Trescott ran around the corner of the house and disappeared from them. He knew from the view he had taken of the main hall that it would be impossible to ascend from there. His hopes were fastened now to the stairway which led from the laboratory. The door which opened from this room out upon the lawn was fastened with a bolt and lock, but he kicked close to the lock and then close to the bolt. The door with a loud crash flew back. The doctor recoiled from the roll of smoke, and then bending low, he stepped into the garden of burning flowers. On the floor his stinging eyes could make out a form in a smouldering blanket near the window. Then, as he carried his son toward the door, he saw that the whole lawn seemed now alive with men and boys, the leaders in the great charge that the whole town was making. They seized him and his burden, and overpowered him in wet blankets and water.

But Hannigan was howling: "Johnson is in there yet! Henry Johnson is in there yet! He went in after the kid! Johnson is in there yet!"

These cries penetrated to the sleepy senses of Trescott, and he struggled with his captors, swearing unknown to him and to them, all the deep blasphemies of his medical-student days. He arose to his feet and went again toward the door of the laboratory. They endeavored to restrain him, although they were much affrighted at him.

But a young man who was a brakeman on the railway, and lived in one of the rear streets near the Trescotts, had gone into the laboratory and brought forth a thing which he laid on the grass.

IX.

There were hoarse commands from in front of the house. "Turn on your water, Five!" "Let 'er go, One!" The gathering crowd swayed this way and that way. The flames, towering high, cast a wild red light on their faces. There came the clangor of a gong from along some adjacent street. The crowd exclaimed at it. "Here comes Number Three!" "That's Three a-comin'!" A panting and irregular mob dashed into view, dragging a hose-cart. A cry of exultation arose from the little boys. "Here's Three!" The lads welcomed Never-Die Hose Company Number Three as if it was composed of a chariot dragged by a band of gods. The perspiring citizens flung themselves into the fray. The boys danced in impish joy at the displays of prowess. They acclaimed the approach of Number Two. They welcomed Number Four with cheers. They were so deeply moved by this whole affair that they bitterly guyed the late appearance of the hook and ladder company, whose heavy apparatus had almost stalled them on the Bridge Street hill. The lads hated and feared a fire, of course. They did not particularly want to have anybody's house burn, but still it was fine to see the gathering of the companies, and amid a great noise to watch their heroes perform all manner of prodigies.

They were divided into parties over the worth of different companies, and supported their creeds with no small violence. For instance, in that part of the little city where Number Four had its home it would be most daring for a boy to contend the superiority of any other company. Likewise, in another quarter, when a strange boy was asked which fire company was the best in Whilomville, he was expected to answer "Number One." Feuds, which the boys forgot and remembered according to chance or the importance of some recent event, existed all through the town.

They did not care much for John Shipley, the chief of the department. It was true that he went to a fire with the speed of a falling angel, but when there he invariably lapsed into a certain still mood, which was almost a preoccupation, moving leisurely around the burning structure and surveying it, puffing meanwhile at a cigar. This quiet man, who even when life was in danger seldom raised his voice, was not much to their fancy. Now old Sykes Huntington, when he was chief, used to bellow continually like a bull and gesticulate in a sort of delirium. He was much finer as a spectacle than this Shipley, who viewed a fire with the same steadiness that he viewed a raise in a large jackpot. The greater number of the boys could never understand why the members of these companies persisted in re-electing Shipley, although they often pretended to understand it, because "My father says" was a very formidable phrase in argument, and the fathers seemed almost unanimous in advocating Shipley.

At this time there was considerable discussion as to which company had gotten the first stream of water on the fire. Most of the boys claimed that Number Five owned that distinction, but there was a determined minority who contended for Number One. Boys who were the blood adherents of other companies were obliged to choose between the two on this occasion, and the talk waxed warm.

But a great rumor went among the crowds. It was told with hushed voices. Afterward a reverent silence fell even upon the boys. Jimmie Trescott and Henry Johnson had been burned to death, and Dr. Trescott himself had been most savagely hurt. The crowd did not even feel the police pushing at them. They raised their eyes, shining now with awe, toward the high flames.

The man who had information was at his best. In low tones he described the whole affair. "That was the kid's room—in the corner there. He had measles or somethin,' and this coon—Johnson—was a-settin' up with 'im, and Johnson got sleepy or somethin' and upset the lamp, and the doctor he was down in his office, and he came running up, and they all got burned together till they dragged ‘em out.”

Another man, always preserved for the deliverance of the final judgment, was saying: “Oh, they’ll die sure. Burned to flinders. No chance. Hull lot of ‘em. Anybody can see.” The crowd concentrated its gaze still more closely upon these flags of fire which waved joyfully against the black sky. The bells of the town were clashing unceasingly.

A little procession moved across the lawn and toward the street. There were three cots, borne by twelve of the firemen. The police moved sternly, but it needed no effort of theirs to open a lane for this slow cortege. The men who bore the cots were well known to the crowd, but in this solemn parade during the ringing of the bells and the shouting, and with the red glare upon the sky, they seemed utterly foreign, and Whilomville paid them a deep respect. Each man in this stretcher party had gained a reflected majesty. They were footmen to death, and the crowd made subtle obeisance to this august dignity derived from three prospective graves. One woman turned away with a shriek at sight of the covered body on the first stretcher, and people faced her suddenly in silent and mournful indignation. Otherwise there was barely a sound as these twelve important men with measured tread carried their burdens through the throng.

The little boys no longer discussed the merits of the different fire companies. For the greater part they had been routed. Only the more courageous viewed closely the three figures veiled in yellow blankets.

X.

Old Judge Denning Hagenthorpe, who lived nearly opposite the Trescotts, had thrown his door wide open to receive the afflicted family. When it was publicly learned that the doctor and his son and the negro were still alive, it required a specially detailed policeman to prevent people from scaling the front porch and interviewing these sorely wounded. One old lady appeared with a miraculous poultice, and she quoted most damning scripture to the officer when he said that she could not pass him. Throughout the night some lads old enough to be given privileges or to compel them from their mothers remained vigilantly upon the kerb in anticipation of a death or some such event. The reporter of the *Morning Tribune* rode thither on his bicycle every hour until three o’clock.

Six of the ten doctors in Whilomville attended at Judge Hagenthorpe’s house.

Almost at once they were able to know that Trescott’s burns were not vitally important. The child would possibly be scarred badly, but his life was undoubtedly safe. As for the negro Henry Johnson, he could not live. His body was frightfully seared, but more than that, he now had no face. His face had simply been burned away.

Trescott was always asking news of the two other patients. In the morning he seemed fresh and strong, so they told him that Johnson was doomed. They then saw him stir on the bed, and sprang quickly to see if the bandages needed readjusting. In the sudden glance he threw from one to another he impressed them as being both leonine and impracticable.

The morning paper announced the death of Henry Johnson. It contained a long interview with Edward J. Hannigan, in which the latter described in full the performance of Johnson at the fire. There was also an editorial built from all the best words in the vocabulary of the staff. The town halted in its accustomed road of thought, and turned a reverent attention to the memory of this hostler. In the breasts of many people was the regret that they had not known enough to give him a hand and a lift when he was alive, and they judged themselves stupid and ungenerous for this failure.

The name of Henry Johnson became suddenly the title of a saint to the little boys. The one who thought of it first could, by quoting it in an argument, at once overthrow his antagonist, whether it applied to the subject or whether it did not.

Nigger, nigger, never die,
Black face and shiny eye.

Boys who had called this odious couplet in the rear of Johnson’s march buried the fact at the bottom of their hearts.

Later in the day Miss Bella Farragut, of No. 7 Watermelon Alley, announced that she had been engaged to marry Mr. Henry Johnson.

XIV.

Reifsnyder’s assistant had gone to his supper, and the owner of the shop was trying to placate four men who wished to be shaved at once. Reifsnyder was very garrulous—a fact which made him rather remarkable among barbers, who, as a class, are austerely speechless, having been taught silence by the hammering reiteration of a tradition. It is the customers who talk in the ordinary event.

As Reifsnyder waved his razor down the cheek of a man in the chair, he turned often to cool the impatience of the others with pleasant talk, which they did not particularly heed.

"Oh, he should have let him die," said Bainbridge, a railway engineer, finally replying to one of the barber's orations. "Shut up, Reif, and go on with your business!"

Instead, Reifsnyder paused shaving entirely, and turned to front the speaker. "Let him die?" he demanded. "How vas that? How can you let a man die?"

"By letting him die, you chump," said the engineer. The others laughed a little, and Reifsnyder turned at once to his work, sullenly, as a man overwhelmed by the derision of numbers.

"How vas that?" he grumbled later. "How can you let a man die when he vas done so much for you?"

"'When he vas done so much for you?'" repeated Bainbridge. "You better shave some people. How vas that? Maybe this ain't a barber shop?"

A man hitherto silent now said, "If I had been the doctor, I would have done the same thing."

"Of course," said Reifsnyder. "Any man vould do it. Any man that vas not like you, you—old—flint-hearted—fish." He had sought the final words with painful care, and he delivered the collection triumphantly at Bainbridge. The engineer laughed.

The man in the chair now lifted himself higher, while Reifsnyder began an elaborate ceremony of anointing and combing his hair. Now free to join comfortably in the talk, the man said: "They say he is the most terrible thing in the world. Young Johnnie Bernard— that drives the grocery wagon—saw him up at Alek Williams's shanty, and he says he couldn't eat anything for two days."

"Chee!" said Reifsnyder.

"Well, what makes him so terrible?" asked another.

"Because he hasn't got any face," replied the barber and the engineer in duet.

"Hasn't got any face?" repeated the man. "How can he do without any face!" "He has no face in the front of his head, in the place where his face ought to grow."

Bainbridge sang these lines pathetically as he arose and hung his hat on a hook. The man in the chair was about to abdicate in his favor. "Get a gait on you now," he said to Reifsnyder. "I go out at 7.31."

As the barber foamed the lather on the cheeks of the engineer he seemed to be thinking heavily. Then suddenly he burst out. "How would you like to be with no face?" he cried to the assemblage.

"Oh, if I had to have a face like yours—" answered one customer.

Bainbridge's voice came from a sea of lather. "You're kicking because if losing faces becomes popular, you'd have to go out of business."

"I don't think it will become so much popular," said Reifsnyder.

"Not if it's got to be taken off in the way his was taken off," said another man. "I'd rather keep mine, if you don't mind."

"I guess so!" cried the barber. "Just think!"

The shaving of Bainbridge had arrived at a time of comparative liberty for him. "I wonder what the doctor says to himself?" he observed. "He may be sorry he made him live."

"It was the only thing he could do," replied a man. The others seemed to agree with him.

"Supposing you were in his place," said one, "and Johnson had saved your kid. What would you do?"

"Certainly!"

"Of course! You would do anything on earth for him. You'd take all the trouble in the world for him. And spend your last dollar on him. Well, then?"

"I wonder how it feels to be without any face?" said Reifsnyder, musingly.

The man who had previously spoken, feeling that he had expressed himself well, repeated the whole thing. "You would do anything on earth for him. You'd take all the trouble in the world for him. And spend your last dollar on him. Well, then?"

"No, but look," said Reifsnyder; "supposing you don't got a face!"

XV.

As soon as Williams was hidden from the view of the old judge he began to gesture and talk to himself. An elation had evidently penetrated to his vitals, and caused him to dilate as if he had been filled with gas. He snapped his fingers in the air, and whistled fragments of triumphal music. At times, in his progress toward his shanty, he indulged in a shuffling movement that was really a dance. It was to be learned from the intermediate monologue that he had emerged from his trials laurelled and proud. He was the unconquerable Alexander Williams. Nothing could exceed the bold self-reliance of his manner. His kingly stride, his heroic song, the derisive flourish of his hands—all betokened a man who had successfully defied the world.

On his way he saw Zeke Paterson coming to town. They hailed each other at a distance of fifty yards.

"How do, Broth' Paterson?"

"How do, Broth' Williams?"

They were both deacons.

"Is you' folks well, Broth' Paterson?"

"Middlin,' middlin.' How's you' folks, Broth' Williams?"

Neither of them had slowed his pace in the smallest degree. They had simply begun this talk when a considerable space separated them, continued it as they passed, and added polite questions as they drifted steadily apart. Williams's mind seemed to be a balloon. He had been so inflated that he had not noticed that Paterson had definitely shied into the dry ditch as they came to the point of ordinary contact.

Afterward, as he went a lonely way, he burst out again in song and pantomimic celebration of his estate. His feet moved in prancing steps.

When he came in sight of his cabin, the fields were bathed in a blue dusk, and the light in the window was pale. Cavorting and gesticulating, he gazed joyfully for some moments upon this light. Then suddenly another idea seemed to attack his mind, and he stopped, with an air of being suddenly dampened. In the end he approached his home as if it were the fortress of an enemy.

Some dogs disputed his advance for a loud moment, and then discovering their lord, slunk away embarrassed. His reproaches were addressed to them in muffled tones.

Arriving at the door, he pushed it open with the timidity of a new thief. He thrust his head cautiously sideways, and his eyes met the eyes of his wife, who sat by the table, the lamp-light defining a half of her face. "Sh!" he said, uselessly. His glance travelled swiftly to the inner door which shielded the one bedchamber. The pickaninnies, strewn upon the floor of the living-room, were softly snoring. After a hearty meal they had promptly dispersed themselves about the place and gone to sleep. "Sh!" said Williams again to his motionless and silent wife. He had allowed only his head to appear. His wife, with one hand upon the edge of the table and the other at her knee, was regarding him with wide eyes and parted lips as if he were a spectre. She looked to be one who was living in terror, and even the familiar face at the door had thrilled her because it had come suddenly.

Williams broke the tense silence. "Is he all right?" he whispered, waving his eyes toward the inner door. Following his glance timorously, his wife nodded, and in a low tone answered,

"I raikon he's done gone t'sleep."

Williams then slunk noiselessly across his threshold.

He lifted a chair, and with infinite care placed it so that it faced the dreaded inner door. His wife moved slightly, so as to also squarely face it. A silence came upon them in which they seemed to be waiting for a calamity, pealing and deadly.

Williams finally coughed behind his hand. His wife started, and looked upon him in alarm. "'Pears like he done gwine keep quiet ter-night," he breathed. They continually pointed their speech and their looks at the inner door, paying it the homage due to a corpse or a phantom. Another long stillness followed this sentence. Their eyes shone white and wide. A wagon rattled down the distant road. From their chairs they looked at the window, and the effect of the light in the cabin was a presentation of an intensely black and solemn night. The old woman adopted the attitude used always in church at funerals. At times she seemed to be upon the point of breaking out in prayer.

"He mighty quiet ter-night," whispered Williams. "Was he good ter-day?" For answer his wife raised her eyes to the ceiling in the supplication of Job. Williams moved restlessly. Finally he tip-toed to the door. He knelt slowly and without a sound, and placed his ear near the key-hole. Hearing a noise behind him, he turned quickly. His wife was staring at him aghast. She stood in front of the stove, and her arms were spread out in the natural movement to protect all her sleeping ducklings.

But Williams arose without having touched the door. "I raikon he er-sleep," he said, fingering his wool. He debated with himself for some time. During this interval his wife remained, a great fat statue of a mother shielding her children.

It was plain that his mind was swept suddenly by a wave of temerity. With a sounding step he moved toward the door. His fingers were almost upon the knob when he swiftly ducked and dodged away, clapping his hands to the back of his head. It was as if the portal had threatened him. There was a little tumult near the stove, where Mrs. Williams's desperate retreat had involved her feet with the prostrate children.

After the panic Williams bore traces of a feeling of shame. He returned to the charge. He firmly grasped the knob with his left hand, and with his other hand turned the key in the lock. He pushed the door, and as it swung portentously open he sprang nimbly to one side like the fearful slave liberating the lion. Near the stove a group had formed, the terror-stricken mother with her arms stretched, and the aroused children clinging frenziedly to her skirts.

The light streamed after the swinging door, and disclosed a room six feet one way and six feet the other way. It was small enough to enable the radiance to lay it plain. Williams peered warily around the corner made by the door-post.

Suddenly he advanced, retired, and advanced again with a howl. His palsied family had expected him to spring backward, and at his howl they heaped themselves wondrously. But Williams simply stood in the little room emitting his howls before an open window. “He’s gone! He’s gone! He’s gone!” His eye and his hand had speedily proved the fact. He had even thrown open a little cupboard.

Presently he came flying out. He grabbed his hat, and hurled the outer door back upon its hinges. Then he tumbled headlong into the night. He was yelling: “Docteh Trescott! Docteh Trescott!” He ran wildly through the fields, and galloped in the direction of town. He continued to call to Trescott as if the latter was within easy hearing. It was as if Trescott was poised in the contemplative sky over the running negro, and could heed this reaching voice—”Docteh Trescott!”

In the cabin, Mrs. Williams, supported by relays from the battalion of children, stood quaking watch until the truth of daylight came as a re-enforcement and made them arrogant, strutting, swashbuckler children, and a mother who proclaimed her illimitable courage.

XVI.

Theresa Page was giving a party. It was the outcome of a long series of arguments addressed to her mother, which had been overheard in part by her father. He had at last said five words, “Oh, let her have it.” The mother had then gladly capitulated.

Theresa had written nineteen invitations, and distributed them at recess to her schoolmates. Later her mother had composed five large cakes, and still later a vast amount of lemonade.

So the nine little girls and the ten little boys sat quite primly in the dining-room, while Theresa and her mother plied them with cake and lemonade, and also with ice-cream. This primness sat now quite strangely upon them. It was owing to the presence of Mrs. Page. Previously in the parlor alone with their games they had overturned a chair; the boys had let more or less of their hoodlum spirit shine forth. But when circumstances could be possibly magnified to warrant it, the girls made the boys victims of an insufferable pride, snubbing them mercilessly. So in the dining-room they resembled a class at Sunday-school, if it were not for the subterranean smiles, gestures, rebuffs, and poutings which stamped the affair as a children’s party.

Two little girls of this subdued gathering were planted in a settle with their backs to the broad window. They were beaming lovingly upon each other with an effect of scorning the boys.

Hearing a noise behind her at the window, one little girl turned to face it. Instantly she screamed and sprang away, covering her face with her hands. “What was it? What was it?” cried every one in a roar. Some slight movement of the eyes of the weeping and shuddering child informed the company that she had been frightened by an appearance at the window. At once they all faced the imperturbable window, and for a moment there was a silence. An astute lad made an immediate census of the other lads. The prank of slipping out and looming spectrally at a window was too venerable. But the little boys were all present and astonished.

As they recovered their minds they uttered warlike cries, and through a side-door sallied rapidly out against the terror. They vied with each other in daring.

None wished particularly to encounter a dragon in the darkness of the garden, but there could be no faltering when the fair ones in the dining-room were present. Calling to each other in stern voices, they went dragooning over the lawn, attacking the shadows with ferocity, but still with the caution of reasonable beings. They found, however, nothing new to the peace of the night. Of course there was a lad who told a great lie. He described a grim figure, bending low and slinking off along the fence. He gave a number of details, rendering his lie more splendid by a repetition of certain forms which he recalled from romances. For instance, he insisted that he had heard the creature emit a hollow laugh.

Inside the house the little girl who had raised the alarm was still shuddering and weeping. With the utmost difficulty was she brought to a state approximating calmness by Mrs. Page. Then she wanted to go home at once.

Page entered the house at this time. He had exiled himself until he concluded that this children's party was finished and gone. He was obliged to escort the little girl home because she screamed again when they opened the door and she saw the night.

She was not coherent even to her mother. Was it a man? She didn't know. It was simply a thing, a dreadful thing.

XVII.

In Watermelon Alley the Farraguts were spending their evening as usual on the little rickety porch. Sometimes they howled gossip to other people on other rickety porches. The thin wail of a baby arose from a near house. A man had a terrific altercation with his wife, to which the alley paid no attention at all.

There appeared suddenly before the Farraguts a monster making a low and sweeping bow. There was an instant's pause, and then occurred something that resembled the effect of an upheaval of the earth's surface. The old woman hurled herself backward with a dreadful cry. Young Sim had been perched gracefully on a railing. At sight of the monster he simply fell over it to the ground. He made no sound, his eyes stuck out, his nerveless hands tried to grapple the rail to prevent a tumble, and then he vanished. Bella, blubbering, and with her hair suddenly and mysteriously dishevelled, was crawling on her hands and knees fearsomely up the steps.

Standing before this wreck of a family gathering, the monster continued to bow. It even raised a deprecatory claw. "Don' make no botheration 'bout me, Miss Fa'gut," it said, politely. "No, 'deed. I jes drap in ter ax if yer well this evenin,' Miss Fa'gut. Don' make no botheration. No, 'deed. I gwine ax you to go to er daince with me, Miss Fa'gut. I ax you if I can have the magnifercent gratitude of you' company on that 'casion, Miss Fa'gut."

The girl cast a miserable glance behind her. She was still crawling away. On the ground beside the porch young Sim raised a strange bleat, which expressed both his fright and his lack of wind. Presently the monster, with a fashionable amble, ascended the steps after the girl.

She grovelled in a corner of the room as the creature took a chair. It seated itself very elegantly on the edge. It held an old cap in both hands. "Don' make no botheration, Miss Fa'gut. Don' make no botherations. No, 'deed. I jes drap in ter ax you if you won' do me the proud of acceptin' ma humble invitation to er daince, Miss Fa'gut."

She shielded her eyes with her arms and tried to crawl past it, but the genial monster blocked the way. "I jes drap in ter ax you 'bout er daince, Miss Fa'gut. I ax you if I kin have the magnifercent gratitude of you' company on that 'casion, Miss Fa'gut."

In a last outbreak of despair, the girl, shuddering and wailing, threw herself face downward on the floor, while the monster sat on the edge of the chair gabbling courteous invitations, and holding the old hat daintily to its stomach.

At the back of the house, Mrs. Farragut, who was of enormous weight, and who for eight years had done little more than sit in an arm-chair and describe her various ailments, had with speed and agility scaled a high board fence.

XVIII.

The black mass in the middle of Trescott's property was hardly allowed to cool before the builders were at work on another house. It had sprung upward at a fabulous rate. It was like a magical composition born of the ashes. The doctor's office was the first part to be completed, and he had already moved in his new books and instruments and medicines.

Trescott sat before his desk when the chief of police arrived. "Well, we found him," said the latter.

"Did you?" cried the doctor. "Where?"

"Shambling around the streets at daylight this morning. I'll be blamed if I can figure on where he passed the night."

"Where is he now?"

"Oh, we jugged him. I didn't know what else to do with him. That's what I want you to tell me. Of course we can't keep him. No charge could be made, you know."

"I'll come down and get him."

The official grinned retrospectively. "Must say he had a fine career while he was out. First thing he did was to break up a children's party at Page's. Then he went to Watermelon Alley. Whoo! He stampeded the whole outfit. Men, women, and children running pell-mell, and yelling. They say one old woman broke her leg, or something, shinning over a fence. Then he went right out on the main street, and an Irish girl threw a fit, and there was a sort of riot. He began to run, and a big crowd chased him, firing rocks. But he gave them the slip somehow down there by the foundry and in the railroad yard. We looked for him all night, but couldn't find him."

"Was he hurt any? Did anybody hit him with a stone?"

"Guess there isn't much of him to hurt any more, is there? Guess he's been hurt up to the limit. No. They never touched him. Of course nobody really wanted to hit him, but you know how a crowd gets. It's like—it's like—"

"Yes, I know."

For a moment the chief of the police looked reflectively at the floor. Then he spoke hesitatingly. "You know Jake Winter's little girl was the one that he scared at the party. She is pretty sick, they say."

"Is she? Why, they didn't call me. I always attend the Winter family."

"No? Didn't they?" asked the chief, slowly. "Well—you know—Winter is—well, Winter has gone clean crazy over this business. He wanted—he wanted to have you arrested."

"Have me arrested? The idiot! What in the name of wonder could he have me arrested for?"

"Of course. He is a fool. I told him to keep his trap shut. But then you know how he'll go all over town yapping about the thing. I thought I'd better tip you."

"Oh, he is of no consequence; but then, of course, I'm obliged to you, Sam."

"That's all right. Well, you'll be down to-night and take him out, eh? You'll get a good welcome from the jailer. He don't like his job for a cent. He says you can have your man whenever you want him. He's got no use for him."

"But what is this business of Winter's about having me arrested?"

"Oh, it's a lot of chin about your having no right to allow this—this—this man to be at large. But I told him to tend to his own business. Only I thought I'd better let you know. And I might as well say right now, doctor, that there is a good deal of talk about this thing. If I were you, I'd come to the jail pretty late at night, because there is likely to be a crowd around the door, and I'd bring a—er—mask, or some kind of a veil, anyhow."

XIX.

Martha Goodwin was single, and well along into the thin years. She lived with her married sister in Whilomville. She performed nearly all the house-work in exchange for the privilege of existence. Every one tacitly recognized her labor as a form of penance for the early end of her betrothed, who had died of small-pox, which he had not caught from her.

But despite the strenuous and unceasing workaday of her life, she was a woman of great mind. She had adamantine opinions upon the situation in Armenia, the condition of women in China, the flirtation between Mrs. Minster of Niagara Avenue and young Griscom, the conflict in the Bible class of the Baptist Sunday-school, the duty of the United States toward the Cuban insurgents, and many other colossal matters. Her fullest experience of violence was gained on an occasion when she had seen a hound clubbed, but in the plan which she had made for the reform of the world she advocated drastic measures. For instance, she contended that all the Turks should be pushed into the sea and drowned, and that Mrs. Minster and young Griscom should be hanged side by side on twin gallows. In fact, this woman of peace, who had seen only peace, argued constantly for a creed of illimitable ferocity. She was invulnerable on these questions, because eventually she overrode all opponents with a sniff. This sniff was an active force. It was to her antagonists like a bang over the head, and none was known to recover from this expression of exalted contempt. It left them windless and conquered. They never again came forward as candidates for suppression. And Martha walked her kitchen with a stern brow, an invincible being like Napoleon.

Nevertheless her acquaintances, from the pain of their defeats, had been long in secret revolt. It was in no wise a conspiracy, because they did not care to state their open rebellion, but nevertheless it was understood that any woman who could not coincide with one of Martha's contentions was entitled to the support of others in the small circle. It amounted to an arrangement by which all were required to disbelieve any theory for which Martha fought. This, however, did not prevent them from speaking of her mind with profound respect.

Two people bore the brunt of her ability. Her sister Kate was visibly afraid of her, while Carrie Dungen sailed across from her kitchen to sit respectfully at Martha's feet and learn the business of the world. To be sure, afterwards, under another sun, she always laughed at Martha and pretended to deride her ideas, but in the presence of the sovereign she always remained silent or admiring. Kate, the sister, was of no consequence at all. Her principal delusion was that she did all the work in the upstairs rooms of the house, while Martha did it downstairs. The truth was seen only by the husband, who treated Martha with a kindness that was half banter, half deference. Martha herself had no suspicion that she was the only pillar of the domestic edifice. The situation was without definitions. Martha made definitions, but she devoted them entirely to the Armenians and Griscom and the Chinese and other subjects. Her dreams, which in early days had been of love of meadows and the shade of trees, of the face of a man, were now involved otherwise, and they were companioned in the kitchen curiously, Cuba, the hot-water kettle, Armenia, the washing of the dishes, and the whole thing being jumbled. In regard to social misdemeanors, she who was simply the mausoleum of a dead passion was probably the most savage critic in town. This unknown woman, hidden in a kitchen as in a well, was sure to have a considerable effect of the one kind or the other in the life of the town. Every time it moved a yard, she had personally contributed an inch. She could hammer so stoutly upon the door of a proposition that it would break from its hinges and fall upon her, but at any rate it moved. She was an engine, and the fact that she did not know that she was an engine contributed largely to the effect. One reason that she was formidable was that she did not even imagine that she was formidable. She remained a weak, innocent, and pig-headed creature, who alone would defy the universe if she thought the universe merited this proceeding.

One day Carrie Dungen came across from her kitchen with speed. She had a great deal of grist. "Oh," she cried, "Henry Johnson got away from where they was keeping him, and came to town last night, and scared everybody almost to death."

Martha was shining a dish-pan, polishing madly. No reasonable person could see cause for this operation, because the pan already glistened like silver. "Well!" she ejaculated. She imparted to the word a deep meaning. "This, my prophecy, has come to pass." It was a habit.

The overplus of information was choking Carrie. Before she could go on she was obliged to struggle for a moment. "And, oh, little Sadie Winter is awful sick, and they say Jake Winter was around this morning trying to get Doctor Trescott arrested. And poor old Mrs. Farragut sprained her ankle in trying to climb a fence. And there's a crowd around the jail all the time. They put Henry in jail because they didn't know what else to do with him, I guess. They say he is perfectly terrible."

Martha finally released the dish-pan and confronted the headlong speaker. "Well!" she said again, poising a great brown rag. Kate had heard the excited new-comer, and drifted down from the novel in her room. She was a shivery little woman. Her shoulder-blades seemed to be two panes of ice, for she was constantly shrugging and shrugging. "Serves him right if he was to lose all his patients," she said suddenly, in bloodthirsty tones. She snipped her words out as if her lips were scissors.

"Well, he's likely to," shouted Carrie Dungen. "Don't a lot of people say that they won't have him any more? If you're sick and nervous, Doctor Trescott would scare the life out of you, wouldn't he? He would me. I'd keep thinking."

Martha, stalking to and fro, sometimes surveyed the two other women with a contemplative frown.

XX.

After the return from Connecticut, little Jimmie was at first much afraid of the monster who lived in the room over the carriage-house. He could not identify it in any way. Gradually, however, his fear dwindled under the influence of a weird fascination. He sidled into closer and closer relations with it.

One time the monster was seated on a box behind the stable basking in the rays of the afternoon sun. A heavy crêpe veil was swathed about its head.

Little Jimmie and many companions came around the corner of the stable. They were all in what was popularly known as the baby class, and consequently escaped from school a half-hour before the other children. They halted abruptly at sight of the figure on the box. Jimmie waved his hand with the air of a proprietor.

"There he is," he said.

"O-o-o!" murmured all the little boys—"o-o-o!" They shrank back, and grouped according to courage or experience, as at the sound the monster slowly turned its head. Jimmie had remained in the van alone. "Don't be afraid! I won't let him hurt you," he said, delighted.

"Huh!" they replied, contemptuously. "We ain't afraid."

Jimmie seemed to reap all the joys of the owner and exhibitor of one of the world's marvels, while his audience remained at a distance—awed and entranced, fearful and envious.

One of them addressed Jimmie gloomily. "Bet you dassent walk right up to him." He was an older boy than Jimmie, and habitually oppressed him to a small degree. This new social elevation of the smaller lad probably seemed revolutionary to him.

"Huh!" said Jimmie, with deep scorn. "Dassent I? Dassent I, hey? Dassent I?"

The group was immensely excited. It turned its eyes upon the boy that Jimmie addressed. "No, you dassent," he said, stolidly, facing a moral defeat. He could see that Jimmie was resolved. "No, you dassent," he repeated, doggedly.

"Ho!" cried Jimmie. "You just watch!—you just watch!"

Amid a silence he turned and marched toward the monster. But possibly the palpable wariness of his companions had an effect upon him that weighed more than his previous experience, for suddenly, when near to the monster, he halted dubiously. But his playmates immediately uttered a derisive shout, and it seemed to force him forward. He went to the monster and laid his hand delicately on its shoulder. "Hello, Henry," he said, in a voice that trembled a trifle. The monster was crooning a weird line of negro melody that was scarcely more than a thread of sound, and it paid no heed to the boy.

Jimmie strutted back to his companions. They acclaimed him and hooted his opponent. Amidst this clamor the larger boy with difficulty preserved a dignified attitude.

"I dassent, dassent I?" said Jimmie to him. "Now, you're so smart, let's see you do it!"

This challenge brought forth renewed taunts from the others. The larger boy puffed out his cheeks. "Well, I ain't afraid," he explained, sullenly. He had made a mistake in diplomacy, and now his small enemies were tumbling his prestige all about his ears. They crowed like roosters and bleated like lambs, and made many other noises which were supposed to bury him in ridicule and dishonor. "Well, I ain't afraid," he continued to explain through the din.

Jimmie, the hero of the mob, was pitiless. "You ain't afraid, hey?" he sneered. "If you ain't afraid, go do it, then."

"Well, I would if I wanted to," the other retorted. His eyes wore an expression of profound misery, but he preserved steadily other portions of a pot-valiant air. He suddenly faced one of his persecutors. "If you're so smart, why don't you go do it?" This persecutor sank promptly through the group to the rear. The incident gave the badgered one a breathing-spell, and for a moment even turned the derision in another direction. He took advantage of his interval. "I'll do it if anybody else will," he announced, swaggering to and fro.

Candidates for the adventure did not come forward. To defend themselves from this counter-charge, the other boys again set up their crowing and bleating. For a while they would hear nothing from him. Each time he opened his lips their chorus of noises made oratory impossible. But at last he was able to repeat that he would volunteer to dare as much in the affair as any other boy.

"Well, you go first," they shouted.

But Jimmie intervened to once more lead the populace against the large boy. "You're mighty brave, ain't you?" he said to him. "You dared me to do it, and I did—didn't I? Now who's afraid?" The others cheered this view loudly, and they instantly resumed the baiting of the large boy.

He shamefacedly scratched his left shin with his right foot. "Well, I ain't afraid." He cast an eye at the monster. "Well, I ain't afraid." With a glare of hatred at his squalling tormentors, he finally announced a grim intention. "Well, I'll do it, then, since you're so fresh. Now!"

The mob subsided as with a formidable countenance he turned toward the impassive figure on the box. The advance was also a regular progression from high daring to craven hesitation. At last, when some yards from the monster, the lad came to a full halt, as if he had encountered a stone wall. The observant little boys in the distance promptly hooted. Stung again by these cries, the lad sneaked two yards forward. He was crouched like a young cat ready for a backward spring. The crowd at the rear, beginning to respect this display, uttered some encouraging cries. Suddenly the lad gathered himself together, made a white and desperate rush forward, touched the monster's shoulder with a far-outstretched finger, and sped away, while his laughter rang out wild, shrill, and exultant.

The crowd of boys reverenced him at once, and began to throng into his camp, and look at him, and be his admirers. Jimmie was discomfited for a moment, but he and the larger boy, without agreement or word of any kind, seemed to recognize a truce, and they swiftly combined and began to parade before the others.

"Why, it's just as easy as nothing," puffed the larger boy. "Ain't it, Jim?"

"Course," blew Jimmie. "Why, it's as e-e-easy."

They were people of another class. If they had been decorated for courage on twelve battle-fields, they could not have made the other boys more ashamed of the situation.

Meanwhile they condescended to explain the emotions of the excursion, expressing unqualified contempt for any one who could hang back. “Why, it ain’t nothin.’ He won’t do nothin’ to you,” they told the others, in tones of exasperation.

One of the very smallest boys in the party showed signs of a wistful desire to distinguish himself, and they turned their attention to him, pushing at his shoulders while he swung away from them, and hesitated dreamily. He was eventually induced to make furtive expedition, but it was only for a few yards. Then he paused, motionless, gazing with open mouth. The vociferous entreaties of Jimmie and the large boy had no power over him.

Mrs. Hannigan had come out on her back porch with a pail of water. From this coign she had a view of the secluded portion of the Trescott grounds that was behind the stable. She perceived the group of boys, and the monster on the box. She shaded her eyes with her hand to benefit her vision. She screeched then as if she was being murdered. “Eddie! Eddie! You come home this minute!”

Her son querulously demanded, “Aw, what for?”

“You come home this minute. Do you hear?”

The other boys seemed to think this visitation upon one of their number required them to preserve for a time the hang-dog air of a collection of culprits, and they remained in guilty silence until the little Hannigan, wrathfully protesting, was pushed through the door of his home. Mrs. Hannigan cast a piercing glance over the group, stared with a bitter face at the Trescott house, as if this new and handsome edifice was insulting her, and then followed her son.

There was wavering in the party. An inroad by one mother always caused them to carefully sweep the horizon to see if there were more coming. “This is my yard,” said Jimmie, proudly. “We don’t have to go home.”

The monster on the box had turned his black crêpe countenance toward the sky, and was waving its arms in time to a religious chant. “Look at him now,” cried a little boy. They turned, and were transfixed by the solemnity and mystery of the indefinable gestures. The wail of the melody was mournful and slow. They drew back. It seemed to spellbind them with the power of a funeral. They were so absorbed that they did not hear the doctor’s buggy drive up to the stable. Trescott got out, tied his horse, and approached the group. Jimmie saw him first, and at his look of dismay the others wheeled.

“What’s all this, Jimmie?” asked Trescott, in surprise.

The lad advanced to the front of his companions, halted, and said nothing. Trescott’s face gloomed slightly as he scanned the scene.

“What were you doing, Jimmie?”

“We was playin,’” answered Jimmie, huskily.

“Playing at what?”

“Just playin.’”

Trescott looked gravely at the other boys, and asked them to please go home. They proceeded to the street much in the manner of frustrated and revealed assassins. The crime of trespass on another boy’s place was still a crime when they had only accepted the other boy’s cordial invitation, and they were used to being sent out of all manner of gardens upon the sudden appearance of a father or a mother. Jimmie had wretchedly watched the departure of his companions. It involved the loss of his position as a lad who controlled the privileges of his father’s grounds, but then he knew that in the beginning he had no right to ask so many boys to be his guests.

Once on the sidewalk, however, they speedily forgot their shame as trespassers, and the large boy launched forth in a description of his success in the late trial of courage. As they went rapidly up the street, the little boy, who had made the furtive expedition cried out confidently from the rear, “Yes, and I went almost up to him, didn’t I, Willie?”

The large boy crushed him in a few words. “Huh!” he scoffed. “You only went a little way. I went clear up to him.”

The pace of the other boys was so manly that the tiny thing had to trot, and he remained at the rear, getting entangled in their legs in his attempts to reach the front rank and become of some importance, dodging this way and that way, and always piping out his little claim to glory.

XXI.

“By-the-way, Grace,” said Trescott, looking into the dining-room from his office door, “I wish you would send Jimmie to me before school-time.”

When Jimmie came, he advanced so quietly that Trescott did not at first note him. “Oh,” he said, wheeling from a cabinet, “here you are, young man.”

“Yes, sir.”

Trescott dropped into his chair and tapped the desk with a thoughtful finger. “Jimmie, what were you doing in the back garden yesterday—you and the other boys—to Henry?”

“We weren’t doing anything, pa.”

Trescott looked sternly into the raised eyes of his son. “Are you sure you were not annoying him in any way? Now what were you doing, exactly?”

“Why, we—why, we—now—Willie Dalzel said I dassent go right up to him, and I did; and then he did; and then—the other boys were ‘fraid; and then—you comed.”

Trescott groaned deeply. His countenance was so clouded in sorrow that the lad, bewildered by the mystery of it, burst suddenly forth in dismal lamentations. “There, there. Don’t cry, Jim,” said Trescott, going round the desk. “Only—” He sat in a great leather reading-chair, and took the boy on his knee. “Only I want to explain to you—”

After Jimmie had gone to school, and as Trescott was about to start on his round of morning calls, a message arrived from Doctor Moser. It set forth that the latter’s sister was dying in the old homestead, twenty miles away up the valley, and asked Trescott to care for his patients for the day at least. There was also in the envelope a little history of each case and of what had already been done. Trescott replied to the messenger that he would gladly assent to the arrangement.

He noted that the first name on Moser’s list was Winter, but this did not seem to strike him as an important fact. When its turn came, he rang the Winter bell. “Good-morning, Mrs. Winter,” he said, cheerfully, as the door was opened. “Doctor Moser has been obliged to leave town to-day, and he has asked me to come in his stead. How is the little girl this morning?”

Mrs. Winter had regarded him in stony surprise. At last she said: “Come in! I’ll see my husband.” She bolted into the house. Trescott entered the hall, and turned to the left into the sitting-room.

Presently Winter shuffled through the door. His eyes flashed toward Trescott. He did not betray any desire to advance far into the room. “What do you want?” he said.

“What do I want? What do I want?” repeated Trescott, lifting his head suddenly. He had heard an utterly new challenge in the night of the jungle.

“Yes, that’s what I want to know,” snapped Winter. “What do you want?”

Trescott was silent for a moment. He consulted Moser’s memoranda. “I see that your little girl’s case is a trifle serious,” he remarked. “I would advise you to call a physician soon. I will leave you a copy of Doctor Moser’s record to give to any one you may call.” He paused to transcribe the record on a page of his note-book. Tearing out the leaf, he extended it to Winter as he moved toward the door. The latter shrunk against the wall. His head was hanging as he reached for the paper. This caused him to grasp air, and so Trescott simply let the paper flutter to the feet of the other man.

“Good-morning,” said Trescott from the hall. This placid retreat seemed to suddenly arouse Winter to ferocity. It was as if he had then recalled all the truths, which he had formulated to hurl at Trescott. So he followed him into the hall, and down the hall to the door, and through the door to the porch, barking in fiery rage from a respectful distance. As Trescott imperturbably turned the mare’s head down the road, Winter stood on the porch, still yelping. He was like a little dog.

XXII.

“Have you heard the news?” cried Carrie Dungen, as she sped toward Martha’s kitchen. “Have you heard the news?” Her eyes were shining with delight.

“No,” answered Martha’s sister Kate, bending forward eagerly. “What was it? What was it?”

Carrie appeared triumphantly in the open door. “Oh, there’s been an awful scene between Doctor Trescott and Jake Winter. I never thought that Jake Winter had any pluck at all, but this morning he told the doctor just what he thought of him.”

“Well, what did he think of him?” asked Martha.

“Oh, he called him everything. Mrs. Howarth heard it through her front blinds. It was terrible, she says. It’s all over town now. Everybody knows it.”

“Didn’t the doctor answer back?”

“No! Mrs. Howarth—she says he never said a word. He just walked down to his buggy and got in, and drove off as co-o-o-l. But Jake gave him jinks, by all accounts.”

“But what did he say?” cried Kate, shrill and excited. She was evidently at some kind of a feast.

“Oh, he told him that Sadie had never been well since that night Henry Johnson frightened her at Theresa Page’s party, and he held him responsible, and how dared he cross his threshold—and—and—and—”

“And what?” said Martha.

“Did he swear at him?” said Kate, in fearsome glee.

"No—not much. He did swear at him a little, but not more than a man does anyhow when he is real mad, Mrs. Howarth says."

"O-oh!" breathed Kate. "And did he call him any names?"

Martha, at her work, had been for a time in deep thought. She now interrupted the others. "It don't seem as if Sadie Winter had been sick since that time Henry Johnson got loose. She's been to school almost the whole time since then, hasn't she?"

They combined upon her in immediate indignation. "School? School? I should say not. Don't think for a moment. School!"

Martha wheeled from the sink. She held an iron spoon, and it seemed as if she was going to attack them. "Sadie Winter has passed here many a morning since then carrying her school-bag. Where was she going? To a wedding?"

The others, long accustomed to a mental tyranny, speedily surrendered.

"Did she?" stammered Kate. "I never saw her."

Carrie Dungen made a weak gesture.

"If I had been Doctor Trescott," exclaimed Martha, loudly, "I'd have knocked that miserable Jake Winter's head off."

Kate and Carrie, exchanging glances, made an alliance in the air. "I don't see why you say that, Martha," replied Carrie, with considerable boldness, gaining support and sympathy from Kate's smile. "I don't see how anybody can be blamed for getting angry when their little girl gets almost scared to death and gets sick from it, and all that. Besides, everybody says—"

"Oh, I don't care what everybody says," said Martha.

"Well, you can't go against the whole town," answered Carrie, in sudden sharp defiance.

"No, Martha, you can't go against the whole town," piped Kate, following her leader rapidly.

"'The whole town,'" cried Martha. "I'd like to know what you call 'the whole town.' Do you call these silly people who are scared of Henry Johnson 'the whole town'?"

"Why, Martha," said Carrie, in a reasoning tone, "you talk as if you wouldn't be scared of him!"

"No more would I," retorted Martha.

"O-oh, Martha, how you talk!" said Kate. "Why, the idea! Everybody's afraid of him."

Carrie was grinning. "You've never seen him, have you?" she asked, seductively.

"No," admitted Martha.

"Well, then, how do you know that you wouldn't be scared?"

Martha confronted her. "Have you ever seen him? No? Well, then, how do you know you *would* be scared?"

The allied forces broke out in chorus: "But, Martha, everybody says so. Everybody says so."

"Everybody says what?"

"Everybody that's seen him say they were frightened almost to death. 'Tisn't only women, but it's men too. It's awful."

Martha wagged her head solemnly. "I'd try not to be afraid of him."

"But supposing you could not help it?" said Kate.

"Yes, and look here," cried Carrie. "I'll tell you another thing. The Hannigans are going to move out of the house next door."

"On account of him?" demanded Martha.

Carrie nodded. "Mrs. Hannigan says so herself."

"Well, of all things!" ejaculated Martha. "Going to move, eh? You don't say so! Where they going to move to?"

"Down on Orchard Avenue."

"Well, of all things! Nice house?"

"I don't know about that. I haven't heard. But there's lots of nice houses on Orchard."

"Yes, but they're all taken," said Kate. "There isn't a vacant house on Orchard Avenue."

"Oh yes, there is," said Martha. "The old Hampstead house is vacant."

"Oh, of course," said Kate. "But then I don't believe Mrs. Hannigan would like it there. I wonder where they can be going to move to?"

"I'm sure I don't know," sighed Martha. "It must be to some place we don't know about."

"Well," said Carrie Dungen, after a general reflective silence, "it's easy enough to find out, anyhow."

"Who knows—around here?" asked Kate.

"Why, Mrs. Smith, and there she is in her garden," said Carrie, jumping to her feet. As she dashed out of the door, Kate and Martha crowded at the window. Carrie's voice rang out from near the steps. "Mrs. Smith! Mrs. Smith! Do you know where the Hannigans are going to move to?"

XXIII.

The autumn smote the leaves, and the trees of Whilomville were panoplied in crimson and yellow.

The winds grew stronger, and in the melancholy purple of the nights the home shine of a window became a finer thing. The little boys, watching the sear and sorrowful leaves drifting down from the maples, dreamed of the near time when they could heap bushels in the streets and burn them during the abrupt evenings.

Three men walked down the Niagara Avenue. As they approached Judge Hagenthorpe's house he came down his walk to meet them in the manner of one who has been waiting.

"Are you ready, judge?" one said.

"All ready," he answered.

The four then walked to Trescott's house. He received them in his office, where he had been reading. He seemed surprised at this visit of four very active and influential citizens, but he had nothing to say of it.

After they were all seated, Trescott looked expectantly from one face to another. There was a little silence. It was broken by John Twelve, the wholesale grocer, who was worth $400,000, and reported to be worth over a million.

"Well, doctor," he said, with a short laugh, "I suppose we might as well admit at once that we've come to interfere in something which is none of our business."

"Why, what is it?" asked Trescott, again looking from one face to another. He seemed to appeal particularly to Judge Hagenthorpe, but the old man had his chin lowered musingly to his cane, and would not look at him.

"It's about what nobody talks of—much," said Twelve. "It's about Henry Johnson."

Trescott squared himself in his chair. "Yes?" he said.

Having delivered himself of the title, Twelve seemed to become more easy. "Yes," he answered, blandly, "we wanted to talk to you about it."

"Yes?" said Trescott.

Twelve abruptly advanced on the main attack. "Now see here, Trescott, we like you, and we have come to talk right out about this business. It may be none of our affairs and all that, and as for me, I don't mind if you tell me so; but I am not going to keep quiet and see you ruin yourself. And that's how we all feel."

"I am not ruining myself," answered Trescott.

"No, maybe you are not exactly ruining yourself," said Twelve, slowly, "but you are doing yourself a great deal of harm. You have changed from being the leading doctor in town to about the last one. It is mainly because there are always a large number of people who are very thoughtless fools, of course, but then that doesn't change the condition."

A man who had not heretofore spoken said, solemnly, "It's the women."

"Well, what I want to say is this," resumed Twelve: "Even if there are a lot of fools in the world, we can't see any reason why you should ruin yourself by opposing them. You can't teach them anything, you know."

"I am not trying to teach them anything." Trescott smiled wearily. "I—It is a matter of—well—"

"And there are a good many of us that admire you for it immensely," interrupted Twelve; "but that isn't going to change the minds of all those ninnies."

"It's the women," stated the advocate of this view again.

"Well, what I want to say is this," said Twelve. "We want you to get out of this trouble and strike your old gait again. You are simply killing your practice through your infernal pig-headedness. Now this thing is out of the ordinary, but there must be ways to—to beat the game somehow, you see. So we've talked it over—about a dozen of us—and, as I say, if you want to tell us to mind our own business, why, go ahead; but we've talked it over, and we've come to the conclusion that the only way to do is to get Johnson a place somewhere off up the valley, and—"

Trescott wearily gestured. "You don't know, my friend. Everybody is so afraid of him, they can't even give him good care. Nobody can attend to him as I do myself."

"But I have a little no-good farm up beyond Clarence Mountain that I was going to give to Henry," cried Twelve, aggrieved. "And if you—and if you—if you—through your house burning down, or anything—why, all the boys were prepared to take him right off your hands, and—and—"

Trescott arose and went to the window. He turned his back upon them. They sat waiting in silence. When he returned he kept his face in the shadow. "No, John Twelve," he said, "it can't be done."

There was another stillness. Suddenly a man stirred on his chair.

"Well, then, a public institution—" he began.

"No," said Trescott; "public institutions are all very good, but he is not going to one."

In the background of the group old Judge Hagenthorpe was thoughtfully smoothing the polished ivory head of his cane.

XXIV.

Trescott loudly stamped the snow from his feet and shook the flakes from his shoulders. When he entered the house he went at once to the dining-room, and then to the sitting-room. Jimmie was there, reading painfully in a large book concerning giraffes and tigers and crocodiles.

"Where is your mother, Jimmie?" asked Trescott.

"I don't know, pa," answered the boy. "I think she is upstairs."

Trescott went to the foot of the stairs and called, but there came no answer. Seeing that the door of the little drawing-room was open, he entered. The room was bathed in the half-light that came from the four dull panes of mica in the front of the great stove. As his eyes grew used to the shadows he saw his wife curled in an arm-chair. He went to her. "Why, Grace," he said, "didn't you hear me calling you?"

She made no answer, and as he bent over the chair he heard her trying to smother a sob in the cushion.

"Grace!" he cried. "You're crying!"

She raised her face. "I've got a headache, a dreadful headache, Ned."

"A headache?" he repeated, in surprise and incredulity.

He pulled a chair close to hers. Later, as he cast his eye over the zone of light shed by the dull red panes, he saw that a low table had been drawn close to the stove, and that it was burdened with many small cups and plates of uncut tea-cake. He remembered that the day was Wednesday, and that his wife received on Wednesdays.

"Who was here to-day, Gracie?" he asked.

From his shoulder there came a mumble, "Mrs. Twelve."

"Was she—um," he said. "Why—didn't Anna Hagenthorpe come over?"

The mumble from his shoulder continued, "She wasn't well enough."

Glancing down at the cups, Trescott mechanically counted them. There were fifteen of them. "There, there," he said. "Don't cry, Grace. Don't cry."

The wind was whining round the house, and the snow beat aslant upon the windows. Sometimes the coal in the stove settled with a crumbling sound, and the four panes of mica flashed a sudden new crimson. As he sat holding her head on his shoulder, Trescott found himself occasionally trying to count the cups. There were fifteen of them.

Source: Crane, Stephen. 1899. *The Monster.* Available at: http://www.underthesun.cc/Classics/Crane/THEMONSTER

Walt Whitman, from "The Wound-Dresser" (1900)

The American poet Walt Whitman found himself working in hospitals as a nurse during the Civil War, when his brother George appeared on a listing of the wounded at the Battle of Fredericksburg. Whitman's description of one new amputee records his nursing duties as well as his sensitivity to the physical details of human pain.

From the stump of the arm, the amputated hand,
I undo the clotted lint, remove the slough, wash off the matter and blood,
Back on his pillow the soldier bends with curv'd neck and side-falling head,
His eyes are closed, his face is pale, he dares not look on the bloody stump,
And has not yet looked on it.

Source: Whitman, Walt. 1900. "The Wound-Dresser." Available at: http://www.princeton.edu/~batke/logr/log_159.html

Helen Keller, from *The Story of My Life* (1902)

Helen Keller's education moves increasingly from learning based on sensation to knowledge of abstraction as her acquisition of language grows. Here Keller explains how she acquires the building blocks for an understanding of such abstract ideas as love on the basis of her experience of the natural world.

Chapter V

I recall many incidents of the summer of 1887 that followed my soul's sudden awakening. I did nothing but explore with my hands and learn the name of every object that I touched; and the more I handled things and learned their names and uses, the more joyous and confident grew my sense of kinship with the rest of the world.

When the time of daisies and buttercups came Miss Sullivan took me by the hand across the fields, where men were preparing the earth for the seed, to the banks of the Tennessee River, and there, sitting on the warm grass, I had my first lessons in the beneficence of nature. I learned how the sun and the rain make to grow out of the ground every tree that is pleasant to the sight and good for food, how birds build

Mark Twain and Helen Keller *(ca. 1908), by Isabelle B. Lyon (1868–1958). The U.S. humorist Mark Twain is photographed here with Helen Keller. Keller was photographed with many other celebrity figures, and here she is positioned in a characteristic pose that emphasizes her deaf-blindness for viewers.*

Source: Art Resource, New York.

their nests and live and thrive from land to land, how the squirrel, the deer, the lion and every other creature finds food and shelter. As my knowledge of things grew I felt more and more the delight of the world I was in. Long before I learned to do a sum in arithmetic or describe the shape of the earth, Miss Sullivan had taught me to find beauty in the fragrant woods, in every blade of grass, and in the curves and dimples of my baby sister's hand. She linked my earliest thoughts with nature, and made me feel that "birds and flowers and I were happy peers."

But about this time I had an experience which taught me that nature is not always kind. One day my teacher and I were returning from a long ramble. The morning had been fine, but it was growing warm and sultry when at last we turned our faces homeward. Two or three times we stopped to rest under a tree by the wayside. Our last halt was under a wild cherry tree a short distance from the house. The shade was grateful, and the tree was so easy to climb that with my teacher's assistance I was able to scramble to a seat in the branches. It was so cool up in the tree that Miss Sullivan proposed that we have our luncheon there. I promised to keep still while she went to the house to fetch it.

Suddenly a change passed over the tree. All the sun's warmth left the air. I knew the sky was black, because all the heat, which meant light to me, had died out of the atmosphere. A strange odour came up from the earth. I knew it, it was the odour that always precedes a thunderstorm, and a nameless fear clutched at my heart. I felt absolutely alone, cut off from my friends and the firm earth. The immense, the unknown, enfolded me. I remained still and expectant; a chilling terror crept over me. I longed for my teacher's return; but above all things I wanted to get down from that tree.

There was a moment of sinister silence, then a multitudinous stirring of the leaves. A shiver ran through the tree, and the wind sent forth a blast that would have knocked me off had I not clung to the branch with might and main. The tree swayed and strained. The small twigs snapped and fell about me in showers. A wild impulse to jump seized me, but terror held me fast. I crouched down in the fork of the tree. The branches lashed about me. I felt the intermittent jarring that came now and then, as if something heavy had fallen and the shock had traveled up till it reached the limb I sat on. It worked my suspense up to the highest point, and just as I was thinking the tree and I should fall together, my teacher seized my hand and helped me down. I clung to her, trembling with joy to feel the earth under my feet once more. I had learned a new lesson—that nature "wages open war against her children, and under softest touch hides treacherous claws."

After this experience it was a long time before I climbed another tree. The mere thought filled me with terror. It was the sweet allurement of the mimosa tree in full bloom that finally overcame my fears. One beautiful spring morning when I was alone in the summer-house, reading, I became aware of a wonderful subtle fragrance in the air. I started up and instinctively stretched out my hands. It seemed as if the spirit of spring had passed through the summer-house. "What is it?" I asked, and the next minute I recognized the odour of the mimosa blossoms. I felt my way to the end of the garden, knowing that the mimosa tree was near the fence, at the turn of the path. Yes, there it was, all quivering in the warm sunshine, its blossom-laden branches almost touching the long grass. Was there ever anything so exquisitely beautiful in the world before! Its delicate blossoms shrank from the slightest earthly touch; it seemed as if a tree of paradise had been transplanted to earth. I made my way through a shower of petals to the great trunk and for one minute stood irresolute; then, putting my foot in the broad space between the forked branches, I pulled myself up into the tree. I had some difficulty in holding on, for the branches were very large and the bark hurt my hands. But I had a delicious sense that I was doing something unusual and wonderful so I kept on climbing higher and higher, until I reached a little seat which somebody had built there so long ago that it had grown part of the tree itself. I sat there for a long, long time, feeling like a fairy on a rosy cloud. After that I spent many happy hours in my tree of paradise, thinking fair thoughts and dreaming bright dreams.

Chapter VI

I had now the key to all language, and I was eager to learn to use it. Children who hear acquire language without any particular effort; the words that fall from others' lips they catch on the wing, as it were, delightedly, while the little deaf child must trap them by a slow and often painful process. But whatever the process, the result is wonderful. Gradually from naming an object we advance step by step until we have traversed the vast distance between our first stammered syllable and the sweep of thought in a line of Shakespeare.

At first, when my teacher told me about a new thing I asked very few questions. My ideas were vague, and my vocabulary was inadequate; but as my knowledge of things grew, and I learned more and more words, my field of inquiry broadened, and I would return again and again to the same subject, eager for further information. Sometimes a new word revived an image that some earlier experience had engraved on my brain.

I remember the morning that I first asked the meaning of the word, "love." This was before I knew many words. I had found a few early violets in the garden and brought them to my teacher. She tried to kiss me: but at that time I did not like to have any one kiss me except my mother. Miss Sullivan put her arm gently round me and spelled into my hand, "I love Helen."

"What is love?" I asked.

She drew me closer to her and said, "It is here," pointing to my heart, whose beats I was conscious of for the first time. Her words puzzled me very much because I did not then understand anything unless I touched it.

I smelt the violets in her hand and asked, half in words, half in signs, a question which meant, "Is love the sweetness of flowers?"

"No," said my teacher.

Again I thought. The warm sun was shining on us.

"Is this not love?" I asked, pointing in the direction from which the heat came. "Is this not love?"

It seemed to me that there could be nothing more beautiful than the sun, whose warmth makes all things grow. But Miss Sullivan shook her head, and I was greatly puzzled and disappointed. I thought it strange that my teacher could not show me love.

A day or two afterward I was stringing beads of different sizes in symmetrical groups—two large beads, three small ones, and so on. I had made many mistakes, and Miss Sullivan had pointed them out again and again with gentle patience. Finally I noticed a very obvious error in the sequence and for an instant I concentrated my attention on the lesson and tried to think how I should have arranged the beads. Miss Sullivan touched my forehead and spelled with decided emphasis, "Think."

In a flash I knew that the word was the name of the process that was going on in my head. This was my first conscious perception of an abstract idea.

For a long time I was still—I was not thinking of the beads in my lap, but trying to find a meaning for "love" in the light of this new idea. The sun had been under a cloud all day, and there had been brief showers; but suddenly the sun broke forth in all its southern splendour.

Again I asked my teacher, "Is this not love?"

"Love is something like the clouds that were in the sky before the sun came out," she replied. Then in simpler words than these, which at that time I could not have understood, she explained: "You cannot touch the clouds, you know; but you feel the rain and know how glad the flowers and the thirsty earth are to have it after a hot day. You cannot touch love either;

but you feel the sweetness that it pours into everything. Without love you would not be happy or want to play."

The beautiful truth burst upon my mind—I felt that there were invisible lines stretched between my spirit and the spirits of others.

From the beginning of my education Miss Sullivan made it a practice to speak to me as she would speak to any hearing child; the only difference was that she spelled the sentences into my hand instead of speaking them. If I did not know the words and idioms necessary to express my thoughts she supplied them, even suggesting conversation when I was unable to keep up my end of the dialogue.

This process was continued for several years; for the deaf child does not learn in a month, or even in two or three years, the numberless idioms and expressions used in the simplest daily intercourse. The little hearing child learns these from constant repetition and imitation. The conversation he hears in his home stimulates his mind and suggests topics and calls forth the spontaneous expression of his own thoughts. This natural exchange of ideas is denied to the deaf child. My teacher, realizing this, determined to supply the kinds of stimulus I lacked. This she did by repeating to me as far as possible, verbatim, what she heard, and by showing me how I could take part in the conversation. But it was a long time before I ventured to take the initiative, and still longer before I could find something appropriate to say at the right time.

The deaf and the blind find it very difficult to acquire the amenities of conversation. How much more this difficulty must be augmented in the case of those who are both deaf and blind! They cannot distinguish the tone of the voice or, without assistance, go up and down the gamut of tones that give significance to words; nor can they watch the expression of the speaker's face, and a look is often the very soul of what one says.

Source: Keller, Helen. 1902. *The Story of My Life.* Available at: http://digital.library.upenn.edu/women/keller/life/part-I.html

▣ W. E. B. Du Bois, from "The Talented Tenth" (1903)

In one of the most famous essays in African American literature, Du Bois champions his vision of an exceptional group of individuals who might set the tone and educate the great majority of African American citizens. The "talented tenth" would represent a notion of intellectual superiority parallel to that espoused by Galton in Hereditary Genius.

The Negro race, like all races, is going to be saved by its exceptional men. The problem of education, then, among Negroes must first of all deal with the Talented Tenth; it is the problem of developing the Best of this race that they may guide the Mass away from the contamination and death of the Worst, in their own and other races. Now the training of men is a difficult and intricate task. Its technique is a matter for educational experts, but its object is for the vision of seers. If we make money the object of man-training, we shall develop money-makers but not necessarily men; if we make technical skill the object of education, we may possess artisans but not, in nature, men. Men we shall have only as we make manhood the object of the work of the schools—intelligence, broad sympathy, knowledge of the world that was and is, and of the relation of men to it—this is the curriculum of that Higher Education which must underlie true life. On this foundation we may build bread winning, skill of hand and quickness of brain, with never a fear lest the child and man mistake the means of living for the object of life.

If this be true—and who can deny it—three tasks lay before me; first to show from the past that the Talented Tenth as they have risen among American Negroes have been worthy of leadership; secondly to show how these men may be educated and developed; and thirdly to show their relation to the Negro problem.

You misjudge us because you do not know us. From the very first it has been the educated and intelligent of the Negro people that have led and elevated the mass, and the sole obstacles that nullified and retarded their efforts were slavery and race prejudice; for what is slavery but the legalized survival of the unfit and the nullification of the work of natural internal leadership? Negro leadership therefore sought from the first to rid the race of this awful incubus that it might make way for natural selection and the survival of the fittest. In colonial days came Phillis Wheatley and Paul Cuffe striving against the bars of prejudice; and Benjamin Banneker, the almanac maker, voiced their longings when he said to Thomas Jefferson, "I freely and cheerfully acknowledge that I am of the African race and in colour which is natural to them, of the deepest dye; and it is under a sense of the most profound gratitude to the Supreme Ruler of the Universe, that I now confess to you that I am not under that state of tyrannical thraldom and inhuman captivity to which too many of my brethren are doomed, but that I have abundantly tasted of the fruition of those blessings which proceed from that free and unequalled liberty with which you are favored, and which I hope you will willingly allow, you have mercifully received from the immediate hand of that Being from whom proceedeth every good and perfect gift.

"Suffer me to recall to your mind that time, in which the arms of the British crown were exerted with every powerful effort, in order to reduce you to a state of servitude; look back, I entreat you, on the variety of dangers to which you were exposed; reflect on that period in which every human aid appeared unavailable, and in which even hope and fortitude wore the aspect of inability to the conflict, and you cannot but be led to a serious and grateful sense of your miraculous and providential preservation, you cannot but acknowledge, that the present freedom and tranquility which you enjoy, you have mercifully received, and that a peculiar blessing of heaven.

"This, sir, was a time when you clearly saw into the injustice of a state of Slavery, and in which you had just apprehensions of the horrors of its condition. It was then that your abhorrence thereof was so excited, that you publicly held forth this true and invaluable doctrine, which is worthy to be recorded and remembered in all succeeding ages: 'We hold these truths to be self evident, that all men are created equal; that they are endowed with certain inalienable rights, and that among these are life, liberty and the pursuit of happiness.'"

Then came Dr. James Derham, who could tell even the learned Dr. Rush something of medicine, and Lemuel Haynes, to whom Middlebury College gave an honorary A. M. in 1804. These and others we may call the Revolutionary group of distinguished Negroes—they were persons of marked ability, leaders of a Talented Tenth, standing conspicuously among the best of their time. They strove by word and deed to save the color line from becoming the line between the bond and free, but all they could do was nullified by Eli Whitney and the Curse of Gold. So they passed into forgetfulness.

But their spirit did not wholly die; here and there in the early part of the century came other exceptional men. Some were natural sons of unnatural fathers and were given often a liberal training and thus a race of educated mulattoes sprang up to plead for black men's rights. There was Ira Aldridge, whom all Europe loved to honor; there was that Voice crying in the Wilderness, David Walker, and saying:

"I declare it does appear to me as though some nations think God is asleep, or that he made the Africans for nothing else but to dig their mines and work their farms, or they cannot believe history sacred or profane. I ask every man who has a heart, and is blessed with the privilege of believing—Is not God a God of justice to all his creatures? Do you say he is? Then if he gives peace and tranquility to tyrants and permits them to keep our fathers, our mothers, ourselves and our children in eternal ignorance and wretchedness to support them and their families, would he be to us a God of Justice? I ask, O, ye Christians, who hold us and our children in the most abject ignorance and degradation that ever a people were afflicted with since the world began—I say if God gives you peace and tranquility, and suffers you thus to go on afflicting us, and our children, who have never given you the least provocation—would He be to us a God of Justice? If you will allow that we are men, who feel for each other, does not the blood of our fathers and of us, their children, cry aloud to the Lord of Sabaoth against you for the cruelties and murders with which you have and do continue to afflict us?"

This was the wild voice that first aroused Southern legislators in 1829 to the terrors of abolitionism.

In 1831 there met that first Negro convention in Philadelphia, at which the world gaped curiously but which bravely attacked the problems of race and slavery, crying out against persecution and declaring that "Laws as cruel in themselves as they were unconstitutional and unjust, have in many places been enacted against our poor, unfriended and unoffending brethren (without a shadow of provocation on our part), at whose bare recital the very savage draws himself up for fear of contagion—looks noble and prides himself because he bears not the name of Christian." Side by side this free Negro movement, and the movement for abolition, strove until they merged in to one strong stream. Too little notice has been taken of the work which the Talented Tenth among Negroes took in the great abolition crusade. From the very day that a Philadelphia colored man became the first subscriber to Garrison's "Liberator," to the day when Negro soldiers made the Emancipation Proclamation possible, black leaders worked shoulder to shoulder with white men in a movement, the success of which would have been impossible without them. There was Purvis and Remond, Pennington and Highland Garnett, Sojourner Truth and Alexander Crummel, and above, Frederick Douglass—what would the abolition movement have been without them? They stood as living examples of the possibilities of the Negro race, their own hard experiences and well wrought culture said silently more than all the drawn periods of orators—they were the men who made American slavery impossible. As Maria Weston Chapman said, from the school of anti-slavery agitation, "a throng of authors, editors, lawyers, orators and accomplished gentlemen of color have taken their degree! It has equally implanted hopes and aspirations, noble thoughts, and sublime purposes, in the hearts of both races. It has prepared the white man for the freedom of the black man, and it has made the black man scorn the thought of enslavement, as does a white man, as far as its influence has extended. Strengthen that noble influence! Before its organization, the country only saw here and there in slavery some faithful Cudjoe or Dinah, whose strong natures blossomed even in bondage, like a fine plant beneath a heavy stone. Now, under the elevating and cherishing influence of the American Anti-slavery Society, the colored race, like the white, furnishes Corinthian capitals for the noblest temples."

Where were these black abolitionists trained? Some, like Frederick Douglass, were self-trained, but yet trained liberally; others, like Alexander Crummell and McCune Smith, graduated from famous foreign universities. Most of them rose up through the colored schools of New York and Philadelphia and Boston, taught by college-bred men like Russworm, of Dartmouth, and college-bred white men like Neau and Benezet.

After emancipation came a new group of educated and gifted leaders: Langston, Bruce and Elliot, Greener, Williams and Payne. Through political organization, historical and polemic writing and moral regeneration, these men strove to uplift their people. It is the fashion of to-day to sneer at them and to say that with freedom Negro leadership should have begun at the plow and not in the Senate—a foolish and mischievous lie; two hundred and fifty years that black serf toiled at the plow and yet that toiling was in vain till the Senate passed the war amendments; and two hundred and fifty years more the half-free serf of to-day may toil at his plow, but unless he have political rights and righteously guarded civic status, he will still remain the poverty-stricken and ignorant plaything of rascals, that he now is. This all sane men know even if they dare not say it.

And so we come to the present—a day of cowardice and vacillation, of strident wide-voiced wrong and faint hearted compromise; of double-faced dallying with Truth and Right. Who are to-day guiding the work of the Negro people? The "exceptions" of course. And yet so sure as this Talented Tenth is pointed out, the blind worshippers of the Average cry out in alarm: "These are exceptions, look here at death, disease and crime—these are the happy rule." Of course they are the rule, because a silly nation made them the rule: Because for three long centuries this people lynched Negroes who dared to be brave, raped black women who dared to be virtuous, crushed dark-hued youth who dared to be ambitious, and encouraged and made to flourish servility and lewdness and apathy. But not even this was able to crush all manhood and chastity and aspiration from black folk. A saving remnant continually survives and persists, continually aspires, continually shows itself in thrift and ability and character. Exceptional it is to be sure, but this is its chiefest promise; it shows the capability of Negro blood, the promise of black men. Do Americans ever stop to reflect that there are in this land a million men of Negro blood, well-educated, owners of homes, against the honor of whose womanhood no breath was ever raised, whose men occupy positions of trust and usefulness, and who, judged by any standard, have reached the full measure of the best type of modern European culture? Is it fair, is it decent, is it Christian to ignore these facts of the Negro problem, to belittle such aspiration, to nullify such leadership and seek to crush these people back into the mass out of which by toil and travail, they and their fathers have raised themselves?

Can the masses of the Negro people be in any possible way more quickly raised than by the effort and example of this aristocracy of talent and character? Was there ever a nation on God's fair earth civilized from the bottom upward? Never; it is, ever was and ever will be from the top downward that culture filters. The Talented Tenth rises and pulls all that are worth the saving up to their vantage ground. This is the history of human progress; and the two historic mistakes which have hindered that progress were the thinking first that no more could ever rise save the few already risen; or second, that it would better the unrisen to pull the risen down. . . .

The problem of training the Negro is to-day immensely complicated by the fact that the whole question of the efficiency and appropriateness of our present systems of education, for any kind of child, is a matter of active debate, in which final settlement seems still afar off. Consequently it often happens that persons arguing for or against certain systems of education for Negroes, have these controversies in mind and miss the real question at issue. The main question, so far as the Southern Negro is concerned, is: What under the present circumstance, must a system of education do in order to raise the Negro as quickly as possible in the scale of civilization? The answer to this question seems to me clear: It must strengthen the Negro's character, increase his knowledge and teach him to earn a living. Now it goes without saying that it is hard to do all these things simultaneously or suddenly and that at the same time it will not do to give all the attention to one and neglect the others; we could give black boys trades, but that alone will not civilize a race of ex-slaves; we might simply increase their knowledge of the world, but this would not necessarily make them wish to use this knowledge honestly; we might seek to strengthen character and purpose, but to what end if this people have nothing to eat or to wear? A system of education is not one thing, nor does it have a single definite object, nor is it a mere matter of schools. Education is that whole system of human training within and without the school house walls, which molds and develops men. If then we start out to train an ignorant and unskilled people with a heritage of bad habits, our system of training must set before itself two great aims—the one dealing with knowledge and character, the other part seeking to give the child the technical knowledge necessary for him to earn a living under the present circumstances. These objects are accomplished in part by the opening of the common schools on the one, and of the industrial schools on the other. But only in part, for there must also be trained those who are to teach these schools—men and women of knowledge and culture and technical skill who understand modern civilization, and have the training and aptitude to impart it to the children under them.

Source: Du Bois, W. E. B. 1903. "The Talented Tenth." In Washington, Booker T., ed. *The Negro Problem: A Series of Articles by Representative Negroes of Today.* New York: Pott and Company.

Carry A. Nation, from *The Use and Need of the Life of Carry A. Nation* (1905)

Carry Nation, who is best known for her radical advocacy of temperance, included in her autobiography a discussion of her child's chronic health issues (and her interpretation of them as "the result of a drunken father and a distracted mother"). The Campbellite religious dimension of this excerpt is particularly strong, and probably strange to many, but it is quite in line with the temperance rhetoric of the time.

About this time my little Charlien, who had been such a help to me, began to go into a decline, until she was taken down with typhoid fever. Her case was violent and she was delirious from the first. This my only child was peculiar. She was the result of a drunken father and a distracted mother. The curse of heredity is one of the most heart-breaking results of the saloon. Poor little children are brought into the world, cursed by disposition and disease, entailed on them. How can mothers be true to their offspring with a constant dread of the nameless horrors wives are exposed to by being drunkards' wives. Men will not raise domestic animals under conditions where the mothers may bring forth weak or deformed offspring. My precious child seemed to have taken a perfect dislike to Christianity. This was a great grief to me, and I used to pray to God to save her soul at any cost; I often prayed for bodily affliction on her, if that was what would make her love and serve God. Anything for her eternal salvation.

Her right cheek was very much swollen, and on examination we found there was an eating sore inside her cheek. This kept up in spite of all remedies, and at last the whole of her right cheek fell out, leaving the teeth bare. My friends and boarders were very angry at the physician, saying she was salivated. From the first something told me this is an answer to your prayer. At this time, when her life was despaired of, I had an intense longing to save my child, who was so dear to me. I said: "Oh, God, let me keep a piece of my child." A minister said: "Don't pray for the life of your child; she will be so deformed it were better she were dead." I could not feel this way. After being at death's door for nine days, she began to recover. The wound in her face healed up to a hole about the size of a twenty-five cent piece. Her jaws closed and remained so for eight years. The sickness of my daughter and the keeping up of the hotel was such a tax on my mind, that for six months all transactions would recede from my memory. For instance, if anyone told me something, in an hour afterwards, I could not tell whether it had been hours, days or months since it was told me. I never entirely recovered from this, still being forgetful of names, dates and circumstances, unless they are particularly impressed upon my mind. When I could afford it, I took my child, then twelve years old, down to Galveston, put her under the care of Dr. Dowell for the purpose of closing the hole in her cheek. I had to leave the little one down there among strangers, for I could not afford to stay with her. A mother only will know what this means. After four operations the place was closed up in her cheek, still her mouth was closed, her teeth close together. I suffered torture all these years for fear she might strangle to death. I took her to San Antonio, Texas, to Dr. Herff, and he and his two sons removed a section of the jawbone, expecting to make an artificial joint, enabling her to use the other side of her jaw. After all this, the operation was a failure, and her jaws closed up again.

Source: Nation, Carry A. 1905. *The Use and Need of the Life of Carry A. Nation.* Available at: www.e-bookshop.gr/gutenberg/files/crntn10.pdf

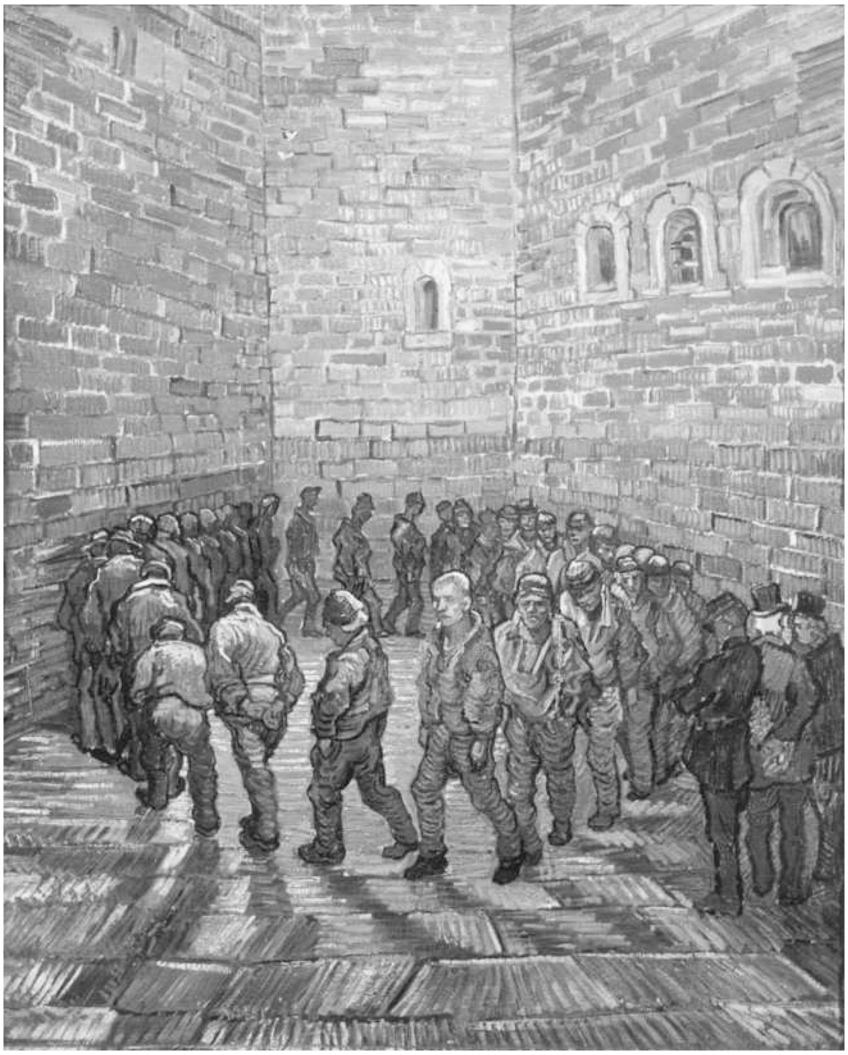
Upton Sinclair, from *The Jungle* (1906)

Sinclair's novel about the ravages of the meatpacking industry in Chicago on the lives of nonunionized labor was instrumental in leading to reforms. The first excerpt below discusses the ubiquitous prevalence of disability among children of the working classes. The second excerpt discusses the descent of the out-of-work protagonist, Jurgis, into abject poverty and a life of begging for work that he can no longer perform physically.

From Chapter 13

During this time that Jurgis was looking for work occurred the death of little Kristoforas, one of the children of Teta Elzbieta. Both Kristoforas and his brother, Juozapas, were cripples, the latter having lost one leg by having it run over, and Kristoforas having congenital dislocation of the hip, which made it impossible for him ever to walk. He was the last of Teta Elzbieta's children, and perhaps he had been intended by nature to let her know that she had had enough. At any rate he was wretchedly sick and undersized; he had the rickets, and though he was over three years old, he was no bigger than an ordinary child of one. All day long he would crawl around the floor in a filthy little dress, whining and fretting; because the floor was full of drafts he was always catching cold, and snuffling because his nose ran. This made him a nuisance, and a source of endless trouble in the family. For his mother, with unnatural perversity, loved him best of all her children, and made a perpetual fuss over him—would let him do anything undisturbed, and would burst into tears when his fretting drove Jurgis wild.

And now he died. Perhaps it was the smoked sausage he had eaten that morning—which may have been made out of some of the tubercular pork that was condemned as unfit for export. At any rate, an hour after eating it, the child had begun to cry with pain, and in another hour he was rolling about on the floor in convulsions. Little Kotrina, who was all alone with him, ran out screaming for help, and after a while a doctor came, but not until Kristoforas had howled his last howl. No one was really sorry about this except poor Elzbieta, who was inconsolable. Jurgis announced that so far as he was concerned the child would have to be buried by the city, since they had no money for a funeral; and at this the poor woman almost went out of her senses, wringing her hands and screaming with grief and despair. Her child to be buried in a pauper's grave! And her stepdaughter to stand by and hear it said without protesting! It was enough to make Ona's father rise up out of his grave to rebuke her! If it had come to this, they might as well give up at once, and be buried all of them together! . . . In the end Marija said that she would help with ten dollars; and Jurgis being still obdurate, Elzbieta went in tears and begged the money from the neighbors, and so little Kristoforas had a mass and a hearse with white plumes on it, and a tiny plot in a graveyard with a wooden cross to mark the place. The poor mother was not the same for months after that; the mere sight of the floor where little Kristoforas had crawled about would make her weep. He had never had a fair chance, poor little fellow, she would say. He had been handicapped from his birth. If only she had heard about it in time, so that she might have had that great doctor to cure him of his lameness! . . . Some time ago, Elzbieta was told, a Chicago billionaire had paid a fortune to bring a great European surgeon over to cure his little daughter of the same disease from which Kristoforas had suffered. And because this surgeon had to have bodies to demonstrate upon, he announced that he would treat the children of the poor, a piece of magnanimity over which the papers became quite eloquent. Elzbieta, alas, did not read the papers, and no one had told her; but perhaps it was as well, for just then they would not have had the carfare to spare to go every day to wait upon the surgeon, nor for that matter anybody with the time to take the child. . . .



Prisoner's Walk *(1890), by Vincent Van Gogh (1853–1890). Painted while Van Gogh was an inmate at the asylum in San Remy, the painting captures the claustrophobia and despair that accompany individual loss of liberty at the hands of institutions.*

Source: Art Resource, New York.

From Chapter 27

Poor Jurgis was now an outcast and a tramp once more. He was crippled—he was as literally crippled as any wild animal which has lost its claws, or been torn out of its shell. He had been shorn, at one cut, of all those mysterious weapons whereby he had been able to make a living easily and to escape the consequences of his actions. He could no longer command a job when he wanted it; he could no longer steal with impunity—he must take his chances with the common herd. Nay worse, he dared not mingle with the herd—he must hide himself, for he was one marked out for destruction. His old companions would betray him, for the sake of the influence they would gain thereby; and he would be made to suffer, not merely for the offense he had committed, but for others which would be laid at his door, just as had been done for some poor devil on the occasion of that assault upon the "country customer" by him and Duane.

And also he labored under another handicap now. He had acquired new standards of living, which were not easily to be altered. When he had been out of work before, he had been content if he could sleep in a doorway or under a truck out of the rain, and if he could get fifteen cents a day for saloon lunches. But now he desired all sorts of other things, and suffered because he had to do without them. He must have a drink now and then, a drink for its own sake, and apart from the food that came with it. The craving for it was strong enough to master every other consideration—he would have it, though it were his last nickel and he had to starve the balance of the day in consequence.

Jurgis became once more a besieger of factory gates. But never since he had been in Chicago had he stood less chance of getting a job than just then. For one thing, there was the economic crisis, the million or two of men who had been out of work in the spring and summer, and were not yet all back, by any means. And then there was the strike, with seventy thousand men and women all over the country idle for a couple of months—twenty thousand in Chicago, and many of them now seeking work throughout the city. It did not remedy matters that a few days later the strike was given up and about half the strikers went back to work; for every one taken on, there was a "scab" who gave up and fled. The ten or fifteen thousand "green" Negroes, foreigners, and criminals were now being turned loose to shift for themselves. Everywhere Jurgis went he kept meeting them, and he was in an agony of fear lest some one of them should know that he was "wanted." He would have left Chicago, only by the time he had realized his danger he was almost penniless; and it would be better to go to jail than to be caught out in the country in the winter time.

At the end of about ten days Jurgis had only a few pennies left; and he had not yet found a job—not even a day's work at anything, not a chance to carry a satchel. Once again, as when he had come out of the hospital, he was bound hand and foot, and facing the grisly phantom of starvation. Raw, naked terror possessed him, a maddening passion that would never leave him, and that wore him down more quickly than the actual want of food. He was going to die of hunger! The fiend reached out its scaly arms for him—it touched him, its breath came into his face; and he would cry out for the awfulness of it, he would wake up in the night, shuddering, and bathed in perspiration, and start up and flee. He would walk, begging for work, until he was exhausted; he could not remain still—he would wander on, gaunt and haggard, gazing about him with restless eyes. Everywhere he went, from one end of the vast city to the other, there were hundreds of others like him; everywhere was the sight of plenty and the merciless hand of authority waving them away. There is one kind of prison where the man is behind bars, and everything that he desires is outside; and there is another kind where the things are behind the bars, and the man is outside. . . .

Source: Sinclair, Upton. 1906. *The Jungle.* New York: The Jungle Publishing Company.

Joseph Conrad, from *The Secret Agent* (1907)

The mind is hierarchically superior to the body in the Western tradition; it follows from this that human beings whose minds are weak are not wise enough to restrain their bodily passions. Here Conrad displays Stevie's inability to control himself, but he also illustrates the split between mind and body in the characters of Mrs. Verloc and Stevie. The question is, how long will Mrs. Verloc be able to exercise mental control over Stevie's powerful physical inclinations?

Stevie, left alone beside the private lamp-post of the Charity, his hands thrust deep into his pockets, glared with vacant sulkiness. At the bottom of his pockets his incapable, weak hands were clenched hard into a pair of angry fists. In the face of anything which affected directly or indirectly his morbid dread of pain, Stevie ended by turning vicious. A magnanimous indignation swelled his frail chest to bursting, and caused his candid eyes to squint. Supremely wise in knowing his own powerlessness, Stevie was not wise enough to restrain his passions. The tenderness of his universal charity had two phases as indissolubly joined and connected as the reverse and obverse sides of a medal. The anguish of immoderate compassion was succeeded by the pain of an innocent but pitiless rage. Those two states expressing themselves outwardly by the same signs of futile bodily agitation, his sister Winnie soothed his excitement without ever fathoming its twofold character. Mrs Verloc wasted no portion of this transient life in seeking for fundamental information. This is a sort of economy having all the appearances and some of the advantages of prudence. Obviously it may be good for one not to know too much. And such a view accords very well with constitutional indolence.

On that evening on which it may be said that Mrs Verloc's mother having parted for good from her children had also departed this life, Winnie Verloc did not investigate her brother's psychology. The poor boy was excited, of course. After once more assuring the old woman on the threshold that she would know how to guard against the risk of Stevie losing himself for very long on his pilgrimages of filial piety, she took her brother's arm to walk away. Stevie did not even mutter to himself, but with the special sense of sisterly devotion developed in her earliest infancy, she felt that the boy was very much excited indeed. Holding tight to his arm, under the appearance of leaning on it, she thought of some words suitable to the occasion.

"Now, Stevie, you must look well after me at the crossings, and get first into the bus, like a good brother."

This appeal to manly protection was received by Stevie with his usual docility. It flattered him. He raised his head and threw out his chest.

"Don't be nervous, Winnie. Mustn't be nervous! Bus all right," he answered in a brusque, slurring stammer partaking of the timorousness of a child and the resolution of a man. He advanced fearlessly with the woman on his arm, but his lower lip drooped. Nevertheless, on the pavement of the squalid and wide thoroughfare, whose poverty in all the amenities of life stood foolishly exposed by a mad profusion of gas-lights, their resemblance to each other was so pronounced as to strike the casual passers-by.

Before the doors of the public-house at the corner, where the profusion of gas-light reached the height of positive wickedness, a four-wheeled cab standing by the kerbstone, with no one on the box, seemed cast out into the gutter on account of irremediable decay. Mrs Verloc recognized the conveyance. Its aspect was so profoundly lamentable, with such a perfection of grotesque misery and weirdness of macabre detail, as if it were the Cab of Death itself that Mrs Verloc, with that ready compassion of a woman for a horse (when she is not sitting behind him), exclaimed vaguely!

"Poor brute."

Hanging back suddenly, Stevie inflicted an arresting jerk upon his sister.

"Poor! Poor!" he ejaculated appreciatively. "Cabman poor, too. He told me himself."

The contemplation of the infirm and lonely steed overcame him. Jostled, but obstinate, he would remain there, trying to express the view newly opened to his sympathies of the human and equine misery in close association. But it was very difficult. "Poor brute, poor people!" was all he could repeat. It did not seem forcible enough, and he came to a stop with an angry splutter. "Shame!" Stevie was no master of phrases, and perhaps for that very reason his thoughts lacked clearness and precision. But he felt with great completeness and some profundity. That little word contained all his sense of indignation and horror at one sort of wretchedness having to feed upon the anguish of the other—as the poor cabman beating the poor horse in the name, as it were, of his poor kids at home. And Stevie knew what it was to be beaten. He knew it from experience. It was a bad world. Bad! Bad!

Mrs Verloc, his only sister, guardian, and protector, could not pretend to such depths of insight. Moreover, she had not experienced the magic of the cabman's eloquence. She was in the dark as to the inwardness of the word "Shame." And she said placidly:

"Come along, Stevie. You can't help that."

The docile Stevie went along; but now he went along without pride, shamblingly, and muttering half words, and even words that would have been whole if they had not been made up of halves that did not belong to each other. It was as though he had been trying to fit all the words he could remember to his sentiments in order to get some sort of corresponding idea. And, as a matter of fact, he got it at last. He hung back to utter it at once.

"Bad world for poor people."

Directly he had expressed that thought he became aware that it was familiar to him already in all its consequences. This circumstance strengthened his conviction immensely, but also augmented his indignation. Somebody, he felt, ought to be punished for it—punished with great severity. Being no sceptic, but a moral creature, he was in a manner at the mercy of his righteous passions.

"Beastly!" he added, concisely.

It was clear to Mrs Verloc that he was greatly excited.

"Nobody can help that," she said. "Do come along. Is that the way you're taking care of me?"

Stevie mended his pace obediently. He prided himself on being a good brother. His morality, which was very complete, demanded that from him. Yet he was pained at the information imparted by his sister Winnie—who was good. Nobody could help that! He came along gloomily, but presently he brightened up. Like the rest of mankind, perplexed by the mystery of the universe, he had his moments of consoling trust in the organized powers of the earth.

"Police," he suggested, confidently.

"The police aren't for that," observed Mrs Verloc, cursorily, hurrying on her way.

Stevie's face lengthened considerably. He was thinking. The more intense his thinking, the slacker was the droop of his lower jaw. And it was with an aspect of hopeless vacancy that he gave up his intellectual enterprise.

"Not for that?" he mumbled, resigned but surprised. "Not for that?" He had formed for himself an ideal conception for the metropolitan police as a sort of benevolent institution for the suppression of evil. The notion of benevolence especially was very closely associated with his sense of the power of the men in blue. He had liked all police constables tenderly, with a guileless trustfulness. And he was pained. He was irritated, too, by a suspicion of duplicity in the members of the force. For Stevie was frank and as open as the day himself. What did they mean by pretending then? Unlike his sister, who put her trust in face values, he wished to go to the bottom of the matter. He carried on his inquiry by means of an angry challenge.

"What are they for then, Winn? What are they for? Tell me."

Winnie disliked controversy. But fearing most a fit of black depression consequent on Stevie missing his mother very much at first, she did not altogether decline the discussion. Guiltless of all irony, she answered yet in a form which was not perhaps unnatural in the wife of Mr Verloc, Delegate of the Central Red Committee, personal friend of certain anarchists, and a votary of social revolution.

"Don't you know what the police are for, Stevie? They are there so that them as have nothing shouldn't take anything away from them who have."

She avoided using the verb "to steal," because it always made her brother uncomfortable. For Stevie was delicately honest. Certain simple principles had been instilled into him so anxiously (on account of his "queerness") that the mere names of certain transgressions filled him with horror. He had been always easily impressed by speeches. He was impressed and startled now, and his intelligence was very alert.

"What?" he asked at once, anxiously. "Not even if they were hungry? Mustn't they?"

The two had paused in their walk.

"Not if they were ever so," said Mrs Verloc, with the equanimity of a person untroubled by the problem of the distribution of wealth and exploring the perspective of the roadway for an omnibus of the right colour. "Certainly not. But what's the use of talking about all that? You aren't ever hungry."

She cast a swift glance at the boy, like a young man, by her side. She saw him amiable, attractive, affectionate and only a little, a very little peculiar. And she could not see him otherwise, for he was connected with what there was of the salt of passion in her tasteless life—the passion of indignation, of courage, of pity, and even of self-sacrifice. She did not add: "And you aren't likely ever to be as long as I live." But she might very well have done so, since she had taken effectual steps to that end. Mr Verloc was a very good husband. It was her honest impression that nobody could help liking the boy. She cried out suddenly:

"Quick, Stevie. Stop that green bus."

And Stevie, tremulous and important with his sister Winnie on his arm, flung up the other high above his head at the approaching bus, with complete success.

Source: Conrad, Joseph. 1907. *The Secret Agent: A Simple Tale.* Available at: http://www.online-literature.com/conrad/secret_agent/

Clifford Beers, from *A Mind That Found Itself* (1910)

The story of Clifford Beers's hallucinations and suicide attempts, which led to his being committed to an asylum, provides the author with an opportunity to reflect upon care methods in U.S. asylums. In this excerpt, he examines the abuse applied to patients by their personal attendants and the way in which such abuse can be fostered by the institutions in which the attendants work.

XXIX

The central problem in the care of the insane is the elimination of actual physical abuse. What I have narrated from my own experience and from the experiences of others makes clear enough the nature of the average attendant. Under a bad regime their baser natures gradually gain the mastery. Surprising as it may seem, many an assault is due in the last analysis to a wanton desire to satisfy what amounts to a craving for human blood. This fact is well illustrated in the remark of an attendant, in the Kentucky institution already referred to, who said, "When I came here if any one had told me that I would be guilty of striking a patient I would have called him crazy himself, but now I take delight in punching hell out of them."

What is responsible for the development of the brutal attendant and his continued existence?

In the first place, not only do locks and bars *protect* men mean enough to abuse the helpless, the sense of security itself really *inspires* them to wicked deeds. And this feeling of security is strengthened by the knowledge that chance witnesses can but rarely testify convincingly in a court of law. Being removed from the restraining influence of sane eyes, the attendant does not fear to abuse, or (the vicious type) even sometimes to kill a patient. At the worst he sees no greater penalty in store for him than the loss of his position. The chance of arrest and trial is so remote as to escape consideration; and a trial has few terrors for such attendants as are arrested, for acquittal is almost certain. Indeed, on those rare occasions when attendants happen to be indicted for murder or manslaughter, the public generally gives them the benefit of the doubt, assuming that their work is highly dangerous, and arguing that the occasional sacrifice of the life of an insane patient is unavoidable, therefore justifiable. In this the public is in error, for, though the work in question may be, and at times *is,* harassing, it is, by no means, peculiarly hazardous. The number of unprovoked attacks made upon attendants by insane patients is, in fact, small, and would become almost negligible were all patients treated kindly from the moment of commitment.

But can we put all the blame on attendants for assaulting patients when the management shows no aggressive disposition to protect the latter? Such indifference is far more reprehensible than the cowardly conduct of ill-paid men, the majority of whom have had few advantages of education. The professional thug-attendant who, when a fellow-attendant is assaulting a patient, deliberately turns his back so that he may say, if ever questioned, that he saw no assault, is, in my opinion, less deserving of censure than those doctors who, knowing that brutality is common in their institution, weakly resign themselves to what they call "conditions."

Much of the suffering among the insane to-day is, in my opinion, due to the giving of too much authority to assistant physicians. Many of them, especially the young and inexperienced, are not to be trusted implicitly. Or, if they are to be given almost absolute authority over the patients in wards assigned to their care, let the superintendent exercise his authority to set aside any order which he may deem inexpedient or unjust. All superintendents have such authority. What I wish to emphasize is that they too often fail to exercise it. As a result of their laxness, or timidity—a timidity perhaps inspired by a misconception of the ethics of their profession—the helpless patient is permitted unnecessarily to suffer; and, I regret to record, frequently is this suffering of the patient due to what seems a selfish desire of the superintendent to preserve peace in his official family—the medical staff. Official peace at such a price amounts to crime.

But quite as culpable as lax discipline is the selfish desire on the part of doctors in authority to escape annoying investigations. When it does happen that they cannot avoid reporting felonious assaults or suspected murders to the proper authorities, their action, I regret to say, is too often in mere self-defense, and not from a righteous desire to protect their patients. Knowing that the battered and mutilated condition of the corpse, or a living victim of abuse, for that matter, will arouse suspicion on the part of the relatives of the victim, those in authority sometimes take the initiative in order to "save their face." In making this assertion I am well within the bounds of charity and truth, and the conduct of this type of doctor at the subsequent trial invariably is such as to support my contention. This behavior is quite human; for, let it be borne in mind that almost every honest investigation into these suspicious deaths reveals a greater or less degree—sometimes a criminal degree—of neglect on the part of the doctors themselves. If cornered at last by an aroused public opinion they are too ready to shift the responsibility upon the ignorant and untrained attendants whose brutality is but the reflex of the doctors' indifference, neglect, or cowardice. But this is the last resort. Usually they will first equivocate to the verge of deliberate falsehood. They will outrun the public by giving the benefit of all doubts to the attendants. Not to do so would in many cases cause the accused to turn on them and reveal conditions they would prefer to hide. Human nature, like Nature herself, is influenced by immutable laws. Self-interest is apt to kill one's higher feelings. To fight the fight of the oppressed, the outraged, the dead, too frequently forces one to abandon a chosen career. Therefore, the still voice of a timid conscience whispers (in a perverted sense): "Let the dead bury their dead."

I cannot lay too much stress on this absolute fact: that hospital managements deliberately, wilfully, and selfishly suppress evidence which, if presented to the proper authorities, would lead to the conviction of guilty attendants, and eventually to their almost complete elimination from asylums. Several instances of such suppression have come to my attention since my discharge, two of which I shall now cite. During the summer of 1907, a Committee of Investigation appointed by the Legislature of the State of New Jersey, uncovered, several months after the commission of the crime, the suppressed evidence of the murder of a patient by attendants at the Trenton State Hospital. On the witness-stand the hospital official in authority admitted that the attendants had killed the patient and that their only punishment had been their prompt discharge as employees. He further admitted that the "scandal" had been deliberately suppressed, and that no evidence or report of the crime had been submitted to the proper authorities as is, of course, required by law. So skilfully was this crime concealed that even the wife of the victim was unable to learn the cause of her husband's death until the investigators laid bare the facts. And this same Committee of Investigation uncovered another alleged and, to my mind, proved murder in another State Hospital for the Insane—at Morris Plains, New Jersey. Here, again, the "scandal" (a hospital euphemism for "murder" and lesser crimes) was "hushed-up" or "whitewashed." When it was finally dragged into the light of day, what happened? Those in authority, making characteristic use of the ignorance of the public regarding such matters, brazenly, I think, denied in sweeping terms, and under oath, the incriminating evidence of supposedly credible witnesses. If an investigation in New Jersey can reveal two unreported murders that occurred within a year in two State Hospitals, how many such crimes would be unearthed should the two hundred and twenty-six public and one hundred and two private hospitals for the insane in this country be *honestly* investigated? The probable figure is too appalling to print. . . .

We must admit that the problem of securing efficiency among attendants is not an easy one. To make it easier several improvements must be made in the lot of the attendants themselves. For one thing, the niggardly salaries now offered make it extremely difficult for a management to secure or keep the right type. Competent men and women can earn two or three times as much in other and more congenial lines of endeavor. The average scale of wages for attendants in hospitals for the insane ranges from sixteen to twenty-four dollars a month, with room and board. Women usually receive sixteen or eighteen dollars at the beginning; men from eighteen to twenty, though the rates vary throughout the country. There is a slight margin, too, for an increase in salary, but even the exceptionally able attendants seldom receive more than thirty dollars a month. This bespeaks a false, a vicious economy. Not that the average attendant deserves a cent more than he receives; but would it not be wiser, more humane, and, in the end, cheaper, to offer inducements calculated to attract to this neglected field of service a higher type of character?—nay, and keep him there, for nothing is more demoralizing than the constant changing that goes on in the ranks of the present attendants. To offer a wage of, say, forty, with a maximum of fifty dollars a month, including board and room, would, no doubt, be a move in the right direction.

However, such a merely pecuniary inducement would not, of itself, accomplish the purpose. Indeed, alone, it might defeat the purpose. For, after discussing this problem with doctors who have employed attendants, I am brought to the conclusion that increased wages, unaccompanied by increased and deserved privileges, and more wholesome and refined surroundings, would probably appeal only to burly workers in rougher fields. Wages high enough to attract a more refined type are, at the present stage of hospital development, out of the question; whereas privileges and refining influences might even now be brought to bear with excellent effect. Model dormitories, and separate cottages for married employees, instead of mere sleeping places, shorter and less exhausting hours, and proper places in which the extra leisure could be enjoyed—a library, billiard room, etc.,—these would go farther than money toward the great task of refinement. It is unfair to keep an attendant on duty twelve or fifteen hours a day (these are now the common working hours) and for the balance of his time confine him to his ward under restrictions nearly as irksome as those to which the patients themselves must perforce submit. A few States, notably New York and Massachusetts, have granted appropriations for the creation of such conditions as I am describing. If these appropriations were enlarged, and if other States followed the same policy, it is safe to predict that thousands of refined men and women would enter this field who are now debarred. And once in the work they should be offered the same chances for advancement as are offered to employees in any well conducted commercial establishment. Such a policy, carried to its logical conclusion, would include also a system of pensions for those attendants who should devote the better part of their lives to this noble service.

Still another effective means of eliminating brutality by the introduction of refining influences would consist in the wider employment of women nurses in men's wards. To the uninitiated this suggestion will no doubt seem ill-advised; yet, at this moment, there are in this country—and abroad, as well,—some hospitals for the insane where women nurses, assisted, of course, by orderlies, as are nurses in general hospitals, are managing men's wards with gratifying success. What is needed is a general adoption of this humane practice. Not all classes of male patients can safely or advantageously be placed in charge of women nurses; but other classes—the more intelligent and less disturbed—comprising thousands, can, if anything, be managed better by women of capacity than by men of any sort. The superior tact and quicker sympathy of women—God-given qualities—work wonders among insane men quite as readily as in the sane world. It cannot be denied that under the present regime women nurses in charge of troublesome women patients have not been entirely free from charges of cruelty; indeed, the contrary has been proved, as the results of investigations show—but they are far less subject to this charge than men attendants. According to those superintendents who have successfully placed women nurses in charge of men's wards, thousands of male patients who now suffer at the hands of unfeeling and incompetent male attendants could be brought under remedial and uplifting influences simply by having women placed over them in positions of authority. And the salutary influence of women in wards where they are available would have a tendency, as experience has demonstrated, to spread throughout all other wards where their immediate presence is impracticable or unsafe. It would therefore seem desirable to substitute female for male nurses wherever possible.

Such a course, too, would further simplify the problem of securing an adequate number of attendants. The services of women are easier to secure, and women readily take up nursing as a profession—as a life-work; whereas men naturally look upon such work simply as a means of providing a livelihood until they can secure work more to their liking.

There are in this country about twenty thousand men and women working as attendants in our asylums and hospitals for the insane. Of this number several thousand are, without doubt, individuals of refinement. Now, if a few thousand persons of refinement can work under such conditions as obtain so generally to-day in our hospitals and asylums, is it not reasonable to suppose that improved conditions would eventually attract a full complement of workers of the same type? Strange as it may seem, many attendants now so employed, enjoy their work and would not of their own choice relinquish it. And I make bold to appeal to those grinding thousands now eking out a livelihood in work apparently more attractive, but, in truth, less endurable, to seek improved conditions and increased usefulness in those hospitals where the application of the Golden Rule to insanity is now possible. In such places a feeling of security and interest soon overcomes the instinctive timidity or repugnance felt by many when, in the capacity of attendants, they first come in contact with the insane. Such contact, barring exceptional cases influenced by a too impressionable temperament on the part of the nurse, renders one, as it were, immune. It would surprise (perhaps annoy) many sane persons, were they to realize how slightly many of the inmates of asylums differ from their more fortunate brothers at large. Yet among those who have been brought into close contact with the insane this is a trite observation; and it is the key to the problem which causes so many to wonder how and why it is that men and women, at liberty to choose their vocations, deliberately cast their lot with that portion of humanity which the average person seems so willing to shun.

Source: Beers, Clifford. 1910. *A Mind That Found Itself.* New York: Longman, Greens, and Company.

Konrad Biesalski, from *Manual for the Care of Cripples* (1911)

The pediatrician, surgeon, and orthopedic specialist Konrad Biesalski (1868–1930) can be regarded as a founder of German rehabilitation and disability policy. Above all, he looked after the care of physically disabled people, who at the beginning of the twentieth century were still called "cripples." In 1906, he initiated the first registry and census of physically disabled children and youth in the German empire; the census produced the proof that disability constituted a major problem with respect to the poor population. In addition, Biesalski defined physical disability as an illness in the medical-orthopedic sense, after which he was able to establish treatment and social policies for physically disabled people.

I. What Is a Cripple?

This question has been answered variously depending on the specific profession or position of the person answering with respect to the cripple's care. In 1906 all crippled youth were officially counted in Germany. As a result of this census, a definition has been established. . . .

It states: 'A cripple in need of institutional care is (as a result of a congenital or acquired nerve or bone and joint condition) a sick person, who is disabled in the use of his trunk or limbs. The interaction between the degree of his ailment (including other illnesses and defects) and the cost of living in his surroundings is so unfavorable that his remaining mental and physical strength can only be developed to the highest possible economic independence in an institution that can offer a variety of medical and pedagogic measures that are necessary for this aim.'

The entire public system of cripples' care [*Krüppelfürsorge*] in Germany deals only with the cripples amongst the poor population. Cripples of affluent parents are not counted in these official statistics.

The above definition emphasizes that the cripple is an ill person, for whose care the doctor is ultimately responsible. The definition goes on to divide the cripple's care into two large groups: the first, in which the level of care requires placement in a special institution—a so-called cripple home—the elaboration of which is included in the above definition, and the second, in which the cripples can also become 'de-crippled' [*entkrüppelt*] without home care. Therefore, the main division is between the 'Institutional' [*Heimbedürftige*] and the 'Non-Institutional' [*Nichtheimbedürftige*].

If a child with a congenitally defective arm is born the son of an affluent father, this child is not subject to the public system of cripples' care, because the father will raise the boy to reach his highest potential work capacity through the father's own fortunes. If a child suffers from a moderate ailment, e.g. from a middle-degree curvature of the spine, however, and is at the same time an orphan or illegitimate child, and feeble-minded, deaf-mute, or blind and poor, this child needs our help. Without it, the child would be neglected physically, morally, and economically.

The uppermost *purpose of all well-ordered cripples' care,* is to make the cripple fit for work, or in short, as expressed in a catchphrase, to change him from an alms recipient into a taxpayer. To achieve this purpose, three separate groups of professionals are active in the cripples' care. The *doctor* cures the cripple's ailment or at least improves it as much as possible. The *teacher* provides the cripple with the necessary school education, the *master craftsman* teaches him a trade. Although these three fields are independent of one another, they do not stand next to each other as strangers, but instead work at the same time with and in one another, so that out of these three occupations a completely new field emerges, namely, that of cripples' care. . . .

Source: Biesalski, Konrad. 1911. Pp. 13–15, 18, in *Leitfaden der Krüppelfürsorge: Im Auftrag der Deutschen Vereinigung für Krüppelfürsorge.* Leipzig and Hamburg, Germany: Leopold Voss. [*Manual for the Care of Cripples: In Contract with the German Organization for Cripples' Care.* Vogt, Sara, trans.].

Randolph Bourne, "The Handicapped" (1911)

In John Dos Passos's sprawling epic U.S.A., *social critic and writer Randolph Bourne (1886–1918) is described as "a tiny twisted unscared ghost in a black cloak hopping along the grimy old brick and brownstone streets still left in New York, crying out in a shrill soundless giggle: War is the health of the state." Bourne's opposition to World War I, his understanding of the changes it would bring, and his appreciation of the role of youth in social movements are usually seen as his primary intellectual contributions. However, he has recently been receiving more attention for his writing about disability. His essay "The Handicapped" originally appeared in the* Atlantic Monthly *in 1911. Bourne died in 1918 in the influenza epidemic that followed in the wake of World War I.*

It would not perhaps be thought, ordinarily, that the man whom physical disabilities have made so helpless that he is unable to move around among his fellows, can bear his lot more happily, even though he suffer pain, and face life with a more cheerful and contented spirit, than can the man whose handicaps are merely enough to mark him out from the rest of his fellows without preventing him from entering with them into most of their common affairs and experiences. But the fact is that the former's very helplessness makes him content to rest and not to strive. I know a young man so helplessly disabled that he has to be carried about, who is happy in reading a little, playing chess, taking a course or two in college, and all with the sunniest good-will in the world, and a happiness that seems strange and unaccountable to my restlessness. He does not cry for the moon.

When the handicapped youth, however, is in full possession of his faculties, and can move about freely, he is perforce drawn into all the currents of life. Particularly if he has his own way in the world to make, his road is apt to be hard and rugged, and he will penetrate to an unusual depth in his interpretation both of the world's attitude toward such misfortunes, and of the attitude toward the world which such misfortunes tend to cultivate in men like him. For he has all the battles of a stronger man to fight, and he is at a double disadvantage in fighting them. He has constantly with him the sense of being obliged to make extra efforts to overcome the bad impression of his physical defects, and he is haunted with a constant feeling of weakness and low vitality which makes effort more difficult and renders him easily fainthearted and discouraged by failure. He is never confident of himself, because he has grown up in an atmosphere where nobody has been very confident of him; and yet his environment and circumstances call out all sorts of ambitions and energies in him which, from the nature of his case, are bound to be immediately thwarted. This attitude is likely to keep him at a generally low level of accomplishment unless he have an unusually strong will, and a strong will is perhaps the last thing to develop under such circumstances.

The handicapped man is always conscious that the world does not expect very much from him. And it takes him a long time to see in this a challenge instead of a firm pressing down to a low level of accomplishment. As a result, he does not expect very much of himself; he is timid in approaching people, and distrustful of his ability to persuade and convince. He becomes extraordinarily sensitive to other people's first impressions of him. Those who are to be his friends he knows instantly, and further acquaintance adds little to the intimacy and warm friendship that he at once feels for them. On the other hand, those who do not respond to him immediately cannot by any effort either on his part or theirs overcome that first alienation.

This sensitiveness has both its good and its bad sides. It makes friendship the most precious thing in the world to him, and he finds that he arrives at a much richer and wider intimacy with his friends than do ordinary men with their light, surface friendships, based on good fellowship or the convenience of the moment. But on the other hand this sensitiveness absolutely unfits him for business and the practice of a profession, where one must be "all things to all men," and the professional manner is indispensable to success. For here, where he has to meet a constant stream of men of all sorts and conditions, his sensitiveness to these first impressions will make his case hopeless. Except with those few who by some secret sympathy will seem to respond, his physical deficiencies will stand like a huge barrier between his personality and other men's. The magical good fortune of attractive personal appearance makes its way almost without effort in the world, breaking down all sorts of walls of disapproval and lack of interest. Even the homely person can attract by personal charm.

The doors of the handicapped man are always locked, and the key is on the outside. He may have treasures of charm inside, but they will never be revealed unless the person outside cooperates with him in unlocking the door. A friend becomes, to a much greater degree than with the ordinary man, the indispensable means of discovering one's own personality. One only exists, so to speak, with friends. It is easy to see how hopelessly such a sensitiveness incapacitates a man for business, professional or social life, where the hasty and superficial impression is everything, and disaster is the fate of the man who has not all the treasures of his personality in the front window, where they can be readily inspected and appraised.

It thus takes the handicapped man a long time to get adjusted to his world. Childhood is perhaps the hardest time of all. As a child he is a strange creature in a strange land. It was my own fate to be just strong enough to play about with the other boys, and attempt all their games and "stunts," without being strong enough actually to succeed in any of them. It never used to occur to me that my failures and lack of skill were due to circumstances beyond my control, but I would always impute them, in consequence of my rigid Calvinistic bringing-up, I suppose, to some moral weakness of my own. I suffered tortures in trying to learn to skate, to climb trees, to play ball, to conform in general to the ways of the world. I never resigned myself to the inevitable, but overexerted myself constantly in a grim determination to succeed. I was good at my lessons, and through timidity rather than priggishness, I hope, a very well-behaved boy at school; I was devoted, too, to music, and learned to play the piano pretty well. But I despised my reputation for excellence in these things, and instead of adapting myself philosophically to the situation, I strove and have been striving ever since to do the things I could not.

As I look back now it seems perfectly natural that I should have followed the standards of the crowd, and loathed my high marks in lessons and deportment, and the concerts to which I was sent by my aunt, and the exhibitions of my musical skill that I had to give before admiring ladies. Whether or not such an experience is typical of handicapped children, there is tragedy there for those situated as I was. For had I been a little weaker physically, I should have been thrown back on reading omnivorously and cultivating my music, with some possible results; while if I had been a little stronger, I could have participated in the play on an equal footing with the rest. As it was, I simply tantalized myself, and grew up with a deepening sense of failure, and a lack of pride in that at which I really excelled.

When the world became one of dances and parties and social evenings and boy-and-girl attachments,—the world of youth,—I was to find myself still less adapted to it. And this was the harder to bear because I was naturally sociable, and all these things appealed tremendously to me. This world of admiration and gayety and smiles and favors and quick interest and companionship, however, is only for the well-begotten and the debonair. It was not through any cruelty or dislike, I think, that I was refused admittance; indeed they were always very kind about inviting me. But it was more as if a ragged urchin had been asked to come and look through the window at the light and warmth of a glittering party; I was truly in the world, but not of the world. Indeed there were times when one would almost prefer conscious cruelty to this silent, unconscious, gentle oblivion. And this is the tragedy, I suppose, of all the ill-favored and unattractive to a greater or less degree; the world of youth is a world of so many conventions, and the abnormal in any direction is so glaringly and hideously abnormal.

Although it took me a long time to understand this, and I continued to attribute my failure mostly to my own character, trying hard to compensate for my physical deficiencies by skill and cleverness, I suffered comparatively few pangs, and got much better adjusted to this world than to the other. For I was older, and I had acquired a lively interest in all the social politics; I would get so interested in watching how people behaved, and in sizing them up, that only at rare intervals would I remember that I was really having no hand in the game. This interest just in the ways people are human, has become more and more a positive advantage in my life, and has kept sweet many a situation that might easily have cost me a pang. Not that a person with disabilities should be a sort of detective, evil-mindedly using his social opportunities for spying out and analyzing his friends' foibles, but that, if he does acquire an interest in people quite apart from their relation to him, he may go into society with an easy conscience and a certainty that he will be entertained and possibly entertaining, even though he cuts a poor enough social figure. He must simply not expect too much.

Perhaps the bitterest struggles of the handicapped man come when he tackles the business world. If he has to go out for himself to look for work, without fortune, training, or influence, as I personally did, his way will indeed be rugged. His disability will work against him for any position where he must be much in the eyes of men, and his general insignificance has a subtle influence in convincing those to whom he applies that he is unfitted for any kind of work. As I have suggested, his keen sensitiveness to other people's impressions of him makes him more than usually timid and unable to counteract that fatal first impression by any display of personal force and will. He cannot get his personality over across that barrier. The cards seem stacked against him from the start. With training and influence something might be done, but alone and unaided his case is almost hopeless. The attitude toward him ranges from, "You can't expect us to create a place for you," to, "How could it enter your head that we should find any use for you?" He is discounted at the start: it is not business to make allowances for anybody; and while people are not cruel or unkind, it is the hopeless finality of the thing that fills one's heart with despair.

The environment of a big city is perhaps the worst possible that a man in such a situation could have. For the thousands of seeming opportunities lead one restlessly on and on, and keep one's mind perpetually unsettled and depressed. There is a poignant mental torture that comes with such an experience,—the urgent need, the repeated failure, or rather the repeated failure even to obtain a chance to fail, the realization that those at home can ill afford to have you idle, the growing dread of encountering people,—all this is something that those who have never been through it can never realize. Personally I know of no particular way of escape. One can expect to do little by one's own unaided efforts. I solved my difficulties only by evading them, by throwing overboard some of my responsibility, and taking the desperate step of entering college on a scholarship. Desultory work is not nearly so humiliating when one is using one's time to some advantage, and college furnishes an ideal environment where the things at which a man handicapped like myself can succeed really count. One's self-respect can begin to grow like a weed.

For at the bottom of all the difficulties of a man like me is really the fact that his self-respect is so slow in growing up. Accustomed from childhood to being discounted, his self-respect is not naturally very strong, and it would require pretty constant success in a congenial line of work really to confirm it. If he could only more easily separate the factors that are due to his physical disability from those that are due to his weak will and character, he might more quickly attain self-respect, for he would realize what he is responsible for, and what he is not. But at the beginning he rarely makes allowances for himself; he is his own severest judge. He longs for a "strong will," and yet the experience of having his efforts promptly nipped off at the beginning is the last thing on earth to produce that will.

If the handicapped youth is brought into harsh and direct touch with the real world, life proves a much more complex thing to him than to the ordinary man. Many of his inherited platitudes vanish at the first touch. Life appears to him as a grim struggle, where ability does not necessarily mean opportunity and success, nor piety sympathy, and where helplessness cannot count on assistance and kindly interest. Human affairs seem to be running on a wholly irrational plan, and success to be founded on chance as much as on anything. But if he can stand the first shock of disillusionment, he may find himself enormously interested in discovering how they actually do run, and he will want to burrow into the motives of men, and find the reasons for the crass inequalities and injustices of the world he sees around him. He has practically to construct anew a world of his own, and explain a great many things to himself that the ordinary person never dreams of finding unintelligible at all. He will be filled with a profound sympathy for all who are despised and ignored in the world. When he has been through the neglect and struggles of a handicapped and ill-favored man himself, he will begin to understand the feelings of all the horde of the unpresentable and the unemployable, the incompetent and the ugly, the queer and crotchety people who make up so large a proportion of human folk.

We are perhaps too prone to get our ideas and standards of worth from the successful, without reflecting that the interpretations of life which patriotic legend, copy-book philosophy, and the sayings of the wealthy give us, are pitifully inadequate for those who fall behind in the race. Surely there are enough people to whom the task of making a decent living and maintaining themselves and their families in their social class, or of winning and keeping the respect of their fellows, is a hard and bitter task, to make a philosophy gained through personal disability and failure as just and true a method of appraising the life around us as the cheap optimism of the ordinary professional man. And certainly a kindlier, for it has no shade of contempt or disparagement about it.

It irritates me as if I had been spoken of contemptuously myself, to hear people called "common" or "ordinary," or to see that deadly and delicate feeling for social gradations crop out, which so many of our upper middle-class women seem to have. It makes me wince to hear a man spoken of as a failure, or to have it said of one that he "doesn't amount to much." Instantly I want to know why he has not succeeded, and what have been the forces that have been working against him. He is the truly interesting person, and yet how little our eager-pressing, on-rushing world cares about such aspects of life, and how hideously though unconsciously cruel and heartless it usually is!

Often I had tried in argument to show my friends how much of circumstance and chance go to the making of success; and when I reached the age of sober reading, a long series of the works of radical social philosophers, beginning with Henry George, provided me with the materials for a philosophy which explained why men were miserable and overworked, and why there was on the whole so little joy and gladness among us, and which fixed the blame. Here was suggested a goal, and a definite glorious future, toward which all good men might work. My own working hours became filled with visions of how men could be brought to see all that this meant, and how I in particular might work some great and wonderful thing for human betterment. In more recent years, the study of history and social psychology and ethics has made those crude outlines sounder and more normal, and brought them into a saner relation to other aspects of life and thought, but I have not lost the first glow of enthusiasm, nor my belief in social progress as the first right and permanent interest for every thinking and true-hearted man or woman.

I am ashamed that my experience has given me so little chance to count in any way either toward the spreading of such a philosophy or toward direct influence and action. Nor do I yet see clearly how I shall be able to count effectually toward this ideal. Of one thing I am sure, however: that life will have little meaning for me except as I am able to contribute toward some such ideal of social betterment, if not in deed, then in word. For this is the faith that I believe we need to-day, all of us,—a truly religious belief in human progress, a thorough social consciousness, an eager delight in every sign and promise of social improvement, and best of all, a new spirit of courage that will dare. I want to give to the young men whom I see,—who, with fine intellect and high principles, lack just that light of the future on their faces that would give them a purpose and meaning in life,—to them I want to give some touch of this philosophy, that will energize their lives, and save them from the disheartening effects of that poisonous counsel of timidity and distrust of human ideals which pours out in steady stream from reactionary press and pulpit.

It is hard to tell just how much of this philosophy has been due to handicap. If it is solely to that that I owe its existence, the price has not been a heavy one to pay. For it has given me something that I should not know how to be without. For, however gained, this radical philosophy has not only made the world intelligible and dynamic to me, but has furnished me with the strongest spiritual support. I know that many people, handicapped by physical weakness and failure, find consolation and satisfaction in a very different sort of faith,—in an evangelical religion, and a feeling of close dependence on God and close communion with him. But my experience has made my ideal of character militant rather than long-suffering.

Source: Bourne, Randolph. 1911. "The Handicapped." *The Atlantic Monthly* 111:320–329.

▣ W. Y. Evans Wentz on Changelings and Fairy Faith (1911)

The Fairy-Faith in Celtic Countries was the first book by W. Y. Evans Wentz, who later went on to translate the essential texts of Tibetan Buddhism, such as The Book of the Dead. *In this work, science meets superstition: Evans Wentz interprets fairy tales in order to explain the treatment of disabled children and beliefs about them. The work grows out of Modernist Primitivism, which emphasized the need to take seriously what earlier generations had dismissed as "primitive." Evans Wentz does this by showing how apparently "superstitious" healing practices actually were real "medicine" in former cultural beliefs and by discussing Celtic stories about changelings.*

Our examination of living children said to have been changed by fairies shows . . . (a) that many changelings are so called merely because of some bodily deformity or because of some abnormal mental or pathological characteristics capable of an ordinary rational explanation, (b) but that other changelings who exhibit a change of personality, such as is recognized by psychologists, are in many cases best explained on the Demon-Possession Theory, which is a well-established scientific hypothesis.

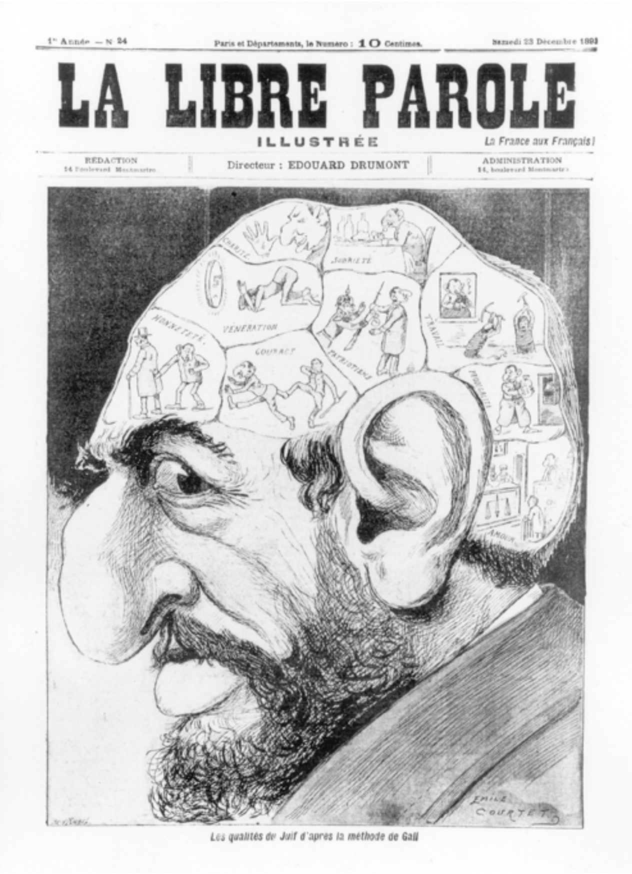
Therefore, since the residuum or x-quantity of the Fairy-Faith, the folk-religion of the Celtic peoples, cannot be explained away by any known scientific laws, it must for the present stand, and the Psychological Theory of the Nature and Origin of the Belief in Fairies in Celtic Countries is to be considered as hypothetically established in the eyes of Science. Hence we must cease to look upon the term *fairy* as being always a synonym for something fanciful, non-real, absurd. We must also cease to think of the Fairy-Faith as being no more than a fabric of groundless beliefs. In short, the ordinary non-Celtic mind must readjust itself to a new set of phenomena that through ignorance on its part it has been content to disregard, and to treat with ridicule and contempt as so much outworn 'superstition.'

Source: Evans Wentz, W. Y. 1911. *The Fairy-Faith in Celtic Countries.* Available at: http://www.public-domain-content.com/books/legends_and_sagas/celt/ffcc/ffcc411.shtml

▣ Charles B. Davenport, "Marriage Laws and Customs" (1912)

Charles Benedict Davenport (1866–1944) was born in Stamford, Connecticut, and received a PhD in biology from Harvard in 1892. He became director of Cold Springs Harbor Laboratory, where he founded the U.S. Eugenics Record office. In his 1912 essay, "Marriage Laws and Customs," Davenport warns that escalating numbers of immigrants will result in a rampant increase in feebleminded, insane, sexually deviant, and impoverished people.

The subject matter of eugenics is offspring and offspring imply parents. For legal and other reasons society regards a knowledge of parentage as very important. Marriage is society's method of securing that knowledge. Incidentally the arrangement of marriage is of



The Qualities of the Jew After Gall's Method *(1893), by Emile Courtet (1857–1938). The "inferiority" of Jewish people and other minorities were often emphasized in caricatures that exaggerated physical features presumed to deviate from those of the dominant culture.*

Source: Art Resource, New York.

value for eugenical studies, in fact the principles of eugenics could hardly be established in its absence.

But society asks not only for a registry of matings but seeks to control, in some degree, the nature of the matings. On the one hand it seeks to protect monogamy and the young from the legal consequences of marriage. On the other hand, the nature of control measures, roughly, the result of society's experience that certain matings result in undesirable offspring. Let us, accordingly, examine some of these laws.

The most widespread marriage regulation of biological import in modern civilized states is that which limits the relationship of those whose mating may receive a legal sanction. In practically all of the States of the Union marriage of brother and sister, of parent and child, even of grandparent and grandchild is forbidden, and it is sometimes expressly stated that such marriages have no legal standing. In most States the marriage of uncle and niece, or of aunt and nephew, are forbidden. When it comes to the mating of cousins, legislators have been in much greater doubt. About a third of the States forbid such marriages, and these are chiefly in the western, or more recently settled, territory. In most European States, I am informed, no legal limitation to the marriage of cousins exists.

Let us now consider in how far there is a biological justification for these laws. I know that there are those who hold that the mating even of brother and sister for generations may result in offspring without blemish. We are referred to the Incas of Peru, about whom we know little in detail, and to the Ptolomies, of whom we know a little more, but not as much as a well-trained field worker of the Eugenics Record Office would discover in two or three days. The last Cleopatra, the daughter of a brother and sister, is pointed out to us as the great argument against the evil effects of incestuous marriages. That she was the crowning flower of a beautiful race may be admitted, but is there any doubt that, were she living to-day, she would be placed in the manic-depressive ward of a hospital for the insane, with further history of paranoia and erotomania? But we, too, have histories of incest, brought in by our field workers, histories of families brought up, not in palaces, but in hovels in the woods. For example, a criminalistic man had, by an unknown woman, a number of boys and girls. One of the boys, who was a drunken, feeble-minded fellow with criminalistic tendencies, has had by his own sister a daughter who is a drunken epileptic. This daughter by her own father has had four children of whom one is epileptic, two are imbecile, and the fourth was an encephalic monster who died at birth. I would undertake to produce two cases of this general sort for each case that may be offered of the "romantic," "vivacious" product of a brother and sister mating. And can we doubt that a sober minded people have been impressed by such cases as I have cited, have stored them up in their memory as part of experience, and have crystallized that experience in laws against incest?

And how about the marriage of first cousins? Are the laws that forbid such marriages justifiable? Our modern knowledge of heredity leads to the conclusion that cousin marriages (like the marriage of sibs, possibly) [are] not injurious per se, but because such marriages enhance the probability that the same defect shall inhere in each of the two germ-cells that unite to start the development of the child. While the prohibition of cousin marriages is doubtless a rough eugenic measure, it were better if the prohibition were qualified somewhat as follows: “The marriage of cousins is forbidden when in the parental fraternity that is common to both, there is a case of inability to learn at school, of dementia precox or manic depressive insanity in any of their forms, of epilepsy, of congenital deafness, of albinism, or of cleft palate.” Such a restriction in the application of the law might well increase the difficulty of administering it, but the law would be rendered more significant and less unjust. . . .

If [laws forbidding cousin marriages under certain conditions] could not be enforced, of what use would they be? Their value would be primarily educational, and this value would be enhanced by a penalty for every enfringement of the law, such as more or less prolonged deprivation of some of the rights of citizenship. In time the reasonableness of the legislation would make a strong appeal.

The second legal limitation of a biological sort is that concerning the physical (including the mental) condition of those who contemplate marriage. Many States provide that if either party is an idiot or insane, the marriage is void, on the legal ground that such persons are incapable of making a valid contract. In not a few States paupers are permitted to marry only under restrictions, the limitation having an economic basis, namely that a male pauper cannot support a wife. In few, if any, of the States of the Union have the legislators or the people grasped the idea of restricting the marriage of the mentally or physically defective in order to diminish the procreation of more defectives. Laws against the marriage of the feebleminded are futile in any case. For so long as a feeble-minded person is at large he will find another feeble-minded person who will live with him and have children by him. It would be as sensible to hope to control by legislation the mating of rabbits. The only way to prevent the reproduction of the feeble-minded is to sterilize or segregate them. As to the marriage of the insane, it seems doubtful if it is wise to refuse this without qualification. Two mentally normal persons who have each an insane parent are more apt to have insane offspring than an insane person who marries one in whom there is no taint of insanity. I think it might be unwise to deny to every person who has shown a tendency to manic depressive insanity in its lighter forms marriage into mentally sound stock. Further study of this matter is needed. The requirement of a physician’s certificate as to bodily soundness, which some clergymen are requiring in the States, is primarily directed toward venereal disease and certainly has eugenical bearings. When a requirement is made of a certificate that both parties come of mentally and physically satisfactory stock, a still more important step in eugenics will have been taken.

Finally, the third legal limitation of a biological sort is that concerning the mixture of races. Most of the States of the Union have laws declaring marriages void when contracted between a white person and a negro or the descendants of a negro for a certain number of generations, usually three; i.e., “having one-eighth of negro blood.” But the law of the State of Georgia prohibits for ever and declares null and void any marriage between a white person and one of “African descent.” The Oregon law renders void any marriage of a white person with a person having one-fourth or more of negro, Chinese or Kanaka blood, or any person having more than one-half Indian blood.

The biological basis for such laws is doubtless an appreciation of the fact that negroes and the other races carry traits that do not go well with our social organization. For the Ethiopian has not undergone that selection that in Europe weeded out the traits that failed to recognize property rights, or that failed to give industry, ambition and sex control. The Southerner looks aghast at the possibility that these traits shall become disseminated throughout his social organization and become part and parcel of the make up of his descendants. So with the cruelty of the Indian. These fears are justified, but the cure is inadequate. Already the south is full of persons of one-eighth negro blood, whose (illegitimate) children may legally marry with whites. The Georgia law which denies marriage of white persons to descendants of blacks, however remote, is equally futile. Many a child arises in the third or later generations that by no test shows evidence of “African descent.” How unjust the Missouri law that provides that the proportion of negro blood is to be determined by the jury from the appearance of the person! The south, indeed, has a problem in its huge “feeble-minded” coloured population; but the problem is of the same order as that in the north and in England, and the solution is this: Forget unessentials, like skin colour, and focus attention on socially important defects. Then, by sterilization or segregation, prevent the reproduction of the socially inadequate. Thus will the mentally incompetent strains be eliminated and the good physical traits of some of the black races be added, as a valued heritage to enhance the physical manhood of the south.

I feel sure that if law will take lessons from biology many of the disasters that have been feared may be averted.

Source: Davenport, Charles B. 1912. "Marriage Laws and Customs." Pp. 153–155 in *Problems in Eugenics: Papers Communicated to the First International Eugenics Congress.* London: Eugenics Education Society.

Maria Montessori on the Orthophrenic School (1912)

In 1896, Maria Montessori (1870–1952) became one of the first female physicians in Italy. During her tenure at the psychiatric clinic of the University of Rome, Montessori developed an interest in disabled children. In 1899, she and Giuseppe Montesano founded the Scuola Magistrale Ortofrenica, which was both an educational institute for disabled children and a training institute for instructors. Montessori was a lecturer of disability pedagogy from 1900 to 1918 at the Regio Instituto Superiore Femminile di Magistero in Rome. Montessori traveled extensively and presented her work in order to disseminate her ideas. Maria Montessori was nominated three times for the Nobel Peace Prize. The excerpt below from her book, The Montessori Method *(1912), provides an overview of the methods she developed for educating disabled children*

From Chapter 2. "History of Methods"

About fifteen years ago, being assistant doctor at the Psychiatric Clinic of the University of Rome, I had occasion to frequent the insane asylums to study the sick and to select subjects for the clinics. In this way I became interested in the idiot children who were at that time housed in the general insane asylums. In those days thyroid organotherapy was in full development, and this drew the attention of physicians to deficient children. I myself, having completed my regular hospital services, had already turned my attention to the study of children's diseases.

It was thus that, being interested in the idiot children, I became conversant with the special method of education devised for these unhappy little ones by Edward Seguin, and was led to study thoroughly the idea, then beginning to be prevalent among the physicians, of the efficacy of 'pedagogical treatment' for various morbid forms of disease such as deafness, paralysis, idiocy, rickets, etc. The fact that pedagogy must join with medicine in the treatment of disease was the practical outcome of the thought of the time. And because of this tendency the method of treating disease by gymnastics became widely popular. I, however, differed from my colleagues in that I felt that mental deficiency presented chiefly a pedagogical, rather than mainly a medical, problem. Much was said in the medical congresses of the medico-pedagogic method for the treatment and education of the feebleminded, and I expressed my differing opinion in an address on *Moral Education* at the Pedagogical Congress of Turin in 1898. I believe that I touched a chord already vibrant, because the idea, making its way among the physicians and elementary teachers, spread in a flash as presenting a question of lively interest to the school.

In fact, I was called upon by my master, Guido Baccelli, the great Minister of Education, to deliver to the teachers of Rome a course of lectures on the education of feeble-minded children. This course soon developed into the State Orthophrenic School, which I directed for more than two years.

In this school we had an all-day class of children composed of those who in the elementary schools were considered hopelessly deficient. Later on, through the help of a philanthropic organisation, there was founded a Medical Pedagogic Institute where, besides the children from the public schools, we brought together all of the idiot children from the insane asylums in Rome.

I spent these two years with the help of my colleagues in preparing the teachers of Rome for a special method of observation and education of feeble-minded children. Not only did I train teachers, but what was much more important, after I had been to London and Paris for the purpose of studying in a practical way the education of deficients, I gave myself over to the actual teaching of the children, directing at the same time the work of the other teachers in our institute.

I was more than an elementary teacher, for I was present, or directly taught the children, from eight in the morning to seven in the evening without interruption. These two years of practice are my first and indeed my true degree in pedagogy. From the very beginning of my work with deficient children (1898 to 1900) I felt that the methods which I used had in them nothing peculiarly limited to the instruction of idiots. I believed that they contained educational principles *more rational* than those in use, so much more so, indeed, that through their means an inferior mentality would be able to grow and develop. This feeling, so deep as to be in the nature of an intuition, became my controlling idea after I had left the school for deficients, and, little by little, I became convinced that similar methods applied to normal children would develop or set free their personality in a marvellous and surprising way.

Source: Montessori, Maria. 1912. George, Anne E., trans. *The Montessori Method.* New York: Frederick Stokes Company. Available at: http://www.moteaco.com/method/method.html

Isabelle Thompson Smart, from *Studies in the Relation of Physical Inability and Mental Deficiency to the Body Social* (1912)

Isabelle Thompson Smart, MD, was the Medical Examiner of Mentally Defective Children to the Department of Education in New York City. Smart wrote numerous eugenics tracts seeking to enlist pediatricians in the task of identifying and reporting potentially "defective" children to social work agencies. Her work demonstrates the prominent role of female professionals in the eugenics intelligentsia. The excerpt below demonstrates efforts in the medical arena by women to apply a more empirical and hard-hitting diagnostic gaze; this involvement by women differs radically from that of the more maternal social workers whom H. H. Goddard believed to be the most effective for assessments and information-gathering tasks.

Emerson once said that "Nothing great was ever achieved without enthusiasm" and perhaps we have here the crux of our problem for the care and training of the mental defective. Certainly, up to within a very short time ago there was no very definite or marked enthusiasm over either the physical or mental qualifications of the ament. The less said about this class of society the better pleased people seemed to be, and, as for our lawmakers and those whose duty it was to make adequate provision for these unfortunates and protect them by the much vaunted "strong arm of the law," they have time and again turned a deaf ear to any plea which was made in their behalf, and we are now reaping in a large harvest of shame and crime as a just reward for the general ignorance and neglect of them.

I have chosen, somewhat at random, a group of 10,000 cases which have been presented to me for medical examination, to determine their physical and mental fitness for the work required of them in the school grades. In every instance the child had fallen behind others of his or her age and grade and had continued to retrogress for some terms. In every instance I found positive physical defects, and, with many, combination of physical unfitness with a serious mental defect, which demanded a proper segregation of the case in question. Oft times the improvable cases had become discouraged because of the ever constant inability to cope with the tasks set by the curriculum, discouragement when the little brother or sister, perhaps years younger than our weakling, was able to reach the same grade with our defective and in a term pass ahead to a higher grade, receiving the praise of parents and teachers, while our unfortunate received the on demand berating which he should never have been called upon to bear. Today the outlook for such a child is a little more favorable, for the sleepiest teachers now have had borne in upon them the fact that there are children who are wholly incapable of doing grade work, and that very many are unable to do even the manual work.

Ten thousand cases! Ten thousand little human beings so seriously handicapped that they will never be able to enter fully into competition in order to earn a livelihood—so seriously handicapped that the major number should be segregated, and marriage and procreation be absolutely denied them.

The greater number of the physical defects could be very much bettered—many of them cured—but the mental unfitness is irreparable. Up to a certain point, all of these cases could be trained to become useful units in a colony life, suited to their individual needs and under proper supervision; but if left to drift, after their brief term of school life ends, will in large measure become derelicts, and will, in time, fill our penal institutions and our homes for fallen women or worse, live at large and procreate their kind in large numbers.

Not a single low-grade case of imbecility or idiocy has been included in the number of cases presented; all would fall within the limits of middle grade and morons.

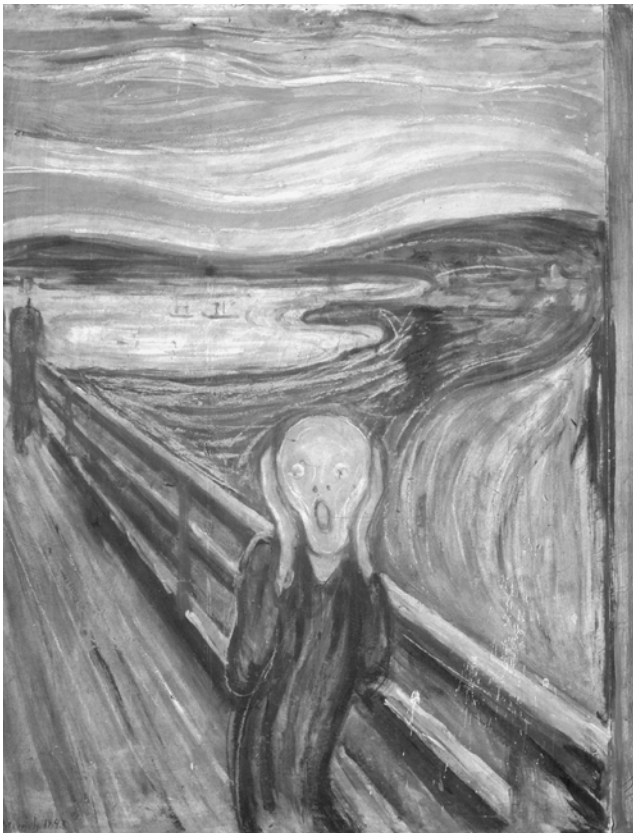
All of the low-grade cases of idiocy, imbecility, and Mongolianism should, without any question, be placed where they may be protected from society and from themselves; but the number is so great in the city and State of New York that adequate provision is, at present, and for some years to come entirely out of the question. . . .

Perhaps one of the most interesting phases of my work has been the attempt to tabulate the nations represented by the children sent up to me for these special examinations. It is only in the natural sequence of the manner of growth of our population that a very large percentage of the cases of mental defect should be found among our alien population, for in such a cosmopolitan city as New York nearly all nations send representatives—one might say misrepresentatives, for, surely, no mental derelict can truly be said to represent his or her native land. Up to the present and, at this time, one cannot tell what changes may occur—the two nations which may be said to lead all others are Russia and Italy. For a long time Russia was first on the list, but now Italy has come up to her and has even surpassed her by a fraction of 1 percent. The German Empire and Austria have contributed no small number, while Britain sends her quota, Ireland leading, followed by England and Scotland; Wales has not contributed any subject for my study. The other countries contributing their quota have been Poland, Scandinavia, France, Bohemia, Romania, Spain, Turkey, Switzerland, Syria, Greece, Arabia, Canada, West Indies, and, of the South American countries, Brazil.

These studies of our urban population are in no way complete, nor can they become so for a very long time, because of the inadequacy of the number employed in making these investigations. The need for more physicians who are specializing in this particular field of research is great, and their work should be augmented by that of an earnest, intelligent corps of social workers, whose time would be entirely devoted to the ferreting out of the kind of statistics which will prove of paramount value.

The hygienic relation of persons of such lowered physical and mental stamina to the body social, it seems to me, is so apparent as to make a summing up practically unnecessary. Surely no one in this audience needs to be prodded to do his duty in seeking the proper housing, proper segregation, and right and just laws for the unfortunate class of individuals we have had under consideration.

What we need in the United States of America is a realizing sense by our thinking people of the enormity of the problem which confronts us. Our immigration problem is tremendous. Gladly do we welcome the poor amid the downtrodden of other nations, but we must be firm in our exclusion of the mentally unfit. Our work there must go on not only at our ports of entry, but at the points of embarking, and the steamship companies must be held responsible for their unprincipled part in the bringing over, under much hardship, of so many cases of mental and physical unfitness.



The Scream *(1893), by Edvard Munch (1863–1944). Munch's painting* The Scream *portrays a figure that is often taken as a quintessential expression of modernity. Munch himself writes that he experienced intense fear during a moment of isolation while on an evening walk: "My friends walked on—I stood there, trembling with fear. And I sensed a great, infinite scream pass through nature." Wavy lines and a red sky capture the sensation of terror he describes, and Munch's effort to capture his own feelings of besiegement by emotions struck a cord of sentiment for many at the time.*

Source: Art Resource, New York.

Without a doubt we will always have the "ament" and the physical defective with us, for so long as we disobey the laws of hygiene and of health we must expect at least a part of the punishment meted out on the innocent offspring. It is largely dependent on those of us who are alive to the immenseness of the problem and who are in vital touch with it to make our voices heard whenever and wherever we find opportunity to do so. We must even make these opportunities, and we must have our law makers become familiar with the class of cases herein described.

They must be made cognizant of the conditions producing such defectives, and then made intelligent as to the direful consequences of legalizing the propagation of the unfit.

The task is stupendous, but if all interested will loyally pull together for the common good of humanity I am hopeful that we may accomplish much. "Nothing great was ever achieved without enthusiasm."

Percental chart of 10,000 cases showing relative physical defects.

Chorea	4.0
Epilepsy	5.1
Heart	29.9
Nose	34.9
Throat	42.6
Neurotic	37.0
Sex	41.5
Speech	42.0
Ears	48.3
Dental	71.4
Indicating general medical care	74.3
Eyes	95.3
Needing residential hospital care	6.9
Needing special open-air school	3.5

Percental chart of 10,000 cases children born in foreign countries.

Italy	15.3
Russia	15.1
Germany	7.7
Austria	3.5
Ireland	3.3
England	.9
Roumania	.8
Scandinavia	.7
Polish Jews	.5
Bohemia	.5
France	.1
Scotland	.1
Greece	.07
West Indies	.07
Turkey	.07
Spain	.06
Syria	.06
Canada	.04
Switzerland	.03
Holland	.03
Brazil	.03
Cuba	.01
Arabia	.01
Unknown or mixed parentage	8.3

Percental chart of 10,000 cases children born in the United States.

Russian parentage	20.5
Italian parentage	18.9
German parentage	13.9
Irish parentage	7.1
Austro-Hungarian parentage	5.8
English parentage	1.9
Scandinavian parentage	1.4
Roumanian parentage	1.1
Bohemian parentage	1.0
Polish parentage	.7
Scotch parentage	.3
French parentage	.2
Spanish parentage	.1
Swiss parentage	.1
West Indian parentage	.1
Turkish parentage	.07
Dutch parentage	.07
Greek parentage	.07
Syrian parentage	.07
Brazilian parentage	.04
Cuban parentage	.04
Arabian parentage	.01
American (whites and negroes)	17.3

Note: 25.42 percent of all cases were of foreign extraction; 48.05 percent of all cases were American born of mixed foreign parentage.

Source: Smart, Isabelle Thompson. 1912. *Studies in the Relation of Physical Inability and Mental Deficiency to the Body Social.* From the Smith Ely Jeliffe Collection, proprietor Dr. David Braddock, University of Colorado, Boulder.

Henry H. Goddard, "The Improvability of Feeble-Minded Children" (1913)

Henry H. Goddard (1866–1957) served as director of the Vineland Training Center for Feebleminded Boys and Girls in New Jersey between 1906 and 1918. An ardent eugenicist who believed that "feeblemindedness" was hereditary, Goddard believed that intelligence could be scientifically measured, because mental capacity was fixed and finite. To measure intelligence, he translated and adapted Binet's Intelligence Test in order to diagnose adolescent residents under his charge at Vineland. However, in order to show the test's wider validity, he also applied it to immigrants at Ellis Island and to U.S. army recruits. He was hired as *a consultant by the New York Public Schools regarding the placement of students into special learning tracks. Ultimately, Goddard renounced many of the positions he had touted for decades in various eugenics contexts.*

How improvable is a feeble-minded child? This question is so fundamental, and so much depends upon the answer to it, that it is no wonder it has been the burning question since the care of the feeble-minded became common. Historically it has played no small part in the progress of the institutional care of these defectives. For years and years it was believed that nothing could be done for them and consequently nothing was done. Then, under the inspiration of the immortal Séguin it was discovered much could be done, and it is no wonder that in the enthusiasm of that discovery many went to the opposite extreme and believed that they could even be cured.

It is somewhat unfortunate that today there are certain belated travelers along the road who will talk of curing feeble-mindedness, while the impossibility of the cure of this condition has long been demonstrated. The question of improvability has had its ups and downs from the time of Séguin until the present. Today we might be said to be in the blackness of confusion. We think feeble-mindedness is improvable, from one standpoint; considering it in another way, we conclude it is not.

We know that there is a time when the feeble-minded have reached their limit, and our institutions are largely filled with individuals who are known to have long since passed their limit of improvement. In the case of younger children we still talk about improvable and unimprovable cases. In the case of any particular individual there is or has been in the past, very little dispute among those who know the case. More recently we have been led to question this, and we at Vineland, have had some dispute as to whether a group of children was improving or not improving.

Viewed from the standpoint of our usual definition of arrested development, the question is: are these persons already arrested in their development, or are they only in the process of arrest? And if the latter, how long does this process continue, and what is its method? Does a child develop at a normal rate up to a certain point and then suddenly stop, or does he develop slowly from birth up to a certain age, and then stop? Or again, does he develop at a normal rate for a few years, and then take a few years in which he keeps getting more and more backward, continually slowing down and finally stopping?

Whatever theories there may have been in answer to these questions, there have never been so far as the writer knows, many facts to substantiate the position until the present time. The reason for this lack of data is, that we never had any adequate means of measuring the mental development of a child at any one time. That difficulty has now been remedied through the Binet-Simon Measuring Scale of Intelligence, and on the basis of this we are now able to present data which seem to go a long way toward answering the question. This scale of intelligence has been in use at Vineland for two years, thereby giving us three annual testings. Upon a study of these results we ought to be able to answer the question, “How many children are improving and how many are standing still?” We had hoped to be able to do this after one year, but we found that there was considerable variability, which experience taught us was entirely normal with feeble-minded children, they doing one day what they cannot do the next, or vice versa; so that we are compelled to wait for the end of the second year giving us the third testing before we could draw any definite conclusion. The facts here presented are based upon the examination of three hundred forty-six children of both sexes, of mental ages from one to twelve, and physical ages from five to forty, with a few beyond this upper limit.

We have had three annual testings by the Binet scale, the result is that from the first to the last testing, two years apart, one hundred and nine persons have made no variation whatever not even a point. This is thirty-two per cent. If we add to this those who have gained or lost one or two points, we have two hundred thirty-two individuals, or about sixty-seven percent whose variation is so slight that it must be considered accidental. The remaining 33 percent have gained or lost three points or more. If we subtract those who have lost, we have left ninety-six persons or twenty-eight percent who at first sight seem to have made some definite progress. Closer examination, however convinces us that some part of this is due to what we have sometimes called the normal variation of the abnormal mind; in other words, that it is somewhat an accident, perhaps of attention, as to whether a child answers one question more or one question less than he did on a former occasion.

A fact which makes us believe that much of this is due to accidental variation, is that these changes occur quite as often in the older persons, who, no one of experience, believes is actually increasing in mentality, as they do among those of the younger years where we might more naturally expect it. These data wait further analysis and study, and the application of further studies, but it seems to be pretty clearly indicated that the vast majority of feeble-minded children are not changing and are not improving in their intellectual level; if there is an improvement it seems to be during the mental ages of three to nine inclusive. Among the idiots, for example, it is very low indeed; here are the figures for the idiots, that is, those having a mentality of one or two.

1. Of twenty-one idiots testing one year mentally, only one is able to do any of the Binet. He (a boy of fifteen) has from the first testing, known his eyes and mouth but has made no improvement. All have stood still. That is, twenty-one idiots, mentality one, age eight to thirty-eight, have made no progress.

2. Of thirty idiots testing two years mentally, twenty-seven, ages ten to thirty six, have not changed; three, aged respectively eleven, twelve and seventeen have learned one point in the Binet.

Of twenty-five idiots testing 2 1–5 to 2 4–5, fifteen have not varied except when the test was given by inexperienced persons and a retesting brought back the former grading. These fifteen range in age from seventeen to thirty six. One, aged thirty, has lost one point, 2 2–5 to 2 1–5, and five aged fourteen to twenty-one, have gained one to three points, none reaching higher than 2 4–5 by this gain. [Goddard's application of IQ scoring was intended to assess the mental age of the person examined, as distinct from chronological age. According to his theory, the mental capacities of "subnormals" became prematurely arrested and no amount of training/education could improve them.]

The remaining four started two years ago with a "potentiality" for three years mentality and have advanced as follows:

F. 14—2 2–5 to 3 2–5.
F. 15—2 3–5 to 3.
F. 16—2 3–5 to 3.
M. 12—2 4–5 to 3 1–5.

The conclusion that we are thus forced to accept, namely, that a very small percentage of feeble-minded children is making any mental improvement, is both surprising and somewhat discouraging, and will even be rejected by some as certainly fallacious; for do we not know that they are improving? Do we not see them improving every day? Are they not learning to do things?

The great group of the so called improvable children are doing things to-day that they could not have done a year ago. This is most certainly true, and in this fact lies our excuse for our institutions with their training departments. Nevertheless it is not difficult to show that this is not incompatible with the conclusion drawn from our data. To make this clear it is only necessary to call attention to the difference between what we may call trainability and raising the intellectual level.

A normal boy of eight, for example, has what we may call for convenience, eight-year-old intelligence; his intelligence is not yet as high as that of a normal boy of nine, still less of ten, but he can do certain things, namely those things which involve nothing more than eight-year-old intelligence. He cannot do anything that involves nine-year-old intelligence or anything higher. Now the normal boy is of eight-year intelligence only one year, and then he becomes nine years old and does the things that involve nine-year intelligence. Then he becomes ten years, and so on, until he reaches his complete development. But the feeble-minded boy who is arrested in his development at the age of eight remains with a mentality of eight year after year. As the years go by he can never learn to do things that require nine or ten-year-old intelligence because he never has that much intelligence, but there is no limit to the number of eight-year-old things that he can learn to do. It is this trainability to do anything and everything that involves only eight-year-old intelligence that is generally mistaken for increase in intelligence itself; and this is the explanation of the misunderstanding when the psychologist says the child has not improved and the teacher says he has; the former means that he has not increased his mental level, the latter means that he has learned to do a number of things that he could not do a year ago. Both are correct. He has learned to do these things and he will continue to learn to do new things for a good many years, but he can never learn to do anything that requires a higher intelligence than that at which he was arrested in his development.

So far we have not answered the question, "How does the child reach his point of arrested development?" Is it by a gradual slowing down or by a sudden stop? Nor can we answer this question surely, as yet. Perhaps it is a matter of the individual. Some develop one way and some another. The full answer to this part of the question must wait further study.

There are some indications, however, that some children arc pretty nearly normal until about eight or nine or ten years of age, and then they stop rather suddenly. For example, children test normal at six, and defective at ten never having developed beyond seven. Or defective at twelve, not having developed beyond nine. Others seem to have always been a little backward, but kept getting more and more backward until the age perhaps of nine or ten, when they seem to have entirely stopped. It must be possible to measure the rate of progress sometime when our psychological methods become more complete. . . .

The capacity for learning at the different ages during the evolutionary period might be likened to tin cups of uniform diameter but varying in height. The short cup can not be made to hold more than its capacity, so no amount of training will enable the child of a low mental age—the short cup—to perform the things which only a person of higher mental age—the long cup—can learn. On the other hand there are things that a child of any given mental age can learn to do,—the number increasing with the advance of mental age to the end of the period of mental evolution.

Source: Goddard, Henry H. 1913. "The Improvability of Feeble-Minded Children." *Journal of Psycho-Asthenics* 17(4). From the Smith Ely Jeliffe Collection, proprietor Dr. David Braddock, University of Colorado, Boulder.

Sigmund Freud, from "On Narcissism: An Introduction" (1914)

Freud develops his concept of narcissism, the pathological focus on one's own person to the exclusion of others, through the example of pain. Pain and suffering supposedly steal a person's interest in other people, thereby approximating the pathological selfishness called narcissism.

It is universally known, and we take it as a matter of course, that a person who is tormented by organic pain and discomfort gives up his interest in the things of the external world, in so far as they do not concern his suffering. Closer observation teaches us that he also withdraws *libidinal* interest from his love-objects: so long as he suffers, he ceases to love. The commonplace nature of this fact is no reason why we should be deterred from translating it into terms of the libido theory. We should then say: the sick man withdraws his libidinal cathexes back upon his own ego, and sends them out again when he recovers. 'Concentrated is his soul,' says Wilhelm Busch of the poet suffering from toothache, 'in his molar's narrow hole.' Here libido and ego-interest share the same fate and are once more indistinguishable from each other. The familiar egoism of the sick person covers both. We find it so natural because we are certain that in the same situation we should behave in just the same way. The way in which a lover's feelings, however strong, are banished by bodily ailments, and suddenly replaced by complete indifference, is a theme which has been exploited by comic writers to an appropriate extent.

Source: Freud, Sigmund. 1953–1964. "On Narcissism: An Introduction." Pp. 82–83 in Strachey, James, ed. *Psychological Works of Sigmund Freud, Vol. 14.* London: Hogarth Press. (Originally published 1914)

Sigmund Freud, from *Some Character-Types Met with in Psycho-Analytic Work* (1916)

Freud explains that pain and physical deformity produce a feeling of extraordinariness in people with disabilities to the point where they may believe that moral laws obeyed by other people do not apply to them. Freud offers the example of Richard III as a disabled person who believes that life's rules do not govern his behavior because he deserves compensation for his suffering. Feelings of being disadvantaged, Freud argues, lead to pathological egotism.

Psycho-analytic work is continually confronted with the task of inducing the patient to renounce an immediate and directly attainable yield of pleasure. He is not asked to renounce all pleasure; that could not, perhaps, be expected of any human being. . . . No, the patient is only asked to renounce such satisfactions as will inevitably have detrimental consequences. His privation is only to be temporary; he has only to learn to exchange an immediate yield of pleasure for a better assured, even though a postponed one. Or, in other words, under the doctor's guidance he is asked to make the advance from the pleasure principle to the reality principle by which the mature human being is distinguished from the child. . . .

When in this way one asks the patient to make a provisional renunciation of some pleasurable satisfaction, to make a sacrifice, to show his readiness to accept some temporary suffering for the sake of a better end, or even merely to make up his mind to submit to a necessity which applies to everyone, one comes upon individuals who resist such an appeal on a special ground. They say they have renounced enough and suffered enough, and have a claim to be spared any further demands; they will submit no longer to any disagreeable necessity, for they are exceptions and, more over, intend to remain so. . . .

Now it is no doubt true that everyone would like to consider himself an ‘exception’ and claim privileges over others. But precisely because of this there must be a particular reason, and one not universally present, if someone actually proclaims himself an exception and behaves as such. This reason may be of more than one kind; in the cases I investigated I succeeded in discovering a common peculiarity in the earlier experiences of these patients’ lives. Their neuroses were connected with some experience or suffering to which they had been subjected in their earliest childhood, one in respect of which they knew themselves to be guiltless, and which they could look upon as an unjust disadvantage imposed upon them. . . . In one of these patients, a woman, the attitude towards life which I am discussing came to a head when she learnt that a painful organic trouble, which had hindered her from attaining her aims in life, was of congenital origin. So long as she looked upon this trouble as an accidental and late acquisition, she bore it patiently; as soon as she found that it was part of an innate inheritance, she became rebellious. The young man who believed that he was watched over by a special providence had in his infancy been the victim of an accidental infection from his wet-nurse, and had spent his whole later life making claims for compensation, an accident pension, as it were, without having any idea on what he based those claims. In this case the analysis, which constructed this event out of obscure mnemic residues and interpretations of the symptoms, was confirmed objectively by information from his family.

For reasons which will be easily understood I cannot communicate very much about these or other case histories. Nor do I propose to go into the obvious analogy between deformities of character resulting from protracted sickliness in childhood and the behaviour of whole nations whose past history has been full of suffering. Instead, however, I will take the opportunity of pointing to a figure created by the greatest of poets—a figure in whose character the claim to be an exception is closely bound up with and is motivated by the circumstance of congenital disadvantage.

In the opening soliloquy to Shakespeare’s *Richard III,* Gloucester, who subsequently becomes King, says:

> But I, that am not shaped for sportive tricks,
> Nor made to court an amorous looking-glass;
> I that am rudely stamp’d, and want love’s majesty
> To strut before a wanton ambling nymph;
> I, that am curtail’d of this fair proportion,
> Cheated of feature by dissembling Nature,
> Deform’d, unfinish’d, sent before my time
> Into this breathing world, scarce half made up,
> And that so lamely and unfashionable,
> That dogs bark at me as I halt by them;
> . . . .
> And therefore, since I cannot prove a lover,
> To entertain these fair well-spoken days,
> I am determined to prove a villain,
> And hate the idle pleasures of those days.

At a first glance this tirade may perhaps seem unrelated to our present theme. Richard seems to say nothing more than: ‘I find these idle times tedious, and I want to enjoy myself. As I cannot play the lover on account of my deformity, I will play the villain; I will intrigue, murder and do anything else I please.’ Such a frivolous motivation could not but stifle any stirring of sympathy in the audience, if it were not a screen for something much more serious. Otherwise the play would be psychologically impossible, for the writer must know how to furnish us with a secret background of sympathy for his hero, if we are to admire his boldness and adroitness without inward protest; and such sympathy can only be based on understanding or on a sense of a possible inner fellow-feeling for him.

I think, therefore, that Richard’s soliloquy does not say everything; it merely gives a hint, and leaves us to fill in what it hints at. When we do so, however, the appearance of frivolity vanishes, the bitterness and minuteness with which Richard has depicted his deformity make their full effect, and we clearly perceive the fellow-feeling which compels our sympathy even with a villain like him. What the soliloquy thus means is: ‘Nature has done me a grievous wrong in denying me the beauty of form which wins human love. Life owes me reparation for this, and I will see that I get it. I have a right to be an exception, to disregard the scruples by which others let themselves be held back. I may do wrong myself, since wrong has been done to me.' And now we feel that we ourselves might become like Richard, that on a small scale, indeed, we are already like him. Richard is an enormous magnification of something we find in ourselves as well. We all think we have reason to reproach Nature and our destiny for congenital and infantile disadvantages; we all demand reparation for early wounds to our narcissism, our self-love. Why did not Nature give us the golden curls of Balder or the strength of Siegfried or the lofty brow of genius or the noble profile of aristocracy? Why were we born in a middle-class home instead of a royal palace? We could carry off beauty and distinction quite as well as any of those whom we are now obliged to envy for these qualities.

Source: Freud, Sigmund. 1953–1964. Ch. 1, "The Exceptions," in *Some Character-Types Met with in Psycho-Analytic Work.* Pp. 311–315 in Strachey, James, ed. *Psychological Works of Sigmund Freud, Vol. 14.* London: Hogarth Press. (Originally published 1916)

▣ D. Amaury Talbot, from *Woman's Mysteries of a Primitive People: The Ibibios of Southern Nigeria* (1915)

This is an ethnography of the Ibibio, a Nigerian tribe. Written by a pioneering Englishwoman in the early twentieth century, this book focuses on the ritual life of women. Despite the naive colonialist attitude, it presents a female perspective that was seldom seen in the ethnographic literature of the period.

From Chapter III. "Birth Customs"

In that part of the district which lies round Awa a reason is given for the killing of twins which is quite unconnected with any idea as to demoniacal origin. The following is the local account of the cause of the custom:

> The first pair of twins sent to Earth, so our mothers tell, unfortunately came to the dwelling of a family poor and of little account. When news of their arrival reached the neighbouring chiefs and members of great houses, these gathered together in much anxiety at such an unprecedented occurrence, and consulted as to what should be done. "Behold," said they, "this woman first bore one child. Now she has given birth to two together; should she continue to go on in the way in which she has begun, next time she may bear four, and after that six or even eight, and so on until her family surpasses any of ours. If poor people are allowed to grow 'strong' at such a rate, what will become of us? We shall have no chance to seize their property on the death of the head of their house, nor to force them to serve us as before when their family was small and of little account and there was none to take their part."

That, so our grandmothers tell, is the reason why the murder of twins was started in the Awa country. Had the first twins come to a rich or powerful family there would have been no killing.

> Not long afterwards the king's head wife also gave birth to a boy and a girl, and a meeting of the townsfolk was called to discuss the matter. The king and his relatives tried their utmost to save the lives of the babes, but the poor folk combined and said, "They shall be killed, as were those of our women." The more the rich strove to save the chief's twin children, the more did the poor insist upon their death, crying, "As you did to us and our babes, so will we do also unto you and yours." That is the reason why twin children were killed even unto our own day. In the country round Awa, however, no "twin mother" is ever put to death, only driven forth from her town.

With this fear before their eyes, it is natural that women about to become mothers should consult a native doctor some time before the expected birth of their babes in order to learn from him if there is any probability of the arrival of twins. Should he answer in the affirmative, medicine is given by which the danger may be averted.

Next to the dread of becoming a mother of twins looms that of bearing a child into whose body some evil spirit has entered. This may be that of ancestor or kinsman undesirable on account of bodily or mental deformity, or because they come from a family tainted with "witchcraft."

So-called "birth-marks" seem to be quite common among this people, although such are here attributed to causes different from those assigned them in northern climes. An Ibibio baby is eagerly scanned for any sign that may reveal the identity of the indwelling Ego. Parents often notice some likeness to a dead friend, or trick of speech or movement in a child that to their minds shows that it is an old spirit reborn in some new body. A striking example of the way in which such deductions are made happened at Ndiya about ten years ago, and was told as follows:

"Patients' Examination" during a mission studying sleeping sickness in French Congo (1907). Colonial infiltration by European powers around the globe was often accompanied by medical studies of native populations. Of particular interest were indigenous diseases that also affected European immigrants residing in these locations. Here, resident people are examined by medical authorities to better understand the nature of sleeping sickness among residents of the Congo.

Source: Art Resource, New York.

> A man named Osim Essiet married a wife, and a little while before the birth of their first child he was attacked by an enemy and left lying in the bush with his head severed from his body. When he did not return, friends set out to look for him. After some time they found the corpse, bore it home and laid it upon a native bed. When the young wife saw this horrible sight, she cried out and flung herself down by the side of the body, calling upon the name of her husband and entreating him not to leave her.
>
> Some weeks afterwards the child was born. Round his neck was the mark as of a line at the place where his father's head had been severed, and, indeed, his neck is still shorter than that of most people. The townsfolk noticed this peculiarity, and felt sure, because of it, that the boy was really Osim Essiet himself come back to life again because he loved his wife very dearly and in answer to her entreaties that she might not be left alone. They therefore gave him, in his new incarnation, the same name as he had borne before.

A somewhat similar case happened at Ikott Atako, near Eket, and is thus related:

> There was once a woman of this town, Etuk Nkokk by name, who, not long after she had left the Fatting-house, bore a boy. At first the babe was like other children save that he was very weak, but as the years went on he hardly seemed to grow at all, and by the age of twenty was not quite four feet high. One day his mother went out and noticed the fine strong children born to her neighbors. When she came home, she looked gloweringly at her sickly son and said, "No other woman has a child like you! I wish you might die that I may be no more shamed by the sight of you!" Not long afterwards the boy sickened and died, and before they brought the coffin in which to lay him for burial the mother said to herself: "This piccan gave me too much trouble! I wish to find some way of punishing him and preventing him from returning to life." So she took thought, and at length cut off his right hand, saying to herself, "Now he will surely be ashamed, and not come back into my family any more."
>
> A few months later another child was born, but lo! it was the same boy come back again, as was plain to be seen because he had only one hand. When the people went to see the mother and the new-born babe, they recognized him at once for the one who had died, and, seeing the handless wrist, asked "How could you do such a cruel thing to your firstborn?" She answered, "It was because I did not want him to come back again, and thought he would be ashamed to show himself among us thus maimed." The people said, "It is a misfortune, but it cannot be helped! This is your punish-

> ment, and you must just do your best for him." So the woman took their advice and did everything possible for the child, in consequence of which he grew up and is still alive, a little taller than during his first earth-life, but smaller than other men.

The mother of Chief Henshaw of Oron regards him as an example of reincarnation. The name Nyung, by which he is everywhere known among black people, means "thrice born"—an appellation which she gave him because her two first babes had died, and she believed that at his birth the same spirit came back once more; this time, not in vain.

The dread of the return of "wandering souls," who reincarnate only to bring trouble upon the family into which they have chosen to come, is common over the greater part of West Africa. Mary Kingsley thus describes the way in which parents seek to protect themselves against the infliction of these annoying spirits:

> When two babes in a family have previously died in suspicious circumstances the father takes the body of the third baby which has also died in the same way and smashes one of its leg bones before it is thrown away into the bush; for he knows he has got a wanderer soul—namely a *sisa*. . . . He just breaks the leg so as to warn the soul he is not a man to be trifled with, and will not have his family kept in a state of perpetual uproar and expense. It sometimes happens, however, in spite of this that when his fourth baby arrives that too goes off in convulsions. Thoroughly roused now, paterfamilias sternly takes a chopper, and chops that infant's remains extremely small, and it is scattered broadcast. Then he holds he has eliminated that sisa from his family.

I am informed, however, that the fourth baby to arrive in a family afflicted by a *sisa* does not usually go off in convulsions, but that fairly frequently it is born lame, which shows that it is that wanderer soul back with its damaged leg.

Source: Talbot, D. Amaury. 1915. Pp. 36–41 in *Woman's Mysteries of a Primitive People: The Ibibios of Southern Nigeria*. Available at: http://www.sacred-texts.com/afr/wmp/wmp00.htm

▣ Frank B. Linderman, from *Indian Why Stories* (1915)

Indian "Why Stories" were collected, translated, and written down by European missionaries and early ethnographers. They presumably helped to capture what was often pejoratively thought of as aboriginal folklore by Native American tribes in North America. The stories attempt to explain physical or cognitive differences that exist among people and other species.

How The Ducks Got Their Fine Feathers

Another night had come, and I made my way toward War Eagle's lodge. In the bright moonlight the dead leaves of the quaking-aspen fluttered down whenever the wind shook the trees; and over the village great flocks of ducks and geese and swan passed in a never-ending procession, calling to each other in strange tones as they sped away toward the waters that never freeze.

In the lodge War Eagle waited for his grandchildren, and when they had entered, happily, he laid aside his pipe and said:

"The Duck-people are travelling to-night just as they have done since the world was young. They are going away from winter because they cannot make a living when ice covers the rivers.

"You have seen the Duck-people often. You have noticed that they wear fine clothes but you do not know how they got them; so I will tell you to-night.

"It was in the fall when leaves are yellow that it happened, and long, long ago. The Duck-people had gathered to go away, just as they are doing now. The buck-deer was coming down from the high ridges to visit friends in the lowlands along the streams as they have always done. On a lake Old-man saw the Duck-people getting ready to go away, and at that time they all looked alike; that is, they all wore the same colored clothes. The loons and the geese and the ducks were there and playing in the sunlight. The loons were laughing loudly and the diving was fast and merry to see. On the hill where Old-man stood there was a great deal of moss, and he began to tear it from the ground and roll it into a great ball. When he had gathered all he needed he shouldered the load and started for the shore of the lake, staggering under the weight of the great burden. Finally the Duck-people saw him coming with his load of moss and began to swim away from the shore.

"'Wait, my brothers!' he called, 'I have a big load here, and I am going to give you people a dance. Come and help me get things ready.'

"'Don't you do it,' said the gray goose to the others; 'that's Old-man and he is up to something bad, I am sure.'

"So the loon called to Old-man and said they wouldn't help him at all.

"Right near the water Old-man dropped his ball of moss and then cut twenty long poles. With the poles he built a lodge which he covered with the moss, leaving a doorway facing the lake. Inside the lodge he built a fire and when it grew bright he cried:

"'Say, brothers, why should you treat me this way when I am here to give you a big dance? Come into the lodge,' but they wouldn't do that. Finally Old-man began to sing a song in the duck-talk, and keep time with his drum. The Duck-people liked the music, and swam a little nearer to the shore, watching for trouble all the time, but Old-man sang so sweetly that pretty soon they waddled up to the lodge and went inside. The loon stopped near the door, for he believed that what the gray goose had said was true, and that Old-man was up to some mischief. The gray goose, too, was careful to stay close to the door but the ducks reached all about the fire. Politely, Old-man passed the pipe, and they all smoked with him because it is wrong not to smoke in a person's lodge if the pipe is offered, and the Duck-people knew that.

"'Well,' said Old-man, 'this is going to be the Blind-dance, but you will have to be painted first.

"'Brother Mallard, name the colors—tell how you want me to paint you.'

"'Well,' replied the mallard drake, 'paint my head green, and put a white circle around my throat, like a necklace. Besides that, I want a brown breast and yellow legs: but I don't want my wife painted that way.'

"Old-man painted him just as he asked, and his wife, too. Then the teal and the wood-duck (it took a long time to paint the wood-duck) and the spoonbill and the blue-bill and the canvasback and the goose and the brant and the loon—all chose their paint. Old-man painted them all just as they wanted him to, and kept singing all the time. They looked very pretty in the firelight, for it was night before the painting was done.

"'Now,' said Old-man, 'as this is the Blind-dance, when I beat upon my drum you must all shut your eyes tight and circle around the fire as I sing. Every one that peeks will have sore eyes forever.'

"Then the Duck-people shut their eyes and Old-man began to sing: 'Now you come, ducks, now you come—tum-tum, tum; tum-tum, tum.'

"Around the fire they came with their eyes still shut, and as fast as they reached Old-man, the rascal would seize them, and wring their necks. Ho! things were going fine for Old-man, but the loon peeked a little, and saw what was going on; several others heard the fluttering and opened their eyes, too. The loon cried out, 'He's killing us—let us fly,' and they did that. There was a great squawking and quacking and fluttering as the Duck-people escaped from the lodge. Ho! but Old-man was angry, and he kicked the back of the loon-duck, and that is why his feet turn from his body when he walks or tries to stand. Yes, that is why he is a cripple to-day.

"And all of the Duck-people that peeked that night at the dance still have sore eyes—just as Old-man told them they would have. Of course they hurt and smart no more but they stay red to pay for peeking, and always will. You have seen the mallard and the rest of the Duck-people. You can see that the colors Old-man painted so long ago are still bright and handsome, and they will stay that way forever and forever. Ho!"

Source: Linderman, Frank, B. [Co Skee See Co Cot]. 1915. "How the Ducks Got Their Fine Feathers." In *Indian Why Stories: Sparks from War Eagle's Lodge-Fire.* Available at: www.e-book shop.gr/gutenberg/files/inwhy10.pdf

▣ Franz Kafka, from *The Metamorphosis* (1915)

Franz Kafka (1883–1924) was born in Prague, Czechoslovakia, to a middle-class Jewish family. His works are often characterized as expressing the essential alienation of the human condition at the beginning of the twentieth century. His experience of tuberculosis played a key role in the cultivation of his distinctive absurdist fictional style, in which characters suffer profoundly from social neglect. The excerpt here from one of his most celebrated stories, The Metamorphosis, *demonstrates his profound identification with individuals whose divergent bodies and minds result in their isolation from the rest of society. Kafka spent his final years moving in and out of sanatoriums that were often indicative of the impersonal bureaucracies of modern life that he critiqued.*

As Gregor Samsa awoke one morning from uneasy dreams he found himself transformed in his bed into a gigantic insect. He was lying on his hard, as it were armor-plated, back and when he lifted his head a little he could see his domelike brown belly divided into stiff arched segments on top of which the bed quilt could hardly stay in place and was about to slide off completely. His numerous legs, which were pitifully thin compared to the rest of his bulk, waved helplessly before his eyes. . . .

First of all he wanted to get up quietly, without any excitement; get dressed; and, the main thing, have breakfast, and only then think about what to do next, for he saw clearly that in bed he would never think things through to a rational conclusion. He remembered how even in the past he had often felt some kind of slight pain, possibly caused by lying in an uncomfortable position, which, when he got up, turned out to be purely imaginary, and he was eager to see how today's fantasy would gradually fade away. That the change in his voice was nothing more than the first sign of a bad cold, an occupational ailment of the traveling salesman, he had no doubt in the least.

It was very easy to throw off the cover; all he had to do was puff himself up a little, and it fell off by itself. But after this, things got difficult, especially since he was so unusually broad. He would have needed hands and arms to lift himself up, but instead of that he had only his numerous little legs, which were in every different kind of perpetual motion and which, besides, he could not control. If he wanted to bend one, the first thing that happened was that it stretched itself out; and if he finally succeeded in getting this leg to do what he wanted, all the others in the meantime, as if set free, began to work in the most intensely painful agitation. "Just don't stay in bed being useless," Gregor said to himself.

First he tried to get out of bed with the lower part of his body, but this lower part—which by the way he had not seen yet and which he could not form a clear picture of—proved too difficult to budge; it was taking so long; and when finally, almost out of his mind, he lunged forward with all his force, without caring, he had picked the wrong direction and slammed himself violently against the lower bedpost, and the searing pain he felt taught him exactly the lower part of his body was, for the moment anyway, the most sensitive.

He therefore tried to get the upper part of his body out of bed first and warily turned his head toward the edge of the bed. This worked easily, and in spite of its width and weight, the mass of his body finally followed, slowly, the movement of his head. But when at last he stuck his head over the edge of the bed into the air, he got too scared to continue any further, since if he finally let himself fall in this position, it would be a miracle if he didn't injure his head. And just now he had better not for the life of him lose consciousness; he would rather stay in bed.

But when, once again, after the same exertion, he lay in his original position, sighing, and again watched his little legs struggling, if possible more fiercely, with each other and saw no way of bring peace and order into this mindless motion, he again told himself that it was impossible for him to stay in bed and that the most rational thing was to make any sacrifice for even the smallest hope of freeing himself from bed. But at the same time he did not forget to remind himself occasionally that thinking things over calmly—indeed, as calmly as possible—was much better than jumping to desperate decisions. At such moments he fixed his eyes as sharply as possible on the window, but unfortunately there was little confidence and cheer to be gotten from the view of the morning fog, which shrouded even the other side of the narrow street. "Seven o'clock already" he said to himself as the alarm clock struck again, "seven o'clock already and still such a fog."

Source: Kafka, Franz. 1948. Muir, Edwin, and Willa Muir, trans. *The Metamorphosis.* In *The Penal Colony: Stories and Short Pieces.* New York: Schocken. (Originally published 1915)

▣ Ada M. Fitts, "Classes and Institutions" (1916)

This excerpt comes from a paper read at the National Conference of Charities and Correction, Indianapolis, Indiana, May 1916, and at the National Educational Association, New York City, July 1916. Ada M. Fitts was the Supervisor of Special Classes for Boston, Massachusetts. The essay identifies various scenarios for educating children diagnosed as feebleminded.

The problem of feeble-mindedness is very much before the public, and everywhere in this country, community surveys, the use of mental tests and studies of family histories are furnishing evidence that the feeble-minded are an increasingly important factor in all forms of social and educational work.

Along with the other agencies that are interested in finding a solution to this far reaching problem, the public school authorities have become aroused and are providing classes which it is hoped will furnish training for pupils who are not able to make good in the regular grades. Before discussing my subject: "How to Fill the Gap Between the Special Classes and Institutions," I wish to review what the public schools have attempted to do in preparation for this time of leaving school. It is generally believed that the special

Photograph of Auguste Renoir at his easel (1914). From 1898 onward, Renoir (1841–1919) experienced bouts of rheumatoid arthritis, which ultimately worked its way to his legs and hands. He continued to paint, often in his studio from his bed, while wedging his brushes between his fingers or binding them with tape. As his paralysis increased, he turned from painting to sculpture, where he would employ an assistant to form the clay to his specifications.

Source: Art Resource, New York.

class is the first step in the attempt to solve the problem. Its function is first: to educate the community and the teachers of normal children to realize the situation; second: to seek out the feeble-minded children and help them, and by so doing, help the normal children who have been retarded; third: to relieve the teacher who gives perhaps thirty percent, of her energy to the few feeble-minded pupils she may have. This energy is taken from her normal pupils and does not materially benefit the feeble-minded, as only in the special class can we do our best for these children; fifth, to secure justice to society, for it is a matter of social justice that the feeble-minded be recognized and trained as far as it is possible to do so.

The pupils should be selected by a trained expert who uses a combination of tests and who will win the confidence of parents as well as give a diagnosis of the child's mental and physical condition. In many places the high grade improvable feeble-minded children have been selected by such experts and then placed in classes under the direction of trained teachers. The number of pupils in a class is wisely limited to fifteen to a teacher, and through individual work she tries to fit her pupils for adult life. Special classes take feeble-minded children as early as possible—say—from seven to eight years of age. Some eventually return to grade and are able to complete a part of the fourth grade work; a few more are transferred directly to the institution; but the majority should remain in special classes till they reach the school age limit.

Three methods have been adopted: first, to have the special class occupy a room in an elementary school building and care for the mentally defective children of that immediate district; second, to group these pupils in a central school; and third, a combination of both individual classes and centers. In Massachusetts until recently, children were allowed to leave school at fourteen, but with the raising of the compulsory school age limit to sixteen, we found ourselves (two years ago) face to face with the problem of what to do with the special class children who must remain in school until they are sixteen years of age. In Boston in order to provide the next necessary step beyond the individual class, the regular grade pupils occupying two six-room buildings, were accommodated elsewhere and these buildings were used as centers: one for special class girls and another for special class boys. Pupils for these centers were selected from individual classes all over the city (one or two from each) as their fitness to profit by this special advantage was recognized. The separation of the sexes has proved to be of distinct advantage both to pupils and teachers, thus adding to the efficiency of the work. Little difficulty has been experienced thus far in transportation over long distances, the city paying the car fares.

At the centers advanced manual work is begun and grading and classification are possible. The program is so arranged that each child has one and one-half hours physical, one and one-half hours academic, and two hours manual work each day. The girls are given a trained teacher to instruct them in domestic science, millinery, sewing, embroidery, crocheting, knitting, mending and preserving. The boys are taught brush making, boot blacking, woodworking, serving of lunches, dish washing, simple tailoring, gardening, assistant janitor work, and other forms of comparatively unskilled labor. In this way we attempt to carry on the training of special class children from seven to sixteen years of age.

The special class, in my opinion, should be still further supplemented by workrooms where, under favorable conditions, pupils over sixteen may be provided with work for which they would be paid. Cobbling, chair caning, tool sharpening, brush and mat making, are industries which might be carried on profitably. They could thus be guarded and controlled in part without being taken from their homes. This brings up the question of how long the public schools should assume the responsibility of these children beyond the school age limit. It seems to me that it should do so for another year or two at least, unless there is some other agency ready to do the work. The school funds are used for work with adults in continuation and evening schools and centers—why not for the much needed work with the feeble-minded?

The most important factor is the teacher who presides over the special class. She must be one who is quick to perceive, able to adapt, whose sympathies are keen and whose outlook is broad, but who combines with these gifts, steadiness of purpose and the power to raise and hold her pupil to his best. A sense of humor will help out in many a situation. In Boston the teachers are given time in which to visit the children's homes, learn the conditions and confer with the parents. The teacher knows how much freedom can safely be given the child; she knows his limitations and when work is undertaken for which he is not adapted, she is able to suggest other lines. She could keep in touch with him and advise him as need arose, if she had the time; but the demands of her classroom are all that should be asked of her strength. In some cities, visiting teachers whose function is that of social workers have done this work most acceptably.

Most will agree that the ideal condition would be for many of the mentally defective to go from the school directly to the institution, and thus safeguard the public from inefficiency, unemployment, pauperism, vagrancy, degeneracy, and all the other social consequences of feeblemindedness. Since this is impossible, we must attempt to fill the gap between the special class and the institution by providing a system of after-care for the feeble-minded who are forced to compete with the normal in the working world. As has been said "It is not sufficient for society that the subnormal should be properly trained in school; it is the business of someone to see that they meet the difficulties of the earn-a-living world. It is of small use to train laboriously in school for shop or farm and then see the graduate enter messenger service or other unskilled and spasmodic labor. Pioneers are needed to make this new adjustment, to study the situation, plan for it, and to enter into it. It is time for them to think together, plan together, and for others to help put the results of the deliberation into operation."

The child may have been prepared for appropriate employment, but he cannot be given the necessary power of self-direction. The subnormal person (young or old) does not have that guiding power within; he must have outside control that should never be relaxed. The need is for a person or persons who will provide this oversight and follow the career of each individual, continuing the guidance begun by the teacher. He should be closely connected with the representatives of various educational, religious, philanthropic, civic and medical organizations. This person should be strong, tactful, persistent one who has been a teacher of mentally defective children and also, if possible, with training as a social worker. The after-care work would naturally divide into two parts: first, the obtaining of information about pupils; second, oversight of pupils at work and knowledge of where suitable positions can be secured. In order to do this it would be necessary to canvass the employers of comparatively unskilled labor to arrange to have notifications sent the officer when there are vacancies to be filled. . . .

At the Massachusetts School for the Feeble-Minded at Waverley, Dr. Fernald is making a careful after-care study of all the patients who have been discharged from the school for the past twenty-five years. He says: "Wherever it is possible our field-workers have visited these patients and the fullest inquiry has been made as to the kind of life they have lived since leaving the institution. The inquiry was planned primarily to furnish a basis of evolution as to the practical results given at the school. The inquiry also sought information as to the social, economic and moral life of the feeble-minded individual in the community."

Source: Fitts, Ada, M. 1916. "Classes and Institutions." From the Smith Ely Jeliffe Collection, proprietor Dr. David Braddock, University of Colorado, Boulder.

Carl Sandburg, "Cripple" (1916)

Carl Sandburg (1878–1967) was a Chicago-based poet well known for his depictions of midwestern life. In poems such as "Cripple," he metaphorized disability as a sign of the ravages of industrialization on the body. Additionally, Sandburg used images of Nature as a sign of robust health compared to the decrepitude of the life of an individual with disability.

Once when I saw a cripple
Gasping slowly his last days with the white plague,
Looking from hollow eyes, calling for air,
Desperately gesturing with wasted hands
In the dark and dust of a house down in a slum,
I said to myself
I would rather have been a tall sunflower
Living in a country garden
Lifting a golden-brown face to the summer,
Rain-washed and dew-misted,
Mixed with the poppies and ranking hollyhocks,
And wonderingly watching night after night
The clear silent processionals of stars.

Source: Sandburg, Carl. 1916. "Cripple." In *Chicago Poems.* New York: Henry Holt and Company. Available at: http://www.bartleby.com/165/26.html

Captain Arthur H. Samuels on Disabled Veterans (1918)

The author of this piece argues that what the general public, and particularly businessmen and employers, owe disabled veterans is not charity, but a job, and a continuing commitment in the postwar period to see to it that the private sector does its part to reintegrate these men, after government programs have rehabilitated and retrained them.

"After the war, if a cripple stops me on the street and asks for help," said a philanthropic business man in New York recently, "how can I tell whether he is a real veteran or just an impostor? Of course, I always want to give something to the boys who went over the top. Will they wear a button to show that they've been soldiers?"

And the answer was this: "Any man who stops you and asks for alms is a beggar whether he was in the war or not. No buttons or insignia will be necessary."

This New Yorker had naïvely got at the very roots of reconstruction. Thousands of men and women everywhere are puzzled over the same thing, for the public does not yet understand the distinction between the cripple who can make good if he wants to, and the beggar who *could* make good but *doesn't* want to.

The gap is wide; and one of the most difficult and vital tasks confronting the Government and the other forces involved in the problem is to reconstruct the public attitude: to destroy utterly the worn-out notion about the cripple and to teach the new.

Picture a soldier who has lost both legs walking—he *will* walk—into the president's office of an industrial plant, where he is received cordially and with honor.

"It happened in the Toul sector," he says "about a year and a half ago and it was nine months before I was discharged from the hospital with these artificial legs. But early in the game I made up my mind to make good. I couldn't go back to railroading—I used to be a conductor—so I decided to take up stenography and typewriting. The Government gave me a fine course, everything I needed. I am qualified to hold down a secretarial job and I need one right now. I can't afford to be idle."

The president who really admired his caller, listened politely. He liked the man's personality. He reached for his check book.

"We are proud of men like you," he said as he wrote, "and you deserve to succeed. Here's fifty dollars. I'm sorry I haven't a position open. Good luck to you. You deserve success."

Now the ex-soldier was human and he accepted the money. He shouldn't have done so. But he is not the one to be blamed. The president, unwittingly, did a vicious thing by offering it to him and every man or woman who gives alms but not opportunity to the disabled man—soldier, sailor, or civilian—is an enemy of reconstruction. One gift of money that is not actually earned may utterly stifle the ambition of the handicapped man.

Business men must be told this again and again. The American public must know that their Government has provided a fair compensation and insurance for the wounded, which, with vocational training, provide our returned soldiers and sailors with adequate means to re-enter civil life. There is a general appreciation of the fact that our men will not be turned loose and allowed to drift as after former wars, but it is natural that a subject so new and complicated has got to be explained, iterated, and reiterated.

This is being done today in an infinite number of ways. The various forces that create and guide public opinion in America are at work enthusiastically and wholeheartedly, offering every possible means of cooperation. For after all, reconstruction is not a matter of propaganda to be jammed through: it is news—one of the biggest pieces of news that has yet found its way into the channels of national publicity.

Newspapers, magazines, motion pictures, pamphlets, speeches—these and other mediums are bringing reconstruction and its significance into the American home and American industry. The Office of the Surgeon General, the American Red Cross, and the Federal Board for Vocational Education are small portion of the factors making it known.

The success of this great plan will depend on the attitude of the public. Public opinion is a pretty loose term as it is generally applied. In this instance, however, it is pat, because it represents several very definite and concrete elements—the man himself, his family, his friends, and his employers. Sympathy and encouragement are plentiful these days while we are in the throes of the conflict, but they will be difficult to maintain when the thrill of battle has passed and the nation has settled down to its normal activities. And after the war—long after—they will be needed most.

Men and women of America by word-of-mouth, house-to-house publicity based on what they read and hear are rapidly developing a new psychology toward the handicapped. Gradually they are reconstructing themselves. And the more thoughtful are beginning to comprehend that physical reconstruction and vocational training will not stop with the coming of peace, but will become powerful and permanent factors in American society and industry.

Source: Samuels, Captain Arthur H. 1918. "Reconstructing the Public." *Carry-On* 1:15–16. [The editors acknowledge the assistance of John Kinder of the University of Minnesota in sharing this document.]

▣ Violet Jacob, "Kirsty's Opeenion" (1918)

In this Scots dialect poem, Violet Jacob (1863–1946) portrays the changed domestic arrangements of the disabled World War I veteran after his return home. In the last lines, the reader is assured that the wife has not become less quarrelsome in consideration of her husband's lost limb; instead, the poet declares that his military experience itself has simply made him less susceptible to nagging.

Fine div I ken what ails yon puddock, Janet,
That aince wad hae her neb set up sae hie;
There's them that disna seem to understaun it,
I'se warrant ye it's plain eneuch to me!

Mibbie ye'll mind her man-a fine wee cratur,
Ower blate to speak (puir thing, he didna daur);
What garred him fecht was jist his douce-like natur;
Gairmans is bad, but Janet's tongue was waur.

But noo he's hame again, ye wadna ken her,
He isna feared to contradick her flet;
He smokes a' day, comes late to get his denner,
(I mind the time she'd sort him weel for that!)

What's garred her turn an tak a road divairgint?
Ye think she's wae because he wants a limb?
Ach! haud yer tongue, ye fuil—the man's a sair-gint,
An there's nae argy-bargyin wi him!

Source: Jacob, Violet. 1918. "Kirsty's Opeenion." In *More Songs of Angus and Others*. Available at: http://www.scotstext.org/makars/violet_jacob/poems.asp

▣ Office of the Surgeon General, "War Cripple Axioms and Fundamentals" (1918)

This document summarizes the influential views of Douglas C. McMurtrie, the director of the Red Cross Institute for Crippled and Disabled Men and editor of the American Journal of Care for Cripples, on the proper assumptions to adopt in order to direct the work of rehabilitation and reintegration of disabled World War I veterans. McMurtrie, along with rehabilitation professionals in every major nation at war at the time, believed that aggressive normalization through systematic vocational retraining must be the basis of any program for rehabilitation of men injured or made chronically ill in consequence of service during the war.

Part 1. Public Policy: The Modern Program of Assistance and Benefit Disabled Veterans in the Twentieth Century

21. To complete physical rehabilitation in amputation cases, artificial limbs must be supplied. That a stump shrinks for some time after amputation introduces one

element of difficulty, in that a limb that fits six months after amputation may come far from doing so after twelve months. For this reason it may be wise to provide the soldier at first with a simple temporary limb, and later with a more elaborate and permanent one. He must be quite explicitly assured of this plan, however, as he will otherwise become suspicious of being put off with an inferior article.

22. Employment of the graduates must be closely integrated with [that] secured for the re-educated soldier, but he must be placed as intelligently as possible. To the man the work must be satisfactory and the environment agreeable; to the employer the personality of the soldier must be acceptable and his product sufficient to the requirements. Of course, this ideal can only be approximated, but a trained and capable employment officer can do much in this direction. Only by skilled and thorough work can permanent results be obtained—and nothing is more costly to all parties concerned than short-time employment and frequent change of job.

23. The first job for the man returned from the front is easy to secure—so easy that we should not be misled by the superficial indications. The employer is patriotic and anxious to help the crippled soldiers. But when the war shall have been over a few years, these motives will be no longer effective. The man taken on in a time of national stress will be just one of the employees, and his retention in service will depend upon performance alone. If the original placement was intelligent the man will have made progress, gained confidence and experience and made his position sure. If, on the other hand, he was ill-fitted for the job, he will have grown progressively less efficient and in consequent discouraged, and his status will be precarious indeed. A permanent injury might thus result from an employment bungle in the first instance. All this simply means that effective placement is not an amateur job.

24. The support and direction of after-care for the war cripple is most emphatically a national one. This can be demonstrated not only as a matter of principle but also by actual experiential results.

From the viewpoint of principle, it may be concluded that the returned soldier should not be dependent for one of his most vital necessities on the dole of private charity, for which is expected a grateful appreciation.

25. The training schools should be under public control and have the advantage of central direction by expert and capable executives. There is also no riper field for the expression of mawkish sentimentality than in caring for the crippled or blind, and the injured soldier must be protected from becoming its victim. With schools operated under local auspices there would be a few good ones, and many of the indifferent variety. And there is no problem more delicate than that of coping with ill-directed and silly charitable enterprises.

26. The chief advantage accruing from centralized public control is the character the work then assumes in its relation to the individual war cripples. It is regarded much as is the public school system; the solder is thus entitled to training by virtue of his rights as a citizen and an honorable public servant. There is of charity no taint whatever.

With an acknowledged national responsibility, the facilities provided can keep pace with—or, indeed, ahead of—the requirements. The work can be carried out on a plan fixed in advance, and its standards be consistent country-wide.

27. Another advantage of federal control lies in the simplicity of integration between the medical and educational interests. The former is under military and, therefore, national authority, and simplification of procedure cannot but result from having the latter of less scope. The training classes must in many instances be carried on in medical institutions, as there is a considerable period of convalescence in which the men should be under re-education.

28. One of the principal methods of restoring disabled soldiers to health is the prescription of specified exercise, and it has been found that this is best gained in workshops rather than with mechanotherapeutic apparatus. Finding that they can do some practical thing, however simple, is immensely encouraging to men who may have lost hope of future usefulness. Occupational therapy plays now one of the leading roles in the convalescent treatment of the wounded, and this makes all the more desirable a close relation between the two branches of the work.

29. A central and national direction of the work for war cripples does not in the least prelude the utilization of volunteer effort and facilities. In fact, voluntary contribution of time and money is highly desirable, particularly in committing more people to a first-hand interest in the enterprise, and in giving the schools root in their local communities. Buildings can be loaned, trade school classrooms and equipment made available, machinery and apparatus for instruction

donated, funds contributed, and personal service volunteered. Existing organizations can offer to provide the necessary social service work in the homes of the men; local employment agencies can be of help by acting [as] links in the national chain.

30. Such private assistance will be more than desirable; it will be essential. Because provision for war cripples is a temporary problem and it would not be wise to erect new buildings, equip expensive machine shops, and build up a complete and self-sufficient organization for a few years' work. For trade classes it will be better to obtain the use for part time of shops in existing schools—institutions which will be in position to afford such facilities on account of the number of their regular students who will have been called to arms. In England, the technical institutes are being wisely used; in France, many war cripples are being instructed in the regular schools of agriculture.

Source: U.S. War Department, Office of the Surgeon General. 1918. "War Cripple Axioms and Fundamentals." Record Group 112, U.S. National Archives.

▣ Alice Duer Miller, "How Can a Woman Best Help?" (1918)

Rehabilitation professionals were keenly aware that a particularly important private agent in the reintegration of the disabled veteran was his mother, wife, or girlfriend. By pampering him, a woman could sap his will to become self-supporting and encourage him to feel it was his right to be taken care of for the rest of his life. On the other hand, by accepting partnership with the government in encouraging him to help himself, a woman was an especially significant influence on the normalization of his postdisability life.

Practical experience of the war shows that the degree to which a soldier can recover is in a large measure a question of his state of mind; and his state of mind is usually a reflection of the state of mind of his wife or his mother. Women have always known in a general way that mental attitude has much to do with a patient's recovery in ordinary illness. Now we see that the same thing is true of the man who has contracted tuberculosis, has been blinded, has lost an arm or a leg, or is suffering from any of the physical or mental diseases that war leaves in its wake. The hope of his future lies in making him believe he has a future. His return to useful activity depends on his own conviction that he can be useful. The instant he is content to be an invalid he will become and remain an invalid.

To prevent his losing hope, to keep up his sense of responsibility is in the power of his womankind. That is why it is necessary that every woman who has a man on the other side should understand what the government is trying to do for him, why it is doing it, and how she can help.

First of all she ought to know that each man's pension will be continued however little or much he progresses on the road to health and self-support. The government does this not only from a sense of justice, but because, knowing that recovery is largely a mental state, it realizes that it would be setting up an obstacle, if it should penalize a man for recovering by taking away or even decreasing his pension.

Then, women should see that the government is doing this for the sake of the wounded men themselves. Protection of the health of soldiers while they are part of the fighting force, is for the sake of the army. But this re-education of wounded men for civil life is done in the interest of the individual. In past times, governments have found it cheaper to entomb such men in institutions for incurables and in soldiers' homes—to pay them their pensions and forget about them. The present idea is that the country owes them more than their pensions; it owes them the fullest possible return to a normal life.

But in order to return them to normal life it will be necessary to retain control of them beyond the military hospital. There must first come bedside treatment, of course—the direct medical or surgical treatment for the disease or wound; then the special treatment necessary to fit him for his selected occupation; then, outside the hospital, his training in a vocational school; and then at last his entrance upon his industrial job.

In every step the help of women is essential; not only in cheering him during the first stages, but in encouraging him to follow patiently and exactly the detail of his training—a routine more wearisome to many natures than fighting.

Our government asks that we use our love to strengthen the will of our wounded—not to weaken it. This may sound like a harsh thing to say to a woman who has sent out a strong healthy man and receives him back blinded or crippled, until we remember that the object of it is to save the soldier and to keep alive in him the courage that was by no means all expended at the front.

The shock to the man who wakes up after the operation to find that he has lost an arm or a leg is not only the shock of his own handicap, but the horror of being a dependent—something useless and abnormal. Too much sympathy of the wrong kind intensifies this feeling, instead of decreasing it. And as a matter of fact, it isn't true; with the help of modern science, the handicapped man can still attain a high degree of usefulness and activity.

The recovery of our disabled soldiers—their return to a useful life—is in the control of the women of this country. No war work that has ever been offered to us is as important—or perhaps as difficult.

But it can be done only with the help of women—only if wives and mothers and sisters will give as much pride and self-sacrifice to the return of their men to civil life as they gave to sending them away to the colors.

Source: Miller, Alice Duer. 1918. "How Can a Woman Best Help?" *Carry-On* 1:17–18. [The editors acknowledge the assistance of John Kinder of the University of Minnesota in sharing this document.]

▣ Two Cripples, "The Sluggard and the Ant" (1918)

Those advancing the new program of aggressive normalization knew that without the cooperation of the public and the disabled veterans themselves, they would not get very far in reintegrating men as self-supporting citizens in the economy and in society. In this selection, we see the effort to shift the terms of the discourse about the character of the ideal disabled veteran ("the ant") away from the tradition that conceived him as a warrior and hero and toward a vision of the veteran as uncomplaining, hardworking, resilient, and—perhaps above all else—industrious. By contrast, "the sluggard" wants to be taken care of by a government pension and to have his children work for him.

The Sluggard

One of my arms below the elbow was shot off in an accident. The other arm was shot off nearer the hand. I cannot and I have not been able to do any work myself. Fortunately for me, I was and am able to control my children who did my work as I directed them. Otherwise I should have been an object of charity. That is how I made my success at farming.

Injured soldiers should live on a pension. Other people should follow gainful occupations.

The Ant

I have both arms off, my right arm is taken off at the shoulder joint and of the left arm I have a three-inch stump, and you have no idea how much this stump helps out. I am farming 180 acres; I have 80 in corn and 80 in oats every year. I have a married man working for me. I always pay my hired help well and keep them satisfied and interested in my work. I plow corn with a riding cultivator, haul corn, or anything, drive the binder when cutting oats, the mower when cutting hay; in fact, everything my hired man does but hitching and harnessing the horses, milking the cows, and a few odd jobs; but while he is doing the rest of the work I am feeding the hogs, horses, and cows and tending to business affairs. I do the feeding by taking a scoop shovel on my shoulder and holding it with my hand and chin and it does not hurt or bother me in the least.

I do my own planting of corn and sowing of oats. Of course, I have things fixed and made handy for me. All the doors and gates are made so I can open them.

I do all my driving with the lines over my shoulder. I drive four and five horses abreast by hitching them so I can drive them all with just two lines. I learn how to do new things every day. I can drive a Ford car as good as any one, cranking it with my feet. Since my accident I have bought 120 acres of land, have not quite paid for it yet, but expect to in three years.

I also have gotten married and, of course, a man in my condition needs a wife. We have a little boy four and a half years old who is also a great comfort to me. I never allow myself to get the blues or discouraged. I try to always look on the bright side of things. I find it helps me. I pay my bills and keep my credit good, and whenever I need money I can get it, and that is what it takes to make the farm go. I do all my own correspondence and write my checks with the pencil between my teeth. I think I have given you a-plenty but there are many things that I can do that I have not written, and if I can help you any in the future will be glad to do so.

Source: Anonymous ["by Two Cripples"]. 1918. "The Sluggard and the Ant," *Carry-On* 1:9.

Douglas C. McMurtrie, from *The Disabled Soldier* (1919)

During and the immediately after World War I, Douglas McMurtrie surveyed the emergence of programs of vocational rehabilitation in all of the major nations at war, including the enemy belligerents, Germany and its allies, whose efforts he admired greatly for their professionalism and dedication, even as he acknowledged the official state of animosity. In these three selections, McMurtrie traces the inception and development during the war of the idea that aggressive normalization is the best method of rehabilitation. He acknowledges the different mix of national and local factors in each example, accounting, to varying degrees in each case, for the relevance of prior programs of assistance to disabled soldiers, wartime contingencies such as labor shortages and fiscal difficulties, the nature of the industrial infrastructure, and the state of public opinion regarding both disability and veterans.

Chapter XIV

Kingdom and Dominion

When England sent her first "contemptible little army" to the continent in defense of the violated rights of Belgium, it was followed not alone by more British but by troops from every corner of the globe. In every dominion of the empire troops were enlisted to "fight for the right" as the home country had seen it, and were dispatched to the front as fast as circumstances allowed.

Great Britain and every one of her dominions, in consequence of their heroic stand for the benefit of civilization, have had to face the problem of the returning disabled soldier. In the solutions attained by these commonwealths, dealing as they have with Anglo-Saxons, men of similar traditions, habits, and impulses as ourselves, the United States must find peculiar interest and derive unusual profit from the showing of their experience.

When the first British disabled began to return to the streets of London, there was scant provision for their care.

Now to every British soldier who lies in the hospital ward three possibilities are open—a visit from the dark-winged Messenger, a period of convalescence and the buckling on again of the sword for another thrust at the Hun, or "Blighty," the old familiar haunts, an economic crutch in the shape of a pension, and a job suited to his physical limitations. As surely as the stricken deer seeks the familiar glades so does the discharged warrior turn his halting steps to the sheep downs of the south or the smoky towns of Lancashire, the heather hills of Scotland, the mines of Cardiff, or the long, long way to *Tipperary.*

If we could visualize the procession of maimed and disabled men in mufti as it leaves the discharge depot we would see it melt away into the economic horizon of every portion of the United Kingdom, to carry to each county, borough, and town the problem of the care of the disabled man as a legacy of the Great War for the stability of those free institutions the Anglo-Saxon prizes above life or sound limbs. And in each and every district he will find that provision has been made to continue his medical treatment, choose for him an occupation suited to the abridgement of his powers, and induct him into it after proper training. Should he be in doubt as to his rights under the new and unusual laws of the realm, the Local Pensions Committee stands ready to secure his rights, succor his family, and educate him to surmount the handicap the enemies of civilization have laid upon him. And this, not because England thought this out as the best way to care for her disabled heroes, but because it chimed in with her way of doing things in the past. Local government has always been a cherished prerogative of the English commonwealth since the days of the petty kingdoms. A representative government may sketch its plans in the large, but the English community must be given a free hand in filling in the local training of disabled soldiers.

So when the Disabled Sailors' and Soldiers' Committee reported to Parliament in 1915 that "the care of the sailors and soldiers, who have been disabled in the war, is an obligation which should fall primarily upon the state" and that body passed the Naval and Military War Pensions Act in 1915 to provide for "the care of officers and men disabled in consequence of the present war," the plan proposed to commit the disabled man to the care of a local committee of his own townsmen. To be sure, later developments of the plan necessitated modifications of this scheme in the interests of coordinated measures for the economic welfare of the realm, but this is essentially the genius of the English plan—local responsibility for bringing the opportunities afforded by the government to the door of each disabled man.

Specific instances of like care [are] not wanting. The Incorporated Soldiers' and Sailors' Help Society, which was established under royal patronage at the close of the South African War, had sought to aid the ex-service man in finding employment by furnishing him with the name of a "friend" in each parish or ward throughout the empire. The Old Age Pensions scheme of the state was administered by local committees in every borough and urban district having a population of 20,000 or over. The necessities of the families of the enlisted men had long been looked after by the Soldiers' and Sailors' Families Association by a ramification of local committees composed largely of clergymen and ladies of leisure in all parts of the country.

It was quite natural, therefore, that Parliament should look to a local committee to take the hand of the disabled man and lead him all the way back to a life of productive and contented activity. It was thought that the necessities of each man could best be assessed and provided for by a committee of his townsmen familiar with the conditions that environed him and his family. The soundness of this principle cannot be questioned, and while it may not make for uniformity it at least has the advantage of intimacy. It is the recognition of a principle, expressed many times in Parliamentary debate and charity organization, that in dealing with individuals in widely differing stations in life and with peculiar necessities, a human element must somehow be provided which the uniformity of governmental regulations does not permit. The human element—a quick sympathy, an intimate knowledge of a disabled man's circumstances, a way to help [those] unfamiliar to rules of a bureau—this can be supplied best by the local committees.

And so England followed the blazed trail of private philanthropic organizations and established Local Pensions Committees in every county, county borough, and urban district having a population of not less than 50,000. The committees are responsible to the Ministry of Pensions, which establishes rules and regulations to secure uniformity in the provisions they make for the men committed to their care. The appointment of these committees is largely left to the local authorities, but in general they must include some women, some representatives of labor, and members of the Soldiers' and Sailors' Families Association, and of the Soldiers' and Sailors' Help Society. A salaried secretary appointed by the Ministry of Pensions is a kind of liaison officer between the local body and the central office.

The duties of the Local Pensions Committee are broadly sketched in the instructions of the Ministry of Pensions: "The local committee should regard themselves as responsible for all discharged men of this class (i.e., disabled) living in their area. They should make it their business to get in touch with every such man, whether or not he has obtained employment or occupation since his discharge, and see that the treatment or training which his condition needs is secured for him when he needs it. . . . It is vitally important both in the man's interest and in that of the Nation that any case which needs either treatment or training should be taken in hand at once. Local committees must not be content with dealing only with the men who happen to present themselves to them for assistance; they must see that they have information as to the condition of all discharged pensioners in their areas, and make it a point of getting in touch with them directly they are discharged."

The committee is to be guided in its decisions in regard to suitable training for a man by several considerations. His previous occupation must have weight. The proposed occupation must be suitable to his age, disablement, and physical condition. If any recommendation as to his training has been indicated on his notification of award for pension or by a hospital visitor, this must be considered. Not least of the factors entering into a solution of the problem before the committee must be the opportunities for a living wage in the occupation chosen for him.

It must be quite clear that if the local committee were left to its own devices wholly in choosing an occupation for the man the result in the field of industry might be disastrous. The influx of a large number of disabled men into a particular occupation without some standard of training might arouse antagonisms that would be unfortunate. This necessitated some rulings by the central office in the interests of coordinated effort. Both the employers of labor and the work people must have some voice in the matter, especially in a country whose labor organization has made such strides. The necessary machinery was provided by the Ministry of Pensions cooperating with the ministry of Labor. Trade Advisory Committees have been appointed *for most of the principal trades.* Each committee is composed of an equal number of employers and work people. It is the duty of each committee to advise the Ministry of Pensions as to conditions under which the training of men in that trade can best be given, the best methods of training, the suitable centers for it, and in general to secure uniformity in the training. The numerous reports already issued contain a valuable fund of information regarding the trade from the viewpoint of the man who is physically handicapped. The analysis of an industry with the man with abridged powers in view is a phase of industrial efficiency that the war has developed. Never again can the old laissez faire policy of allowing the handicapped man to stumble along the industrial road undirected and unassisted prevail. Society cannot again close its eyes to this waste of human efficiency and the heartbreak of the man whose work powers are unappreciated because of some physical abridgement he has suffered.

The question of wages to be paid to a disabled man will always be a vexing problem. Where a disabled man can do his full stint of the work and compete with his normal fellows, he should plainly receive the equal wages whether he is receiving a pension or not. But there are grounds for debate when the man is physically unable to perform a full task either in hours or output. The inevitable tendency will be for the employer to depreciate the man's ability. The exploitation of the disabled man, especially when he is receiving a pension, is feared by organized labor, jealous of its wage standards. An effort has been made to provide machinery for obviating his difficulty. The Ministry of Labor has set up in the principal industrial centers advisory wages boards composed of representatives of employers and work people and three members of the Local Pensions Committee. This committee is to advise the local committee, or an employer desirous of employing a handicapped man, what would be an equitable wage in his particular case, taking into consideration the man's physical capacity and the current rate of wages for the industry in that locality. The question of a man's pension is not to be taken into account. The committee acts purely in an advisory capacity, but it is hoped by these means to provide against the exploitation of cripples or the lowering of trade standards.

It is the duty of the Local Pensions Committee to provide facilities for the training of its disabled ex-service men. It was soon seen that the training facilities of a larger area than that within the jurisdiction of most local committees must be made available if the variety of occupations demanded were to be provided. So Joint Advisory Committees, composed of the representatives of local committees, were formed in 1916 to arrange comprehensive schemes for utilizing the facilities for technical education within whole counties or groups of counties. Twenty-two of these joint committees were formed in the United Kingdom. They surveyed the technical facilities in their respective districts and syndicated them in the interests of all.

For many years the British government has had local technical schools, and the result has been a surprisingly large number of institutions where one or more trades are taught. These trades cover the principal industries of the country. The number of technical schools in the industrial counties of Lancashire and Yorkshire is particularly noticeable. Both of these counties formulated ambitious schemes for the training of disabled men in every variety of industry pertaining to the soil, the mine, the factory, and the sea. The cooperation of all the principal technical schools in the training of disabled men was secured. The offer of facilities seems to have greatly exceeded the demand.

Not only have the technical schools been utilized for re-education but many men have been trained directly in workshops and factories. The plan advocated by several of the trades advisory committees provides that a man shall spend part of his time at a school and part of his time in actual work in a factory or workshop; by this means a balance is maintained between the theoretical and the practical.

It must not be supposed that every man returns to his home district absolutely unprepared for an altered industrial career. Many of the men avail themselves of the opportunities afforded by the workshops connected with the hospitals in which they have spent their period of convalescence. Early in the history of the war lucrative workshops were established in the hospitals of Roehampton and Brighton, whither men who have suffered some amputation are sent. Major Mitchell, the director of one of the leading technical institutes, was chosen to direct the courses. The therapeutic value of manual work has been fully recognized, and many a man, invited to busy himself in a workshop with the tools of a man's job ready to his hands, has not only found a stimulus to the functional activity of injured members but has actually learned a trade while waiting for nature to heal his wounds and the government to furnish him with an artificial limb. Not every man avails himself of the opportunities offered him in the hospital and must look to his local committee to furnish the opportunities for training he slighted or to supplement his training by continuations courses.

Upon his discharge from military service the disabled man is granted a pension based upon the degree of physical disability he has suffered and is free to return to his home locality. His future lies within the advisory jurisdiction of his Local Pensions Committee acting for the ministry of Pensions. He may choose to live a life of inactivity depending for a scanty subsistence upon the slender stipend granted him by the Ministry of Pensions. He may accept a job ready to his hand, because of acute industrial conditions caused by the war, from which he is likely to be ousted by the return of able-bodied men upon the demobilization of the army. Or, he may accept training at the expense of the state and become a skilled worker with better prospects of continued employment when normal times return. The good sense of the man and the persuasiveness of the local committee will largely determine what course he is to pursue.

If he elects to take training he will receive, during the time required for his re-education up to six months, his total disability pension together with a family allowance, all necessary fees will be paid for him and at the end of his course he will receive a bonus for each week of training. The state cares for both himself and his family during his period of re-education. At the end of his course he will be fortified against the exigencies of the future by the wages he can earn at a skilled trade and the regular pension to which his injuries entitle him. It is expressly stipulated that his pension shall never suffer diminution because of his increased earning capacity. Many disabled men are now receiving from this dual source larger incomes than they enjoyed before they entered the service of their country.

The demand for disabled men who have received training has been so great that no difficulty has been found in finding employment for them. The admirable system of state labor exchanges provides the facilities for placing disabled men in industry and their services will be in still greater demand when peace returns and conditions of employment are greatly altered by the return of men from the front.

While the preparation of disabled men to enter into competition with their normal fellows seems to promise the best results on the whole, still it must be recognized that many men with severe physical limitations must be provided for in special institutions under favorable work conditions. Specialized machinery and carefully planned team work can make productive units of badly handicapped men with whom the average employer is not willing to bother. Large provision for this class of men has been made by the Lord Roberts' Workshops, which are being multiplied in different parts of the country. Some ten years before the war the Soldiers' and Sailors' Help Society opened workshops in London to provide employment for disabled ex-service men for whom it was extremely difficult to find work. The work has been greatly expanded since the war, and the enterprise has taken the name of the nation's military idol, who was greatly interested in the project. Toy-making, with the many processes involved, has been found a suitable industry for many types of disability, and the enterprise has been successfully conducted on a sound commercial basis. The plans of the society contemplate facilities in the eleven workshops in different parts of the country for the accommodation of between four and five thousand men.

Across the Firing Line

Prepared as she was for war, so also was Germany prepared for the consequences of war. At the outbreak of the war, she had of all other countries laid the most solid foundation for the care of the crippled soldier. The German National Federation for the Care of Cripples is an organization of long standing. There had been developed, during half a century's experience, fifty-eight cripple homes, under private auspices, ranging in size from six to three hundred beds. Some of them were already taking adults as well as children, and they had among them 221 workshops, teaching 51 trades. In addition, there were sanatoria and re-educational workshops for industrial cripples under the employers' accident insurance companies; there were orthopedic hospitals operated by municipalities, and there were trade schools and employment bureaus under various government auspices.

All these resources accumulated in peacetime for the rehabilitation of cripples were mobilized immediately after the outbreak of the war—almost simultaneously with the military mobilization. Eight days after the outbreak of hostilities, the Empress, at the instance of Dr. Biesalski, Germany's leading orthopedist and secretary of the National Federation for the Care of Cripples, address[ed] to existing institutions for the crippled a letter pointing out the necessities ahead and urging them to open their doors and provide facilities for the treatment and training of disabled soldiers. To this all the homes immediately consented. Dr. Biesalski undertook a tour of Germany and visited the principal cities urging the formation of voluntary committees for the care of war cripples. The immediate result was the formation of volunteer committees in many cities and of larger ones in some states and provinces. At the present time, Germany is thoroughly covered by a network of such organizations. A local committee usually comprises representatives of the municipality, of the military district command, the accident insurance associations, the Red Cross, the women's leagues, the employers, the chamber of commerce, the chamber of handwork, and the labor unions. In the fall of 1915, a national committee was formed with the object of coordinating the work and making investigations and plans for the future.

There are four stages in the treatment of the disabled soldier: (1) medical treatment; (2) provision of artificial limbs and functional re-education; (3) vocational advice and vocational re-education; and (4) placement. Of these activities, the first two are controlled by the imperial military authorities and are conducted on uniform lines. With regard to vocational and economic rehabilitation, on the contrary, there is no general direction given by any central authority; the re-education schools are of varying types and most unevenly distributed; the work is in the hands of local and private or semi-private agencies; it is done mostly by volunteers and is not even supervised by the imperial government.

However, in spite of the absence of any general system of organization, there is a complete unity of purpose and the work is everywhere carried on in accordance with certain universally accepted and officially sanctioned principles. These were formulated by Dr. Biesalski in this way:

1. No charity, but work for the war disabled.
2. Disabled soldiers must be returned to their homes and to their old conditions; as far as possible, to their old work.
3. The disabled soldier must be distributed among the mass of the people as though nothing had happened.
4. There is no such thing as being crippled, while there exists the iron will to overcome the handicap.
5. There must be the fullest publicity on this subject, first of all among the disabled men themselves.

The possibility of rehabilitation is accepted as a creed by all the institutions working to this end, it is put in practice, and the statement is that in ninety percent of the cases the desired results are attained.

There is a fairly complete network of orthopedic homes distributed all over the empire. Their number has been put at about two hundred. They are all under military discipline. The time for treatment for a man in the orthopedic hospital is from two to six months. Men are kept here until they are ready to go back to the army or are pronounced definitely unfit for service. Even if they are so unfit, the war department does not discharge them until they are pronounced by the physician physically fit to go back to civil life.

The best hospitals are excellently equipped. Complaints have been made, however, that the remote hospitals have very incomplete arrangements and that the great demand for orthopedists leaves some places unsupplied.

More and more emphasis is being placed on physical exercise as a means of bringing disabled men back to the standard. The plan is that a man shall begin very simple but systematic physical exercises even before he is out of bed. These are gradually increased until finally he has two or three hours a day under a regular gymnasium instructor. Games and outdoor sports are found to have an immense therapeutic value, both psychological and physiological, as compared with medico-mechanical treatment. Thus we find, at the different hospitals, as part of the regular regime, ball playing, spear throwing, bowling, shooting, quoits, handball, jumping, club swinging, and swimming. Finally, though the hospitals do not attempt to train a man to a trade, many of them have attached workshops for purposes of functional re-education. There is great emphasis placed on the fact that even this occupational therapy should be really useful and should lead the patient direct[ly] to some practical occupation.

All artificial limbs are furnished and kept in repair by the government. The government has prescribed maximum prices for prostheses of different types. Otherwise there is no official supervision. No standard pattern is prescribed, and the matter is left to the doctors and engineers of the country. The result is an immense stimulation of activity. The magazines are full of descriptions of new prostheses recommended by doctors and manual training teachers from all parts of the country. At an exhibition of artificial limbs, held at Charlottenburg, they were shown thirty kinds of artificial arms and fifty types of artificial legs in actual use.

The principle now thoroughly accepted is that the prosthesis should reproduce not the lost limb but the lost function. It should not be an imitation arm or leg, but a tool. The standard of merit is the number of activities it makes possible.

Re-education in Germany goes on at the same time as the medical treatment. This has two causes. First, there is the strong conviction among all cripple welfare workers that results can be obtained only by getting hold of a patient at the earliest possible moment of convalescence, and second, the fact that, since the government does not pay anything towards re-education, it is more economical for the care committees to attend to it while the men are in the hospitals and thus save themselves the expense of maintenance.

The local care committee usually appoints vocational advisers whose appointments have to be sanctioned by the local military authorities, who control the visits to the men in the hospitals. As soon as a soldier is well enough to be visited, the committee sends representative to get full data on his experience and his physical condition, and then advise him as to re-education or immediate return to work. The principle is fast held to that man must, if humanly possible, go back to his old trade, or, failing that, to an allied one.

The trade training is given while the men are still in the military hospital, beginning, in fact, as soon as they are able to be out of bed. The workshops are maintained by the local care committees; they can be located either in the hospital, or at an outside point to which the men go every day. The first plan is followed by but a few of the larger institutions; in most instances there are no workshops maintained at the hospitals. The local care committee may utilize the local trade schools. There are excellent facilities for this, since every town has at least one trade school. Some representative of the educational authorities generally serves on the local care committee and the schools are eager, in any case, to offer free instruction. German magazines are full of advertisements of free courses for war cripples, offered by schools of the most varying kind, public and private, from agricultural and commercial schools to professional schools and universities. On the other hand, in a large town, with a number of hospitals, the committee may create a school of its own. Thus, in Dusseldorf, for instance, where there are fifty hospitals, the committee has taken possession of a school building equipped with shops and tools and given twenty courses open to men from all the hospitals.

It is planned that none of the courses shall take more than six months, the maximum time for hospital care. These short courses are intended for men of experience who need further practice in their old trade or in an allied one. If a man needs further training after this short course, he becomes the charge of the local care committee, which supports him while he attends a technical school or pays the premium for apprenticing him to a master workman.

A special effort is being made to return to the land all who have any connection with it, such as farmers, farm laborers, and even hand-workers of country birth. All the hospitals that have any land give courses in farming and gardening for their patients. It is estimated that there are several hundred such hospital farms, small or large, operated by the wounded. In addition to this, there are definite summer farm courses at agricultural schools and universities, which are free to cripples. There are in the empire ten regular agricultural schools for war cripples.

Since the one-armed man has one of the gravest handicaps, special arrangements have been made in several places for his training. The purpose of these courses for the one-armed is to accustom the soldier to exercise the stump and the remaining member performing the daily duties such as eating, washing, dressing, tying knots, using simple tools, and the like. This is a preliminary to specialized trade training, and the process is said usually to require about six weeks.

An essential feature of the course is left-handed writing for those who have lost the right arm, not only for men in preparation for clerical work but for others as well. This training banishes to a marked degree the feeling of helplessness and likewise gives the hand greater flexibility and skill. German teachers have made a scientific study of this question and state that left-handed writing can be made as legible and characteristic as right-handed. Samples of left-handed writing from Nurnberg show excellent script after from twelve to twenty lessons.

Left-handed drawing, designing, and modeling are often added subjects of instruction. Men with clerical experience are taught to use the typewriter, sometimes using the stump, sometimes a special prosthesis, and sometimes with a shift key worked with the knee.

All the schools for one-armed put great emphasis on physical training. In the school at Heidelberg, under a regular gymnasium instructor, the men do almost all the athletic feats possible to two-armed men.

There is no uniform machinery for the placement of war cripples. The care committees, while interviewing the man in the hospital, also get in touch with his former employer. Sometimes a position is thus secured even before the man has started his training, and the latter is then adapted to the requirements of that particular position. But it is not always possible to place a man with his old employer. Some of the larger care committees run employment bureaus of their own. Others turn over to some other agency the man who cannot be taken back to his old position—usually to the regular employment bureaus. Germany has a system of public employment bureaus supported by the municipalities. The bureaus in each state or province are united under a state or provincial directorate, and the directorates in an imperial federation. Some of these had before the war, special divisions for the handicapped, and others have established them since the outbreak of hostilities. Employers' and workmen's associations are of considerable assistance in the placement of war cripples, especially the Federation of German Employers' Associations, which has been recently formed for this particular purpose, and the many master guilds of handworkers. There are also a number of agencies due to charitable or private initiative.

Finally, there are open to war cripples a very large number of positions in government service. The imperial government has promised that all former employees of the railways, post office, and civil service will be re-employed, if not in their old capacity, in a kindred position. These men are to be paid without consideration of their pensions. The post office department has decided to give all future agencies and sub-agencies in the rural districts to war cripples, provided they are fit for the positions and want to settle on the land. Many city governments make efforts to take in cripples. There are reserved for cripples a number of employments under the war department, which through its recently created welfare department attempts also to develop placement activity wherever there is no very active local care committee, publishing twice a week a journal which lists positions open for war cripples.

Chapter XVI: For the U.S. Forces

The situation of the United States with regard to making provision for the disabled soldier is perhaps slightly different from that of the other belligerents. One of the principal causes of difference is the selective influence on the personnel of the military forces of the conscription law.

This legislation has specifically exempted, temporarily at any rate, agricultural workers, highly skilled mechanics, and those who, because of their special qualifications, are necessary to the maintenance of the national interest at home. In Italy and France the situation with regard to the make-up of the army is vastly different. There we find almost all the able-bodied agricultural workers in the service, and battalions of highly skilled mechanics and experienced workmen in uniform.

The problem of refitting for industry the disabled soldiers of the European forces is therefore very unlike that of the United States. Up to the present time the force sent to the front consists practically of men between the ages of twenty-one and thirty-one. This means that the majority of men disabled will not be highly skilled or long experienced in any occupation and thus will be more plastic from the vocational point of view. Past experience has in European practice been the main determinant of training for the future. It may be expected that in many of the American cases this will afford no definite criterion. Either the soldier may have entered the service direct from school or college or if he has been at work for some time, it is likely to have been in a dozen different jobs of varying character. Many of the men, therefore, can answer definitely to no "former occupation." As has been found in Canadian experience, the soldier when asked his trade will report that for three months prior to the war he worked on a railroad. "Then you are a railroad man?" is the question. "No," is the answer, "for the two months before that I was in a cotton mill, and still earlier drove a delivery wagon for a local firm." In such a case past experience is almost a negligible factor, and the man may properly be restudied vocationally in order that he may be trained in the skilled trade most suited to his qualifications and talents.

An interesting experiment in vocational analysis and allocation has been carried out by the military authorities in classifying drafted men for special lines of army service. The new recruits have been given simple psychological tests prior to their assignment to work as radio operators, oxy-acetylene welders, linemen in the signal corps, drivers or mechanicians in the motor transport service, and so forth. The results have been encouraging and the experience gained will undoubtedly be helpful in further vocational guidance of the men returning for discharge.

In the general process, it is likely that many men who were previously undifferentiated as to occupation, who possibly looked forward to careers as clerks or general utility men, may be directed into skilled trades which will afford to them a much greater financial opportunity, and will contribute more largely to the national stability and efficiency.

The recent wave of interest in the United States in vocational education has put the country in better shape to deal with the instructional requirements of the disabled soldier than would have been the case ten years ago. Although not claiming facilities to compare with those afforded by the fine system of technical institutes in Great Britain, there are in practically every important urban community of America, one or more vocational schools. Industrial education is well provided for by schools, the first of which were founded by private initiative but operated on a noncommercial basis. The later institutions have been established by local educational authorities as part of the public school systems.

Commercial education, to a noteworthy extent, is still in the hands of business colleges that are run as profit-making enterprises. But the work of many of them is efficient to a creditable degree.

Agricultural education has been splendidly provided for by the agricultural colleges and experiment stations maintained by the several states, with assistance, in some instances, from the national government. These institutions have the most modern equipment, expert teaching staffs, and the finest facilities for imparting a practical knowledge of agriculture.

And finally, it must be recalled that practically every American university has industrial departments with shop equipment, which afford to students not only the theoretical, but also the practical, type of instruction. As the war goes on the universities will be drained of students, while the vocational schools whose regular pupils are of younger age, will tend to continue full. In Canada the university plants have been put to good use in the training of disabled soldiers. Even more extensive facilities of this character are available in the United States.

Prior to the entry of America into the war there had been almost no provision for rehabilitation of the disabled adult. There had been several employment bureaus for cripples, in New York, Boston, Cincinnati, and Philadelphia. These agencies had been struggling bravely, without recourse to training facilities, and with scant public support, to solve the economic problems of the disabled, and were attaining an encouraging degree of success. About five years previous there had been started, but later discontinued, a training school for crippled men.

So in spite of the excellent foundation of general vocational education the United States, at her entrance into hostilities, stood practically without special facilities for the re-education of the disabled. The need of such special provision had been long recognized by workers with the handicapped and was repeatedly discussed in a special journal on cripples that was their organ.

The first move to meet this need was taken the second month after America's declaration of war, when a public-spirited citizen offered to the American Red Cross funds sufficient to establish and maintain in New York City a training school for crippled men. While an original motive of the fight was a desire to make provision that might be helpful to the disabled American soldier, the school was started for crippled men in general, without distinction as to their civilian or military affiliation. Thus came into being the Red Cross Institute for Crippled and Disabled Men.

It became soon evident that this organization had logical responsibilities much wider in scope than the conduct of a local school of re-education. Legislation making government provision for the training of disabled soldiers did not appear on the statute books until fourteen months after the inception of hostilities, so for a considerable period there was no official agency to which to turn for information and advice. Yet there was wide interest in provision for the disabled soldier. To meet demands from the public for data on the organization, methods, and principles of re-education, as derived from experience abroad, and to provide a scientific foundation for the development of its own activities, the Institute initiated in July 1917, a department of research. There was early issued a bibliography of the subject, followed by reports on activity in different countries, monographs, and translations, which have been freely distributed for the information of all interested in the subject.

This Institute, which undertook at once the training of crippled industrial workers, has established courses in the manufacture of artificial limbs, oxy-acetylene welding, printing, motion picture operating, jewelry-making, and mechanical drafting. There are also departments of employment, industrial surveys, and public education.

During the incubation of the national program the Red Cross Institute for Crippled and Disabled Men thus served as an experiment station and proving ground, and unofficially met demands upon it to the best of its ability.

In the formulation of the government plans there was considerable difference of opinion as to what authority or authorities should be charged with the responsibility of re-educating the disabled soldier. It was urged on the one hand that the entire task of rehabilitation in all its aspects should be entrusted to the Surgeon General of the Army; on the other hand that it might be handled by the Bureau of War Risk Insurance—a government department administering family allotments and allowances and the new life and disability insurance, privilege of which was offered to men entering upon military service. A later suggestion advanced by the Council of National Defense was that re-education be entrusted to a commission under the War Department, made up of representatives of all the official and non-official interests concerned. Another proposal which was approved by a conference called by the Surgeon General of the army at the instance of the Secretary of War, and which was embodied in the draft of a legislative proposal, called for an independent commission of five, composed of representatives of the Surgeon General of the Army, the Surgeon General of the Navy, the Treasury Department, the Department of Labor, and the Federal Board for Vocational Education.

The Administration felt, however, the unwisdom of erecting more independent boards or commissions unrelated to the regular executive mechanism. For this reason it was decided to fix the task on some already existing government department. The one designated in legislation introduced with executive approval, and later enacted, assigned the responsibility of providing for the rehabilitation of the disabled soldier and sailor to the Federal Board for Vocational Education, a body which had been created a year earlier to administer federal aid to vocational education by the states. The bill committing this new function to the Board became law on June 27, 1918.

Meantime, the Surgeon General of the Army had been establishing reconstruction hospitals for the intensive treatment of physical disablement. In connection with each of these medical centers educational work had been undertaken—with three ends in view. The first was to provide to convalescent patients occupation for therapeutic purposes; the second to provide educational opportunities during the period of invalidism to men who would be returned to the front or discharged without permanent disability; the third to train disabled men whom it was desired to retain in the military organization for special or limited service. In carrying out the two latter aims, the educational departments of the hospitals have entered well within the vocational field.

Important links in the military hospital chain are the reception hospitals at Fox Hills, Staten Island, N.Y.; at Ellis Island, in New York harbor and at Newport News, VA. At these institutions there are first received from hospital ships or transports all soldiers invalided home from overseas. The men are classified as to treatment need and district of residence, and promptly “cleared” to the appropriate institution.

During the period of hospital or convalescent care the soldier has advantage of physical and occupational therapy administered by a corps of trained workers known as “reconstruction aides” but more familiarly named “blue gowns” on account of their uniform.

Classes in the various military hospitals have already been established. The subjects taught at General Hospital No. 6, for McPherson, Atlanta, Ga., for example are motor mechanics, telegraphy, wireless telegraphy, typewriting, mechanical drafting, cabinet-making, carpentry, harness repairing, poultry raising, reading and writing English, penmanship and bookkeeping, and printing.

When a candidate for discharge from the military forces is so disabled as to entitle him to compensation for disability, his case is discussed with him, while he is still in the hospital, by a vocational adviser of the Federal Board for Vocational Education. He is told that the United States Government will train him free of charge for a new trade. It is entirely optional with the man whether he take advantage of this opportunity for training or not, but every influence is brought to bear to make his decision affirmative.

After the disabled man is discharged from the hospital, he becomes a civilian and his dealings are with the Federal Board and the Bureau of War Risk Insurance.

If the man decides to take a course of training, he is supported during the period of re-education through payment by the Bureau of War Risk Insurance of his compensation for disability or his former military pay, whichever is the greater. During this period the compulsory allotments and allowances to his dependents are continued just as if he were still in military service. He is given instruction that is paid for and supervised by the Federal Board for Vocational Education in one of the schools approved by that body.

The Federal Board for Vocational Education has announced that its provision of re-education will be made, so far as possible, through the use of existing schools, or by placement for training, under a modified system of apprenticeship, with manufacturing or commercial establishments. Special institutions will be founded only where absolutely necessary.

The Board is establishing district offices to decentralize the work, is making training arrangements for current cases, and is following up to their homes men who were discharged from the army prior to the inception of re-educational activity, and who stand in possible need of training. Local offices are already in operation in New York, Boston, Philadelphia, Cincinnati, Atlanta, Washington, D.C., New Orleans, Minneapolis, Chicago, St. Louis, Dallas, Denver, San Francisco, and Seattle.

After training is complete, the re-educated soldier will be placed in a job by the Federal Board, acting, as provided by the law, in cooperation with the United States Employment Service of the Department of Labor. The Board also includes in its placement function any man physically rehabilitated in an army or navy hospital, whether he be a candidate for retraining or not.

The American Red Cross has offered to the government authorities the facilities of its extensive home service organization throughout the country. This service, directed by the Department of Civilian Relief, can help to align the family as an encouraging force behind the re-education program, can keep the family wheels moving smoothly during the period of training, can provide to the vocational officers much useful information on the home conditions and community record of any individual soldiers, can follow up the case after return to employment, and help in many ways to make the re-education permanently effective.

The actual work of putting the disabled American soldier back on his feet is still in its infancy, and many details still remain to be worked out in experience. But in principle, the United States has followed the best example of her Allies—in accepting provision for the disabled soldiers as a national responsibility to be met at public expense. It is clear that no American soldier need be dependent upon the alms of charity for his rehabilitation.

But the complete success of the work rests with the people of the United States—upon whether we sympathetically grasp and effectively express in our relations with the graduates of re-education the new spirit of dealing with the disabled—upon whether we sense the glory of restoring the ex-soldier's ability to earn his own living, or whether we continue the old temporary hero worship and permanent pauperization. The self-respect of self-support or the ignominy of dependence—which shall the future hold for our disabled soldiers? The credit or the blame for the decision will largely rest with the American public.

The open road is before us.

Source: McMurtrie, Douglas C. 1919. Pp. 185–195, 209–217, and 223–232 in *The Disabled Soldier.* New York: Macmillan.

Sherwood Anderson, from *Winesburg, Ohio* (1919)

In the preface to his story of oppressive midwestern small-town life, Sherwood Anderson discusses his narrator's obsession with disabled characters, or, as he calls them, "grotesques." The act of characterization requires a "deforming" precept in that characters are brought to life through their defining idiosyncrasies. In this excerpt, the narrator imagines a procession of such characters with their "misshapen bodies" parading before him in dreams.

The writer, an old man with a white mustache, had some difficulty in getting into bed. The windows of the house in which he lived were high and he wanted to look at the trees when he awoke in the morning. A carpenter came to fix the bed so that it would be on a level with the window.

Quite a fuss was made about the matter. The carpenter, who had been a soldier in the Civil War, came into the writer's room and sat down to talk of building a platform for the purpose of raising the bed. The writer had cigars lying about and the Carpenter smoked.

For a time the two men talked of the raising of the bed and then they talked of other things. The soldier got on the subject of the war. The writer, in fact, led him to that subject. The carpenter had once been a prisoner in Andersonville Prison and had lost a brother. The brother had died of starvation, and whenever the carpenter got upon that subject, he cried. He, like the old writer, had a white mustache, and when he cried he puckered up his lips and the mustache bobbed up and down. The weeping old man with the cigar in his mouth was ludicrous. The plan the writer had for the raising of his bed was forgotten and later the carpenter did it in his own way and the writer, who was past sixty, had to help himself with a chair when he went to bed at night.

In his bed, the writer rolled over on his side and lay quite still. For years he had been beset with notions concerning his heart. He was a hard smoker and his heart fluttered. The idea had got into his mind that he would come to die unexpectedly and always when he got into bed he thought of that. It did not alarm him. The effect in fact was quite a special thing and not easily explained. It made him more alive, there in bed, than any other time. Perfectly still, he lay and his body was old and not much use any more, but something inside him was altogether young. He was like a pregnant woman, only that thing inside him was not a baby but a youth. No it wasn't a youth, it was a woman, young, and wearing a coat of mail like a knight. It is absurd, you see, to try to tell what was inside the old writer as he lay on his high bed and listened to the fluttering of his heart. The thing to get at is what the writer, or the young thing within the writer, was thinking about.

The old writer, like all of the people in the world, had got, during his long life, a great many notions in his head. He had once been quite handsome and a number of women had been in love with him. And then, of course, he had known people, many people, known them in a peculiarly intimate way that was different from the way in which you and I know people. At least that is what the writer thought and the thought pleased him. Why quarrel with an old man concerning his thoughts?

In bed, the writer had a dream that was not a dream. As he grew somewhat sleepy but was still conscious, figures began to appear before his eyes. He imagined the young indescribable thing within himself was driving a long procession of figures before his eyes.

You see interest in all this lies in the figures that went before the eyes of the writer. They were all grotesques. All of the men and women the writer had ever known had become grotesques.

The grotesques were not all horrible. Some were amusing, some almost beautiful, and one, a woman all drawn out of shape, hurt the old man by her grotesqueness. When she passed he made a noise like a small dog whimpering. Had you come into the room you might have supposed the old man had unpleasant dreams or perhaps indigestion.

For an hour the procession of the grotesques passed before the eyes of the old man, and then, although it was a painful thing to do, he crept out of bed and began to write. Some one of the grotesques had made a deep impression on his mind and he wanted to describe it.

At his desk the writer worked for an hour. In the end he wrote a book which he called "The Book of the Grotesque." It was never published, but I saw it once and it made an indelible impression on my mind. The book had one central thought that is very strange and has always remained with me. By remembering it I have been able to understand many people and things that I was never able to understand before. The thought was involved but a simple statement of it would be something like this:

That in the beginning when the world was young there were a great many thoughts but no such thing as a truth. Man made the truths himself and each truth was a composite of a great many vague thoughts. All about in the world were the truths and they were all beautiful.

The old man had listed hundreds of the truths in his book. I will not try to tell you all of them. There was the truth of virginity and the truth of passion, the truth of wealth and of poverty, of thrift and of profligacy, of carelessness and of abandon. Hundreds and hundreds were the truths and they were all beautiful.

And then people came along. Each as he appeared snatched up one of the truths and some who were quite strong snatched up a dozen of them.

It was the truths that made the people grotesques. The old man had quite an elaborate theory concerning the matter. It was his notion that the moment one of the people took one of the truths to himself, called it his truth, and tried to live his life by it, he became a grotesque and the truth he embraced became a falsehood.

You can see for yourself how the old man, who had spent all his life writing and was filled with words, would writes hundreds of pages concerning this matter. The subject would become so big in his mind that he himself would be in danger of becoming a grotesque. He didn't, I suppose, for the same reason that he never published the book. It was the young thing inside him that saved the old man.

Concerning the old carpenter who fixed the bed for the writer, I only mentioned him because he, like many of what are called very common people, became the nearest thing to what is understandable and lovable of all the grotesques in the writer's book.

Source: Anderson, Sherwood. 1919. Pp. 21–24 in *Winesburg, Ohio.* New York: Penguin.

John Dos Passos on Randolph Bourne (1919)

In this obituary for Randolph Bourne, John Dos Passos identifies the profound lack of choices afforded to those with body differences, while also noting that choice persists as the American value par excellence. As a person with a disability, one's freedom to choose is already curtailed at birth, and one's body becomes a constant reminder of this foreclosure on bodily liberties. In addition, Dos Passos uses the occasion to comment upon the radical insights into war and the wages of social disenfranchisement possessed by disabled thinkers and writers.

Randolph Bourne

Randolph Bourne came as an inhabitant of this earth without the pleasure of choosing his dwelling or his career. He was a hunchback, grandson of a congregational minister, born in 1886 in Bloomfield, New Jersey; there he attended grammar school and high school. At the age of seventeen he went to work as a secretary to a Morristown businessman. He worked his way through Columbia working in a pianola record factory in Newark, working as proofreader, piano tuner, accompanist in a vocal studio in Carnegie Hall.

At Columbia he studied with John Dewey, got a traveling fellowship that took him to England Paris Rome Berlin Copenhagen, wrote a book on the Gary schools. In Europe he heard music, a great deal of Wagner and Scriabine and bought himself a black cape.

This little sparrowlike man
tiny twisted bit of flesh in a black cape,
always in pain and ailing,
put a pebble in his sling
and hit Goliath square in the forehead with it.
War, he wrote, is the health of the state.

Half musician, half educational theorist (weak health and being poor and twisted in body and on bad terms with his people hadn't spoiled the world for Randolph Bourne; he was a happy man, loved die Meistersinger and playing Bach with his long hands that stretched so easily over the keys and pretty girls and good food and evenings of talk. When he was dying of pneumonia a friend brought him an eggnog; Look at the yellow, its beautiful, he kept saying as his life ebbed into delirium and fever. He was a happy man.) Bourne seized with feverish intensity on the ideas then going around at Columbia he picked rosy glasses out of the turgid jumble of John Dewey's teaching through which he saw clear and sharp.

the shining capitol of reformed democracy,
Wilson's New Freedom;
but he was too good a mathematician;
he had to work the equations out;
with the result that in the crazy spring of 1917
he began to get unpopular where his bread was buttered at the New Republic;
for New Freedom read Conscription, for Democracy,
Win the War, for Reform, Safeguard the Morgan
Loans for Progress Civilization Education Service,
Buy a Liberty Bond, Strafe the Hun, Jail the Objectors.

He resigned from the New Republic; only The Seven Arts had the nerve to publish his articles against the war. The backers of the Seven Arts took their money elsewhere; friends didn't like to be seen with Bourne, his father wrote him begging him not to disgrace the family name. The rainbowtinted future of reformed democracy went pop like a pricked soapbubble.

The liberals scurried to Washington; some of his friends pled with him to climb up on Schoolmaster Wilson's sharabang; the war was great fought from the swivel chairs of Mr. Creel's bureau in Washington.

He was cartooned, shadowed by the espionage service and the counter-espionage service; taking a walk with two girl friends at Wood's Hole he was arrested, a trunk full of manuscript and letters stolen from him in Connecticut. (Force to the utmost, thundered Schoolmaster Wilson).

He didn't live to see the big circus of the Peace of Versailles or the purplish normalcy of the Ohio Gang. Six weeks after the armistice he died planning an essay on the foundations of future radicalism in America.

If any man has a ghost
Bourne has a ghost,
a tiny twisted unscared ghost in a black cloak
hopping along the grimy old brick and brownstone
streets still left in downtown New York,
crying out in a shrill soundless giggle;
War is the health of the state.

Source: Dos Passos, John. 1919. *U.S.A.* Available at: http://www.art4exec.org/who-was-bourne.htm

Karl Binding and Alfred Hoche, from *Permission for the Destruction of Worthless Life, Its Extent and Form* (1920)

Binding and Hoche's influential work argued that the German state was failing under the burden of caring for disabled people who were using up a disproportionate amount of resources. They referred to such individuals as "lives unworthy of life" and divided potential candidates for state-sponsored "euthanasia" into three groups: war wounded, patients in permanent comas, and "idiots" housed in psychiatric hospitals. The work proved critical in fashioning a medical industry that would recognize killing as a viable application of medical technology.

Are there humans who have lost their human characteristics to such an extent that their continued existence has lost all value for themselves and for society? One only needs to pose the question and a feeling of anxiety stirs in anyone who is used to assessing the value of individual lives both to the people themselves and to the community. He is painfully aware of how wasteful we are with the most valuable and self-sufficient lives which are full of energy and vigour and what labor, patience, and resources are squandered simply in order to try and sustain worthless lives until nature—often cruelly tardy—removes the last possibility of their continuation. If, at the same time, one thinks of a battlefield covered with thousands of young corpses, or of a mine in which hundreds of hard-working miners have been buried, and if one compares them to our institutions for idiots, with the care which is devoted to their inmates—one is deeply shocked by the sharp discrepancy between, on the one hand, the sacrifice of man's most precious resource and, on the other, the tremendous care devoted to creatures which are not only completely worthless but are of negative value.

It cannot be doubted that there are people for whom death would come as a release and, at the same time, for society and the state in particular, would represent liberation from a burden which, apart from being an example of a great self sacrifice, is not of the slightest use. . . .

However, I am firmly of the opinion that rational calculation should not be the sole basis on which to answer this question; the reply must win approval through a deep sense of correctness. Every killing which is permitted must be felt, at least by the person concerned, as a release; otherwise, such permission must be ruled out.

It follows from this, however, that it is absolutely vital to respect completely everybody's will to live, even that of the most sick, tortured, or useless people.

The legal order can never be allowed to operate as a murderer and a killer forcibly breaking the will to live of its victims. Naturally, there can be no question of permitting the killing of the feeble-minded person who feels happy with his life.

Source: Binding, Karl, and Alfred Hoche. 2001. *Permission for the Destruction of Worthless Life, Its Extent and Form.* In Noakes, Jeremy, and Geoffrey Pridham, eds. *Nazism 1919–1945: State, Economy and Society, 1933–1939: A Documentary Reader.* Exeter, UK: University of Exeter Press. (Originally published 1920)

W. E. B. Du Bois, "Race Intelligence" (1920)

In this comment, Du Bois attacks the legacy of scientific racism in efforts to find a physical source for proving African American inferiority.

For a century or more it has been the dream of those who do not believe Negroes are human that their wish should find some scientific basis. For years they depended on the weight of the human brain, trusting that the alleged underweight of less than a thousand Negro brains, measured without reference to age, stature, nutrition or cause of death, would convince the world that black men simply could not be educated. Today scientists acknowledge that there is no warrant for such a conclusion and that in any case absolute weight of the brain is no criterion for racial ability. Measurements of the bony skeleton followed and great hopes of the scientific demonstration of race inferiority were held for a while. But they had to be surrendered when Zulus and Englishmen were found in the same dolichocephalic class. Then came psychology: The children of the public schools were studied and it was discovered that some colored children ranked lower than white children. This gave wide satisfaction even though it pointed out that the average included most of both races and that considering the educational opportunities and social environment of the races the differences were measurements simply of the ignorance and poverty of the black child's surroundings.

Source: Du Bois, W. E. B. 1987. "Race Intelligence." In Huggins, Nathan I., ed. *Du Bois: Writings.* New York: Library of America. (Originally published 1920)

O Hwa-Su, "The Bride Who Would Not Speak" (1920)

This tale was told by O Hwa-Su and collected by Zong In-Sob in Korea in 1920. The tale includes a common Korean saying given to a woman getting married: she should be "mute for three years, deaf for three years and blind for three years." This indicates women's difficult position in their parents-in-law's family and patriarchal culture. They were admonished to perform a disabled person, but they could never be actually disabled to remain in marriage.

Once upon a time a man said to his daughter when she was setting out to go for her wedding, 'A daughter-in-law's life is very hard. She must pretend that she does not see the things that are to be seen, that she does not hear the words spoken around her, and she must speak as little as possible.'

So for three years after her marriage the girl spoke never a word. Her husband's family thought she was deaf and dumb, and so they decided to send her back to her father's house.

As she went back riding in a palanquin she chanced to hear a mountain pheasant call, and she said, 'Dear pheasant! I have missed your voice these long years.' Her father-in-law, who was walking beside the palanquin, was overjoyed to hear her speak and took her back to her husband at once. Then he sent his servants to catch the pheasant.

As she cooked the pheasant the daughter-in-law sang, 'The wings that protected me I will serve to my father-in-law. And the rolling nagging beak I will serve to my mother-in-law. And the rolling eyes will do for my husband's sister.'

Source: Zong In-Sob. 1969. "The Bride Who Would Not Speak." In *Folk Tales from Korea.* New York: Greenwood Press.

Ewald Meltzer, Survey Sent to German Parents of 162 Disabled Children (1920)

In 1920, Ewald Meltzer sent around the following survey to the parents of 162 disabled children in order to assess attitudes toward euthanasia. Nazi advocates of medical murder later referenced the poll as evidence that parents would not protest the death of their institutionalized disabled children. In fact, the architects of the children's "euthanasia" program employed parental comments about how such killings might be carried out with their consent.

Meltzer Questionnaire

Given in 1920 to male parents or guardians of two hundred children living at the Katharinehof State Home for Non-Educable, Feeble-Minded Children in Grosshennersdorf, Germany.

> Would you give your consent in every circumstance to a painless shortening of your child's life, after an expert had determined him incurably imbecilic?
>
> Would you give your consent only if you could no longer care for your child, for example if you were about to pass away?

Would you give your consent if your child were suffering serious physical and mental anguish?

What is your wife's opinion of questions 1–3?

Source: Burleigh, Michael. 2000. *The Third Reich: A New History.* New York: Hill and Wang.

Martin Barr, "Some Notes on Asexualization" (1920)

Martin Barr, MD, served as chief physician of the Pennsylvania Training School for Feeble-minded Children in Elwyn, Pennsylvania. He was one of the fiercest advocates of coerced sterilization of individuals diagnosed as feebleminded in the United States.

Asexualization is not a new subject. Indeed as practiced in many lands, in many forms, for thousands of years, it is almost as old as the world itself. In the Scriptures we find mention of it, notably in the Book of Job, and in some parts of the New Testament; and it is often referred to in other ancient writings: the Histories of Assyria, China, Egypt, India, Persia, Rome and Greece speak of it again and again. It was practiced before the reign of Semiramis; and Andramgtis, King of Lydia, sanctioned sterilization in both sexes. . . .

Goethe said: "Fools and sensible people are alike harmless. It is only the half-foolish and half-wise who are most dangerous." Surely this is a truth verified by the fact that the feeble-minded have so multiplied and increased as to become a distinct race, now beginning to be recognized as such; needing protection for themselves and the world from them. But what is not *fully* *recognized,* as yet, is the fact that mental defectives suffer not only from exaggerated sexual impulses; but from mental and moral debility, causing always a minimum of judgment and of will-power, leaving them greater slaves to the impulse of the moment, than are many normal children.

There is consequently little, if any, balance between the intellectual and moral faculties, and but a rudimentary idea of relative values, constituting inability to recognize or to resist coming in; rendering them therefore mere creatures of the moment and slaves of temptation. Indeed they are so crooked that they are parallel to nothing, and one can hardly fathom how protean are the vagaries of mental defect.

That the quieting of nervous and exaggerated emotional excitation is a primary and necessary factor in developing and training mental defectives, experience has proven; it further points to asexualization as a powerful agent; a measure therefore contributing to the protection and advancement of the individual, either within or without institution walls.

Moreover this quieting of, or power of holding in abeyance, the sexual impulses, is the surest weapon for combating prostitution, providing thus a protection to society as well as to the irresponsible who, recognized or unrecognized, proves either seducer or victim.

"Race betterment," thus once secured, insures not only diminution of the defective, but also of the criminal ranks, now continually recruited from that class.

This movie still is from The Hunchback of Notre Dame, *Lon Chaney's first big-budget film and the one that made him a star of the cinema screen. Chaney delivers a remarkable performance as Quasimodo, using heavy weights to simulate a "crippled" gait but still managing to retain the expressive power of his body.*

Source: *The Hunchback of Notre Dame* (1923), directed by Wallace Worsley. B&W, 69 minutes. Reprinted by permission of Paul Darke.

The jails, penitentiaries, almshouses and reformatories are filled with defectives, many of whom are allowed to return unprotected to life outside, where—as before stated, with the sexual impulses ever exaggerated—they reproduce their kind from 2 to 6 times more rapidly than do normal people.

Heredity being the primary factor in production, the natural means of arrest is the removal of sexual desire in the unfit, and destruction of power to procreate.

A very conservative estimate places the number of mental defectives in the United States at between 300,000 and 400,000, while it is fairly computed that of these only 39,000 are cared for in institutions.

There are 51,000 avowed cases of feeble-minded in the state of New York, over 14,000 in Massachusetts, and in Pennsylvania the number has been estimated at 20,000.

It has been conjectured that over 50 percent of the prostitutes in the United States are feeble-minded.

We quarantine influenza, leprosy and venereal diseases and have laws governing the use of alcohol and of narcotics; and, while we have some laws for the *protection* of the feeble-minded, we have accomplished but little to stem the tide of degeneracy, and pollution of our normal population.

In 1892 the Training School at Elwyn demonstrated the benefit of asexualization by the sterilization of two patients. When in 1894 Dr. P. Hoyt Pilcher, of Winfield, Kansas, reported that he had operated upon a number [of] boys (38 cases) with gratifying results, a howl went up throughout the length and breadth of our land, the like of which was never heard before or since. The political papers censured him, and the medical journals, in the main praised and upheld him.

Later, Dr. Everett Flood, in Massachusetts, operated upon 26 cases, with the result that sexual appetite disappeared absolutely in all but two, and in these was markedly reduced.

Necessity for the adoption of heroic measures has been found, in the experience of a large proportion of institutions, asylums and prisons, and is now being persistently urged by leaders in the work.

That mere sentimental prejudice is gradually succumbing to the promulgation of this prevention of "True Race Suicide" is shown in the action of the legislatures of some thirteen states legalizing the asexualization of imbeciles, criminals and rapists.

Pennsylvania, the first to demonstrate by operation the beneficial results attained by asexualization, was also the first to demand legislative authority in broadening the work. In this thrice have her efforts been defeated—each time suppressed by a single voice—the veto of two governors (1905–1909) and the influence of one legislator (1911).

In 1907 Indiana passed the first bill authorizing operations upon confirmed criminals, idiots, imbeciles and rapists in state institutions.

Some 800 were vasectomied; and of these 200 were operated upon at their own request.

California followed with a law to permit the asexualization of inmates of state hospitals for feebleminded, and convicts in state institutions.

In 1909 Connecticut enacted a similar law, followed by New Jersey, Wisconsin and New Hampshire; the operations to be oophorectomy in the females and castration, or vasectomy, in the males.

We must face the fact that the very life-blood of the nation is being poisoned by the rapid production of mental and moral defectives, and the only thing that will dam the flood of degeneracy and insure the survival of the fittest, is abrogation of all power to procreate.

The shibboleth of the day is "lock up all degenerates once so proven." And this we do. But sooner or later the brighter ones, whose defects for a time are masked by the benefits received from training, are removed from the protection of sequestration, either by parents or guardians convinced of "cure" so-called; or again by the misdirected philanthropy of idle women; or some charitable societies, eager to set them at liberty "that they may have their chance." They have all right—and pressing forward they go out to meet the "Years to Come" and tramp through the black morasses of sexual filth until precipitated into the whirlpool of the stormy "Sea of Life" from which few, if any, ever return: and double prisoners and captives of the victims and their own passions, they sink lower and lower, consorting with the muck and filth, the scum and dregs of mankind. Then these hereditary irresponsibles—degenerates, imbeciles, defective delinquents and epileptics—the very nightmare of the human race, ever with sexual impulses exaggerated, find their "chance" in reproduction. Unconsciously innocent poisoners of a normal race, they are nevertheless its worst enemy.

In regard to the character of operations: Personally I prefer castration for the male, and oophorectomy for the female, as insuring security beyond adventure; and when performed on the young, desire almost entirely ceases, or is at least held in reasonable abeyance.

If for sentimental reasons the removal of the organs are objected to, vasectomy or fellectomy may be substituted.

Source: Barr, Martin W. 1920. "Some Notes on Asexualization, with a Report of Eighteen Cases." *Journal of Nervous and Mental Diseases* 51:231–241. From the Smith Ely Jeliffe Collection, proprietor Dr. David Braddock, University of Colorado, Boulder.

Helen MacMurchy, from *The Almosts: A Study of the Feebleminded* (1920)

This excerpt provides an early example of literary analysis that considers artistic attention to disabled characters. While the author gives credit for this representational "kindness," she also affirms a eugenics divide between "normal" and "abnormal" citizens.

Chapter V. The Case for the Feeble-minded

Great writers have recognized the feeble-minded. They know that there are such people. When they painted the great world there was a place found on the canvas for the feeble-minded. Great writers discovered long before the modern "uplifter" was born that we must reckon with the mental defective as one of those many things in heaven and earth that are not dealt with by some philosophers, and yet that makes a great difference to the community and to social progress.

Kindness is the key that unlocks the problem of the feeble-minded—kindness and wisdom. The feeble-minded must have a permanent guide, philosopher and friend, so Wamba has Cedric and Gurth, Maggy has Little Dorrit, Billy has Dr. Amboyne, and Henry Little, and Barnaby Rudge has his mother. Mental defectives cannot manage by themselves, though we have tried to pretend to the contrary.

As to our attitude towards them: Nicholas Nickleby "treated Smike like a human creature." So he was. So was the Fool in "Lear." So with the rest. They are human creatures—human beings, and differ among themselves in reactions, in character, in endowment, in emotion, almost as much as the rest of us. Yet while this is true, there remains a world of difference even in fiction between the normal and the mentally defective. Little Dorrit and Maggy, Gurth and Wamba, Gabriel Varden and Barnaby Rudge—the verdict is never in doubt for a moment. The one makes upon the reader the definite impression of a normal person, but the other is "not all there."

Source: MacMurchy, Helen. 1920. Pp. 169–170 in *The Almosts: A Study of the Feebleminded.* Boston: Houghton Mifflin.

T. S. Eliot, from *The Waste Land* (1922)

Eliot builds on the classical tradition that links disability to superhuman gifts through the figure of Tiresias, the blind seer. However, what the blind prophet foretells in The Waste Land is the banality and insignificance of modern existence.

From "The Fire Sermon"

At the violet hour, when the eyes and back
Turn upward from the desk, when the human engine waits
Like a taxi throbbing waiting,
I Tiresias, though blind, throbbing between two lives,
Old man with wrinkled female breasts, can see
At the violet hour, the evening hour that strives
Homeward, and brings the sailor home from sea,
The typist home at teatime, clears her breakfast, lights
Her stove, and lays out food in tins.
Out of the window perilously spread
Her drying combinations touched by the sun's last rays,
On the divan are piled (at night her bed)
Stockings, slippers, camisoles, and stays.
I Tiresias, old man with wrinkled dugs
Perceived the scene, and foretold the rest—
I too awaited the expected guest.
He, the young man carbuncular, arrives,
A small house agent's clerk, with one bold stare,
One of the low on whom assurance sits
As a silk hat on a Bradford millionaire.
The time is now propitious, as he guesses,
The meal is ended, she is bored and tired,
Endeavours to engage her in caresses
Which still are unreproved, if undesired.
Flushed and decided, he assaults at once;
Exploring hands encounter no defence;
His vanity requires no response,
And makes a welcome of indifference.
(And I Tiresias have foresuffered all
Enacted on this same divan or bed;
I who have sat by Thebes below the wall
And walked among the lowest of the dead.)
Bestows one final patronizing kiss,
And gropes his way, finding the stairs unlit . . .

Source: Eliot, T. S. 1922. *The Waste Land.* Available at: http://www.bartleby.com/201/1.html

William Carlos Williams, "To Elsie" (1923)

Perhaps the premier imagist poet in the United States, William Carlos Williams also served as a physician in New Jersey. His poem "To Elsie" metaphorizes modernist concerns with collapsing social institutions in the figure of Elsie, the "broken-brained" maid who took care of his house. Enshrining a common eugenics theme of hereditary degeneration, Elsie represents both an infantilized disabled woman and a symbol of capitalism's unbridled pursuit of consumerist lifestyles.

The pure products of America
go crazy—
mountain folk from Kentucky

or the ribbed north end of
Jersey
with its isolate lakes and

valleys, its deaf-mutes, thieves
old names
and promiscuity between

devil-may-care men who have taken
to railroading
out of sheer lust of adventure—

and young slatterns, bathed
in filth
from Monday to Saturday

to be tricked out that night
with gauds
from imaginations which have no

peasant traditions to give them
character
but flutter and flaunt

sheer rags—succumbing without
emotion
save numbed terror

under some hedge of choke-cherry
or viburnum—
which they cannot express—

Unless it be that marriage
perhaps
with a dash of Indian blood

will throw up a girl so desolate
so hemmed round
with disease or murder

that she'll be rescued by an
agent—
reared by the state and

sent out at fifteen to work in
some hard-pressed
house in the suburbs—

some doctor's family, some Elsie—
voluptuous water
expressing with broken

brain the truth about us—
her great
ungainly hips and flopping breasts

addressed to cheap
jewelry
and rich young men with fine eyes

as if the earth under our feet
were
an excrement of some sky

and we degraded prisoners
destined
to hunger until we eat filth

while the imagination strains
after deer
going by in fields of goldenrod in

the stifling heat of September
Somehow
it seems to destroy us

It is only in isolate flecks that
something
is given off

No one
to witness
and adjust, no one to drive the car

Source: Williams, William Carlos. 1923. "To Elsie." Available at: http://eir.library.utoronto.ca/rpo/display/poem2318.html

Henry Edward Abt, from *The Care, Cure, and Education of the Crippled Child* (1924)

Henry Edward Abt was a progressive social reformer during the early twentieth century in the United States. This excerpt provides a good example of the ways in which Abt sought to champion the treatment and education of disabled children as a primary sign of modern U.S. enlightenment.

In the course of this book we shall first step back and examine those darker ages when physical imperfection was a horrible stigma. We shall examine in a cursory manner those physical conditions which cause children to be handicapped. We shall then follow the little cripple as he is carried to the modem clinic, subjected to modern miracles of surgery, brought to the cheerful convalescent home, where he perhaps stands erect for the first time in his life, and where he is brought from the darkness of ignorance and introduced to the delights of education; and we shall finally gaze upon him and his fellows as they step forth into life and find themselves fully able to cope with their problems as if they had never been prostrate. . . .

Chapter I: Introduction

On a hot summer afternoon in 1863, a foreign representative to the United States, several members of the Cabinet, and the President of the United States are said to have been traversing one of the broad avenues of Washington. They were discussing matters of international importance. It was, therefore, somewhat surprising to the others when Abraham Lincoln abruptly interrupted the conversation and left the group. Stooping at a nearby tree, the emancipator lifted a fallen baby bird to its nest. Returning to his associates, Lincoln remarked, “And now, gentlemen, continue.”[1]

Although one of the greatest leaders the world has ever known found time to give his attention to an unfortunate little bird, until the past century all humanity has carelessly and consistently neglected its own unfortunate crippled children. For centuries of the Christian Era men have declared, like Mr. Scrooge in Charles Dickens’ immortal *Christmas Carol,* “What then, if he be like to die, he had better do it, and decrease the surplus population.” Hundreds of millions of those declaring themselves followers of the Master who said, “Suffer little children to come unto me, for such is the kingdom of God,”[2] and again, to the hunchback woman, “Woman, thou art loosed from thine infirmity,”[3] have made crippled children public jests, exiles from society.

The movement to care for and educate children, maimed or deformed by disease or accident, may be considered to have two aspects, the humanitarian and the sociological. This classification is recorded not because any such distinct cleavage exists, but to satisfy those who insist upon a mechanistic interpretation of life. Unless the “science” of sociology succeeds in making life more beautiful for its students, for the immediate spiritual happiness of the largest proportion of human beings, or for generations to come, it is an inexcusable waste of time. Were life really the dismal mechanical existence that some of our sociological scholars are pleased to interpret, it would seem that this information had best be transmitted to as few humans as possible. If life, properly understood, were truly nothing but a birth-to-death struggle, devoid of joy or pleasure, it would seem that the “laissez-faire” policy of those who interpret it in this manner had best be extended to education and study of the sort they pursue. The popular proverb, “ignorance is bliss” is easily extended to this sort of knowledge, for the ignorant might then grasp their few momentary transports of ecstasy without realizing their error.

As a matter of fact, no such situation exists. The study of crippled children brings to the right-minded man an appreciation of his own happy, healthy existence, a deeper understanding of the suffering and distress of his neighbors, leading to a deeper and finer emotional experience, as well as the knowledge of how to reduce and alleviate this suffering.

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[1] The author has searched unsuccessfully for the source of this anecdote. It is a story he heard as a young child, and is one which he has never forgotten. It is very appropriately illustrative of the spirit of the movement to aid crippled children.

[2] St. Mark, Chapter X, 14.

[3] St. Luke, Chapter XIII, 12.

Source: Abt, Henry Edward. 1924. *The Care, Cure, and Education of the Crippled Child.* International Society for Crippled Children. Available at: http://www.disabilitymuseum.org/lib/docs/1449.htm

Thomas Mann, from *The Magic Mountain* (1924)

Mann, for whom the modern world resembles a hospital, examines life at the microscopic level where matter experiences a ceaseless cycle of renewal and decay. Human life is the awakened consciousness of this relation between living and dying.

What then was life? It was warmth, the warmth generated by a form-preserving instability, a fever of matter, which accompanied the process of ceaseless decay and repair of albumen molecules that were too impossibly complicated, too impossibly ingenious in structure. It was the existence of the actually impossible-to-exist, of a half-sweet, half-painful balancing, or scarcely balancing, in this restricted and feverish process of decay, and renewal, upon the point of existence. It was not matter and it was not spirit, but something between the two, a phenomenon conveyed by matter, like the rainbow on the waterfall, and like the flame. Yet why not material—it was sentient to the point of desire and disgust, the shamelessness of matter become sensible of itself, the incontinent form of being. It was a secret and ardent stirring in the frozen chastity of the universal; it was a stolen and voluptuous impurity of sucking and secreting; an exhalation of carbonic acid gas and material impurities of mysterious origin and composition. It was a pullulation, an unfolding, a form-building (made possible by the over-balancing of its instability, yet controlled by the laws of growth inherent within it), of something brewed out of water, albumen, salt and fats, which was called flesh, and which became form, beauty, a lofty image, and yet all the time the essence of sensuality and desire. For this form and beauty were not spirit-borne; nor, like the form and beauty of sculpture, conveyed by a neutral and spirit-consumed substance, which could in all purity make beauty perceptible to the senses. Rather was it conveyed and shaped by the somehow awakened voluptuousness of matter, of the organic, dying-living substance itself, the reeking flesh.

Source: Mann, Thomas. 1927. Lowe-Porter, H. T., trans. *The Magic Mountain.* New York: Random House.

▣ Oliver Wendell Holmes, *Buck v. Bell*, 274 U.S. 200 (1927)

In one of the most notorious eugenics-based legal cases, U.S. Supreme Court Justice Oliver Wendell Holmes based his decision in support of sterilization on the longstanding prejudice that cognitively disabled women were more promiscuous than non-disabled women. Eugenics historians have since established that Carrie Buck—the woman targeted in the case because of a diagnosis of "feeblemindedness"—had been raped by a relative of her foster parents. Further study of the case has revealed that her lawyer in the case acted in collusion with the lawyer for the Virginia Colony to ensure that the sterilization law was upheld.

Mr. Justice Holmes delivered the opinion of the Court.

This is a writ of error to review a judgment of the Supreme Court of Appeals of the State of Virginia, affirming a judgment of the Circuit Court of Amherst County, by which the defendant in error, the superintendent of the State Colony for Epileptics and Feeble Minded, was ordered to perform the operation of salpingectomy upon Carrie Buck, the plaintiff in error, for the purpose of making her sterile. 143 Va. 310. The case comes here upon the contention that the statute authorizing the judgment is void under the Fourteenth Amendment as denying to the plaintiff in error due process of law and the equal protection of the laws.

Carrie Buck is a feeble minded white woman who was committed to the State Colony above mentioned in due form. She is the daughter of a feeble minded mother in the same institution, and the mother of an illegitimate feeble minded child. She was eighteen years old at the time of the trial of her case in the Circuit Court, in the latter part of 1924. An Act of Virginia, approved March 20, 1924 recites that the health of the patient and the welfare of society may be promoted in certain cases by the sterilization of mental defectives, under careful safeguard, &c.; that the sterilization may be effected in males by vasectomy and in females by salpingectomy, without serious pain or substantial danger to life; that the Commonwealth is supporting in various institutions many defective persons who if now discharged would become a menace but if incapable of procreating might be discharged with safety and become self-supporting with benefit to themselves and to society; and that experience has shown that heredity plays an important part in the transmission of insanity, imbecility, &c. The statute then enacts that whenever the superintendent of certain institutions including the above named State Colony shall be of opinion that it is for the best interests of the patients and of society than an inmate under his care should be sexually sterilized, he may have the operation performed upon any patient afflicted with hereditary forms of insanity, imbecility, &c., on complying with the very careful provisions by which the act protects the patients from possible abuse.

The superintendent first presents a petition to the special board of directors of his hospital or colony, stating the facts and the grounds for his opinion, verified by affidavit. Notice of the petition and of the time and place of the hearing in the institution is to be served upon the inmate, and also upon his guardian, and if there is no guardian the superintendent is to apply to the Circuit Court of the County to appoint one. If the inmate is a minor notice also is to be given to his parents if any with a copy of the petition. The board is to see to it that the inmate may attend the hearings if desired by him or his guardian. The evidence is all to be reduced to writing, after the board has made its order for or against the operation, the superintendent, or the inmate, or his guardian, may appeal to the Circuit Court of the County. The Circuit Court may consider the record of the board and the evidence before it and such other admissible evidence as may be offered, and may affirm, revise, or reverse the order of the board and enter such order as it deems just. Finally any party may apply to the Supreme Court of Appeals, which, if it grants the appeal, is to hear the case upon the record of the trial in the Circuit Court and may enter such order as it thinks the Circuit Court should have entered. There can be no doubt that so far as procedure is concerned the rights of the patient are most carefully considered, and as every step in this case was taken in scrupulous compliance with the statute and after months of observation, there is no doubt that in that respect the plaintiff in error has had due process of law.

The attack is not upon the procedure but upon the substantive law. It seems to be contended that in no circumstances could such an order be justified. It certainly is contended that the order cannot be justified upon the existing grounds. The judgment finds the facts that have been recited and that Carrie Buck "is the probable potential parent of socially inadequate offspring, likewise afflicted, that she may be sexually sterilized without detriment to her general health and that her welfare and that of society will be promoted by her sterilization," and thereupon makes the order. In view of the general declarations of the legislature and the specific findings of the Court, obviously we cannot say as matter of law that the grounds do not exist, and if they exist they justify the result. We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. *Jacobson* v. *Massachusetts,* 197 U.S. 11. Three generations of imbeciles are enough.

But, it is said, however it might be if this reasoning were applied generally, it fails when it is confined to the small number who are in the institutions named and is not applied to the multitudes outside. It is the usual last resort of constitutional arguments to point out shortcomings of this sort. But the answer is that the law does all that is needed when it does all that it can, indicates a policy, applies it to all within the lines, and seeks to bring within the lines all similarly situated so far and so fast as its means allow. Of course so far as the operations enable those who otherwise must be kept confined to be returned to the world, and thus open the asylum to others, the equality aimed at will be more nearly reached.

Judgment affirmed.

Mr. Justice Butler dissents.

D. H. Lawrence, from *Lady Chatterley's Lover* (1928)

Lawrence uses Clifford, the cripple in the motor-chair, to criticize modernity's embrace of technology to the exclusion of love and the natural world. On the one hand, Clifford wants Connie to bear a son for him and to preserve the natural world from destruction. On the other hand, he wants a son only to carry forward his name, and he represents the forces of technology that attack nature. How easy would it be for Lawrence to embody these contradictory positions had Clifford not been disabled?

On a frosty morning with a little February sun, Clifford and Connie went for a walk across the park to the wood. That is, Clifford chuffed in his motor-chair, and Connie walked beside him.

The hard air was still sulphurous, but they were both used to it. Round the near horizon went the haze, opalescent with frost and smoke, and on the top lay the small blue sky; so that it was like being inside an enclosure, always inside. Life always a dream or a frenzy, inside an enclosure.

The sheep coughed in the rough, sere grass of the park, where frost lay bluish in the sockets of the tufts. Across the park ran a path to the wood-gate, a fine ribbon of pink. Clifford had had it newly gravelled with sifted gravel from the pit-bank. When the rock and refuse of the underworld had burned and given off its sulphur, it turned bright pink, shrimp-coloured on dry days, darker, crab-coloured on wet. Now it was pale shrimp-colour, with a bluish-white hoar of frost. It always pleased Connie, this underfoot of sifted, bright pink. It's an ill wind that brings nobody good.

Clifford steered cautiously down the slope of the knoll from the hall, and Connie kept her hand on the chair. In front lay the wood, the hazel thicket nearest, the purplish density of oaks beyond. From the wood's edge rabbits bobbed and nibbled. Rooks suddenly rose in a black train, and went trailing off over the little sky.

Connie opened the wood-gate, and Clifford puffed slowly through into the broad riding that ran up an incline between the clean-whipped thickets of the hazel. The wood was a remnant of the great forest where Robin Hood hunted, and this riding was an old, old thoroughfare coming across country. But now, of course, it was only a riding through the private wood. The road from Mansfield swerved round to the north.

In the wood everything was motionless, the old leaves on the ground keeping the frost on their underside. A jay called harshly, many little birds fluttered. But there was no game; no pheasants. They had been killed off during the war, and the wood had been left unprotected, till now Clifford had got his game-keeper again.

Clifford loved the wood; he loved the old oak-trees. He felt they were his own through generations. He wanted to protect them. He wanted this place inviolate, shut off from the world.

The chair chuffed slowly up the incline, rocking and jolting on the frozen clods. And suddenly, on the left, came a clearing where there was nothing but a ravel of dead bracken, a thin and spindly sapling leaning here and there, big sawn stumps, showing their tops and their grasping roots, lifeless. And patches of blackness where the woodmen had burned the brushwood and rubbish.

This was one of the places that Sir Geoffrey had cut during the war for trench timber. The whole knoll, which rose softly on the right of the riding, was denuded and strangely forlorn. On the crown of the knoll where the oaks had stood, now was bareness; and from there you could look out over the trees to the colliery railway, and the new works at Stacks Gate. Connie had stood and looked, it was a breach in the pure seclusion of the wood. It let in the world. But she didn't tell Clifford.

This denuded place always made Clifford curiously angry. He had been through the war, had seen what it meant. But he didn't get really angry till he saw this bare hill. He was having it replanted. But it made him hate Sir Geoffrey.

Clifford sat with a fixed face as the chair slowly mounted. When they came to the top of the rise he stopped; he would not risk the long and very jolty down-slope. He sat looking at the greenish sweep of the riding downwards, a clear way through the bracken and oaks. It swerved at the bottom of the hill and disappeared; but it had such a lovely easy curve, of knights riding and ladies on palfreys.

'I consider this is really the heart of England,' said Clifford to Connie, as he sat there in the dim February sunshine.

'Do you?' she said, seating herself in her blue knitted dress, on a stump by the path.

'I do! this is the old England, the heart of it; and I intend to keep it intact.'

'Oh yes!' said Connie. But, as she said it she heard the eleven-o'clock hooters at Stacks Gate colliery. Clifford was too used to the sound to notice.

'I want this wood perfect . . . untouched. I want nobody to trespass in it,' said Clifford.

There was a certain pathos. The wood still had some of the mystery of wild, old England; but Sir Geoffrey's cuttings during the war had given it a blow. How still the trees were, with their crinkly, innumerable twigs against the sky, and their grey, obstinate trunks rising from the brown bracken! How safely the birds flitted among them! And once there had been deer, and archers, and monks padding along on asses. The place remembered, still remembered.

Clifford sat in the pale sun, with the light on his smooth, rather blond hair, his reddish full face inscrutable.

'I mind more, not having a son, when I come here, than any other time,' he said.

'But the wood is older than your family,' said Connie gently.

'Quite!' said Clifford. 'But we've preserved it. Except for us it would go . . . it would be gone already, like the rest of the forest. One must preserve some of the old England!'

‘Must one?’ said Connie. ‘If it has to be preserved, and preserved against the new England? It’s sad, I know.’

‘If some of the old England isn’t preserved, there’ll be no England at all,’ said Clifford. ‘And we who have this kind of property, and the feeling for it, must preserve it.’

There was a sad pause. ‘Yes, for a little while,’ said Connie.

‘For a little while! It’s all we can do. We can only do our bit. I feel every man of my family has done his bit here, since we’ve had the place. One may go against convention, but one must keep up tradition.’ Again there was a pause.

‘What tradition?’ asked Connie.

‘The tradition of England! of this!’

‘Yes,’ she said slowly.

‘That’s why having a son helps; one is only a link in a chain,’ he said.

Connie was not keen on chains, but she said nothing. She was thinking of the curious impersonality of his desire for a son.

‘I’m sorry we can’t have a son,’ she said.

He looked at her steadily, with his full, pale-blue eyes.

‘It would almost be a good thing if you had a child by another man,’ he said. ‘If we brought it up at Wragby, it would belong to us and to the place. I don’t believe very intensely in fatherhood. If we had the child to rear, it would be our own, and it would carry on. Don’t you think it’s worth considering?’

Connie looked up at him at last. The child, her child, was just an ‘it’ to him. It . . . it . . . it!

‘But what about the other man?’ she asked.

‘Does it matter very much? Do these things really affect us very deeply? . . . You had that lover in Germany . . . what is it now? Nothing almost. It seems to me that it isn’t these little acts and little connexions we make in our lives that matter so very much. They pass away, and where are they? Where . . . Where are the snows of yesteryear? . . . It’s what endures through one’s life that matters; my own life matters to me, in its long continuance and development. But what do the occasional connexions matter? And the occasional sexual connexions especially! If people don’t exaggerate them ridiculously, they pass like the mating of birds. And so they should. What does it matter? It’s the life-long companionship that matters. It’s the living together from day to day, not the sleeping together once or twice. You and I are married, no matter what happens to us. We have the habit of each other. And habit, to my thinking, is more vital than any occasional excitement. The long, slow, enduring thing . . . that’s what we live by . . . not the occasional spasm of any sort. Little by little, living together, two people fall into a sort of unison, they vibrate so intricately to one another. That’s the real secret of marriage, not sex; at least not the simple function of sex. You and I are interwoven in a marriage. If we stick to that we ought to be able to arrange this sex thing, as we arrange going to the dentist; since fate has given us a checkmate physically there.’

Connie sat and listened in a sort of wonder, and a sort of fear. She did not know if he was right or not. There was Michaelis, whom she loved; so she said to herself. But her love was somehow only an excursion from her marriage with Clifford; the long, slow habit of intimacy, formed through years of suffering and patience. Perhaps the human soul needs excursions, and must not be denied them. But the point of an excursion is that you come home again.

‘And wouldn’t you mind *what* man’s child I had?’ she asked.

‘Why, Connie, I should trust your natural instinct of decency and selection. You just wouldn’t let the wrong sort of fellow touch you.’

She thought of Michaelis! He was absolutely Clifford’s idea of the wrong sort of fellow.

‘But men and women may have different feelings about the wrong sort of fellow,’ she said.

‘No,’ he replied. ‘You care for me. I don’t believe you would ever care for a man who was purely antipathetic to me. Your rhythm wouldn’t let you.’

She was silent. Logic might be unanswerable because it was so absolutely wrong.

‘And should you expect me to tell you?’ she asked, glancing up at him almost furtively.

‘Not at all, I’d better not know. . . . But you do agree with me, don’t you, that the casual sex thing is nothing, compared to the long life lived together? Don’t you think one can just subordinate the sex thing to the necessities of a long life? Just use it, since that’s what we’re driven to? After all, do these temporary excitements matter? Isn’t the whole problem of life the slow building up of an integral personality, through the years? living an integrated life? There’s no point in a disintegrated life. If lack of sex is going to disintegrate you, then go out and have a love-affair. If lack of a child is going to disintegrate you, then have a child if you possibly can. But only do these things so that you have an integrated life, that makes a long harmonious thing. And you and I can do that together . . . don't you think? . . . if we adapt ourselves to the necessities, and at the same time weave the adaptation together into a piece with our steadily-lived life. Don't you agree?'

Connie was a little overwhelmed by his words. She knew he was right theoretically. But when she actually touched her steadily-lived life with him she . . . hesitated. Was it actually her destiny to go on weaving herself into his life all the rest of her life? Nothing else?

Was it just that? She was to be content to weave a steady life with him, all one fabric, but perhaps brocaded with the occasional flower of an adventure. But how could she know what she would feel next year? How could one ever know? How could one say Yes? for years and years? The little yes, gone on a breath! Why should one be pinned down by that butterfly word? Of course it had to flutter away and be gone, to be followed by other yes's and no's! Like the straying of butterflies.

'I think you're right, Clifford. And as far as I can see I agree with you. Only life may turn quite a new face on it all.'

'But until life turns a new face on it all, you do agree?'

'Oh yes! I think I do, really.'

She was watching a brown spaniel that had run out of a side-path, and was looking towards them with lifted nose, making a soft, fluffy bark. A man with a gun strode swiftly, softly out after the dog, facing their way as if about to attack them; then stopped instead, saluted, and was turning downhill. It was only the new game-keeper, but he had frightened Connie, he seemed to emerge with such a swift menace. That was how she had seen him, like the sudden rush of a threat out of nowhere.

He was a man in dark green velveteens and gaiters . . . the old style, with a red face and red moustache and distant eyes. He was going quickly downhill.

'Mellors!' called Clifford.

The man faced lightly round, and saluted with a quick little gesture, a soldier!

'Will you turn the chair round and get it started? That makes it easier,' said Clifford.

The man at once slung his gun over his shoulder, and came forward with the same curious swift, yet soft movements, as if keeping invisible. He was moderately tall and lean, and was silent. He did not look at Connie at all, only at the chair.

'Connie, this is the new game-keeper, Mellors. You haven't spoken to her ladyship yet, Mellors?'

'No, Sir!' came the ready, neutral words.

The man lifted his hat as he stood, showing his thick, almost fair hair. He stared straight into Connie's eyes, with a perfect, fearless, impersonal look, as if he wanted to see what she was like. He made her feel shy. She bent her head to him shyly, and he changed his hat to his left hand and made her a slight bow, like a gentleman; but he said nothing at all. He remained for a moment still, with his hat in his hand.

'But you've been here some time, haven't you?' Connie said to him.

'Eight months, Madam . . . your Ladyship!' he corrected himself calmly.

'And do you like it?'

She looked him in the eyes. His eyes narrowed a little, with irony, perhaps with impudence.

'Why, yes, thank you, your Ladyship! I was reared here . . . '

He gave another slight bow, turned, put his hat on, and strode to take hold of the chair. His voice on the last words had fallen into the heavy broad drag of the dialect . . . perhaps also in mockery, because there had been no trace of dialect before. He might almost be a gentleman. Anyhow, he was a curious, quick, separate fellow, alone, but sure of himself.

Clifford started the little engine, the man carefully turned the chair, and set it nose-forwards to the incline that curved gently to the dark hazel thicket.

'Is that all then, Sir Clifford?' asked the man.

'No, you'd better come along in case she sticks. The engine isn't really strong enough for the uphill work.' The man glanced round for his dog . . . a thoughtful glance. The spaniel looked at him and faintly moved its tail. A little smile, mocking or teasing her, yet gentle, came into his eyes for a moment, then faded away, and his face was expressionless. They went fairly quickly down the slope, the man with his hand on the rail of the chair, steadying it. He looked like a free soldier rather than a servant. And something about him reminded Connie of Tommy Dukes.

When they came to the hazel grove, Connie suddenly ran forward, and opened the gate into the park. As she stood holding it, the two men looked at her in passing, Clifford critically, the other man with a curious, cool wonder; impersonally wanting to see what she looked like. And she saw in his blue, impersonal eyes a look of suffering and detachment, yet a certain warmth. But why was he so aloof, apart?

Clifford stopped the chair, once through the gate, and the man came quickly, courteously, to close it.

'Why did you run to open?' asked Clifford in his quiet, calm voice, that showed he was displeased. 'Mellors would have done it.'

'I thought you would go straight ahead,' said Connie.

'And leave you to run after us?' said Clifford.

'Oh, well, I like to run sometimes!'

Mellors took the chair again, looking perfectly unheeding, yet Connie felt he noted everything. As he pushed the chair up the steepish rise of the knoll in the park, he breathed rather quickly, through parted lips. He was rather frail really. Curiously full of vitality, but a little frail and quenched. Her woman's instinct sensed it.

Connie fell back, let the chair go on. The day had greyed over; the small blue sky that had poised low on its circular rims of haze was closed in again, the lid was down, there was a raw coldness. It was going to snow. All grey, all grey! the world looked worn out.

The chair waited at the top of the pink path. Clifford looked round for Connie.

'Not tired, are you?' he said.

'Oh, no!' she said.

But she was. A strange, weary yearning, a dissatisfaction had started in her. Clifford did not notice: those were not things he was aware of. But the stranger knew. To Connie, everything in her world and life seemed worn out, and her dissatisfaction was older than the hills.

They came to the house, and around to the back, where there were no steps. Clifford managed to swing himself over on to the low, wheeled house-chair; he was very strong and agile with his arms. Then Connie lifted the burden of his dead legs after him.

The keeper, waiting at attention to be dismissed, watched everything narrowly, missing nothing. He went pale, with a sort of fear, when he saw Connie lifting the inert legs of the man in her arms, into the other chair, Clifford pivoting round as she did so. He was frightened.

'Thanks, then, for the help, Mellors,' said Clifford casually, as he began to wheel down the passage to the servants' quarters.

'Nothing else, Sir?' came the neutral voice, like one in a dream.

'Nothing, good morning!'

'Good morning, Sir.'

'Good morning! it was kind of you to push the chair up that hill . . . I hope it wasn't heavy for you,' said Connie, looking back at the keeper outside the door.

His eyes came to hers in an instant, as if wakened up. He was aware of her.

'Oh no, not heavy!' he said quickly. Then his voice dropped again into the broad sound of the vernacular: 'Good mornin' to your Ladyship!'

'Who is your game-keeper?' Connie asked at lunch.

'Mellors! You saw him,' said Clifford.

'Yes, but where did he come from?'

'Nowhere! He was a Tevershall boy . . . son of a collier, I believe.'

'And was he a collier himself?'

'Blacksmith on the pit-bank, I believe: overhead smith. But he was keeper here for two years before the war . . . before he joined up. My father always had a good opinion of him, so when he came back, and went to the pit for a blacksmith's job, I just took him back here as keeper. I was really very glad to get him . . . its almost impossible to find a good man round here for a gamekeeper . . . and it needs a man who knows the people.'

'And isn't he married?'

'He was. But his wife went off with . . . with various men . . . but finally with a collier at Stacks Gate, and I believe she's living there still.'

'So this man is alone?'

'More or less! He has a mother in the village . . . and a child, I believe.'

Clifford looked at Connie, with his pale, slightly prominent blue eyes, in which a certain vagueness was coming. He seemed alert in the foreground, but the background was like the Midlands atmosphere, haze, smoky mist. And the haze seemed to be creeping forward. So when he stared at Connie in his peculiar way, giving her his peculiar, precise information, she felt all the background of his mind filling up with mist, with nothingness. And it frightened her. It made him seem impersonal, almost to idiocy.

And dimly she realized one of the great laws of the human soul: that when the emotional soul receives a wounding shock, which does not kill the body, the soul seems to recover as the body recovers. But this is only appearance. It is really only the mechanism of the re-assumed habit. Slowly, slowly the wound to the soul begins to make itself felt, like a bruise, which only slowly deepens its terrible ache, till it fills all the psyche. And when we think we have recovered and forgotten, it is then that the terrible after-effects have to be encountered at their worst.

So it was with Clifford. Once he was 'well,' once he was back at Wragby, and writing his stories, and feeling sure of life, in spite of all, he seemed to forget, and to have recovered all his equanimity. But now, as the years went by, slowly, slowly, Connie felt the bruise of fear and horror coming up, and spreading in him. For a time it had been so deep as to be numb, as it were non-existent. Now slowly it began to assert itself in a spread of fear, almost paralysis. Mentally he still was alert. But the paralysis, the bruise of the too-great shock, was gradually spreading in his affective self.

And as it spread in him, Connie felt it spread in her. An inward dread, an emptiness, an indifference to everything gradually spread in her soul. When Clifford was roused, he could still talk brilliantly and, as it were, command the future: as when, in the wood, he talked about her having a child, and giving an heir to Wragby. But the day after, all the brilliant words seemed like dead leaves, crumpling up and turning to powder, meaning really nothing, blown away on any gust of wind. They were not the leafy words of an effective life, young with energy and belonging to the tree. They were the hosts of fallen leaves of a life that is ineffectual. . . .

Source: Lawrence, D. H. 1928. *Lady Chatterley's Lover.* Available at: http://www.web-books.com/Classics/Lawrence/Chatterley/

Nicholas O. Isaacson, "The Tie That Binds" (1928)

Disabled veterans are frequently seen exclusively as clients of the welfare state, whose identities and organizations are a product exclusively of their effort to exact benefits and assistance from governments. While this perspective does speak to an aspect of the experience of disabled veterans in the modern era, it fails to understand the larger sources of the disabled veterans' solidarity in such common experiences as war, incurring a disability, and rehabilitation. It also fails to account for idealism born of these common experiences and informing their solidarity. Founded in the wake of World War I, the Disabled American Veterans of the World War included men with the complete spectrum of service-related impairments and chronic illnesses; the organization had a membership of approximately 25,000 men in the interwar period.

Born in the tumult of bloody battle—brotherhood is a bond that has endured, and will endure on down from ages past to aeons yet to come—the tie of comradeship.

Men who have bared their breasts to the barbs of a common foe, who have taken in their bodies the lethal gas, the rending shot and the macerating shell of a national enemy are joined together in a union eternal.

Soldier organizations have that bond in common.

But only in the Disabled American Veterans of the World War is that bond sanctified by the blood sacrifice, welded by the heat of passion that rises as comrade sees the soul of comrade torn from body and sent to the haven of the souls of those gone West.

We stand, all for one, one for all.

We are the DAV.

For those who made the supreme sacrifice we have reverence and cherished memories.

For those who bled, but did not die, who won back some measure of their splendid young manhood offered so freely that the nation might not be crushed beneath the heel of foreign oppression, we hold comradeship, and the hand of congratulation.

For those who still fight on, weary, tired, but dauntless, who spend their days gazing at wall and ceiling in the hospitals, we have sympathy and extend the hand and pledge of eternal loyalty.

Some of us have fared well, in those days since the dawn of Armistice broke over a world soon to be at peace, a world in which no screaming shells flew through the air, seeking lodgement in the flesh of men. Some of us have fought a bitter fight, seeking to retrace that pathway to success. Some of us are still at the lower levels of that upward path.

But whatever our condition, whatever our present status, we are Comrades. We are, as ever and for always, one for all and all for one.

Much has been done, in the years that have passed, to better conditions. Far more is yet to be encompassed.

Together, in unison, constantly striving to attain our objectives, we can wear away the opposition that stands between us and our hopes. As a great, unified power we can go forward to that state where no veteran may suffer further as a result of sacrifices for his country.

Bring in the comrade who is not a member, that we may grow in power. Bring in the comrade who may need our combined power of organization to win that which may be his just due, but of which he has been deprived.

Live, think, talk the bond that binds us.

With that thought in mind, of loyalty, faith, and love for one another, as your commander for the glorious organization year that closes with this convention, I greet you.

NICHOLAS O. ISAACSON,
State Commander.

Source: Isaacson, Nicholas O. 1928. “The Tie That Binds.” In the convention program for the State Convention of the Disabled American Veterans of the World War, Department of Illinois, May 24–26, 1928. The editors acknowledge the assistance of Dr. Jeffrey S. Resnick of the Orthotic and Prosthetic Assistance Fund, Inc., in sharing this document, which is part of his private collection. Permission granted by the Illinois Chapter of Disabled American Veterans.

William Faulkner, from *The Sound and the Fury* (1929)

William Faulkner (1897–1962), one of the most celebrated writers of the American modernist period, created lasting stories about the experiences of people with disabilities in the early twentieth century. Sometimes these were deployed as metaphors of social decay, but Faulkner also wrote memorable portraits by imagining disabled people’s subjective perspective of the world. This excerpt from The Sound and the Fury*, a novel narrated by multiple characters, opens with a first-person narrative of Benjamin Compson (“Benjy”), a 33-year-old man diagnosed with “idiocy” who was based on a neighbor of Faulkner’s with Down syndrome. The second excerpt is narrated by Benjy’s brother, Jason Compson, a violent eugenicist who would like to have his sibling institutionalized so he would no longer “disgrace” his fallen aristocratic Southern family. The dialectic between the two demonstrates the violence directed at cognitively disabled people during the eugenics period.*

Benjy Compson narrating the event leading up to his castration:

They came on. I opened the Gate and they stopped, turning. I was trying to say, and I caught her, trying to say, and she screamed and I was trying to say and trying and the bright shapes began to stop and the bright shapes began to stop and I tried to get out. I tried to get it off my face, but the bright shapes were going again. They were going up the hill to where it fell away and I tried to cry. But when I breathed in, I couldn’t breathe out again to cry, and I tried to keep from falling off the hill and I fell off the hill into the bright, whirling shapes.

Jason Compson’s internal narrative about his brother Benjamin:

How to stop my clock with a nose spray and then you can send Ben to the Navy I says or to the Calvary anyway, they use geldings in the Calvary. Then when she sent Quentin home for me to feed too I says I guess that’s right too, instead of me having to go way up north for a job they sent the job down here to me and then Mother begun to cry and I says it’s not that I have any objection to having it here; if it’s any satisfaction to you I’ll quit work and nurse it myself and let you and Dilsey keep the flour barrel full, or Ben, rent him out to a sideshow; there must be folks somewhere that would pay a dime to see him, then she cried more and kept saying my poor afflicted baby and I says yes he’ll be quite a help to you when he gets his growth not being more than one and a half times high as me now and she says she’d be dead soon and then we’d all be better off and so I says all right, all right, have it your way.

Source: Faulkner, William. 1990. *The Sound and the Fury.* New York: Vintage. Originally published 1929. Copyright 1929 and renewed 1957 by William Faulkner. Used by permission of Random House, Inc.

The Beginning of Korean Special Education (1929)

George Paik explains the origin of education for disabled children as American missionary Dr. Rosetta Hall’s effort. In his description, blind people’s traditional occupation is introduced. The Braille applied by Hall was later replaced with Pak Du Seong’s Hunmaengjeongeum, the Korean alphabet.

All persons suffering from deformities claim our sympathy, but the blind in Korea deserve a double share, not only for their physical misfortune, but also because they are often forced to become sorcerers and exorcists. In order to make “the blind girls of Korea happy, useful members of the Christian home circle,” Mrs. Rosetta S. Hall, M.D., initiated education for them. When Mrs. Hall was a girl she had learned, as an amusement, the use of the “New York point” system of raised letters. When she came to Korea as a missionary, she found that her casually acquired knowledge was most useful.

As early as the spring of 1894 she began to give instruction to the blind daughter of a Christian. When her husband died, in 1894, she returned to America. During her stay in the United States, she visited the

The Wizard of Oz *is the classic fantasy of the girl Dorothy, from middle America (Kansas), who finds herself in a surreal world populated by Munchkins and anthropomorphized animals and inanimate figures.*

Source: *The Wizard of Oz* (1939), directed by Victor Fleming. B&W/color, 100 minutes. Reprinted by permission of Paul Darke.

Institution for the Blind in New York and relearned the "Point" system. Upon her return to Korea in 1897, she adapted this to the Korean alphabet and syllabary, preparing part of a primer and the Ten Commandments, and taught the girl whom she had begun to instruct in 1894. The work thus commenced so attracted the attention of the people that by 1906 there were seven students. With money given her by friends in America, Mrs. Hall maintained a class-room in connection with her dispensary, where these girls were taught. They were not only given regular day school education, but also lessons in the practical arts.

Source: Paik, L. George. 1929. Pp. 324–325 in *The History of Protestant Missions in Korea 1832–1910.* Seoul, South Korea: Yonsei University Press.

Thomas "Fats" Waller, Harry Brooks, and Andy Razaf, "What Did I Do To Be So Black and Blue" (1929)

The blues classic, recorded by Louis Armstrong, plays with the metaphor of bruising—black and blue marks—to explore racism in the United States.

Cold empty bed . . . springs hurt my head
Feels like ole Ned . . . wished I was dead
What did I do . . . to be so black and blue
Even the mouse . . . ran from my house
They laugh at you . . . and all that you do
What did I do . . . to be so black and blue

I'm white . . . inside . . . but, that don't help my case
That's life . . . can't hide . . . what is in my face
How would it end . . . ain't got a friend
My only sin . . . is in my skin
What did I do . . . to be so black and blue
How would it end . . . I ain't got a friend
My only sin . . . is in my skin
What did I do . . . to be so black and blue

Source: Waller, Thomas "Fats," Harry Brooks, and Andy Razaf. 1929. "What Did I Do To Be So Black and Blue." Recorded by Louis Armstrong. © Alpha Music Inc. All Rights Reserved. Used by permission.

"Where Work of Salvaging Human Beings Goes Forward" (1930)

The following article details the philosophy of 1930s-era segregated schooling for physically disabled children in the United States by describing the School for Crippled Children (later named Condon School) in Cincinnati, Ohio. These institutions were established as an alternative to hospital schools, but they were largely nonintegrated, both racially and in terms of developmental disability, until the 1960s. This particular school included a full therapeutic regimen—physical, occupational, speech, medical, and dental—that functioned parallel to academic and technical training.

Cincinnati is the scene of one of the greatest human experiments going on in the present-day world—the reconstruction of human salvage. While the best that Cincinnati affords [in] medical and surgical skill is concentrated in trying to make normal as possible, misshapen bodies and twisted limbs, the best educational thought of the city is directed to preparing them to cope with the problems of life in competition with the normal persons of the community.

The experiment is being conducted and conducted happily—in the School for Crippled Children, operated by the Board of Education on Rockdale avenue, near Burnet, Avondale. The school has just about everything needed to sustain life and keep residents happy. It's a self-contained structure, and inside its walls one might eat, sleep, work, play, see the doctor, read and learn without ever finding it necessary to leave.

Cincinnati treats its unfortunate children well here. They're taught to make the most of themselves. They're taught to forget that they're handicapped. They're taught to lead normal lives. They're taught to earn a living among normal persons.

It is this psychological background, this self-confidence, that is the school's primary objective, Mrs. Mary T. Betts, principal, explains. And, proudly she conducts visitors through the structure.

She shows them the modern pediatric orthopedic, cardiac and dental offices, each fitted with the latest and most perfect of instruments and other equipment, but it is with more pride that she shows the class rooms, where the students are given a cultural background, and the handicraft rooms, where they are given a vocational background.

Handicraft Rooms

There are two principal handicraft rooms and a number of smaller ones. The one for boys is fitted out exactly like those in schools for normal children. There are work benches, equipped with vises, and there are wood-working tools of every sort. Off on the side is a smaller room, where the finished products are painted.

The work of the students shows quite the professional touch. They produce everything from small bookends on up, and each piece is carefully tooled and decorated.

On the girls' side is a large sewing room and a large kitchen. The students here learn everything from lowering hems to delicate embroidery, and from frying eggs to preparing exotic salads.

"We attempt to teach them to do the unusual sort of work," Mrs. Bett explains, "The unusual provides them a better market and a better chance to make a living."

Even while they're in school the students may make part of their expenses, for much of the work they produce finds a ready market, not only in Cincinnati, but throughout the country.

For Regular Study

The classrooms for regular study, too, are like ordinary classrooms, except that the desks and chairs may be fitted with special apparatus to make the child more comfortable.

But in spite of all such things as these, most of the pupils must be treated for their afflictions, and the school provides for them thoroughly.

In one respect it differs from other such institutions. Most of them are either only one story high, or have ramps, instead of stairways, to link the several floors. The Cincinnati school has stairways.

"After all," Mrs. Betts says, "in ordinary conditions [the] children must climb stairs. Here we can teach them to do it, increase their confidence in their ability to do it."

The stairways are provided with banisters of several heights, to aid the children, and their instructors, of course help them further. And there are elevators for wheel-chair patients.

The various clinics are each considered complete. There [are] complete orthopedic and pediatric suites, where each case receives special attention and corrective treatment. Outstanding specialists contribute their services.

There is a large restroom, open in warm weather and gassed in in cold weather, where, on cloudy days the children lie on cots in a circle under a gargantuan ray machine which substitutes for the sun.

Source: "Where Work of Salvaging Human Beings Goes Forward." 1930, December 11. *Cincinnati Times Star* 18:1.

Virginia Woolf, from *On Being Ill* (1930)

In this excerpt from an essay that was published as a slim book in 1930, Woolf proclaims the universal, the inescapable, the invisible, and the overwhelming nature of the embodied experience. Everyone has a body that endures illness and pain, and no one can be in the world separate from the body. However, the literary reflection of these truths is minimal (to Woolf's eye), because the whole idea of "this monster, the body, this miracle, its pain" is so fearsome to contemplate.

Considering how common illness is, how tremendous the spiritual change that it brings, how astonishing, when the lights of health go down, the undiscovered countries that are then disclosed, what wastes and deserts of the soul a light attack of influenza brings to view, what precipices and lawns sprinkled with bright flowers a little rise of temperature reveals, what ancient and obdurate oaks are uprooted in us by the act of sickness, how we go down into the pit of death and feel the waters of annihilation close above our heads and wake thinking to find ourselves in the presence of the angels and the harpers when we have a tooth out and come to the surface in the dentist's armchair and confuse his "Rinse the mouth—rinse the mouth" with the greetings of the Deity stooping from the floor of Heaven to welcome us—when we think of this, as we are so frequently forced to think of it, it becomes strange indeed that illness has not taken its place with love and battle and jealousy among the prime themes of literature. Novels, one would have thought, would have been devoted to influenza; epic poems to typhoid; odes to pneumonia; lyrics to toothache. But no; with a few exceptions—De Quincey attempted something of the sort in *The Opium Eater;* there must be a volume or two about disease scattered through the pages of Proust—literature does its best to maintain that its concern is with the mind; that the body is a sheet of plain glass through which the soul looks straight and clear, and, save for one or two passions such as desire and greed, is null, and negligible and non-existent. On the contrary, the very opposite is true. All day, all night the body intervenes; blunts or sharpens, colours or discolours, turns to wax in the warmth of June, hardens to tallow in the murk of February. The creature within can only gaze through the pane—smudged or rosy; it cannot separate off from the body like the sheath of a knife or the pod of a pea for a single instant; it must go through the whole unending procession of changes, heat and cold, comfort and discomfort, hunger and satisfaction, health and illness, until there comes the inevitable catastrophe; the body smashes itself to smithereens, and the soul (it is said) escapes. But of all this daily drama of the body there is no record. People write always of the doings of the mind; the thoughts that come to it; its noble plans; how the mind has civilised the universe. They show it ignoring the body in the philosopher's turret; or kicking the body, like an old leather football, across leagues of snow and desert in the pursuit of conquest or discovery. Those great wars which the body wages with the mind a slave to it, in the solitude of the bedroom against the assault of fever or the oncome of melancholia, are neglected. Nor is the reason far to seek. To look these things squarely in the face would need the courage of a lion tamer; a robust philosophy; a reason rooted in the bowels of the earth. Short of these, this monster, the body, this miracle, its pain, will soon make us taper into mysticism, or rise, with rapid beats of the wings, into the raptures of transcendentalism.

Source: Woolf, Virginia. 2003. *On Being Ill.* Ashfield, MA: Paris Press. Originally published 1930. Reprinted by permission of the Society of Authors as the literary representative of the estate of Virginia Woolf.

Erich Maria Remarque, from *The Road Back* (1931)

Another source of the solidarity of disabled veterans has been their persistent difficulties in dealing with the state in its capacity as a provider of assistance and benefits. Impersonal and insensitive administration of programs, declining commitment to fund programs during periods of fiscal stringency, and ignorance of specific disabling conditions have consistently plagued relations between disabled veterans and government. These difficulties are exacerbated under circumstances of defeat, in which governments have to contend with demoralization as well as economic collapse. In this selection, from a novel written by the most significant German interpreter of the World War I experience, the desperate situation of German disabled veterans after World War I is captured, as is the terrible toll of war upon the bodies of the veterans involved in the ghostly protest demonstration that Remarque describes.

In Freaks, *a community of circus "freaks" takes revenge on a female trapeze artist and her strong-man lover after she has married Hans, a short-statured performer, for his fortune. The director, Tod Browning, cast in key parts disabled actors, including Harry Earles, Daisy Earles, Daisy and Violet Hilton, Johnny Eck, Randion, and others. The film became deeply controversial in its day, largely because of the fact that living disabled people were employed in key roles. In the 1960s, the film experienced a revival as a cult classic as an insightful social allegory about intolerance.*

Source: *Freaks* (1932), directed by Tod Browning. B&W, 60 minutes.

Demonstrations in the streets have been called for this afternoon. Prices have been soaring everywhere for months past, and the poverty is greater even than it was during the war. Wages are insufficient to buy the bare necessities of life, and even though one may have the money it is often impossible to buy anything with it. But ever more and more gin palaces and dance halls go up, and ever more and more blatant is the profiteering and swindling.

Scattered groups of workers on strike march through the streets. Now and again there is a disturbance. A rumor is going about that troops have been concentrated at the barracks. But there is no sign of it as yet.

Here and there one hears cries and counter-cries. Somebody is haranguing at a street corner. Then suddenly everywhere is silence.

A procession of men in the faded uniforms of the frontline trenches is moving slowly toward us. It is formed up by sections, marching in fours. But white placards are carried before: *Where is the Fatherland's gratitude?—The War Cripples are starving.*

The men with one arm are carrying the placards, and they look around continually to see if the procession is still coming along properly behind them, for they are the fastest.

These are followed by men with sheep dogs on short, leather leads. The animals have the red cross of the blind at their collars. Watchfully they walk along beside their masters. If the procession halts they sit down, and then the blind men stop. Sometimes dogs off the street will rush in among the column, barking and wagging their tails, wanting to romp and play with them. But these merely turn their heads and take no notice of all the sniffing and yapping. Yet their ears are erect, pricked and alert, and their eyes are alive; but they walk as if they no longer wished to run and to jump, as if they understood for what they are there. They have separated themselves from their fellows, as Sisters of Mercy separate themselves from jolly shop girls. Nor do the other dogs persist long; after a few minutes they give up and make off in such haste that it looks almost as if they were flying from something. Only a powerful mastiff stands still, and with front legs widely straddling, barks slowly, deep and hollow, till the procession is past.

It is strange how a face without eyes alters—how in the upper half it becomes extinct, smooth and dead; and how odd the mouth is in comparison, when it speaks! Only the lower half of the face lives. All these have been shot blind; and so they behave differently from men born blind. They are more violent, and at the same time more cautious, in their gestures that have not yet gained the sureness of many years of darkness. The memory of colors, of sky, earth and twilight still lives with them. They move still as if they had eyes; involuntarily they lift and turn their heads to see who it is that speaks to them. Some have black patches or bandages over their eyes, but most go without them, as if by that means they would stand nearer to colors and the light. Their eyelids are withered and closed: only the narrow strip of the lower lid still protrudes a little, blotched, wet and red like a dim, cheerless dawn. Many of them are healthy, powerful fellows with strong limbs that would like well to move freely and have play. The pale sunset of the March sky gleams behind their bowed heads. In shop windows the first lamps are being lighted. But they hardly feel the mild, sweet air of evening on their brow. In their heavy boots they move slowly through the everlasting darkness that stretches about them like a cloud; and troubled and persistent, their thoughts clamber up and down the meager scale of figures that would mean bread and comfort and life to them, and yet cannot be. Hunger and penury stir idly in the darkened rooms of their mind. Helpless and full of dull fear, they sense their nearness; yet they cannot see them nor do aught against them but to walk slowly in their numbers through the streets, lifting up their dead faces from the darkness toward the light, in dumb appeal to others, who can still see.

Behind the blind come the men with one eye, the tattered faces of men with head wounds: wry, bulbous mouths, faces without noses and without lower jaws, entire faces one great red scar with a couple of holes where formerly were a mouth and a nose. But above this desolation, quiet, questioning, sad human eyes.

On these follow the long lines of men with legs amputated. Some already have artificial limbs that spring forward obliquely as they walk and strike clanking on the pavement, as if the whole man were artificial, made up of iron and hinges. Others have their trouser legs looped up and made fast with safety pins. These go on crutches or sticks with black rubber pads.

Then come the shakers, the shell-shocked. Their hands, their heads, their clothes, their bodies quake as though they still shuddered with horror. They no longer have control of themselves; the will has been extinguished, the muscles and nerves have revolted against the brain, the eyes become void and impotent.

One-eyed and one-armed men are pushing along wicker carriages with oilcloth covers, wherein are other men so badly wounded that they can now only live in wheeled chairs. Among them a few men come trailing a flat handcart, such as carpenters use to transport bedsteads or coffins. On it there sits a torso. The legs are gone from the hips. It is the upper half of a powerful man, nothing more. He has broad, stalwart shoulders and a big, brave face with a heavy moustache. On his head he wears a peaked cap. It may be that he was formerly a furniture mover. Beside him is a placard with wobbly lettering that he has, no doubt, painted himself—I should like to walk too, mate. With solemn face he sits there; now and then, supporting himself on his arms, he will swing a little farther up the wagon so as to change his seat.

A young, pale fellow without arms, and legs amputated at the knees, follows after him. The knees stand in thick, leather wrappings like great hooves. It appears so odd that one involuntarily looks under the wagon, as if the legs must surely carry on there beneath it. In his arm stumps he carries a placard: Many thousands of us are still lying in the hospitals.

The procession drags slowly along the streets. Wherever it passes, all is still. Once, at the corner of Hook Street, it has to wait a long time. A new dance palace is being erected there, and the street is blocked with heaps of sand, cement mixers and girders. Between the struts over the entrance is the name in illuminated letters: "Astoria Dance-Palace and Wine Saloon." The trolley with the torso stands directly beneath it, waiting until some iron girders have been shifted. The dull glow of the lighted sign floods over him, coloring the silent face to an awful red, as if it were swelling with some terrible fury and must suddenly burst into a hideous cry.

But then the column moves on, and again it is just the face of the furniture mover, pallid from the hospital in pale evening, and smiling gratefully as a comrade puts a cigarette between his lips.

Quietly the groups pass on through the streets, without cries, without indignation, resigned—a complaint, not an accusation. They know that those who can shoot no more need not expect over-much help. They will go on to the Town Hall and stand there a while; some secretary or other will say something to them, then they will break up and return singly to their rooms, their narrow dwellings, their pale children and their awful misery, without much hope, prisoners of the destiny that others made for them.

Source: Remarque, Erich Maria. 1931. Wheen, A. W., trans. Pp. 266–271 in *The Road Back.* Boston: Little, Brown, and Co. Copyright © 1931 by A.G. Ullstein; copyright renewed © 1958 by Erich Maria Remarque.

Ernest Hemingway, from "A Way You'll Never Be" (1933)

Here Hemingway plays with the stream-of-consciousness technique used by modernist writers, the style of writing by association, to represent Nick Adams's shell-shocked state of mind. This story is one of Hemingway's most successful experiments with how to picture the cognitive breakdown of a protagonist.

"I am a veteran of the Eritrea campaign," said the adjutant stiffly. "I fought in Tripoli."

"It's quite something to have met you," Nick put out his hand. "Those must have been trying days. I noticed the ribbons. Were you, by any chance, on the Carso?"

"I have just been called up for this war. My class was too old."

"At one time I was under the age limit," Nick said. "But now I am reformed out of the war."

"But why are you here now?"

"I am demonstrating the American uniform," Nick said. "Don't you think it is very significant? It is a little tight in the collar but soon you will see untold millions wearing this uniform swarming like locusts. The grasshopper, you know, what we call the grasshopper in America, is really a locust. The true grasshopper is small and green and comparatively feeble. You must not, however, make a confusion with the seven-year locust or cicada which emits a peculiar sustained sound which at the moment I cannot recall. I try to recall it but I cannot. I can almost hear it and then it is quite gone. You will pardon me if I break off our conversation?"

"See if you can find the major," the adjutant said to one of the two runners. "I can see you have been wounded," he said to Nick.

"In various places," Nick said. "If you are interested in scars I can show you some very interesting ones but I would rather talk about grasshoppers. What we call grasshoppers, that is, and what are, really, locusts. These insects at one time played a very important part in my life. It might interest you and you can look at the uniform while I am talking."

Source: Hemingway, Ernest. 1987. "A Way You'll Never Be." In *The Complete Short Stories of Ernest Hemingway.* New York: Charles Scribner's Sons. Copyright 1933 by Charles Scribner's Sons. Copyright renewed © 1961 by Mary Hemingway. Reprinted with permission of Scribner, an imprint of Simon and Schuster Adult Publishing Group.

Nathanael West, *Miss Lonelyhearts* (1933)

The medium of film creates and reinforces a series of socially horrific predicaments that are seen as simply generated by an obscene body. These are largely located around disfigurement and around those bodies that have been deemed to be repulsive in a field of vision. Many novelists of the twentieth century, including Elizabeth Bowen in Death of the Heart, *Harper Lee in* To Kill a Mockingbird, *and Manuel Puig in* The Kiss of the Spider Woman, *wrestled with the implications of film as a burgeoning and influential mode of storytelling. Because film operates as a more visual narrative medium than printed text, film stories have tended to emphasize physical appearance as a social value. Similarly, film mobilizes audiences around the suspense and shock value that can be precipitated in a simple narrative premise: the placing of visually different bodies on exhibition.*

Hence, the crafting of narratives around repulsive bodies and the development of film as a craft have occurred hand in hand. In the history of film production, one finds an entire genre of horror films developing within the visually sophisticated era of silent cinema and remaining heavily influential into the 1930s. For example, during the eugenics era in Germany, influential films developed at Babelsburg studios made the new "horror" genre a principal part of their repertoire. In the United States, subsequent to a break with Edison's efforts to control production, an alliance among Hollywood studios became the central source of filmed story products. The excerpt below is from Nathanael West's Miss Lonelyhearts. *West was among the authors who wrote about the culture and effects of classic or "golden"-era Hollywood.*

In his novels, West, like the cinema of which he writes, explored the implications of a predominantly visual medium upon those it casts as visually repulsive. This excerpt is also significant because it appears as a preface to Erving Goffman's influential, and contemporaneous, study entitled Stigma: Notes on the Management of Spoiled Identity. *Most important, primary sources on film narrative and disability are significant because a central strand of disability studies involves a critique of the misrepresentations of cinema in its presentation of disability as a horror and a personal tragedy.*

Dear Miss Lonelyhearts—

I am sixteen years old now and I don't know what to do and would appreciate it if you could tell me what to do. When I was a little girl it was not so bad because I got used to the kids on the block makeing fun of me, but now I would like to have boy friends like the other girls and go out on Saturday nites, but no boy will take me because I was born without a nose—although I am a good dancer and have a nice shape and my father buys me pretty clothes.

I sit and look at myself all day and cry. I have a big hole in the middle of my face that scares people even myself so I cant blame the boys for not wanting to take me out. My mother loves me, but she crys terrible when she looks at me.

What did I do to deserve such a terrible bad fate? Even if I did do some bad things I didn't do any before I was a year old and I was born this way. I asked Pape and he says he doesnt know, but that maybe I did something in the other world before I was born or that maybe I was being punished for his sins. I dont believe that because he is a very nice man. Ought I commit suicide?

Sincerely yours,
Desperate

Source: West, Nathanael. 1933. *Miss Lonelyhearts.* New York: James Loughlin.

Kye Yong Muk, from "Adada the Idiot" [*Paegch'i Adada*] (1935)

"Adada the Idiot" depicts Adada, a disabled woman with speech and cognitive impairment. This short story has been interpreted as offering a critique of the increasing materialism of Korean society by depicting that society as morally disabled. The story was made into films in 1956 and 1987.

Adada was a mute. When she tried to talk the only sounds she could make were a stuttering "a-da-da" over and over. Sometimes however, when she really tried, the words would come out one at a time fairly well, but this was so only with simple words.

So people ridiculed her and even though her real name was Hwak-sil, everyone called her "Adada." Naturally the name stuck, with even her father and mother coming to call her that. And for her part, whenever anyone called "Adada" she responded as though it were her real name.

"I'm getting gray hair because of you, bitch," her mother spat. "Either go on back to your husband or get the hell out of here and go somewhere and die. Bitch! Bitch! Bitch!" . . .

As if to say, "I'll do as you wish," Adada shook her head sadly and filled with fright, uncertain as to what she should do, dragged herself outside the gate.

Once outside, she still had no idea where she could go. . . .

The realization that she had no place to go made her feel a deep longing for her husband's home of five years ago, which was now useless except for the solace of tears. In those days her mother- and father-in-law had treated her well. They were concerned lest she be cold or warm, whether the work was too hard for her or whether she was tired. How eagerly they had humored her. And at night her husband had held her close to his bosom, melting her weariness. Ah, how well her husband and his parents had treated her!

And it was true. For the first five years of her marriage she had been loved by the whole family. Not that the idea of marrying a mute had been particularly appealing, but otherwise he never could have married without actually buying a wife. At 28 and still single he was finding it difficult enough to fill his own gullet. . . .

On top of that, Adada was a good worker. She docilely did whatever she was told and had never complained in the least. So it was that this family whose poverty had kept them at each other's throats with sullen looks and unpleasant words suddenly became wreathed in smiles of harmony, like a garden blessed with spring showers.

Of course, Adada was not normal and she did make mistakes, but [the] in-laws, who were being supported by her, did not look upon her with disgust, but rather made every effort to console her and to cover up her faults.

It was there that Adada felt human happiness for the first time in her life. She felt bitter whenever she thought of how her own parents had not even considered her as a human being because she was a "worthless child," or more to the point that she was a "wicked child" who was disgracing the family's good name. . . .

The years have passed and the one somjigi of paddy field which had been the foundation of their existence gradually brought them to a comfortable life. And with several hundred yen in savings, this man who was her husband began to hate his mute wife for no reason. . . .

"Bitch," he would say, "I'm sick of looking at you. Go back to your parents." And that would be followed by a beating. Still, Adada suffered patiently and did her duty as a wife and as a daughter-in-law. All of this endeared Adada even more to her in-laws. Finally the son, sensing that the daughter-in-law could not be pried away from the father and feeling domestic frustration, sold off the entire year's harvest and left home. In his quest for emotional solace he squandered all his money on sex and drink, lived a worthless life and then, joining up with some friends, crossed over the river into Antung in Manchuria.

Immersing himself in the life of this speculative city he managed, by dint of physical labor, to get together some capital, and with a few good speculative investments his dream of wealth began miraculously to come true, and almost inadvertently he managed to accumulate close to 20,000 yen. With this small fortune he picked, from the vast number of women who had been following his money, a true love for this perfect wife and took her home with him.

Then dreaming of a completely new way of life, he built another house, and his cruelty toward Adada became even worse than before. [On] top of this, his father was much taken with the intelligent, gracious new daughter-in-law whom they had no reason to be ashamed of.

No longer in favor with her in-laws, with no one to take her side, and unable to bear the beatings of her insensitive husband, she was finally driven out. . . .

But where to go? As she turned the problem over in her mind she came to the conclusion that the only one in this world she could turn to was Surong.

A bachelor, now over thirty, Surong had no parents, no brothers or sisters, no cousins. . . .

Surong had been playing up to Adada for the past year. Even though she was a mute and had been driven from her husband's home, she was nevertheless Kim Ch'o-si's daughter, so he was self-effacing, and taking care not to act too boldly, he trained his sights on her and watched carefully to determine her feelings toward him. . . .

[The] two of them exchanged wedding vows without a formal ceremony and at daybreak left the village and slipped away to an island called Simmi-do to settle down to a peaceful life. . . .

"Look," he said. "It doesn't look like a lot but there's 1,500 ryang here—that's 150 in yen. At today's prices we can easily buy 2,000 p'yŏng of land." Adada did not answer. A definite tinge of sadness flashed across her face. . . . Adada simply shook her head without speaking. . . . As a matter of fact, even when he said he had money, Adada never imagined it was so much, and when she heard Surong say he was going to buy land with all that money she could feel all the happiness she had dreamed of slipping away from her. . . .

Adada put down the basket on the sand and removed the roll of money from the waist of her trousers. With a twirl she loosened the piece of rag which had been wrapped around the money in who knows how many layers. Adada stood there staring vacantly, waiting, wishing that they would quickly either sink beneath the water of float out to sea. . . .

Adada felt exhilarated beyond description. When she thought how those countless pieces of money which were being pulled down into the water were taking all of her own misfortunes with them into the great boundless sea from which there would be no return, Adada was so happy she could have danced. . . .

"Ya, ya. Adada! The money! Did you take the money? The money, the money . . . !" he shouted. His voice a shattering bolt from the blue. . . .

Little by little the sweep and flow of the waves quickened their pace. The bills flowed to and fro, playing a game of hide and seek with him, as if trying to lure him into the deep waters. . . .

Surong realized that the money was gone now, but he could not lift his eyes from the water and stood there like a man bereft of his senses staring dumbfoundedly. Then like a shot, he became running to the small hill by the water's edge where Adada stood trembling and, without saying a word, kicked her viciously in the midsection. The sound of a grunt pierced the air at almost the same time the muck splattered in all directions as Adada slid down head first into the slime of the edge of the sea. And then a scream. . . .

Surong, his fist still clenched, stands there like a statue peering into the heaving waves. . . .

Above, flocks of seagulls wheel about and glide in circles looking for their mates, oblivious to the grim human tragedy which has taken place. They screech noisily and with the sound of their wings beating in great flaps they grace the seaside panorama with a joyful dance.

Source: Kye Yong Muk. 1974. Clippinger, Morgan E., trans. "Adada the Idiot." *Korea Journal* (April):45–52, 67. Originally published 1935; reprinted by permission of the *Korea Journal.*

The League of the Physically Handicapped (1935)

In 1935, at the height of the Great Depression, a group of disabled people joined together as the League of the Physically Handicapped to protest job discrimination. Bureaucratic rules and individual prejudices kept many disabled people from benefiting from the government employment supports provided by President Roosevelt's New Deal programs. This excerpt includes the League's assessment of the problem and their demands for change.

The fliers handed out by members of the League of the Physically Handicapped, explained that people with handicaps "cannot get regular jobs as teachers or librarians in New York State. . . . Even a typist must pass a physical examination. . . . In private business the Physically Handicapped invariably are discriminated against. They work harder for less wages. [Given this disability-based employment bias,] our League demands that handicapped people receive a just share of the millions of jobs being given out by the government. . . . The Handicapped still are discriminated against by Private Industry. It is because of this discrimination that we demand the government recognize its obligation to make adequate provisions for handicapped people in the Works Relief Program."

Source: Blumberg, Barbara. 1979. P. 49 in *The New Deal and the Unemployed: The View from New York City.* Lewisburg, PA: Bucknell University Press. Blumberg & Brown: Reprinted by permission of the Associated University Presses.

Kang Kyong-Ae, from *The Underground Village [Jihachon]* (1936)

Kang Kyong-Ae, a feminist novelist, focused on depicting people in the lower classes and women's lives in colonial Korea in a form of critical realism. The Underground Village is a novella portraying the impoverished countryside life of a man with partially paralyzed limbs, Ch'il-sŏng; his love interest, the blind woman K'ŭnnyon; and his mother and siblings. The excerpts include Ch'il-sŏng's encounters with another man with a physical disability from a work injury as well as the end of the story.

The sun was burning upon the western hill. Ch'il-sŏng, as usual, staggered past this village with his beggar's sack slung over his shoulder. He kept pulling down his crownless straw hat, but the sun continued broiling his forehead, and drops of sweat rolled down. Dust rose up from the parched road like smoke and made it difficult for him to breathe.

"There he comes again!"

"Come on!"

The little urchins at play by the roadside shouted and ran toward him. Ch'il-sŏng swore to himself and hurried his steps, but the children soon overtook him and pulled at his clothes.

"Cry, lad! Cry!" One of the urchins blocked Ch'il-sŏng's way and laughed. The children surrounded him in a circle.

"Hey, kid, how old are you?"

"Show us what you earned today."

One of the urchins snatched at the beggar's sack, and all the others clapped their hands. Ch'il-sŏng stood immobile and glared at the biggest of the group. He knew that if he tried to advance or swore at them they would pester him still more vigorously.

"Oh, he looks like a gentleman today."

One bristly-haired urchin brandished a stick before him with a bit of cowdung at the tip. The children all giggled and made as if to smear cowdung on Ch'il-sŏng with their sticks. Ch'il-sŏng could not stand it, so he ran as fast as he could. . . .

It was not the first time that he had been chased away by a dog; and countless times he had been abused and persecuted by men, too.

But somehow he felt an uncontainable fury today.

"Why are you standing there like that?"

He looked back in surprise to find that he was standing before a small building which was a water-mill. The man who was looking at him with outstretched neck seemed between forty and fifty, and Ch'il-sŏng could instantly tell that he was a cripple and a beggar like himself. The man grinned. He did not feel like going in, but entered after some hesitation. With a strong smell of rice husks came also the stink of horse droppings.

"Come to this side . . . Oh, your clothes are all wet."

The man stood on his crutches, spread the straw mat he had been sitting on, and sat down on one corner of it. Ch'il-sŏng quickly noted the man's gray hair and beard. He feared that the man might try to take away his earnings.

"You must be cold because of those wet clothes. You put on my old clothes and take them off and dry them." The man searched his bundle and said, "Here it is. Come here."

Ch'il-sŏng looked back. It was a dark western jacket patched in several places. He envied him such a good garment and looked directly in his smiling eyes. He did not look like a man who would try to snatch away other beggars earnings. Ch'il-sŏng dropped his glance and looked at the water dripping from his sleeves. The man walked toward him, leaning on his crutch.

"Why are you standing there like that? Put this on."

"Oh, no." Ch'il-sŏng stepped back one step and looked at the western jacket. His heart throbbed before a garment the like of which he had never worn in his life.

"Oh, aren't you a stubborn fellow! Then come here and sit on this mat." The man led him by the hand and made him sit on the straw mat. The man pretended not to notice Ch'il-sŏng's twisted legs. . . .

"Are you a born cripple?" the man suddenly asked. Ch'il-sŏng bowed his head and, after much hesitation, answered, "No."

"Then it was because of an illness. Did you get any treatment?"

Ch'il-sŏng looked long at his legs again, hesitating. At last he muttered: "No. None at all."

"Ugh, in this world sound legs get broken. It's no surprise not to get treatment for sicknesses."

The man laughed into void. The laughter made Ch'il-sŏng shudder. He glanced at the man. As he looked out at the road with fiercely dilated eyes, blue veins stood out on the man's forehead and his lips were tightly shut.

"Oh, I curse myself to think how stupid I was! I should have fought till death! What a damned stupid fool I was." . . .

"Listen fellow. I was head of a family once. I was a model worker in a factory, too. A first-rate engineer . . . After my leg was broken I was fired from the factory, and my woman ran away and the kids cried from hunger. . . . My parents died of sorrow. Oh, there's no use telling it."

The man stared at Ch'il-sŏng. Ch'il-sŏng's heart throbbed for some reason and he could not face the man's glance, so he looked at his broken leg, and at the mute bovine earth beneath that leg. . . .

"Oh, ours will all be swept away now! Our field can't escape being flooded when K'ŏnnyon's field got swept away. . . . Oh, K'ŏnnyon's lucky she doesn't have to live through this. She got married yesterday."

"What?" Ch'il-sŏng screamed. The precious material stored in his bosom struck his skin like a rock. His mother, startled, looked at her son.

"Mom, look at that!" Ch'il-un jumped up and groaned. They all looked. The cloth wrapped round the baby's head was about half torn off and maggots big as rice grains were crawling out of it.

"Oh, God! What has happened? What has happened!" His mother went over to the baby and snatched away the cloth. The rat skin came away at that, and from it dropped hordes of maggots bathed in blood.

"Baby! My baby! Wake up! Oh, wake up!" Hearing his mother's scream, Ch'il-sŏng ran outside frantically. The rain poured down fiercely and the gale blew like mad, and the sky, torn mercilessly by the lightning, wailed with thunder. Ch'il-sŏng glared at the sky.

Source: Kang Kyong-Ae. 1983. Suh Ji-moon, trans. "The Underground Village" [Jihachon]. In *The Rainy Spell and Other Korean Stories.* London: Onyx Press. Originally published 1936; reprinted by permission of the *Korea Journal.*

National Socialist Propaganda, *Volk und Rasse* (1936)

The National Socialist propaganda machine got up to speed in the 1930s as the German population was infiltrated with eugenic ideology. The German people were supposed to consider their family planning and reproduction as entirely in the service of creating a healthy, national body. The following is an example from the monthly newsletter, Volk und Rasse ["Nation and Race"].

"Healthy marriage is a national duty."

"The nation has the duty to return consecration to the institution of marriage, which is appointed the task of conceiving images of God and not freaks between man and ape."

Source: *Volk und Rasse: Illustrierte Monatsschrift für das deutsche Volkstum: Zeitschrift des Reichausschusses für Volksgesundheitsdienst und der Deutschen Gesellschaft für Rassenhygiene.* 1936. Berlin, Germany: H8, title page. [*Volk and Race: Illustrated Monthly Magazine for the German Volk: Magazine of the Reich's Commission for the Medical Service of the Volk and the German Society for Race Hygiene.* Vogt, Sara, trans.].

Japanese Schools for the Physically and Mentally Handicapped (1937)

The following excerpt about the history of schools for students with physical and sensory disabilities is taken from a book written in 1937 about the educational history of Japan. The discussion demonstrates the country's commitment to schooling disabled children but also the common practice of educating them in separate facilities. The discussion ends with a critique of nonsystematic education for students with cognitive disabilities.

The Imperial Ordinance relating to schools for the blind, deaf and dumb makes it compulsory for each prefecture and the Hokkaido to establish at least one school of each class of the afflicted. Further, permission is given to cities, towns and villages, or to private persons, to found schools for the blind, deaf and dumb. At the present time in Japan there are two government institutions of this type, one the Tokyo School for the Blind and the other the Tokyo School for the Deaf and Dumb. Both are under the immediate control of the Department of Education. In addition, there are twenty-nine public schools for such afflicted persons, and forty-two private schools. The discrepancy between the number of public schools is explained by the fact that the government rules permit prefectures to adopt schools established by private individuals or by cities or towns as prefectural schools, and advantage has been taken of this regulation by a number of prefectures.

Schools of this type generally consist of two departments, the elementary and the middle grade, although in some schools permission is granted to dispense with either department. To be admitted to the elementary department of any school for the blind, or the deaf and dumb, candidates must be over six years of age. For admission to the middle grade department they must have completed the elementary training or give proof of an equivalent standard.

In the schools for the blind the curriculum in general emphasizes such subjects as music, acupuncture and massage. Teaching by the Braille method is not so advanced as in the West. But there is a system adapted by a Japanese teacher, and based on the Braille, by which the blind are taught to read. For the most part, however, blind Japanese students are taught by ear and memory-training. Throughout the whole period of Japanese history, massage, which plays so large a part in the therapeutics of the country, has been looked upon as an art particularly suited to the blind. This traditional attitude is still maintained, so that the schools for the blind offer a first-class training in massage.

The annual number of applicants for admission to the Tokyo School for the Blind is about 125, of whom approximately 60 are admitted. The subsequent careers of the graduates from this school, to take a typical year, are as follows:

Teachers	14
Engaged in acupuncture and massage	6
Hospital workers	2
Further study	10
Others	2

The schools for the deaf and dumb are similarly divided into two departments, providing an elementary and a middle course. The ordinary curriculum is confined very largely to drawing, sewing and the industrial arts. Some success has been achieved in teaching articulation and lip-reading, for which purpose the most modern Western methods have been introduced into a few schools, which have thereby trained instructors for other schools.

The Tokyo School for Deaf-mutes has in the neighbourhood of 130 applicants each year, but of these only about 90 are admitted.

Unfortunately, there is as yet in Japan no well-arranged system of training mentally defectives. Their education in separate classes is carried on experimentally in a few schools, thanks to the initiative of the local authorities. There is, however, no properly organized public system designed to provide the care and training that could so well be utilized by this unfortunate type, which for the most part are left to the care, or otherwise, of their families.

In The Story of Alexander Graham Bell, *the inventor of the telephone, whose mother is deaf, marries a woman who is deaf as well. The film depicts Bell as heroic in his efforts to assist individuals with hearing and speech impairments to communicate.*

Source: *The Story of Alexander Graham Bell* (1939), directed by Irving Cummings. B&W, 105 minutes. Reprinted by permission of Paul Darke.

Source: Keenleyside, Hugh, and A. F. Thomas. 1937. Pp. 259–261 in *History of Japanese Education and Present Educational System.* Tokyo, Japan: Hokuseido Press. Reprinted by permission of Hokuseido Press.

John Steinbeck, from *Of Mice and Men* (1937)

Steinbeck plays with the stereotype of the well-meaning but dangerous idiot. Lennie is attracted to beautiful things but destroys them, turning the world against him and his brother, George. George is his brother's keeper, but the job seems too hard to bear when that brother is mentally disabled.

Lennie went behind the tree and brought out a litter of dried leaves and twigs. He threw them in a heap on the old ash pile and went back for more and more. It was almost night now. A dove's wings whistled over the water. George walked to the fire pile and lighted the dry leaves. The flame cracked up among the twigs and fell to work. George undid his bindle and brought out three cans of beans. He stood them about the fire, close in against the blaze, but not quite touching the flame.

"There's enough beans for four men," George said.

Lennie watched him from over the fire. He said patiently, "I like ‘em with ketchup."

"Well, we ain't got any," George exploded. "Whatever we aint' got, that's what you want. God a'mighty, if I was alone I could live so easy. I could go get a job an' work, an' no trouble. No mess at all, and when the end of the month come I could take my fifty bucks and go into town and get whatever I want. Why, I could stay in a cat house all night. I could eat any place I want, hotel or any place, and order any damn thing I could think of. An' I could do all that every damn month. Get a gallon of whisky, or set in a pool room and play cards or shoot pool." Lennie knelt and looked over the fire at the angry George. And Lennie's face was drawn with terror. "An' whatta I got," George went on furiously. "I got you! You can't keep a job and you lose me ever' job I get. Jus' keep me shovin' all over the country all the time. An' that ain't the worst. You get in trouble. You do bad things and I got to get you out." His voice rose nearly to a shout. "You crazy son-of-a-bitch. You keep me in hot water all the time." He took on the elaborate manner of little girls when they are mimicking one another. "Jus' wanted to feel that girl's dress—jus' wanted to pet it like it was a mouse—Well, how the hell did she know you jus' wanted to feel her dress? She jerks back and you hold on like it was a mouse. She yells and we got to hide in a irrigation ditch all day with guys lookin' for us, and we got to sneak out in the dark and get outta the country. All the time somethin' like that—all the time. I wisht I could put you in a cage with about a million mice an' let you have fun." His anger left him suddenly. He looked across the fire at Lennie's anguished face, and then he looked ashamedly at the flames.

It was quite dark now, but the fire lighted the trunks of the trees and the curving branches overhead. Lennie crawled slowly and cautiously around the fire until he was close to George. He sat back on his heels. George turned the bean cans so that another side faced the fire. He pretended to be unaware of Lennie so close beside him.

"George," very softly. No answer. "George!"

"Whatta you want?"

"I was only foolin,' George. I don't want no ketchup. I wouldn't eat no ketchup if it was right here beside me."

"If it was here, you could have some."

"But I wouldn't eat none. George. I'd leave it all for you. You could cover the beans with it and I wouldn't touch none of it."

George still stared morosely at the fire. "When I think of the swell time I could have without you, I go nuts. I never get no peace."

Lennie still knelt. He looked off into the darkness across the river. "George, you want I should go away and leave you alone?"

"Where the hell could you go?"

"Well, I could. I could go off in the hills there. Some place I'd find a cave."

Source: Steinbeck, John. 1993. *Of Mice and Men.* New York: Penguin. Copyright 1937 renewed © 1965 by John Steinbeck. Used by permission of Viking Penguin, a division of Penguin Group (USA) Inc.

Social Security Report on Disability Insurance (1938)

The report demonstrates the degree of U.S. government resistance to efforts to adjust the Social Security Act in order to include permanent disability within its provisions.

The Board recognizes that the administrative problems involved are difficult, although it does not believe them insuperable. It also recognizes that provision for permanent total disability would increase the cost of the system both now and in the future. For these reasons it is not making any positive recommendations on this matter at this time.

Source: Proposed Changes in the Social Security Act, Report of the Social Security Board to the President and to the Congress of the United States, 30 Dec. 1938, H.R. 110, 76th Cong., 1st sess. (1939).

Public Speech by the Bishop of Munster (1941)

This sermon, delivered August 3, 1941, by Cardinal August Count von Galen, Bishop of Munster, came as a bombshell. Thousands of copies were printed and circulated. Nazi leaders were furious but helpless to prohibit the critique without fueling public opposition.

Fellow Christians! In the pastoral letter of the German Bishops of 26 June 1941, which was read out in all the Catholic churches in Germany on 6 July, 1941, it states among other things: It is true that there are definite commandments in Catholic moral doctrine which are no longer applicable if their fulfillment involves too many difficulties. However, there are sacred obligations of conscience from which no one has the power to release us and which we must fulfill even if it costs us our lives. Never under any circumstances may a human being kill an innocent person apart from war and legitimate self-defence. On 6 July, I already had cause to add to the pastoral letter the following explanation: for some months we have been hearing reports that, on the orders of Berlin, patients from mental asylums who have been ill for a long time and may appear incurable, are being compulsorily removed. Then, after a short time, the relatives are regularly informed that the corpse has been burnt and the ashes can be delivered. There is a general suspicion verging on certainty, that these numerous unexpected deaths of mentally ill people do not occur of themselves but are deliberately brought about, that the doctrine is being followed, according to which one may destroy so-called 'worthless life' that is kill innocent people if one considers that their lives are of no further value to the nation and the state.

I am reliably informed that lists are also being drawn up in the asylums of the province of Westphalia as well of those patients who are to be taken away as so called 'unproductive national comrades' and shortly to be killed. The first transport left the Marienthal institution near Munster during this past week.

German men and women §211 of the Reich Penal Code is still valid. It states: 'he who deliberately kills another person will be punished by death for murder if the killing is premeditated.'

Those patients who are destined to be killed are transported away from home to a distant asylum presumably in order to protect those who deliberately kill those poor people, members of our families, from this legal punishment. Some illnesses are then given the cause of death. Since the corpse has been burnt straight away the relatives and also the criminal police are unable to establish whether the illness really occurred and what the cause of death was. However, I have been assured that the Reich Interior Ministry and the office of the Reich Doctor's Leader, Dr. Conti, make no bones about the fact that in reality a large number of mentally ill people in Germany have been deliberately killed and more will be killed in the future.

Autopsy area where murdered disabled inmates with gold teeth or "unusual" anatomies were studied after the gassing. The autopsy table itself continued to be used into the 1970s by occupational and physical therapists for stretching exercises into the 1970s. Today the site exists as memorial to the victims of National Socialist medical violence during World War II.

Source: Photo by Sharon Snyder.

The Penal Code lays down in §139: 'he who receives credible information concerning the intention to commit a crime against life and neglects to alert authorities or the person who is threatened in time will be punished.' When I learnt of the intention to transport patients from Marienthal in order to kill them, I brought a formal charge at the State Court in Munster and with the Police President in Munster by means of a registered letter which reads as follows: 'According to information which I have received, in the course of this week a large number of patients from the Marienthal Provincial Asylum near Munster are to be transported to the Eighberg asylum so-called "unproductive national comrades" and will then be soon deliberately killed, as is generally believed has occurred with such transports from other asylums. Since such an action is not only contrary to the moral laws of God and Nature but is also punishable by death as murder under §211 of the Penal Code, I hereby bring a charge in accordance with my duty under §139 of the Penal Code, and request you to provide immediate protection for national comrades threatened in this way by taking action against those agencies who are intending the removal and murder, and that you inform me of the steps that have been taken.' I have received no news concerning intervention by the Prosecutor's Office or by the police. . . .

Thus we must assume that the poor helpless patients will soon be killed. For what reason? Not because they have committed a crime worthy of death. Not because they attacked their nurses or orderlies so that the latter had no other choice but to use legitimate force to defend their lives against their attackers. Those are cases where, in addition to the killing of an armed enemy in a just war, the use of force to the point of killing is allowed and is often required. No, it is not for such reasons that these unfortunate patients must die but rather because, in the opinion of some department, or the testimony of some commission, they have become 'worthless life' because according to this testimony they are 'unproductive national comrades.' The argument goes: they can no longer produce commodities, they are like an old machine which no longer works, they are like an old horse which has become incurably lame, they are like a cow which no longer gives milk. What does one do with such an old machine? It is thrown on the scrap heap. What does one do with a lame horse, with such an unproductive cow? No, I do not want to continue the comparison until the end—however fearful the justification for it and the symbolic force of it are. We are not dealing with machines, horses and cows whose only function is to serve mankind, to produce goods for man. One may smash them, one may slaughter them as soon as they no longer fulfill this function. No, we are dealing with human beings, our fellow human beings, our brothers and sisters. With poor people, sick people, if you like unproductive people. But have they for that reason forfeited the right to life? Have you, have I the right to live only so long as we are productive, so long as we are recognised by others as productive? If you establish and apply the principle that you can kill 'unproductive' fellow human beings then woe betide us all when we become old and frail! If one is allowed to kill the 'unproductive' people then woe betide the invalids who have used up, sacrificed and lost their health and strength in the productive process. If one is allowed forcibly to remove one's unproductive fellow human beings then woe betide loyal soldiers who return to the homeland seriously disabled, as cripples, as invalids. If it is once accepted that people have the right to kill 'unproductive' fellow humans—and even initially if it only affects the poor defenceless mentally ill—then as a *matter of principle* murder is permitted for all unproductive people, in other words for the incurably sick, the people who have become invalids through labor and war, for us all when we become old, frail, and therefore unproductive.

Then, it is only necessary for some secret edict in order that the method developed for the mentally ill should be extended to other 'unproductive' people, that it should be applied to those suffering from incurable lung disease, to the elderly who are frail or invalids, to the severely disabled soldiers. Then none of our lives will be safe any more. Some commission can put us on the list of the 'unproductive,' who in their opinion have become worthless life. And no police force will protect us and no court will investigate our murder and give the murderer the punishment he deserves. Who will be able to trust his doctor any more? He may report the patient as 'unproductive' and receive instructions to kill him. It is impossible to imagine the degree of moral depravity, of general mistrust that would then spread even through families if this dreadful doctrine is tolerated, accepted, and followed. Woe to mankind, woe to our German nation if God's holy commandment 'Thou shalt not kill,' which God proclaimed on Mount Sinai amidst thunder and lightning, which God our Creator inscribed in the conscience of mankind from the very beginning, is not only broken, but if this transgression is actually tolerated and permitted to go unpunished.

I'll give you an example of what is going on. In Marienthal there was a man of about 55, a peasant from a rural parish in the Munster area—I could give you his name—who for some years had been suffering from mental disturbance and who had therefore been put in the care of the Marienthal asylum. He was not really mentally ill, he could receive visitors and was very pleased whenever his relatives came to see him. Only a fortnight ago, he received a visit from his wife and from one of his sons who is a soldier at the front and had home leave. So the farewell was a sad one: who knows if the soldier will return, will see his father again, for after all he may die in the struggle on behalf of his national comrades. The son, the soldier, will almost certainly never see his father again here on earth because since then he has been put on the list of the 'unproductive.' A relative who wanted to visit the father in Marienthal last week was turned away with the news that the patient has been transported away from here on the orders of the Ministerial Council for the Defence of the Reich. Nobody could say where to: the relatives would be informed in a few days time. What will the news be? Will it be the same as in other cases? That the person had died, that the corpse had been burnt, that the ashes can be delivered after payment of a fee? In that case, the soldier who is at the front risking his life for his German national comrades, will not see his father again here on earth because German national comrades at home have killed him . . .

Source: Noakes, J., and G. Pridham, eds. 1988. Pp. 1036–1039 in *Nazism: A History in Documents and Eyewitness Accounts, 1919–1945,* V*olume 3, Foreign Policy, War and Racial Extermination. A Documentary Reader.* Published with permission of the University of Exeter Press.

Katharine Butler Hathaway, from *The Little Locksmith* (1943)

The Little Locksmith is an extraordinary autobiography written by a woman who spent 10 years of her life strapped to a board in an unsuccessful attempt to prevent curvature of the back from a spinal tumor. The first excerpt included here discusses her transition from a carefree childhood to a "bedridden" and contemplative existence. During the course of the story, she changes from a child repulsed by the hunchbacked figure of a local locksmith to one who longs to find a house best fitted to her life as a disabled woman.

This is the story of such transformations, both large and small, and now in the beginning I will tell the nature of the predicament which first made this kind of magic dear to me—the predicament and the magic together which made necessary and possible at last my visit to the almond-shaped island which lay in the palm of my right hand. For of course, without a predicament, there is no need of magic.

When I was five years old I was changed from a rushing, laughing child into a bedridden, meditative one. As the years passed, my mother explained to me just what had happened, and why I had to be so still. She told me how lucky I was that my parents were able to have me taken care of by a famous doctor. Because, without the treatment I was having, I would have had to grow up into a—well, I would have had to be, when I grew up, like the little locksmith who used to come to our house once in a while to fix locks. I knew the little locksmith, and after this, when he came, I stared at him with a very strange intimate feeling. He never looked back at me. His eyes were always down at what he was doing, and he apparently did not want to talk with or look at anybody. He was very fascinating indeed. He was not big enough to be considered a man, yet he was not a child. In the back his coat hung down from an enormous sort of peak, where the cloth was worn and shiny, between his shoulders, and he walked with a sort of bobbing motion. In front his chin was almost down on his chest, his hands were long, narrow, and delicate, and his fingers were much cleverer than most people's fingers. There was something about him, something that was indescribably alluring to a child. Because he was more like a gnome than a human being he naturally seemed to belong to our world more than to the grown-up world. Yet he seemed to refuse to belong to our world or anybody else's. He acted as if he lived all alone in a very private world of his own.

Somehow I knew that there was a special word that the grownups called a person shaped like the little locksmith, and I knew that to ordinary healthy grownups it was a terrible word. And the strange thing was that I, Katharine, the Butlers' darling little girl, had barely escaped that uncanny shape and that terrible word. Because I was being taken care of by a famous doctor nobody would ever guess, when I grew up, that I might have been just like the little locksmith.

Staring wonderingly at him, I knew it. I knew that compared with him I was wonderfully lucky and safe. Yet deep within me I had a feeling that underneath my luck and safeness the real truth was that I really belonged with him, even if it was never going to show. I was secretly linked with him, and I felt a strong, childish, amorous pity and desire toward him, so that there was even a queer erotic charm for me about his gray shabby clothes, the strange awful peak in his back, and his cross, unapproachable sadness which made him not look at other people, not even at me lying on my bed and staring sideways at him. (Pp. 14–15)

A house such as I was dreaming of would be only another example, I thought, of the easy magic of transformation by which one thing becomes its opposite. All that was needed, I thought, was a person bold and independent enough to undertake it. That person would need to be very bold indeed, because the process of transformation was so entirely a matter of faith and magic and simplicity that nobody would believe that it could be done until after it had been done. I thought for several reasons that I might be the bold person.

Sometimes a worm will sew a stitch in a young leaf, and even though the leaf may partly unfold, and partly grow and live, it will always be a crumpled and imperfect leaf. My body, like the leaf, represented that mysterious element of imperfection in Nature, which allows the worm to maim the leaf; I represented the flaw which exists side by side with a design which appears to be flawless. Because the worm had sewed a stitch in me and made me forever crumpled, I belonged to the fantastic company of the queer, the maimed, the unfit. It was understood that I could not play a part in the ordained dance of love, in obedience to the design. I was obliged, therefore, in a certain sense, to skip in my own life all the years and all the force and strength which other women gave to love and to the bearing of children. I was obliged to skip the years of sexual activity and become, while I was still young and joyous, the equivalent of an old woman, a detached, sexless, meditative observer. But I was too sympathetic and ardent to be a passive observer. I had to act in some way. I had to participate, myself, in the ritual of love and experience. With my belief in the magic of transformation and my belief in my own power to exert it, I suddenly knew that I was the suitable bold person, the little, old, young crumpled person who could accomplish, if anyone could, this amazing project. I saw myself as the potent little figure, not old and not young, conspicuously lacking in size and in beauty, who appears and reappears in all folk tales as the good godmother, the talismangiver, the magic-bringer, who inevitably comes to the rescue of young people who are much bigger and more beautiful than she is, yet who get themselves entangled in their life-size and more than life-size human troubles and are weak and helpless until that familiar little nonhuman figure arrives on the scene. I knew that my destiny would reach its mark if I could work this unheard-of transformation and make my house the place of refuge and solace I had been dreaming of. I sat on my doorstep in Castine in the still autumn sunlight, and I began to be quite astonished and a little appalled by the things that I found myself thinking. But I did not let that scare me. For my third wish I wrote in my imagination across the panel under the mantelpiece in the square room behind me the last two lines of Shelley's Epipsychidion. "Come, leave the crowd which errs and which reproves, And come and be my guest, for I am Love's."

I wrote them only in my imagination, but in my imagination they were always there, as long as the house belonged to me—the invitation which I wanted to give to all the people in the world who needed it. I might have written beside it, "Unto the pure all things are pure; but unto them that are defiled and unbelieving is nothing pure"; but it seemed to me it came to the same thing.

I wanted my house, then, to be a safe refuge for three kinds of people, who are all alike in being at a particular disadvantage in the outside world because they all possess and are guided by the mystic's innocence toward life, the fearless innocence which is not afraid of facing everything, and, facing everything, dares to believe, as Blake says, that all that is, is holy. My feeling of affinity toward that fundamental kind of innocence was the basis of each of my three wishes concerning the future of the house. It was the essential attitude which I wanted my house to prove possible and to defend. (Pp. 199–201)

Source: Hathaway, Katharine Butler. 2000. Excerpts from *The Little Locksmith*: *A Memoir*. Copyright 1942, 1943 by Coward-McCann, Inc., renewed © 1974 by Warren H. Butler. Reprinted with permission of The Feminist Press at the City University of New York, www.feministpress.org.

▣ "N-P": The Case of Neuropsychiatric Disability (1944)

The program of aggressive normalization remained in force throughout the twentieth century and was improved and expanded on in numerous ways, especially as new understandings of disability and new conditions of war demanded. One particularly significant area of transformation was in the provision of psychological services, especially to those sustaining neuropsychiatric disabilities, which were as old as warfare itself, but largely misunderstood until the twentieth century as evidence of cowardice and malingering. Through preinduction testing, some armed forces tried to weed out men unlikely to have the emotional stability to serve under wartime conditions, but the greater the manpower needs, the more such standards were relaxed, and the more the armed services needed to be able to provide psychological treatment.

Every month thousands of men return home from preinduction examinations or from the U.S. Army with N-P stamped on their medical records. N-P (neuropsychiatric) sometimes means insane but usually means psychoneurotic. What psychoneurotic means, few laymen know. Most psychoneurotics do not know either. Many of them think they are insane or soon will be. So do family and neighbors who look askance, and employers who sometimes refuse jobs. (Last week the Army changed its N-P stamp to read "Unsuited for military service.") Because few N-Ps discuss their plight, few people realize how many there are.

But last week 2,000 psychiatrists at the 100th meeting of the American Psychiatric Association heard some startling figures from the Army's Colonel William Clare Menninger (brother of famed Psychiatrist Karl Menninger). Since Pearl Harbor the Army has turned down 1,340,000 men for neuropsychiatric causes, has discharged 216,000. These figures would be even higher if the men in Army neuropsychiatric wards were included.

Most practical report on the N-P problem was made to the meeting by New York Hospital's white-haired, 40-year-old Dr. Thomas Alexander Cumming Rennie. Dr. Rennie realized that discharged and deflected N-Ps need psychiatric care, without it might develop real mental illness. He also realized that there was no place where they could get such help. So last August he started a psychiatric clinic at the hospital, manned one night a week by twelve psychiatrists, a psychologist, seven social workers. The clinic gives psychiatric interviews, group treatment, occupational therapy, arranges social gatherings, dates, helps men get jobs.

Dr. Rennie told last week's meeting that the clinic has definitely proved its value to N-Ps. Of its 200 patients (about one-third from the Army, only 14 actual combat veterans) 104 are improved (some became perfectly well after only one one-hour psychiatric interview), many are still under treatment: a very few had to be sent to mental hospitals. (Some of these have since been discharged, now hold jobs.)

New York City already has six such psychiatric clinics; Boston has four, and there are a few others. But Dr. Rennie will not be satisfied until all available psychiatrists are helping in such clinics. Even so most of the cases would go untended—the U.S. has only about 3,000 psychiatrists altogether, of whom 800 are at war.

Source: "N-P." 1944. *Time* (May 29):44–45. © TIME Inc. Reprinted by permission.

Gwendolyn Brooks, from *A Street in Bronzeville* (1945)

This poem provides reflections on heaven from the perspective of a physically disabled African American girl. The poem focuses on locating a "straight" environment that will better accommodate and accept the speaker's differences.

hunchback girl: she thinks of heaven

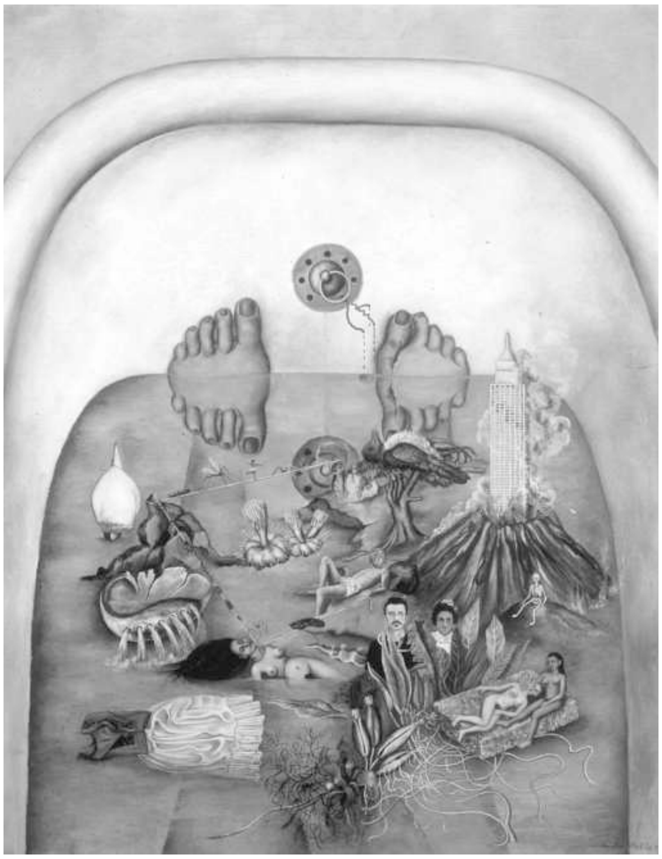
My Father, it is surely a blue place
And straight. Right. Regular. Where I shall find
No need for scholarly nonchalance or looks
A little to the left or guards upon the
Heart to halt love that runs without crookedness
Along its crooked corridors. My Father,
It is a planned place surely. Out of coils,
Unscrewed, released, no more to be marvelous,
I shall walk straightly through most proper halls
Proper myself, princess of properness.

Source: Brooks, Gwendolyn. 1999. *Selected Poems.* New York: Harper Perennial. Originally published 1945. Reprinted by consent of Brooks Permissions.

Frida Kahlo (1907–1954)

Frida Kahlo constructed images of a disabled female body out of seemingly disparate pieces. Her work interweaves traditional Mexican votive painting, technical images of the body that emerged from modern medical science (x-rays, surgical implements, hospital experience), and Christian iconography of redemption through physical suffering. In this way, she rendered an entirely new view of personal experience. Kahlo is among the first, and perhaps the most daring, to render a portrait of transparent, explicit, literalized bodily trauma. Prior to her work, pain was shown through the gestures of agony (e.g., scenes of crucifixion or martyrdom, as in the work of Käthe Kollwitz or Picasso's *Guernica*) or explicit gore (e.g., battle scenes, beheadings by Salome or Judith, any number of mythological illustrations).

Kahlo's work is particularly of interest to disability studies not only for the autobiographical renditions of her injuries, illnesses, and surgeries, but also because of the nature of the body she invents. Often the interior of the body is visible and continuous with the exterior in a kind of psychic Möbius strip. In works such as *The Broken Column, The Two Fridas, Roots, The Tree of Hope,* and *Without Hopes,* there is no clear division between inner reality and outer appearance, and thus the unsharable nature of individual pain becomes explicit. By the 1930s, x-ray technology had been in public use for some time, ending the concept of the opaque body, and public hospitals had also been established as places of collective community experience. Kahlo demolishes the idea of the body in pain as a shameful or hidden object. Her body is offered up in many contexts, but her pain imagery is never separate from her life at large, and her pain is never represented as a different sphere of experience



What the Water Gave Me *(1938), by Frida Kahlo (1907–1954). Frida's body is both intimately present and hidden, while the water of her private bathtub transforms into the river of life. She contemplates the flow of her history as images of her family, her European and Mexican heritage, and intense love relationships emerge from the reflecting pool of the self.*

Source: Art Resource, New York.

Without Hopes *(1945), by Frida Kahlo (1907–1954). The painting depicts a postsurgery Frida vomiting her insides into a harsh, Aztec landscape. Fears of internal decay, the seeds of death, and the rotten remains of still-life objects erupt and seem to be a truer representation of her body than the hidden form under the infected blanket.*

Source: Art Resource, New York.

in kind or degree. Her illnesses are fully in context of the rest of her life. The examinations of marriage, sexuality, cultural patrimony, and family are in the same visual iconographies as those of disability.

Her paintings must also be seen in the context of the traditional image of the female body as a mysterious, irrational, and secretive vessel. The baring of her body inside and out is more transgressive than a simple nude self-portrait. Her body is small and doll-like. It appears as a toy in the thrall of immense forces, not as a mythic goddess-like being. In embedding the matter-of-fact details of her medical experiences within a highly emotional language, she both demystifies disability and presents it outside of the context of the casebook (again, she may be the first to do this). To open oneself to a Kahlo painting is to feel the vulnerability of one's own body and to immediately experience its transcendence through art.

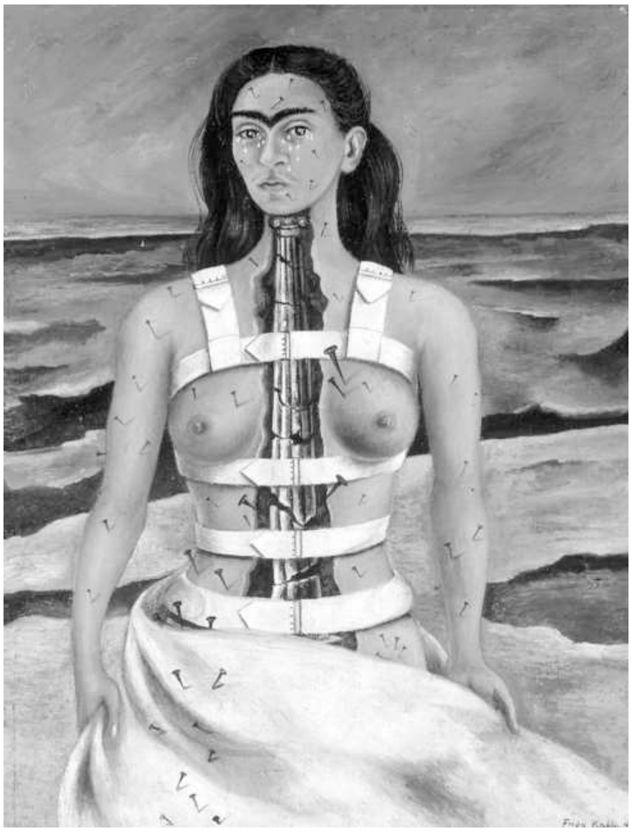
Another aspect of disability is the mutability of her body (a factor of chronic but unpredictable illness), symbolized in her portrayals of her body in partial transmutation with animals, partners, or the natural world in general. One could view her deep pairing with monkeys, with Diego, with the Little Deer, and with her doubled self as a reflection of the way that disabled people must often render all control or custody over their bodies. A kind of permeability arises, a thinning of boundaries that enables her to see herself as an amalgam of parts. History, love, and culture build her self-portraits. She depicts herself or others in isolation only when in a state of deep emotional pain and despair (*Self-Portrait with Cropped Hair, Suicide of Dorothy Hale*).

Disability is often imagined as a state of weakness and withdrawal. Frida Kahlo gives us a world in which pain becomes a fire in the machine, a state of wild ferocity, a disrobing to reveal a body in full communion.

—Riva Lehrer

The Two Fridas *(1939), by Frida Kahlo (1907–1954). Kahlo painted this immediately after her divorce from Diego Rivera. Reminiscent of a wedding portrait, one Frida (in traditional Mexican Tehuna dress) comforts an injured and bleeding Frida (in Victorian gown). In nurturing her discarded self, she also seems to marry her disabled self, equating the states of emotional and physical pain.*

Source: Art Resource, New York.



The Broken Column *(1944), by Frida Kahlo (1907–1954). The most explicit image in her canon of work, this painting fully exposes the nature of Kahlo's injury and gives no hint of the possibility of relief inside or outside her body. It is a brilliant rendering of the way in which illness can cause the entire world to seem bleak and hostile to the body in pain.*

Source: Art Resource, New York.

Further Reading

Herrera, Hayden. 1983. *Frida: A Biography of Frida Kahlo.* New York: Harper & Row.

Part Three

Culture and Resistance

▣ 1946–present

Disability protest at the World Social Forum in Mumbai, India, 2004. Participants from across India shout slogans such as "WSF Shame! Shame!" and "WSF Inaccessible, Inaccessible!"

Source: National Centre for Promotion of Employment for Disabled People, New Delhi, India.

Culture and Resistance
1946–Present

▣ William Carlos Williams, from *Paterson* (1946)

The American imagist poet-physician William Carlos Williams quotes from a lengthy newspaper account of a visit to "a natural curiosity" as a metaphor for humanity as a monstrous exhibit.

A gentleman of the Revolutionary Army, after describing the Falls, thus describes another natural curiosity then existing in the community: "In the afternoon we were invited to visit another curiosity then existing in the neighborhood. This is a monster in human form, he is twenty-seven years old, his face from the upper part of his forehead to the end of his chin, measures *twenty-seven inches,* and around the upper part of his head is twenty-one inches: his eyes and nose are remarkably large and prominent, chin long and pointed. His features are coarse, irregular and disgusting, his voice rough and sonorous. His body is twenty-seven inches in length, his limbs are small and much deformed, and he has the use of one hand only. He has never been able to sit up, as he cannot support the enormous weight of his head; but he is constantly in a large cradle, with his head supported in pillows. He is visited by great numbers of people, and is peculiarly fond of the company of clergymen, always inquiring for them among his visitors, and taking great pleasure in receiving religious instruction. General Washington made him a visit, and asked 'whether he was a Whig or a Tory.' He replied that he had never taken an *active* part on either side."

Source: Williams, William Carlos. 1946. *Paterson.* New York: New Direction. Copyright © 1946, 1948, 1949, 1951, 1958 by William Carlos Williams. Reprinted by permission of New Directions Publishing Corporation.

▣ Ann Petry, from *The Street* (1946)

One of the great works of African American literature, Ann Petry's The Street *documents the corrupt systems of economic inequity and food distribution that undermine the community's health and well-being. In the second excerpt, the story describes the physically massive and largely immobile body of Mrs. Hedges, who functions in the novel as a moral center.*

She thought about the stores again. All of them—the butcher shops, the notion stores, the vegetable stands—all of them sold leavings, the sweepings, the impossible unsalable merchandise, the dregs and dross that were reserved especially for Harlem.

Yet the people went on living and reproducing in spite of the bad food. Most of the children had straight bones, strong white teeth. But it couldn't go on like that. Even the strongest heritage would one day run out. Bub was healthy, sturdy, strong, but he couldn't remain that way living here. (P. 153)

In the middle of the block there was a sudden thrust of raw, brilliant light where the unshaded bulbs in the big poolroom reached out and pushed back the darkness. A group of men stood outside its windows watching the games going on inside. Their heads were silhouetted against the light.

Lutie, walking quickly through the block, glanced at them and then at the women coming toward her from Eighth Avenue. The women moved slowly. Their shoulders sagged from the weight of the heavy shopping bags they carried. And she thought, That's what's wrong. We don't have time enough or money enough to live like other people because the women have to work until they become drudges and the men stand by idle.

She made an impatient movement of her shoulders. She had no way of knowing that at fifty she wouldn't be misshapen, walking on the sides of her shoes because her feet hurt so badly; getting dressed up for church on Sunday and spending the rest of the week slaving in somebody's kitchen.

It could happen. Only she was going to stake out a piece of life for herself. She had come this far poor and black and shut out as though a door had been slammed in her face. Well, she would shove it open; she would beat and bang on it and push against it and use a chisel in order to get it open. (Pp. 185–186)

Lutie's mouth closed. She had never seen Mrs. Hedges outside of her apartment and looked at closely she was awe-inspiring. She was almost as tall as the Super, but where he was thin, gaunt, she was all hard, firm flesh—a mountain of a woman.

She was wearing a long-sleeved, high-necked flannelette nightgown. It was so snowy white that her skin showed up intensely black by contrast. She was barefooted. Her hands, her feet, and what could be seen of her legs were a mass of scars—terrible scars. The flesh was drawn and shiny where it had apparently tightened in the process of healing.

The big white nightgown was so amply cut that, despite the bulk of her body, it had a balloon-like quality, for it billowed about her as she stood panting slightly from her exertion, her hands on her hips, her hard, baleful eyes fixed on the Super. The gaudy bandanna was even now tied around her head in firm, tight knots so that no vestige of hair showed. And watching the wide, full nightgown as it moved gently from the draft in the hall, Lutie thought Mrs. Hedges had the appearance of a creature that had strayed from some other planet.

Her rich, pleasant voice filled the hallway, and at the sound of it the dog slunk away, his tail between his legs. 'You done lived in basements so long you ain't human no more. You got mould growin' on you,' she said to Jones.

Lutie walked away from them, intent on getting up the stairs as quickly as possible. Her legs refused to carry her and she sat down suddenly on the bottom step. The long taffeta skirt dragged on the tiled floor. Bits of tobacco, the fine grit from the street, puffed out from under it. She made no effort to pick it up. She put her head on her knees, wondering how she was going to get the strength to climb the stairs.

'Ever you even look at that girl again, I'll have you locked up. You oughtta be locked up, anyway,' Mrs. Hedges said.

She scowled at him ferociously and turned away to touch Lutie on the shoulder and help her to her feet. 'You come sit in my apartment for a while till you get yourself back together again, dearie.'

She thrust the door of her apartment open with a powerful hand, put Lutie in a chair in the kitchen. 'I'll be right back. You just set here and I'll make you a cup of tea. You'll feel better.'

The Super was about to go into his apartment when Mrs. Hedges returned to the hall. 'I just wanted to tell you for your own good, dearie, that it's Mr. Junto who's interested in Mis' Johnson. And I ain't goin' to tell you again to keep your hands off,' she said.

'Ah, shit!' he said vehemently.

Her eyes narrowed. 'You'd look awful nice cut down to a shorter size, dearie. And there's folks that's willin' to take on the job when anybody crosses up they plans.'

She stalked away from him and went into her own apartment, where she closed the door firmly behind her. In the kitchen she put a copper teakettle on the stove, placed cups and saucers on the table, and then carefully measured tea into a large brown teapot. Lutie, watching her as she walked barefooted across the bright-colored linoleum, thought that instead of tea she should have been concocting some witch's brew.

The tea was scalding hot and fragrant. As Lutie sipped it, she could feel some of the shuddering fear go out of her.

'You want another cup, dearie?'

'Yes, thank you.'

Lutie was well on the way to finishing the second cup before she became aware of how intently Mrs. Hedges was studying her, staring at the long evening skirt, the short coat. Again and again Mrs. Hedges' eyes would stray to the curls on top of Lutie's head. She should feel grateful to Mrs. Hedges. And she did. But her eyes were like stones that had been polished. There was no emotion, no feeling in them, nothing visible but shiny, smooth surface. It would never be possible to develop any real liking for her.

'You been to a dance, dearie?'

'Yes. At the Casino.'

Mrs. Hedges put her teacup down gently. 'Young folks has to dance,' she said. 'Listen, dearie,' she went on. 'About tonight'—she indicated the hall outside with a backward motion of her head. 'You don't have to worry none about the Super bothering you no more. He ain't even going to look at you again.'

'How do you know?'

'Because I scared him so he's going to jump from his own shadow from now on.' Her voice had a purring quality.

Lutie thought, You're right, he won't bother me any more. Because tomorrow night she was going to find out from Boots what her salary would be and then she would move out of this house.

'He ain't really responsible,' Mrs. Hedges continued. 'He's lived in cellars so long he's kind of cellar crazy.'

'Other people have lived in cellars and it didn't set them crazy.'

'Folks differs, dearie. They differs a lot. Some can stand things that others can't. There's never no way of knowin' how much they can stand.'

Lutie put the teacup down on the table. Her legs felt stronger and she stood up. She could get up the stairs all right now. She put her hand on Mrs. Hedges' shoulder. The flesh under the flannel of the gown was hard. The muscles bulged. And she took her hand away, repelled by the contact.

'Thanks for the tea,' she said. 'And I don't know what I would have done if you hadn't come out in the hall—' Her voice faltered at the thought of being pulled down the cellar stairs, down to the furnace room—

'It's all right, dearie.' Mrs. Hedges stared at her, her eyes unwinking. 'Don't forget what I told you about the white gentleman. Any time you want to earn a little extra money.'

Lutie turned away. 'Good night,' she said. She climbed the stairs slowly, holding on to the railing. Once she stopped and leaned against the wall, filled with a sick loathing of herself, wondering if there was something about her that subtly suggested to the Super that she would welcome his love-making, wondering if the same thing had led Mrs. Hedges to believe that she would leap at the opportunity to make money sleeping with white men, remembering the women at the Chandlers' who had looked at her and assumed she wanted their husbands. It took her a long time to reach the top floor.

Mrs. Hedges remained seated at her kitchen table, staring at the scars on her hands and thinking about Lutie Johnson. It had been a long time since she thought about the fire. But tonight, being so close to that girl for so long, studying her as she drank the hot tea and seeing the way her hair went softly up from her forehead, looking at her smooth, unscarred skin, and then watching her walk out through the door with the long skirt gently flowing in back of her, had made her think about it again—the smoke, the flame, the heat. (Pp. 237–241)

Source: Petry, Ann. 1992. *The Street.* Boston: Beacon Press. Copyright 1946, renewed 1974 by Ann Petry. Reprinted by permission of Houghton Mifflin Company. All rights reserved.

Murrogh De Burgh Nesbitt, from *The Road to Avalon* (1949)

In 1944, after 40 years of energetic life with physical disability, and having experience of counseling many South Africans with serious impairments, Murrogh Nesbitt sketched his dream of a rehabilitation center run by disabled people in a mountain setting that would enhance the self-healing process. Focusing initially on servicemen disabled in World War II, Nesbitt believed they needed more than surgical and medical interventions, more than aids and gadgets. They needed a time and context in which their spirits could heal. They needed the comradeship of active disabled people to prepare for the challenges ahead.

Disabled men do not want to be coddled. They must never be allowed to think that they have lost any of their potential manhood because of their disabilities.

I know that the real battle for the disabled men will begin when they face the world and have to earn their own living. The medical men and the surgeon have their place in the scheme when these men have to be treated for their wounds. The psychiatrist and psychologist have their places, but surely there is also room in rehabilitation schemes for the services of disabled men who have conquered all difficulties and have lived normal lives.

Disabled men have told me that I have changed their mental outlook. They have told me that when they have seen what I can do the urge comes to them to do likewise. They know that I have trekked out of the valley of shadows, that I have climbed mountains. I am not saying these things in a spirit of egoism. These are facts, and facts are worth all your tons of theory.

Source: Nesbitt, Murrogh De Burgh. 1949. P. 218 in *The Road to Avalon.* London: Hodder & Stoughton.

In the 1946 film The Best Years of Our Lives, *three men return from World War II to a small town in middle America and have varying degrees of success adjusting to postwar civilian life. The part of Homer Parrish, a Navy veteran who has lost both his hands, is played by nonprofessional actor Harold Russell. While serving as a demolitions instructor at a military base in North Carolina in 1944, Russell's hands were blown off in an accident involving a defective fuse. Ten days after his accident, he was transferred from the base hospital to the amputees' ward at Walter Reed General Hospital for advanced medical care. There, he was fitted for prosthetic replacements for his hands and given instruction in how to use them. His proficiency in their use was profiled in an army documentary, Diary of a Sergeant. For his role as Homer Parish, Russell received two Oscars: one for Best Supporting Actor and one for "bringing aid and comfort to disabled veterans." The film also received the Academy Award for Best Picture.*

Russell became an advocate for veterans and people with disabilities. He helped organize the World Veterans Federation and served as vice president of its World Veterans Fund, served three terms as the National Commander of the AMVETS, and was appointed chair of the President's Committee on Hiring the Handicapped by President Lyndon Johnson. He wrote two autobiographies, Victory in My Hands *(1949, with Victor Rosen) and* The Best Years of My Life *(1981, with Dan Ferullo). Russell died in 2002 at the age of 88.*

Anzia Yezierska, from Red *Ribbon on a White Horse* (1950)

One of 10 children who immigrated at age 15 from Russian Poland to New York City's Lower East Side, Yezierska's writing spoke eloquently to the plight of Yiddish immigrants, the poor, and aged. Yezierska had a significant visual impairment, and her daughter hired transcribers to allow her to continue writing after she became blind. This excerpt from her fictionalized autobiography details her childhood friendship with a disabled man.

Always whenever I saw Zalmon Shlomoh I would feel that I too was a cripple. It leaped out of my eyes like the guilt of secret sin, that devouring hunger in me. People ran away from it as from a deformity. Only Zalmon Shlomoh, the hunchback, could feel and see the wild wolves of that hunger and not be frightened away.

I wondered, as I recalled the days when Zalmon was my only friend, whether he was still alive. If I could reach him, would he be glad to see me? Dared I look him up, to find out? But I knew he could never forgive my becoming one of the bloody rich. I never would look him up.

I thought of the time Zalmon had come to see me with a newspaper package under his arm. In the secondhand shop he had picked up, for a dime, an old record of Beethoven's "Moonlight Sonata." Instead of talking, he turned on the record again and again, filling the small room with the melancholy tenderness of all the unspoken love in the world.

One night he had taken me to hear Caruso in Pagliacci. The grief of the clown reached up to us in the gallery. That glorious voice cried out the ache of our own unlived lives.

Even while we sat together, cousins in sorrow, I was affronted by Zalmon's fish smells. In his new suit he looked as incongruous as a dog in a praying shawl. His charm was great enough to make me forget the dwarfed deformity of his body, but his fish smells drove me away. I could smell them even now.

Source: Yezierska, Anzia. 1950. *Red Ribbon on a White Horse.* New York: Scribner.

Josephine Miles, Poems (20th c.)

Josephine Miles (1911–1985), an award-winning poet who taught at the University of California at Berkeley during the mid-twentieth century, was the first woman ever to be tenured in the English Department there. Miles lived with severe rheumatoid arthritis and, in the absence of elevators and wheelchair-accessible entrances, had to be carried across campus and up stairs by male assistants.

Reason (1955)

Said, Pull her up a bit will you, Mac, I want to unload there.
Said, Pull her up my rear end, first come first serve.
Said, Give her the gun, But, he needs a taste of his own bumper.
Then the usher came out and got into the act.
Said, Pull her up, pull her up a bit, we need this space, sir.
Said, For God's sake, is this still a free country or what?
You go back and take care of Gary Cooper's horse
And leave me handle my own car.
Saw them unloading the lame old lady,
Ducked out under the wheel and gave her an elbow,
Said, all you needed to do was just explain;
Reason, Reason is my middle name.

Doll (1979)

Through the willows bent down to shelter us where we played
House in the sandy acres, though our dolls,
Especially Lillian, weathered all the action,
I kept getting so much earlier home to rest
That medical consultation led to cast
From head to toe. It was a surprise for my parents
And so for me also, and I railed
Flat out in the back seat on the long trip home
In which three tires blew on our trusty Mitchell.
Home, in a slight roughhouse of my brothers,
It turned out Lillian had been knocked to the floor and broken
Across the face. Good, said my mother
In her John Deweyan constructive way,
Now you and Lillian can be mended together.
We made a special trip to the doll hospital
To pick her up. But, They can't fix her after all, my father said,
You'll just have to tend her with her broken cheek.
I was very willing. We opened the box, and she lay
In shards mixed among tissue paper. Only her eyes
Set loose on a metal stick so they would open
And close, opened and closed, and I grew seasick.
A friend of the family sent me a kewpie doll.
Later Miss Babcox the sitter,
After many repetitious card games,
Said, We must talk about bad things.
Let me tell you
Some of the bad things I have known in my life.
She did not ask me mine, I could not have told her.
Among the bad things in my life, she said.
Have been many good people, good but without troubles;
Her various stories tended
To end with transmigrations of one sort or another,
Dishonest riches to honest poverty; kings and queens
To Indians over an adequate space and time.

In The Secret Garden, *an adaptation of Frances Hodgson Burnett's classic story, Margaret O'Brien stars as the orphan who transforms the lives of her embittered uncle and his bedridden son when she starts tending a garden on the grounds of their country mansion. The sobriety of black and white gives way to a blast of Technicolor.*

Source: *The Secret Garden* (1949), directed by Fred M. Wilcox. United Kingdom. B&W/color, 92 minutes. Reprinted by permission of Paul Darke.

Take this cat coming along here, she said,
A glossy black cat whom she fed her wages in salmon,
He is a wise one, about to become a person.
Come to think of it, possibly Lillian
Is about to become a cat.
She will have different eyes then, I said.
Obviously. Slanted, and what is more
Able to see in the dark.

Source: Miles, Josephine. 1983. *Collected Poems, 1930–1983.* Urbana: University of Illinois Press. Copyright © 1983 by Josephine Miles. Used with permission of the University of Illinois Press.

Hah Keun-Chan, from "Ill-fated Father and Son" [*Sunan I'dae*] (1957)

The title "Ill-fated Father and Son" can also be translated as "The Sufferings of Two Generations." In the story, the father, Man-do, who lost his arm in World War II during his conscripted labor in the South Pacific, greets his son, Chin-su, who is returning from the Korean War with one leg. Hah Keun-Chan's works mostly deal with national tragedy such as war experience and the lives of the lower class.

Chin-su comes back alive; there is the lingering sad news that some have died in the war and some haven't heard whether or not their sons were killed! Oh my son Chin-su is still alive, he's coming back.

Thinking of it has made Mr. Pak Man-do climb to the top of Yongmaru hill in one breath; usually he would sit and rest once or twice in order to climb the hill. . . .

It was not hard to climb down the hill. As Man-do's only arm, his right, swung back and forth, his pace naturally began to quicken. The sleeve of his left arm was carelessly stuck in the pocket of his vest. My only son to be shot dead in the war was unimaginable! Of course he had to come back alive! But since he's coming back from a hospital, he must have been wounded slightly. But surely not like I was.

Man-do looked down at the sleeve stuck in the pocket of his vest. Nothing in it. It was merely a cloth cylinder without any left arm. The sleeve was always stuck in the pocket of his vest; it hung and swung from the left shoulder. Perhaps a bullet only slightly grazed Chin-su's calf or buttocks. If he was wounded so badly as to lose an arm like me, that cry baby surely couldn't put up with the pain. Inwardly worried about his son, Man-do muttered to himself. . . .

Squatting down at the edge of the brook, Man-do untied his belt, passed water, and felt better. Bubbles formed due to the urine on the mirror surface of the water, and a school of fishes swam up. There were some fish as big as your thumb.

I sure wish I could have a drink and some of those raw fish dipped in red pepper sauce. His mouth watered at the sight of the fish as he thought about a drink. But he blew his nose noisily and began to cross the log bridge carefully. . . .

He lit a cigarette. He never sat on a bench in the waiting room of the station without recalling a memory which always struck terror into his heart. His lost arm with fingers turned black and blue like a moss-clad log, seemed to lie heavily on his mind.

At that time there had been a crowd of over a hundred people in this station. Among them had been Man-do. Waiting for a train to carry them away, none of them had known their destination. They had been draftees pressed into service by the Japanese government-general; none of them had any choice but to get on the train; all of them like puppets had been manipulated by order of the Japanese.

Some of them had been told they would be sent to the coal-mines in Hokkaido and others had asserted that the islands of Southeast Asia would be their destination. There had been some people who said even Manchuria would be alright for them. Man-do, thinking that any place would be alright for him, [had] puffed out his cigarette smoke through the nostrils of his turned-up nose. . . .

When he had heard the train enter the vicinity, its sad warning whistle merged into his deep vast grief, . . . Man-do felt his eyes misty with tears. But as the train pulled away from the station, his sad feeling began to fade from his mind. Man-do, then, found himself somewhat inwardly pleased. . . .

On the day of the accident they were, as usual, preparing a hole in which to set dynamite in the crack of a rock. When everything was ready all but one would get out of the tunnel. . . . Man-do was almost out of the entrance when he heard a bombshell blast with a gust of wind. He nearly went crazy. It was bombs from a plane flying directly over the entrance. Backing and falling, he saw another plane swooping down from the mountain ridge, and dashed back. As soon as he plunged inside, the tremendous explosion of the dynamite swept the inside of the tunnel. Man-do felt his consciousness dimmed in a flash. . . .

He found himself on a soft mattress of a hospital, after regaining consciousness. He felt the terrible pain making a sudden attack on his ill-fated shoulder. They had already operated on his disfigured shoulder.

The sudden whistle of a train from the bend of the mountain awoke him, drenched in the mournful memory. Jumping up from the bench, he gripped the bunch of mackerel beside him. His heart throbbed more quickly as the whistle became closer and louder. . . .

In the wave of people moving toward the exit, he saw a wounded soldier limping on crutches; he did not pay any attention. It seemed there were no more people getting off at this stop. A few people who had not yet gotten aboard were only walking up and down along the platform to get on the train.

I think he wouldn't lie about this coming in his letter to me. . . . Feeling his heart somewhat troubled, Man-do muttered to himself.

"Father!"

A voice from behind him came to him. He started and turned his head in a great hurry. At the moment he looked back, he became pop-eyed and opened his mouth wide. The man standing on his crutches was surely his son, but utterly unlike before. A trouser leg of his pants was flapping in the wind!

Astounded by Chin-su's disfigurement, Man-do found himself falling into despair. At last, his eyes began to water with tears.

"Oh, my goodness!"

They were the first words that came from Man-do, in a tone trembling with excitement. He doubled up his fist firmly, holding the bunch of mackerel.

"God, what on earth is the matter with you?"

"Father!"

"Oh, you poor boy!"

Man-do's [turned]-up nose was running snivel. Tears were flowing down Chin-su's cheeks. "Come on, let's go!" said Man-do bluntly as he began to walk briskly ahead of Chin-su with the grim look that the unexpected misfortune was entirely due to Chin-su himself. Chin-su, licking the salty tears that ran down over his upper lip, limped after his father.

Man-do, never turning his head toward his son, went on walking, averting his eyes. Looking down at the ground like a man with a heavy load on his back, Man-do went on walking without a pause. Chin-su, supported by crutches, couldn't by any means keep up with the pace of a healthy man, and to make him more miserable, Man-do was quickening his steps. At last the distance between the two became so great that the low voice hardly reached Man-do. . . .

Then both father and son came out of the wine house and walked along a footpath between the rice-fields.

This time, unlike before, Chin-su walked ahead of his father. From behind, looking at his son who was limping on his crutches, Man-do followed him at a snail's pace, dangling the mackerel from his one arm. Man-do felt uneasy in his stomach, and staggered. He drank too much, he thought. He began to lose his senses. But it didn't matter, he felt.

"Hey, Chin-su!"

"Yes."

"What happened to your leg?"

"I was hit by a grenade fragment."

"By a grenade fragment?"

"Yes."

"Um . . ."

"The whole leg turned bad so they had to cut it off at the hospital."

There was a brief silence.

"Father."

"What?"

"I'm afraid I can't live like this!"

"What do you mean? Until they die, everyone struggles to live. Don't be so stupid!"

Again the silence.

"Look, son! I live well enough with only one arm, don't I? Of course, it doesn't look too good, but that doesn't have anything to do with living."

"I wish I were you. Walking on this one leg is killing me."

"Oh, boy, you're wrong. What's the use of walking? You can do any work you want with two good hands."

"Really?"

"Sure. In fact, we can share the work between us; you can do the indoor housework sitting down, while I take care of the heavy work outside. We'll have no problems at all."

"I guess not."

Chin-su, sighing slightly, looked back at his father. Man-do smiled gently, turning his face toward him. The alcohol had passed through his system quickly and Man-do's bladder was bursting.

Man-do squatted by the roadside and tried to grasp the string binding the mackerel with his teeth. Seeing this, Chin-su said, "Let me hold the fish, father."

Until his father finished urinating, Chin-su with his crutches in one hand and the fish in the other waited in the road. After finishing, Man-do promptly took the bunch of fish from his son.

At last, they arrived at the brook with the narrow log bridge across it. Chin-su saw that he was going to have a problem getting across. The sandy stream-bed didn't seem firm enough to support him on his crutches, though the water was shallow enough. What's more, it was absolutely impossible for him to cross the narrow log bridge. The only thing, he believed, left to him was to roll up his trousers after all, and so flopping on the bank, he began to do so.

"That's alright, just ride on my back, son."

Man-do looked down at Chin-su a little vacantly.

"All you have to do is climb on my back and we can both get across. Come on. Take the fish."

He thrust out the bunch of mackerel toward Chin-su.

With a look of embarrassment, Chin-su hesitatingly took it. With his back to his son, Man-do stretched out his only arm and said,

"Climb on, son."

Chin-su rode gently on the back of his father, holding his crutches in one hand and the mackerel in the other. With his single arm stretched behind, Man-do clutched Chin-su's leg firmly, and told him, "You'd better hold on to my neck tightly."

Clutching the fish and crutches as he hugged his father with both arms, Chin-su's eyes began to fill and his face tightened with emotion. Man-do, straining his stomach muscles, stood up slowly. His knees were shaking slightly under the weight, but he thought he could make it.

Stepping out on the narrow log bridge, Man-do began muttering to himself: How pitiful for this strong young body to be disfigured! Chin-su, you have met a sad lot in this misguided world. Damn it! Your whole future is hopelessly doomed. Hopeless!

While these thoughts were running through Man-do's mind, Chin-su, clinging to his father's back with his face shrouded in despair, groaned inwardly: Now I have been cursed too. My father has no luck at all. It'd have been better if I'd . . . died. . . .

Still swayed by the wine and weighted down by his son, Man-do stepped carefully on the bridge.

The Yongmaru hill standing tall before them looked down silently on this ill-fated father and son.

Source: Hah Keun-Chan. 1972, August 1. Choi, W. S., trans. "Ill-fated Father and Son" [*Sunan I'dae*]. *Korea Journal:* 7–12. (Originally published 1957) Reprinted by permission of the *Korea Journal.*

German Movement of Mentally Disabled People (1958)

The Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung (Federal Association of Assisted Living for People with Cognitive Disabilities) is one of the most successful and largest disability self-help organizations in Germany. It was founded in 1958 as Lebenshilfe für das geistige behinderte Kind

(Assisted Living for the Mentally Handicapped Child) by a small group of experts and parents of cognitively disabled children. Its foundation was a reaction to the crimes perpetrated against disabled people during the National Socialist era. Thanks to the Bundesvereinigung, the Federal Republic of Germany was able to connect with the standard of education for cognitively disabled children and youth in other Western countries and in Northern European countries.

Letter of Invitation to the First Meeting, being held in Marburg/Lahn, November 13, 1958

Re: Preliminary discussion towards the foundation of a German organization of parents and friends of the mentally handicapped.

On the 23rd of November at 1:30 p.m., a meeting will take place in the educational counseling center in Marburg/Lahn regarding the possibility of founding a German national organization of parents and friends of the mentally handicapped as well as the goals and purposes of such an organization.

You are cordially invited to this meeting.

Organizations of this type already exist in many countries. The largest and so far most successful of such is the "National Association for Retarded Children" in the United States. . . .

The fact that the general public in Germany has to date done so relatively little for the general welfare of the mentally handicapped, has for many affected families needlessly increased the difficulties with their problem children in such a way that not seldom they become hardly bearable burdens.

As we know from the U.S., England, Holland, and a few other countries, institutions such as remedial kindergartens, schools for children that are only on the motor level trainable (imbeciles), schools for mongoloid children, training schools [*Anlernwerkstätten*], sheltered workshops, short-stay homes, summer camps, night schools, and evening clubs for the mentally handicapped, can highly contribute to limiting this problem to its narrowest borders.

The suggestion to call into being such institutions in this country as well will have to come from an influential parent organization, which will not grow weary in fighting again and again, wherever necessary for the welfare and happiness of its charges. With the help of the collective experiences from parent organizations in other countries, it should be possible in the foreseeable future to achieve a fundamental expansion of facilities for the mentally handicapped here as well. Also, the present period of economic prosperity should undoubtedly favor the success of such efforts. . . .

1958—Protocol of the Inaugural Meeting from November 23, 1958, Marburg

. . . After greeting those individuals present, the Summoner of the meeting, Mr. Tom Mutters, gave an overview of parental organizations for mentally handicapped children in other countries and underlined . . . the goals and purposes of a similar organization in Germany. . . . There was agreement, above all, on the following individual items:

- Contact should be made with all neighboring institutions that have similar objectives.
- The new organization should fight for, above all, a reform of home care; in particular, it should aim at supporting the institutions to stay in contact with the families.
- For the time being, the reform movement will emphasize the promotion of 'sheltered workshops and remedial kindergartens.' . . .

There was also a warning given to the new organization of following too strongly the course of already existing umbrella organizations of a denominational or solicitous sort, and it was unanimously pleaded for the creation of an independent organization that is fundamentally led by parents of disabled children.

The main task of the association was defined as fostering exemplary helping institutions, not however, to establish or maintain such institutions itself. The planned assistance should benefit all mentally handicapped (not only mongoloids and not only children). However, out of psychological grounds it seems opportune to anchor the expression, "Help for Children" in the association's description.

After a thorough discussion of the various possibilities, the group reached an agreement on the following description: "Lebenshilfe für das geistig behinderte Kind e.V." [Assisted Living for the Mentally Handicapped Child, a Registered Organization].

Source: Möckel, Andreas, Heidemarie Adam, and Gottfried Adam, eds. 1999. Pp. 154–157 in *Quellen zur Erziehung von Kindern mit geistiger Behinderung.* Würzburg, Germany: Bentheim. [*Sources on the Education of Children with Cognitive Disabilities: Vol. 2. 20th Century.* Vogt, Sara, trans.]

Harper Lee, from To *Kill a Mockingbird* (1960)

Harper Lee's classic novel about growing up in the racially segregated U.S. South hinges on a variety of disability-based revelations. The falsely accused African American character, Tom Robinson, is proven innocent by Atticus Finch on the basis of an impairment he received when his arm was caught in a cotton gin. Nevertheless, the all-white jury finds him guilty of the crime of raping a lower-class white woman, Mayella Ewell. Additionally, a cognitively disabled character, Boo Radley, ultimately saves the children from a violent attack by Mayella's father, who is enraged by their father's willingness to defend a black man. In this excerpt, the children (Jem, Scout, and Dill) create horror stories about Boo's disability and incarceration within his family home.

Jem gulped down his second glassful and slapped his chest. "I know what we are going to play," he announced. "Something new, something different."

"What?" asked Dill.

"Boo Radley."

Jem's head at times was transparent: he had thought that up to make me understand he wasn't afraid of Radleys in any shape or form, to contrast his own fearless heroism with my cowardice.

"Boo Radley? How?" asked Dill.

Jem said, "Scout, you can be Mrs. Radley—"

"I declare if I will. I don't think—"

"Smatter?" said Dill. "Still scared?"

"He can get out at night when we're all asleep . . ." I said.

Jem hissed. "Scout, how's he gonna know what we're doin'? Besides, I don't think he's still there. He died years ago and they stuffed him up the chimney."

Dill said "Jem, you and me can play and Scout can watch if she's scared."

I was fairly sure Boo Radley was inside that house, but I couldn't prove it, and felt it best to keep my mouth shut or I would be accused of believing in Hot Steams, phenomena I was immune to in the daytime.

Jem parceled out our roles: I was Mrs. Radley, and all I had to do was come out and sweep the porch. Dill was old Mr. Radley: he walked up and down the sidewalk and coughed when Jem spoke to him. Jem, naturally, was Boo: he went under the front steps and shrieked and howled from time to time.

The Men *focuses on a ward full of paraplegic war veterans, including Marlon Brando as a wheelchair user, who struggle to come to terms with their altered bodies and a hostile social world beyond the rehabilitation unit.*

Source: *The Men* (1950), directed by Fred Zinnemann. United States. B&W, 85 minutes. Reprinted by permission of Paul Darke.

As the summer progressed, so did our game. We polished and perfected it, added dialogue and plot until we had manufactured a small play upon which we ran changes every day.

Dill was a villain's villain: he could get into any character part assigned him, and appear tall if height was part of the devilry required. He was as good as his worst performance; his worst performance was Gothic. I reluctantly played assorted ladies who entered the script. I never thought it was as much fun as Tarzan, and I played that summer with more than vague anxiety despite Jem's assurances that Boo

Radley was dead and nothing would get me, with him and Calpurnia there in the daytime and Atticus home at night.

Jem was a born hero.

It was a melancholy little drama, woven from bits and scraps of gossip and neighborhood legend: Mrs. Radley had been beautiful until she married Mr. Radley and lost all her money. She lost most of her teeth, her hair, and her right forefinger (Dill's contribution. Boo bit it off one night when he couldn't find any cats or squirrels to eat.); she sat in the living room and cried most of the time, while Boo slowly whittled away at all the furniture in the house. The three of us were the boys who got into trouble; I was the probate judge, for a change; Dill led Jem away and crammed [him] beneath the steps, poking him with the brush broom. Jem would reappear as needed in the shapes of the sheriff, assorted townsfolk, and Miss Stephanie Crawford, who had more to say about the Radleys than anybody in Maycomb.

When it was time to play Boo's big scene, Jem would sneak into the house, steal the scissors from the sewing machine drawer when Calpurnia's back was turned, then sit in the swing and cut up newspapers. Dill would walk by, cough at Jem, and Jem would fake a plunge into Dill's thigh. From where I stood it looked real.

When Mr. Nathan Radley passed on his daily trip to town, we would stand still and silent until he was out of sight, then wonder what he would do to us if he suspected. Our activities halted when any of the neighbors appeared, and once I saw Miss Maudie Atkinson staring across the street at us, her hedge clippers in mid-air.

One day we were busily playing Chapter XXV, Book II of One Man's Family, we did not see Atticus standing on the sidewalk looking at us, slapping a rolled magazine against his knee. The sun said twelve noon.

"What are you all playing?" he asked.

"Nothing," said Jim.

Jem's evasion told me our game was a secret, so I kept quiet.

"What are you doing with the scissors, then? Why are you tearing up that newspaper? If its today's I'll tan you."

"Nothing."

"Nothing what?" said Atticus.

"Nothing sir."

"Give me those scissors," Atticus said. "They're nothing to play with. Does this, by any chance have anything to do with the Radleys?"

"No sir," said Jem, reddening.

"I hope it doesn't," he said shortly, and went inside the house.

"Jem-m . . .."

"Shut up! He's gone into the living room, he can hear us in there."

Safely in the yard, Dill asked Jem if we could play anymore.

"I don't know. Atticus didn't say we couldn't—"

"Jem," I said, "I think Atticus knows it anyway."

I was not so sure, but Jem told me I was being a girl, that girls always imagine things, that's why other people hated them so, and if I started behaving like one I could just go off and find some to play with.

"All right, you just keep it up then," I said. "You'll find out."

Atticus's arrival was the second reason I wanted to quit the game. The first reason happened the day I rolled into the Radley front yard. Through all the head-shaking, quelling of nausea and Jem-yelling, I heard another sound, so low I could not have heard it from the sidewalk. Someone inside the house was laughing.

Source: Lee, Harper. 1960. Pp. 38–41 in *To Kill a Mockingbird.* New York: Warner. Copyright © 1960 by Harper Lee, renewed 1988 by Harper Lee, foreword © 1993 by Harper Lee. Reprinted by permission of HarperCollins Publishers.

Erving Goffman, from *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (1961)

Many psychiatric survivors credit Erving Goffman's work as significant in revealing how a dependency on long-term institutionalization creates an inherently disempowering system of psychiatric care.

Like the neophytes in many of these total institutions, the new inpatient finds himself cleanly stripped of many of his accustomed affirmations, satisfactions, and defenses, and is subjected to a rather full set of mortifying experiences: restriction of free movement, communal living, diffuse authority of a whole echelon of people, and so on. Here one begins to learn about the limited extent to which a conception of oneself can be sustained when the usual setting of supports for it are suddenly removed. . . . While undergoing these humbling moral experiences, the inpatient learns to orient himself in terms of the "ward system." (P. 148)

. . . Once lodged on a given ward, the patient is firmly instructed that the restrictions and deprivations he encounters are not due to such blind forces as tradition or economy—and hence dissociable from self—but are intentional parts of his treatment, part of his need at the time, and therefore an expression of the state that his self has fallen to. Having every reason to initiate requests for better conditions, he is told that when the staff feel he is "able to manage" or will be "comfortable with" a higher ward level, then appropriate action will be taken. In short, assignment to a given ward is presented not as a reward or punishment, but as an expression of his general level of social functioning, his status as a person. (P. 149)

Source: Goffman, Erving. 1961. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates.* New York: Doubleday.

The Korean Child Welfare Committee, from *Handicapped Children's Survey Report* (1961)

These excerpts are from the first nationwide disability census in Korea, which has unique categories of disability different from later statistics. For example, children of mixed races were classified as socially handicapped, but this classification disappears from the disability category in later statistics. The survey was funded by various international social welfare foundations, the U.S. Army, and Korean governmental and church-related organizations. The report was published in Korean and English. The report includes the history of welfare services for handicapped children, case studies, essays by professionals on social issues and concerns of each category, and statistical descriptions of the results.

Foreword

Soon Yung Kwon

The Korea Child Welfare Committee has contributed to the promotion of child welfare in Korea in many ways for the past ten years, and this survey of children with physical, mental or social handicaps was one of its largest undertakings to date.

The Children's Survey Sub-committee, organized in September 1960 prepared for the nation-wide survey that was effectively carried out as of 10 April 1961. The Committee received financial assistance from both Korean and international voluntary agencies and individuals, administrative and technical participation of the Ministry of Health and Social Affairs, and those of provincial and local government.

Based on the decision of the Committee to use as interviewers, the Tong or Dong chiefs of villages who have little knowledge in handicaps of people, the survey had to be limited to such severe handicaps as a layman could plainly identify. Therefore, the children with slight handicaps and the children who are suffering from sicknesses or diseases that might cause handicaps in the future were not included in the Survey.

Some socially handicapped children such as juvenile delinquents; orphans; children born outside marriage, children of leper parents, and children of widows were not included in this survey. . . .

Healthy children of leper parents find themselves rejected by and ostracized from society. However, the survey did not include the group because of technical difficulties in the method of survey that was employed. An article on the subject was included in this report. Loss of husbands and fathers during the Korean War produced many widows and orphans. Widows living with their dependent children often find it difficult to get married again in this society and feel that they are a complicated social problem.

As the result of this survey many facts have been discovered. Handicapped boys are 27.2% more in number than the girls, as the total 77,903 handicapped children include 49,560 boys and 28,343 girls. The largest in number of handicaps is "paralytic or palsied" with 31,475 children with paralytic handicaps (38.7% is the total). The four Provinces that have the largest number of handicapped children are in order of Cheju-do, Cholla Namdo, Kyongsang Namdo and Cholla Pukdo. Seoul City has the smallest. 46,563 handicapped children or 82.6% are the children of low income families whose tax assessment is under category number 5. 58,947 handicapped children or 65.9% of the total indicated their desire for medical care.

Introduction

In Korea, many national crises and rapid social changes during the past twenty years have spawned serious problems contributing to human suffering in all walks of life. A large number of these problems are related directly to the welfare of children, such as care of orphans, prevention of and guidance for steadily increasing juvenile delinquents, rehabilitation of children with physical or mental handicaps, as well as protection of children placed under social discrimination. There is a growing awareness of the need for better provision of educational opportunities for the less fortunate, attention for child health, cultivation of recreational activities and other programs and services promoting general welfare of children.

Faced with the tremendous task of meeting so many needs on every side with little experience and resources, both government and voluntary agencies have been placed under pressure to develop adequate welfare services based on systemic assessment of needs and resources through a social survey. The need to fill this gap in the development of social welfare services was well demonstrated by the fact that there was extremely meager statistical information available on the nation's children when this committee began the collection of preliminary statistics.

This survey on handicapped children was the first such experiment on a nation-wide scale in the social welfare field, undertaken with scientific approach in an effort to introduce facts which we hope will be used for planning and implementation of needed services. It has been duly recognized by the committee that the problems of handicapped children are only a small portion of those related to the total family and child welfare needs in Korea. (P. 14)

In A Stolen Face*, a plastic surgeon attempts to transform the face of a female convict into that of a lost lover.*

Source: *A Stolen Face* (1952), directed by Terrence Fisher. United Kingdom. B&W, 80 minutes. Reprinted by permission of Paul Darke.

The Mixed Racial Child, by Anne M. Davison

Most of the mixed racial children in Korea are illegitimate because mothers are casual or regular prostitutes of foreign servicemen. Of course the girl does not want to remain in that category, and she hopes constantly that he will marry her and take her away. If he is a white serviceman, he is the most [desirable]. If she lives with him and has his child, the baby may be used as a lever to try to press him into marriage. In the marriage of an oriental and an occidental, the marriage custom of one or the other or both may be followed. If a western marriage is registered, the Korean community accepts it, but if the eastern custom is followed in a mixed marriage, the western country may not recognise it legally. When there is a marriage by Korean custom, as long as her "husband" remains in Korea, she is a respectable member of society, but when her "husband" leaves and returns to his own country, leaving her behind, everyone feels that he is a deserter. She is then thrust back into the community as an outcast and joins the group of cast-off wives, and other rejected people. Her chances of rehabilitation become very small.

There are girls as well as men who use the present social situation for their own ends. Sometimes the girl leads the man on, with no intention of leaving her way of life. She promises to marry and emigrate. Their marriage is made a legal one. If he must leave early, then she may refuse to follow him. She blames legal offices, friends and welfare worker, as excuses for her own indecision. The husband on the other side of the world feels that her delays in joining him are caused by outside attitudes of prejudice against his oriental wife because he does not really understand her basic problem.

What happens to the children in all these situations? They follow along and share the insecurity that their parents have made for them. They share the hope of the mother, that the father will return and marry her and take them all away, or marry the mother for debts, living expenses, and school fees. Such hopes keep the child's life uncertain and constantly insecure. Sometime the father says, "Send my son, even if my wife won't come." Very often another foreign man will feel that this girl has been badly treated, and pity may drive him to marry her and adopt her illegitimate children as well.

The decision to release a child for foreign adoption abroad is reached in various ways.

1. It may be complete economic inability to support that is the deciding factor. Having a child is costly, and the mother has probably become deeply indebted to the brothel keeper. Legally she cannot be made to meet debts of this nature, but she knows that she has a social obligation, that will weigh heavily on her until it is met.
2. A release for adoption may be given by a girl who has reached the end of her hope that the father will return as he promised he would do. By this time the child may be ten years old.
3. She may release her baby because he hampers her movement, is costly, and may remind her of a man who is no longer around. An oriental girl finds it hard to accept the fact that a foreign man is not interested in what happens to his child, especially if the child is a boy, and she constantly wants to have the father consulted about plans for their child. This may delay an adoption for years.
4. Some girls realise that foreign adoption in the long view will give more opportunity to the child, than anything they can give, and unselfishly they face the separation and make plans together with the adoption agency for his emigration.

Girls who make a success of prostitution financially are in a position where they can hire an older woman or a friend to care for the child. The mother can then write directly to the father, ask for support, or better still, from her point of view, beg him to divorce his wife and come back and marry her. The children are being held for blackmail purposes, and not loved by the mother or given the security of a home environment. These are the children that suffer the most and the longest. They are usually living in the middle of a prostitute community, and they must face each day the fact that they are consequences that have made no one happy, and often no one wants. Girls who move to some sections of an urban community, and who thus lose their identity somewhat, may find themselves and their children accepted more readily in the new community. This is so especially if the school teacher's attitude is one of acceptance and understanding. Of course children tease each other unmercifully, but if the teacher and the mother understand, and are a strength to a child, an adjustment may by made. However, when that point is reached, often the child may be behind in his school grade. It may mean that if the mother has no money for school fees, the child may have to leave school altogether, even though he is getting along well. As most of the prostitutes have very little education themselves, few of them having completed primary school, and have lost their self for an education for their children as other parents in the community.

The social and psychological handicaps of these children may be complicated by the addition of the physical or mental ones as well, such as polio, tuberculosis, feeble-mindedness etc.

Until the channel is opened to change a child's surname legally, there is not likely to be extensive adoption of mixed racial children in Korea. There needs to be a great deal more publicity and supervised assistance before families will be able to accept the challenge and do anything as radical as this. However, the government has taken the stand that a child should not be penalised for any misbehaviour of the parents. They have made . . . provisions for legal birth registrations for *all* [children]. As mixed racial marriage are increasing, there are growing numbers of mixed racial legitimate children in the community.

Foreign adoption is only a partial solution for the problems of mixed racial children's problems. There has not been enough time yet to evaluate the results of placing oriental children in western homes. For the present, plans should be made for the best possible solution to each situation may be found, either here in Korea or aboard. (Pp. 71–74)

Source: The Korean Child Welfare Committee. 1961. *Handicapped Children's Survey Report.* Seoul, South Korea: Korean Child Welfare Committee. Reprinted by permission of the Korean Department of Social Welfare.

▣ Thomas S. Szasz, from *The Myth of Mental Illness* (1961)

Thomas S. Szasz's popular work remains controversial. Recommended by psychiatric survivor/user advocates who are also affiliated with the antipsychiatry movement, many credit Szasz's ideas as providing instrumental theoretical support during the movement's early years.

It is customary to define psychiatry as a medical specialty concerned with the study, diagnosis, and treatment of mental illnesses. This is a worthless and misleading definition. Mental illness is a myth. Psychiatrists are not concerned with mental illnesses and their treatments. In actual practice they deal with personal, social, and ethical problems in living.

Source: Szasz, Thomas S. 1961. P. 262 in *The Myth of Mental Illness: Foundations of a Theory of Personal Conduct.* New York: Harper & Row. Copyright 1961 by Paul B. Hoeber, Inc. © 1974 by Thomas S. Szasz, M.D. Reprinted by permission of HarperCollins Publishers Inc.

▣ Michel Foucault, from *The Birth of the Clinic* (1963)

In The Birth of the Clinic, *Foucault analyzes the objectifying rhetoric of diagnosis applied by clinical medicine to its human objects. The work, along with his* Madness and Civilization, *furthers his anatomy of institutions as disciplinary spaces. Collectively, the two works demonstrate Foucault's lifelong critique of pathology as a distancing formula of empiricism that empties subjects of their humanity.*

From the Preface

Commentary questions discourse as to what it says and intended to say; it tries to uncover that deeper meaning of speech that enables it to achieve an identity with itself, supposedly nearer to its essential truth; in other words, in stating what has been said, one has to re-state what has never been said. In this activity known as commentary which tries to transmit an old, unyielding discourse seemingly silent to itself, into another, more prolix discourse that is both more archaic and more contemporary—is concealed a strange attitude toward language: to comment is to admit by definition an excess of the signified over the signifier; a necessary, unformulated remainder of thought that language has left in the shade—a remainder that is the very essence of thought, driven outside its secret—but to comment also presupposes that this unspoken element slumbers within speech (*parole*), and that, by a superabundance proper to the signifier, one may, in questioning it, give voice to a content that was not explicitly signified. . . . Is it not possible to make a structural analysis of discourses that would evade the fate of commentary by supposing no remainder, nothing in excess of what has been said, but only the facts of its historical appearance?

From Chapter One: Spaces and Classes

In order to know the truth of the pathological fact the doctor must abstract the patient . . . paradoxically, in relation to that which he is suffering from, the patient is only an external fact; the medical reading must take him into account only to place him in parentheses. . . .

Medical perception must be directed neither to series nor to groups; it must be structured as a look through a magnifying glass, which, when applied to different parts of an object, makes one notice other parts that one would not otherwise perceive, thus initiating the endless task of understanding the individual. . . .

In fact, no hostile disease is a pure disease. . . .

From Chapter Two: A Political Consciousness

Being a collective phenomenon, it [an epidemic] requires a multiple gaze; a unique process, it must be described in terms of its special, accidental, unexpected qualities. The event must be described in detail but it must also be described in accordance with the coherence implied by multi-perception: being an imprecise form of knowledge, insecurely based while ever partial, incapable of acceding of itself to the essential or fundamental, it finds its own range only in the cross-checking of viewpoints, in repeated, corrected information, which finally circumscribes,

In Rear Window, *a news photographer, confined to his room by a broken leg, believes that he has seen a murder committed in an apartment on the other side of the courtyard. The film employs physical mobility as a metaphor for masculine oedipal conflicts with women.*

Source: *Rear Window* (1954), directed by Alfred Hitchcock. United States. Color, 110 minutes. Reprinted by permission of Paul Darke.

where gazes meet, the individual, unique nucleus of these collective phenomena. At the end of the eighteenth century this form of experience was being institutionalized. . . .

A medicine of epidemics could exist only if supplemented by a police. . . .

The myth of a nationalized medical profession, organized like the clergy, and invested, at the level of man's bodily health, with power similar to those exercised by the clergy over men's souls; in the myth of a total disappearance of disease in an untroubled, dispassionate society restored to its original state of health. . . .

Medicine will also embrace a knowledge of *healthy man* that is a study of *nonsick-man* and a definition of the model man. . . .

From Chapter Three: The Free Field

For these, "communal houses for the sick" must be set up that would function as family substitutes and spread, in the form of reciprocity, the gaze of compassion; in this way, the poor would find "in companions of their own kind naturally sympathetic creatures who are not necessarily strangers to them." Thus disease would everywhere find its natural, or almost natural, locale, where it would be free to follow its own course and to abolish itself in its truth. . . .

The hospital is an anachronistic solution that does not respond to the real needs of the poor and that stigmatizes the sick in a state of penury. . . .

From Chapter Four: The Old Age of the Clinic

The clinic, on the other hand, was thought to be the element of its positive accumulation: it was this constant gaze upon the patient, this age-old, yet ever renewed attention that enabled medicine not to disappear entirely with each new speculation, but to preserve itself, to assume little by little the figure of the truth that is definitive, if not completed, in short, to develop, below the level of the noisy episodes of its history, in a continuous historicity. In the non-variable of the clinic, medicine, it was thought, had bound truth and time together. . . .

From Chapter Five: The Lesson of the Hospitals

What allows man to resume contact with childhood and to rediscover the permanent birth of truth is this bright, distant, open naivety of the gaze. . . .

Once the criteria of competence had been laid down, a selection could be made of those to whom the lives of citizens might be safely entrusted; medicine would then become a closed profession. . . .

A structure had to be found for the preservation of both the hospitals and the privileges of medicine, that was compatible with the principles of liberalism and the need for social protection—the latter understood somewhat ambiguously as the protection of the poor by the rich and the protection of the rich against the poor. . . .

But to look in order to know, to show in order to teach, is not this a tacit form of violence, all the more abusive for its silence, upon a sick body that demands to be comforted, not displayed? . . .

And in accordance with a structure of reciprocity, there emerges for the rich man the utility of offering help to the hospitalized poor: by paying for them to be treated, he is, by the same token, making possible a greater knowledge of the illnesses with which he himself may be affected; what is benevolence towards the poor is transformed into knowledge that is applicable to the rich. . . .

From Chapter Six: Signs and Cases

The symptom—hence its uniquely privileged position—is the form in which the disease is presented: of all that is visible, it is closest to the essential; it is the first transcription of the inaccessible nature of the disease. . . .

The sign announces: the prognostic sign, what will happen; the anamnestic sign, what has happened; the diagnostic sign, what is now taking place. . . . Through the invisible, the sign indicates that which is further away, below, later. It concerns the outcome, life and death, time, not that immobile truth, that given, hidden truth that the symptoms restore to their transparency as phenomena. . . .

Individual variations are spontaneously effaced by integration. In the medicine of species, this effacement of particular modifications was assured only by a positive operation: in order to accede to the purity of essence, it was first necessary to possess it, and then to use it to obliterate the excessively rich content of experience; it was necessary, by a prior choice, "to distinguish what is constant from what is variable in it, the essential from the purely accidental." . . .

From Chapter Seven: Seeing and Knowing

The glance, on the other hand, does not scan a field: it strikes at one point, which is central or decisive; the gaze is endlessly modulated, the glance goes straight to its object. . . .

From Chapter Eight: Open up a Few Corpses

A fine transmutation of the corpse had taken place: gloomy respect had condemned it to putrefaction, to the dark work of destruction; in the boldness of the gesture that violated only to reveal, to bring to the light of day, the corpse became the brightest moment in the figures of truth. . . .

Anatomy could become pathological only insofar as the pathological spontaneously anatomizes. Disease is an autopsy in the darkness of the body, dissection alive. . . .

From Chapter Nine: The Visible Invisible

Life, with its finite, defined margins of variation, was to play the same role in pathological anatomy as the broad notion of nature played in nosology: it was the inexhaustible, but closed basis in which disease finds the ordered resources of its disorders. . . .

Death is disease made possible in life . . . deviation in life is of the order of life but of a life that moves towards death. . . .

Source: Foucault, Michel. 1975. Sheridan, Alan, trans. *The Birth of the Clinic: An Archaeology of Medical Perception.* New York: Vintage. Copyright © 1975 Alan Sheridan. Originally published in French as *Naissance de la Clinique—Une archeologie du regard medical,* copyright © 1963 by Editions Gallimard, reprinted by permission of Georges Borchardt, Inc. for Editions Gallimard.

Thomas Pynchon, from *The Crying of Lot 49* (1966)

This excerpt from the American postmodern writer's first novel provides an important example of disability as a marker of social ostracism. However, rather than foregrounding physical difference as undesirable, the passages employ disability as that which identifies the existence of alternative political communities outside of a stultifying mainstream.

Out at the airport Oedipa, feeling invisible, eavesdropped on a poker game whose steady loser entered each loss neat and conscientious in a little balance-book decorated inside with scrawled post horns. "I'm averaging a 99.37 percent return, fellas," she heard him say. The others, strangers, looked at him, some blank, some annoyed. "That's averaging it out, over 23 years," he went on, trying a smile. "Always just that little percent on the wrong side of breaking even. Twenty-three years. I'll never get ahead of it. Why don't I quit?" Nobody answering.

In one of the latrines was an advertisement by ACDC, standing for Alameda County Death Cult, along with a box number and post horn. Once a month they were to choose some victim from among the innocent, the virtuous, the socially integrated and well-adjusted, using him sexually, then sacrificing him. Oedipa did not copy the number.

Catching a TWA flight to Miami was an uncoordinated boy who planned to slip at night into aquariums and open negotiations with the dolphins, who would succeed man. He was kissing his mother passionately goodbye, using his tongue. "I'll write, ma," he kept saying. "Write by WASTE," she said, "remember. The government will open it if you use the other. The dolphins will be mad." "I love you, ma," he said. "Love the dolphins," she advised him. "Write by WASTE."

So it went. Oedipa played the voyeur and listener. Among her other encounters were a racially-deformed welder, who cherished his ugliness, a child roaming the night who missed the death before birth as certain outcasts do the dear lulling blankness of the community; a Negro woman with an intricately-marbled scar along the baby-fat of one cheek who kept going through rituals of miscarriage each for a different reason, deliberately as others might the ritual of birth, dedicated not to continuity but to some kind of interregnum; an aging night-watchman, nibbling at a bar of Ivory Soap, who had trained his virtuoso stomach to accept also lotions, air-fresheners, fabrics, tobaccoes and waxes in a hopeless attempt to assimilate it all, all the promise, productivity, betrayal, ulcers, before it was too late; and even another voyeur, who hung outside one of the city's still-lighted windows, searching for who knew what specific image. Decorating each alienation, each species of withdrawal, as cufflink, decal, aimless doodling, there was somehow always the post horn. She grew so to expect it that perhaps she did not see it quite as often as she later was to remember seeing it. A couple-three times would really have been enough. Or too much.

She busrode and walked on into the lightening morning, giving herself up to a fatalism rare for her. Where was the Oedipa who'd driven so bravely up here from San Narciso? That optimistic baby had come on so like the private eye in any long-ago radio drama, believing all you needed was grit, resourcefulness, exemption from hidebound cops' rules, to solve any great mystery.

But the private eye sooner or later has to get beat up on. This night's profusion of post horns, this malignant, deliberate replication, was their way of beating up. They knew her pressure points, and the ganglia of her optimism, and one by one, pinch by precision pinch, they were immobilizing her.

Source: Pynchon, Thomas. 1966. Pp. 123–124 in *The Crying of Lot 49*. Philadelphia: Lippincott.

▣ From the Social Security Act of 1967, Section 223 (d)(3) (United States)

The U.S. Social Security Act presented a variety of iterations of the definition of disability over the course of its development and implementation. In the 1967 version, disability was narrowed to a category of incapacity to work.

An individual . . . shall be determined to be under a disability only if his physical or mental impairment or impairments are of such severity that he is not only unable to do his previous work but cannot, considering his age, education, and work experience, engage in any kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area in which he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work.

▣ R. D. Laing, from *The Politics of Experience* (1968)

R. D. Laing, a psychiatrist who came to be known as the father of the antipsychiatry movement, stressed that our modern sense of "normality" creates and then camouflages deep intrinsic loss. The antipsychiatry movement is often associated with the psychiatric survivor/user movement.

What we call "normal" is a product of repression, denial, splitting, projection, introjection and other forms of destructive action on experience. . . . It is radically estranged from the structure of being.

The more one sees this, the more senseless it is to continue with generalized descriptions of supposedly specifically schizoid, schizophrenic, hysterical "mechanisms."

There are forms of alienation that are relatively strange to statistically "normal" forms of alienation. The "normally" alienated person, by reason of the fact that he acts more or less like everyone else, is taken to be sane. Other forms of alienation that are out of step with the prevailing state of alienation are those that are labeled by the "normal" majority as bad or mad.

The condition of alienation, of being asleep, of being unconscious, of being out of one's mind, is the condition of normal man.

Source: Laing, R. D. 1968. Pp. 27–28 in *The Politics of Experience.* New York: Ballantine Books. Copyright © R. D. Laing, 1967.

▣ From the Rehabilitation Act of 1973 (United States)

The Rehabilitation Act of 1973 was one of the earliest efforts to formalize legislation in the United States that guaranteed disabled people protection from discrimination under the law. The Vocational Rehabilitation Act of 1920 had marked the first major legislation establishing public rehabilitation programs for persons with disabilities in the United States. Funds were provided for vocational guidance, training, occupational adjustment, prosthetics, and placement services. Amendments during subsequent decades expanded the scope of federal programs. The Rehabilitation Act of 1973, which changed the name of the legislation from the Vocational Rehabilitation Act to the Rehabilitation Act, man dated a priority to serve persons with severe disabilities and affirmative action programs were established in Title V, Sections 501, 502, 503, and 504.

The Rehabilitation Act of 1973 was the predecessor of the 1990 Americans with Disabilities Act and promoted equal access throughout all segments of society. This excerpt is from the act as it was amended in 1998 by the Workforce Investment Act.

Section 2 (a): Findings

Congress finds that—

(1) millions of Americans have one or more physical or mental disabilities and the number of Americans with such disabilities is increasing;

(2) individuals with disabilities constitute one of the most disadvantaged groups in society;

(3) disability is a natural part of the human experience and in no way diminishes the right of individuals to—

- (A) live independently;
- (B) enjoy self-determination;
- (C) make choices;
- (D) contribute to society;
- (E) pursue meaningful careers; and
- (F) enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society;

(4) increased employment of individuals with disabilities can be achieved through implementation of statewide workforce investment systems under title I of the Workforce Investment Act of 1998 that provide meaningful and effective participation for individuals with disabilities in workforce investment activities and activities carried out under the vocational rehabilitation program established under title I, and through the provision of independent living services, support services, and meaningful opportunities for employment in integrated work settings through the provision of reasonable accommodations;

(5) individuals with disabilities continually encounter various forms of discrimination in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and public services; and

(6) the goals of the Nation properly include the goal of providing individuals with disabilities with the tools necessary to—

(A) make informed choices and decisions; and

(B) achieve equality of opportunity, full inclusion and integration in society, employment, independent living, and economic and social self-sufficiency, for such individuals.

(b) Purpose

The purposes of this Act are—

(1) to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society, through—

(A) statewide workforce investment systems implemented in accordance with title I of the Workforce Investment Act of 1998 that include, as integral components, comprehensive and coordinated state-of-the-art programs of vocational rehabilitation;

(B) independent living centers and services;

(C) research;

(D) training;

(E) demonstration projects; and

(F) the guarantee of equal opportunity; and

(2) to ensure that the Federal Government plays a leadership role in promoting the employment of individuals with disabilities, especially individuals with significant disabilities, and in assisting States and providers of services in fulfilling the aspirations of such individuals with disabilities for meaningful and gainful employment and independent living.

Laurence Olivier directs and stars in Richard III*, a triple Bafta-winning adaptation of Shakespeare's "hump-backed" king turned power-mongering usurper of the British throne.*

Source: *Richard III* (1955), directed by Laurence Olivier. United Kingdom. Color, 158 minutes. Reprinted by permission of Paul Darke.

(c) Policy

It is the policy of the United States that all programs, projects, and activities receiving assistance under this Act shall be carried out in a manner consistent with the principles of—

(1) respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers, based on informed choice, of individuals with disabilities;

(2) respect for the privacy, rights, and equal access (including the use of accessible formats), of the individuals;

(3) inclusion, integration, and full participation of the individuals;

(4) support for the involvement of an individual's representative if an individual with a disability requests, desires, or needs such support; and

(5) support for individual and systemic advocacy and community involvement.

Section 7: Definitions

(20) Individual with a disability

(A) In general

Except as otherwise provided in subparagraph (B), the term "individual with a disability" means any individual who—

(i) has a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment; and

(ii) can benefit in terms of an employment outcome from vocational rehabilitation services provided pursuant to title I, III, or VI.

(21) Individuals with a significant disability

(A) In general

Except as otherwise provided in subparagraph (B), the term "individual with a significant disability" means an individual with a disability—

(i) who has a severe physical or mental impairment which seriously limits one or more functional capacities (such as mobility, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) in terms of an employment outcome;

(ii) whose vocational rehabilitation can be expected to require multiple vocational rehabilitation services over an extended period of time; and

(iii) who has one or more physical or mental disabilities resulting from amputation, arthritis, autism, blindness, burn injury, cancer, cerebral palsy, cystic fibrosis, deafness, head injury, heart disease, hemiplegia, hemophilia, respiratory or pulmonary dysfunction, mental retardation, mental illness, multiple sclerosis, muscular dystrophy, musculo-skeletal disorders, neurological disorders (including stroke and epilepsy), paraplegia, quadriplegia, and other spinal cord conditions, sickle cell anemia, specific learning disability, end-stage renal disease, or another disability or combination of disabilities determined on the basis of an assessment for determining eligibility and vocational rehabilitation needs described in subparagraphs (A) and (B) of paragraph (2) to cause comparable substantial functional limitation.

(B) Independent living services and centers for independent living

For purposes of title VII, the term "individual with a significant disability" means an individual with a severe physical or mental impairment whose ability to function independently in the family or community or whose ability to obtain, maintain, or advance in employment is substantially limited and for whom the delivery of independent living services will improve the ability to function, continue functioning, or move towards functioning independently in the family or community or to continue in employment, respectively.

(C) Research and training

For purposes of title II, the term "individual with a significant disability" includes an individual described in subparagraph (A) or (B).

(D) Individuals with significant disabilities

The term "individuals with significant disabilities" means more than one individual with a significant disability.

(E) Individual with a most significant disability

(i) In general

The term "individual with a most significant disability," used with respect to an individual in a State, means an individual with a significant disability who meets criteria established by the State under section 101(a)(5)(C).

(ii) Individuals with the most significant disabilities

The term "individuals with the most significant disabilities" means more than one individual with a most significant disability.

(22) Individual's representative; applicant's representative

The terms "individual's representative" and "applicant's representative" mean a parent, a family member, a guardian, an advocate, or an authorized representative of an individual or applicant, respectively.

(23) Institution of higher education

The term "institution of higher education" has the meaning given the term in section 1201(a) of the Higher Education Act of 1965 (20 U.S.C. 1141(a)).

(24) Local agency

The term "local agency" means an agency of a unit of general local government or of an Indian tribe (or combination of such units or tribes) which has an agreement with the designated State agency to conduct a vocational rehabilitation program under the supervision of such State agency in accordance with the State plan approved under section 101. Nothing in the preceding sentence of this paragraph or in section 101 shall be construed to prevent the local agency from arranging to utilize another local public or nonprofit agency to provide vocational rehabilitation services if such an arrangement is made part of the agreement specified in this paragraph.

(25) Local workforce investment board

The term "local workforce investment board" means a local workforce investment board established under section 117 of the Workforce Investment Act of 1998.

(26) Nonprofit

The term "nonprofit," when used with respect to a community rehabilitation program, means a community rehabilitation program carried out by a corporation or association, no part of the net earnings of which inures, or may lawfully inure, to the benefit of any private shareholder or individual and the income of which is exempt from taxation under section 501(c)(3) of the Internal Revenue Code of 1986.

(27) Ongoing support services

The term "ongoing support services" means services—

(A) provided to individuals with the most significant disabilities;

(B) provided, at a minimum, twice monthly—

(i) to make an assessment, regarding the employment situation, at the worksite of each such individual in supported employment, or, under special circumstances, especially at the request of the client, off site; and

(ii) based on the assessment, to provide for the coordination or provision of specific intensive services, at or away from the worksite, that are needed to maintain employment stability; and

(C) consisting of—

(i) a particularized assessment supplementary to the comprehensive assessment described in paragraph (2)(B);

(ii) the provision of skilled job trainers who accompany the individual for intensive job skill training at the worksite;

(iii) job development, job retention, and placement services;

(iv) social skills training;

(v) regular observation or supervision of the individual;

(vi) followup services such as regular contact with the employers, the individuals, the individuals' representatives, and other appropriate individuals, in order to reinforce and stabilize the job placement;

(vii) facilitation of natural supports at the worksite;

(viii) any other service identified in section 103; or

(ix) a service similar to another service described in this subparagraph.

(28) Personal assistance services

The term "personal assistance services" means a range of services, provided by one or more persons, designed to assist an individual with a disability to perform daily living activities on or off the job that the individual would typically perform if the individual did not have a disability. Such services shall be designed to increase the individual's control in life and ability to perform everyday activities on or off the job.

(29) Public or nonprofit

The term "public or nonprofit," used with respect to an agency or organization, includes an Indian tribe.

(30) Rehabilitation technology

The term "rehabilitation technology" means the systematic application of technologies, engineering methodologies, or scientific principles to meet the needs of and address the barriers confronted by individuals with disabilities in areas which include education, rehabilitation, employment, transportation, independent living, and recreation. The term includes rehabilitation engineering, assistive technology devices, and assistive technology services.

Source: The complete text of the Rehabilitation Act (29 U.S.C. 701 et seq.) is available at http://204.245.133.32/law/rehabact.htm

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Toni Morrison, from *The Bluest Eye* (1970)

In this novel, Morrison employs disability as a constitutive feature of several of her most memorable characters. In the excerpt here, Polly's identity forms around a limp that she develops after stepping on a rusty nail in childhood. The work's key argument explores concepts of racial beauty as "the most destructive idea in western culture."

Polly

The easiest thing to do would be to build a case out of her foot. That is what she herself did. But to find out the truth about how dreams die, one should never take the word of a dreamer. The end of her lovely beginning was probably the cavity in one of her front teeth. She preferred, however, to think always of her foot. Although she was the ninth of eleven children and lived on a ridge of red Alabama clay seven miles from the nearest road, the complete indifference with which a rusty nail was met when it punched clear through her foot during her second year of life saved Pauline Williams from total anonymity. The wound left her with a crooked archless foot that flopped when she walked—not a limp that would have eventually twisted her spine, but a way of lifting the bad foot as though she were extracting it from little whirlpools that threatened to pull it under. Slight as it was, this deformity explained for her many things that would have been otherwise incomprehensible: why she alone of all the children had no nickname; why there were no funny jokes and anecdotes about funny things she had done; why no one ever remarked on her food preferences—no saving of the wing or neck for her—no cooking of the peas in a separate pot without rice because did not like rice; why nobody teased her; why she never felt at home anywhere, or that she belonged anyplace. Her general feeling of separateness and unworthiness she blamed on her foot. Restricted as a child, to this cocoon of her family's spinning, she cultivated quiet and private pleasures. She liked, most of all, to arrange things. To line things up in rows—jars on shelves at canning, peach pits on the step, sticks, stones, leaves—and the members of her family let these arrangements be. When by some accident somebody scattered her rows, they always stopped to retrieve them for her, and she was never angry, for it gave her a chance to rearrange them again. Whatever portable plurality she found, she organized into neat lines, according to their size, shape or gradations of color. Just as she would never align a pine needle with the leaf of a cottonwood tree, she would never put the jars of tomatoes next to the green beans. During all of her four years of going to school, she was enchanted by numbers and depressed by words. She missed—without knowing she missed—paints and crayons. . . . When the war ended and the twins were ten years old, they too left school to work. Pauline was fifteen, still keeping house, but with less enthusiasm. Fantasies about men and love and touching were drawing her mind and hands away from her work. Changes in weather began to affect her, as did certain sights and sounds. These feelings translated themselves into extreme melancholy. She thought of the death of newborn things, lonely roads, and strangers who appear out of nowhere simply to hold one's hand, woods in which the sun was always setting. In church especially did these dreams grow. The songs caressed her, and while she tried to hold her mind on the wages of sin, her body trembled for redemption, salvation, a mysterious rebirth that would simply happen, with no effort on her part. In none of her fantasies was she ever aggressive; she was usually idling by the river bank, or gathering berries in a field when a someone appeared, with gentle and penetrating eyes, who—with no exchange of words—understood; and before whose glance her foot straightened and her eyes dropped. The someone had no face, no form, no voice, no odor. He was a simple Presence, an all-embracing tenderness with strength and a promise of rest. It did not matter that she had no idea of what to do or say to the Presence—after the wordless knowing and the soundless touching, her dreams disintegrated. But the Presence would know what to do. She had only to lay her head on his chest and he would lead her away to the sea, to the city, to the woods . . . forever. . . . Thus it was that when the Stranger, the someone, did appear out of nowhere, Pauline was grateful but not surprised. He came, strutting right out of a Kentucky sun on the hottest day of the year. He came big, he came strong, he came with yellow eyes, flaring nostrils, and he came with his own music.

Pauline was leaning idly on the fence, her arms resting on the crossrail between the pickets. She had just put down some biscuit dough and was cleaning the flour from under her nails. Behind her at some distance she heard whistling. One of these rapid, high-note riffs that black boys make up while sweeping, shoveling. Or just walking along. A kind of city-street music where laughter belies anxiety, and joy is as short and straight as the blade of a pocketknife. She listened carefully to the music and let it pull her lips into a smile. The whistling got louder, and still she did not turn around, for she wanted it to last. While smiling to herself and holding fast to the break in somber thoughts, she felt something tickling her foot. She laughed aloud and turned to see. The whistler was bending down tickling her broken foot and kissing her leg. She could not stop her laughter—not until he looked up at her and she saw the Kentucky sun drenching the yellow, heavy-lidded eyes of Cholly Breedlove.

Source: Morrison, Toni. 1993. Pp. 110–116 in *The Bluest Eye.* Plume: New York. (Originally published 1979) Reprinted by permission of International Creative Management, Inc. Copyright © Toni Morrison.

▣ Toni Morrison, from *Sula* (1973)

In this novel, African American novelist Toni Morrison explores disability as a source of individual authority rather than a disqualification. In this scene, her protagonist, Eva Peace, presides over her neighborhood while communal memory grows dim about her previous life as a nondisabled woman. For Morrison, Eva's power becomes increasingly the subject of her mythical qualities as a communal storyteller.

1921

The creator and sovereign of this enormous house with the four sickle-pear trees in the front yard and the single Elm in the back yard was Eva Peace, who sat in a wagon on the third floor directing the lives of her children, friends, strays, and a constant stream of boarders. Fewer than nine people in the town remembered when Eva had two legs, and her oldest child, Hannah was not one of them. Unless Eva introduced the subject, no one ever spoke of her disability; they pretended to ignore it, unless, in some mood of fancy, she began some fearful story about it—generally to entertain children. How the leg got up by itself one day and walked on off. How she hobbled after it but it ran too fast. Or how she had a corn on her toe and it just grew and grew and grew until her whole foot was a corn and then it traveled on up her leg and wouldn't stop growing until she put a red rag at the top but by that time it was already at her knee.

Somebody said Eva stuck it under a train and made them pay off. Another said she sold it to a hospital for

$10,000—at which Mr. Reed opened his eyes and asked, "Nigger gal legs goin' for $10,000 *a piece?*" as though he could understand $10,000 *a pair*—but for *one?*

Whatever the fate of her lost leg, the remaining one was magnificent. It was stockinged and shod at all times and in all weather. Once in a while she got a felt slipper for Christmas or her birthday, but they soon disappeared, for Eva always wore a black laced-up shoe that came well above her ankle. Nor did she wear overlong dresses to disguise the empty place on her left side. Her dresses were mid-calf so that her one glamorous leg was always in view as well as the long fall of space below her left thigh. One of her men friends had fashioned a kind of wheelchair for her: a rocking-chair top fitted to a large child's wagon. In this contraption she wheeled around the room, from bedside to dresser to the balcony that opened out the north side of her room or to the window that looked out on the back yard. The wagon was so low that children who spoke to her standing up were eye-level with her, and adults, standing or sitting, had to look down at her. But they didn't know it. They all had the impression that they were looking up at her, up into the open distances of her eyes, up into the soft black of her nostrils and up at the crest of her chin.

Source: Morrison, Toni. 1973. Pp. 30–31 in *Sula.* New York: Plume. Reprinted by permission of International Creative Management, Inc. Copyright © Toni Morrison.

Union of the Physically Impaired Against Segregation, from *Aims* (1974)

This reading is excerpted from a policy statement created by British disability protestors as a critique against social obstacles to their full equality. The group was started by disabled activist Paul Hunt when he wrote an open letter to a local newspaper, The Guardian, *and invited other disabled people to join him in his protest. Hunt spent a number of years as a resident of an institution and actively sought to expose the lack of control allowed to disabled people. The Union of the Physically Impaired Against Segregation also engaged in key struggles for the rights to integrated education, accessible housing, as well as meaningful employment. The organization disbanded in 1990 but still serves as one of the earliest examples of organizing against socially created obstacles to disabled peoples' integration.*

The Union aims to have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society. These arrangements must include the necessary financial, medical, technical, educational and other help required from the State to enable us to gain the maximum possible independence in daily living activities, to achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives.

Policy Statement

1. *Disability and Segregation.* Britain today has the necessary knowledge and the advanced technology to bring physically impaired people into the mainstream of life and enable us to contribute fully to society. But instead of the Country's resources being concentrated on basic human problems like ours, they are frequently misspent, for example, on making sophisticated weapons of destruction, and on projects like Concorde and Centre Point. So despite the creation today of such an enormous capacity, which could help overcome disability, the way this capacity is misdirected means that many physically impaired people are still unnecessarily barred from full participation in society. We find ourselves isolated and excluded by such things as flights of steps, inadequate public and personal transport, unsuitable housing, rigid work routines in factories and offices, and a lack of up-to-date aids and equipment.

2. There are a few individual examples of severely impaired people being able to overcome many of these barriers by the use of sufficient resources in the right way. They prove that integration is possible. But as a group we are still often forced to put up with segregated and inferior facilities. We get sent to special schools, colleges or training centres. We are systematically channelled into segregated factories, centres, Homes, hostels and clubs. If we do manage to become mobile, it is often in antiquated tricycles or specially labelled transport. All these segregated forms of help represented progress in years past. But since the means for integration now undoubtedly exists, our confinement to segregated facilities is increasingly oppressive and dehumanising. . . .

5. *Low Bargaining-Power.* When we do succeed in getting employment, our comparatively low productivity means that we have low bargaining-power when it comes to negotiating decent treatment and facilities. Our position is similar to that of many people who are middle-aged or elderly, who have had break-downs,

or are mentally handicapped, black, ex-prisoners, unskilled workers, etc. We are usually among the first to lose our jobs and be cast on the scrap-heap when it suits the needs of the economy. If we are lucky we may be drawn in again, to do the worst paid work, when business starts to boom once more. If we are unlucky, then we could face a lifetime on the degrading, means-tested poverty line. If we are very unlucky we may be consigned to a soul-destroying institution.

6. *Institutions—The Ultimate Human Scrap-Heaps.* The union of the Physically Impaired believes that the reality of our position as an oppressed group can be seen most clearly in segregated residential institutions, the ultimate human scrap-heaps of this society. Thousands of people, whose only crime is being physically impaired, are sentenced to these prisons for life—which may these days be a long one. For the vast majority there is still no alternative, no appeal, no remission of sentence for good behaviour, no escape except the escape from life itself.

The Seventh Seal *is a doom-laden allegory set in medieval times when plague is raging through the land. A knight is challenged to a game of chess by Death, and the knight attempts to reveal the goodness of humankind in order to stave off his own encroaching mortality.*

Source: *The Seventh Seal* (1957), directed by Ingmar Bergman. Sweden. B&W, 100 minutes. Reprinted by permission of Paul Darke.

7. The cruelty, petty humiliation, and physical and mental deprivation suffered in residential institutions, where isolation and segregation have been carried to extremes, lays bare the essentially oppressive relations of this society with its physically impaired members. As in most similar places, such as special schools, there are some staff and volunteers doing their best to help the residents. But their efforts are systematically overwhelmed by the basic function of segregated institutions, which is to look after batches of disabled people— and in the process convince them that they cannot realistically expect to participate fully in society and earn a good living. This function was generally appropriate when special residential institutions first came into being, since in the competitive conditions of the time many physically impaired people could not even survive without their help. But now it has become increasingly possible for severely impaired people not just to survive, but also to work and become fully integrated, the need for segregated institutions no longer exists in the way it did. They have become seriously out of step with the changed social and technological conditions of Britain today. . . .

12. *Disablement Outside Institutions.* Our Union maintains that the present existence of segregated institutions and facilities is of direct relevance even for less severely impaired people who may expect to avoid having to use them. Those of us who live outside institutions can fully understand the meaning of disability in this society only when we take account of what happens to the people who come at the bottom of our particular group. Their existence and their struggles are an essential part of the reality of disability and to ignore them is like assessing the condition of elderly people in this society without considering the existence of geriatric wards.

13. It is also true that the kind of prejudiced attitudes we all experience (other people being asked if we take sugar in our tea is the usual example) are related to the continued unnecessary existence of sheltered institutions. Those who [do this] are indicating that they think we are not capable of participating fully and making our own decisions. They are harking back to the time when disabled people had to be sheltered much more, and they imply that really we ought to be back in our rightful place—that is, a special school, club, hospital unit, Home or workshop. Physically impaired people will never be fully accepted in ordinary

society while segregated institutions continue to exist, if only because their unnecessary survival today reinforces out of date attitudes and prejudices.

14. *Medical Tradition.* Both inside and outside institutions, the traditional way of dealing with disabled people has been for doctors and other professionals to decide what is best for us. It is of course a fact that we sometimes require skilled medical help to treat our physical impairments—operations, drugs and nursing care. We may also need therapists to help restore or maintain physical function, and to advise us on aids to independence and mobility. But the imposition of medical authority, and of a medical definition of our problems of living in society, have to be resisted strongly. First and foremost we are people, not "patients," "cases," "spastics," the "deaf," "the blind," "wheelchairs," or "the sick." Our Union rejects entirely any idea of medical or other experts having the right to tell us how we should live, or withholding information from us, or [making] decisions behind our backs.

15. We reject also the whole idea of "experts" and professionals holding forth on how we should accept our disabilities, or giving learned lectures about the "psychology" of disablement. We already know what it feels like to be poor, isolated, segregated, done good to, stared at, and talked down to—far better than any able-bodied expert. We as a Union are not interested in descriptions of how awful it is to be disabled. What we are interested in, are ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top our physical impairments by the way this society is organised to exclude us. In our view, it is only the actual impairment which we must accept; the additional and totally unnecessary problems caused by the way we are treated are essentially to be overcome and not accepted. We look forward to the day when the army of "experts" on our social and psychological problems can find more productive work.

Source: Union of the Physically Impaired Against Segregation. 1974. *Union of the Physically Impaired Against Segregation: Aims.* Available at: www.leeds.ac.uk/disability-studies/archiveuk/UPIAS/UPIAS.pdf. Reprinted by permission of Paul Hunt.

Alice Walker, from *Meridian* (1976)

Following in a long tradition of stories about children raised without parents in nature (such as Itard's writings on Victor of Aveyron, for instance, described in Fernald's excerpt in Part Two), Walker's chapter extends the analogy to dehumanizing beliefs about African Americans during the civil rights era. In order to "tame" the wild child's renegade nature, she is captured by administrators at an all-black university for women. However, the do-gooders tragically decide that she is incapable of living alongside other educated individuals and attempt to find a school for "special children" in which to house her.

The Wild Child

The Wild Child was a young girl who had managed to live without parents, relatives or friends for all of her 13 years. It was assumed she was thirteen, though no one knew for sure. She did not know herself, and even if she had known, she was not capable of telling. Wile Chile, as the people in the neighborhood called her (saying it slowly, musically, so that it became a kind of lewd, suggestive song), had appeared one day in the slum that surrounded Saxon College when she was already five or six years old. At that time there were two of them, Wile Chile and a smaller boy. The boy soon disappeared. It was rumored that he was stolen by the local hospital for use in experiments, but this was never looked into. In any case, Wile Chile was seen going through garbage cans and dragging off pieces of discarded furniture, her ashy black arms straining at the task. When a neighbor came out of her house to speak to her, Wile Chile bolted, not to be seen again for several weeks. This was the pattern she followed for years. She would be seen scavenging for food in the garbage cans, and when called to, she would run.

In the summer she wore whatever was available in castoff shorts and cotton tops. Or she would wear a pair of large rayon panties, pulled up under her arms, and nothing else. In winter she put together a collection of wearable junk and topped it with a mangy fur jacket that came nearly to the ground. By the age of eight (by the neighbors' reckoning) she had began to smoke, and, as she dug about in the debris, kicking objects this way and that (cursing, the only language she knew), she puffed on cigarette butts with a mature and practiced hand.

It was four or five winters after they first spotted her that the neighbors noticed Wile Chile was pregnant. They were critical of the "low-down dirty dog" who had done the impregnating, but could not imagine what to do. Wile Chile rummaged about as before, eating rancid food, dressing herself in castoffs, cursing and bolting, and smoking her brown cigarettes.

It was while she was canvassing voters in the neighborhood that Meridian first heard of the Wild Child. The neighbors had by then tried to capture her: A home for her lying-in had been offered. They failed to catch her, however. As one neighbor explained it, Wile Chile was slippier than a greased pig, and unfortunately the comparison did not end there. Her odor was said to be formidable. The day Meridian saw the Wild Child she withdrew to her room in the honors house for a long time. When the other students looked into her room they were surprised to see her lying like a corpse on the floor beside her bed, eyes closed and hands limp at her sides. While lying there she did not respond to anything; not the call to lunch, not the phone, nothing. On the second morning the other students were anxious, but on that morning she was up.

With bits of cake and colored beads and unblemished cigarettes she tempted Wile Chile and finally captured her. She brought her onto the campus with a catgut string around her arm; when Wile Chile tried to run Meridian pulled her back. Into a tub went Wile Chile, whose body was caked with mud and rust, whose hair was matted with dust, and whose loud obscenities mocked Meridian's soothing voice. Wile Chile shouted words that were never uttered in the honors house. Meridian, splattered with soap and mud, broke down and laughed.

At dinner Wile Chile upset her tablemates with the uncouthness of her manners. Ignoring their horrified stares she drank from the tea pitcher and put cigarette ashes in her cup. She farted, as if to music, raising a thigh.

The housemother, called upon in desperation by the other honor students, attempted to persuade Meridian that the Wild Child was not her responsibility.

"She must not stay here," she said gravely. "Think of the influence. This is a school for young ladies." The housemother's marcel waves shone like real sea waves, and her light-brown skin was pearly under a mask of powder. Wile Chile trembled to see her and stood cowering in a corner.

The next morning, while Meridian phoned schools for special children and then homes for unwed mothers—only to find there were none that would accept Wile Chile—The Wild Child escaped. Running heavily across a street, her stomach the largest part of her, she was hit by a speeder and killed.

Source: Walker, Alice. 1976. Pp. 35–37 in *Meridian.* New York: Pocket Books. Copyright © 1976 by Alice Walker, reprinted by permission of Harcourt, Inc.

John Gliedman and William Roth, from "The Grand Illusion" (1976)

In the fall of 1976, the organizers of the 1977 White House Conference on Handicapped Individuals invited John Gliedman and William Roth to submit an "Awareness Paper" on the communications disabilities. Deciding to run with the topic, they responded with "The Grand Illusion," a 37-page Goliath of an essay, typeset on an IBM Selectric Composer to conserve space, that contained large chunks of the 1976 working draft of their book The Unexpected Minority *(1980). Although "The Grand Illusion" was not the first work to highlight the analogies between the disabled and other stigmatized minorities, the essay's relentless emphasis on the degree to which disability is a social construction was unusual for the times. The authors developed their analysis further in* The Unexpected Minority, *where they presented the first comprehensive critique of traditional lay and expert views of disability and embedded the need for legal and political action within a perspective that integrated the minority group model with what today is variously called the postmodern or "disability as human variation" model. Perhaps because of its laser-like focus on developing the minority group model of disability, "The Grand Illusion" had its intended effect of shaking people up. "The Grand Illusion" was distributed to all who attended the White House conference, but it was not included in the volume of Awareness Papers that the organizers subsequently published, an omission that the authors have always considered a signal bureaucratic honor.*

The individual's communication options are generated by the nature of the setting. Is the individual among friends? Is he among strangers who respect him for what he is rather than see him as a handicap? And to an equally remarkable extent, the social possibilities of any normal setting are in turn partly determined by an individual's earlier social experience. Has he had a good education? Has he had sexual experience? Has he been able to travel? What was (or is) the individual's childhood like? The answers to these questions are as decisive as the answers to the medical questions. Indeed, in a certain sense, they are far more decisive because they determine the ultimate significance of the medical answers in the individual's life.

One of the most recognized disability films in the history of cinema, The Miracle Worker *tells the story of Annie Sullivan's struggles to teach the deaf and blind Helen Keller how to communicate in sign language.*

Source: *The Miracle Worker* (1962), directed by Arthur Penn. United States. B&W, 106 minutes. Reprinted by permission of Paul Darke.

In recent years there has been much talk about the emphasis upon meaningless academic credentials in American life. [In] a cruel and largely unperceived way, the able-bodied world practices a parallel kind of credentialing on the disabled. All too often the child or the newly disabled adult learns that the prerequisite for being in social settings where a simple cry by a person with CP, a touch by a blind person, or a nod or grimace of joy is exactly right—and communicates far more than mere words—is a normal body. As much as anything our emphasis on the most mechanical aspects of communication reflects (or at least is congruent with) an important fact about cultural attitudes toward disability. To focus so exclusively on the sensory and motor obstacles to the message—and to overlook the sociological medium upon which all communication depends—is, in effect, to ratify the systematic exclusion of large numbers of disabled individuals from situations of genuine intimacy. It is to ratify their exile to the impoverished setting of the classroom, the doctor's office, the hospital ward, and the family bedroom which visitors are not shown. All too often we wind up helping the severely communication-disabled communicate as *patients* not as self-sufficient adults.

In sum, even if we restrict ourselves to the considerations of the classically defined communications disabilities, much of what the individual experiences as the most limiting and destructive aspect of his communications disability is the result of an ultimately social and ultimately arbitrary set of decisions, not an inevitable consequence of his biological deficit. Society not biology decrees that individuals crippled by severe CP are denied access to the mainstream of life. Society not biology decrees that the deaf must use cumbersome visual devices or speech instead of sign language to communicate with the hearing.

If most communications disabilities contain a sociological component of no mean importance, what of other kinds of handicaps? Might their not inconsiderable

But to even mention in passing the importance of a rich and varied life experience to successful communication—however communication be defined—is to touch upon one of the great tragedies of handicap. Characteristically we make every effort to help the disabled individual compensate for his reduced ability to transmit or receive messages by teaching him how to be more explicit. In the process what is often forgotten—especially in the education of the handicapped child—is the positive functions of ellipsis for the able-bodied. Nowhere is this clearer than in the most meaningful and intimate situations of life—the touch of two lovers, the telegraphic speech of two old friends on the same wavelength, the poetry of silence. Here again the severely communication disabled individual often possesses more than enough biological capacity for effective communication. What is often lacking is not the biological potential but the social potential—i.e., a life in which intimacy is possible with anyone.

sociological component also produce significant obstacles to communication—obstacles whose ultimate origins are to be found not in the bodies of the disabled but in the minds of the able-bodied?

To broach these questions requires a significant expansion of the definition of communication common in the specialized literature which treats [of] communication disorders. It requires that we explore all kinds of communication, verbal and nonverbal. It requires that we recognize that each of us speaks many "languages" besides English—languages which communicate our self image to the other, our state of mind, our character, our social status, and our feelings about the other; language which communicates to the other whether we think he has a future and whether we have a future, in our private life and in professional life; language which passes judgment on the quality of the interaction between self and other, whether we might be compatible acquaintances, business associates, friends or lovers. And it is to recognize that each of us broadcasts this information on many "wavelengths" simultaneously, only one of these wavelengths being captured by a summary of what was actually said. We broadcast by means of our oral speech style, our grammar, our choice of words, our wit, and our accent. We broadcast by means of our tone of voice, our intonation, our clarity of articulation; by the way we pause between phrases and words: by our pitch, and our timber. We broadcast by means of the gestures we consciously or unconsciously make with our arms and legs, and if our arms and legs are paralyzed that very fact broadcasts a message. We broadcast by means of our facial expressions. We do so even if we are blind and do not control what the other reads into our face. We broadcast by our posture, our motor control, and by the overall way we look; an atrophied limb broadcasts a message; so does a wheel chair or an iron lung. We broadcast information by means of each of these channels, and what is communicated on one channel affects what is communicated on the other channels. Indeed, even our interpretation of the literal meaning of spoken speech is far more dependent upon what is broadcast on other "wavelengths." As anyone who has puzzled his way through transcripts of taped conversations knows, much that is self-evident face-to-face becomes unclear and ambiguous when we do not know what gestures, and tones of voice were used—or, even, upon occasions, the physical context in which the words were uttered, or the speaker's job, status, or sex.

But to adopt a definition of communication which is more in consonance with current linguistic, anthropological, and sociological practice, is to see that the communication problems of the disabled represent one side of what is perhaps the root problem of handicap in America—a problem which might aptly be called "The Other American Dilemma." The problem of handicap is multitudinous in its complexity. It involves medicine, rehabilitation, education, psychiatry. But first and foremost it is a problem of the able-bodied. By accident or by design, the world which the able-bodied have built interposes all manner of physical and social obstacles to the achievement of an adult identity for the disabled. For the individual with a relatively minor disability, these obstacles exert at the very least a severe psychic toll in unnecessarily low self-esteem, anxiety, demoralization, and diminished communication possibilities and abilities. For the more severely handicapped, biologically imposed limitations loom larger, but the really insuperable obstacles remain those imposed upon the individual by an able-bodied world which all too often returns his efforts for self-realization and communication with stigma, indifference, ignorance, and even, upon occasion, systematic efforts to persuade him to adjust to a life of needless dependency.

In the pages which follow we shall pursue a path which arches back and forth between these two faces of "The Other American Dilemma." In sections II and III, by means of analysis and copious example we explore some of the more important sociological obstacles experienced by most handicapped individuals. First appearing in the very act by which an able-bodied person sees a handicapped person, they are rooted in deep-seated cultural definitions of the meaning of disability. These definitions impede communication on many levels. After exploring some of these levels, we briefly examine some of the strategies the handicapped adopt to overcome these sociological obstacles—strategies which also often exact a terrible human cost. In sections IV and V we turn to a consideration of possible ways of improving the sociological situation of handicap. As we will see, one of the best ways may lie through the handicapped, as a social group, seeking to emulate the strategy which has proven so successful for the members of other stigmatized minority groups in the last generation. An important precondition for pursuing this course is the elimination of the many environmental barriers to the mobility of disabled individuals—e.g., buildings without ramps or adequate rest rooms, public telephones, and elevators not coded in Braille, and automobiles and public transportation systems which often are virtually unusable. Besides sharply curtailing the exercise of fundamental civil liberties, these physical barriers also represent a major obstacle to interpersonal communication on their own account. Next we briefly examine some of the other obstacles to communication, self-realization, and the achievement of an adult identity that that society puts in the way of the handicapped child and adult. These obstacles range from the way in which our helping services treat an individuals handicap and not the needs of the whole person, to the way society structurally discriminates against the handicapped as independent producers and consumers. We shall see that the effects of these institutional obstacles parallel the effects of environmental barriers to mobility: both represent concrete social precipitates of our underlying cultural definition of handicap. Finally, in the Appendix, we attempt systematically to catalogue some of the main ways in which break downs in communication between able-bodied and handicapped individuals can occur.

* * *

Before we can perceive a biological difference as a handicap, we must know—or have reason to believe—that it is chronic. Because this knowledge is not unambiguously transmitted by the rays of light which are focused into an image on the retina, the fact that we seem to instantaneously see that the man is handicapped reflects an interpretation of what our retina receives. To be sure, knowledge that a biological deficit is chronic is, in the everyday sense of the word, a reasonably objective matter. One consults a doctor, a textbook, or one's own experience. There is nothing subjective about knowing that a man with a spinal cord injury will not be able to use his legs again unless there is a breakthrough in treating his kind of spinal block. But suppose that in addition to such facts, other, less impeccable and less objective pieces of knowledge intervene between the image of the handicapped man on our retina and our seeing him, suppose that beliefs with little or no basis in reality intervene and govern what we see?

In her biography of Moshe Dayan, the general's daughter writes that after he lost his right eye in battle, her father was mystified by the fascination which his injury seemed to hold for many women. Dayan's disability is one of the few which change dramatically in character as one moves from childhood to adulthood. The nature of this change tells us something important about what we have to assume before we perceive something as a handicap.

A thought experiment. Conjure up in your mind a military man with an eye-patch. Now examine your feelings. Is there not something romantic and heroic about the injury? Doesn't it suggest a dark and complex past, a will of uncommon strength, perhaps a capability for just enough brutality to add an agreeable trace of sinister and virile unpredictability to the man? Depending on one's politics, it can suggest a resourceful ally or a dangerous enemy. Mustn't one be very tough and very competent indeed, to escape so lightly from a brush with death? No doubt these reactions explain why the only time Madison Avenue used a disability to enhance the glamour (and salability) of a commodity was in the Hathaway shirt ads of the 1960's.

Now replace the image of the Hathaway man with an eye-patch with the image of a young child with an eye-patch. For most people, something strange happens. The romance and mystery of the disability disappear. What we see is a handicapped child. There is something sad and even pitiful about him. Looking at his face we fear for his future and worry about his present. We think: this poor kid is going to have a hard time growing up and making it in this world. Where the presence of an eye-patch made the Israeli leader seem even more of a general (an adult role), the presence of an eye-patch on a child is a sign of damage, a cause for pity, an indication that this is a child whose ability to fit into some adult role in the future is in serious jeopardy.

Similar shifts in valence as a function of age or sex occur with a host of minor disfigurements or cosmetic blemishes—with scars and with certain kinds of ugliness which seem quite terrible in a child or a woman and seem sexy or virile in an adult male. Such shifts also appear to occur with certain kinds of limps requiring the use of a cane, as an acquaintance of ours learned to his astonishment when, after a hiking accident which left him hobbling about for several weeks, he was told by a number of friends that he looked very distinguished using a cane and should consider always using one. Needless to say, this is not something which anyone ever says to a young child who is forced to use a cane.

But General Dayan's eye-patch also points to something else. It points to a class of fairly serious physical disabilities which shuttle back and forth between being perceived as handicaps, or as enhancers, the direction of the shuttle being a function of one's adult role. (All of them, let us add at once, are perceived as handicaps when they appear in women and children.) In Jean Renoir's "La Grand Illusion," Erich von Stroheim plays the part of a man with a brace under his chin, a lame leg, a body scarred by burns, and a back injury which requires that he wear a steel corset. While the enumeration of these disabilities suggests a rather severely disabled man, we do not perceived the commandant as handicapped when we watch the film.

There are at least three possible explanations for this, and each suggests a cluster of special adult roles which are able to assimilate certain kinds of major handicaps more readily than most adult roles.

First, the movie is set during wartime. During war, our tacit definitions of handicap are relaxed. We adopt—if that be the word—a more sane approach, what counts is not so much how a man looks (within limits) but whether he can still function. And while von Stroheim is no longer fit for combat duty, he is perfectly capable of running a prisoner of war camp, and controlling the lives of hundreds of able-bodied people.

The second explanation involves the kind of character von Stroheim plays. An old Prussian aristocrat with a Spartan sense of morality and honor which elicits respect, he quite literally refuses to cease being an adult. And because society gives him the means—a war, a position of responsibility behind the lines and an aristocratic identity—he carries it off.

The final explanation is, we believe, generic. It is easier to integrate (and therefore to defuse) a disability into one's adult identity if one is cast as a villain. Villains are supposed to be scary. They are also supposed to be cunning, resourceful, and capable of outwitting death. A disability or two serves to indicate these characteristics—hence the false arm of Dr. No in the James Bond thriller, *The Island of Dr. No,* or in Bond's *From Russia With Love,* the thug with the hook on his arm which can cut through metal and glass. Hence the cluster of disabilities which afflict Dr. Strangelove, in Stanley Kubrick's "Dr. Strangelove," but which do not always succeed in causing us to view him as handicapped—the arm which is not fully under his control, the partial paralysis which results in his being pushed about in a wheelchair and wearing braces on his legs.

Closely related to these implicit rules about when a physical imperfection is perceived as a disability or a handicap, is the phenomenon of anthropomorphicization.

All of us remember childhood stories about four-footed creatures of the plains and forests—horses running wild and free, lion cubs overcoming the dangers of the veldt and becoming hunters, deer and bear living out their lives in the green solitude of the forest. When we heard these stories as children—and when we retell them to our own children—there seems nothing strange or unnatural to ascribing a full range of (juvenile and adult) human characteristics to creatures who hunt with their claws or live by grazing on grass and shrubbery. One thinks of *Winnie-The-Pooh,* of *Bambi,* of *Lassie,* or Jack London's *The Call of the Wild,* of *Black Beauty,* of *Born Free,* of a multitude of other stories about animals in which a perfect equation is made between human child and animal child, human adult and animal adult.

But now perform the following thought experiment. Replace the animal figures in one of these stories with human beings who possess exactly the same range of functional capacities as the animals in question. For a deer who can run swiftly but can only manipulate objects with his mouth and tongue, substitute the image of a man paralyzed from the neck down who is as mobile as a deer in his electric wheelchair, and who can also manipulate objects with his mouth and tongue. Or instead of a family of lions, imagine a family of severely retarded individuals with intact bodies. Here, too, there is a perceptual "snap." Our willingness to expand the category of human to include juvenile and adult forms other than our own dissolves when we try to make it embrace severely handicapped people as well. Indeed, the very idea seems a contradiction in terms, an exercise in sick humor, and certainly something that we are not about to expose our children to.

Yet reflect a moment. Why is it a contradiction in terms to ascribe human characteristics to a man in an electric wheelchair or to a profoundly retarded person? Is it not because, bound up in our perception of animals, is the belief that on their own terms, they are complete, whole, and either adult or in the process of growing up to become adult, whereas it is precisely this quality of adultness (future or present) which is absent in our perception of these people we perceive as handicapped?

Source: Gliedman, John, and William Roth. 1977. "The Grand Illusion: Stigma, Role Expectations, and Communication: A Sociological Overview of the Problem of Handicap." In *The White House Conference on Handicapped Individuals Delegate Workbook.* New York: The Carnegie Corporation.

▣ Judi Chamberlin, from *On Our Own: Patient-Controlled Alternatives to the Mental Health System* (1978)

Described by many in the antipsychiatric movement as a landmark work, On Our Own *represents one of the earliest writings by a self-proclaimed psychiatric survivor.*

In Whatever Happened to Baby Jane? *two former movie stars live in their gloomy Hollywood mansion; one is in a wheelchair, and the other is mentally ill. The plot revolves around the responsibility for the accident that confined the matinee star to a wheelchair.*

Source: *Whatever Happened to Baby Jane?* (1962), directed by Robert Aldrich. United States. B&W, 130 minutes. Reprinted by permission of Paul Darke.

This excerpt, from the chapter entitled "Consciousness Raising," discusses the importance of raising the consciousness of both mental patients and others.

Consciousness raising is an ongoing process. Negative stereotypes of the "mentally ill" are everywhere and are difficult not to internalize, no matter how sensitive one becomes. This stereotyping has been termed "sane chauvinism" or "mentalism" by mental patients' liberation groups. Like sexism, mentalism is built into the language—*sick* and *crazy* are widely used to refer to behavior of which the speaker disapproves. The struggle against mentalism is one of the long-range activities of mental patients' liberation. . . . My feelings began to change when I discovered the existence of the Mental Patients' Liberation Project in New York, one of the earliest mental patients' liberation groups. We talked about our experiences and discovered how similar they were. Whether we had been in grim state hospitals or expensive private ones, whether we were there voluntarily or involuntarily, whether we had been called schizophrenic, manic-depressive, or whatever, our histories had been extraordinarily similar. We had experienced depersonalization, the stupefying effects of drugs, the contempt of those who supposedly "cared" for us. Out of this growing awareness came a deeper understanding of the true purpose of the mental health system. It is primarily social control.

Source: Chamberlin, Judi. 1978. Pp. 66–67 in *On Our Own: Patient-Controlled Alternatives to the Mental Health System.* New York: McGraw-Hill. Printed with permission from Slack, Inc.

Sherwood Hall, from *With Stethoscope in Asia: Korea* (1978)

Sherwood Hall was the son of Dr. Rosetta S. Hall and Dr. William Hall, American missionaries and physicians in Korea. Dr. Rosetta Hall established modern special education in Korea in 1894. Sherwood Hall wrote a book based on his mother's diary. This excerpt shows the Western Christian perspective on disabled people in traditional Korea and the missionaries' roles.

Dr. [William?] Hall's first Christian convert in Pyong Yang was Mr. O Syok Hyong (who was among those cast into prison and later released during the recent persecutions). Mr. O had a little daughter who was blind. Mrs. Hall had encountered blind and deaf-mute patients in her medical work and longed to be able to do something to help them. However, the condition of both the blind and deaf-mutes in Korea at that time, Mrs. Hall discovered, was indeed pitiable. The deaf-mutes were considered imbeciles who survived by their animal instincts and the blind became fortune tellers or sorcerers (*mudongs*) if their parents were rich enough to have them thus trained. Otherwise, they were neglected and ignored, often poorly fed and clothed and allowed to sit in a corner until eventually they lost even the ability to walk.

Although Mrs. Hall had wanted to do something to help blind children, she had been cautioned that the Koreans might not understand her purpose. In time of any disturbances, they might point to the blind students as proof of the false tale that circulated during the Baby Riots of 1888 that doctors were taking out the children's eyes to make medicine.

When Mrs. Hall observed that Mr. O's eldest daughter was blind, she thought, "Here's my chance to begin. Her father is a Christian, and will not misinterpret my motive." . . .

Pongnai responded so eagerly and with such intelligence, that Mrs. Hall felt that she could be helped to learn to read if only Mrs. Hall had knowledge of the proper technique for teaching the blind. She resolved to learn more about it, for it could be a means of combating the superstition which prevented the blind from enjoying a life of usefulness. . . .

After moving to Pyong Yang, my mother had started working again with Mr. O's blind daughter, Pongnai. Teaching Pongnai with these new resources was at first slow and tedious work, but once she had mastered the alphabet and the syllabary, it was plain sailing. In a year, Pongnai could read all that my mother had been able to prepare and she learned to write in point and to make her own lessons from dictation. My mother also taught her to knit.

Patients, seeing Pongnai so happy and industrious, would ask my mother if other blind girls they knew might join her. Thus began the first school for the blind in Korea, and after the Pyong Yang Girls' School was built, a classroom for blind girls was added. My mother's belief was that the blind girls should be taught together with the seeing girls and should participate in their games. All that was necessary was to add a special teacher to the school staff for the beginners. Pongnai eventually became such a teacher as the work for the blind and deaf expanded.

Source: Hall, Sherwood. 1978. *With Stethoscope in Asia: Korea.* McLean, VA: MCL Associates. Copyright © 1978. Reprinted by permission.

▣ Leslie Fiedler, from *Freaks, Myths and Images of the Secret Self* (1978)

In one of the earliest analyses of freak shows as a social forum for producing difference, Fiedler adopts his characteristic psychoanalytic framework from which to read freak relations in the sideshow context. For Fiedler, the freak show provided audiences with opportunities to more directly encounter the Other of embodiment. One gazed at freaks while experiencing an internal catharsis that ultimately confirmed one's own membership in the ranks of the normal.

Even the ritualized murder of Freaks, however, seemed in ancient times to verge on sacrilege, and its incidence, therefore, was much lower than we might suppose. Sometimes, indeed, they were preserved and worshipped, as was clearly the case of a hideously distorted shamanka (female medicine woman) found in an underground cave in Czechoslovakia in the midst of ritual splendor 25,000 years after her interment. And even the Emperor Augustus, convinced that all freaks, especially Midgets, possessed the Evil Eye, nonetheless had created for his court a gold statue with diamond eyes representing his pet Dwarf, Lucius.

So there never was in earlier times any total genocidal onslaught against Freaks like that launched by Hitler against Dwarfs in the name of modern "eugenics." And it is even likely that fewer monsters were denied a chance to live in "priest-ridden" societies than in an AMA-controlled age like our own, in which "therapeutic abortions" are available to mothers expecting monstrous births, and infanticide is practiced under the name of "removal of life-supports from non-viable major terata."

At any rate, the word "monster" retains much of the awe once felt in the presence of newborn malformations, and the word, therefore, along with its variant form, "monstrosity," has never disappeared from the working vocabulary of carnivals and side shows. Indeed, I can still play in my head a spiel of a "freak show talker," familiar to me since childhood. Jo-Jo, the dog-faced boy, that ghost of a voice keeps saying, the greatest an-thro-po-log-i-cal-mon-ster-os-i-ty in captivity Brought back at great expense from the jungles of Bary-zil. Walks like a boy. Barks like a dog. Crawls on his belly like a snake. And at the drawled five syllables of mon-ster-os-i-ty, I feel my spine tingle and my heart leap as I relive the wonder of seeing for the first time my own most private nightmares on public display out there.

Why have I not used the word "monster," then, to describe those "unnatural creatures" whose natural history I am trying to write? In 1930, C. J. S. Thompson called a similar study, *The Mystery and Lore of Monsters.* But over the more than four decades since its appearance, the term "monster," has been preempted to describe creations of artistic fantasy like *Dracula, Mr. Hyde,* the *Wolf Man, King Kong,* and the nameless metahuman of Mary Shelley's *Frankenstein. . . .*

To be sure, monsters have a mythological dimension like Freaks, and in this respect they are unlike the category of unfortunates whom early French teratologists called mutiles: the blind, deaf, dumb, crippled, perhaps even hunchbacks and harelips, though these are marginal; along with amputees, paraplegics, and other victims of natural or man-made disaster. Children who are born legless or armless, their limbs amputated by a tangled umbilical cord, are sometimes hard to tell from true phocomelics, or seal children, with vestigial hands and feet attached directly to the torso. But once identified, they are primarily felt as objects not of awe but of pity.

Source: Fiedler, Leslie. 1978. Pp. 21–23 in *Freaks, Myths and Images of the Secret Self.* New York: Simon and Schuster. Reprinted by permission.

Self-Advocacy in Australia (1981)

The Code of Rights of REINFORCE, the Victorian Association for Intellectually Disadvantaged Citizens, was drawn up in August 1981 at the Fifth Strand, an international conference of people labeled as mentally retarded. The Fifth Strand was an alternative conference that ran parallel with a "professional" conference on mental retardation.

Code of Rights

We want more training for jobs outside.

We want to see more people out of institutions.

We want better transport and lower fares and better services.

We are humans first and disadvantaged second.

All theatres to have concessions for each session.

We need more access to community facilities.

Everybody living in institutions has the right to community living, to be trained for jobs and to education.

We want more group homes to be built and more half-way houses.

Each pension should be above the poverty line and increase quarterly.

We want the right to have our own choice of medical insurance and our own doctor.

We have the right to have our rights protected, to be protected from violence and crime.

We have the right to information about marriage and relationships.

We have the right to live in our own home.

We have the right to spend our own money.

Kubrick's cool cynicism and screenwriter Terry Southern's caustic humor are perfectly wedded in Dr. Strangelove, *a vision of nuclear apocalypse brought about by a mad U.S. general's paranoia about women and Commies. Peter Sellers excels as a black-gloved, wheelchair-using, Kissinger-esque president.*

Source: *Dr. Strangelove* (1964), directed by Stanley Kubrick. United Kingdom. B&W, 93 minutes. Reprinted by permission of Paul Darke.

We demand all discrimination to cease.

We have the right to live with whom we want.

We have the right to know where our money is going.

Intellectually disadvantaged citizens should have access to low-rent flats and houses in the community.

We demand the closing of institutions for intellectually disadvantaged people.

We have the right to education.

We have the right to privacy.

We have the right to private ownership.

We have the right to equal day's pay for a fair day's work.

We have the right to worker's compensation.

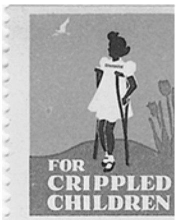
Images of Disability on Stamps

Stamps reveal a lot about a country—both how it sees itself and how it wants others to see it. As such, disability is almost always seen in terms of impairment and little else on stamps across the world. Africa is the continent that has most "exploited" impairment on stamps and can often be interpreted as a country fulfilling First World expectations in an attempt to demonstrate its own sense of impairment of wealth, health, and education. But, to be fair, the First World (Western and wealthy countries) has almost unanimously exploited impairment, not only by making it the definition of disablement but also by creating an intrinsic cultural link between impairment and charity.

Charity and education about the prevention of impairment are givens and are seen as a wholly "good" thing. Thus, some images of impairment on stamps are so gloriously non-PC that they seem almost a joy in their celebration of otherness. Though a massive explosion of postal images of disability and impairment took place after the United Nations' 1981 International Year of the Disabled, prior to that, postal images of disability had appeared consistently in relation to wars (veterans), charity, immunization programs (polio in particular), and health education programs.

As with any stamp-collecting theme, there are always many more examples of the theme than one would ever hope for, be it images of disabled people; of particular impairments; or of wheelchairs, crutches, hearing aids, and the like. Stamps have been—and still are—advertisements for a (usually dubious) collective ideology of disablement; thus, we see the current increase in representations of disability on stamps linked to current issues such as stem cell research or HIV issues. But, like disability itself, disability and impairment are now and will continue to be on stamps in virtually every country in the world. (See www.outside-centre.com for listing and images.)

Paul Darke



▣ Tetsuko Kuroyanagi, from *Totto-chan: The Little Girl at the Window* (1981)

This excerpt is from Totto-chan: The Little Girl at the Window, *a best-selling memoir by Japanese television talk show host and author Tetsuko Kuroyanagi. The book recalls her year as a first grader at Tomoe Academy, a progressive school created and run by Sosaku Kobayashi. (The school was destroyed in 1945 when the United States bombed Tokyo.) Kuroyanagi appreciated Headmaster Kobayashi's philosophy of "leveling the playing field" for all children, a very unusual approach to education in Japan before the surrender and occupation. The title of the book draws on a Japanese expression: people who were "over by the window" were marginalized, not part of the larger group (a similar Western expression would be to say that someone at work was "moved to a corner office" and thus taken out of the mainstream—though of course this expression conveys a positive separation). There isn't much mention of physical disability in this context in the book, but the epilogue refers to one particular classmate of the author's, Akira Takahashi. The reference to Sports Day is to a day when everyone in a school (and sometimes the parents as well) takes part in a festival of track and field events. Normally, a person of short stature would stand little chance at such events; however, the Headmaster had arranged for first-grade events that would actually be simpler for a person of short stature than for a child of average height. "Lunchtime speeches" at Tomoe referred to the Headmaster having children get up during lunch and make short speeches about almost anything, in order to help them develop self-confidence. At least in the first grade at Tomoe, swimming was "clothing optional"; the Headmaster thought that the children would get over any "morbid curiosity" about their bodies, especially with someone like Akira Takahashi in the class.*

The Swimming Pool

That was a red-letter day for Totto-chan. It was the first time she had ever swum in a pool. And without a stitch on!

It happened in the morning. The headmaster said to them all, "It's become quite hot all of a sudden, so I think I'll fill the pool."

"Wow!" everybody cried, jumping up and down. Totto-chan and the first grade children cried "Wow" too, and jumped up and down with even greater excitement than the older students. The pool at Tomoe was not rectangular like most pools, as one end was narrower than the other. It was shaped pretty much like a boat. The lay of the land probably had something to do with it. But nonetheless, the pool was a large and splendid one. It was situated between the classrooms and the Assembly Hall.

All during their lessons, Totto-chan and the others kept stealing glances out of the window at the pool. When empty it had been littered with fallen leaves just like the playground. But now that it was clean and beginning to fill up, it started to look like a real swimming pool.

Lunchtime finally arrived, and when the children were all gathered around the pool, the headmaster said, "We'll do some exercises and then have a swim."

"Don't I need a swimsuit to go swimming?" thought Totto-chan. When she went to Kamakura with Mother and Daddy, she took a swimsuit, a rubber ring, and all sorts of things. She tried to remember if the teacher had asked them to bring swimsuits.

Then, just as if he had read her thoughts, the headmaster said, "Don't worry about swimsuits. Go and look in the Assembly Hall."

When Totto-chan and the other first graders got to the Assembly Hall the bigger children were taking off their clothes with shrieks of delight as if they were going to have a bath. They ran out, one after the other, stark naked, onto the school grounds. Totto-chan and her friends hurriedly followed them. In the warm breeze it felt wonderful not to have any clothes on. When they got to the top of the steps outside the Assembly Hall they found the others already doing warm-up exercises. Totto-chan and her classmates ran down the steps in their bare feet.

The swimming instructor was Miyo-chan's elder brother—the headmaster's son and an expert in gymnastics. He wasn't a teacher at Tomoe but he was on the swimming team of a university. His name was the same as the school's—Tomoe. Tomoe-san wore swimming trunks.

After their exercises, the children let out screams as cold water was poured over them, and then they jumped into the pool. Totto-chan didn't go in until she had watched some of the others and satisfied herself they could stand. It wasn't hot, like a bath, but it was lovely and big, and as far as you could stretch your arms there was nothing but water.

Thin children, plump children, boys, girls—they were all laughing and shouting and splashing in their birthday suits.

What fun, thought Totto-chan, and what a lovely feeling! She was only sorry [her dog] Rocky couldn't come to school. She was sure that if he knew he could go in without a swimsuit he'd be in the pool, too.

You might wonder why the headmaster allowed the children to swim naked. There were no rules about it. If you brought your suit and wanted to wear it, that was perfectly all right. On the other hand, like today, when you suddenly decided to go in and hadn't a suit, that was perfectly all right, too. And why did he let them swim in the nude? Because he thought it wasn't right for boys and girls to be morbidly curious about the differences in their bodies, and he thought it was unnatural for people to take such pains to hide their bodies from each other.

He wanted to teach the children that all bodies are beautiful. Among the pupils at Tomoe were some who had had polio, like Yasuaki-chan, or were very small, or otherwise handicapped, and he felt if they bared their bodies and played together it would rid them of feelings of shame and help to prevent them developing an inferiority complex. As it turned out, while the handicapped children were shy at first, they soon began to enjoy themselves, and finally they got over their shyness completely.

Some parents were worried about the idea and provided their offspring with swimsuits which they insisted should always be worn. Little did they know how seldom the suits were used. Observing children like Totto-chan—who right from the start decided swimming naked was best—and those who said they had forgotten to bring their suits and went in anyway, most of them became convinced it was much more fun swimming naked like the others, so all they did was make sure they took wet swimsuits home! Consequently, almost all the children at Tomoe became as brown as berries all over, and there were hardly any with white swimsuit marks. (Pp. 66–69)

Takahashi

One morning, when they were all running about the school grounds, the headmaster said, "Here's a new friend for you. His last name is Takahashi. He'll be joining the first grade train."

The children, including Totto-chan, looked at Takahashi. He took off his hat and bowed, and said shyly, "How do you do?"

Totto-chan and her classmates were still quite small, being only in the first grade, but Takahashi, although he was a boy, was much smaller still, with short arms and legs. His hands, in which he held his hat, were small, too. But he had broad shoulders. He stood there looking forlorn.

"Let's talk to him," said Totto-chan to Miyo-chan and Sakko-chan. They went over to Takahashi. As they approached him he smiled affably, and they smiled back. He had big round eyes and looked as if he wanted to say something.

"Would you like to see the classroom in the train?" Totto-chan offered.

"Mm!" replied Takahashi, putting his hat back on his head.

Totto-chan was in a great hurry to show him the classroom and bounded over to the train, calling to him from the door, "Hurry up."

Takahashi seemed to be walking fast but was still a long way off.

"I'm coming," he said as he toddled along trying to run.

Totto-chan realized that while Takahashi didn't drag his leg like Yasuaki-chan, who had had polio, he was taking the same amount of time to get to the train. She quietly waited for him. Takahashi was running as fast as he could and there was no need to say, "Hurry," for he *was* hurrying. His legs were very short and he was bow-legged. The teachers and grown-ups knew that he had stopped growing. When he saw that Totto-chan was watching him, he tried to hurry faster, swinging his arms, and when he got to the door, he said, "You do run fast." Then he said, "I'm from Osaka."

"Osaka?" cried Totto-chan excitedly. Osaka was a dream city she had never seen. Mother's younger brother—her uncle—was a university student, and whenever he came to the house he used to take her head in both his hands and lift her up as high as he could, saying, "I'll show you Osaka. Can you see Osaka?"

It was just a game grown-ups used to play with children, but Totto-chan believed him. It stretched the skin of her face horribly and pulled her eyes out of shape and hurt her ears, but she would frantically look into the distance to try and see Osaka. But she never could. She always believed, however, that one day she would be able to see it, so whenever her uncle came, she would ask, "Show me Osaka." So Osaka had become the city of her dreams. And Takahashi came from there!

"Tell me about Osaka," she said to Takahashi.

"About Osaka?" he asked, smiling happily. His voice was clear and mature. Just then the bell rang for the first class.

"What a pity," said Totto-chan. Takahashi went in gaily, swinging the little body that was almost hidden by his bag, and sat down in the front row. Totto-chan hurriedly sat down next to him. She was glad you could sit anywhere you liked. She didn't want to leave him. Thus, Takahashi became one of her friends, too. (Pp. 90–100)

Sports Day

Tomoe's Sports Day was held every year on the third of November. The headmaster had decided on that day after a lot of research, in which he found out that the third of November was the autumn day on which it had rained the fewest times. Perhaps it was due to his skill in collecting weather data, or perhaps it was just that the sun and clouds heeded his desire—that no rain should mar the Sports Day so anticipated by the children, who had decorated the school grounds the day before and made all sorts of preparations. Whatever it was, it was almost uncanny the way it never rained on that day.

As all kinds of things were done differently at Tomoe, its Sports Day, too, was unique. The only sports events that were the same as at other elementary schools were the Tug of War and the Three-Legged Race. All the rest had been invented by the headmaster. Requiring no special or elaborate equipment, they made use of familiar everyday school things.

For instance, there was the Carp Race. Large tubular cloth streamers, shaped and painted like carp—the kind that are flown from poles in May for the Boys' Day Festival—were laid in the middle of the school grounds. At the signal, the children had to start running toward the carp streamers and crawl through them from the mouth end to the tail end and then run back to the starting point. There were only three carp—one red and two blue—so three children raced at a time. The race looked easy but was quite difficult. It was dark inside, and the carp were long, so you could easily lose your sense of direction. Some children, including Totto-chan, kept coming out of the mouth, only to realize their mistake and hurriedly burrow inside again. It was terribly funny to watch because the children crawling backward and forward inside made the carp wriggle as if they were alive.

There was another event called Find-A-Mother Race. At the signal the children had to run toward a wooden ladder propped up on its side, crawl through it between the rungs, take an envelope from a basket, open it, and if the paper inside said, for instance, "Sakko-chan's mother," they would have to find her in the crowd of spectators, take her hand, and return together to the finishing line. One had to ease oneself through the ladder with catlike grace or one's bottom could get stuck. Besides that, a child might know well enough who Sakko-chan's mother was, but if the paper read "Miss Oku's sister," or "Mr. Tsue's mother," or "Mrs. Kuninori's son," whom one had never met, one had to go to the spectators' section and call in a loud voice, "Miss Oku's sister!" It took courage. Children who were lucky and picked their own mothers would jump and down shouting, "Mother! Mother! Hurry!" The spectators, too, had to be alert for this event. There was no telling when their names might be called, and they would have to be ready to get up from the bench or from the mat where they were sitting, excuse themselves, and wend their way out as fast as they could to where someone's child was waiting, take his or her hand, and go running off. So when a child arrived and stopped in front of the grown-ups, even the fathers held their breath, wondering who was going to be called. There was little time for idle chit-chat or nibbling food. The grown-ups had to take part in events almost as much as the children.

The headmaster and other teachers joined the children in the two teams for the Tug of War, pulling and shouting, "Heave-ho, heave-ho!" while handicapped children, like Yasuaki-chan, who couldn't pull, had the task of keeping their eyes on the handkerchief tied to the center of the rope to see who was winning.

The final Relay Race involving the whole school was also different at Tomoe. No one had to run very far. All one had to do was run up and down the semicircular flight of concrete steps leading to the Assembly Hall. At first glance it looked absurdly easy, but the steps were unusually shallow and close together, and as no one was allowed to take more than one step at a time, it was quite difficult if you were tall or had large feet. The familiar steps, bounded up each day at lunchtime, took on a fresh, fun aspect on Sports Day, and the children hurried up and down them shrieking gaily. To anyone watching from afar, the scene would have looked like a beautiful kaleidoscope. Counting the top one there were eight steps in all.

The first Sports Day for Totto-chan and her classmates was a fine day just as the headmaster had hoped. The decorations of paper chains and gold stars made by the children the day before and the phonograph records of rousing marches made it seem like a festival.

Totto-chan wore navy blue shorts and a white blouse, although she would have preferred to wear athletic bloomers. She longed to wear them. One day after school the headmaster had been giving a class in eurythmics to some kindergarten teachers, and Totto-chan was very taken with the bloomers some of the women were wearing. What she liked about them was that when the women stamped their feet on the ground, their lower thighs showing beneath the bloomers rippled in such a lovely grown-up way. She ran home and got out her shorts and put them on and stamped on the floor. But her thin, childish thighs didn't ripple at all. After trying several times, she came to the conclusion it was because of what those ladies had been wearing. She asked what they were and Mother explained they were athletic bloomers. She told Mother she definitely wanted to wear bloomers on Sports Day, but they couldn't find any in a small size. That was why Totto-chan had to make do with shorts, which didn't produce any ripples, alas.

Something amazing happened on Sports Day. Takahashi, who had the shortest arms and legs and was the smallest in the school, came first in everything. It was unbelievable. While the others were still creeping around inside the carp, Takahashi was through it in a flash, and while the others only had their heads through the ladder, he was already out of it and running several yards ahead. As for the Relay Race up the Assembly Hall steps, while the others were clumsily negotiating them a step at a time, Takahashi—his short legs moving like pistons—was up them in one spurt and down again like a speeded-up movie.

"We've got to try and beat Takahashi," they all said.

Determined to beat him, the children did their utmost, but try as they might, Takahashi won every time. Totto-chan tried hard, too, but she never managed to beat Takahashi. They could outrun him on the straight stretches, but lost to him over the difficult bits.

Takahashi went up to collect his prizes, looking happy and as proud as Punch. He was first in everything so he collected prize after prize. Everyone watched enviously.

"I'll beat Takahashi next year!" said each child to himself. But every year it was Takahashi who turned out to be the star athlete.

Now the prizes, too, were typical of the headmaster. First Prize might be a giant radish; Second Prize, two burdock roots; Third Prize, a bundle of spinach. Things like that. Until she was much older Totto-chan thought all schools gave vegetables for Sports Day prizes.

In those days, most schools gave notebooks, pencils, and erasers for prizes. The Tomoe children didn't know that, but they weren't happy about the vegetables. Totto-chan, for instance, who got some burdock roots and some onions, was embarrassed about having to carry them on the train. Additional prizes were given for various things, so at the end of Sports Day all the children at Tomoe had some sort of vegetable. Now, why should children be embarrassed about going home from school with vegetables? No one minded being sent to buy vegetables by his mother, but they apparently felt it would look odd carrying vegetables home from school.

A fat boy who won a cabbage didn't know what to do with it.

"I don't want to be seen carrying this," he said. "I think I'll throw it away."

The headmaster must have heard about their complaints for he went over to the children with their carrots and radishes and things.

"What's the matter? Don't you want them?" he asked. Then he went on, "Get your mothers to cook them for dinner tonight. They're vegetables you earned yourselves. You have provided food for your families by your own efforts. How's that? I'll bet it tastes good!"

Of course, he was right. It was the first time in her life, for instance, that Totto-chan had ever provided anything for dinner.

"I'll get Mother to make spicy burdock!" she told the headmistress. "I haven't decided yet what to ask her to make with the onions."

Whereupon the others all began thinking up menus, too, describing them to the headmaster.

"Good! So now you've got the idea," he said, smiling so happily his cheeks became quite flushed. He was probably thinking how nice it would be if the children and their families ate the vegetables while talking over the Sports Day events.

No doubt he was thinking especially of Takahashi—whose dinner table would be overflowing with First Prizes—and hoping the boy would remember his pride and happiness at winning those First Prizes before developing an inferiority complex about his size and the fact he would never grow. And maybe, who knows, the headmaster had thought up those singularly Tomoe-type events just so Takahashi would come first in them. (Pp. 109–114)

From the Epilogue

What are they doing now, those friends of mine who "traveled" together with me on the same classroom "train?"

Akira Takahashi

Takahashi, who won all the prizes on Sports Day, never grew any taller, but entered, with flying colors, a high school famous in Japan for its rugby team. He went on to Meiji University and a degree in electronic engineering.

He is now personnel manager of a large electronics company near Lake Hamana in central Japan. He is responsible for harmony in the work force and he listens to complaints and troubles and settles disputes. Having suffered much himself, he can readily understand other people's problems, and his sunny disposition and attractive personality must be a great help, too. As a technical specialist, he also trains the younger men in the use of the large machines with integrated circuitry.

I went to Hamamatsu to see Takahashi and his wife—a kindly woman who understands him perfectly and has heard so much about Tomoe she says it is almost as if she had gone there herself. She assured me Takahashi has no complexes whatever about his dwarfism. I am quite sure she is right. Complexes would have made life very difficult for him at the prestigious high school and university he attended, and would hardly enable him to work as he does in a personnel department.

Describing his first day at Tomoe, Takahashi said he immediately felt at ease when he saw there were others with physical handicaps. From that moment he suffered no qualms and enjoyed each day so much he never even once wanted to stay home. He told me he was embarrassed at first about swimming naked in the pool, but as he took off his clothes one by one, so he shed his shyness and sense of shame bit by bit. He even got so he did not mind standing up in front of the others to make his lunchtime speeches.

He told me how Mr. Kobayashi had encouraged him to jump over vaulting-horses higher than he was, always assuring him he could do it, although he suspects now that Mr. Kobayashi probably helped him over them—but not until the very last moment, letting him think he had done it all by himself. Mr. Kobayashi gave him confidence and enabled him to know the indescribable joy of successful achievement. Whenever he tried to hide in the background, the headmaster invariably brought him forward so he had to develop a positive attitude to life willy-nilly. He still remembers the elation he felt at winning all those prizes. Bright-eyed and sensible as ever, he reminisced happily about Tomoe.

A good home environment must have contributed, too, to Takahashi's developing into such a fine person. Nevertheless, there is no doubt about the fact that Mr. Kobayashi dealt with us all in a very far-sighted way. Like his constantly saying to me, "You're really a good girl, you know," the encouraging way he kept saying to Takahashi, "You can do it!" was a decisive factor in shaping his life.

As I was leaving Hamamatsu, Takahashi told me something I had completely forgotten. He said he was often teased and bullied by children from other schools on his way to Tomoe and would arrive there crestfallen, whereupon I would quickly ask him what children had done it and was out of the gate in a flash. After a while I would come running back and assure him it was all right now and wouldn't happen again.

"You made me so happy then," he said when we parted. I had forgotten. Thank you, Takahashi, for remembering. (Pp. 193–195)

Source: Kuroyanagi, Tetsuko. 1982. Britton, Dorothy, trans. *Totto-chan: The Little Girl at the Window.* Tokyo: Kodansha. Copyright © 1981 by Tetsuko Kuroyanagi. English translation copyright © 1982 by Kodansha International. Reproduced by permission. All rights reserved.

Stanley Elkin, from *The Magic Kingdom* (1985)

Elkin's novel exposes the absurdities lurking beneath charity efforts to treat terminally ill children to fantasy vacations in order to lessen their "suffering." Instead, the trip descends into sentimental nightmare that benefits no one other than the resort owners. In this excerpt, the group's aptly named personal assistant, Colin Bible, uses the Disneyland parade as an opportunity for a lesson about human variation across body types.

"Come, children," Colin said.

"We already seen that parade," said Benny Maxine.

"I want you to see it again."

In Coming Home, *Jane Fonda portrays a woman who is married to a man fighting in Vietnam. After volunteering to work at a local veteran's hospital, she falls in love with a paralyzed veteran who becomes an active antiwar protester.*

Source: *Coming Home* (1978), directed by Hal Ashby. United States. Color, 126 minutes. Reprinted by permission of Paul Darke.

"Where are you taking them?" Nedra Carp asked.

"You needn't come, Miss Carp, if you don't wish to."

"Oh, I couldn't let you go by yourself. Who'd push the girl's wheelchair?"

"I'll push it. Benny can handle Mudd-Gaddis's."

Maxine looked at the nurse.

"Anyway, I don't see what the rush is. The parade don't start for nearly an hour yet."

There were frequent parades in the Magic Kingdom. Mr. Moorhead had given them permission to stay up one night to watch the Main Street Electrical Parade, a procession of floats outlined in lights like the lights strung across the cables, piers, spans, and towers of suspension bridges. There were daily "character" parades in which the heroes and heroines of various Disney films posed on floats, Alice perched on her mushroom like the stem on fruit; Pinocchio in his avatar as a boy, his strings fallen away, absent as shed cocoon; Snow White flanked by her dwarfs; Donald Duck, his sailor-suited, nautical nephews. They'd seen this one, too. There'd been high school marching bands, drum majors, majorettes, pom-pom girls, drill teams like a Swiss Guard. Tall, rube-looking bears worked the crowd like advance men, parade marshals. Some carried balloons in the form of Mickey Mouse's trefoil-shaped head, vaguely like the club on a playing card. (Pluto marched by, a Mickey Mouse pennant over his right shoulder like a rifle. "Dog soldier!" Benny Maxine had shouted through his cupped hands. The mutt turned its head and, in spite of its look of pleased, wide-eyed, and fixed astonishment, had seemed to glare at him.) Everywhere there were Mickey Mouse banners, guerdons, pennants, flags, color pikes, devices, and standards, the flash heraldics of all blazoned envoy livery. Music blared from the floats, from the high-stepping tootlers: Disney's greatest hits, bouncy and martial as anthems. It could almost have been a triumph, the bears, ducks, dogs, and dwarfs like slaves, like already convert captives from exotic far-flung lands and battlefields. The Mouse stood like a Caesar in raised and isolate imperiality on a bandbox like a decorated cake. He was got up like a bandmaster in his bright red jacket with its thick gold braid, his white, red-striped trousers. His white gloves were held stiff and high as a downbeat against his tall, white-and-red shako. His subjects cheered as he passed. (You wouldn't have guessed that Minnie was his concubine. In her polka dot dress that looked almost like homespun, and riding along on a lower level of a lesser float, she could have been another pom-pom girl.)

It was toward this parade they thought they were headed.

But Main Street was practically deserted.

"What was the rush?" Nedra Carp asked.

"Yeah, where's the fire?" said Benny Maxine.

"Hang on," Colin Bible told them. "You'll see."

"It's another half hour yet," Lydia Conscience said.

"Are we just going to stand around?" Janet Order asked from her wheelchair.

"We could be back in our rooms resting," Rena Morgan said.

"We can sit over there," Colin said. He pointed across Main Street to the tiny commons.

Old-fashioned wood benches were placed outside a low iron railing that ran about a fenced green.

"We sit here we won't see a thing once it starts," Noah Cloth said.

"He's right," Tony Word said. "People will line up along the curb and block out just everything."

"Hang on," Colin Bible said. "You'll see."

About twenty minutes before the parade was scheduled to start, a few people began to take up positions along the parade route.

"Look there," Colin said.

"Where, Colin?" Janet said.

"There," he said, "the young berk crossing the street, coming toward us." He was pointing to an odd-looking man with a wide thin mustache, macho and curved along his lip like a ring around a bathtub. His dark thick sideburns came down to a level just below his mouth. "They're dyed, you know," Colin whispered. "They're polished with bootblack."

"How would you know that, Colin?" Noah asked.

"Well, not to blind you with science, I'm a nurse, aren't I? And 'haven't a nurse eyes, 'haven't a nurse 'air? When you see stuff so inky? There ain't such darkness collected together in all the dark holes."

"All the dark holes," Benny Maxine repeated, pretending to swoon.

"Look alive, mate," Colin scolded, "we're on a field trip, a scientifical investigation."

"We're only waiting for the parade to begin," Lydia said.

"A parade we already seen."

"Two times."

"By day and by night."

"M-I-C-K-E-Y M-O-U-S-E."

"Can't we give the parade a pass?"

"*This,*" Colin hissed, "*This* is the parade! This is the parade and you've *never* seen it! All you seen is the cuddlies, all you seen is the front runner, excellent dolls, happy as Larry and streets ahead of life."

"Really, Mister Bible," Nedra Carp said, "such slangy language!"

"Lie doggo, dearie, please. Keep your breath to cool your porridge, Miss Carp."

"I don't think this is distinguished, Mister Bible," Miss Carp said.

"Jack it in," he told her sharply. "Distinguished? *Distinguished?* I'm showing them the popsies; I'm showing them the puppets. I'm displaying the nits and flourishing the nut cases. The bleeders and bloods, the yobbos and stooges. I'm furnishing them mokes and bringing them muggings. All the mutton dressed as lamb. No one has yet, God knows, so old Joe Soap will must."

"Why?"

"Ask me another," he said.

"Why?"

"They've got to find out how many beans make five, don't they? It's only your ordinary level pegging, merely keeping abreast. There's a ton of niff in this world, you know. There's just lashings and lashings of death. Hark!" He broke off. "*Watch what you think you're going to miss.* Hush! Squint!" The man in the mustache and sideburns was passing in front of them.

And now you couldn't have dragged them away. You couldn't have rolled Janet Order's or Mudd-Gaddis's wheelchair downhill.

"Uh-oh," Colin Bible said, "we've been sold a pup."

"Snookered!" said one of the children.

"Skinned!" said another.

"Socked!"

"Some mothers have 'em," Benny Maxine said.

Because they saw that Colin had been wrong.

The man was not young, after all. He could have been in his fifties. He wore cowboy boots, the cheap imitation leather not so much worn as peeling, chipped as paint and mealy and rotten as spoiled fruit. His high raised heels were of a cloudy translucent plastic. Flecks of gold-colored foil were embedded in them like sparks painted on a loud tie. Up close he had the queer, pale, lone, and fragile look of men who cut themselves shaving. Of short-order cooks, of men wakened in drunk tanks or beaten in fights. A bolo tie, like undone laces, hung about a bright pink rayon shirt that fit over a discrete paunch tight and heavy as muscle. A chain that ran through a wallet in the back pocket of his pants was attached to his belt.

Nor were his broad sideburns dyed. They were tattooed along his ears and down his cheeks. His mustache was tattooed. The actual gloss and sheen tattooed too—like highlights in a landscape. Everything only indelible, deep driven inks among the raised scars of his illustrious whiskers.

They were gathering, coming together quickly now, lining up along the curbs, building a crowd, rapidly taking up the best vantage points like people filling a theater. "See 'em? They look like fans at the all-in wrestling," Colin said wickedly. And they did. Something not so much supportive as impatient and partisan about them. Apple Annies of style, Typhoid Marys of spirit, the men as well as the women, they could have been carriers, not of disease but of vague, pandemic strains on the psyche, on tastes not depleted but somehow made to accommodate to the surrender terms of their lives and conditions. As though they'd survived their dreams, even their lives, only to find a need to be at a parade of cartoon characters at Disney World.

It was different with the children, their parents. Oddly in the minority, Colin barely made mention of them, as though most lives came with a grace period, thirty or thirty-five years, say, some fifty-thousand-mile guarantee of the agreeable and routine. It was the widows traveling together he pointed out, the senior citizens up from Miami or down from such places as Detroit or Cleveland on package tours. It was the retirees, the couples unescorted by kids. They were casually dressed, the women in pants suits or sometimes in shorts—it was a mild fall day—the men in Bermudas, in slacks the color of artificial fruit flavors, in white shoes, in billed caps with fishermen's patches. (Cinderella Castle, towering above them in the background, made them seem even more like subjects than ever, reasonably content, well off, even, but with a whiff of the indentured about them, of an obligated loyalty.)

"Look there!" Colin Bible said. "And *there.* Look at those over there!"

There was a couple with the lined, bloated, and satisfied heads of midgets. Wens were sprinkled across their faces like a kind of loose change of flesh.

There was a potbellied, slack-breasted man, his wife with bad skin, wrinkled, scarred, pitted as scrotum. They had smooth, fat fingers, and their hands were balled into the ineffectual, hairless fists of babies.

"Look, look there, how ugly!" Colin said.

An angry woman with long dark hair, her back to the street, stood near the couple with the wens. Her hair, tied beneath her chin, looked like a babushka. She stared back at Colin and the children, her black, thick eyebrows exactly the color and shape of leeches above eyes set so deep in her skull they seemed separated from her face, hidden as eyes behind a mask or holes cut from portraits in horror films. A set of tiny lips, Kewpie-doll, bow-shaped, red and glossy as wet paint, and superimposed, grafted onto her real lips like a botched bookkeeping or clumsy work in a child's coloring book, tinted an additional ferocity into her scrutiny.

"It breaks your heart," Colin said. "Imperfection everywhere, everywhere. Not like in nature. What, you think stars show their age? Oceans, the sky? No fear! Only in man, only in woman. Trees never look a day older. The mountains are better off for each million years. Everywhere, everywhere. Bodies mismanaged, malfeasance, gone off. Like styles, like fashions gone off. It's this piecemeal surrender to time, kids. You can't hold on to your baby teeth. Scissors cut paper, paper covers rock, rock smashes scissors. A bite of candy causes tooth decay, and jaw lines that were once firm slip off like shoreline lost to the sea. Noses balloon, amok as a cancer. Bellies swell up and muscles go down. Hips and thighs widen like jodhpurs. My God, children, we look like we're dressed for the horseback! (And everywhere, everywhere, there's this clumsy imbalance. You see these old, sluggish bodies on thin-looking legs, like folks carrying packages piled too high. Or like birds puffed out, skewed, out of sorts with their foundations.) And hair. Hair thins, recedes, is gone. Bodies fall away from true. I don't know. It's as if we've been nickel-and-dimed by the elements: by erosion, by wind and water, by the pull of gravity and the oxidation of the very air. Look! Look there!"

A middle-aged woman in a print dress waited in house slippers for the parade to begin. She was crying. Tears pushed over the ledges of her eyes. A clear mucus filled a corner of one nostril.

A dowager's hump draped a pretty young woman's shoulders and back like a shawl.

They saw the details of a man's face, the stubble, lines, cleft, dimples, and pores, sharp and clarified as close-ups in black-and-white photographs.

Sunglasses in the form of swans, masks, butterflies, or random as the form of costume jewelry. Odd-shaped wigs and hairdos sat on people's heads like a queer gardening, a strange botany. And, everywhere, penciled eyebrows, painted lips, like so many prostheses of the cosmetic.

It had begun now, the parade. A well-dressed man in a business suit stood at attention as the floats passed by. He held his hat over his heart. (And sanity, sanity too, marred, scuffed as a shoe, wrinkled as laundry.) It had begun now, but the children weren't watching. They couldn't take their eyes off the crowd. ("*This, this* is the parade!") They stared at the special area the park had provided for guests in wheelchairs, at the old men and women who sat in them, bundled against some internal chill on even this warm day, wrapped in blankets that tucked over their feet, in sweaters, in scarves, in wool gloves and mittens, covered by hats, by caps, Mickey Mouse's eared beanies, dark as *yarmulkes,* on top of their other headgear; at, among them, an ancient woman in a rubber Frankenstein mask for warmth; at her nurse, feeding her cigarettes, venting her smoke through a gap in the monster's wired jaws. At other women, depleted, tired, who sat on benches, their dresses hiked well above their knees, their legs (in heavy stockings the color of miscegenetic, coffee-creamed flesh) not so much spread as forgotten, separated, guided by the collapsing, melted lines of their thighs. At their husbands (or maybe just the men they lived with, for convenience, for company, for making the welfare checks go farther), their hands in their laps, incurious as people who have just folded in poker. (And *everywhere* those dark glasses. "It ain't for the glare," Colin told them, "it's for the warmth!") At grown men and women wearing the souvenirs of the Magic Kingdom: sweat shirts, T-shirts, with Eeyore, with Mickey Mouse, with Jiminy Cricket, Alice-in-Wonderland pinafores, Minnie Mouse dresses, carryalls with Dumbo and Tigger and Tramp. At a woman in her sixties, inexplicably wearing a boa, a turban, a veil of wide, loose black mesh; at hands and arms and shoulders blotched by liver spots; at a man in baggy pants suspiciously, unscrupulously bulging. At a man in shorts, the enlarged veins on his legs like wax dripping down Chianti bottles in Italian restaurants.

At a woman with oily skin and pores like a sort of goose-flesh, visible as the apertures of chickens where their pinfeathers had been plucked. At a still handsome woman with bare, shapely, but hairy legs (hair even on the tops of her feet), carefully trimmed as sideburns or rolled as stockings two inches below her knee; at a powerfully built man in his sixties whose chest hair, visible through his sheer tank top, had been as lovingly, patiently groomed as a high school boy's. (Everywhere, everywhere hair—the strange feeling they had that they were among birds, the wigs, the boa, the babushka of hair beneath the woman's chin, the piled hairdos, the thinning hair, the penciled eyebrows, the tattooed mustache and sideburns of the strange Westerner. Mudd-Gaddis's own baldness and the chemotherapeutic fuzz of several of the children. Because everything has a reasonable explanation, and almost all had heard that hair didn't stop growing after you died. Because everything has a reasonable explanation and hair was the gnawed, tenuous rope by which they hung on to immortality.)

Everywhere there were peculiar couples. A boy and a girl who couldn't have been more than twelve but looked in their runt intimacy as if they could have been married. The boy held his arm protectively about the girl's shoulder, his free hand in the pocket of his three-quarter-length trench coat as though he fondled a gun. He wore a jacket, a shirt, and a tie. His floods, honed as a knife along their permanent crease, rose above sharp, snazzy shoes. The girl, shorter than her small boyfriend, in a decent wool coat that looked as if it had been bought at a back-to-school sale, smiled wanly. Her black full hair showed signs of gray and she seemed a little nervous, wary, even long-suffering, beneath the arm of her protector, as if she knew his faults, perhaps, his diseases—which weren't diseases in her book—his excessive drinking, his compulsive gambling, his quick fists and rude abuse.

And stared openly at the mismatched couples: at the big, powerful girls next to undersized men and the men large as football players beside bloodless, scrawny women, at the couples widely discrepant in age in open attitudes of love and regard, handholding or clutching butts, the men's fingers casually resting along breasts as if they lolled in water. Or their arms thrown abruptly across each other's shoulders. Sending the smug signals of secret satisfactions, like the wealthy, perhaps, like people in drag.

And at a closely supervised group of the retarded, oddly ageless, the males in overalls, the females in loose, shapeless dresses and rolled stockings, clutching one another with their short fat fingers, their strange, pleased eyes fixed in their happy Smile Faces like raisins in cakes, beaming above their neglected teeth, beaming, beaming beneath their close-cropped hair on their broad, short skulls.

(Yet most were not defective, merely aging or old, or anyway beyond that thirty- or thirty-five-year grace period that seemed to come with most lives.)

Not even needing Colin now to direct their attention, to point things out. In it themselves now, raising their voices, like people outbidding each other in some hot contest, not even listening; or, if listening, then listening for the break in the other's discourse, for that opportune moment when they could have their say, get in their licks; or, if listening, then listening not just for the other to finish but for some generalized cue, some more or less specific tag on which they could build, add, like players of dominoes, say, or card games that followed strict suit. But generally too excited even for that. Only half listening, really, less, fractionally, marginally, seeing how it was with them and concentrating only on the essence, pith, and gist of what they would say, thinking in a sort of deliberate and polite headlines but settling finally into a kind of conversation and still using the language of that other kingdom, the one they'd come from to get to this one.

"Lord love a duck!" said Janet Order. "Just clap eyes on these gaffers."

"My word, Janet! They're for it, I'd say so," Rena Morgan agreed.

"Lamb turning to mutton." Janet sighed.

"Fright fish."

"Blood puddles."

"Lawks!" said Benny Maxine. "Look at the bint with the healthy arse. I'm gone dead nuts on that fanny."

"Ooh, it's walloping big, ain't it?" Tony Word said.

"If it ever let off it wouldn't 'alf make a pongy pooh," Benny asserted.

"Like Billy-O!" Tony said.

"Good gracious me!" said Lydia Conscience. "Say what you will, my heart goes out to the old biddy what looks like someone put her in the pudding club."

"Yar, ain't she dishy? There's one in every village."

Tony Ward considered. "No," he said. "She's just put on the nose bag. It's simply a case of your lumping, right grotty greedguts."

"Only loads of grub then, you think?" Lydia asked.

"Oh, yes," said Tony. "Oodles of inner man. Tub and tuck."

"Jesus weeps!" said illiterate Noah Cloth, looking about, his gaze settling on the little group of the retarded. "He weeps for all the potty, pig-ignorant prats off their chumps, for all the slow-coach clots and dead-from-the-neck-up dimbos, and wonky, puddle coots and gits, goofs and goons, for all his chuckle-headed, loopy muggings and passengers past praying for."

"Put a sock in it, old man," Benny Maxine said softly.

"For all the nanas," Noah said, crying now. "For all the bright specimens."

"Many's the nosh-up gone down that cake hole," Tony Ward said, his eyes fixed on the fat woman Lydia Conscience had thought pregnant. "Many's the porky pots of tram-stopper scoff and thundering stodge through that podge's gob," he said without appetite.

"She's chesty," Rena Morgan said, weeping, of a woman who coughed. "She should put by the gaspers."

"She's had her day," said Janet Order.

"Coo! Who ain't?" Rena, sobbing, wanted to know. "Which of us, hey? Which of them?"

"Are they all on the dream holiday then?" Charles Mudd-Gaddis asked.

"All, old son, and no mistake," Lydia Conscience said wearily.

"A shame," he said. "Letting themselves go like that. And them with their whole lives in front of them."

And, at last, just rudely pointing. (They could have been mutes waving at entrées, aiming at desserts in a cafeteria line.) Whirling, indiscriminate, flailing about in some random *"J'accuse"* of the spontaneous. Whining, wailing, whimpering, weeping.

Because everything has a reasonable explanation. They lived in England's cold climate. They came from a place where clothes made their men and their women. They were unaccustomed to sportswear, to shorts and the casual lightweights and washables of the near tropics. They were unaccustomed, that is, to the actual shapes of people and simply did not know that what they saw was just the ordinary let-hung-out wear and tear of years, of meals, of good times and comforts and all the body's thoughtless kindnesses to itself. So that when Colin said what he said they believed him.

"I tell you," he told them, "that's you in a few years, never mind those three-score-and-ten you thought was your birthright. All that soured flesh, all those bitched and bollixed bodies. You see? You see what you thought you were missing?"

"Bodies," Nedra Carp said. "Don't tell me about bodies. I *know* about bodies."

Source: Elkin, Stanley. 2000. Pp. 218–229 in *The Magic Kingdom.* Normal, IL: Dalkey Archive Press. Copyright © 1985 by Stanley Elkin. Reprinted by permission of Georges Borchardt, Inc.

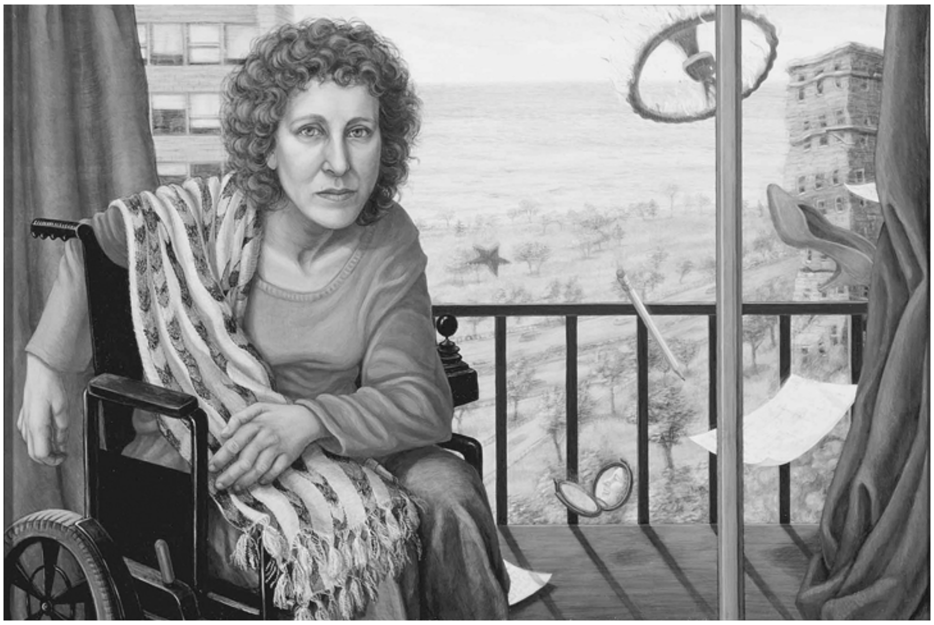
Australian Disability Advocacy (1980s)

The Disability Services Act of 1986 shapes funding for disability services in Australia. It marks a shift away from charitable, segregated services and toward community-based services aimed at community integration and participation, increased workforce participation, independence, and promoting positive images of persons with disabilities. The entry of "advocacy services" into the program represented a significant triumph for activist groups in the Australian disability scene, which had increased voice after the International Year for Disabled Persons in 1981.

From Disability Services Act of 1986 Part II, Divisions 1 and 7

Advocacy services means:

(a) self advocacy services, namely, services to assist persons with disabilities to develop or maintain



"Circle Story #3: Susan Nussbaum," *by Riva Lehrer. 1998. Acrylic on panel. 16" by 26." Susan Nussbaum is a playwright, actress, director, and disability rights activist. She has starred in, written and/or directed productions at the Goodman, Victory Gardens, and Blue Rider theaters, and other major venues. Her play Mishuganismo is included in Staring Back, and her latest play, No One As Nasty, opened at Chicago's Victory Gardens Theater in 2000. She also teaches pla writing at the Mark Taper Forum in Los Angeles. Nussbaum was injured in a car accident twenty years ago, and she has examined the disability experience with an unsparing, critical wit.*

the personal skills and self confidence necessary to enable them to represent their own interests in the community;

(b) citizen-advocacy services, namely, services to facilitate persons in the community to assist:

(i) persons with disabilities; or

(ii) the families of, and other persons who provide care or assistance, to persons with disabilities; to represent their interests in the community; or group-advocacy services, namely, services to facilitate community organisations to represent the interests of groups of persons with disabilities.

Commentary

Australian disability activist groups were influenced by two main streams of analysis. Physical disability activists, shaped by the disability rights movement emerging from the United Kingdom and the United States, adopted a "social model" of disability. This analysis was taken up by some individuals with intellectual impairment, arguing that with skills and training individuals previously judged incompetent could speak up for themselves. This stream is characterized as the empowerment model of advocacy.

The other stream emerged from the Syracuse University Training Institute for Human Service Planning, Leadership and Change Agentry. The theory of social devaluation was taken into the model for citizen advocacy. It also influenced many parents, especially those with family members with intellectual or multiple impairments. This stream can be characterized as the social role valorization model. It was this stream that gave the advocacy services section of the Disability Services Act of 1986 its name and configuration—thereby providing great opportunities as well as opening up continuing debates.

The two streams have many points of confluence, especially the centrality of the demand for community life and the dissolution of institutional and congregate services and for the defense of certain rights. However, many contested issues continue to reflect their divergence: the clash between a collectivist rights movement and the incipient individualism of social valorization.

But this can never be the full story. Such a division is too crude. Disability advocacy in Australia has taken on a new spirit of cooperation, building on contributions from community development, enriched by understandings of new social movements. Activists and scholars are expanding the social model of disability with wisdom about relationality, the learnings of seeking normalization, and the critical insights of postmodern thought.

The quest remains—to hold faith with the streams of this history while developing creative theory and practice that can deal with the challenges still faced by many people with impairments.

Source: Disability Services Act of 1986 (Australia). Available at: http://www.comlaw.gov.au/comlaw/Legislation/ActCompilation1.nsf/0/A92AC1C00AC724E0CA256F71004CD94F/$file/DisabilityServices1986.pdf

Cheryl Marie Wade, "I Am Not One of The" (1987)

In this work, disabled U.S. poet and performance artist Cheryl Marie Wade celebrates the differences across disabilities that normative culture rejects. In doing so, the poem creates an alternative value system that turns socially imposed "deviance" into a revelation about the persistence of human variation.

I am not one of the physically challenged
I'm a sock in the eye with gnarled fist
I'm a French kiss with cleft tongue
I'm orthopedic shoes sewn on a last of your fears
I am not one of the differently abled
I'm an epitaph for a million imperfect babies left untreated
I'm an ikon carved from bones in a mass grave at Tiergarten, Germany
I'm withered legs hidden with a blanket
I am not one of the able disabled
I'm a black panther with green eyes and scars like a picket fence
I'm pink lace panties teasing a stub of milk white thigh
I'm the Evil Eye
I'm the first cell divided
I'm mud that talks
I'm Eve I'm Kali
I'm The Mountain That Never Moves
I've been forever I'll be here forever
I'm the Gimp
I'm the Cripple
I'm the Crazy Lady
I'm The Woman With Juice

Source: Wade, Cheryl Marie. 1987. "I Am Not One of The." Available at: http://www.disabledandproud.com/prideart.htm. Reprinted by permission.

Sally Zinman, Howie T. Harp, and Su Budd, from *Reaching Across: Mental Health Clients Helping Each Other* (1987)

In this excerpt from this groundbreaking self-help manual for psychiatric survivors, Su Budd explains why client-centered, peer-driven support is a keystone of the psychiatric survivor/user movement.

In a mutual support group, we can develop our own power base. As we reach out horizontally to each other, recipients become providers and vice versa. We can feel a certain independence or distance from the mental health system that empowers us to discern the differences between available services more clearly, and to choose only those services provided by that system, which we find to be beneficial to us. This makes the mental health system more accountable to us and holds it responsible to answer our needs as we define them. Since we are not part of the mental health system, we do not keep medically oriented records, which dehumanize people. We do not need records to provide each other with good support. We do not have to wonder what is being written into our "charts" by others, and we do not have to deal with the feelings that come up with being diagnosed.

Source: Zinman, Sally, Howie T. Harp, and Su Budd, eds. 1987. Ch. 5 in *Reaching Across: Mental Health Clients Helping Each Other.* Sacramento, CA: California Network of Mental Health Clients. Reprinted by permission.

"Position of the Students, Faculty and Staff of Gallaudet University" (1988)

In March 1988, students at Gallaudet University protested the selection of a hearing president out of three candidates—the other two were deaf. The excerpt below lays out the demands of the protestors, which successfully resulted in the hiring of the deaf university's first deaf president.

The appointment of the new president of Gallaudet University has resulted in an OVERWHELMING vote of NO CONFIDENCE in the Board of Trustees!

DEMANDS

1) We demand that the Board of Trustees appoint one of the two deaf finalists as President, Gallaudet University . . . NOW!

2) We demand that Jane Basset Spilman resign from the Board immediately and that a deaf Board Member be elected as chairperson.

3) We demand that the Board [initiate] the process of changing its By-Laws to conform with the C.O.E.D.'s [recommendations] to Congress of a 51% deaf member representation on the Board of Trustees.

4) We demand that no student, staff or faculty member of Gallaudet University be subject to any reprisals as a result of their standing on this matter.

11:30 am, March 7, 1988

Source: President's Council on Deafness. 1988. "Position of the Students, Faculty and Staff of Gallaudet University." Available at: http://pr.gallaudet.edu/dpn/issues/pcddemands.html. Copyright © 1995–2003 Gallaudet University.

Audre Lorde, "A Burst of Light: Living with Cancer" (1988)

Born in New York in 1934 to West Indian parents, Audre Lorde went on to be a teacher and international lecturer. Her book The Cancer Journals *details her efforts to survive breast cancer while also combating the sexism, racism, and able-ism of the medical industry. She refused to separate the struggle for dignity in the wake of her diagnosis from other civil rights agendas, and her writing insightfully dovetails with these political concerns to form a new alignment for collective action.*

If I am to put this all down in a way that is useful, I should start with the beginning of the story.

Sizable tumor in the right lobe of the liver, that's what the doctors said. Lots of blood vessels in it means it's most likely malignant. Let's cut you open right now and see what we can do about it. Wait a minute, I said. I need to feel this thing and see what's going on inside myself first, I said, needing some time to absorb the shock, time to assay the situation and not act out of panic. Not one of them said, I can respect that, but don't take too long about it.

Instead, that simple claim to my body's own process elicited such an attack from a reputable Specialist in Liver Tumors that my deepest—if not necessarily most useful—suspicions were totally aroused.

What a doctor could have said to me that I would have heard was, 'You have a serious condition going on in your body and whatever you do about it you must not ignore it or delay deciding how you are going to deal with it because it will not go away no matter what you think it is.' Acknowledging my own responsibility for my own body. Instead, what he said to me was, 'if you do not do exactly what I tell you to do right now without questions you are going to die a horrible death.' In exactly those words.

I felt the battle lines Danny being drawn up within my own body.

I saw this specialist in liver tumors at a leading cancer hospital in New York City, where I had been referred to as an outpatient by my own doctor.

The first people who interviewed me in white coats from behind a computer were only interested in my health care benefits and proposed method of payment. Those crucial facts determined what kind of plastic ID card I would be given, and without a plastic ID card, no one at all was allowed upstairs to see any doctor, as I was told by the uniformed, pistoled guards at all the stairwells.

From the moment I was ushered into the doctor's office and he saw my x-rays, he proceeded to infantilize me with an obviously well practiced technique. When I told him I was having second thoughts about a liver biopsy, he glanced at my chart. Racism and Sexism joined hands across the table as he saw I taught at a university. 'Well, you look like an *intelligent* girl,' he said, staring at my one breast all the time he was speaking. 'Not to have this biopsy immediately is like sticking your head in the sand.' Then he went on to say that he would not be responsible when I wound up screaming in agony one day in the corner of his office!

I asked this specialist in liver tumors about the dangers of a liver biopsy spreading an existing malignancy, or even encouraging it in a borderline tumor. He dismissed my concerns with a wave of his hand, saying, instead of answering, that I really did not have any other sensible choice.

I would like to think that this doctor was sincerely motivated by a desire to me to seek what he truly believed to be the only remedy for my sickening body, but my faith in that scenario is considerably diminished by his $250 consultation fee and his subsequent report to my own doctor containing numerous supposedly clinical observations of remaining pendulous breast.

In any event, I can thank him for the fierce shard lancing through my terror that shrieked there must be some other way, this doesn't feel right to me. If this is cancer and they cut me open to find out, what is stopping that intrusive action from spreading the cancer, or turning a questionable mass into an active malignancy? All I was asking for was the reassurance of a realistic [answer] to my real questions, and that was not forthcoming. I made up my mind that if I was going to die in agony on someone's office floor, it certainly wasn't going to be his! I needed information, and pored over books on the liver in Barnes & Noble Medical Textbook Section on Fifth Avenue for hours. I learned, among other things, that the liver is the largest, most complex, and most generous organ in the human body. But that did not help me very much.

In this period of physical weakness and psychic turmoil, I found myself going through an intricate inventory of rage. First of all at my breast surgeon—had he perhaps done something wrong? How could such a small breast tumor have metastasized? Hadn't he assured me he'd gotten it all, and what was this now anyway about micro-metastases? Could this tumor in my liver have been seeded at the same time as my breast cancer? There were so many unanswered questions, and too much that I just did not understand.

But my worst rage was the rage at myself. For a brief time I felt like a total failure. What had I been busting my ass doing these past six years if it wasn't living and loving and working to my utmost potential? And wasn't that all a guarantee supposed to keep exactly this kind of thing from ever happening again. So what had I done wrong and what was I going to have pay for it? Why Me?

Elephant Man *tells the extraordinarily moving tale of the unfortunate Joseph Merrick, born with a rare disease, who was taken from the world of the freak show to the pinnacle of Victorian society.*

Source: *Elephant Man* (1980), directed by David Lynch. United Kingdom. B&W, 124 minutes. Reprinted by permission of Paul Darke.

But finally a little voice inside me said sharply 'Now really, is there any other way you would have preferred living the past six years that would have been any more satisfying? And be that as it may, *should* or *shouldn't* isn't even the question. How do you want to live the rest of your life from now on and what are you going to do about it?' Time's awasting!

Gradually, in those hours in the stacks of Barnes & Noble, I felt myself shifting into another gear. My resolve strengthened as my panic lessened. Deep breathing regularly. I'm not going to let them cut into body again until I'm convinced that there's no other alternative. And this time, the burden of proof rests with the doctors because their record of success with liver cancer is not so good that it would make me jump at a surgical solution. And scare tactics are not going to work. I have been scared for six years and that hasn't stopped me. I've given myself plenty of practice in doing whatever I need to do, scared or not, so scare tactics are just not going to work. Or I hoped they were not going to work. At any rate, thank the goodness, they were not working yet. One step at a time.

But some of my nightmares were pure hell, and I started having trouble sleeping.

In writing this I have discovered how important some things are that I thought were unimportant. I discovered this by the high price they exact for scrutiny. At first I did not want to look again at how slowly I came to terms with my own mortality on a deeper level than before. Medical textbooks on the liver were fine, but there were appointments to be kept, and bills to pay, and decisions about the upcoming trip to Europe to be made. And what do I say to my children. Honesty has always been the bottom line between us, but did I really need them going through this with me during their final, difficult years at college? On the other hand, how could I shut them out of the most important decision of my life?

I made a visit to my breast surgeon, a doctor with whom I have always been able to talk frankly, and it was

In Whose Life Is It Anyway?, *a wisecracking sculptor, paralyzed from the neck down after a car crash, struggles for his right to die.*

Source: *Whose Life Is It Anyway?* (1981), directed by John Badham. United States. Color, 118 minutes. Reprinted by permission of Paul Darke.

from him that I got my first trustworthy and objective sense of timing. It was from him that I learned that the conventional forms of treatment for liver metastases made little more than one year's difference in the survival rate. I heard my old friend Clem's voice coming back to me through the dimness of thirty years: 'I see you coming here trying to make sense where there is no sense. Just try living in it. Respond, alter, see what happens.' I thought of the African way of perceiving life, as experience to be lived rather than as problem to be solved.

Homeopathic medicine calls cancer the cold disease. I understand that down to my bones that quake sometimes in their need for heat, for the sun, even for just a hot bath. Part of the way in which I am saving my own life is to refuse to submit my body to cold whenever possible.

In general, I fight hard to keep my treatment scene together in some coherent and serviceable way, integrated into my daily living and absolute. Forgetting is no excuse. It's as simple as one missed shot could make the difference between a quiescent malignancy and one that is growing again. This not only keeps me in an intimate, positive relationship to my own health, but it also underlies the responsibility for attending to my own health. I cannot simply hand over that responsibility to anyone else.

Which does not mean I give into the belief, arrogant or naïve, that I know everything I need to know in order to make informed decisions about my body. But attending to my own health, gaining enough information to help me understand and participate in the decisions made about my body by people who know more medicine than do I, are all crucial strategies in my battle for living. They also provide me with important prototypes for doing battle in all other areas of my life.

Battling racism and battling sexism and battling apartheid share the same urgency inside me as battling cancer. None of these struggles are ever easy, and even the smallest victory is never to be taken for granted. Each victory must be applauded, because it is so easy not to battle at all, to just accept and call that acceptance inevitable.

And all power is relative. Recognizing the existence as well as the limitations of my own power, and accepting the responsibility for using it in my own behalf, involve me in direct and daily actions that preclude denial as a possible refuge. Simone de Beauvoir's words echo in my head: 'It is in the recognition of the genuine conditions of our lives that we gain the strength to act and our motivation for change.'

Source: Lorde, Audre. 1999. "A Burst of Light: Living with Cancer." In Price, Janet, and Margaret Shildrick, eds. *Feminism and the Body.* New York: Routledge. (Originally published 1988)

▣ Michelle Cliff, "If I Could Write This in Fire, I Would Write This in Fire" (1988)

In this passage, the Jamaican American writer Michelle Cliff describes how race and disability conjoin in the minds of English and American missionaries during a girl's experience of a grand mal seizure.

Some of the girls were out-and-out-white (English and American), the rest us were colored—only a few were dark. Our uniforms were blood-red Gabardine, heavy and hot in buildings meant to re-create England; damp with stone floors, facing onto a cloister, or quad as they called it. We began each day with the headmistress leading us in English hymns. The entire school stood for an hour in the zinc-roofed Gymnasium.

Occasionally a girl fainted, or threw up. Once, a girl had a grand mal seizure. To any such disturbance the response was always "keep singing." While she flailed on the stone floor, I wondered what the mistress would do. We sang "Faith of our Fathers," and watched our classmate as her eyes rolled back in her head. I thought of people swallowing their tongues. This student was dark—here on a scholarship—and the only woman who came forward to help her was the gamesmistress, the only dark teacher. She kneeled beside the girl and slid the white webbed belt from her tennis shorts, clamping it between the girl's teeth. When the seizure was over, she carried the girl to a tumbling mat in a corner of the gym and covered her so she wouldn't get chilled.

Were the other women unable to touch the girl because of her darkness? I think that now. Her darkness and her scholarship. She lived on Windward Road with her grandmother; her mother was a maid. But darkness is usually enough for women like those to hold back. Then, we usually excused that kind of behavior by saying they were "ladies" (we were constantly being told that we should be ladies also. One teacher went so far as to tell us many people thought Jamaicans lived in trees and we had to show these people they were mistaken). In short, we felt insufficient to judge the behavior of these women. The English ones (who had the corner on power in the school) had come all this way to teach us. Shouldn't we treat them as missionaries they were certain they were?

The Creole Jamaicans had a different role; they were passing on those of us who were light-skinned the Creole heritage of collaboration, assimilation, loyalty to our betters. We were expected to be willing subjects in this outpost of civilization.

The girl left school that day and never returned.

Source: Cliff, Michelle. 1988. "If I Could Write This in Fire, I Would Write This in Fire." Pp. 66–67 in Simonson, Richard, and Scott Walker, eds. *Multicultural Literacy.* St. Paul, MN: Greywolf.

▣ Katherine Dunn, from *Geek Love* (1989)

In these excerpts from Dunn's fantasy novel, the bald, albino, hunchbacked, female narrator, Olympia, describes her status in a disabled family that purposefully breeds "human oddities" for their freak show exhibition. The second passage details the loss of anonymity often experienced by disabled people in public settings.

I was born three years after my sisters. My father spared no expense in these experiments. My mother had been liberally dosed with cocaine, amphetamines, and arsenic during her ovulation and throughout her pregnancy with me. It was a disappointment when I emerged with such commonplace deformities. My albinism is the regular pink-eyed variety and my hump, though pronounced, is not remarkable in size or shape as humps go. My situation was far too humdrum to be marketable on the same scale as my brother's and sisters.' Still, my parents noted that I had a strong voice and decided I might be an appropriate shill and talker for the business. A bald albino hunchback seemed the right enticement toward the esoteric talents of the rest of the family. The dwarfism, which was very apparent by my third birthday, came as a pleasant surprise to the patient pair and increased my value. From the beginning I slept in the built-in cupboard beneath the sink in the family living van, and had a collection of exotic sunglasses to shield my sensitive eyes. (P. 8)

She talks. People talk easily to me. They think a bald albino hunchback dwarf can't hide anything. My worst is all out in the open. It makes it necessary for people to tell you about themselves. They begin out of simple courtesy. Just being visible is my biggest confession, so they try to set me at ease by revealing our equality, by dragging out their own less-apparent deformities. That's how it starts. But I am like a stranger on the bus and they get hooked on having a listener. They go too far because I am one listener who is in no position to judge or find fault. They stretch out their dampest secrets because a creature like me has no virtues or morals. If I am “good” (and they assume that I am), it’s obviously for lack of opportunity to be otherwise. And I listen. I listen eagerly, warmly, because I care. They tell me everything eventually. (P. 156)

My tall stool was cutting off blood to my legs and I squirmed and craned my neck. Arty was turned away from me, watching McGurk, who slumped down and sat on the bed. “I’ll show you the lubrication and drainage system, but . . .” He hiked at his trousers until both knees were bare, white and hairless. The shoes came up his shins and turned into grey socks. “But I guess you want my credentials,” McGurk said. He reached up his right pant leg. There was a snap and the shoe toppled over with the plastic shin and knee sticking out of it. A dim gleam came from the dark fold of the empty trouser leg. He slid his hand up the other trouser leg and both legs lay on the floor with steel shining out of the hollow tops of the knees. He pulled his pant legs up his thighs and showed the steel caps on the stumps. There were a groove, a few grip protrusions, and a number of electrical contact points protruding from each unit. He looked up, calmly waiting. (P. 169)

Source: Dunn, Katherine. 1989. *Geek Love.* New York: Knopf. Copyright © 1989 by Katherine Dunn. Used by permission of Alfred A. Knopf, a division of Random House, Inc.

In My Left Foot, *Daniel Day-Lewis re-creates the Irish painter/writer Christy Brown with extraordinarily matter-of-fact detail and precision. Brown emerges not just as a victim of cerebral palsy but as a complex and often vexing character.*

Source: *My Left Foot* (1989), directed by Jim Sheridan. United Kingdom. Color, 103 minutes. Reprinted by permission of Paul Darke.

From the Americans with Disabilities Act of 1990 (United States)

Building on the landmark protections established in Section 504 of the Rehabilitation Act (see entry above), the Americans with Disabilities Act codified the definition of disability beneath three sweeping categories: (a) incapacity in at least one major life function, (b) an established history of such an impairment, or (c) a belief that one has such an impairment. While the first two designations continued a long tradition of medical pathology as a key qualifying category, the third definition established the social basis of disability. The Act further established disability as involving a class of individuals protected under the law against discrimination in employment, education, public access, and so forth. Most legal analysts are in agreement that, since its passage, its protections have been significantly eroded by conservative U.S. judiciary forces that have ruled in favor of businesses and other public institutions seeking to protect their monetary interests.

Sec. 2. Findings and Purposes

(a) Findings.—The Congress finds that—

(1) some 43,000,000 Americans have one or more physical or mental disabilities, and this number is increasing as the population as a whole is growing older;

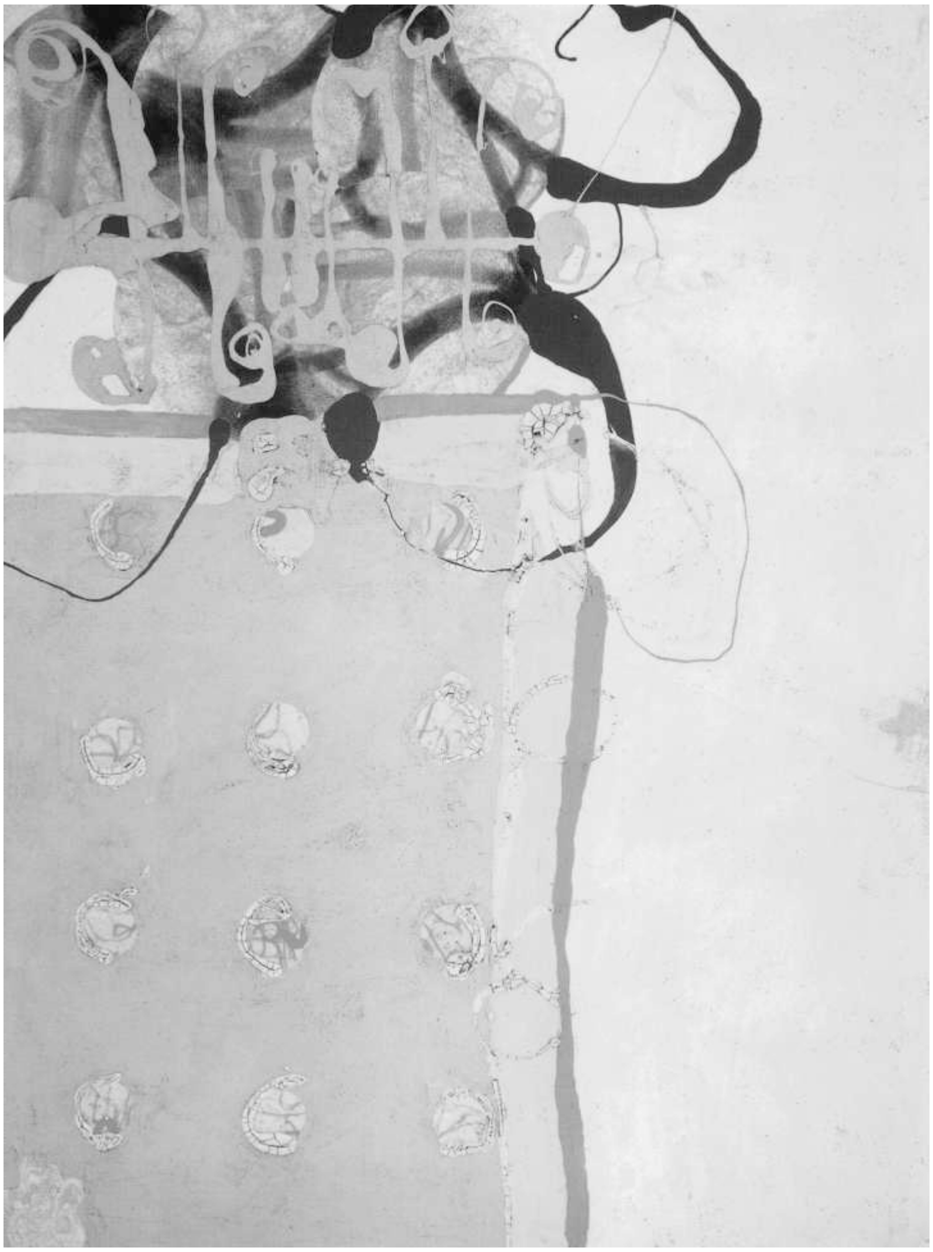
(2) historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against

individuals with disabilities continue to be a serious and pervasive social problem;

(3) discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;

(4) unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced discrimination on the basis of disability have often had no legal recourse to redress such discrimination;

(5) individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities;



"Fidelity," by Katherine Sherwood. 2000. Mixed media on paper. An artist with a visual impairment, Sherwood works with abstract imagery that comments on ways of seeing and perceiving the world.

(6) census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally;

(7) individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society;

(8) the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and

(9) the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity.

(b) Purpose.—It is the purpose of this Act—

(1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities;

(2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities;

(3) to ensure that the Federal Government plays a central role in enforcing the standards established in this Act on behalf of individuals with disabilities; and

(4) to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.

Sec. 3. Definitions

As used in this Act:

(1) Auxiliary aids and services.—The term “auxiliary aids and services” includes—

(A) qualified interpreters or other effective methods of making aurally delivered materials available to individuals with hearing impairments;

(B) qualified readers, taped texts, or other effective methods of making visually delivered materials available to individuals with visual impairments;

(C) acquisition or modification of equipment or devices; and

(D) other similar services and actions.

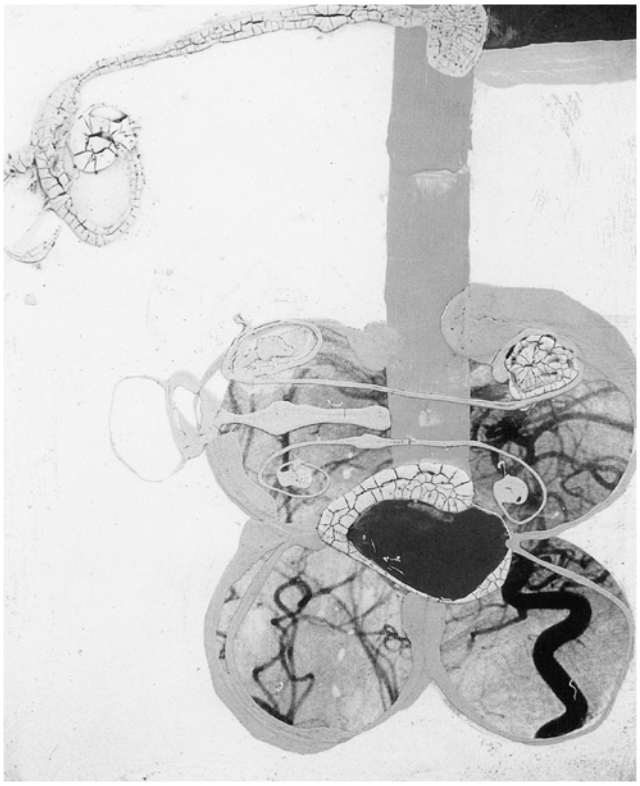
(2) Disability.—The term “disability” means, with respect to an individual—

(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;

(B) a record of such an impairment; or

(C) being regarded as having such an impairment.

(3) State.—The term “State” means each of the several States, the District of Columbia, the Commonwealth of Puerto Rico, Guam, American Samoa, the Virgin Islands, the Trust Territory of the Pacific Islands, and the Commonwealth of the Northern Mariana Islands.



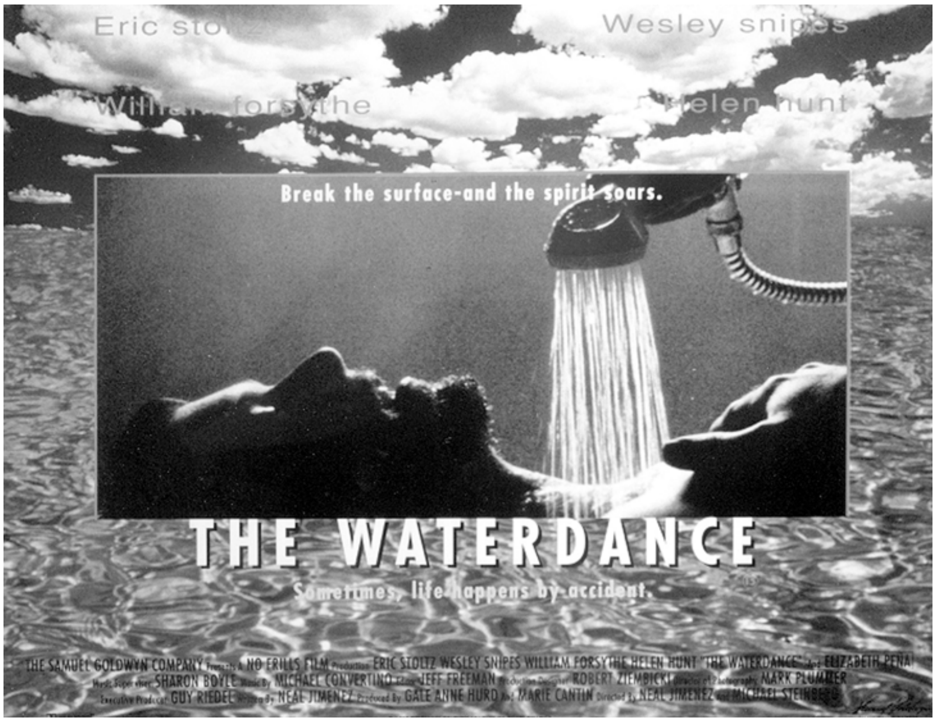
“Fidelity II,” by Katherine Sherwood. 2000. Mixed media on canvas. An artist with a visual impairment, Sherwood works with abstract imagery that comments on ways of seeing and perceiving the world.

▣ Law on the Protection of Disabled Persons of 1990 (China)

The Law of the People’s Republic of China on the Protection of Disabled Persons was passed at the 17th Meeting of the Standing Committee of the Seventh National People’s Congress on December 28, 1990, and was implemented on May 15, 1991. This is a significant and landmark legal document, because it is the first disability law to safeguard the legal rights and interests of disabled people since the founding of the People’s Republic of China. Although many terms in the law are too general to implement in practice, it does mark the beginning of a recognition of basic human rights of this much-neglected group of people in China.

Article 1 [Purpose and Basis]

This Law is formulated in accordance with the Constitution for the purpose of protecting the lawful rights and interests of, and developing undertakings for disabled persons, and ensuring their equal and full



The Waterdance *is an important film about author Joel Garcia's efforts to adjust to his paralysis after a hiking accident. The story delves into the hassles and humiliations of life in a rehabilitation center, including the tensions that erupt between disabled residents.*

Source: *The Waterdance* (1992), directed by Neil Jimenez and Michael Steinberg. United States. Color, 106 minutes. Reprinted by permission of Paul Darke.

participation in social life and their share of the material and cultural wealth of society.

Article 2 [Definition,Categories and Criteria]

A disabled person refers to one who suffers from abnormalities or loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and has lost wholly or in part the ability to perform an activity in the way considered normal.

The term "disabled persons" refers to those with visual, hearing, speech or physical disabilities, mental retardation, mental disorder, multiple disabilities and/or other disabilities.

The criteria for classification of disabilities shall be established by the State Council.

Article 3 [Protection of Rights]

Disabled persons shall enjoy equal rights with other citizens in political, economic, cultural and social fields, in family life and other aspects. The citizen's rights and personal dignity of disabled persons shall be protected by law.

Discrimination against, insult of and infringement upon disabled persons shall be prohibited.

Article 4 [Special Assistance]

The state shall provide disabled persons with special assistance by adopting supplementary methods and supportive measures with a view to alleviating or eliminating the effects of their disabilities and external barriers and ensuring the realization of their rights.

Article 5 [Special Assurance]

The state and society shall provide special assurance, preferential treatment and pension for wounded or disabled servicemen and persons disabled while on duty or for protecting the interests of the state and people.

Article 6 [Responsibilities of Government]

The people's governments at all levels shall incorporate undertakings for disabled persons into plans for economic and social development through budget arrangement, overall planning and coordination and other measures under strengthened leadership with a view to ensuring that undertakings for disabled persons develop in coordination with economic and social progress.

The State Council and the people's governments of provinces, autonomous regions and municipalities directly under the Central Government shall adopt organizational measures to coordinate departments concerned in the work for people with disabilities. The establishment of specific institutions shall be decided upon by the State Council and/or the people's governments of provinces, autonomous regions and municipalities directly under the Central Government.

Departments concerned under the people's governments at various levels shall keep in close contact with disabled persons, solicit their opinions and fulfill respectively their own duties in the work for disabled persons.

Article 7 [Responsibilities of the Society]

The whole society should display socialist humanitarianism, understand, respect, care for and assist people with disabilities and support the work for disabled persons.

State organs, non-governmental organizations, enterprises, institutions and urban and rural organizations at grassroots level should do their work for disabled persons well, as is within their responsibility.

State functionaries and other personnel engaged in the work for disabled persons should work hard to fulfill their lofty duties in serving disabled people.

In Afraid of the Dark, *an 11-year-old boy with a blind mother worries about the identity of the psychopath who is attacking blind women and begins to suspect those around him.*

Source: *Afraid of the Dark* (1992), directed by Mark Peploe. United Kingdom/France. Color, 91 minutes. Reprinted by permission of Paul Darke.

Article 8 [Responsibilities of Disabled Persons' Federation]

China Disabled Persons' Federation (CDPF) and its local branches shall represent the common interests of disabled persons, protect their lawful rights and interests, unite, educate disabled persons, and provide service for disabled persons.

CDPF shall undertake tasks entrusted by the government, conduct work for disabled persons and mobilize social forces in developing undertakings for disabled persons.

Article 9 [Responsibilities of Fosterer, Guardian and Family Member]

Legal fosterers of disabled persons must fulfill their duties towards their charges.

Guardians of disabled persons must fulfill their duties of guardianship and protect the lawful rights and interests of their charges.

Family members and guardians of disabled persons should encourage and assist disabled persons to enhance their capability of self-reliance.

Maltreatment and abandoning of disabled persons shall be prohibited.

Article 10 [Obligations of Disabled Persons]

Disabled persons must abide by laws, carry out their due obligations, observe public order and respect social morality.

Disabled persons should display an optimistic, and enterprising spirit, have a sense of self-respect, self-confidence, self-strength and self-reliance, and make contributions to the socialist construction.

Article 11 [Prevention of Disabilities]

The state shall undertake, in a planned way, the work of disability prevention, strengthen leadership in this regard, publicize and popularize knowledge of good pre-natal and post-natal care as well as disability prevention, formulate laws and regulations dealing with disability causing factors such heredity, diseases, medical poisoning, accidents, calamity and environmental pollution and adopt measures to prevent the occurrence and aggravation of disabilities by organizing and mobilizing social forces.

Article 12 [Award]

Governments and departments concerned shall award those disabled persons who have made notable achievements in socialist construction and those units or individuals who have made remarkable contributions to safeguarding the lawful rights and interests of disabled people, promoting undertakings and providing service for disabled persons.

Source: Law of the People's Republic of China on the Protection of Disabled Persons. 1990. Available at: http://www.apcdproject.org/trainings/web-based/pant_homepages/jiang/laws.html

Walt Stromer on the Functional Brutality of Military Medicine (1990)

Dealing with large numbers of often desperately injured or chronically ill men and believing in the program of aggressive normalization, military doctors were known to spare few feelings in informing men that their disabilities were permanent and that they needed to begin to adjust to them immediately, without self-pity or self-deception. While this often caused great resentment, it also served for many as a stimulus to make the necessary adjustments to new circumstances. Walt Stromer, long a member of the Blinded Veterans Association, went on to become a Professor of Speech at Cornell College in Iowa, where he was on the faculty for 32 years before retiring.

The View From Here

Editor's Note: Walt Stromer, guest columnist for this issue, lives in Mt. Vernon, Iowa. He is retired from Cornell College, where he taught speech for 32 years. Now he reaches adult education classes in other subjects he likes, and goes to the library a lot.

A Letter Too Late

By Walt Stromer

It was March 1945, and we were headed home on the Queen Mary. We sailed at 23 knots, zigzagging for fear of torpedoes. There were more than three thousand survivors aboard, wounded and disabled of the great crusade. Going home to cold drinks, hot dogs and assorted miracles.

A month later at Dibble General Hospital in California, no one had talked to me about miracles, so I made an appointment to see Lt. Fritchie, the ward officer. At ten the next morning, I knocked on his door. He opened it saying, "There's a chair straight ahead of you—sit down." He rustled through papers for a few seconds. Then he said, "I've looked through your files. I guess you know your case is hopeless. You'll never see again. Any questions?" After a few seconds, I said, "No." He said, "All right," and opened the door.

I walked out and closed the door. I didn't slam it. Lying back in my bunk, I don't remember all the thoughts, but suicide did come to mind. In about fifteen minutes, someone yelled, "Chow," which changed my thinking for the moment.

Before that morning I had just disliked Lt. Fritchie. After that I hated him. But a strange thing happened. I began to think about it from his position. He had to give that same terrible news to several hundred young men . . . news that could tear a man apart. Also some of us needed to be told to stop wishing and dreaming and to get on with living and the business of rehabilitation.

Five years later, I wrote to the Lieutenant to tell him I understood why he had been so brusque. His wife wrote back to say he had died two years earlier of cancer.

Sorry, sir.

Source: Stromer, Walt. 1990. "A Letter Too Late." *The BVA Bulletin* 45(July–August):8. Printed with permission of the Blinded Veterans Association.

World Federation of Psychiatric Users, Minutes of the First Committee Meeting (1991)

The first organizational committee meeting for the World Federation of Psychiatric Users was held in Mexico City on August 23, 1991. Representatives included those from the United States, Mexico, Japan, Netherlands, and New Zealand.

Mexico City, 23 August 1991

Present: Jan Dirk van Abshoven (Netherlands), Paolo del Vecchio (USA), Bob Long (USA)—replacing Esperanza Isaac, Mary O'Hagan (New Zealand), Pauline Hinds (New Zealand), Natosughi (Japan), Masaji Koganezawa (Japan) Adriana Lopez (Mexico)

Agenda

1. Meeting rules
2. Name for organisation
3. Priority tasks
4. Who will do what and when

1. Meeting Style and Voting Rules

Mary began by stating the need for cooperation. She said the meeting would run by consensus but there will be a vote for some agenda items. There will be no formal 'rules of order.' Each country represented will have one vote.

2. Name

There was some discussion about what term to call ourselves by. Survivor, client, inmate, psychiatrically labelled, purchaser and ex-patient were rejected. Opinion was divided between "user" and "consumer." The USA favoured "consumer." Mexico, New Zealand, Japan and the Netherlands favoured "user."

The following suggestions for the name of the organisation were put to the vote.

World Federation of Mental Health Users	Holland
World Federation of Psychiatric Users	Mexico, NZ
International Federation of Psychiatric Survivors	
Worldwide Congress of MH Consumers	
Worldwide Network of Psych Users	Japan
World Union of Mental Health Consumers	USA

The name of the organisation is:
World Federation of Psychiatric Users

3. Prioritising Tasks for the Next Two Years

The following tasks were developed before the meeting. Each country voted on what they thought should be the top three priorities for the next two years.

1. Network and inform users and user groups of the WFPU and increase membership. Produce and distribute a newsletter.

2. Hold international teleconferences

3. Produce and distribute discussion papers to users, professionals etc on the following issues:

- ECT
- Neuroleptics
- third world issues
- self-help / self-advocacy
- psychiatric labelling
- international bill of rights

4. Unified and coordinated response to any major rights violations that occur

5. Administrative tasks:

- fundraising
- yearly lists and censuses
- information storage
- coordination of tasks
- development of rules
- correspondence
- logo / letterhead
- committee meetings
- pamphlets

6. Continue user contact with WFMH and encourage users to go to Tokyo and to organise a user only conference before or after the World Congress for Mental Health, in Tokyo in 1993.

All countries voted for 1, 5 and 6 as priorities for the next two years.

- Newsletter / Networking / Membership
- Administrative tasks
- Contact with WFMH / Users to Tokyo

The non-priority tasks could still be done if there was time and energy for it.

4. Details on Priority Tasks

Many of the details decided on about the priority tasks are in the WFPU Plan (enclosed) which allocates who will do what and by when. Discussion not included in the Plan follows.

Newsletter

The newsletter will be free. It will be published every 6 months.

Membership

Membership shall be US $5.00 but users will have the option of paying no fee if they cannot afford it.

Administration

New Zealand will provide the office and administrative tasks for WFPU for the next two years.

Funding

There was a wide ranging discussion on ways to get funding. People felt it would be unethical to get sponsorship from drug companies. Funding will be needed for a pamphlet on WFPU. The Japanese could be approached for funding for user travel/conference to Tokyo. Fifty percent of funding should go to groups in originating country once WFPU is well-established.
MEETING ENDS

Source: World Federation of Psychiatric Users. 1991. *First Committee Meeting.* Available at: http://www.wnusp.org/wnusp%20evas/Dokumenter/mexico1991.html. Reprinted bypermission.

▣ Robert Brown and Hope Schutte, from *Our Fight: A Battle against Darkness* (1991)

A wealthy nation, fortunate to have never suffered the humiliation of total defeat, surrender, and occupation, the United States nonetheless has seen many of the same general problems in administering benefits and programs of assistance for disabled veterans that we see in defeated nations, such as Germany after the world wars. The history of American disabled veterans' organizations, especially at the level of the national office, has often been a struggle against bureaucratic lethargy, incompetence, and insensitivity. As this selection makes clear, the Blinded Veterans Association, which was founded by 100 blinded veterans of World War II then undertaking mobility and orientation training at an Army facility in Connecticut, has a long history of representing a wide variety of visually impaired veterans in their struggles with the bureaucracies in charge of overseeing programs relevant to its members' interests.

There is a special room on the first floor of the Blinded Veterans Association national headquarters building in Washington, D.C. It's where we keep our files, the records of all the men and women who, over nearly the past 46 years, have come to us for help.

Well, it isn't really a room—just an area walled off by an arrangement of room dividers, room dividers obscured by long rows of gray, brown, and green filing cabinets. Many of the cabinets are quite old and beat up. Yet they contain the names and experiences of men and women, thousands of blinded veterans who have been a part of BVA.

They tell stories, true stories, of the individual struggles of veterans blinded in combat, or though accident or disease, to regain their dignity and independence—stories of sacrifice and courage, of suffering and damaged lives and disappointment. Theirs is an accounting, a history of the desperation, and the hopes and dreams of thousands of American veterans who lost their sight.

And the file cabinets contain the story of the early days of the Blinded Veterans Association, the joyous successes and disappointing failures, the work accomplished and the work left undone by our early founders—a group of dedicated, determined young blinded veterans pulling together to do all they could to help their comrades so that they, too, might reclaim the basic rights of any human—dignity and independence.

One evening after all the other office staff had left for home, and feeling somewhat tired after a day of "working the phones," I stopped by the file room. I had some time to spend until I could get a ride home so I started opening some of the older cabinets and thumbing through the files I found there.

The file folders themselves are all different sizes and colors. Some, dating back to BVA's beginnings in the mid-1940s, are yellowed with age and have that dusty, old paper odor. Yet whether from World War II or the present time, each folder contains the personal history of a blinded veteran who has asked BVA for help.

Most of them contain letters, frequently laboriously hand written by the blinded servicemen themselves. These are quite difficult to read. Others are typewritten and frequently full of typing errors made by veterans struggling to communicate the best they could.

Usually, there are also military service records, medical records, and letters from doctors chronicling what had happened to the veteran, i.e., explaining the source of his blindness and other injuries, if he has them. There are copies of applications to the Veterans Administration for whatever benefits were needed and available copies of completed forms for compensation of injuries, educational and vocational training programs, and prosthetic equipment; and copies of job applications and resumes. The records of the men and women in the files come from every branch of service. Folder after folder, the lives of the blinded veterans who have come to BVA for help.

I continued pulling files and reviewing the old records, although with some hesitation, with a feeling that I was unearthing old troubles and sufferings long laid to rest and, probably, best left as they were. With a sense that there might be more in the old folders than I wanted to know about right then, because I had worked on veterans cases all that day and some of the blinded veterans who come to BVA asking for help have problems so daunting, so intractable that each and every one of us here has questioned our own ability and competence. We frequently wonder and worry: Did we do enough? Could we have done more? Perhaps done a better job? Did we try hard enough?

But my curiosity overcame my hesitation and I continued looking back in the early days, in 1946 and 1947, just after World War II had ended and just after BVA was organized, our headquarters office was located in New York City. We didn't have much to offer then—no Field Service Program, no Service Officers, no board of Veterans Appeals Claims Representative. Not much but togetherness.

Still, it was obvious that the early BVA staff did an excellent job. And the value of blinded veterans helping other blinded veterans was also apparent because our early workers took a realistic, down-to-earth approach, accepting the fact of their blindness and building upon what was left. They were good advice to their fellow blinded veterans; and they were tough, pushing and prodding much needed changes through the frequently unyielding Veterans Administration bureaucracy.

In many ways, these files are almost a chronology of America's wars in the Twentieth Century: World War II; Korea; Vietnam; and even the "cold war" in Europe, the Mid-East and the Pacific. There are even folders on blinded veterans from World War I, the folders of blinded servicemen who came to BVA for help after we were formed.

The files showed me that the injuries of the men blinded in Korea were much the same as those of the men blinded in World War II: bullet wounds to the head, grenade fragments in the eyes, artillery bursts, land mines, burns, airplane crashes. All the horrible aspects of war.

A large number of files show an initial date of contact with the BVA as the late 1960s and early 1970s. The awful consequences of the Vietnam War: men and women, most in their forties now, many of whom are still struggling to build a life for themselves. Soldiers, marines and airmen whose eyes were blasted or burned away by rocket propelled grenades, or "RPGs" as the men called them; or by AK-47s; or in the fires of downed airplanes or helicopters. And land mines, land mines, land mines—dirt and stones and metal fragments blasted into faces and eyes. Records on men and women blinded in exploding ammunition dumps; blinded in vehicle crashes; blinded by artillery malfunctions. And although we haven't reached as many of these veterans as we'd like to, or been able to do all that we know needs doing, we at BVA are still trying to help them as much as we possibly can.

Then, there are folders with more recent dates, too, because each year a substantial number of servicemen go blind whether or not there is a war in progress: servicemen who are blinded in accidents or by disease while on active duty; those who go blind after leaving service; or servicemen manifesting age-related diseases which cause blindness. In fact, many of the files dated 1980 and up belong to veterans of World War II, Korea, and the long years of the cold war and show a real change in the origins of blindness—Diabetes, Glaucoma, Macular Degeneration, Retinitis Pigmentosa, Multiple Sclerosis, Optic Atrophy—diseases with strange names that usually do not strike until later in life, yet with devastating impact. They all destroy precious sight.

To me, on that late night, I realized that the files at BVA speak not only of war, of suffering, but of bravery and courage and sacrifice, of the meaning of service and the price of freedom. And I believe they also speak of fellowship. Because we at BVA are all blinded veterans—whether we served during war or peacetime; were blinded in combat or in an accident; lost our sight to disease while in service or many years later. And we are all bound together by our love of country and our desire for a peaceful world. We do our best to serve and help one another without regard to race, creed, sex, religion or political affiliation.

To receive our assistance, you need only be a veteran and be "legally blind." Currently, the standard definition of legal blindness is: "best corrected vision in the better eye of no more than 20/200 or a visual field of no more than 20 percent in the better eye."

Since World War II, America's blinded veterans have encountered many frustrations in their dealings with the Veterans Administration. Continual turnover in Veterans Administration Regional Office . . . staff; lack of training about the special needs of blinded veterans; indifference caused by heavy workloads; difficulties with communicating and implementing updated benefit rulings; and a pervasive ignorance about the causes of blindness and its actual—as opposed to imagined—limitations have all resulted in inequities in the VA's treatment of blinded soldiers. Unfortunately, many of these inequities are still prevalent today. For example, up until 1972 blinded veterans who had suffered anatomical loss of both eyes usually received much larger VA disability compensation awards than those veterans who were equally sightless but whose eyes had not been enucleated.

And because one of the most serious problems facing nearly all blinded veterans is not having enough money to meet even the most basic of their living expenses, the matter of compensation or pensions has become an overriding issue.

It is, in fact, along with our personal advocacy of blind rehabilitation for nearly all blinded veterans, the most prevalent issue involved with the blinded veterans we try to help and, therefore, occupies a great deal of our time.

The issue is a complex one. Originally disability compensation was awarded for injuries sustained during battle. It was conceived as unrelated to economic need: the Military Service or the Veterans Administration was simply "compensating" the veteran for his blindness or other injuries incurred in combat as a means for insuring that his future standard of living would not be affected by his diminished earning capacity. The amount, or rate, of service-connected compensation was to be proportionately related to the severity of his disability or loss. Basically, this is the system still in effect today.

Therefore, in most cases, veterans blinded while on active duty through either disease or injury, and through no fault of their own, are subsequently compensated for their loss. Additionally, veterans whose "aggravation" of blindness can be proven—that is, if a veteran has a certain disease affecting vision, for example Multiple Sclerosis, which manifests itself following active duty and, if the disease follows an abnormally rapid progression which can be presumed to be a consequence of the stresses of military service—may also be certified as service connected, and thus become eligible to receive all corresponding service-connected compensation. Today, these benefits now also include medical care, educational and vocational training benefits, housing grants, automobile grants and dependent benefits.

Pension, on the other hand, was established as recompense or recognition for services rendered to the nation. It was a means of assisting veterans in living out their days with the dignity that comes from having one's basic needs met and was, therefore, intended for any veteran in temporary or permanent need of financial assistance due to non-service-connected illness or disability, or old age. Current criteria for being awarded a VA pension generally include: total disability; service during a wartime period; and low-income status. Today's VA pensions also entitle the veteran to medical care and several other benefits as well.

Determining amounts for either compensation or pension awards is a complex process based upon an elaborate and highly detailed rating system. Compensation and pension amounts are also frequently revised upward to reflect increases in cost of living.

When a veteran contacts BVA, we immediately try to determine whether or not the veteran may be eligible for either service-connected or non-service-connected benefits. If so, we assist him or her in preparing claims applications and monitor the application as it works its way through the VA process, solving whatever problems arise and helping track down whatever additional information is needed to insure that the compensation or pension award received is an equitable one.

Our experiences over the years have taught us the sad truth that fairness and equity on the part of the VA, as well as other service agencies, simply cannot be assumed. For some reason, VA rating officials sometimes seem to take an almost whimsical approach to blinded veterans, denying their legitimate compensation claims and insisting on injury ratings far below those allowed by regulation. Part of the problem seems to lie in the misreading of medical evaluations; and part of it from medical evaluations that were performed poorly to begin with, resulting in inadequate measures and descriptions of the nature and extent of veterans' blindness. Strange as it may sound, despite the high level of technology that exists in medical science today, many doctors remain incredulously ignorant of blindness—of its sources and of its attendant problems.

Consequently, much of our work on behalf of blinded veterans becomes very technical. In response, we have established, and maintain, a high level of technical expertise that enables us to challenge the bureaucracy when such mistakes are made.

Naturally, wherever and whenever possible we try to get the blinded veteran "service connected." As need dictates, we search for old records and documents from military service years that may show a service-related cause for the blindness. We review old claims and claim denials to see if errors have been made. And when we feel that a veteran's claim has been unfairly turned down at the VA Regional Office level, we represent the veteran's case at the next level of appeal, the Board of Veterans Appeals.

Indeed, many, if not most, of the benefits blinded veterans receive today stem from BVA's efforts over the years, and the work continues. Through often bitter experience we have learned that the VA, like many other federal agencies, simply cannot be trusted to look after us. The present system of blind rehabilitation centers and clinics and of Visual Impairment Service Teams . . . and many other services now available to all veterans will persist only as long as BVA and its sister veterans organizations remain vigilant.

We at BVA are here to help all blinded veterans, both individually and collectively. We, sometimes alone, sometimes in conjunction with our sister veterans service organizations, present legislative initiatives and frequently attend hearings on veteran's legislation. Our officers, directors, national office and field staff all represent blinded veterans before departments and agencies at the state, regional, and national levels, including the U.S. Congress, the Department of Veterans Affairs, the President's Committee on Employment of People with Disabilities, the Small Business Administration, the U.S. Office of Personnel Management, the U.S. Department of Labor, the Department of Health and Human Services and the Department of Education—as we have since our formation in 1945.

We also testify on behalf of blinded veterans at hearings of the House and Senate Committees on Veterans Affairs, on problems related to blind rehabilitation, veterans' access to health care, improved prosthetic services, and on the budget for the Department of Veterans Affairs.

Over the years BVA has taken on a lot. But we know that many pressing needs of blinded veterans remain unmet. And it is our sincere hope that one day, funds and continuing strong leadership providing, we will be given the opportunity to grapple with these issues, too, in order to more completely fulfill our mission to provide mutual support and assistance to all blinded veterans.

Source: Brown, Robert, and Hope Schutte. 1991. Pp. 26–33 in *Our Fight: A Battle against Darkness.* Washington, DC: Blinded Veterans Association. Printed with permission of the Blinded Veterans Association.

▣ From *Dendron News* (1992)

This excerpt, which appeared on the back page of Dendron News, *provides a brief explanation of the name chosen for one of the first "Psychiatric Survivors & Allies Independent Media."*

What is "Dendron" anyway?

Your brain has billions of cells called *neurons.* Information flows between neurons through the branches of DENDRITES, which comes from the Greek word for *tree,* DENDRON. This paper is printed on recycled paper from dendrons (post-consumer). Brains look like ancient, wild forests. Psychiatry is like modern forestry—clearcutting brains to prop up the current failing, dominating system. So connect your liberating thoughts with others globally through DENDRON.

Source: *Dendron News* (27–29). 1992, May 1. Eugene, OR: Clearinghouse on Human Rights & Psychiatry. Reprinted with permission of Mindfreedom International (www.mindfreedom.org), formerly known as *Dendron News.*

▣ Disability Discrimination Act of 1992 (Australia)

The Australian Disability Discrimination Act (DDA) 1992 was enacted at a time in Australia's history when there was a concerted effort to address the social exclusion of disability people. The Australian Disability Discrimination Act 1992 reflected many of the principles enshrined in the Americans with Disabilities Act 1990 and included coverage for work, education, accommodation, sport and recreation.

While the initial proposal for the enactment of the legislation appeared as an unprecedented move by government to redress discrimination on the grounds of disability, increasingly, the limitations of the DDA are being revealed. The national legislative framework pursued a policy of restrained social recognition of equality before the law. Reforming social institutions for the collective good of disabled people has been constrained by the legislation's "complaints framework," as the onus of reporting experiences of discrimination is placed on disabled individuals. Further, organizations and social institutions can be absolved of legal accountability and *compliance with the DDA if they can prove "unjustifiable hardship" on economic grounds. Other constraining factors consist of the Australian Government's National Competition Policy. In Australia, national legislation is reviewed to ensure that it does not impede the competitive capacity of the economy, in line with competitive market ideology. During 2003 and 2004, the DDA underwent extensive review with national public consultations. There was overwhelming public support to strengthen the DDA, particularly in the area of employment. However, many of the recommendations and the current government's commitment to National Competition Policy do not appear to redress discrimination on the grounds of disability.*

Section I—This Act may be cited as the Disability Discrimination Act 1992

Objects

The objects of this Act are:

(a) to eliminate, as far as possible, discrimination against persons on the ground of disability in the areas of

- (i) work, accommodation, education, access to premises, clubs and sport; and
- (ii) the provision of goods, facilities, services and land; and
- (iii) existing laws; and
- (iv) the administration of Commonwealth laws and programs; and

(b) to ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community; and

(c) to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community.

Disability discrimination

(1) For the purposes of this Act, a person (*discriminator*) discriminates against another person (*aggrieved person*) on the ground of a disability of the aggrieved person if, because of the aggrieved person's disability, the discriminator treats or proposes to treat the aggrieved person less favourably than, in circumstances that are the same or are not materially different, the discriminator treats or would treat a person without the disability.

(2) For the purposes of subsection (1), circumstances in which a person treats or would treat another person with a disability are not materially different because of the fact that different accommodation or services may be required by the person with a disability.

Indirect disability discrimination

For the purposes of this Act, a person (*discriminator*) discriminates against another person (*aggrieved person*) on the ground of a disability of the aggrieved person if the discriminator requires the aggrieved person to comply with a requirement or condition:

(a) with which a substantially higher proportion of persons without the disability comply or are able to comply; and (b) which is not reasonable having regard to the circumstances of the case; and (c) with which the aggrieved person does not or is not able to comply.

Disability discrimination–interpreters, readers and assistants

For the purposes of this Act, a person (*discriminator*) discriminates against another person with a disability (*aggrieved person*) if the discriminator treats the aggrieved person less favourably because of the fact that the aggrieved person is accompanied by:

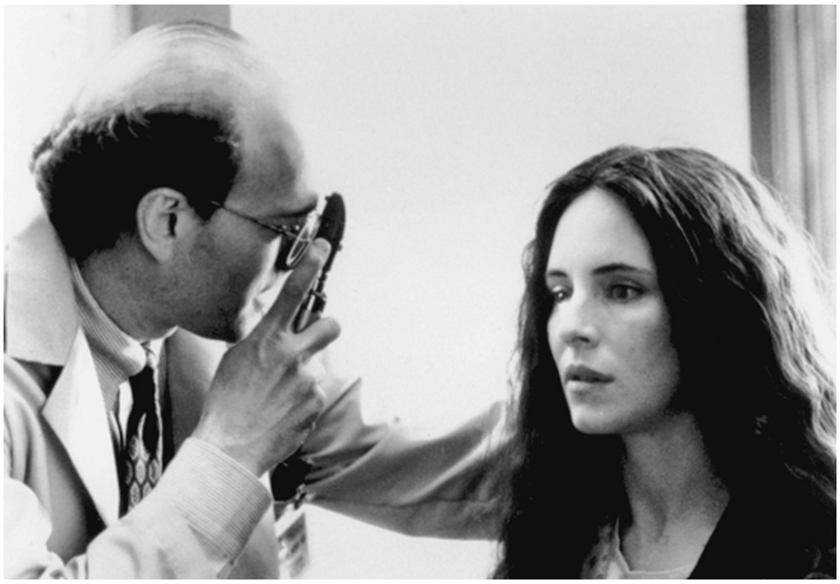
(a) an interpreter; or (b) a reader; or (c) an assistant; or (d) a carer; who provides interpretive, reading or other services to the aggrieved person because of the disability, or because of any matter related to that fact, whether or not it is the discriminator's practice to treat less favourably any person who is accompanied by: (e) an interpreter; or (f) a reader; or (g) an assistant; or (h) a carer.

Disability discrimination–guide dogs, hearing assistance dogs and trained animals

(1) For the purposes of this Act, a person (*discriminator*) discriminates against a person with: (a) a visual disability; or (b) a hearing disability; or (c) any other disability; (*aggrieved person*) if the discriminator treats the aggrieved person less favourably because of the fact that the aggrieved person possesses, or is accompanied by: (d) a guide dog; or (e) a dog trained to ssist the aggrieved person in activities where hearing is required, or because of any matter related to hat fact; or (f) any other animal

trained to assist the aggrieved person to alleviate the effect of the disability, or because of any matter related to that fact; whether or not it is the discriminator's practice to treat less favourably any person who possesses, or is accompanied by, a dog or any other animal.

(2) Subsection (1) does not affect the liability of a person with a disability for damage to property caused by a dog or other animal trained to assist the person to alleviate the effect of the disability or because of any matter related to that fact.



In Blink, *a musician recovers her sight after 20 years and believes that she has witnessed a murder. A detective decides to trust her account and protects her from danger.*

Source: *Blink* (1994), directed by Michael Apted. United States. Color, 102 minutes. Reprinted by permission of Paul Darke.

Act done because of disability and for other reason

If: (a) an act is done for 2 or more reasons; and (b) one of the reasons is the disability of a person (whether or not it is the dominant or a substantial reason for doing the act); then, for the purposes of this Act, the act is taken to be done for that reason.

Unjustifiable hardship

For the purposes of this Act, in determining what constitutes unjustifiable hardship, all relevant circumstances of the particular case are to be taken into account including: (a) the nature of the benefit or detriment likely to accrue or be suffered by any persons concerned; and (b) the effect of the disability of a person concerned; and (c) the financial circumstances and the estimated amount of expenditure required to be made by the person claiming unjustifiable hardship; and (d) in the case of the provision of services, or the making available of facilities—an action plan given to the Commission under section 64.

Discrimination in employment

(1) It is unlawful for an employer or a person acting or purporting to act on behalf of an employer to discriminate against a person on the ground of the other person's disability or a disability of any of that other person's associates: (a) in the arrangements made for the purpose of determining who should be offered employment; or (b) in determining who should be offered employment; or (c) in the terms or conditions on which employment is offered.

(2) It is unlawful for an employer or a person acting or purporting to act on behalf of an employer to discriminate against an employee on the ground of the employee's disability or a disability of any of that employee's associates: (a) in the terms or conditions of employment that the employer affords the employee; or (b) by denying the employee access, or limiting the employee's access, to opportunities for promotion, transfer or training, or to any other benefits associated with employment; or (c) by dismissing the employee; or (d) by subjecting the employee to any other detriment.

(3) Neither paragraph (1)(a) nor (b) renders it unlawful for a person to discriminate against another person, on the ground of the other person's disability, in connection with employment to perform domestic duties on the premises on which the first-mentioned person resides.

(4) Neither paragraph (1)(b) nor (2)(c) renders unlawful discrimination by an employer against a person on the ground of the person's disability, if taking into account the person's past training, qualifications and experience relevant to the particular employment

and, if the person is already employed by the employer, the person's performance as an employee, and all other relevant factors that it is reasonable to take into account, the person because of his or her disability: (a) would be unable to carry out the inherent requirements of the particular employment; or (b) would, in order to carry out those requirements, require services or facilities that are not required by persons without the disability and the provision of which would impose an unjustifiable hardship on the employer.

Accommodation

(1) It is unlawful for a person, whether as principal or agent, to discriminate against another person on the ground of the other person's disability or a disability of any of that other person's associates: (a) by refusing the other person's application for accommodation; or (b) in the terms or conditions on which the accommodation is offered to the other person; or (c) by deferring the other person's application for accommodation or according to the other person a lower order of precedence in any list of applicants for that accommodation.

(2) It is unlawful for a person, whether as principal or agent, to discriminate against another person on the ground of the other person's disability or a disability of any of the other person's associates: (a) by denying the other person access, or limiting the other person's access, to any benefit associated with accommodation occupied by the other person; or (b) by evicting the other person from accommodation occupied by the other person; or (c) by subjecting the other person to any other detriment in relation to accommodation occupied by the other person; or (d) by refusing to permit the other person to make reasonable alterations to accommodation occupied by that person if:

(i) that person has undertaken to restore the accommodation to its condition before alteration on leaving the accommodation; and

(ii) in all the circumstances it is likely that the person will perform the undertaking; and

(iii) in all the circumstances, the action required to restore the accommodation to its condition before alteration is reasonably practicable; and

(iv) the alteration does not involve alteration of the premises of any other occupier; and

(v) the alteration is at that other person's own expense.

(3) This section does not apply to or in respect of:
(a) the provision of accommodation in premises if:

(i) the person who provides or proposes to provide the accommodation or a near relative of that person resides, and intends to continue to reside on those premises; and

(ii) the accommodation provided in those premises is for no more than 3 persons other than a person referred to in subparagraph (a)(i) or near relatives of such a person; or

(b) the accommodation is provided by a charitable or other voluntary body solely for persons who have a particular disability and the person discriminated against does not have that particular disability; or

(c) the provision of accommodation in premises where special services or facilities would be required by the person with a disability and the provision of such special services or facilities would impose unjustifiable hardship on the person providing or proposing to provide the accommodation whether as principal or agent.

National Empowerment Center's Mission Statement (1992)

The National Empowerment Center was founded in 1992 through a grant from the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, to act as a consumer-run National Technical Assistance Center. Located in Lawrence, Massachusetts, it remains a significant component of the psychiatric survivor/user movement. The group's website is at http://www.power2u.org.

Our Mission

The mission of the National Empowerment Center Inc. is to carry a message of recovery, empowerment, hope and healing to people who have been diagnosed with mental illness. We carry that message with authority because we are a consumer/survivor/expatient-run organization and each of us is living a personal journey of recovery and empowerment. We are convinced that recovery and empowerment are not the privilege of a few exceptional leaders, but rather are possible for each person who has been diagnosed with mental illness. Whether on the back ward of a state mental institution or working as an executive in a corporation, we want people who are mental health consumers/survivors/ex-patients to know there is a place to turn to in order to receive the information they might need in order to regain control over their lives and the resources that affect their lives. That place is the National Empowerment Center.

Source: National Empowerment Center. 1992. *Mission Statement.* Available at: http://www.power2u.org/what.html. Reprinted by permission.

▣ Richard Powers, from *Operation Wandering Soul* (1993)

Powers's dystopic novel takes place on a pediatric ward for disabled children in Los Angeles. Rather than passively submitting to their destiny as wards of the state, medical guinea pigs, or sentimentalized charity objects, the children begin to do research in order to re-create a more meaningful history of disability and adult neglect for themselves. Specifically, they spend each evening having their nurse, Linda, read tales about other disabled children from around the world from whom they might better learn to navigate their own stigmatized lives. In this excerpt, they listen to a version of the ancient Japanese myth of Hiruko, the Leech Child, who is abandoned by his parents to die because of his disabilities but ends up sailing around the world in search of comradeship (see an excerpt from the original version of this story in Part One).

(Night 57, Japan)

This is how the world begins. At first, the All was no more than a blurry egg, full of seeds and shaken together. After a time beyond telling, the heavier parts began to sink down and the lighter floated upon them, forming the plain of high heaven. On this plain, three gods were born of no one, lived out an eternity, and then vanished back into nothing.

How you gonna be born of no one? Everybody got . . .

Shh. Come on. It's a makeup; that's how it opens. Next there came about, on their own, a few pairs of gods who lived in the drifting middle of nowhere. The youngest couple among them were called Izanami and Izanagi, or She-the-Inviter and He-the-Inviter. She and He were ordered by their elders to collect a solid world from out of the shapeless, muddy waters that flowed beneath the high plain of heaven. They stood on the bridge of the sky and dipped a jeweled spear into the sandy broth below them, stirring it slowly. They pulled their spear out of the waters. A drop of brine sticking to the shaft fell off to form Onogoro, the first island.

She-the-Inviter and He-the-Inviter climbed down onto the island and began exploring it. They circled slowly around one another at the pillar at the center of the solid world. Slowly, they discovered each other, and learned that they wanted one another.

Uh-oh. They in trouble now. When my daddy found my big brother and me . . .

No, sweetheart; it wasn't like that. Remember, these two gods had no parents. Slowly, by experiment and chance, She-the-Inviter and He-the-Inviter learned how to make a baby. But their first child was born with something wrong with it. Because She did not yet know the rules of courtship she accidentally broke them. So the first infant who laid eyes on the world was born deformed.

Heh. Like me, you mean?

Yes, Chuck, my man. A little like you. She and He named their boy Hiruko, the Leech Child. They didn't know what they were supposed to do with him, so they built him a boat of reeds and set the boy adrift on the open sea. So you see, the very first child *ever* was abandoned. As soon as the Leech Child drifted out of sight, his parents began making other babies, more deities to cover every walk of creation.

Among their new children were the eight main islands of the world. She-the-Inviter was burned to death while giving birth to her last child, Fire. Gods spilled out of her dying body. Other gods arose from the tears of her husband's eyes. In a rage, He-the-Inviter swung his great blade and cut off the head of Fire, his son. From out of the bleeding neck of Fire there sprang Thunder, with several more gods.

The soul of She-the-Inviter went down into Yomi, the land of darkness, where He-the-Inviter madly followed. He wanted to find her and bring her back to life. But his wife had already eaten food cooked in the land of darkness, so she could not come back. The dead She warned her husband not to look upon her. But he disobeyed her command. He looked at her face, and saw something horrible. His wife was rotting. Maggots covered her. Shh! Yes, like the ones in old garbage. He-the-Inviter ran back up into the world in terror. She was hurt and angry, and She sent a pack of Furies to chase after her husband.

When He reached the surface once again, He sealed up the entrance to the land of darkness with an enormous rock. His wife became furious. She threatened to kill a thousand of their children every day that He kept her trapped. But He just sneered at her. He said that he would father fifteen hundred new children for every thousand that She killed. She and He knew they had come to an end.

To purify himself, He bathed in the waters. As He washed, more gods sprang from him. From the water sprinkling from his left eye was born the Sun, and from his right the Moon. Out of his nose there came Susanoo, the God of the Wind and Storm.

Korean Protest of Socially Marginalized Peoples: Intersexed. Lesbian, Disabled, Prostitutes, Seoul, Korea, 2003.

His nose? Gross. But what about the boy in the boat? The Leech?

It doesn't say. He must have floated for a long, long time. Reeds can be very watertight in these stories. But the ocean can be pretty big too. The Leech Child probably drifted in the current for years, farther and farther away, into places where land was completely unheard of.

Maybe the boat was held together by little metal clasps. That's it; I once read something like this. He pulled one of these metal strands loose and fashioned a bit of tinsel from it, which he dangled in the water just to amuse himself, because it looked pretty. And that's how, by accident, he learned that fish will bite at a hook. And he figured out that by eating fish, he could live pretty much as long as he needed.

Yeah? Well, all right. It's possible. Read us another one.

(Night 139, central Italy. Twin infant sons of a vestal virgin and the God of War are sentenced by the king to be drowned in the Tiber. Miraculously, the cask they are put in floats. They are found and suckled by a wolf more loving than human parents. The foundlings grow up to invent the West.)

Go on. We want more.

(Night 21, the Near East. Another terrified tyrant orders all the male offspring of a certain tribe to be drowned to death. The mother makes a little reed ark for the boy, and lays him in the rushes on the riverbank. The tyrant's daughter finds the infant, and hires the boy's own mother to nurse him. The boy grows up to bring God's law to . . .)

Why drowning? Why water all the time? Why little boats?

Yes, that's odd, isn't it? Happens all over the place. Look at this: Night 308, the Mississippi. Night 145, Norway. Night 98, Kashmir. Night 114, Zimbabwe.

(Across the planet, attempted drownings, tiny bound bodies thrown deliberately back into the sea. All through the time line, vanishing into the current, carried along by the undertow. Every other story in any anthology—children sealed up, locked in casks, keelhauled, strapped on rafts, sucked down by the departing tide. A few miraculously saved, for future purposes.)

And some mom and dad always want to kill them.

Yes, true! Notice how the stories always blame some evil step-something, or foster fathers, or kings? Guilty conscience, I'll bet you anything. These cats have something to hide, I'm here to tell you. If they're not putting the kids out to drown in chests, then they're

Enchanted Cottage *is a queasily sentimental tale in which a blind pianist persuades a disfigured war veteran and a homely woman that they are, in fact, beautiful.*

Source: *Enchanted Cottage* (1994), directed by John Cromwell. United States. B&W, 90 minutes. Reprinted by permission of Paul Darke.

leaving them on church steps or by a roadside out of town. Or here, look: dropped off deep in the woods, bricked up into cornerstones, rolled over on in the parents' shared bed . . .

(. . . swaddled too tightly, delivered with a club to the skull or butterfly slit in the trachea, wrung with a bit of old cloth, or, for maximum efficiency—Night 3, Greece—eaten.)

Awesome. Any that stuff really happen?

(Night Before Last, Pacific Islands: two thirds of offspring. West Africa: any twins. Sarawak: boys strung from trees. China: daughters given instant turnaround chance to return as sons. Germany, Italy, France: 1.8 "live birth" males to one female. SE England: "Three drowned in pond, two in well, five buried, two suffocated by pillow, two left in ditch, one thrown on dung heap, one slammed against bedpost, two twisted necks . . . Chicago; Houston; Portland, OR: discreet suburban fatalities, malign neglect, everyday police roundups dribbling out of radio speakers in the dark, on all-night talk stations turned down low, between choruses of that old folk tune, *I am no stranger to your town.*)

Why?

(Tales 101 and 343: postpartum birth control.)

Source: Powers, Richard. 1993. Pp. 80–89 in *Operation Wandering Soul.* New York: William Morrow. Reprinted by permission.

The Hunter College Disability Studies Project, "Definition of Disability Studies" (1990s)

One effort at the university level to gain recognition of disability as a multicultural experience was undertaken in the 1990s by disability studies faculty at Hunter College in New York City. The following is an excerpt from the rationale offered to allow disability to serve as fulfillment of the multicultural studies requirement. Although the proposal ultimately failed, the effort sparked other efforts to adopt similar requirements at U.S. universities and colleges across the country.

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Disability Studies

Disability Studies reframes the topic of disability by focusing on disability as a social phenomenon, as a social construct, as a metaphor and in fact as a culture. It does this by examining myths and ideas related to disability in all forms of cultural representations and throughout history. This focus shifts the emphasis away from examining the characteristics of impairments and their prevention, treatment and remediation to the study of disability as a social/cultural/political phenomenon. This shift does not indicate a denial of the presence of impairments and physical limitations, nor a rejection of the utility of intervention and treatment. Rather, the examination of disability as a socially constructed category is conducted in order to disentangle those impairments and limitations from the myth, ideology and stigma that influence social interaction and social policy. This analysis challenges the idea that the economic and social status and the assigned roles of people with disabilities are an inevitable outcome of their impairments, an idea similar to the argument that women's roles and status are biologically determined.

It is useful to disentangle the social construction from the physical realities of disability. One can begin to understand the breadth and depth of discrimination, marginalization, alienation and oppression of people with disabilities. In addition, Disability Studies is a prism through which we can gain a broader understanding of society and human experience, and the significance of human variation. Just as looking at American Studies from an African-American perspective provides a more comprehensive view of America's history, Disability Studies provides a more complex view [of] many critical social issues: competence, wholeness, independence/dependence, autonomy, health, physical appearance, aesthetics, and community, which pervade every aspect of the civic and pedagogical culture. Scholarship in this field addresses such fundamental ideas as who is considered a burden and who is a resource, who is expendable and who is esteemed, who should engage in the activities that might lead to reproduction and who should not, and if reproduction is not the aim, who can engage in erotic pleasures and who should not. Disability Studies examines the eugenics ideology that informs the discourse on abortion, pre-natal screening, birth control, euthanasia and medical ethics. And as Longmore (1992) points out, it also deepens the "historical comprehension of a broad range of subjects, for instance the history of values and beliefs regarding human nature, gender and sexuality; American notions of individualism and equality, and the social and legal definitions of what constitutes a minority group."

Circle Story #5: Mike Ervin and Anna Stonem, *by Riva Lehrer. 1998. Mixed media on paper, 22" by 21." Mike Ervin, journalist, writer and playwright, and Anna Stonum, poet, and visual artist, are shown in a double portrait. Ervin and Stonum were both dedicated disability rights activists and traveled the country to participate in political actions. They had been married for a decade before Anna Stonum's sudden death of heart failure in February 1999. Ervin's disability is Duchenne's muscular dystrophy, and Stonum's was Friedreich's ataxia.*

The field of Disability Studies is multidisciplinary, includes both theory and research and has relevance to both liberal arts and applied fields. It draws on paradigms and constructs from anthropology, literature, sociology, history, political science, education and others. Incorporated into the liberal arts curriculum, it has the potential to organize and critique the existing representations of disability and ability in the culture. This process can expose ways that disability has been socially constructed and reveal the consequences of that construction for the pedagogic and civic cultures.

The myths and ideologies about disability entrenched in the curriculum parallel those that wield influence in the civic culture. The present curriculum supports the social organization and practices within the civic culture whose institutions often maintain an inequitable distribution of power and opportunity based on perceptions of competence and value. Therefore, a goal of Scholars in Disability Studies is to expose, deconstruct, and analyze fallacies and inconsistencies and examine their implications for social interaction. When incorporated into the curriculum, Disability Studies has the potential to redress the inadequacies in the structure and content of the curriculum by approaching disability as a phenomenon that organizes social, political and intellectual experience.

▣ Mike Ervin, *The History of Bowling* (1999)

The History of Bowling *is the story of Chuck, a 32-year-old quadriplegic college freshman who, after 15 years of watching TV in his mother's attic, has gathered the courage to return to college. As he begins to relish coming out of the disability closet, he finds love in, of all places, PE class. His paramour, Lou, is a senior with an invisible disability (epilepsy) who has spent her life trying to hide her condition. When an insensitive coach forces the two to collaborate on a project, love blossoms and lovers' quarrels ensue, comically spurred on by Chuck's seductive roommate, Cornelius, who is deaf and blind, as well as a cad and a con. The playwright, Mike Ervin, is a well-known Chicago writer and disability rights activist. He coordinates the Victory Gardens Access Project, a program that uses technology to make live theater accessible for persons with disabilities.*

Act I : Scene I: Lou and Chuck
are in opposite corners of the stage.

LOU (to audience): I finally broke down and got a doctor's note. I hated to do it but I had to. It was the only way I could get out of that stupid mandatory PE credit. I had the doctor at the student infirmary write me a note saying it was unsafe for me to take PE because it could set off a seizure if I got hit in the head with a ball. Of course it was bull shit. But the doctors at the student infirmary are like retired podiatrists. They don't know any better. I felt cheap and sleazy after I did it. Not because it was a lie, but because I played the cripple game. I only played the cripple game once before in my whole life. I could have played it a thousand times. But the only time I ever did, I stood up and said, "Well, your honor, sir, it's just that I have epilepsy. And if I were to have a seizure in the jury box . . ."

CHUCK (to audience): I, on the other hand, am the king of the doctor's notes. I could fill [the] gymnasium with all the doctor's notes I've had to get. When I got the license plates with the little wheelchair hieroglyphic, I had to get a doctor's note. When I got this wheelchair, doctor's note. When I applied to this university, doctor's note again. One time I was in a shoe store and the manager rushed up and he said that before he would let any of his sales people touch my feet, I would have to bring a doctor's note.

LOU (to audience): I know, I know, I should have stood up and said, "I have epilepsy, your honor, but it will in no way interfere with my ability to do the job!" But I didn't have time for jury duty.

CHUCK (to audience): The shoe store manager was so uptight. He said, "I'm sorry sir, but I don't

In The Piano, *a mute Scottish woman travels with her young daughter for an arranged marriage to a landowner in New Zealand. She is forced to leave her most treasured possession, her piano, on the beach, but she enters into a bizarrely erotic relationship with the half-Maori who purchases it.*

Source: *The Piano* (1994), directed by Jane Campion. Australia. Color, 120 minutes. Reprinted by permission of Paul Darke.

want them to be responsible if something should happen." I said, "What, you had a cripple come in here once and his feet exploded?" And he said, "It's not that I don't have empathy for your situation." That really made me laugh. I said, "How can YOU feel sorry for ME? You manage a shoe store!"

LOU (to audience): My mother would hate it if she knew I got a doctor's note. The one thing she has no patience for is "those people who use their handicap as a weapon."

CHUCK (to audience): Beggars on the street are like that too. They try to hit up everyone who comes by, but never me. It's an insult. They're wearing shoes they found in the dumpster, but they think they're better off than me. I wish I could afford to flash 500 bucks at one of them! I'd show them boy!

LOU (to audience): I should have known it wouldn't be that easy. I delivered my doctor's note to Mr. Barnes, the PE teacher. I tried to act like I was really broken up about not being able to take PE.

(Enter BARNES, perusing a note. He's the devil wearing gym teacher's clothes with a whistle around his neck.)

BARNES: Oh dear. Epilepsy, huh?

LOU: Yes. And I really can't [take] the risk.

BARNES: Oh, mercy no. Most certainly not.

LOU: I'm really sorry. I'll have to get an exemption, I guess.

BARNES: We'll have to put you in the special section.

LOU: What!

BARNES: Oh yes. The special section. For the people with handicaps. Maybe you can't literally participate in athletic activities, but you surely can write term papers about them. You and your partner.

LOU: Partner?

BARNES: But of course. Another handicapped person.

LOU: You mean, someone who's blind, or in a wheelchair?

BARNES: Could be a hemophiliac. (Laughs a diabolical laugh.)

(Barnes exits.)

CHUCK *(to audience):* The street preachers are the worst. I try my best to ignore them, until they start with that, "Pray to Jesus and he'll make you walk!" One day I passed that one who's always in front of the drug store with the bullhorn shouting, "Jesus! Jesus! Jesus!" And he says to me, "You better get right with Jesus, or he ain't never gonna make you walk!"

LOU (*to audience*): Oh God! A partner! My mother would say, "Serves you right! You can either use your handicap to make excuses or you can stand on your own two feet!"

CHUCK (*to audience*): "You better get right with Jesus or he ain't never gonna make you walk!" Who the hell does he think he is? So I turned to him and I said, "You better get right with Jesus, or he ain't never gonna make you white!"

LOU (*to audience*): I had to meet my partner at the cafeteria. Two o'clock Tuesday. All I knew was his name was Chuck. That's all I knew. Oh God! I don't belong here!

CHUCK (*to audience*): He told me don't think my wheelchair will keep me from going to hell! I said I hope not. One time I made airplane reservations and they told me before I could board I'd have to have a doctor's note. I just bet you if I did go to hell, Satan would hit me up for a doctor's note.

LOU (*to audience*): There was this black boy named Terry. His face was hideously burned. It was like his face was made of wax and big wax tears dripped down and solidified. His face was smeared, like someone tried to put it back in place with a putty knife.

(Lou walks toward Chuck and sees him sitting at a cafeteria table.)

LOU: Chuck?

CHUCK: Yeah.

LOU: I'm Lou.

CHUCK: My partner?

LOU: Yes.

CHUCK: What are you? Hemophiliac?

LOU: Epilepsy.

CHUCK: Epilepsy people can't take PE?

LOU: There's been a mistake. I was supposed to get an exemption.

CHUCK (*Laughing*): An exemption from Barnes? That sadistic bastard? They say he wouldn't let his dead grandma off the hook for P.E. We're lucky he's not making us run laps.

LOU: I wish he was.

CHUCK: Thanks.

LOU: I didn't mean it like that.

CHUCK: Right.

LOU: I didn't.

(Pause.)

CHUCK: You a freshman?

LOU: No. A senior. It's my last semester.

CHUCK: A senior? And just taking PE now?

LOU: I put it off until the last minute. And now I can't avoid it anymore. What are you?

CHUCK: A freshman.

LOU: How old are you?

CHUCK: Thirty two.

LOU: And you're a freshman?

CHUCK: It's a long story.

(Pause.)

LOU: I didn't mean anything by what I said. It's just that I hate writing term papers. And especially about sports. I don't know anything about sports. I hate sports. I have no idea what to write about.

CHUCK: Yeah well that's OK. I know a lot about sports. That's all I did for the last fucking 15 years. Watch sports on cable. Stock car racing, water polo, the world table tennis championships. But I was about to tell Barnes he could shove his busy work. Then I got to thinking about it and pretty soon I got real excited. So don't worry. I know exactly what we're gonna write about!

LOU: Oh good. What?

CHUCK (*bitterly*): Bowling!

LOU: Bowling?

CHUCK: Bowling.

LOU: I hate bowling.

CHUCK: So do I.

LOU: I don't know anything about bowling. I've never set foot in a bowling alley.

CHUCK: That's all right. I know all about bowling. I did it enough times.

LOU: You? Bowling?

CHUCK: Yep. Bowling Buddies. Crippled kids bowling club. Every third Saturday. The bastards! I think they were Christian kids. Real clean rah-rah types. I think maybe we were extra credit. They'd close down Rainbow Lanes for the afternoon and bring the cripples in. Sons of bitches!

LOU: My God.

CHUCK: I know. And bowling buddies motto was "anybody can bowl a strike." They had this ramp. It looked like a miniature playground slide. They'd put the ball on top and you'd push it and would roll down the ramp and head down the lane. Anybody could do it. There was this kid with no arms. He pushed the ball with his head.

LOU: Please. I don't want to hear anymore

CHUCK: He was a maniac. He'd get a running start and butt heads with the bowling ball. They made him wear a leather helmet. We called him kamikaze. And in bowling buddies, no one ever threw a gutter ball. You know why?

LOU: Don't tell me.

CHUCK: Because the Christians ran along side the lane and if the ball headed for the gutter, they'd kick it back on course.

LOU: All right! All right! We'll do bowling!

CHUCK: It's all true. Every word.

LOU (*to audience*): He made me feel how I felt when my friend Amy told me about the bastard she was married to who beat her up for years. The Amy I knew was the head of an agency, served on several boards. She was an activist. If any man tried that with the Amy I knew, she'd break his neck. Same way with Chuck. I couldn't believe he let them do that to him. Somewhere along the line, he'd completely transformed.

(Lou approaches Chuck.)

CHUCK: Still exists, bowling buddies. Chapters all over the country.

(Lou crawls up onto his lap and kisses him long and hard. Barnes runs out frantically blowing his whistle and he throws a penalty flag.)

Scene II: The cafeteria. Lou and Chuck sit at a table with food trays on it. Lou has a pen and writing pad.

CHUCK: OK. Read that back.

LOU: Again?

CHUCK: Yes. Again. Got to get it right. You know what a fucker Barnes is.

LOU: All right, all right! (*reading*). The history of bowling.

CHUCK: Not from the top. Start from the part about Old Lady McDonald.

LOU (Reading): Bowling buddies was founded in 1962 by Mrs. Roger McDonald as a monument to her late husband. She wanted to combine his two great passions in life: service to the less fortunate and bowling.

CHUCK: Ok. Great. Now skip down to the part about the blind kids.

LOU: This is depressing.

CHUCK: I know. Keep reading.

LOU: Blind kids . . . blind kids. . . . Ok: (*Reading*) The blind kids were the worst bowlers in the world. Everybody ran for cover. But even the blind kids never threw a gutter ball. No one ever threw a gutter ball in bowling buddies. That was another one of our proud mottoes. But why not? What's wrong with throwing a gutter ball? What were they afraid of? And we all accepted it. No one questioned it. Not one of us ever demanded our inalienable right to throw a gutter ball!

CHUCK: OK. Good. Now add, "In life, there's gutter balls. It's a fact. Better learn how to deal with it."

Big Picture, *by Tim Lowly. 1997. Tempera on panel. 120" by 120," In this work, Lowly captures the students and teachers interacting in a special education class in Seoul, Korea.*

LOU: That's sick!

CHUCK: I know. I told you he's a sadist. That's how he gets his jollies. Him and the jocks. But we're gonna get the last laugh.

LOU: Oh God! Why did I try to get an exemption!

CHUCK: Oral presentation's a tough job. Takes a tough woman. So see. I have respect for you.

LOU: No way! Why don't you do it?

CHUCK: Oh don't worry. I'll be there. I just haven't figured out in what capacity.

LOU: No way am I doing any oral presentations!

CHUCK: We need to finish this.

LOU: I'm serious.

CHUCK: We'll discuss it later. Now what did I say before? Life is full of gutter balls.

(Lou reluctantly picks up the pad.)

LOU: Oh screw it. I don't care. Write about whatever you want. I just want to get this over with so I can graduate.

CHUCK: Good. Ok so write that down about gutter balls.

LOU: The minute I get out of here, I've already decided what I'm gonna do. You know what I'm gonna do?

CHUCK: I'd love to hear every detail. Really I would. But let's do the gutter balls first.

LOU: I'm gonna hop a boxcar. I don't care which one. Just pick one and go. I did it once before. All by myself. Rode all the way across Indiana. Changed my life. I know it's hard to believe riding across Indiana could change your life. But it's the boxcar. It's magic. The moonlight.

CHUCK: Even Indiana.

LOU: Yes! Even Indiana! Exactly. That's the beauty of it. I'm glad I wasn't in West Virginia or some place that really is beautiful or I wouldn't have got the full impact. It was the only time I rode. It scares me when I think back. Not because I was alone.

LOU: This is bull shit. You don't have any respect for me. We're supposed to be partners! I'm just a fucking secretary!

CHUCK: No. I just think better out loud.

LOU: And this whole paper is all about you.

CHUCK: No way. It's more about you than me. It's your worst nightmare.

LOU: What the hell is that supposed to mean?

CHUCK: They're gonna kidnap you and make you a bowling buddy!

LOU: Write your own fucking paper!

CHUCK (*mocking Lou*): Help! Help! Zombies! Hey, you think I don't have respect for you? You get the toughest job of all. You get to do the oral presentation.

LOU: Presentation? To whom?

CHUCK: To Barnes. He didn't tell you that part?

LOU: No!

CHUCK: Oh yeah. Oral presentation. To the whole gym class. It's our final. At the end of the semester he parades all the cripples into the gym and they present their papers to all the jocks.

I'm glad I was alone. I wouldn't have got the full impact if I wasn't alone. But when I think back, I'm lucky I didn't kill myself when I jumped off. I could've broken both legs. Then what? In the middle of a prairie. I could've died out there. I could've been eaten by wolves. People hop moving boxcars and they get sucked under the train and killed. That's the thing. I was so depressed and I did it all with such a sudden rush of abandon—almost suicidal. Not completely suicidal. It wasn't guaranteed death like jumping off a cliff. There was just a chance. But I didn't care. But I trust my motivations now. They're positive. I'm doing it to reward myself. And I'll wait until the train is stopped from now on before I hop on and off. But God, it's so amazing out in a box car. I was howling at the moon like a coyote.

CHUCK: Yeah well I wouldn't know. I don't do boxcars.

LOU: Oh. Sorry. Where were we?

CHUCK: Gutter balls. Ever since the dawn of time there have been gutter balls.

LOU: I want to tell you something.

CHUCK (*irritated*): Can we write that down first?

LOU: I want to tell you now before we go any further.

CHUCK: OK! What!

LOU: Because it may make a difference.

CHUCK: In what?

LOU: In general.

CHUCK: It won't. What?

LOU: This is my third college.

CHUCK: Uh huh?

LOU: And I'm only 22.

CHUCK: OK?

LOU: I started college when I just turned 17. I was double promoted twice. I was honor society.

CHUCK: Congratulations.

LOU: So I dropped out of two colleges in two years. I was running from lovers.

CHUCK: So?

LOU: So the second one was a woman.

CHUCK: Was it fun?

LOU: Fun? I don't know. I guess. Mostly. Until the end.

CHUCK: Well good. Can we finish with the gutter balls?

LOU: Will you pose for me?

CHUCK: What?

LOU: I'm a photographer too. I want you pose for me. Please?

CHUCK: OK sure. Now please—

LOU: Nude.

(Pause.)

CHUCK: You're kidding, right?

LOU: No. It's an on-going series I'm doing. People I know. I don't ask everybody I know to pose. Very few, actually. They have to have a certain charisma. Not really charisma. More like audacity. Audacity and a certain playfulness. The audacity to be playful. But I guess that's charisma. I've only asked four or five of my friends. And my aunt.

CHUCK: You took naked pictures of your aunt?

LOU: She's not like most aunts. She's real cool. What I do is I take their picture in their natural habitat—doing something they do every day, except nude. And they do it like they don't even realize they're nude. Just go about their business. Except nude. Like the one I took of my aunt, she was vacuuming. And my friend Gordon, the thing he does every day is wait for the stupid subway. So we went down to the subway late at night when no one was around. And he stood there naked waiting for the train. So with you, I'd probably do it in your dorm room working on your bowling paper. Except nude. It's the juxtaposition of the mundane and the extraordinary. A statement about freedom. So will you do it?

CHUCK: I don't know.

LOU: Why not? Can't you handle it?

CHUCK: I can handle it!

LOU: Then you'll do it?

CHUCK: Maybe.

Source: Ervin, Mike. 2005. *The History of Bowling.* In Lewis, Victoria Ann, ed. *Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights.* Minneapolis, MN: Consortium Books. (Originally performed 1999)

Steven Brown, *Institute on Disability Culture Manifesto* (1999)

This manifesto documents the long list of disability activist complaints against media spectacles such as Jerry Lewis's Labor Day Telethon for Muscular Dystrophy. In his cyber newsletter, author Steven Brown galvanizes public opposition to the telethon by explaining why charity activities do more harm than good for disabled populations. In this excerpt, he *brings together some of his previous publications in his cyber newsletter.*

August 1999, Number Six

IT'S TELETHON TIME–AGAIN

Labor Day will be here before we know it—and once again Jerry Lewis and hopefully Jerry's Orphans, the protest group developed to oppose the MDA telethon, will be in the spotlight. Telethons have the ability to bring about some of the most vituperative arguments about disability issues. Here's what I've written about telethons in the past:

THE TRUTH ABOUT TELETHONS

"Recently, I chanced upon an article in DISABLED USA describing the efforts of a person with Multiple Sclerosis first to retain her well-paying job, then to find a new one that matched her abilities and expectations. She failed. Or, more properly, her society failed her. She unnerved prospective employers who were afraid her dreaded disease would frighten both co-workers and the public, not to mention render her unfit to be a productive, and compatible, employee. After several years of searching for appropriate employment she has determined that her best route to continued success and continued productivity is through free-lance photography and other artistic endeavors. Her disability did not force her out of the employment mainstream. Society's handicapping barriers did.

For several years now, I've been receiving the GAUCHER'S DISEASE REGISTRY NEWSLETTER. I've even published articles in it addressing the importance of the disability movement. I was pleased to note that the Newsletter's editor was starting to refer to "people with disabilities" and to include articles about disability rights and advocacy. But two issues ago, I was horrified to read two articles concerning a young Englishwoman with Gaucher's Disease. She was constantly being described, and describing herself, as being victimized by this disease. Now I'm not going to maintain that Gaucher's Disease is a welcome guest that should be greeted with a fervor of hospitality. I'm much too familiar with its broken bones, heartaches, and physical pain. But I'm also unwilling to be labeled a victim who has survived its ravages. You see, "victim" has an ugly connotation that offends—no, enrages—me. Being told, or believing, I'm a victim places all the responsibility for the results of the disease in the disease itself. Now I ask you, does a disease feel; is it cognizant, does it manipulate? As far as I know, disease does none of these things, but people do. I resent being called a victim because that implies that I have no control over the way I react to my disease, to my disability. But the fact is, I do have control. I can decide whether to succumb to my pain or to adapt myself to it. I can decide whether I want to grind my bones into pieces or to use a wheelchair for mobility. I can decide whether to risk passing this inherited disease onto my own natural children or to remain childless. I can decide. I am a victim only when I let my disease rule me. I am a person with a disability when I choose how to react to the characteristics of my disease. Anyone can choose to be a victim of anything. And anyone can choose not to be.

You're probably wondering, if you've been tenacious enough to read this far, what these thoughts have to do with telethons. Two things. First, I chose that title to grab your attention, just like telethons are supposed to do. Second, it has occurred to me that the way the majority of us think and feel about disability has been shaped by telethons, by what we might call "the telethon mentality." When I think about Multiple Sclerosis, the first phrase that comes to me is "killer of young adults." When I think about Muscular Dystrophy, it is "Jerry's Kids." Telethons may do some good. They may expose some people to disability. They may raise money for research and charity. They may give attention to people who need it. But they also isolate people with disabilities as victims, as subjects of charity, as a "thing" to be considered annually when their group's time comes to appear on TV. While disability advocates continue to insist that we want to be integrated into a society organized to allow us access to all its avenues, telethons continue to segregate us as a population to be pitied, to be identified as distinct, and to be helped. The truth about telethons is that they are mechanisms of segregation. The truth about accessibility is that it is a mechanism of integration.

The long-winded point of this essay is that it is time for us to stop being victims. It is time for us to stop being ruled by our diseases, our impairments, our limitations. It is time for us to stop being ruled by our disabilities. It is time for us to control our lives, our environments, ourselves. It is time for us to control our disabilities. It is time for us to make telethons and "the telethon mentality" a thing of the past. It is time."

(From Volume VII, Summer/Fall 1985 OKLAHOMA COALITION OF CITIZENS WITH DISABILITIES NEWSLETTER, 4–5)

"Telethons have generated great controversy for the past decade or so. Entertainer Jerry Lewis has become the focal point of this conflict. Best known for his comedy routines and slapstick movie roles, Lewis has been identified with the Muscular Dystrophy Association (MDA) for many years. The MDA has sponsored an annual telethon during the Labor Day weekend since 1981. Each year Lewis takes the opportunity to write an article about MDA in PARADE magazine which is distributed with many Sunday papers. Lewis' articles have tended to bemoan the plight of children who have Muscular Dystrophy and to include pleas to support "his children," some of whom are almost as old as he is.

Several years ago Lewis spent some time in a wheelchair to see what it was like. He wrote about his experiences in PARADE. His comments were so disparaging that two advocates with Muscular Dystrophy formed a group called, "Jerry's Orphans," to sponsor annual Labor Day weekend demonstrations to protest Lewis' demeaning approach to disability.

The two combatants have waged a public battle, which led to a 1993 article in VANITY FAIR magazine characterizing Lewis' personality and the substance of the issues involved. In the article, Paul Longmore, a historian with a disability known for his studies of the media and telethons, described the impact of telethons on the American public.

> Four major telethons—Easter Seals, the Arthritis Foundation, United Cerebral Palsy, and the M.D.A.— are the single most powerful cultural mechanism defining the public identities of people with disabilities in our society today, mainly because they reach so many people. . . . The telethon sponsors claim that, collectively, they have a combined audience of 250 million people.
>
> That's the equivalent of the population of this country. The message of telethons is that whatever condition people with disabilities have, that condition has essentially spoiled their lives, and the only way to correct that is to cure them. The message of the disability-rights movement is that it's possible to be a whole person with a disability.

The final two sentences of Longmore's analysis form a precise description of the models of charity and celebration of disability that have emerged in the late twentieth century. The most comprehensive assessment of the charity mentality comes from an English photographer with a disability, David Hevey. In his 1992 book, THE CREATURES TIME FORGOT, Hevey exposes charities as the most visible appendage of what he calls the "disability industry." Hevey contends that charities have created a hegemony, an almost complete dominance, of what the public perceives as the one voice of people with disabilities. But in reality, disabled people wait at the end of the line of the disability industry's priorities.

Foremost among any charity's goals are survival and ensuring that those individuals who contribute to the agency's success feel good about themselves. This can be accomplished by attaining the dual objectives of raising money for the organization and determining how to distribute it to the organization's needy clientele.

One result of this model [is] that the needs of the charity, or disability industry, must come before all other concerns. A more invidious consequence is that the only way charities and their ilk can continue to exist and to feel good about their selfless contributions to those less fortunate than themselves is to have a perpetual supply of victims of disability's tragic ravages." . . .

In 1999, the biggest problem I have with telethons of any kind continues to be that they promote segregation, not integration. It is long beyond time to be rid of telethons. Since they are not going away, I can only suggest the next best thing: do whatever you can to oppose them, including not sending money to any of them! If you want to make a charitable donation, find another way to do it. Let's give telethons a simple message: GO AWAY.

Source: Brown, Steven. 1999. *Institute on Disability Culture Manifesto*. Available at: http://www.dimenet.com/disculture/archive.php?mode=A&id=18

Emma Morgan, "Attention Deficit Disorder" (1996)

In this ironically entitled poem, the disabled poet Emma Morgan demonstrates how attention deficit disorder (ADD) proves a reasonable response to the chaotic backdrop of world events in the mid-1990s. Rather than portraying her own mental state and tendency to shift from activity to activity as a liability, the poem helps readers recognize ADD as a viable mode of attention that allows the narrator to sift through seemingly insignificant details in order to highlight their overlooked importance.

In my world of mental anarchy
The task "to clean the house"
Breaks into ten
And ten again
Like a seven breaking into two and five
One and six then three and four
Each another sum of parts
So that I might wash a dish
Dust three shelves
Read one page
And return a phone call
Before I finally settle
Into sweeping half the stairs
Or scouring one sink
With a ferocity of purpose.

When you speak to me
of Russian borders rearranging—
your hair-do
the glimmer of your nail polish
the dream I had last night
and one pattern on the wallpaper

at your back
vie for my attention
like a class of eager children
sliding off their seats
with the sheer potency of right answers
Your world of global puzzles
Loses me in a grand collage of universes
Each the size of the pen cap
Held between your teeth
But give me just your shoe
Or one braided lace
To you a detail—
To me a world of six strands
Each a set of threads
The tension of the weave precise
And I can see what isn't visible to you

You couldn't stand to pay attention
In that small world
Snaking through the eyelets of your shoe

I dismiss the boundaries

Of minute, hour, day
Until there's only task—
Task so focused it becomes world
My mind a sheet of paper
Folded in on itself
And again
Until it becomes a crane
A Moor on horseback
Or a hummingbird
Poised on the lip of a blossom
Balanced on a stillness
Built of motion

Source: Morgan, Emma. 1996. "Attention Deficit Disorder." Available at: http://www.realityengineering.org/poetrycastle/viewthread.php?fid=143&tid=1826&action=printable

Michael Bérubé, from *Life as We Know It: A Father, a Family, and an Exceptional Child* (1996)

This essay on the birth of the author's son, Jamie, with Down syndrome reinterprets the meaning of a pathologized genetic condition as valued difference. Employing arguments from evolutionary biology, civil rights politics, and science fiction film, Bérubé rejects a pitying or patronizing attitude in order to reclaim the social context for almost a half million people in the United States.

There has never been a better time to be born with Down syndrome—and that's really saying something, since Down syndrome appears to have been with us for ten million years or more. How do we know? Because in the 1970s, Down syndrome was reported in gorillas and chimpanzees. Since there's no chance that we humans "gave" Down syndrome to other primate species, it would seem that trisomy 21 has been an integral part of being "human" ever since our evolutionary tree split off from that of apes. Cro-Magnons and Neanderthals had babies with Down syndrome; even those ape-men and ape-women in the opening scene of Stanley Kubrick's *2001: A Space Odyssey*—they had kids with Down syndrome, too. For whatever reason, we've produced offspring with Down syndrome with remarkable regularity at every point in our history as hominids—even though it's a genetic anomaly that's not transmitted hereditarily (except in extremely rare instances) and has no obvious survival value. The statistical incidence of Down's in the current human population is no less staggering; there

Japanese protesters with wheelchair barricade, 2004.

Source: Photo by Nagase Osamu.

may be almost half a million people with Down's in the United States alone, or just about one on every other street corner.

But although *Homo sapiens* and all our hominid forebears have always experienced some difficulty dividing our chromosomes properly, Down syndrome was not identified and named until 1866, when British physician J. Langdon Down diagnosed it as "mongolism" (because it produced children with almond- shaped eyes reminiscent, to at least one nineteenth- century British mind, of Central Asian faces). At the time, the average life expectancy of children with Down's was under ten. And for a hundred years thereafter—during which the discovery of antibiotics lengthened the lifespan of Down's kids to around twenty—Down syndrome was known as "mongoloid idiocy."

The 1980 edition of my college genetics textbook, *The Science of Genetics: An Introduction to Heredity,* opens its segment on Down's with the words, "An important and tragic instance of trisomy in humans involves Down's Syndrome, or mongoloid idiocy." It includes a picture of a toddler-age mongoloid idiot along with a cellular photograph of his chromosomes (called a "karyotype") and the completely erroneous information that most people with Down's have IQs in the low 40s. The presentation is objective, dispassionate, and strictly "factual," as it should be in a college textbook. But reading it again in 1991, I began to wonder: is there a connection between the official textual representation of Down syndrome in medical discourses (including college textbooks) and the social policies by which people with Down syndrome are understood and misunderstood?

You bet your life there is. Now, anyone who's paid attention to the "political correctness" wars on American campuses knows how stupid the academic left can be. We're always talking about language instead of reality, whining about "lookism" and "differently abled persons" instead of changing the world the way the real he-man left used to do. But you know, there really is a difference between calling someone a "mongoloid idiot" and calling him or her "a person with Down syndrome." There's even a difference between calling people "retarded" and calling them "delayed." These words may appear to mean the same damn thing when you look them up in Webster's, but I remember full well from my days as an American male adolescent that I never taunted my peers by calling them "delayed." Even for those of us who were shocked at the frequency with which "homo" and "nigger" were thrown around in our fancy Catholic high school, "retard" aroused no comment, no protest. In other words, a retarded person is just a retard. But *delayed* persons will get where they're going eventually, if you'll only have some patience with them. (Pp. 25–26)

In retrospect, it's beginning to look as if many of the developmental deficits attributed to Down syndrome could instead be attributed to institutionalization. Of course, the phrase "mongoloid idiocy," and its attendant policies, did not cause Down syndrome. But words and phrases are the devices by which we beings signify what homosexuality, or Down syndrome, or anything else, will mean. There surely were, and are, the most intimate possible relations between the language in which we spoke of Down's and the social practices by which we understood it—and refused to understand it. You don't have to be a poststructuralist or a postmodernist or a post-*anything* to get this; all you have to do is meet a parent of a child with Down syndrome. Not long ago, we lived next door to people whose youngest child had Down's. After James was born, they told us of going to the library to find out more about their baby's prospects and wading through page after page of outdated information, ignorant generalizations, and pictures of people with Down's in mental institutions, face down in their feeding trays. These parents demanded the library get some better material on Down syndrome and throw out the garbage. [This garbage] has had its effects *for generations.* It may look to you like it's only words, but perhaps the fragile neonates whose lives were impeded by the policies—and conditions—of institutionalization can testify in some celestial court to the power of mere language, to the intimate links between words and social policies.

Some of my friends tell me this sounds too much like "strict social constructionism"—that is, too much like the proposition that culture is everything and biology is only what we decide to make (of) it. But although James is pretty solid proof that human biology exists independent of our understanding of it, every morning when he gets up, smiling and babbling to his family, I can see for myself how much of his life depends on our social practices. On one of those mornings I turned to my mother-in-law and said, "He's always so full of mischief, he's always so glad to see us—the only thought I can't face is the idea of this little guy waking up each day in a state mental hospital." To which my mother-in-law replied, "Well, Michael, if he were waking up every day in a state mental hospital, he wouldn't *be* this little guy."

As it happens, my mother-in-law doesn't subscribe to any strict social constructionist newsletters; she was just passing along what she took to be good common sense. But every so often I wonder how common that sense really is. Every ten minutes we hear that the genetic basis of something has been "discovered," and we rush madly to the newsweeklies: disease is genetic! Homosexuality is genetic! Infidelity, addiction, adventurousness, obsession with mystery novels—all genetic! The discourses of genetics and inheritance, it would seem, bring out the hidden determinist in more of us than will admit it. Sure, there's a baseline sense in which our genes "determine" who we are. We can't play the tune unless the score is written down somewhere in the genome. But one does not need or require a biochemical explanation for literary taste, or voguing, or faithless lovers. In these as in all things human, including Down's, the genome is but a template for a vaster and more significant range of social and historical variation. That's true even from human attributes that are clearly more "biological" than voguing and reading. Figuring out even the most rudimentary of relations between the genome and the immune system (something of great relevance to us wheezing asthmatics) involves so many trillions of variables that a decent answer will win you an all-expense-paid trip to Stockholm. Nor can you predict allergic reactions from the genes alone: because the body's immune system takes a few years to go on-line, your environmental variables (from dioxin to cat dander) are very likely going to be more important to you than most hereditary "constants" you care to name.

Yet even if you don't think that biology is destiny, and even if you don't believe evolution follows any plan, there's still something very seductive about the thought that Down syndrome wouldn't have been so prevalent in humans for so long without good reason. Indeed, there are days when, despite everything I know and profess, I catch myself believing that people with Down syndrome are here for a specific purpose—perhaps to teach us patience, or humility, or compassion, or mere joy. A great deal can go wrong with us *in utero,* but under the heading of what goes wrong, Down syndrome is among the most basic, the most fundamental, the most common, *and* the most innocuous, leavening the species with children who are somewhat slower, and usually somewhat gentler, than the rest of the human brood. It speaks to us strongly of design—if design govern in a thing so small. (Pp. 32–35)

Source: Bérubé, Michael. 1996. *Life as We Know It: A Father, a Family, and an Exceptional Child.* New York: Random House. Copyright © 1996 by Michael Bérubé. Used by permission of Pantheon Books, a division of Random House, Inc.

European Union Disability Policy (1997)

The European Union's disability policy has gradually shifted from one that emphasizes disability as an *individual trauma of adjustment to that of socially created barriers that inhibit disabled people's participation in society. In particular, the barriers identified here are identified as economic and attitudinal in nature. These obstacles affect the quality of life experienced by disabled people in their daily lives.*

THE COUNCIL OF THE EUROPEAN UNION AND THE REPRESENTATIVES OF THE GOVERNMENTS OF THE MEMBER STATES MEETING WITHIN THE COUNCIL,

Whereas the Commission has issued a communication entitled 'Equality of opportunity for people with disabilities—A new European Community disability strategy';

Whereas people with disabilities constitute a significant proportion of the population of the Community and, as a group, they face a wide range of obstacles which prevent them from achieving equal opportunities, independence and full economic and social integration;

Whereas respect for human rights is a fundamental value of the Member States which is underlined in Article F.2 of the Treaty on European Union;

Whereas the principle of equality of opportunity for all, including people with disabilities, represents a core value shared by all Member States; whereas this implies the elimination of negative discrimination against people with disabilities and improving their quality of life; and whereas access to mainstream education and training, where appropriate, can play an important role in successful integration in economic and social life;

Whereas the Community charter on the fundamental social rights of workers, adopted at the European Council in Strasbourg on 9 December 1989 by the Heads of State or Government of 11 Member States, proclaims inter alia, in point 26:

'26. All disabled persons, whatever the origin and nature of their disability, must be entitled to additional concrete measures aimed at improving their social and professional integration.

These measures must concern, in particular, according to the capacities of the beneficiaries, vocational training, ergonomics, accessibility, mobility, means of transport and housing';

Whereas in its recommendation of 24 July 1986 on the employment of disabled people in the Community (1) the Council recommended Member States to take all appropriate measures to promote fair opportunities for disabled people in the field of employment and vocational training including initial training and employment as well as rehabilitation and resettlement;

Whereas the free movement of persons must be ensured in accordance with the existing Community legislation for the benefit of all the citizens of the European Union, including those with disabilities and those who are responsible for people with disabilities;

Whereas the overall purpose of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities, adopted by the General Assembly on 20 December 1993 (2) is to ensure that all people with disabilities may exercise the same rights and obligations as others;

Whereas these Rules call for action at all levels both within States as well as through international cooperation to promote the principle of equality of opportunity for people with disabilities;

Whereas in its White Paper 'European social policy—a way forward for the Union,' adopted on 27 July 1994, the Commission indicated that it intended to prepare an appropriate instrument endorsing the principles of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities;

Whereas, while responsibility in this field lies with the Member States, the European Community can make a contribution in fostering cooperation between Member States and in encouraging the exchange and development of best practice in the Community and within the policies and activities of the Community institutions and organs themselves;

Whereas the aims set out in this resolution on the equalization of opportunities for people with disabilities and the ending of negative discrimination are without prejudice to the right of each Member State to lay down its own rules and provisions for achieving the said aims, in accordance with the principle of subsidiarity and to the full extent that the resources of society permit:

I. REAFFIRM THEIR COMMITMENT TO:

1. the principles and values that underline the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities;

2. the ideas underlying the Council of Europe's resolution of 9 April 1992 on a coherent policy for the rehabilitation of people with disabilities;

3. the principle of equality of opportunity in the development of comprehensive policies in the field of disability, and

4. the principle of avoiding or eliminating any form of negative discrimination on the sole grounds of disability.

Japanese protest organizers preparing for press conference, 2004.

Source: Photo by Nagase Osamu.

II. CALL ON MEMBER STATES:

1. to consider if relevant national policies take into account, in particular, the following orientations:

- empowering people with disabilities for participation in society, including the severely disabled, while paying due attention to the needs and interests of their families and carers,
- mainstreaming the disability perspective into all relevant sectors of policy formulation,
- enabling people with disabilities to participate fully in society by removing barriers,
- nurturing public opinion to be receptive to the abilities of people with disabilities and toward strategies based on equal opportunities;

2. to promote the involvement of representatives of people with disabilities in the implementation and follow-up of relevant policies and actions in their favour.

III. INVITE THE COMMISSION:

1. to take account, where appropriate, and within the provisions of the Treaty, of the principles set out in this resolution in any relevant proposal it submits on Community legislation, programmes or initiatives;

2. to promote—in collaboration with the Member States and with non-governmental organizations of and for people with disabilities—the exchange of useful information and experience especially concerning innovative policies and good practice;

3. to submit periodic reports to the European Parliament, the Council, the Economic and Social Committee and the Committee of the Regions on the basis of information supplied by the Member States, describing the progress made and the obstacles encountered in implementing this resolution;

4. to take account of the results of the evaluation of the Helios II programme when considering whether it would be appropriate to bring forward proposals for follow up.

IV. INVITE OTHER COMMUNITY INSTITUTIONS AND ORGANS:

to contribute to the realization of the aforementioned principles in the framework of their own policies and activities.

(1) OJ No L 225, 12. 8. 1986, p. 43.

(2) United Nations General Assembly Resolution 48/46 of 20 December 1993.

Source: European Council. 1997. Resolution of the Council and of the Representatives of the Governments of the Member States meeting within the Council of 20 December 1996 on Equality of Opportunity for People with Disabilities. *Official Journal C 012* (January 13), pp. 0001–0002.

Not Dead Yet

Organized in 1996 to oppose a lethal resurgence of physician-assisted suicide campaigns, Not Dead Yet began to publicly protest efforts by various factions to legalize the right to die. These efforts particularly came in the wake of some people's unwillingness to prosecute Jack Kevorkian, who devised a "suicide machine" used to end the life of those with "terminal illness." However, the group's research successfully demonstrated that such a justification both was false—Kevorkian assisted in the suicides of many individuals with nonterminal illnesses—and cultivated

Japanese protest banner, 2004.

Source: Photo by Nagase Osamu.

a lethal atmosphere for all disabled people in the country. In recent years, the movement has also made public protests against other "pro-death" perspectives, such as Clint Eastwood's film Million Dollar Baby, *and during the court-ordered death of Terry Schiavo. For more information, contact: Not Dead Yet, 7521 Madison Street, Forest Park, IL; phone (708) 209–1500; fax: (708) 209–1735; website: www.notdeadyet.org.*

Not Dead Yet is a national grassroots organization of people with disabilities formed in response to the increasing threat of legalized physician assisted suicide and euthanasia in the United States and around the world. Not Dead Yet's mission is to advocate against legalization of physician assisted suicide, active euthanasia, and non-voluntary withholding of life-sustaining medical treatment. Not Dead Yet works to bring a disability-rights perspective to the public policy debate, and an awareness of the effects of disability discrimination in the health care system and society overall.

Formed in 1996, Not Dead Yet has worked to educate, support, coordinate and lead the disability community's effort to stop the so-called "right to die" from becoming a duty to die or a right to kill. To date, eleven other national disability groups have adopted formal positions against assisted suicide. Twenty-six national disability organizations supported Not Dead Yet's opposition to the starvation and dehydration of Terri Schiavo based on the lack of clear and convincing evidence of her wishes.

Not Dead Yet grassroots members have undertaken specific activities in the name of the organization and in support of its mission in at least 30 states, and conducted national actions targeting Jack Kevorkian, Princeton Professor Peter Singer, the Hemlock Society, and the World Federation of Right To Die Societies. Over 500 Not Dead Yet members rallied at the U.S. Supreme Court in 1997 to oppose a constitutional right to assisted suicide. Not Dead Yet's amicus brief filed in the U.S. Supreme Court in the case of *Vacco v. Quill* was among a handful, out of over 60 such briefs, cited by the High Court in its final opinion. Not Dead Yet has also led in the filing of disability rights briefs in several other cases, including but not limited to the Conservatorship of the Person of Robert Wendland in the California Supreme Court (2000), three briefs in the Guardianship of Theresa Marie Schiavo (Florida and federal courts, 2002–2003), and *Oregon v. Ashcroft* (Ninth Cir. 2002). Not Dead Yet has also given invited testimony three times before the U.S. Congress, and its leaders have appeared on over twenty national television news and talk show broadcasts.

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▣ Stephen Kuusisto, from "Harvest" (1997)

In "Harvest," visually impaired poet Stephen Kuusisto captures his own way of seeing as part of the pleasure of living in a visual world that is not distorted by his vision but enhanced.

My temporal task is to hear music,
drink a cup of chrysanthemum tea,
admire the white moon of the morning,
even if my eyes tell me there are two moons.

Source: Kuusisto, Stephen. 1997. "Harvest." In Fries, Kenny, ed. *Staring Back: The Disability Experience from the Inside Out.* New York: Plume Books. Reprinted by permission.

Judi Chamberlin, from "Confessions of a Noncompliant Patient" (1998)

Nearly 30 years after the release of her landmark work On Our Own, *Judi Chamberlin continues to write about psychiatric survivorship and resistance to the psychiatric system. This is the closing paragraph of her 1998 article "Confessions of a Noncompliant Patient."*

Let us celebrate the spirit of noncompliance that is the self struggling to survive. Let us celebrate the unbowed head, the heart that still dreams, the voice that refuses to be silent. I wish I could show you the picture that hangs on my office wall that inspires me every day, a drawing by Tanya Temkin, a wonderful artist and psychiatric survivor activist. In a gloomy and barred room, a group of women sit slumped in defeat, dressed in rags, while on the opposite wall their shadows, upright, with raised arms and wild hair and clenched fists, dance the triumphant dance of the spirit that will not die.

Source: Chamberlin, Judi. 1998. P. 52 in "Confessions of a Noncompliant Patient." *Journal of Psychosocial Nursing and Mental Health Services* 36(4):49–52. Printed with permission from Slack, Inc.

Sally Clay, "People Who" (1998)

This poem was read during the Million Mad March on May 2, 1998. Held in Washington, D.C., the march coincided with an International Day of Madness, creating an opportunity for psychiatric consumers/survivors to raise their voices and increase their visibility.

Those people lock the door before us
And stay on the other side.
They inject us with poison
And electrocute our soul.
They are those who hold the keys
And pull all the strings.

Those people take our money
And use it to build prisons.
They go home at night to suburban houses
Where we are not allowed to live.

We the people are People Who
Are cherished by none
Except our own.

Our feet move to the beat of free verse,
And our souls sing in silent places.
Warm blood flows through invisible hearts
That can't be treated.

We are not puppets, there are no strings attached.
We cut the cord and walk through open doors.

We are People Who
Leap and dare to imagine.
We spend our talent
Furnishing the place of hope.
We are people who will treat those others
By acting out, and dreaming.

Those people are People Who
Are our own.
We are people who
Also care for them.

Source: Clay, Sally. 1998. "People Who." Available at: http://home.earthlink.net/~sallyclay/z.poems/peoplewho.html. Reprinted by permission of Sally Clay.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (United States)

This act, P.L. 106–402, is the 2000 reauthorization of the original act (P.L. 95–602); it is significant in being the first introduction (in statutory terms) of the term developmental disabilities (DD). The general intent was (and largely remains) to fill in the gap on services, policy, and planning for DD populations. The national network of state DD Councils, Protection and Advocacy agencies, and University Centers for Excellence are funded under DD Act authorization.

Developmental Disability

(A) In General

The term “developmental disability” means a severe, chronic disability of an individual that—

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

- (I) Self-care.
- (II) Receptive and expressive language.
- (III) Learning.
- (IV) Mobility.
- (V) Self-direction.
- (VI) Capacity for independent living.
- (VII) Economic self-sufficiency; and

(v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

114 Stat. 1684 P.L. 106–402 (2000).

Jim Ferris, “Poems with Disabilities” (2000)

The Americans with Disabilities Act signaled a change in awareness of people with disabilities in the United States. Wheelchair-accessible parking spaces and bathroom stalls became more common, and resentment toward disabled people often was expressed in absurd jokes about extreme accommodations. This poem spoofs those jokes and the attitudes that spawn them while suggesting that disabled people are deserving of prominent places in the American scene.

I’m sorry—this space is reserved
For poems with disabilities. I know
It’s one of the best spaces in the book,
But the Poems with Disabilities Act
Requires us to make reasonable
Accommodations for poems that aren’t
Normal. There is a nice space just
A few pages over—in fact (don’t
Tell anyone) I think it’s better
Than this one. I myself prefer it.
Actually I don’t see any of those
Poems right now myself, but you never know
When one might show up, so we have to keep
This space open. You can’t always tell
Just from looking at them, either. Sometimes
They’ll look just like a regular poem
When they roll in—you’re reading along
And suddenly everything
Changes, the world tilts
A little, angle of vision
Jumps, focus
Shifts. You remember
Your aunt died of cancer at just your age
And maybe yesterday’s twinge means
Something after all. Your sloppy,
Fragile heart beats
A little faster
And then you know.
You just know.
And the poem is right
Where it
belongs.

Source: Ferris, Jim. 2000. “Poems with Disabilities.” *Ragged Edge Online* (March/April). Available at: http://www.raggededge magazine .com/0300/b0300poem.htm. Reprinted by permission.

Parade by Susan Nussbaum (2000)

In this dramatic satire, Susan Nussbaum takes on critical disability issues such as physician-assisted suicide and medical health care rationing. The work establishes the imperative of normative “good” health as an oppressive expectation for disabled people in late twentieth-century United States.

Two disabled women enter.

One Glad we got here early.

Two Mmm. Wanna get good spots.

One Because why go to the trouble if you can’t see everything.

Two No, I agree. This is—you know, we’ll be able to see the whole—

One We won’t miss a thing.

Pause while they look through their binoculars.

Two So it’s just us?

One What? No, Jeanette couldn’t come.

Two She just couldn’t make it, huh?

One No, she wasn’t—

Two Feeling well?

One She wasn't feeling—she's fine but she wasn't feeling—

Two Up to it?

One Right. I don't know. Well, she's caught in that cycle of—

Two Yeah.

One Oh, well.

Two It happens.

One Anyway, I'm glad we're here.

Two Yeah. Can I say something?

One What?

Two I don't want to sound—jumping the gun—but—and I don't want to—she has an aura of—I just don't like being with her. I like her, don't—I'm not saying I don't respect her.

Disability protester at the 2004 World Social Forum in Mumbai, India, holding sign stating that the venue was not accessible to disabled participants.

Source: Photo by Meenu Bhambhani.

One Well, there's a difference between liking and spending time with. I like her, too, but she doesn't—I don't know . . .

Two Take care of herself.

One She doesn't take care of herself.

Two And, you know, what does that say about her? Between the two of us. It reflects back.

One I'm glad you said it, and not me. Really, thank you.

Two It can have the effect of making *us* look—like we're . . .

One No, I know. Is it wrong to be aware of the effect of how it looks to be with people who, for whatever reason, don't have a *consciousness* about what's— about priorities—the things *we* feel are important? I don't think so.

Two I'm sick of feeling guilty about it.

One Me, too! Exactly!

Beat.

Two But you look well.

One Thank you. Thanks. I am well. I feel good. What about you? How's your quality of life?

Two Very high, thanks. I've been moving up in the point range.

One Good for you. Where—do you mind if I ask—where on the scale?

Two I was a four, now I'm a five.

One You're kidding. What did you do? I mean, what'd you—?

Two I've been contributing a lot lately. Which makes me feel great and which you have to feel great in order to do! A vicious cycle. But not *vicious,* just cyclical.

One A whole point just for contributing. No, but that's great. From four to five.

Two It's a good feeling.

One Mm hmm.

Two So. What're you these days?

One Me? I'm a seven.

Two Whoa. That's—I thought I was in good shape. You're a seven?

One Yup. You know, because I don't lose credit for burdening.

Two Individual or collective?

One Oh, I was an individual burden. What about you?

Two Oh, same old. I'm a burden to several individuals and society as a whole.

One Actually, I wasn't really a burden, but my mom needed the extra credit for caretaking, so she claimed me as a burden. So, technically—

Two Officially, you were a burden.

One Uh huh.

Two Is that legal? For your mom to—?

One What? Yeah. Well, pretty much. I mean . . .

Two So—your mom needed the extra points . . .

One Before she was kevorked, yeah.

Two Huh.

One What? It's not like we were making *money* off it. It's not like we're Point Scalpers, or anything.

Two No, I know. I mean, it's not like you were *selling* your mom the extra credit. Which, far be it from me—I'd do the same thing, except my mom was liberated in one of the early Ethical Life Rationings. So, you know . . .

One You must be proud.

Two Oh, yeah. She was a great example. She was very unselfish.

One How old was she?

Two Sixty.

One Well, that's the age.

Two Yeah.

One That's when my mom's quality of life scale started dropping. And after she broke her hip and became a burden to society herself, it just got to the point where her safeguards were really, you know, in the toilet, and finally she just said forget it and got liberated.

Two That's show biz.

Beat.

Well, at least you got that extra point back.

One Yeah, I'm happy about that. Let's face it, I needed the point. I'm still a collective burden.

Two Well, who isn't? The collective burden stuff is killing me. So to speak. Ha ha.

One I know. It's not so much the environmental category as the cosmetic. It's an automatic two points off the quality of life scale to be born this way.

Two Sure. Plus, the extra points off as you grow out of childhood. Losing the cuteness credits.

One Well, the kids are cuter.

Two Yeah, they get those little wheelchairs . . .

One Remember those telethons they used to have? With the kids?

Two Yeah, and people would actually give money, right? They would donate all this—

One Oh, yeah, they'd raise millions and millions of dollars and—

Two Hundreds of millions of—

One God, I wonder what ever happened to all that money.

Two No one knows.

Beat.

One And what happened to that guy? The—you know—the telethon guy?

Two Murdered.

One Oh, right, yeah. That real gruesome—

Two Yeah. Anyway, it's weird, because for me, I lose a point and a half for—you know, the sight of me makes people—feel agitated—

One So do I.

Two Wait. You lose points in addition to the—

One Right. Public Physical Appropriateness Ratio. Minus one point five.

Two I'm surprised we're the same.

One 1.5's pretty standard. I mean, we probably upset people about the same amount.

Two I guess. I get a .3 credit, though.

One How come?

Two For being a visual reminder to wear seatbelts. So . . .

One Wow, that's a—lucky girl. Hey, look, that guy must be in the parade.

Two Where? That guy?

One Yeah, in the Eskimo outfit.

Two Oh, right. The Eskimo float.

One Do they still do that?

Two What?

One Walk out into glaciers and stuff when they're too old to be useful?

Two I don't think there're very many of 'em left to do that. They die the regular way, I think. They just have an Eskimo thing in the parade as a, like a symbol . . .

One Like an example . . .

Two Yeah, like a nostalgia thing.

One Hey, heads up. There's a doctor.

Two Where?

One There! There! Jesus, he's walking right toward us!

Two Oh, shit! (*calls out*) Hello, Doctor! How's your quality of life today?

One Beautiful day for the parade, Doctor!

Two Fine, thank you! High quality today, Doctor! Feeling like a full ten today!

One I feel like a twelve, Doctor!

Two Who needs safeguards on a day like today!

One Enjoy the parade, Doctor!

Two Viva Voluntary Self-elimination!

They salute as Doctor passes.

One Doctors make me nervous.

Two Tell me about it.

One Yeah. Hey look, there's the Global Insurance Corporation float! What—can you see what the banner says?

They take out their binoculars.

Two "Better Dead Than Sick in Bed."

One Oh, uh huh. Boy, I guess it's really starting now.

Two Yeah, here goes. There's supposed to be some new stuff this year. New floats.

One Well, new legislation. So, naturally. I—you know, I do feel kind of bad Jeanette couldn't make it.

Two I know. Even though she drives me crazy, it's not like I don't kind of miss her.

One Not that I think she—I mean, she's *fine*—

Two Right. She's doing fine, she's—she's not feeling well for one *day,* it's not the end of—

One No, it's not.

Two Which is all it is. Right?

One I told her she had to take *care* of herself better. Get her points up.

Two Name of the game.

Beat.

They look through binoculars.

Two Look, the Doctor's float is passing. I like their new uniforms, don't you?

One Oh, absolutely, I love leather. I wonder if my doctor's up there.

Two Mine is. He's real patriotic.

One Didn't your doctor write that book? That real famous—what's it called?

Two "The Depression Myth: No Excuses."

One Right. He's really a hardliner, I guess.

Two Let's just say I better not get a bad case of the flu.

One Hey, remember that time we were—the three of us—you, me and Jeanette—and we were at that concert—and—god, remember that song?—about how ethical life rationing was this forced thing—

Two And the police came and stopped the concert and Jeanette wouldn't—

One Yeah, she refused to leave and she started shouting and stuff and—

Two She was chanting—wait, what was it—I don't know, something really—

One Right, right. The Supreme Court are Hit Men, that kind of—

Two She was always a radical.

One It's turns people off to say the Supreme Court are hit men. People don't wanna hear that.

Two I don't wanna hear it.

One Too extreme.

Two Way out there.

Beat.

They look through their binoculars.

One There's the Afterlife float. Wow. Pretty.

Two They must spend a lot of money on that one.

One Mmm. Well, they have it. Afterlife Industry is huge. Wow. The Afterlife must really be fantastic.

Two You can see why people look forward to it.

One You know, in ancient Egypt, the pharoahs would be buried with all their earthly posessions, like gold and stuff.

Two I know. It's amazing the stuff people believe in.

One Really.

They look through binocs.

Two Ooh, look at that float. That's beautiful. Someone must've spent ages blowing up all those latex exam gloves.

One Where? Oh, the Preventive Chronic Care Float. Yeah. That's new this year. I read all about it in the Liberation newsletter.

Two Look, it's so big they had to have two floats.

One Huh? Oh, no, the second float is for the surpluses.

Two What?

One You know, the surplus people.

Two Oh, yeah. That's a new thing this year. You know, some of those people don't even look sick.

One Oh, well, you don't have to be sick anymore. To be euthanized.

Two What? But—

One Well, that's the preventive part. Because they found out you can sort of predict who's gonna get sick, how much it'll cost, and you know, that kinda thing.

Two They can predict? Boy, it's amazing what they can—

One Uh huh. Like people from a lower income brackett, who don't have insurance—

Two They don't take very good care of themselves—

One Yeah, so they can predict that those people are gonna be like, Burden City.

Two Wow.

One And they put this float at the end of the parade, and after the parade, the deal is all the surplus people go off and get euthanized.

Two That's why it's at the end. Sort of a *piece de resistance* thing.

One I mean, there's all these incentives and stuff. Tax breaks for survivors. It's really a good deal for some people. Some of them, they don't have jobs, they don't have skills, so you know.

Two Their quality of life numbers must stink. I guess, you know, the thing is, if they want to live, they'll do something about their situation. Work on their numbers, try not to burden. Like we did.

They look thru binocs.

Two Hey, wait. Wait! Look! That's her!

One What? Who?

Two Jeanette! She's on that float!

One Oh my god! What's she—? She said she couldn't come. She said she wouldn't be here. There must be a mistake!

Two But that's her. Why would she volunteer to be liberated? She doesn't even believe in it.

One She didn't volunteer! They—Somebody made a mistake! (*calling out*) Hey! Hey! You've got the wrong person up there! Hey!

Two (under her breath)

Wait! Stop! Are you crazy? If she's up there it's because she's supposed to be up there. Don't make a big thing of it! You're just gonna get yourself—both of us—a lot of attention that we don't need. Just get a grip on yourself. Just calm down.

One But—

Two Just shut up!

They look through their binocs.

One Well, that's it. Parade's over.

Two Yeah.

One I'm sorry I—I'm sorry about that outburst.

Two Well. No harm done.

One No.

Two That's the main thing.

One Right. It came as a surprise. Seeing someone you know makes you think how—it makes you aware of your own—

Two Yeah, but we're in good shape. Our numbers are up and our safeguards are in place.

Just keep reminding yourself of that.

One She was always a radical.

Two That's right. I just didn't want anyone to think you and she were—Everyone is so paranoid these days.

One We're in good shape.

Two No, I know. We are.

One That's right.

Two So I guess I'll see you.

One Yeah. Well, this was fun.

Two It was. The floats were really—

One They were absolutely—

Two They were terrif.

One So, dinner next week, okay?

Two Sounds good.

One Okay. Keep your numbers up!

Two You, too.

One and Two Viva Voluntary Self-elimination!

Blackout.

From the Charter of Fundamental Rights of the European Union, (2000)

The Charter of Fundamental Rights of the European Union is the result of a unique procedure in the history of the European Union (EU). For the first time, the EU proclaimed the civil, political, economic, and social rights of European citizens and all persons living in the EU. On December 7, 2000, the presidents of the European Parliament, of the Council, and of the Commission signed and proclaimed the Charter on behalf of their institutions in Nice, France.

SOLEMN PROCLAMATION

The European Parliament, the Council and the Commission solemnly proclaim the text below as the Charter of Fundamental Rights of the European Union.

Done at Nice on the seventh day of December in the year two thousand.

PREAMBLE

The peoples of Europe, in creating an ever closer union among them, are resolved to share a peaceful future based on common values.

Conscious of its spiritual and moral heritage, the Union is founded on the indivisible, universal values of human dignity, freedom, equality and solidarity; it is based on the principles of democracy and the rule of law. It places the individual at the heart of its activities, by establishing the citizenship of the Union and by creating an area of freedom, security and justice.

The Union contributes to the preservation and to the development of these common values while respecting the diversity of the cultures and traditions of the peoples of Europe as well as the national identities of the Member States and the organisation of their public authorities at national, regional and local levels; it seeks to promote balanced and sustainable development and ensures free movement of persons, goods, services and capital, and the freedom of establishment.

To this end, it is necessary to strengthen the protection of fundamental rights in the light of changes in society, social progress and scientific and technological developments by making those rights more visible in a Charter.

This Charter reaffirms, with due regard for the powers and tasks of the Community and the Union and the principle of subsidiarity, the rights as they result, in particular, from the constitutional traditions and international obligations common to the Member States, the Treaty on European Union, the Community Treaties, the European Convention for the Protection of Human Rights and Fundamental Freedoms, the Social Charters adopted by the Community and by the Council of Europe and the case-law of the Court of Justice of the European Communities and of the European Court of Human Rights.

Enjoyment of these rights entails responsibilities and duties with regard to other persons, to the human community and to future generations.

The Union therefore recognises the rights, freedoms and principles set out hereafter.

CHAPTER III

EQUALITY

Article 20
Equality before the law

Everyone is equal before the law.

Article 21
Non-discrimination

1. Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited. . . .

Article 26
Integration of persons with disabilities

The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

Source: Charter of Fundamental Rights of the European Union. 2000. *Official Journal C 364* (December 18), pp. 0001–0022.

Council Decision of 3 December 2001 on the European Year of People with Disabilities 2003 (2001)

The Council Decision is the document that establishes agreement among European countries to hold a year dedicated to the forwarding of the political agenda of disabled people. Full inclusion involves the development of a barrier-free Europe as an ideal of access for all individuals.

THE COUNCIL OF THE EUROPEAN UNION,

Having regard to the Treaty establishing the European Community, and in particular Article 13 thereof,

Having regard to the proposal from the Commission,

Having regard to the opinion of the European Parliament,

Having regard to the opinion of the Economic and Social Committee,

Having regard to the opinion of the Committee of the Regions,

Whereas:

(1) The promotion of a high level of employment and of social protection, and the raising of the standard of living and quality of life of the population of the Member States, are objectives of the European Community.

(2) The Community Charter of the Fundamental Social Rights of Workers recognises the need to take appropriate action for the social and economic integration of disabled people.

(3) The Resolution of the Council and the Ministers for Education, meeting within the Council, of 31 May 1990 concerning integration of children and young people with disabilities into ordinary systems of education stresses that "the Member States have agreed to intensify, where necessary, their efforts to integrate or encourage integration of pupils and students with disabilities, in all appropriate cases, into the ordinary education system."

(4) The Resolution of the Council and of the Representatives of the Governments of the Member States meeting within the Council of 20 December 1996 on equality of opportunity for people with disabilities, and the Council Resolution of 17 June 1999 on equal employment opportunities for people with disabilities, reaffirm the basic human rights of disabled people to equal access to social and economic opportunities.

Disability protest at the World Social Forum in Mumbai, India, 2004. Participants from across India shout slogans such as "WSF Shame! Shame!" and "WSF Inaccessible, Inaccessible!"

Source: National Centre for Promotion of Employment for Disabled People, New Delhi, India.

(5) The conclusions of the Lisbon European Council of 23 and 24 March 2000 call upon Member States to take greater account of social exclusion in their employment, education and training, health and housing policies and to define priority actions for specific target groups, such as people with disabilities.

(6) The European social agenda approved by the Nice European Council meeting on 7, 8 and 9 December 2000 states that the European Union will develop, in particular during the European Year of People with Disabilities (2003), "all action intended to bring about the fuller integration of disabled people in all areas of life."

(7) The year 2003 will mark the 10th anniversary of the adoption by the UN General Assembly of the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, which have enabled considerable progress to be made in an approach to disability in accordance with human rights principles.

(8) This Decision respects fundamental rights and observes the principles recognised in particular by the Charter of Fundamental Rights of the European Union. In particular, this Decision seeks to promote application of the principles of non-discrimination and integration of people with disabilities.

(9) The European Parliament, the Economic and Social Committee and the Committee of the Regions have all urged the Community to strengthen its contribution to efforts in Member States to promote equal opportunities for people with disabilities, with a view to their integration into society.

(10) On 10 May 2000 the Commission adopted a communication entitled "Towards a barrier-free Europe for people with disabilities," in which it commits itself to developing and supporting a comprehensive and integrated strategy to tackle social, architectural and design barriers that unnecessarily restrict access for people with disabilities to social and economic

opportunities. The Parliament has unanimously adopted a similar resolution.

(11) The general framework in favour of equal treatment in employment and occupation provided for by Directive 2000/78/EC and the Community action programme to combat discrimination in order to support and supplement legislative measures at Community and Member State level set up by Decision 2000/ 750/EC aim at changing practices and attitudes by mobilising the players involved and fostering the exchange of information and good practice.

(12) Since exclusion from the labour market of people with disabilities is inextricably linked to problems of attitude and a lack of information about disability, it is necessary to increase society's understanding of the rights, needs and potential of disabled persons, and a joint effort by all the "different partners is required to develop and promote a flow of information and an exchange of good practice.

(13) Raising awareness relies primarily on effective action at Member State level which should be supplemented by concerted efforts at Community level. The European Year could act as a catalyst in raising awareness and in building momentum.

(14) Consistency and complementarity with other Community action is needed, in particular with action to combat discrimination and social exclusion, and to promote human rights, education, training and gender equality.

(15) The joint statement of 20 July 2000 provides for the budget authority to deliver an opinion on whether the new proposals with budgetary implications are compatible with the financial framework, without any reduction in existing policies.

(16) The Agreement on the European Economic Area (EEA Agreement) provides for closer cooperation in the social field between the European Community and its Member States, on the one hand, and the countries of the European Free Trade Association participating in the European Economic Area (EFTA/EEA), on the other. Provision should be made for participation, on the one hand, by the candidate countries of central and eastern Europe, in accordance with the conditions established in the Europe Agreements, in their additional protocols and in the decisions of the respective Association Councils, on the other hand, by Cyprus, Malta and Turkey, funded by additional appropriations in accordance with the procedures to be agreed with those countries.

(17) A financial reference amount within the meaning of paragraph 34 of the Interinstitutional Agreement of 6 May 1999 between the European Parliament, the Council and the Commission on budgetary discipline and improvement of the budgetary procedure is included in this Decision without thereby affecting the powers of the budgetary authority as they are defined by the Treaty.

(18) Since the objectives of the proposed action aimed at generating at European level awareness of the rights of people with disabilities, cannot be adequately achieved by the Member States on account, inter alia, of the need for multilateral partnerships, the transnational exchange of information and the Community-wide dissemination of good practice, and can therefore be better achieved at Community level, the Community may adopt measures, in accordance with the principle of subsidiarity as set out in Article 5 of the Treaty. In accordance with the principle of proportionality, as set out in that Article, this Decision does not go beyond what is necessary to achieve those objectives.

(19) The measures necessary for the implementation of this Decision should be adopted in accordance with Council Decision 1999/468/EC of 28 June 1999 laying down the procedures for the exercise of implementing powers conferred on the Commission,

HAS DECIDED AS FOLLOWS:

Article 1
Establishment of the European Year of People with Disabilities

The year 2003 shall be designated as the "European Year of People with Disabilities."

Article 2
Objectives

The objectives of the European Year of People with Disabilities shall be:

(a) to raise awareness of the rights of people with disabilities to protection against discrimination and to full and equal enjoyment of their rights;

(b) to encourage reflection on and discussion of the measures needed to promote equal opportunities for people with disabilities in Europe;

(c) to promote the exchange of experience of good practice and effective strategies devised at local, national and European level;

(d) to reinforce the cooperation between all parties concerned, namely government, the social partners, NGOs [nongovernmental organizations], the social services, the private sector, communities, voluntary sector groups, people with disabilities and their families;

(e) to improve communication regarding disability and promote a positive image of people with disabilities;

(f) to raise awareness of the heterogeneity of people with disabilities and of the various kinds of disability;

(g) to raise awareness of the multiple discrimination facing people with disabilities;

(h) to pay special attention to awareness of the right of children and young people with disabilities to equality in education, so as to encourage and support their full integration in society and to promote the development of European cooperation between those professionally involved in the education of children and young people with disabilities, in order to improve the integration of pupils and students with special needs in ordinary or specialised establishments and in national and European exchange programmes.

Article 3
Content of measures

1. The measures designed to meet the objectives set out in Article 2 may entail the development or the provision of support to:

(a) meetings and events;

(b) information and promotional campaigns throughout the Member States;

(c) cooperation with broadcasting and media organisations;

(d) surveys and studies on a Community-wide scale;

2. Details of the measures referred to in paragraph 1 are set out in the Annex.

Article 4
Implementation at Community level

The Commission shall ensure the implementation of the Community actions covered by this Decision in conformity with the Annex.

It shall conduct a regular exchange of views with representatives of people with disabilities at Community level on the design, implementation and follow-up of the European Year of People with Disabilities. To that end, the Commission shall make the relevant information available to these representatives. The Commission shall inform the Committee established under Article 6(1) of their opinion.

Article 5
Cooperation and implementation at national level

1. Each Member State shall be responsible for the coordination and implementation at national level of the measures provided for in this Decision, including the selection of projects under Part B of the Annex.

To this end, each Member State shall establish or designate a national coordinating body or an equivalent body to organise the participation of the Member State in the European Year of People with Disabilities. This body shall ensure that it is representative of a range of organisations representing people with disabilities and other relevant stakeholders.

2. The measures required to determine global grants to be allocated to the Member States to support actions at national, regional and local level shall be adopted in accordance with the procedure referred to in Article 6(2). Global grants shall be awarded only to public-law bodies or bodies which have a public-service mission guaranteed by the Member States.

3. The procedure for the use of global grants shall be subject to an agreement between the Commission and the Member State concerned.

The procedure shall detail in particular, in compliance with the Financial Regulation of 21 December 1977 applicable to the general budget of the European Communities:

(a) the measures to be implemented;

(b) the criteria for choosing beneficiaries;

(c) the conditions and rates of assistance;

(d) the arrangements for monitoring, evaluating and ensuring the financial control of the global grant.

Article 6
Committee

1. The Commission shall be assisted by a Committee, (hereinafter referred to as “the Committee”).

2. Where reference is made to this paragraph, Articles 3 and 7 of Decision 1999/468/EC shall apply.

3. The Committee shall adopt its rules of procedure.

Article 7
Financial arrangements

1. Measures which are Community-wide in nature, as described in Part A of the Annex, may be subsidised up to 80 % or give rise to procurement contracts financed from the general budget of the European Communities.

2. Measures which are local, regional or national, possibly with a transnational dimension, as described in Part B of the Annex, may be co-financed from the general budget of the European Communities up to a maximum of 50 % of the total cost.

Article 8
Application and selection procedure

1. Decisions on the financing and co-financing of measures under Article 7(1) shall be adopted in accordance with the advisory procedure referred to in Article 6(2). The Commission shall ensure a balanced distribution among the different fields of activity involved.

2. Requests for financial assistance for measures under Article 7(2) shall be submitted to the Member States. On the basis of the opinion expressed by the national coordinating bodies, Member States shall select beneficiaries and allocate financial assistance to the applicants selected in accordance with Article 5(3).

Article 9
Consistency and complementarity

The Commission, in cooperation with the Member States, shall ensure consistency between the measures provided for in this Decision and other Community actions and initiatives.

The Commission shall also ensure that appropriate efforts are made to enable people with disabilities to participate equally in Community programmes and initiatives.

It shall also ensure optimal complementarity between the European Year of People with Disabilities and other existing Community, national and regional initiatives and resources, where these can contribute to fulfilling the objectives of the European Year of People with Disabilities.

Article 10

Participation by the EFTA/EEA countries, the associated countries of central and eastern Europe, Cyprus, Malta and Turkey

The European Year of People with Disabilities shall be open to participation by the following countries:

(a) EFTA/EEA countries in accordance with the conditions established in the EEA Agreement;

(b) the candidate countries of central and eastern Europe . . . in accordance with the conditions established in the Europe Agreements, in their additional protocols and in the decisions of the respective Association Councils;

(c) Cyprus, Malta and Turkey, their participation being funded by additional appropriations in accordance with procedures to be agreed with those countries.

Article 11
Budget

1. The financial reference amount for the implementation of this Decision is hereby set at EUR 12 million.

2. The annual appropriations shall be authorised by the budgetary authority within the limits of the financial perspective.

3. Actions aimed at preparing the launching of the European Year of People with Disabilities may be financed as from 1 January 2002.

Article 2
International cooperation

Within the framework of this Decision, the Commission may cooperate with relevant international organisations.

Article 13
Monitoring and evaluation

The Commission shall submit, by 31 December 2004 at the latest, a report to the European Parliament, the Council, the Economic and Social Committee and the Committee of the Regions on the implementation, results and overall assessment of the measures provided for in this Decision, including an assessment of the long-term effects of the measures. The Commission shall ensure that the report is drawn up in formats accessible to people with disabilities.

Article 14
Entry into force

This Decision shall be published in the Official Journal of the European Communities.

It shall take effect on the day of its publication.

Done at Brussels, 3 December 2001.
For the Council
The President
F. Vandenbroucke

Source: European Council. 2001. 2001/903/EC: Council Decision of 3 December 2001 on the European Year of People with Disabilities 2003. *Official Journal L 335* (December 19), pp. 0015–0020.

The Disability Media Action and Awareness Project, "'Do You Mean to Say What We Hear?' A Disability Language Reference"

(2000–2001)

From 2000 to 2001 a group of disabled activists, academics, artists, and community residents in Chicago compiled the following guidelines about appropriate language use in coverage of disability issues. The creation of such guidelines was intended to steer journalists toward less objectifying and demeaning portrayals of disabled people and to demonstrate the lack of objectivity in current rhetorical constructions of disability in mainstream U.S. journalism.

We include below some "street" perspectives on terms that continue to circulate around (and even impinge upon) people with disabilities. These terms have been selected as worthy of more thoughtfulness. They name affinities (and not) among a group of people with disabilities who have put some thought into the matter of representation; the mainstream media; diagnostic labels; and disability subcultures. The definitions reflect widely shared perspectives across Chicago disability groups.

Terms were compiled by the Disability Media Action and Awareness Project—a group that monitors coverage of disability communities and disability issues in the Chicago media. Our purpose? To serve as a link between Chicago media professionals and the authentic voices of disabled persons in Chicago.

Language is important because our language reflects our ideas about being human! The terms we use when referring to each other shape our values. We want to help media professionals reflect on terms that have traditionally dehumanized people with disabilities. This is not a comprehensive list and not everyone would agree. These are just the twists of language that most sock it to us in the gut—good and bad.

—The Disability Media Action and Awareness Project, University of Illinois at Chicago, Disability Studies a.k.a. Michael Ervin, Sharon Snyder, Gary Arnold, Larry Biondi, Kenneth Borst, Will Cowing, Stephen Drake, Herbert Hoffman, Ayo Maat, Gloria Nichols, Joan Porter, Harvey Rabin, and Monique Streff.

Blind People: Technically blind people recognize one another as those with 2200 or less sight with correction. Those with limited sight are usually referred to as people with low vision. But some people who are blind think this is a nit-picky distinction. They say you are either legally blind or not.

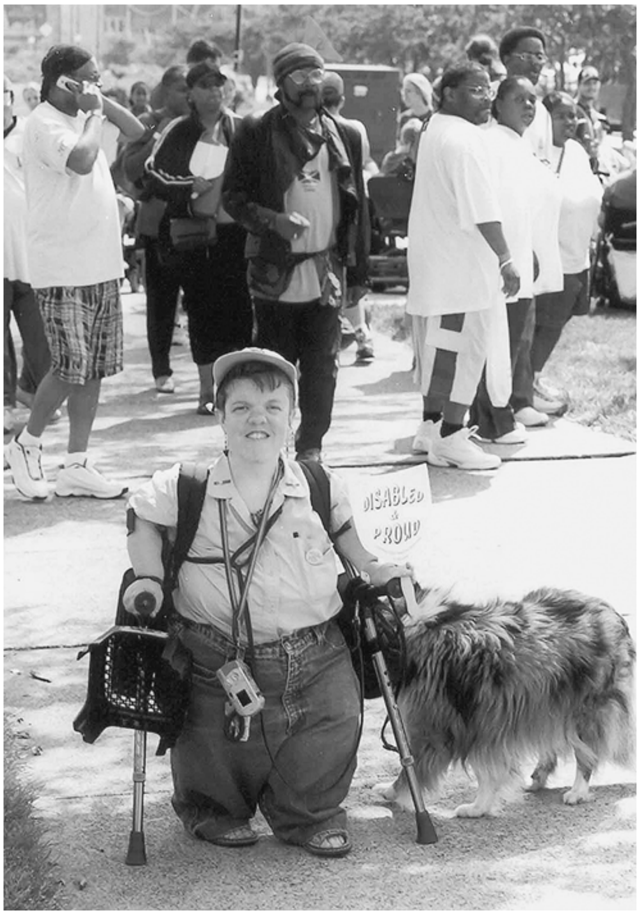
Cerebral Palsy: The most common misconception about people with cerebral palsy is that they have intellectual problems involving thinking and reasoning. Most people who bear the label C.P. have cognition that operates in similar ways to other general non disabled groups. Cerebral palsy is a misleading term when you think about it. Palsy is an archaic word meaning muscular inability to move part or all of the body. Put it all together and it implies a paralyzed brain. No one has come up with a better term so go ahead and use it. But understand its shortcomings when applied to real people.

Confined to a wheelchair: Confined means "limited, small, cramped or completely enclosed." A wheelchair is the opposite. It is liberating. Why not be accurate and say he/she is a wheelchair user or uses a wheelchair?

Courageous: Why are we insulted when someone says we are brave and courageous? Doesn't everyone want to be considered brave and courageous? Well, these words are often used to describe people with disabilities who are just living their lives. They are doing nothing spectacular, just activities everyone does. But if nothing is expected of us, when we are successful it may be viewed as extraordinary. To say we are brave and courageous just for living life implies that we would be justified in giving up and doing nothing.

Crippled: Before we get too far we should talk about out and out Hate Speech usage such as Cripple, Retard, Spastic, Freak. These are words that kept us fearful when we were growing up. Some still use crippled as "completely ruined or damaged." Of course, crippled is archaic, too, and still sounds like Victorian back bedrooms. Note: we sometimes call ourselves crippled to "be real" and nitty gritty among ourselves—or to off-set the hate tossed our way. That does not mean you should.

Deaf and dumb/mute: This was used a lot in an old Jane Wyman movie, which shows how out of date it is. Dumb implies stupid, and mute means unable to speak. Most deaf people can use their voices, though many choose not to. These terms should be consigned to the linguistic basement. Why not he/she does not speak with his/her voice?



Proud Short-Statured Woman and Dog at the Chicago Disability Pride Parade, 2004.

Defects: As in "only you can prevent birth defects." Propagandizes the idea that a disabled person should be prevented instead of accepted and included. Assumes everyone's body falls short of some ideal "whole." An inaccurate and frequently abusive idea.

Guide dog: The proper term for dogs assisting blind people. Seeing-eye dog is the name of one of the guide dog training schools. Dogs that assist sighted people with disabilities are called service dogs.

Invalid: Changing the accent doesn't change the meaning of the word. It wouldn't be any less offensive to call a woman a bim-BO. No matter how you slice it, it still means In-VA-lid.

Handicapped: We don't like this one for a lot of reasons. Mainly it places the emphasis on the wrong spot by saying the disability is what handicaps us. Sounds like one is the perpetual object of charity, emblem of a telethon, or in need of pity. Barriers are what handicap. Besides, "handicapped" sounds whiney, doesn't it?

Hard of hearing: This has emerged again as a term for those who have partial hearing. And no, people who have partial sight are not hard of sight.

Mental Retardation: This sounds like a permanent unalterable predicament—that one's life and brain [are] fixed and that one will be forever stunted. Developmental delay implies that people are always catching up rather than perceiving the world in cognitively varied ways. Please say people with cognitive or developmental disabilities.

Midget: Went out of fashion with court dwarves. Seems to assume that everyone of short stature is there to entertain. Assumes that the person's size accounts for their amicable or sometimes devilish personality. Please say person of short stature.

Non disabled: Whatever.

Normal: Who's to say what is normal? Let ye who is normal cast the first stone.

Overcome: This implies that [those who don't] overcome their disability . . . are the one[s] with the problem. They are either not trying hard enough or don't have the right attitude. It's not our disabilities we have to overcome. It's the barriers that disallow our participation.

Patient: This implies that we are always ill or in need of being fixed. People with disabilities are only patients in our relations with our doctors, just like the nondisabled.

People with disabilities: This has evolved as the proper term because it puts the person first. We know it can become literarily cumbersome when used repeatedly. "Disabled people" is fine and actually preferred in some countries as a claim of pride and solidarity. "The disabled," however, makes everyone sound like an item or immovable object.

Physically Challenged, Handicapable, Differently-abled: Ridiculous terms that are used by people who seem uncomfortable with disabled people or with their own disabilities. Why bend over backward not to say disabled as if it is a bad word?

Special: The word gives an inaccurate impression that people born with disabilities get special treatment throughout life. It even perpetuates the myth that children with disabilities are spoiled. Sugar coats an experience or makes it cute. Even sounds like luck is involved!

Suffering: Bears the automatic coding that a disabled life is miserable such as in "he suffers from brain damage." Instead of saying a person suffers from, is stricken by or afflicted with (etc!) a disability, [j]ust say he/she has a disability.

Vegetable: A favorite of legal defense teams and those of pro-euthanasia persuasions. Someone who is supposed to be a burden upon family, society and country. A waste of space. No longer animal, thus no longer human. What next, mineral?

Victim: Assumes that all people with disabilities are suffering from some great tragedy. When people with disabilities are victims, it's usually for reasons that have little to do with the bodily experiences from their disability. See also "burden."

Wheelchair bound: Makes it sound as if we are tied up, being held hostage. Some people with disabilities are into bondage, but not all. No one is bound to their wheelchair. Everyone gets out of it at least once a day.

A Special Bonus for Being a Good Sport and Sticking It Out!! SLANG!

Some throw these words around with abandon while others find some of them too dangerous in any context, no matter how self-deprecating or ironic. WARNING: DO NOT ATTEMPT TO USE WITHOUT PROPER CONTEXT:

Some examples:

Blind people: Blinks, bats.

People with physical disabilities: Gimps, crips.

Nondisabled people: Uprights, verticals, walkie-talkies, bipeds.

Super duper overcoming disabled people (i.e. jocks): Supercrips.

Super duper passive and subservient disabled people: Tiny Tims.

▣ Apology on the 75th Anniversary of the *Buck v. Bell* Decision (2002)

In the most notorious sterilization case, Buck v. Bell (1927; see excerpt from the decision on pp. 390–391, this volume), the argument supporting sterilization was based on the longstanding prejudice that cognitively disabled women were more promiscuous than nondisabled women. Eugenics historians have since established that Carrie Buck (the cognitively disabled woman targeted in the case) had been raped by a relative of her foster parents. The statement, by Virginia Governor Mark R. Warner, was read by Delegate Mitch Van Yahres at a ceremony on May 2, 2002, to dedicate a highway marker commemorating the Buck v. Bell decision. The highway marker's wording was authorized by the Virginia Board of Historic Resources.

I am sorry that I am unable to be with you on this important occasion.

In 1924, Virginia, like many states, passed a law permitting involuntary sterilization. In 1927, Carrie Buck was the first person sterilized by the Commonwealth pursuant to that law. Virginia's actions were upheld by the Supreme Court of the United States, and the government ultimately sterilized approximately 8,000 people.

Last year, the General Assembly passed a resolution expressing profound regret for the Commonwealth's role in the eugenics movement. Today, I offer the Commonwealth's sincere apology for Virginia's participation in eugenics. As I have previously noted, the eugenics movement was a shameful effort in which state government never should have been involved.

We must remember the Commonwealth's past mistakes in order to prevent them from recurring. This highway marker will serve as a constant reminder of how our government failed its citizens and how we must always strive to do better.

▣ International Commemoration Committee on Eugenic Mass Murder (2003)

On May 2, 2003, the following elegy was read in public ceremonies throughout Europe and the United States. These commemoration events sought to remind populations of the eugenics-based killings in National Socialist Germany that ultimately led to the Holocaust against Jews, Romany ("gypsy"), and gay people. The document details some of the processes and technology implemented against those with disabilities and psychiatric diagnoses in German psychiatric institutions. These practices were later exported to Nazi death camps during the implementation of the "final solution" involving mass extermination.

In Memoriam,

In 1939 at a psychiatric institution in Germany a group of patients were told to undress and take a shower. After the "shower" door was locked, one psychiatrist turned a valve, releasing poisonous gas through pipes into the "shower" room. Then the psychiatrists looked on through a glass aperture as the patients slowly asphyxiated to death in the fumes.

Disabled protesters at the 2004 World Social Forum in Mumbai, India, march toward the podium to press for their demands.

Source: National Centre for Promotion of Employment for Disabled People, New Delhi, India.

By 1941, before the mass murders in the concentration camps had begun, hundreds of thousands of defenseless people, men, women, children, the elderly, and infants, who had been defined by doctors as "life unworthy of living," had been gassed, drugged, shot, or deliberately starved to death. The murders continued even after 1945.

It is often incorrectly assumed that the murders were ordered by Hitler. In fact, doctors proceeded independent of government approval. In 1941 after Hitler ordered a stop to the murders, doctors committed what has since been dubbed "wild euthanasia."

These eugenic mass murders had been endorsed by the medical establishment decades before the [N]azis came to power. They were sanctioned by proponents of eugenics in other countries, including doctors in the United States and England.

History has failed to do justice to the hundreds of thousands of victims. Therefore, we, the International Commemoration Committee on Eugenic Mass Murder, set aside the date May 2 in memoriam, and demand that no person, with or without disability, ever fall victim to medical murder again.

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Disabled Students Union Meeting (2003)

The formation of the Disabled Students Union (DSU) was one of the first successful organizing efforts around disability issues in colleges and universities in the United States. Below is an excerpt from the organization's call for members at the University of Illinois at Chicago (UIC). The group's founders also went on to successfully create a National Disabled Students Union that organized disabled students and their close advocates at the national level.

January 28, 2003 11:30 a.m.–1:00 p.m.
Room 448 IIDD

ACCESS IS A CIVIL RIGHT!
About the Disabled Students Union

The purpose of this cross-disability organization is to mobilize, organize, and represent students with disabilities at UIC in order to promote empowerment and community solidarity among people with disabilities on campus. Students with disabilities at UIC are one of the most underrepresented and marginalized minority groups on campus. DSU was created (Feb. 2000) with the express intent of strengthening the political voice and power of students with disabilities on campus. DSU is a socio-political advocacy organization that seeks to build disability community, culture, pride and power.

If you are a student with a disability and you are interested in participating in the DSU to promote disability access and disability pride, then we need your input and involvement!

▣ *Los Angeles Times* on Eugenics Apologies (2003)

At the outset of the twenty-first century, numerous states issued formal apologies to disabled people and their families who were negatively affected by sterilization practices. The following journalistic article discusses the larger issue of such apologies, and particularly California's longstanding lack of inquiry into the state's ambitious eugenics effort to sterilize more than 20,000 disabled people.

To make amends for a state program that sterilized 7,600 people against their will, North Carolina's governor created a panel last year to probe the history of the effort, interview survivors and consider reparations.

In Oregon, then-Gov. John Kitzhaber last year apologized in person to some of the 2,600 people sterilized there, and he created an annual Human Rights Day to commemorate the state's mistake. On the day Virginia Gov. Mark R. Warner apologized, Jesse Meadows and other victims unveiled a roadside marker.

"It felt pretty good to be there, even though it was so late," said Meadows, 80.

Some historians and advocates for the disabled had a mixed reaction to the apology issued Tuesday by Gov. Gray Davis for California's policy, the most aggressive in the nation, which sterilized an estimated 20,000 mentally disabled people and others from 1909 through the 1960s.

Davis offered his apology in a press release. No survivors or disability groups were on hand to accept it. There was no order to probe for more details of a history that, according to scholars, is still largely unexplored and not fully understood.

"It's like a preemptive apology. . . . We don't know yet who to apologize to," said Alexandra Stern, a University of Michigan historian who is writing a book about California's sterilization program.

"An apology with no attempt to find the people who deserve to receive it is meaningless," said Stephen Drake, research analyst with Not Dead Yet, a national disability rights group. "If the governor is serious about wanting to understand this shameful chapter of California history, then you need an effort to study the records of just how this was done."

"I think it's premature," said Paul Lombardo, a University of Virginia historian who revived interest in the state policy when he lectured Tuesday to a California Senate committee. The lecture, which some officials said was the first time they had heard of the sterilization policy, triggered a statement within hours from Davis and a separate apology from state Atty. Gen. Bill Lockyer.

Lombardo and Drake said the apologies were welcome as acknowledgments of past abuse. "But if they don't try to understand the history, then I don't know what it's worth," Lombardo added.

Historians have only recently begun to explore California's sterilization effort. Primarily at institutions for the mentally ill and the developmentally disabled, the state sterilized thousands of people under the premise that the "unfit" should be removed from the gene pool so their children would not burden society.

But some of the basic details still are missing. Among them: exactly how many people were sterilized.

The mentally ill and developmentally disabled were the initial focus of the policy, but some historians believe that it also targeted Mexican and Asian immigrants, criminals, juvenile delinquents and sexually active women.

Even the date that the practice ended is unclear, though it may have been as late as 1969.

"We checked that and we haven't been able to determine that," said Bertha Gorman, spokeswoman for the California Health and Human Services Agency. Because of patient confidentiality rules, historians have had little access to state records that might shed light on the state's sterilization history.

"Shouldn't we demand that the state fill in the history?" asked David Mitchell, who runs a disabilities studies program at the University of Illinois at Chicago. "That would be the foundation of a meaningful apology."

Russell Lopez, a spokesman for the governor, said he had called three state departments last week in an attempt to find survivors but was told no names could be released because of patient confidentiality rules.

"The governor just learned about this," Lopez said, "and he decided it was something he must do: apologize for what the Legislature did in the past."

In Virginia, North Carolina and Oregon, a combination of media interest and university research brought attention to past sterilization programs and led to the state apologies.

Although some details remain clouded, there is no doubt that California was once home to the largest sterilization program in the nation and to some of the most influential supporters of the practice, including the publisher of the *Los Angeles Times* in the 1930s.

At least 30 states passed laws in the first decades of the 1900s that aimed to shape society by denying the so-called unfit the ability to reproduce. Scientists already had shown how careful breeding could improve crops and livestock. Now, they were arguing that selective breeding could improve humanity and wipe out poverty, prostitution and mental illness, which were thought to have genetic roots.

The concept, known as eugenics, led to the sterilization of more than 63,000 people in the United States from about 1907 through the 1970s.

California accounted for one-third of all operations. Its sterilization law was the second in the nation, after Indiana's.

The state's enthusiasm for eugenics was so well known that it is mentioned in "The Great Gatsby." When Nazi Germany wrote its sterilization policy, it borrowed from California's law, historians say.

"Why California more than other states? That's a key question," Stern said. "I think it has to do with the need to civilize the frontier."

In better breeding practices, Californians saw a way to control the chaos of nature. And their use in human reproduction had the support of prominent citizens, including then-Stanford University President David Starr Jordan and Pasadena citrus magnate Ezra Gosney, who founded one of the most influential think tanks devoted to eugenics, the Human Betterment Foundation, in 1926.

Another cheerleader was *The Times,* whose publisher, Harry Chandler, was listed as a member of the Human Betterment Foundation in a 1938 pamphlet by the group.

"We have secured the ardent support of the *Los Angeles Times,*" Gosney wrote in a 1937 dispatch to the *Eugenical News,* a monthly periodical. "They are running an article each week in their Sunday magazine edition which, while not as good as the editor-owner of the paper would like, keeps the subject before the people and does much to encourage us in carrying on."

That Sunday column, called "Social Eugenics," ran from 1935 to 1941 and argued for strong sterilization laws, said Lombardo of the University of Virginia. The paper ran at least 120 of them, he added.

Through much of the 1930s, many sterilization advocates also cheered on the eugenics policies in Germany. "Why Hitler Says: 'Sterilize the Unfit!'" ran a headline in a 1935 issue of *The Times'* magazine. "Here, perhaps, is an aspect of the new Germany that America, with the rest of the world, can little afford to criticise."

Under California law, people with "mental disease" could be sterilized if doctors believed the condition could be passed to descendants. The superintendents of state institutions had broad authority to decide how often to use the procedure, Stern said.

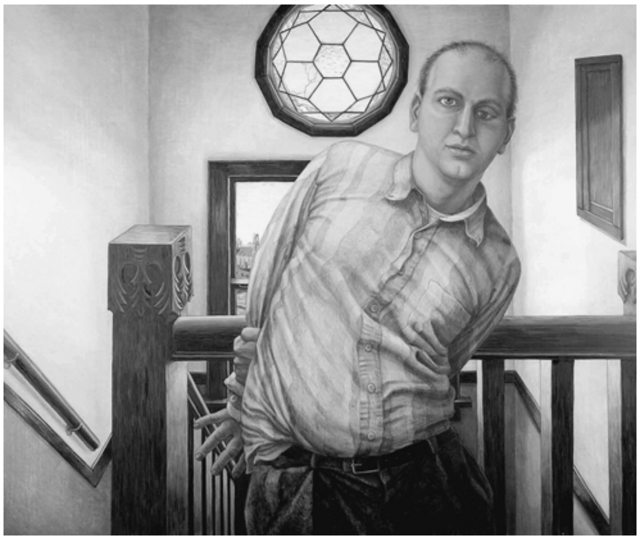
"The term 'mental disease' could be interpreted broadly," she said. "People who were epileptics were lumped in there, and people with 'perverse' sexual tendencies, so you had gay men."

Some who were sterilized had landed in state institutions on grounds of theft, forgery and truancy from school. In some places, women appear to have been sterilized merely for promiscuity.

"Something like 25% of the girls who have been sterilized were sent up here solely, or primarily, for that purpose," wrote Paul Popenoe, director of the Human Betterment Foundation, during a 1926 research trip to the Sonoma State Home for the Feeble-Minded. "They are kept only a few months—long enough to operate and instill a little discipline in them; and then returned home."

Stern and Lombardo believe that hundreds of prisoners, as well as many of the women and others at the Sonoma facility, are not included in the commonly cited figure of 20,000 sterilizations in California.

They also suspect that the state's strong anti-immigrant movement of the early 1900s targeted Mexicans and other nonwhite groups with sterilization, an attempt to dilute their presence in the population. But no broad survey of the racial and ethnic profile of sterilization patients has been done.



Circle Story #1: Jeff Carpenter, *by Riva Lehrer. 1997. Jeff Carpenter, a comedian, writer and teacher, works with an improvisational troupe and also performs solo work. Carpenter was injured in a random drive-by shooting several years ago, and he has written darkly sardonic pieces about its difficult aftermath.*

Joel Braslow, an associate professor of psychiatry at UCLA, says critiques of sterilization laws often misstate how the policy was practiced.

In state institutions, he says, doctors cared little about eugenics. Instead, they saw sterilization as a humane and beneficial treatment for patients, along with lobotomies and other now-discredited practices.

“In practice, we didn't sterilize the severely retarded,” said Dr. William Keating, a surgeon at Sonoma State Hospital throughout the 1950s. “They had very little opportunity for sex. The people we concentrated on were people who were moderately retarded, who had a chance of going out and getting pregnant.”

In an interview, Keating said he performed 500 to 600 tubal ligations and vasectomies at the institution. Individuals who could perform some sort of job outside the institution would be released, but not if they were at risk of getting pregnant or impregnating someone. In effect, sterilization was a ticket to a work furlough, or general release.

Keating recalled a young man who had an IQ he estimated to be 85. After his vasectomy, the man was released, only to return for a visit one day—in full Army uniform. He had become a first lieutenant during the Korean War.

Eugenic sterilizations tailed off through the 1950s and 1960s but remained legal until 1979. Today, state law allows sterilization for mentally incompetent people who cannot give informed consent. A court-appointed conservator must petition a judge for permission.

Victim Jesse Meadows said that Virginia, at least, “ought to pay people for what they did.” Meadows, of Lynchburg, was sent to the Virginia Colony for Epileptics and the Feebleminded in 1940, after his mother died and his father remarried. He was sterilized there, at age 17.

“They said it was to help my health . . . and so I wouldn't have no feeble-minded children,” Meadows said.

Virginia's apology and roadside marker “helped me some,” Meadows said. “But it's hard to forget that somebody ruined your life like that.”

Source: Zitner, Aaron. 2003, March 16. “Davis' Apology Sheds No Light on Sterilizations in California: Lack of an Inquiry into the State's Ambitious Eugenics Effort and Its 20,000 Victims Angers Some Historians and Disabled Advocates.” *Los Angeles Times.* Available at: http://www.geocities.com/madelinefelkins/CAeugenics.htm. Copyright © *Los Angeles Times.* Reprinted by permission.

Margaret Talbot, from “The Executioner's I.Q. Test” (2003)

One of the more contentious issues in the United States at the beginning of the twenty-first century is the issue of capital punishment for people with cognitive disabilities. Given the lengthy history of IQ testing and its controversial status as a valid scientific evaluation tool, the following excerpt from a journalistic article provides an important commentary on the continuing use of such testing to determine ultimate decisions about “ability to reason” as the basis for enactments of state-sponsored murder.

Most people will never take an I.Q. test, and if they do, it probably won't have a big impact on them. Generally speaking, I.Q. tests do not carry much weight anymore. Not with vague charges of cultural bias still clinging to them. Not at a time when multiple intelligences—that happy, inclusive vision in which nearly everybody is good at something—are on the ascendancy. If you do take a Stanford-Binet or a Wechsler, and you score in the average range, well, there you'll be, with hardly a reason to mention it. If you score high, the particular number won't matter much—unless you're the sort to join Mensa, and then it will matter only to your fellow Mensa members. But if you are in the bottom 3 percent of the population that scores 70 or lower, your actual I.Q. number will mean a great deal. Scores in that range will most likely lead to a diagnosis of mental retardation, and that diagnosis will entail many things, starting with mandated special education. Since last June, across the United States, it has also entailed exemption from capital punishment. And so, for someone who has committed a capital crime, an I.Q. score can mean the difference, quite literally, between life and death. It can mean, if we want to be blunt about it, that there is such a thing as being too dumb to die, at least at the hands of the state.

Source: Talbot, Margaret. 2003, July 29. "The Executioner's I.Q. Test." *New York Times Magazine.* Available at: http://www.newamerica.net/index.cfm?sec=Documents&pg=article&DocID=1275&T2=Article

▣ Andrea Dworkin, "Through the Pain Barrier" (2005)

This is the last piece written by Andrea Dworkin, composed just a month before she died. Few knew that she had suffered from an agonizing bone disease for several years. She describes with grim humor her worst moments and why she felt she was starting to heal.

The doctor who knows me best says that osteoarthritis begins long before it cripples—in my case, possibly from homelessness, or sexual abuse, or beatings on my legs, or my weight.

John, my partner, blames *Scapegoat,* a study of Jewish identity and women's liberation that took me nine years to write; it is, he says, the book that stole my health. I blame the drug-rape that I experienced in 1999 in Paris. I returned from Paris and finished *Scapegoat* over a period of months while caring for my dying father. Shortly after he died I was in hospital, delirious from a high fever, with infection and blood clots in my legs. I was there for a month. John had been told that I was dying. I forgot that in hospitals when one is dying, nurses abrogate the rules. John was allowed in after visiting hours; nurses would pull the curtain around my bed and let him lie with me. This was my happiness. Doctors tell me that there is no medical truth to my notion that the rape caused this sickness or what happened after it. I believe I am right: it was the rape. They don't know because they have never looked.

A few months after I got out of the hospital, my knees began to change. They lost their flexibility. Slowly they stiffened. As they stiffened they became sore. They started to hurt terribly—as if injured but not visibly injured. I got a cellphone—this was before they were ubiquitous—so that if I couldn't walk any more I could call a car. I had given up on New York City subways: my knees could no longer bend enough to use them.

I went to an orthopaedic surgeon. I was diagnosed with osteoarthritis in my knees. I was treated with the anti-inflammatory Celebrex and, when that didn't work, its stronger cousin, Vioxx. Vioxx was recently taken off the market by its makers because of a risk of heart attacks or strokes; I was on it for three years. I had cortisone shots in my knees, followed by prednisone. The cortisone shots, which are painful, worked only once. Then I could walk without pain; in joy I sat on my front steps and talked with my neighbour—inconsequential chat. When I tried to stand up, my knees were rigid and excruciating. I managed to stand and swivel around; I took the remaining two steps up to my front door and used the door to drag me inside. I had had an hour-and-a-half of freedom.

My mobility lessened as the pain increased. Eventually I found myself housebound. I could walk only a few steps at a time, intimidated by the pain and the refusal of my knees to bend. John and I lived in a three-floor house. I could barely make my way up or down the steps. I'd crawl up the steps on hands and feet. I'd try to go down on my butt, step by step. The kitchen was on the first floor; the toilet on the second; my desk, books and shower on the third. My physical world became tiny and pain-racked. I stayed in my bed when I could. John brought me up food. I'd go out only to the doctors.

The orthopaedist started giving me narcotics, most of which contained acetaminophen, a common, nonprescription analgesic. My pharmacist persuaded the doctor that the liver damage caused by too much acetaminophen was more dangerous to me than stronger drugs. Through her advocacy I got a drug normally given only to cancer patients. It was a little yellow lollipop and when in pain one was supposed to lick. I licked a lot. I was told that I had to have my knees replaced. The prostheses are made out of titanium and plastic. I had both knees replaced at once, a normal practice now but unusual even a few years ago. My surgeon would later tell me that if I had had one done, I would never have returned for the second. He got that right.

"Bodies in Commotion." Dancers at the annual Society for Disability Studies Dance, 2003.

Source: Photo by Sharon Snyder.

I still don't know what he did to me but I came to the conclusion that the operation was barbaric, involving as it did the sawing out of the arthritis, which meant sawing through bones. It was like being kneecapped, twice, or having one's knees and bones hammered and broken into bits. After the operation I was in a nightmare of narcotics and untouchable pain. There were morphine shots. I asked for them and got them often. Even morphine shots in the upper arm hurt.

I had a hallucination but it is still real as rain to me. I was in Virginia Woolf's house and I was happy. But "they" wanted me to go down the stairs. I can't, I begged, I can't. My hospital bed was at the top of the stairs and I was afraid that they were going to push me down. I saw the steep decline of the steps. I couldn't get over my visceral fear of falling or being pushed or being turned over from the bed down the flight of steps. I kept experiencing my bed as being on the edge of a precipice.

One day, I remember, a nurses' aide braided my hair and I felt cooler, cleaner. I was on the bedpan, but raising myself up to use it—knees—was so fiercely painful that I would rather lie in my piss.

Then the day came when I had to walk. There was a vinyl chair next to my hospital bed. The physical therapist's name was Carl. He was like a tree trunk, big and solid. You can do it, he said. I'll help you; we'll just go over to the chair. It was impossible, outside the realm of the imaginable. Carl let me hold on to him in a desperate, tight embrace as he carried me over to the chair. My legs dangled, my knees twisted, I sweated, I screamed. See, you could do that, he said, without a shred of irony. I had to sit there for two hours, which meant knees bent but not weight-bearing. Nurses came by and gave verbal approval: good dog, good dog. Eventually Carl carried me back to bed.

Pain is a four-letter word. There is no way to recreate it through memory. It is not like the flashback arising from traumatic events such as rape or battery. The flashback is as if it is happening now, in the present, even if it is from decades ago. Pain can be recent yet inaccessible to immediate experience. Torturers know that people can't die from pain. The consequences of pain—for instance a heart attack—yes, but not from pain itself, however intense. The horror is that no one dies from pain. This means that suffering can be immeasurable, enduring, without respite. So it would be for me for the next two years.

I was taken to an institute for physical rehabilitation. A nurses' aide took me to shower in a wheelchair. I used a walker from the cot on which I slept to the wheelchair, maybe two miserable steps. I had two responsibilities—take my pain medications (Vicodin or Percocet) and show up at the right room at the right time for the scheduled rehabilitative class. I was not allowed to go to class if I did not take the painkillers. In fact, the pain was unrelenting. I lived for the next pill.

Physical therapy is based on tiny movements, increments of change that almost defy detection; it is built on the repetition of the minuscule. Yet to the hurt person these motions or movements or minute steps are hard. The first time is daunting and the 10th is like climbing Mount Everest. I sit in a big room, my wheelchair in a big circle of wheelchairs. Big is good because it means that my turn does not come often. I stand up by holding on to a walker and take a step. Then I step back and sit down. The cycle is hideous. The steps with the walker increase to two, then three. After several weeks I am assigned a means of locomotion: crutches.

Rehabilitation also includes so-called occupational therapy: throw a ball around in a circle; put round pegs in round holes; stand up, arms on a table, and read a page of a magazine; water a plant; play checkers or cards; and the pièce de résistance, cook and serve a simple meal. I am guided in the intricacies of shopping while crippled; I learn how to use a "grabber" to latch on to things I have dropped or cannot reach; I am taught again how to put on shoes and socks and tie shoelaces.

I also have to meet the institution's psychologist once. I keep getting called back.

When I ask why, I am told that I am "interesting." Well, yes, I think, I used to be. The narcotics help me deal with the psychologist but the physical pain simply marches on. It does not lessen or change or stop.

I learn three rules in my occupational therapy classes: never hold on to anything that moves; if it rains or snows, stay inside, even if that means cancelling doctors' appointments (to those medicalised this is nearly profane); and kick the cat—if a cat curls up in front of your feet, kick it away. I learned to use my crutch to kick the cat. I will go to hell for this.

On discharge, social services are provided. My male partner is not expected to be a care-giver. I am sent an itinerant nurse, a young, poorly paid and badly trained social aide to help me with baths and to do light housework, and a freelance physical therapist who will do the drill: stand up, take steps, bend your knees, and—the killer—stand on your toes.

And on discharge a wreck like me is sent to a "pain management centre." Despite my small successes at physical rehabilitation I am in agony. I spend almost all my time in bed, a bed of nails, all through the knees. The pain management centre is run by Curly, Larry and Moe. First there is a 10-page questionnaire. Rate from 1 to 10 your pain (I modestly assert an 8; my social conscience, atavistic as it is, tells me that there are others in more pain). Rate from 1 to 10: is your mother dead; how many people in your family have died of cancer; how is your sex life; how many times a week do you have sex?

They want me to undress so they can examine me. This is absurd. I refuse. There is a table they want me to lie on that they claim lessens pain. The bottom line is that New York State regulates narcotics to such an extent that regular doctors are reluctant to write prescriptions for painkillers; and so Curly, Larry and Moe at pain management put you through whatever rigmarole and then write prescriptions, none of which, according to state law, can be refilled. So one is in a cycle of coming back for new prescriptions and new indignities every 30 days.

Curly eventually puts me on Percocet, fentanyl patches and methadone. I am on these drugs for nearly two years. I become slightly indifferent to the awful pain. My speech slurs and my memory is impaired. It is during this time that I write my memoir Heartbreak. I want to remember some good things in my life. I work for one hour a day. The narcotics do not make me Coleridge; but I hold my own.

One day I wake up and the pain is gone from my right knee—as if God had intervened. The pain in the left one is the same. I begin to go outside on my crutches. I can walk half a block to my local Starbucks. One day I sit there, still on my meds, and I see the ballet going on outside. The sidewalk is heavy with pedestrian traffic. They are so unselfconscious, these normal walkers. They have different gaits; they move effortlessly; each dances without knowing it. I used to be one of them. I want to be again.

The anti-drama of small gesticulations continues, this time in physical therapy several blocks from where I live. My left knee is still rotten. After another year of physical therapy they give me a cane. I put away all the crutches and other signs of what I call "disability chic." I can sort of walk. The cane means victory. The pain in my left knee keeps me on my meds. Over the course of another year, that pain lessens. It's a whisper, a shadow—it goes. I give up the pills, though I go through a nasty withdrawal from methadone.

Alas, there is no happy ending. John and I move to Washington so that he can take a job as managing editor of a large-circulation magazine. We live in an apartment without steps. I am on the cane. I go into physical therapy because, unable to stand up straight, I hunch over the cane. A few days later I am at the kitchen table reading a magazine. I stand up to get something and my right knee cannot bear any weight, none. I can't use it because I can't step on it. I have no pain; I have had no warning. I get to my crutches, which are in a closet. I need both of them in order to move. My right knee remains useless. The physical therapist determines that the quadriceps above the knee has stopped working, because imperceptible pain occasions the quad muscle to give out. Then my knee buckles and I fall. It is dangerous to fall. I see the physical therapist twice a week.

The orthopaedic surgeon ("a genius with knees," says my internist) puts me in a restrictive brace that allows

"Disabled and Proud" wheelchair lovers hug each other during the Chicago Disability Pride Parade, 2004.

my knee to bend only so far. That way, if my knee fails, I am unlikely to fall. After nearly a year of physical therapy my quad muscle is not much stronger and my knee still buckles. The surgeon sends me to a rehabilitation hospital where they make me a new brace, specifically fitted to my leg. This brace works on the opposite principle to the first one: it immobilises the knee so that no buckling is possible, thus, no fall is possible.

It takes months for artisans to make the brace. It goes from beneath my calf to the top of my thigh. It is made of a black space-age material created to go to Mars or Saturn. Nothing makes it bend or stretch or break. It is completely unforgiving. I call it Darth Vader. It is the principle of evil incarnate. The straps that attach front to back are Velcro. I am supposed to lock it when I walk and unlock it when I want to sit. The brace is worn under my pants leg so no one can see it. Each manipulation is distinct: in public locking it makes me look as if I am masturbating, and unlocking it makes me look as if I am fondling my thigh. The brace must be very tight and positioned perfectly to work. It takes me nearly two months to learn how to put it on and use it. I lose my balance in efforts to lock it. Once I flip backward, magically landing on a chair.

Self-respect demands that I clean up the faecal mess that my cat has made. It is the immobilized knee that makes bending down to the floor fraught with peril. I start falling and know that I must not hit the floor. I fight against gravity, my fingernails clawing at the walls and my hand grasping for the door frame. I know that if I fall I probably will not be able to get up. Somehow I raise myself.

I was slow with the first brace. I had to remind myself to be patient. With Darth I make the turtle look like the hare. The landscape is one of hazard. Anything can reach up and bite me: a break in the sidewalk; leaves; sand; mud; a sudden slope up or down; a stone; some pebbles. Anything threatening balance is dangerous: first the brace itself; then wind, people running or bicycling or being too close or too many; a fast car; a step; a curb; a puddle; heavy doors; slick surfaces. Crowds are impossible and so are stairs.

I want to be able to carry a cup along with a plate to the kitchen sink in one trip. I don't want to have to make two trips. The cup slips and breaks. This happens several times. Is it a small thing? I can't bear it or accept it. I reject the extent of my disability. I find myself in a silent rage that stretches over weeks. I am utterly exhausted by my incapacity. I am worn out from walking. I am sick of physical therapy.

There are little humiliations. I keynote a conference on the Holocaust. The organiser picks me up. She is driving a truck. I try to climb up into it. She physically pushes me under my ass without permission, all the while talking to me in baby talk, put your tooshie there, keep your cute little fanny there. I turn to her and say, I am disabled, not stupid. A friend throws a party for me in Washington. I ask how many steps there are to the apartment. He doesn't know. I assume he will get back to me. John and I go to the party. There are three flights of steps. I can't get to the party being given for me. We could have given it in another venue, the friend says the next day. It cuts. I go to a bar and need to use the rest room. The men's is filthy, the bartender says; the women's is two flights up. I use the dirty one. I go to a new movie theatre that has elevators and disability bathrooms but the polished stone of the floor is so slick that my crutches cannot safely navigate it. I am walking with a friend who suddenly looks at my crutches and says, you don't want to be this way the rest of your life, do you? Her repulsion is barely masked. I feel unutterably alone.

Each disabled person has a story, often including pain, impairment, disorientation and loss of control. Each disabled person lives always on the threshold of separation, exile and involuntary otherness. Only a determined policy of public access can help to mitigate the loneliness. One needs to be able to enter buildings; have a cup of coffee; go to a restaurant, the theatre, cinema or a concert; attend school; go to lectures or readings; use public transport, bathrooms, hotel showers; go to museums and sporting events and political rallies. One needs equal opportunity in employment. One needs to be integrated into the world, not separated from it; yet one has special needs, ones that able-bodied people rarely consider. The low consciousness of the able-bodied increases alienation.

For mobility problems, one needs a new geography: kerb ramps; ramps in addition to steps; handrails; grab bars; high toilets; light doors; wheelchairs; room for wheelchairs in public bathrooms and hotel rooms; elevators; safety in floor surfaces including carpeting; entry and egress from public transport as well as acceptable seating; and a host of other considerations. Other disabilities require other remedies. In 1990 Congress passed the landmark Americans with Disabilities Act, which articulated in great detail the requirements for making the world available to disabled people. This is a civil rights law that recognises the exclusion of disabled people from the larger community as outright discrimination.

The law had its impact because disabled people found aggressive trial lawyers to sue commercial and private venues for noncompliance. The plaintiffs went after big-money damages for violating the civil rights mandated by the ADA. Eventually it became clear that compliance would be cheaper than continuing litigation. Losing money does put the fear of God into Americans.

I have to say that the ADA increases the quality of my life, Darth notwithstanding. I get through airports in a wheelchair provided by the airline; John takes me to the zoo a few blocks from where we live [and] the zoo provides a wheelchair; local coffee houses to which I gravitate have disability-standard bathrooms; there are special seats for me in cinemas and theatres and in rock venues; there are kerb ramps at pedestrian crossings and ramps or elevators in addition to steps and escalators in most public accommodations. In my neighbourhood I see many other disabled people outside all the time. We are not rare or invisible, because we are not hidden as if in shame.

And bless those nasty trial lawyers, whom George W Bush and the Republicans hate so much. Without them the ADA would be a useless pile of paper.

For myself—despite physical therapy, the breaking cups, and my immobilised knee—in the middle of the night, worn down, I listen to Yo-Yo Ma playing Bach or Loretta Lynn's Van Lear Rose; and I am, I think, healing. Surely music must be more powerful than bad luck.

Source: Dworkin, Andrea. 2005, April 23. "Through the Pain Barrier." *The Guardian.* Available at: http://books.guardian.co.uk/news/articles/0,6109,1468336,00.html. Reprinted by permission of the Guardian News Service.

CHRONOLOGY

1500 BCE Egypt: The Ebers Papyrus, a medical textbook, devotes an entire chapter to eye diseases. It also shows that deafness is well understood and that clinical knowledge has developed.

400 BCE Graeco-Anatolian Hippocratic writings coin the word e*pilepsy* for a convulsive condition they view as a disease rather than a possession or punishment. Today, it is estimated that more than 80 percent of the 40 million people who currently have epilepsy throughout the world have little access or no access to contemporary treatments.

300 BCE China: *The Yellow Emperor's Internal Classic* is the first text to outline acupuncture. Ordinances on emergency relief for the disabled date to the Han Dynasty, 206 BCE–AD 220. Fiscal and administrative disability classification date at least to the Tang Dynasty, 618–907.

1250–1350 High point of medieval medicalization during which theoretical explanations for conditions gain currency in Western Europe. Prior to this time, in the most general of terms, lay explanations held more sway, ranging from the superstitious to the spiritual to the vindictive. With the founding of the universities, medical theory, typified by the four humors, became more influential in governmental, legal, and elite social circles. Disabling conditions like epilepsy, strokes, and paralyses, as well as psychiatric conditions, increasingly fell under the social control of doctors.

1400 Turkey: Deaf people work in the Ottoman Court from the 15th to the 20th centuries. Sign language becomes a recognized means of communication among both hearing and deaf courtiers.

1593 England: The origins of disability as a social and political category emerge with the first state disability benefits being enacted by Parliament for those disabled in war.

1593 Europe and the United States: English Parliament initiates Europe's first national system of benefits for rank-and-file disabled veterans. The first veterans' homes—France's Hôtel des Invalides, Britain's Chelsea Hospital, and Frederick the Great's Invalidenhaus in Berlin—are established in 1633, 1685, and 1748, respectively. Following the American Civil War, the U.S. government responds with a system of homes, preferences in government hiring, land grants, free prosthetics, and pensions for disabled veterans (however, southern veterans were limited to usually scanty state pensions).

1601 England: The Poor Law is passed to provide family and community support for those unable to make a living for themselves.

1604 Laws on witchcraft in the colonies all evolve from a 1604 English Statute that makes "being a witch" punishable by death. During outbreaks of witch-hunting, the "different" body itself is targeted as a sign and symptom of one's confederation with demonic forces.

1697 England: The first English workhouse for people with mental and physical disabilities is established in Bristol in 1697.

1704 Bethlem Hospital in the United States has 130 residents housing the "furiously mad."

1714 Canada: The Bishop of Quebec opens the first building in Canada exclusively for the confinement of mentally disturbed individuals. It is adjacent to Quebec General Hospital.

1749 France and England: Denis Diderot pens one of the most influential treatises on the blind and education in his *Letter on the Blind* in which he argues that the blind can be educated. In 1784, Valentin Haüy opens the first school for the blind in Paris. He perfects a system of raised *letters* to enable the blind to read. In 1828, Louis Braille modifies a raised *dot* system invented by Charles Barbier, which is used today by blind persons to read and communicate. In 1847, William Moon, an Englishman, develops an embossed script based on Roman capitals that blind adults can learn to read in a few days. It is the first reading system for the blind to be widely adopted across the world, but because it is costly to print, the Braille system, which can be produced by blind individuals for themselves, overtakes Moon's system.

1755 France, the United States, and Germany: The Abbé Charles-Michel de l'Épée establishes the first state-supported school for the training of young deaf children, where he teaches sign language. The school serves as an inspiration for the establishment of other European schools and has a dramatic impact on social attitudes toward the deaf. In 1817, Thomas Gallaudet and Laurent Clerc establish the Asylum for the Deaf (now American School for the Deaf) in Hartford, Connecticut. Clerc imports the French sign system, which influences the makeup of contemporary American Sign Language (ASL). In 1778, Samuel Heinicke establishes a school in Leipzig, Germany, where the "oral method" is used.

1800 France: Victor of Aveyron, a "feral child" found in southern France, is brought to Paris. Jean Marc Gaspard Itard, a French physician, develops a systematic training program for the boy and works intensively with him for five years. Itard considered his attempt at educating Victor to be a failure because the boy did not learn to use a language. Nevertheless, Itard's disciples, including Edouard Séguin, Maria Montessori, and Alfred Binet, continue his work by establishing classes for children considered to be "mentally retarded."

1802 France: The world's first pediatric hospital, L'Hôpital des Enfants Malades, is founded.

1817 The American School for the Deaf is founded in Hartford, Connecticut. It is the first school for disabled children in the Western Hemisphere.

1817 James Parkinson, a London physician, describes what is to become known as Parkinson's disease.

1817 Thomas Gallaudet and Laurent Clerc open the American Asylum for the Education of the Deaf and Dumb in Hartford, Connecticut.

1828 Frenchman Louis Braille, blind from childhood, modifies a raised-dot system of code, one of the most important advances in blind education. It not only allows the blind to read at a much faster rate but also makes it possible for the blind to be teachers of the blind. UNESCO creates the World Braille Council in 1952.

1829 France: Louis Braille publishes an explanation of his embossed dot code.

1832 Samuel Gridley Howe is chosen to direct what is later to be called the Perkins School for the Blind in Boston. It becomes the model for schools around the nation. Laura Bridgman and Helen Keller attend Perkins. In 1837, Ohio establishes the first state-sponsored school for the blind.

1834 England: The English Poor Law Amendment stipulates five categories of those unable to work: children, the sick, the insane, defectives, and the aged and infirm. This sets the stage for the development of specialty institutions that isolate the disabled from the community.

1841 P. T. Barnum purchases Scudder's American Museum in New York City. This moment is considered to be the beginning of the "Golden Age" of freaks, which persists until the 1940s. The tension

between freaks and disability rights comes to a head in 1984, when disability rights activist Barbara Baskin successfully lobbies the New York State Fair to remove Sutton's Incredible Wonders of the World Sideshow, featuring a limbless man who performs as the "Frog Boy," from the midway.

1843 Due to the influence of Dorothea Dix, an American social reformer, the Massachusetts legislature allocates funds to greatly expand the State Mental Hospital at Worcester. Dix also plays an instrumental role in the creation of 32 mental hospitals and becomes nationally known for her reform efforts. By the late 1840s, Dix focuses on developing a national plan that addresses the treatment of people with mental illness.

1846 William Thomas Green Morton discovers anesthesia and in 1867 Joseph Lister provides a model for antisepsis. These new technologies play a central role in the future of aesthetic surgery as well as surgical intervention for every type of disability that calls for it. Penicillin is discovered in 1929, cutting mortality rates in hospitals dramatically.

1848 The North Carolina School for the Deaf begins the first publication for Deaf persons with its school newspaper, *The Deaf Mute.* First published in 1907, the *Matilda Ziegler Magazine for the Blind* is an ongoing Braille publication.

1848 Samuel Gridley Howe founds the first residential institution for people with mental retardation at the Perkins Institution in Boston.

1851 In the United States there are 77 residential institutions for children, 1,151 by 1910, and 1,613 by 1933. By the 1950s and 1960s, family members and politicians throughout Western Europe, Canada, and the United States push for the deinstitutionalization of people with disabilities.

1851 The first International Sanitary Conference is held in Paris, France, with 12 countries participating. It leads to the World Health Organization, the WHO, which formally comes into existence in 1948.

1857 Edward Miner Gallaudet, youngest son of Thomas Hopkins Gallaudet, establishes the Columbian Institution for the Instruction of the Deaf, Dumb, and Blind, located in Washington D.C. Its college division, eventually known as the National Deaf-Mute College, is the world's first institution of higher education for deaf people. Abraham Lincoln signs its charter on April 8, 1864; today it is known as Gallaudet University.

1857 English philosopher Herbert Spencer is first to use the expression "survival of the fittest." The application of his idea in combination with Charles Darwin's theories in his 1859 book, *The Origin of the Species,* is called Social Darwinism. It is widely accepted and promoted in Germany in the 1920s and leads Adolf Hitler to express prejudice against the weak, sick, and disabled.

1863 Louis Agassiz, a significant American naturalist, advocates the permanence of different races and worries about the "tenacious influences of physical disability" if races were mixed.

1864 Germany: Karl Ferdinand Klein, teacher for deaf-mutes, and Heinrich Ernst Stotzner are considered the founding fathers of the *training school,* which calls for schools to be created for less-capable children with the goal of improving their lot. Training schools remain in effect today, but critics maintain that there is an over-representation of socially and economically underprivileged students in this type of setting experiencing little academic success.

1868 Sweden: The Stockholm Deaf Club is the first recorded organization of people with disabilities.

1870 England and Wales: Education for children with disabilities begins when universal elementary education is first introduced around this time. From 1895 onward, schools for "defective" children spring up. In 1899, Alfred Eichholz, an inspector of special education, draws up key recommendations, which leave their mark on the historic 1994 Education Act legislation. In 1978, the Warnock report

introduces the term *special needs education,* which soon gains acceptance worldwide. With the 1994 UNESCO Salamanca Statement and Framework for Action on Special Needs Education, a major shift in organizing educational services for children with disabilities is confirmed internationally.

1876 Isaac Newton Kerlin, Edouard Séguin, and others establish the Association of Medical Officers of American Institutions for the Idiotic and Feeble-Minded Persons. Today, it is known as the American Association on Mental Retardation. Séguin, who staunchly believes in the educability of those with significant cognitive disabilities, is styled as "apostle to the idiots," by Pope Pius X, reflecting the attitude of the time.

1880 The United States National Association of the Deaf (NAD), the first organization of deaf or disabled people in the Western Hemisphere, is established. In 1964, the Registry of Interpreters for the Deaf (RID) is formed to establish a national body of professionals who are trained and certified to enable communication between deaf, signing persons and nondeaf, speaking persons.

1880 Helen Keller is born in Tuscumbia, Alabama. An illness at the age of 19 months leaves her totally deaf and blind. In 1887, Anne Sullivan, recently graduated from Perkins Institution for the Blind, joins the Keller household as Helen's teacher and remains Keller's companion for nearly 50 years. For many, Keller's story is the quintessential overcoming narrative.

1881 The Chicago City Council enacts the first American "ugly law" forbidding "any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself to public view."

1882 The first major federal immigration law in the United States, the Immigration Act of 1882, prohibits entry to "lunatics," "idiots," and persons likely to become unable to take care of themselves. Most of the restrictions that apply specifically to disability are removed from U.S. law in 1990. Today, disabled immigrants are still denied an entry visa if they are deemed "likely to become a public charge."

1887 Walter Fernald serves as superintendent of the Massachusetts School for the Feeble-Minded (now known as the Fernald Center) from 1887 to 1924. Unlike most of his colleagues, Fernald moderates some of his earlier extreme views and eventually develops one of the country's largest "parole" systems for moving institutional residents back into smaller, community-based residences.

1887 The American Orthopaedic Association is founded. German and British counterparts are founded in 1901 and 1918, respectively.

1895 The chiropractic profession is founded. This type of care is used to relieve musculoskeletal pain, one of the most common causes of disability.

1899 Maria Montessori and a colleague open the Scuola Magistrale Ortofrenica in Rome, an educational institute for disabled children and a training institute for instructors. Her method relies on the concept of sensory-based instruction as a means for developing intellectual competence. Her methods allow the child the greatest possible independence in order to foster his or her own development (the child's own inner "building plan").

1904 Sir Francis Galton, half first cousin of Charles Darwin, defines the term e*ugenics* (which he coined in 1883) in a paper he presents to the Sociological Society on May 16. He argues for planned breeding among the "best stock" of the human population, along with various methods to discourage or prevent breeding among the "worst stock." Galton also develops the idea for intelligence tests. The term *feeblemindedness* is defined as broadly as possible and is widely used by eugenic social reformers to conflate myriad social problems. Further naming, classification, and labeling provides eugenicists with a troubling rationale for treating people with coercion, disrespect, and profound inhumanity. Persons within the various categories of sub-normality become particularly vulnerable

to state-sanctioned segregation, institutional confinement, and enforced sterilization. Eugenics is widely practiced in Europe, the United States, and Canada, culminating in the systemic murder of more than 260,000 disabled people by the Nazis between 1939 and 1945. Today, the so-called new eugenics, known as "human genetics," appeals to the needs of the individual. Critics (some of the first in Germany), however, criticize individualistic eugenic approaches and disclose the connections between human genetics, national socialist racial hygiene, and eugenics.

1905 Alfred Binet and Theodore Simon publish the first intelligence scale, known as the Binet-Simon Test.

1908 The publication of Clifford Beers's *A Mind That Found Itself* initiates the mental health hygiene movement in the United States. Speaking out against mistreatment and neglect within the system, Beers establishes the Connecticut Committee of Mental Hygiene, which expands in 1909, becoming the National Committee for Mental Hygiene and is now known as the National Mental Health Association. In 1940 there are 419,000 patients in 181 state hospitals. In 1943, the patient-doctor ratio is 277:1, and by the mid-1950s in New York state alone, there are 93,000 inpatients. The Bazelon Center for Mental Health Law, founded in 1972 by a group of committed lawyers and professionals in mental health and mental retardation, attempt to improve mental health service provision through individual and class action suits. In 1980, a group of these lawyers form the National Association of Rights Protection and Advocacy (NARPA). One-third of its board of directors must identify themselves as current or former recipients of mental health care. The association is committed to the abolishment of all forced treatment.

1908 Pastor Ernst Jakob Christoffel establishes a home in Turkey for blind and otherwise disabled and orphaned children. This grows into Christoffel-Blindenmission (CBM), an independent aid organization of Christians of various denominations united to help disabled people in third world countries. Today, it supports more than 1,000 development projects in 108 countries. In 1999, CBM, other agencies, and the World Health Organization initiate VISION 2020: The Right to Sight, a global initiative for the elimination of avoidable blindness by the year 2020.

1909 Germany: The German Organization for the Care of Cripples is created as an umbrella organization for the care of the physically disabled. The Prussian Cripples' Care Law of 1920 for the first time provides a right to medical care and scholarly and occupational education for this group.

1912 Henry H. Goddard publishes *The Kadikak Family,* supports the beliefs of the eugenics movements, and helps create a climate of hysteria in which human rights abuse of the disabled, including institutionalization and forced sterilization, increases. In 1927, the U.S. Supreme Court, in *Buck v. Bell,* rules in favor of forced sterilization of people with disabilities, further fueling eugenics movements—the number of sterilizations increases.

1914 By this date, Sigmund Freud develops his most enduring influence on the study of disability, namely, the theory of psychosomatic illness in which a psychopathological flaw is given corporeal form as a symptom, thereby establishing the notion that people succumb to disease or disability because they feel guilty about past or present repressed desires.

1918 The Smith-Sears Veterans Rehabilitation Act passes, authorizing VR services for World War I veterans. In 1916, the National Defense Act marks the beginning of the U.S. government's supportive attitude toward rehabilitation. In 1920, the Smith-Fess Act marks the beginnings of the civilian VR program. The Social Security Act of 1935 establishes state-federal VR as a permanent program that can be discontinued only by an act of Congress.

1919 Edgar "Daddy" Allen establishes what becomes known as the National Society for Crippled Children. In the spring of 1934, the organizational launches its first Easter "seals" money-making campaign. Donors place seals on envelopes containing their contributions. The seal is so well-known that it

becomes part of the organization's official name. Today, Easter Seals assists more than one million children and adults with disabilities and their families annually through a nationwide network of more than 500 service sites. During the 1920s, Franklin D. Roosevelt inspires the March of Dimes.

1920 At about this time, the Shriners open hospitals for the care of crippled children. President Herbert Hoover establishes a "Children's Charter" in 1928 highlighting the need to attend to the needs of crippled children.

1921 Franklin D. Roosevelt contracts poliomyelitis. Despite damage to his legs (which makes him a wheelchair user) and deep depression, through enormous rehabilitative effort, he eventually re-enters politics and becomes president of the United States. His triumph over personal disability becomes legendary. Critics, however, fault him for choosing to minimize his disability in what is called his "splendid deception." He establishes a center for the treatment of polio patients in Warm Springs, Georgia, called the Georgia Warm Springs Foundation (1927), which hires medical specialists from Atlanta to direct orthopedics. In 1937, President Roosevelt becomes the prime mover behind the National Foundation for Infantile Paralysis Research.

1921 Mary L. McMillan (Molly) establishes the American Women's Physical Therapeutic Association, which is known today as the American Physical Therapy Association (APTA).

1921 The American Foundation for the Blind is established.

1921 Canada: Researchers isolate the hormone insulin. In 1922, Frederick Banting, Charles Best, J. B. Collip, and J.R.R. Macleod produce and test the pancreatic extract on people with diabetes, for which they are awarded a Nobel Prize. Insulin becomes a wonderful treatment for diabetes, but not a cure.

1921 France: Three historical waves of advocacy movements can be identified beginning with the National Federation of Injured Workers (FNAT) in 1921 and other organizations that focus essentially on the protection of rights. Another factor that stimulates advocacy groups in the first wave is the wounded veterans of World Wars I and II. A second wave dates from the period after World War II. Many advocacy groups form between 1950 and 1970, such as the Union of Associations of Parents of Maladjusted Children (UNAPEI) in 1960. A third wave finds a gradual emergence of three types of associations: those that run specialized facilities (for example, Living Upright, which, in 1970, leads to the creation of the first group living facility); those interested in trade unions; and those represented by user-advocate associations. Financing comes in large part from public funds, thereby creating a government-association partnership.

1922 The founding of Rehabilitation International sets the stage for the establishment of other international organizations of and for people with disabilities that link together throughout the world. Later international organizations include, among numerous others, the World Federation of the Deaf (1951), Inclusion International (1962), the International Association for the Scientific Study of Intellectual Disability (1964), Disabled Peoples' International (1981), and the International Disability Alliance (1999).

1925 The American Speech-Language-Hearing Association, today the American Academy of Speech Correction, is established to provide high-quality services for professionals in speech-language pathology, audiology, and speech and hearing science, and to advocate for people with communication disabilities.

1928 Charles Nicolle is the first deaf person to be awarded a Nobel Prize.

1929 Seeing Eye establishes the first dog guide school in the United States.

1930 The Veterans Administration is created to administer benefits, promote vocational rehabilitation, and return disabled veterans to civil employment. There is a record of provision for disabled veterans in the United States since the Revolutionary War and the Civil War. After World War I, three agencies administer veteran's benefits.

1932 Herbert A. Everest, a mining engineer with a disability, and Harry C. Jennings collaborate to design and patent the cross-frame wheelchair, which becomes the standard for the wheelchair industry that exists today. Developed during World War I, the first powered wheelchair appears, but doesn't gain popularity for another 30 years.

1935 President Franklin D. Roosevelt signs the Social Security Act of 1935 on August 14. Beginning in 1956, SSA amendments provide disability benefits.

1935 By 1935, in the United States more than 30 states pass laws allowing for the compulsory sterilization of those deemed genetically unfit in state and federal institutions. By 1970, more than 60,000 people are sterilized under these laws.

1935 As a result of being denied participation in the Works Progress Administration (WPA), six young people with disabilities hold a sit-in at the offices of New York City's Emergency Relief Bureau, demanding jobs in non-segregated environments and explicitly rejecting charity. The League of the Physically Handicapped is born out of this activism and operates in New York from 1935 to 1938. The League identifies social problems that remain issues today.

1935 Peer support in the United States is traced to the establishment of Alcoholics Anonymous in this year. Interest in peer support increases in the 1960s and is adopted by the disabled community. Movements, such as the Center for Independent Living, and groups, such as the National Spinal Cord Injury Association, make peer support one of their major activities.

1936 The American Academy of Physical Medicine & Rehabilitation is founded, leading to the approval of the American Board of Physical Medicine & Rehabilitation by the American Medical Association in 1947.

1937 The Fair Housing Act of 1937 passes with a mandate to assist the poor, a group that includes people with disabilities, by creating public housing. However, it is not until the Rehabilitation Act of 1973 that housing law specifically deals with discrimination faced by individuals with disabilities in housing programs that receive federal funding. The 1988 amendment to the Fair Housing Act of 1968 extends protection for people with disabilities beyond those of Section 504 of the Rehabilitation Act to include private housing.

1939 The Nazi regime institutes the Aktion T4 program in Germany. Children and, later, adults with disabilities are selectively killed both in hospitals and in special centers. The program was officially terminated by Adolf Hitler in August 1941, but practitioners "informally" continued it through a phase historians have called "wild euthanasia."

1940 State activists for the blind, including Jacobus Broek, come together in Wilkes-Barre, Pennsylvania, to charter the National Federation of the Blind (NFB). In 1957, the NFB publishes the first edition of the *Braille Monitor,* which is still in print today. In 1960, dissatisfied NFB members form the American Council of the Blind (ACB).

1940 Paul Strachan establishes the American Federation of the Physically Handicapped, the nation's first cross-disability, national political organization.

1942 The American Psychiatric Association develops a position statement in favor of the euthanasia of children classified as *idiots* and *imbeciles.*

1943 The LaFollette-Barden Act, also known as the Vocational Rehabilitation Amendments, adds physical rehabilitation to federally funded vocational rehabilitation programs.

1943 The United Nations is established on October 24 by 51 countries. The global Programme on the Disability is the lead program concerning disability. Many other types of programs, activities, and instruments include the 1975 Declaration on the Rights of Disabled Persons, the 1981 International Year of

Disabled Persons, the 1982 World Programme of Action Concerning Disabled Persons, the 1983–1992 UN Decade of Disabled Persons, and the 1993 Standard Rules on the Equalization of Opportunities for Persons with Disabilities. In 1988, the first UN Disability Database (DISTAT) publishes statistics from 63 national studies covering 55 countries and the 2001 publication presents 111 national studies from 78 countries, indicating a growing interest worldwide for the collection of usable data. In 2005, a UN Ad Hoc Committee continues to consider a Convention on the Rights of Disabled Persons that is a legally binding human rights instrument. Today the UN membership totals 191 countries.

1943 ◆ Sweden: In possibly the first reference to the concept of normalization, the most significant driving force in the ongoing closure of state-run or state-funded institutions for people with a disability is made by the Committee for the Partially Able-Bodied, established by the Swedish Government. Through the advocacy of people such as Niels Erik Bank-Mikkelsen, normalization, with its profound positive effect on the lives of people who were once removed and segregated from society, remains relevant today.

1944 ◆ Richard Hoover invents long white canes known as Hoover canes that are used by many blind people.

1944 ◆ The word *genocide* first appears in a book by a Polish lawyer Raphael Lemkin titled *Axis Rule in Occupied Europe* in which he describes Nazi Germany's practices but also seeks the adoption of legal restrictions so that genocide will not occur. In 1948, the United Nations adopts a declaration and then a convention on genocide that describe both against whom genocide might be directed and acts constituting genocide. Article 6 of the Rome Statute of the International Criminal Court (ICC), established in 2002, uses language identical to that in the UN convention to define genocide. More than 90 countries are parties to the ICC, but not the United States.

1945 ◆ President Harry Truman signs into law an annual National Employ the Handicapped Week. In 1952, it becomes the Presidents' Committee on Employment of the Physically Handicapped, a permanent organization, which reports to the President and Congress.

1945 ◆ Canada: Lyndhurst Lodge, the first specialized rehabilitation center for spinal cord injury (SCI) in the world, and the Canadian Paraplegic Association, the first association in the world administered by individuals with SCI, are established.

1946 ◆ The first chapter of what will become the United Cerebral Palsy Association, Inc. is established in New York City. It is chartered in 1949, and along with the Association for Retarded Children, it becomes a major force in the parents' movement of the 1950s.

1946 ◆ The National Mental Health Foundation is founded by attendants at state mental institutions who aim to expose abusive conditions. Their work is an early step toward deinstitutionalization.

1946 ◆ The National Institutes of Mental Health (NIMH) are founded in the United States.

1946 ◆ Europe: The European Union is founded on September 17 in Paris. It consistently shows its commitment to eliminating discrimination on many fronts through joint declarations, resolutions, directives, and action programs. With regard to disability, the European Union supports actions in favor of people with disabilities, principally in the form of European Social Fund interventions. Action programs aim at facilitating the exchange of information between member states and nongovernmental organizations with a view to identifying good practices, integrating people with disabilities into society, and raising awareness of related issues. The EU Council of Ministers Recommendation on the Employment of Disabled People (1986) calls on member states to "eliminate negative discrimination by reviewing laws, regulations and administrative provisions to ensure that they are not contrary to the principle of fair opportunity for disabled people." Further

steps are taken in 1996 when a communication on equality of opportunities for disabled people sets out a new European disability strategy that promotes a rights-based approach, rather than a welfare-type approach. This is strengthened in 1997 when the heads of state act to strengthen Article 13 of the European Community Charter of Fundamental Social Rights of Workers (1989), giving the European Community specific powers to take action to combat a broad spectrum of discrimination that includes disability.

1948 ◆ The National Paraplegia Foundation is established as the civilian branch of the Paralyzed Veterans of America.

1948 ◆ The World Health Organization is established. The WHO actively promotes human rights and the principle of equity in health among all people of the world, including persons with disabilities. Today it consists of 191 member states, but strives for universal membership. In 1980, the WHO publishes the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and issues a revised version in 2001, the International Classification of Functioning, Disability, and Health (ICF).

1948 ◆ The United Nations General Assembly adopts the "Universal Declaration of Human Rights," which promotes and affirms the fundamental rights to life, liberty, and security; to medical care and social services; and to the benefit from scientific progress and its uses.

1948 ◆ Sir Ludwig Guttmann organizes the first Stoke Mandeville (England) Games for the Paralysed, thus launching the Paralympic movement. The Games become international in 1952. In 1960, the first Paralympic Summer games are held in Rome and the first Paralympic Winter Games follow in 1976. The Paralympic Games are multi-disability, multi-sport competitions and have become the second-largest sporting event in the world, only after the Olympic Games.

1948 ◆ World War II bomber pilot and war hero Leonard Cheshire establishes what is to become the largest charitable supplier of services for disabled people in the United Kingdom. In the 1960s, the resistance of disabled people who live in one Leonard Cheshire home, Le Court, plays a major role in establishing the British disabled people's movement. In the late 1990s, the Leonard Cheshire organization establishes the Disabled People's Forum, which is run by disabled people and supports disabled people's involvement and empowerment.

1949 ◆ Timothy Nugent founds the National Wheelchair Basketball Association, and the first Annual Wheelchair Basketball Tournament takes place.

1949 ◆ Europe: The Council of Europe, an intergovernmental organization, is founded. Its activities cover all major issues facing European society other than defense. Human dignity, equal opportunities, independent living, and active participation in the life of the community form the heart of the Council of Europe's activities in relation to people with disabilities. The European Social Charter of 1961 and its revision in 1996 include specific wording and expand the rights of individuals with disabilities.

1950 ◆ The Social Security Amendments of 1950 provide federal-state aid to the permanently and totally disabled (APTD), which serves as a limited prototype for future Social Security assistance programs for disabled people.

1950 ◆ The National Mental Health Association is formed with the mission to continue 1908-advocate Clifford W. Beers's goals of "spreading tolerance and awareness, improving mental health services, preventing mental illness, and promoting mental health."

1950 ◆ The National Association for Retarded Children (NARC) is established by families in Minneapolis. It is the first and most powerful parent-driven human-services lobby in the nation to emerge in the 1950s.

1950 Amniocentesis is developed by a Uruguayan obstetrician. Later, advanced prenatal testing provides a battery of powerful medical tools to predict risk of disability and provide information to parents about their pregnancies.

1951 With the founding of the World Federation of the Deaf, the deaf community becomes international.

1953 Francis Crick and James Watson propose a three-dimensional structure for the DNA molecule. The paper they publish also gives clues to genetic mechanisms. Today, more than 6,000 monogenic disorders have been identified, and these affect approximately 1 in 200 live births.

1955 The polio vaccine, developed by Dr. Jonas Salk, becomes available, thus ending polio epidemics in the Western world. A new oral vaccine, developed by Dr. Albert B. Sabin, is approved for use in 1961.

1956 Social Security Disability Insurance (SSDI) becomes available through amendments to the Social Security Act of 1935 (SSA) for those aged 50–64. Other important amendments to SSA include the following: 1958: provides for dependents of disabled workers; 1960: removes age limit; 1965: Medicare and Medicaid provide benefits within the framework of the SSA (until 1977); 1967: provides benefits to widows and widowers over the age of 50; 1972: Supplemental Security Income (SSI) establishes a needs-based program for the aged, blind, and disabled; 1984: the Social Security Disability Reform Act responds to the complaints of hundreds of thousands of people whose disability benefits have been terminated; 1996: President Clinton signs the Personal Responsibility and Work Opportunity Reconciliation Act, making it more difficult for children to qualify as disabled for SSI purposes.

1959 The UN Declaration of the Rights of the Child is adopted; the UN Convention on the Rights of the Child is adopted in 1989. A central principle of both documents is access to education for all children including those with disabilities. In 1993, a related UN document, the Standard Rules for the Equalization of Opportunity, extends this to preschool children, and in 1994, UNESCO's Salamanca Statement and Framework for Action specifies the provision of special education for children with disabilities or learning difficulties. These documents constitute a universal bill of rights that can serve as a framework in the development of national policies worldwide.

1961 The American Council of the Blind is established.

1961 Europe: The European Social Charter (ESC) protects "the right of physically and mentally disabled persons to vocational training, rehabilitation and social resettlement." In 1996, it is revised, updated, and expanded to take account of social changes.

1961 Michel Foucault's work *The History of Madness in the Classical Age* becomes obligatory reading for those concerned with the archaeology of madness and its treatments. It continues to be an academic *rite de passage.*

1962 Battered child syndrome is defined. Researchers estimate that the incidence of maltreatment of children with disabilities is between 1.7 and 3.4 times greater than of children without disabilities.

1962 Russia: The Moscow Theater of Mime and Gesture is the first professional deaf theater in the world. It has been in continuous operation for more than 40 years and has staged more than 100 classic and modern plays.

1963 Congress enacts new legislation to ensure funding for a comprehensive program of research on mental retardation through the National Institute on Child Health & Human Development. In 1965, the Office of Economic Opportunity launches the Elementary and Secondary Education Act (ESEA), commonly known as Project Head Start. The goal is to prevent developmental disability by providing increased opportunities for disadvantaged children in the preschool years.

1963 The Developmentally Disabled Assistance and Bill of Rights Act (DD ACT) is authorized, with its last reauthorization in 1996. It focuses on individuals with developmental disabilities such as intellectual disability, autism, cerebral palsy, epilepsy, and hearing and visual impairments, among others.

1964 The Civil Rights Act is passed. It becomes the model for future disability rights legislation.

1964 France: L'Arche is established. By the beginning of the twentieth-first century, it includes more than 113 communities in 30 countries. "The Ark" is a distinctive style of community living, based on "core members" and "assistants," who view their commitment as sharing life *with* people with disabilities, rather than as caregivers.

1965 Newly enacted Medicare and Medicaid provide national health insurance for both elderly (over 65) and disabled persons.

1965 The Vocational Rehabilitation Amendments of 1965 are passed. They provide federal funds for the construction of rehabilitation centers and create the National Commission on Architectural Barriers to Rehabilitation of the Handicapped.

1965 The Autism Society of America is founded.

1967 Deaf actors establish the National Theatre of the Deaf (NTD). It is the world's first professional deaf theater company and the oldest continually producing touring theater company in the United States. Today, after almost 40 years, the NTD chronicles over 6,000 performances. The National Theatre Workshop for the Handicapped begins in 1977 and the Other Voices Project in 1982. These groups are among the earliest groups formally to place the disability experience at the heart of their creative endeavors.

1967 Heart transplantation is introduced. This technology is preceded by open-heart surgery developed in the 1950s and coronary bypass and internal pacemakers in the1960s. The Framingham Heart Study begins in 1948. It collects data over the next decades that help identify major risk factors contributors to heart disease.

1967 Paul Lemoine in France in 1967 and Kenneth Jones and David Smith in the United States in 1973 independently describe the condition fetal alcohol syndrome (FAS), which comprises a recognizable pattern of birth defects attributable to the adverse effects of maternal alcohol abuse during pregnancy.

1967 England: St. Christopher's Hospice in South London opens. It is the first attempt to develop a modern approach to hospice and palliative care.

1968 Congress enacts the Architectural Barriers Act. The ABA requires access to facilities designed, built, altered, or leased with federal funds.

1968 The Fair Housing Amendments to the Civil Rights Act of 1968 guarantees civil rights of people with disabilities in the residential setting. The amendments extend coverage of the fair housing laws to people with disabilities and establish accessible design and construction standards for all new multifamily housing built for first occupancy on or after March 13, 1991.

1968 Sweden: The origins of People First® go back to a meeting of parents of children with intellectual disabilities whose motto is "we speak for them." However, the people with disabilities in attendance wish to speak for themselves and start their own self-advocacy group. Similar groups quickly spread to England and Canada. The name People First is chosen at a conference held in Salem, Oregon, in 1974. People First is an international self-advocacy organization run by and for people with intellectual disabilities to work on civil and human rights issues.

1970 Landmark legal cases such as *Diana v. State Board of Education* (1970; Latino students) and *Larry P. v. Riles* (1971–1979; minority students) challenge biases inherent in standardized testing procedures used to identify students as eligible for special education. Both cases call into question the widespread use of "scientifically" objective measures to gauge intellectual ability. Today, despite reforms, a disproportionate number of students from racial, ethnic, and linguistic minorities continue to be placed in special education classes.

1970 Japan: The Disabled Persons' Fundamental Law (DPFL) becomes one of the 27 fundamental laws that stipulate basic principles in each policy area. Major revision takes place in 1993 reflecting a progress of guiding principles in disability policy that are deeply influenced by international movements such as the International Year of Disabled Persons (1981) and the UN Decade of Disabled Persons (1983–1992). Disability Studies as well as modern disability movements are born this same year, when members of Aoi Shiba, a group of people with cerebral palsy, protest publicly for the first time against sympathetic views toward the killing of disabled children by their parents. Aoi Shiba and other disability movements join in the establishment of Disabled Peoples' International in 1981. In 1986, the Rehabilitation Engineering Society of Japan (RESJA) is established. In 1992, disability movements in Japan initiate the Asian and Pacific Decade of Disabled Persons 1993 to 2002. The Japan Society for Disability Studies is established in 2003 and a unified national organization, Japan Disability Forum (JDF), is established in 2004.

1970 United Kingdom: The Chronically Sick and Disabled Persons Act (CSDPA) strengthens the provisions in the 1948 National Assistance Act (NAA). Later, the Disability Discrimination Acts of 1995 and 2005, together with the Disability Rights Commission Act of 1999, constitute the primary source of antidiscrimination legislation for disabled people.

1971 A U.S. District Court decision in *Wyatt v. Stickney* is the first important victory in the fight for deinstitutionalization.

1971 WGBH Public Television establishes the Caption Center, which provides captioned programming for deaf viewers.

1971 Gerontologist M. Powell Lawton defines *functional assessment* as any systematic attempt to objectively measure the level at which a person is functioning in a variety of domains. Over 30 years later, functional assessment, in combination with *outcomes analysis,* is considered one of the "basic sciences" of rehabilitation. In 1980, the World Health Organization proposes a series of definitions, which have a profound impact on the assessment of functional status and outcomes in rehabilitation. It is modified and revised in 1993 and 2001.

1971 The Declaration on the Rights of Mentally Retarded Persons (UN 1971), the Declaration on the Rights of Disabled Persons (UN 1975), and the World Programme of Action Concerning Disabled Persons (UN 1982) indicate the emergence of a global discourse of rights for disability.

1972 A group of people with disabilities (including Ed Roberts, John Hessler, and Hale Zukas), known as the Rolling Quads, living together in Berkeley, California, formally incorporate as the Center for Independent Living (CIL). This first CIL in the country becomes the model for Title VII of the Rehabilitation Act of 1973. In the late 1980s and early 1990s the group's advocacy efforts help pass the Americans with Disabilities Act (ADA). CILs are always controlled by disabled people. Accepted by most people as the birth of the modern independent living movement, the Berkeley concept migrates to other countries. In 1999, a global summit on independent living is held in Washington D.C. The summit brings together more than 70 countries. The Washington Declaration that comes out of the conference establishes a set of basic principles. In 1996, the Ed Roberts Campus, an international center and a service facility, is created in Berkeley, California, in memory of Edward V. Roberts, founder of the independent living concept.

1972 ◆ A young television reporter for the ABC network, Geraldo Rivera, is given a key to one of the wards at Willowbrook State School on Staten Island, New York. Established in the late 1930s as a state-of-the-art facility for the "mentally deficient," by 1972, Willowbrook becomes a warehouse for the "socially undesirable" of New York City, with a substantial minority having no disability at all. The inhumane conditions deteriorate to the extent that a visitor remarks, "In Denmark we don't let our cattle live this way." Rivera's exposé leads to a lawsuit that results in the Willowbrook Consent Decree of 1975, which creates a detailed system of monitoring and oversight of all residents living there at that time, to be met until the last of the "class clients," as they are sometimes referred to, pass on. The property has since been sold to a college.

1972 ◆ Paul Hunt's call for a consumer group to promote the views of actual and potential residents of institutional homes for the disabled in the United Kingdom results in the establishment of the Union of the Physically Impaired against Segregation (UPIAS). The group's aim is to formulate and publicize plans for alternative forms of support in the community. Hunt is regarded by many disability activists as the founder of the modern disabled people's movement.

1972 ◆ New Zealand: Three key pieces of legislation pass have long-term effects on the disabled community: the 1972 no-fault Accident Compensation Act that provides monetary compensation to victims based on level of impairment suffered; the 1975 Disabled Persons Community Welfare Act, giving assistance to disabled people, parents, and guardians, as well as voluntary associations; and the Human Rights Act of 1977, which does not include disability as a recognized grounds for discrimination. Today, disabled populations in New Zealand continue to fight to establish an identity as disabled people rather than a group needing "welfare." One task is to promote legislation that includes disability as a group against whom discrimination is outlawed.

1973 ◆ The Rehabilitation Act of 1973 lays the foundation for the disability rights movement. Its Section 504 asserts that people with disabilities have equal rights that prevent discrimination based on their disability in programs or activities that receive federal funding. This is the first major nationwide antidiscriminatory legislation designed to protect disabled Americans. These rights are further protected with the landmark Americans with Disabilities Act (ADA) of 1990.

Section 501 of the Act requires affirmative action and nondiscrimination in employment by federal agencies of the executive branch. Section 502 creates the Access Board, which grows out of the 1965 National Commission on Architectural Barriers to Rehabilitation of the Handicapped. As a result of the commission's June 1968 report, Congress enacts the Architectural Barriers Act (ABA). Section 503 requires that to receive certain government contracts, entities must demonstrate that they are taking affirmative action to employ people with disabilities. The enduring hallmark of the act, Section 504, provides that no otherwise qualified individual with a disability shall, solely by reason of his or her disability, be excluded from the participation in, denied the benefits of, or subjected to discrimination under any program or activity receiving federal funds. However, it would take five years of lobbying and protesting before the American Coalition of Citizens with Disabilities (ACCD) wins the release of regulations that allow Section 504 to be implemented.

The Act is in many ways the direct predecessor to the ADA. However, the primary focus is vocational training and rehabilitation, and over the next half-century, disability law and advocacy move from the medical (medical issues) and vocational (often a justification for welfare and benefits) models to a civil rights model, which seeks to remove the barriers that impede the full integration of people with disabilities into society.

1973 ◆ The term *mainstreaming* emerges within the educational jargon associated with the Education for All Handicapped Children Act (EHA), the early U.S. legislation subsequently reauthorized as the Individuals with Disabilities Act (IDEA) in 1990.

1973 ◆ Ronald Mace is the driving force behind the creation of the first accessible state building code in the United States (North Carolina, 1974) and in the drafting of national accessibility codes and

standards. He coins the term *universal design* to capture and promote his expanded philosophy of "design for all ages and abilities"—curb cuts being his favorite example.

1973 ◆ Washington D.C. introduces the first handicap parking stickers. The Federal-Aid Highway Act funds curb cuts.

1974 ◆ First Lady Betty Ford and investigative reporter Rose Kushner are diagnosed with breast cancer. They help break the public silence on this topic. In 1954, Terese Lasser begins Reach to Recovery, a program of volunteers who have previously undergone radical mastectomies who provide emotional support to hospitalized women who have just had the operation. Today, one in eight women is diagnosed with breast cancer during her lifetime.

1975 ◆ The Education for All Handicapped Children Act, the first separate federal legislation authorizing special education for children and youth, passes, due, in part, to the advocacy efforts of a group of parents. In 1990, it becomes known as the Individuals with Disabilities Education Act, or IDEA.

1975 ◆ The Developmentally Disabled Assistance and Bill of Rights Act, providing federal funds for programs that provide services for people with developmental disabilities, passes.

1975 ◆ The Association of Persons with Severe Handicaps (TASH) is founded. It calls for the end of aversive behavior modification and deinstitutionalization of people with disabilities.

1975 ◆ The UN General Assembly adopts the Declaration on the Rights of Disabled Persons, which states that all persons with disabilities have the same rights as other people. This document is not legally binding and can be attributed in part to a UN Ad Hoc Committee set up in 2001 to consider a Convention on the Rights of Disabled Persons that is legally binding.

1975 ◆ United Kindom: The Union of the Physically Impaired against Segregation (UPIAS) publishes a paper that redefines the term *disability,* which becomes known as the social model of disability as it radically transforms the way disabled people see themselves and their place in society.

1976 ◆ The Higher Education Act of 1965, which establishes grants for student support services aimed at fostering an institutional climate supportive of low-income and first-generation college students, is amended to include individuals with disabilities. In March 1978, the Association on Handicapped Student Service Programs in Post-Secondary Education is founded. It later becomes the Association on Higher Education and Disability (AHEAD).

1976 ◆ Sponsored by Ralph Nader's Center for the Study of Responsive Law, the Disability Rights Center is founded in Washington D.C.

1977 ◆ Protesting the federal government's delayed enactment of the rules and regulations for the implementation of the Rehabilitation Act of 1973, disabled activists on April 1 organize protests at the federal offices of the Department of Health and Human Services in various cities across the United States. In San Francisco, protesters hold the regional offices hostage for 28 days, gaining national attention and resulting in an agreement with federal officials for the rapid establishment of the rules and regulations to implement Section 504 of the Act.

1977 ◆ Max Cleland is appointed to head the U.S. Veterans Administration. He is the first severely disabled person to hold this post.

1977 ◆ S. Z. Nagi defines *disability* as an individual's performance of tasks and activities related to achievement of social roles—a distinct concept, different from *impairment.* It is further formalized with the introduction of the World Health Organization's International Classification of Impairments, Disabilities, and Handicaps in 1980 and further refined in 2001 in its International

Classification of Functioning, Disability, and Health. Nagi's model is used as the basis for the Americans with Disabilities Act, for almost all disability social policy in the United States, and for statistics at the United Nations and in Europe.

1978 ◆ The Child Abuse Prevention and Treatment and Adoption Reform Act of 1978 and the Adoption Assistance and Child Welfare Act of 1980 promote the adoption of children with special needs, including disabilities.

1978 ◆ The Atlantis Community, the second independent living center in the country after Berkeley, is established in Denver, Colorado, in 1975. On July 5–6, 1978, twenty disabled activists from the Atlantis Community block buses with their wheelchairs and bodies and bring traffic to a standstill at a busy downtown intersection. This act of civil disobedience results in the American Disabled for Accessible Public Transit, the original name for the American Disabled for Attendant Programs Today, or ADAPT.

1978 ◆ Legislation creates the National Institute on Handicapped Research. In 1986, it is renamed the U.S. National Institute on Disability and Rehabilitation Research (NIDRR). Its mission is to contribute to the independence of persons of all ages who have disabilities. It is located in the Department of Education under the Office of Special Education and Rehabilitation Services.

1978 ◆ The World Health Organization starts to promote the concept of community-based rehabilitation (CBR) as a means of helping people with disabilities in the developing world. It emerges, in part, from the WHO primary health care campaign Health for All by the Year 2000. Around the same time, in Western countries, home-visiting programs in which a trained worker regularly visits the family to advise on ways of promoting child development become one of the success stories of modern disability services. Among the best-known programs are those based on a model originating in Portage, Wisconsin, and now used in many countries.

1978 ◆ England: The Warnock report introduces the term *special needs education.* It marks a major shift in organizing educational services for children with disabilities and results in the new conceptualization of special needs education. This change is confirmed internationally by the Salamanca Statement and Framework for Action on Special Needs Education at the UNESCO's Conference held in Salamanca in 1994. This theoretical shift is marked with the change of the term *integration* to *inclusion* or *inclusive education.*

1978 ◆ USSR: The Action Group to Defend the Rights of the Disabled is established to advocate for legal rights for Soviets with disabilities.

1979 ◆ The Disability Rights Education and Defense Fund (DREDF) establishes itself as a leading cross-disability civil rights law and policy center. It is founded by people with disabilities and parents of children with disabilities. Because its philosophy is closely aligned with other civil rights struggles, in 1981, DREDF is invited to join the executive committee of the national's largest coalition of civil rights groups, the Leadership Conference on Civil Rights. In 1987, DREDF establishes the Disability Rights Clinical Legal Education Program and begins teaching disability rights law at the University of California's Boalt Hall School of Law.

1979 ◆ The National Alliance for the Mentally Ill (NAMI) is founded. NAMI is an advocacy and education organization.

1979 ◆ Germany: The first Cripples' Group is founded as a cross-disability group with emancipatory aims. In an attempt to reinterpret disability in positive terms, the cofounders choose the term *Krüppel* over handicapped or disabled.

1979 ◆ Nicaragua: The Organization of the Revolutionary Disabled is set up in the wake of the Sandinista victory.

1980 ◆ The California Governor's Committee on Employment of People with Disabilities and entertainment and media industry professionals establish the Media Access Office (MAO).

1980 ◆ About the time Congress is considering passage of the ADA (1990), marketers begin to acknowledge the economic potential of the disabled community; consequently, the appearance of disabled characters in consumer goods advertising mushroom and ability-integrated advertising becomes much more commonplace. Organizations such as MAO and NOD (National Organization on Disability) provide advertising strategies and guidance.

1980 ◆ The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), an interdisciplinary association composed of individuals interested in technology and disability, is founded.

1980 ◆ The World Health Organization's International Classification of Impairments, Disabilities, and Handicaps (ICIDH), a groundbreaking, but controversial, classification system is tentatively released for trial purposes with the goal of uniform information collection worldwide. It has a negligible impact on disability statistics or data collection; however, researchers argue that it is a vast improvement over available tools. It is renamed and vastly revised in 2001.

1980 ◆ England: Graeae Theatre Group, composed of disabled actors, directors, and other theater professionals, is founded in London by Nabil Shaban and Richard Tomlinson. It takes its name from the the Graeae of Greek mythology, three gray-haired sisters who shared one eye and one tooth. Graeae's first production is *Sideshow*.

1980 ◆ Netherlands: The Liliane Foundation starts by assisting 14 children. In 2002, it helps 31,982 children spread over 80 countries. The Foundation's efforts are directed primarily toward children with disabilities living at home. Its aim is to have direct contact with the child within the home situation and to assist the personal growth and happiness of the child, thus providing "tailor-made" assistance.

1980 ◆ Taiwan: The Physically and Mentally Disabled Citizens Protection Law is promulgated. It guarantees legal rights for the disabled and creates a significant improvement in their welfare. Although most of the disabled people in Taiwan still struggle to earn their due respect, today, public awareness of this group is emerging gradually and significantly.

1980 ◆ United Kingdom and Europe: The Black Report (*Report of the Working Group on Inequalities in Health)* is published. Among other groups it targets disabled people for better conditions that lead to better health. The report does not find favor with the Conservative government, but begins to be implemented under the Labour government in 1997. With its central theme of equity, the report plays a central role in the shaping of the World Health Organization's Common Health Strategy of the European Region.

1981 ◆ The Reagan Administration begins to amend and revoke disability benefits, a policy that continues throughout his administration and leads several disabled people who are in despair over the loss of their benefits to commit suicide.

1981 ◆ Justin Dart, recognized as the founder of the Americans with Disabilities Act (ADA, 1990), is appointed to be vice-chair of the National Council on Disability. The council drafts a national policy on equal rights for disabled people; the document becomes the foundation of the ADA.

1981 The Committee on Personal Computers and the Handicapped is established in Illinois, an indicator of the disabled community's interest in information technology (IT) accessibility, but in order to stimulate the development of suitable products, activists lobby for legislative protections, which are included in the Americans with Disabilities Act of 1990. In 2000, a suit brought by the National Federation of the Blind against AOL is suspended when AOL agrees to make its software accessible by April 2001. The World Wide Web Accessibility Initiative (WAI) launches in 1997. It raises the level of awareness of disability accessibility issues within the Internet community, especially among those who design and implement web pages.

1981 The first reported cases of AIDS in the United States appear in June. Today, the World Health Organization estimates that worldwide, approximately 40 million people are living with HIV/AIDS; 22 million men, women, and children have died; and 14,000 new infections are contracted every day. Around the world, in the year 2003, the AIDS epidemic claims an estimated 3 million lives, and almost 5 million people acquire HIV, 700,000 of them children. Currently, 6 million people infected with HIV in the developing world are estimated to need access to antiretroviral therapy to survive, but only 400,000 have this access.

1981 Disabled Peoples' International (DPI) is officially founded at a meeting in Singapore. The establishment of such international organizations around this time represents the disability movement becoming a global social movement instead of a national one. DPI is directed by persons with disabilities working in human rights advocacy. It sponsors World Assemblies, which are held every four years to develop a multiyear action plan. The most recent one is held in 2002 in Sapporo, Japan, where delegates from more than 100 countries come together. A leading slogan for DPI and other disability groups, coined in the early 1990s, is "nothing about us without us."

1981 The International Year of Disabled Persons encourages governments to sponsor programs that assimilate people with disabilities into mainstream society. Despite the positive worldwide effects it has, the UN program also creates some angry activists with disabilities who protest against the charity approach officially adopted for the event. Consequently, the activists build their own infrastructure consisting of counseling and advocacy facilities as well as job creation programs.

1981 Australia: Australia's modern disability policy takes shape after the 1981 International Year of Disabled Persons. Examples: The 1980s see a shift away from institutional care; the Commonwealth Disability Service Act provides a framework for the provision of disability services; and in 1991, the federal Disability Reform Package maximizes the employment of disabled. In 1995, a legal decision represents a watershed in telecommunications policy for people with disabilities when a commission's inquiry finds the national carrier, Telstra, guilty of discrimination against people with severe hearing or speech impairments. The success of the action results in the Telecommunications Act of 1997, which includes new provisions for the deaf community.

1981 Mexico: The Program of Rehabilitation Organized by Disabled Youth of Western Mexico begins as a rural community-based rehabilitation program.

1981 Soweto: The Self Help Association of Paraplegics begins as an economic development project.

1981 United Kingdom: Disabled people set up the British Council of Disabled Persons (BCOPD), the United Kingdom's national organization of disabled people, to promote their full equality and participation in UK society.

1981 Zimbabwe: The National Council of Disabled Persons, initially registered as a welfare organization, becomes a national disability rights group.

1982 ◆ Disability Studies originates with the formation of the Society for the Study of Chronic Illness, Impairment, and Disability. In 1986, it officially changes its name to the Society for Disability Studies (SDS). Disability Studies is a critical field of study based in human and social science.

1982 ◆ *In re Infant Doe* (commonly known as the Baby Doe case) launches the debate as to whether parents or medical authorities should choose to let a disabled infant die rather than provide the necessary medical treatment and nourishment essential to sustain life. In response to this and other cases, the U.S. Department of Health and Human Services creates a rule maintaining it unlawful for any federally funded hospital to withhold medical treatment from disabled infants. In 1984, the U.S. Congress enacts the Child Abuse Amendments, which calls for the medical treatment of newborns with disabilities unless the child would die even with medical intervention. The issue makes it to the U.S. Supreme Court in 1986 with the *Bowen v. American Hospital Association* case. The Court holds that denying treatment to disabled infants does not constitute legally protected discrimination under Section 504 of the Rehabilitation Act and that hospitals and physicians are to implement the decision of the parents. The decision results in the passage of the Child Abuse Prevention and Treatment Act Amendments of 1984. In the year 2000, a scholar argues that the Amendments, presidential commission writings, and disability advocates "have all combined to ensure that most babies who can benefit from medical interventions do receive them."

1982 ◆ Disability Awareness in Action (DAA) and other groups such as the Disabled Peoples' International (DPI) and International Disability Alliance (IDA) are the driving force behind the globalization of disability issues through the World Program of Action (1982), the United Nations Standard Rules of Equalization of Opportunities for People with Disabilities (1993), the World Summit for Social Development (1995), and the Education for All Framework for Action (2000), as well as the current campaign to secure a UN convention on the rights of disabled people.

1982 ◆ The National Council on Independent Living (NCIL) is formed in the United States. It provides an excellent example of leadership for people with disabilities by people with disabilities.

1982 ◆ Canada: The Charter of Rights and Freedoms section of the Constitution provides protection to persons with disabilities.

1982 ◆ France: Handicap International is founded in Lyon. It is active in various areas associated with all the causes of handicaps, both traumatological (land mines, road accidents) and infectious (polio, leprosy). In the 1990s it begins working on mental disability issues as a result of experience with Romanian orphanages and the war in the Balkans. In 1992, Handicap International creates its first two mine clearance programs and in 1997 it is the joint winner of the Nobel Peace Prize for its leading role in the fight against landmines.

1983 ◆ Rights-based approaches to disability rapidly gain currency in many developing countries since the UN Decade of Disabled Persons, 1983–1992. UNESCAP's Biwako Millennium Framework for Action towards an Inclusive, Barrier-Free and Rights-Based Society for People with Disabilities in Asia and the Pacific sets the priorities for the extended Decade of Disabled Persons, 2003–2012.

1983 ◆ Access and accessibility are concepts discussed throughout the World Programme of Action Concerning Disabled Persons passed by the UN General Assembly. The General Assembly in 1993 passes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

1983 ◆ England: The first Covent Garden Day of Disabled Artists is held in London.

1983 ◆ Thailand: DPI-Thailand is established.

1984 ◆ The Access Board issues the "Minimum Guidelines and Requirements for Accessible Design," which today serves as the basis for enforceable design standards. The 1990 Americans with

Disabilities Act (ADA) expands the board's mandate to include developing the accessibility guidelines for facilities and transit vehicles. The Rehabilitation Act Amendments of 1998 give the Access Board additional responsibility for developing accessibility standards for electronic and information technology. In 2001, Section 508 of federal law establishes design standards for federal websites, making them accessible to individuals with disabilities.

1985 The U.S. Department of Health and Human Services issues the first comprehensive national minority health study, which shows racial disparity in health and concludes that the difference in mortality is not acceptable. In 1998, studies indicate that racial disparity has not improved as much as hoped; consequently, President Bill Clinton launches an initiative that sets a national goal of eliminating disparities in six key areas by the year 2010. Some of these areas include diseases and conditions considered to be disabling as well as life threatening.

1986 The Air Carrier Access Act (ACAA) passes. It requires the U.S. Department of Transportation to develop new regulations that ensure that disabled people are treated without discrimination in a way consistent with the safe carriage of all passengers. The relevant regulations, Air Carrier Access rules, are published in March 1990.

1986 The National Council on the Handicapped publishes its report *Toward Independence.* It recommends that "Congress should enact a comprehensive law requiring equal opportunity for individuals with disabilities" and suggests that the law be called "the Americans with Disabilities Act." In its 1988 follow-up report, *On the Threshold of Independence,* the council takes the somewhat unusual step of publishing its own draft of the ADA bill.

1986 The Equal Opportunities for Disabled Americans Act allows recipients of federal disability benefits to retain them even after they obtain work, thus removing a disincentive that keeps disabled people unemployed.

1986 Australia: The Disability Services Act provides that a person with disability has the right to achieve his or her individual capacity for physical, social, emotional, and intellectual development. In 1992, the Disability Discrimination Act supports nondiscrimination in education and training. It also makes it unlawful to discriminate in relation to access to premises, including public transportation.

1986 Canada: The Employment Equity Act mandates the institution of positive policies and practices to ensure that persons in designated groups, including persons with disabilities, achieve at least proportionate employment opportunities.

1986 England: The first issue of the magazine *Disability Arts in London* (DAIL) is produced in London.

1986 Southern Africa: The Southern Africa Federation of the Disabled is formed as a federation of nongovernmental organizations of disabled persons.

1988 The Technology Act (Technology-Related Assistance for Individuals with Disabilities Act of 1988 and its 1994 amendments), and, in 1998, the Assistive Technology Act (AT) provide financial assistance to states to support programs of technology-related assistance for individuals with disabilities of all ages. The1988 act defines *assistive technology* (AT). The Americans with Disabilities Act of 1990 prohibits discrimination against people with disabilities in employment, public institutions, commercial facilities, transportation, and telecommunications, which includes accessibility to all entrances, bathrooms, program areas, and parking spaces as well as interpreters for the deaf and Braille and large-print materials for the blind. The Telecommunications Act of 1996 requires the telecommunication industry to make equipment that will support transmission of information in forms accessible to people with disabilities including broadband and television program captioning. By 2000, approximately 10 percent of the U.S. population uses AT devices and/or modifications to their home, work, or school that allow them to participate in major life activities.

1988 ◆ Congress introduces a series of amendments to the Civil Rights Act of 1968, including a prohibition of housing discrimination against people with disabilities. These amendments are known as the Fair Housing Act Amendments of 1988.

1988 ◆ China: Deng Pufang, a wheelchair user and son of the late Chinese leader Deng Xiaoping, is the driving force behind a series of laws and programs initiated to improve life for the disabled. In 1984, he sets up the China Welfare Fund for Disabled Persons and, in 1988, the China Disabled Persons' Federation, which endeavors to improve public images of disabled people. Today, there are 60 million disabled people in China.

1989 ◆ The European Network on Independent Living (ENIL) is set up. It focuses on personal assistance as a key component of independent living.

1990 ◆ ADAPT, the American Disabled for Attendant Programs Today, originally called the American Disabled for Accessible Public Transit, continues to gain public awareness through tactics of civil disobedience until regulations are finally issued with the passage of the Americans with Disabilities Act (ADA).

The ADA passes, after ADAPT uses tactics of civil disobedience, in the tradition of other civil rights movements, in one of the largest disability rights protests to date (600 demonstrators), the "Wheels of Justice March," during which dozens of protesters throw themselves out of their wheelchairs and begin crawling up the 83 marble steps to the Capitol to deliver a scroll of the Declaration of Independence. The following day 150 ADAPT protesters lock wheelchairs together in the Capitol rotunda and engage in a sit-in until police carry them away one by one.

George H.W. Bush signs the ADA on July 26. It provides employment protections for qualifying persons with disability. It is the most prominent and comprehensive law prohibiting discrimination on the basis of disability in the United States, expanding the mandate of Section 504 of the Rehabilitation Act of 1973 to eliminate discrimination by prohibiting discrimination in employment, housing, public accommodations, education, and public services.

In June 2000, the National Council on Disability issues a report, *Promises to Keep: A decade of Federal Enforcement of the Americans with Disabilities Act,* which includes 104 specific recommendations for improvements to the ADA enforcement effort. On December 1, 2004, the council issues a final summary report, *Righting the ADA,* in order to address "a series of negative court decisions [that] is returning [Americans with disabilities] to 'second-class citizen' status that the Americans with Disabilities Act was supposed to remedy forever."

1990 ◆ The ADA requires public entities and businesses to provide effective communication to individuals with disabilities. Title IV of the ADA mandates that nationwide telecommunication systems be accessible to persons with speech or hearing disabilities. The Federal Communications Commission (FCC) requires relay services to be in place by July 26, 1993. The Telecommunications Act of 1996 adds provisions to the Communications Act of 1934 that requires manufactures and providers of telecommunications equipment and services to ensure accessibility to persons with disabilities. In 2000, President Bill Clinton establishes regulations governing the accessibility to people with disabilities of the electronic and information technology used within the federal government.

1990 ◆ The Individuals with Disabilities Education Act (IDEA) is enacted. It guarantees the right to free and appropriate education for children and youth with disabilities and focuses on higher expectations, mainstreaming students where possible, and an increased federal rule in ensuring equal educational opportunity for all students. IDEA requires schools to provide a free and appropriate public education to eligible children with disabilities. It also requires schools to develop an individualized education plan (IEP) for each child and placement in the least restrictive environment (LRE) for their education. IDEA is amended in 1997 and reauthorized again in 2004 as the Individuals with Disabilities Education Improvement Act.

1990 ◆ Legislation establishes the National Center for Medical Rehabilitation Research (NCMRR), whose mission is to foster development of scientific knowledge needed to enhance the health, productivity, independence, and quality of life of persons with disabilities. It has primary responsibility for the U.S. Government's medical rehabilitation research that is supported by the National Institutes of Health (NIH).

1990 ◆ The World Declaration on Education for All (EFA) is adopted in Jomtien, Thailand, by more than 1,500 persons representing the international community. Article 23 of the UN Convention on the Rights of the Child states that disabled children have the right to a "full and decent life" and that member nations provide free education and training to disabled children whenever possible in order to provide the "fullest possible social integration and individual development." UNESCO is the lead UN organization for special needs education.

1990 ◆ Korea: The disability movement celebrates the passage of the Employment Promotion Act for People with Disabilities. The government imposes control over the disabled population in the 1960s and 1970s by forwarding institutionalization under the banner of "protection," promoting sterilization, and violating the rights of disabled people in general. The 1981 International Year of Disabled Persons influences the government, and new laws, such as the Welfare Law for Mentally and Physically Handicapped, are enacted, and the human rights of disabled people becomes the dominant rhetoric of the disability movement.

1990 ◆ United Kingdom: The National Disability Arts Forum is launched at the UK-OK Conference at Beaumont College in Lancashire, UK.

1991 ◆ The Resolution on Personal Assistance Services is passed at the International Personal Assistance Symposium. Personal assistance services are the most critical services for individuals. Critical aspects of these services are that they must be available up to 24 hours a day, 7 days a week, to people of all ages, and with access to governmental payments. In the United States alone, personal assistance services affect the lives of more than 9.6 million citizens with disabilities.

1991 ◆ Australia: The federal Disability Reform Package is introduced; the Disability Discrimination Act, which covers issues of discrimination in education, is enacted in 1992; and the Commonwealth Disability Strategy, designed to provide equal access to government services for people with disabilities, is first introduced in 1994 and then revised in 2000. During the 1990s similar discrimination legislation emerges in other countries, such as New Zealand's Human Rights Act, the U.K.'s Disability Discrimination Act, Israel's Disabled Persons Act, Canada's Human Rights Act, and India's Disabled Person's Act.

1991 ◆ China: The most important laws and initiatives reside in the 1991 Law on Protection of Disabled Persons and a series of National Work Programs for Disabled Persons (1988, 1991, 1996, 2001), which integrate disability into the government's Five-Year Plans. China participates heavily in the United Nations Decade of Disabled Persons, 1983–1992, and initiates the Asia Pacific Decade of the Disabled Persons, 1993–2002. China continues to collaborate with UN projects involving the disabled and will host the 2007 International Special Olympics in Shanghai.

1991 ◆ Serbia and Montenegro: From the 1960s to the 1980s, post–World War II Yugoslavia is lauded for being a socially advanced nonaligned nation, but the contemporary wars that decimate Yugoslavia begin in 1991, and today there are more than one million disabled citizens, refugees, and casualties due to the wars. Disabled people in Serbia and Montenegro (formally named the Federal Republic of Yugoslavia—FRY) are left with shattered pieces of the spent past with little hope for the near future. Although the FRY constitution prescribes special protection of disabled persons in accordance with legal provisions and Serbia is party to numerous UN documents and acts, a disabled expert in 2004 admits that discrimination against persons with disability in Serbia and Montenegro is a

long-term problem that people without disability tend to ignore. Two of the most effective advocacy groups making in-roads today are the Association of Students with Disabilities and the Center for Independent Living in Belgrade.

1992 ◆ The UN Economic and Social Commission of Asia and the Pacific (ESCAP) proclaims a 10-year program known as the Asian and Pacific Decade of Disabled Persons 1993–2002 with goals of full participation and equality for persons with disabilities.

1993 ◆ The United Nations publishes the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, which becomes the international legal standards for disability programs, laws, and policies. Although not legally enforceable this instrument sets an inclusive and antidiscriminatory standard that is used when national policies are developed. It marks a clear shift from the rehabilitation and prevention paradigm to the human rights perspective on disability.

1993 ◆ Slovak Republic: The Czech and Slovak Republics separate into two independent countries. They both join the European Union in 2004. In Slovakia, a large number of highly innovative and resourceful grassroots nongovernmental organizations emerge to address the human rights, quality-of-life, and independent living priorities of citizens with disabilities. They pursue this mission, however, with extremely limited resources and with varying degrees of support from a multiparty parliament.

1993 ◆ Sweden: The Independent Living Institute (ILI) is founded.

1994 ◆ Two networks, one for elderly persons and the other for persons with disabilities, join together to form the U.S. National Coalition on Aging and Disability. In following years, policy makers and advocates begin to see the benefits of merging some services.

1994 ◆ Germany: The disability rights movement is successful in using for its own aims the reform of the German constitution, which is made necessary by the reunification process. An amendment to the constitution forbids discrimination on the grounds of disability. Other such laws as the Rehabilitation of Participation Law (2001) and the Federal Equal Rights Law (2002) are formulated with the active contribution of disability rights activists, and in 2003, the official German program of the European Year of People with Disabilities is organized by a prominent activist.

1994 ◆ Sweden: The Swedish Disability Act (LSS) comes into force. It expands the 1985 Special Services Act. The LSS is also more ambitious than its predecessor, calling for “good living conditions” rather than just an “acceptable standard of living.”

1995 ◆ The National Council on Disability, a federal agency, makes recommendations to the president and Congress on disability issues. Among other issues, it calls for the end to the use of aversives (techniques of behavior control such as restraints, isolation, and electric shocks) because they are abusive, dehumanizing, and psychologically and physically dangerous. Other organizations follow, such as the Autism National Committee in 1999, TASH in 2004, and the International Association for the Right to Effective Treatment in 2003.

1995 ◆ The Commission for Case Management Certification (CCMC) incorporates. Case management is a process of care planning and coordination of the services and resources used by people with disabilities and their families.

1995 ◆ Europe: The Association for the Advancement of Assistive Technology in Europe (AAATE) is founded as an interdisciplinary association devoted to increasing awareness, promoting research and development, and facilitating the exchange of information. AAATE is composed of more than 250 members from 19 countries. It interacts with sister organizations in North America, Japan, and Australia to advance assistive technology worldwide. The Tokushima Agreement, signed in 2000 by AAATE, the Rehabilitation Engineering and Assistive Technology Society of North America

(RESNA), the Rehabilitation Engineering Society of Japan (RESJA), and the Australian Rehabilitation and Assistive Technology Association (ARATA), promotes exchange of information and collaboration.

1995 United Kingdom: The campaign for antidiscrimination legislation begins in earnest with the emergence of the disability movement in the late 1970s. The Disability Discrimination Act of 1995 (DDA) together with the Disability Rights Commission Act of 1999 constitute the primary source of antidiscrimination legislation for disabled people in the United Kingdom. The Disability Discrimination Act 2005 extends the protection.

1996 There are 1.4 million fewer disabled older persons in the United States than would have been expected if the health status of older people had not improved since the early 1980s.

1996 Advocates for mental health parity such as the National Alliance for the Mentally Ill (NAMI; 1979) believe that mental illnesses are real illnesses and that health insurance and health plan coverage for treatment should be equal with coverage of treatment for all other illnesses. Due in part to advocacy, the Mental Health Parity Act becomes law in 1996. In 1999, mental illness ranks first in causing disabilities among many industrialized nations, including the United States, which experiences a loss of productivity in this year of $63 billion. In the United States, 5 to 7 percent of adults suffer from serious mental disorders and 5 to 9 percent of children suffer from serious emotional disturbances that severely disrupt their social, academic, and emotional functioning.

1996 Costa Rica: Approval of a law called Equal Opportunities for People with Disabilities is a turning point for the population with disabilities, which is among the most excluded sectors of society. The law is inspired in part by the United Nations Standard Rules on the Equalization of Opportunities for Disabled People (1993). Disability experience in Costa Rica is definitely transformed as a result of the mandates of this generic law, as people with disabilities and their families start to use this legal instrument as a strategy to empower themselves.

1996 Europe: Created in 1996, the European Disability Forum (EDF) is today the largest independent, trans-European organization that exists to represent disabled people in dialogue with the European Union (EU) and other European authorities. Its mission is to promote equal opportunities for disabled people and to ensure disabled citizens full access to fundamental and human rights through its active involvement in policy development and implementation in the EU. The EDF has national councils in 17 European countries and has 127 member organizations. The European Year of People with Disabilities 2003 is one of the EDF's most important campaigns.

1996 India: The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, becomes law. It is the first legislation for equal opportunities for disabled people. Prior to this, disabled persons receive services but not legal protection. Improvements in conditions begin in 1981 with the International Year of Disabled Persons. India is a signatory to the UN resolution of 1976 establishing it and is thereby committed to improving the lot of the disabled. The Lunacy Act of 1912 is repealed and the National Mental Health Act is passed in 1987. Nonetheless, with approximately 70 million disabled people residing in India (in a population of over a billion), the government does not include the domain of disability in the 2001 census, which reflects the attitudinal barriers in acknowledging the disabled identity.

1997 Government expenditures on behalf of persons with disabilities may total as much as $217.3 billion (taking into account the costs that would be expected among persons with disabilities in the absence of the disability), the equivalent of 2.6 percent of the gross domestic product in the United States for 1997.

1997 The landmark 1997 UNESCO Universal Declaration on the Human Genome and Human Rights frames the actual application of the new scientific developments raised by genetics. As a policy

statement, it provides the first signs that genetics will be applied in ways that maintain human rights. In 2003, the Council of Europe and the council's Steering Committee in Bioethics issue policy statements in a working document titled Application of Genetics for Health Purposes. In the case of gene therapy, in 1994, the Group of Advisors on the Ethical Implications of Biotechnology of the European Commission voices concern regarding equity, maintaining that all genetic services that are available for the entire population should be equally available for persons of disability. Today, UNESCO's Human Genome Organization's Ethics Committee, the World Health Organization, the Council of Europe, and consumer organizations such as Inclusion International, Rehabilitation International, and Disabled Peoples' International play major roles in translating genetic innovations into health service and public health fields, helping develop policies that focus on the general recognition, respect, and protection of the rights to which all people, whether disabled or nondisabled, are entitled. Concerns related to the possible undermining of human rights are expressed in 2003 when Disabled People's International demands a prohibition on compulsory genetic testing.

1997 Colombia: The General Act for People with Disabilities, also known as the Disability Act: Law for Opportunity, passes. The 2003–2006 National Plan of Attention to Persons with Disabilities estimates that 18 percent of the general population has some type of disability. Despite the existence of at least 37 disability-related legal policies (2001), the government provides limited spending on programs that protect the rights of people with disabilities, and the lack of enforcement of rights remains a major concern. Today's awareness efforts include marathons with the participation of the general population to raise money for educational programs for children with special needs, Special Olympics, new organizations such as the Colombian Association for the Development of People with Disabilities, and media awareness campaigns.

1998 President Bill Clinton issues an executive order ensuring that the federal government assumes the role of a model employer of adults with disabilities.

1998 President Clinton signs into law the Rehabilitation Act of 1973 Amendments. Section 508 requires that electronic and information technology (EIT), such as federal websites, telecommunications, software, and information kiosks, must be usable by persons with disabilities.

1998 Ireland: The Irish Employment Equality Act entitles all individuals, including disabled persons, equal treatment in training and employment opportunities. The Education Act of 1998 requires schools to provide education to students that is appropriate to their abilities and needs. The Education for Persons with Disabilities Bill passes in 2003. A Disability Bill published in 2001 fails to underpin a rights-based approach and is withdrawn amid a storm of protest in 2002; a redrafting of a new Disability Bill is suffering from continuing delays. Traditionally, Irish voluntary organizations play a reactionary role in the development of services for people with disabilities and a key role as pressure groups trying to keep disability issues on the political agenda.

1999 The National Center on Physical Activity and Disability (NCPAD) is established as an information and resource center that offers people with disabilities, caregivers, and professionals the latest information on fitness, recreation, and sports programs for people with disabilities.

1999 Established by a panel of experts brought together to evaluate the UN Standard Rules on the Equalization of Opportunities for Persons with Disability, the International Disability Alliance (IDA) encourages cross-disability collaboration and supports the participation of international disability organizations in the elaboration of a proposed UN convention on disability.

1999 England: The first disability film festival, Lifting the Lid, is held at the Lux Cinema in London.

2000 The National Telability Media Center collects documentation of 3,000+ newsletters, 200 magazines, 50 newspapers, 40 radio programs, and 40 television programs dedicated to disability in the United States alone. *The Ragged Edge, Mainstream* (Internet-based), and *Mouth* are examples of disability rights-focused publications.

2000 *Healthy People 2000,* the second edition of the Surgeon General's report on health promotion and disease prevention (the first edition published in 1979), includes some reference to the health and well-being of people with disabilities, but few data are available. In the mid-1990s, the U.S. Department of Health and Human Services begins a dialogue with the Centers for Disease Control and Prevention to include people with disabilities in the third edition, *Healthy People 2010.* The resulting report includes more than 100 objectives that include "people with disabilities" as a subpopulation for data gathering.

2000 The World Bank, increasingly concerned with how to include disabled persons in the economies and societies of developing nations, establishes an online clearinghouse to make documents concerning the disabled readily available to member nations and the general public and holds its first course on disability issues in 2004 in Guatemala.

2000 Africa: The African Decade of Persons with Disabilities, 2000–2009, is adopted by the Declaration of the Organization of African Unity. The African Network of Women with Disabilities (2001) and the community-based rehabilitation organization CBR Africa Network (CAN) are examples of the many activities that result from the African Decade.

2000 Brazil is one of the few countries to include an entire section on disability in its 2000 census. Results show that 14.5 percent of the population, roughly 24 million people, report having some form of disability, the poorest region, the northeast, reporting the highest percentage and the richest, in the south, the lowest. People with disabilities in the first half of the twentieth century have no voice or representation. In 1932, the first Pestalozzi Society, a community-based school for children with intellectual disabilities, is founded. By the end of the twentieth century, there are 146 Pestalozzi Societies and more than 1,700 chapters of the Association of Parents and Friends of the Exceptional. The first center for independent living is established in 1988 (CVI-RIO). In 1992 and 1995, CVI-RIO organizes two international conferences on disability issues called DefRio, out of which comes "Goals of the ILM," a document that delineates the basis for the independent living movement in Brazil; however, financial support is not provided by the government, creating a struggle for sustainability. Brazil has progressive policies toward disability. The constitution includes sections on the rights of people with disabilities, and laws have been passed with regard to accessibility, education, and employment.

2000 Europe: A European Community directive requires all member states to have introduced antidiscrimination laws in the fields of employment and training by the end of 2006. It seeks to establish a general framework for equal treatment in employment and occupation and to render unlawful discrimination based on, among other categories, disability. The European Union Charter of Fundamental Rights sets out in a single text, for the first time in the EU's history, the whole range of civil, political, economic, and social rights of European citizens. Disability is included in the general nondiscrimination clause (Article 21), but Article 26 specifically states that the Union recognizes and respects the rights of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration, and participation in the life of the community.

2000 The Human Genome Project (HGP), an international effort to specify the 3 billion pairs of genes that make up the DNA sequence of the entire human genome, produces its first draft in June 2000. Formally begun in October 1990, it is completed in 2003.

2001 ◆ President Clinton declares in Executive Order No. 13217 the commitment of the United States to community-based alternatives for individuals with disabilities. This ensures that the *Olmstead v. L.C.* decision (1999), which mandates the right for persons with disability to live in the least-restrictive setting with reasonable accommodations, is implemented in a timely manner. The executive order directs federal agencies to work together to tear down the barriers to community living.

2001 ◆ In the United States, census data indicate that only 48 percent of citizens 25 to 64 years old with severe disabilities have health insurance compared with 80 percent of individuals with nonservere disabilities and 82 percent of nondisabled Americans. Women with disabilities in general are more likely to live in poverty than men. Minorities with disabilities are more likely to live in poverty than nonminorities with disabilities. In 2003, in the United States, about 28 percent of children with disabilities live in poor families compared with 16 percent of all children.

2001 ◆ A UN Ad Hoc Committee begins discussions for a legally binding convention under the draft title Comprehensive and Integral Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Its fifth session is held in early 2005.

2001 ◆ A new World Health Organization classification of people with disabilities, the International Classification of Functioning, Disability, and Health (ICF), replaces the old International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The ICF definition shifts the focus from disability as an innate deficit ("medical model") to disability as constructed through the interaction between the individual and the environment ("social model"). This shift encourages a focus on the kinds and levels of interventions appropriate to the needs of individuals.

2001 ◆ UNESCO launches pilot education projects for disabled children in Cameroon, the Dominican Republic, Egypt, Ghana, India, Madagascar, Mauritius, Nicaragua, Paraguay, South Africa, Vietnam, and Yemen. The global initiative Education for All 2000 has as its primary millennium development goal universal education by the year 2015.

2002 ◆ The U.S. Supreme Court rules that executing persons with mental retardation is unconstitutional.

2002 ◆ Disabled Peoples' International's 2002 Sapporo Platform, developed by 3,000 delegates from more than 90 countries, urges members to take every opportunity to seek publicity and awareness in order to change negative images of disabled people.

2002 ◆ Canada: The Canadian International Development Bank announces the approval of the Canada-Russia Disability Program, a four-year $4 million project, focusing on education, disability studies, social work practice, social policy, and information dissemination.

2003 ◆ A national survey that updates the Disability Supplement to the 10-year-old National Health Interview Survey highlights barriers to care among the uninsured. The uninsured are four times as likely to postpone care and three times as likely to go without needed supplies.

2003 ◆ The National Association of Social Workers (NASW) issues a policy statement that discusses their core values with respect to working with people with disabilities, including self-determination, social justice, and dignity and worth of the person. The statement emphasizes that social workers are responsible to take action with people who have disabilities in advocating for their rights to fully participate in society.

2003 ◆ The Disability Awareness in Action (DAA) database contains a total of 1,910 reports of known abuse affecting nearly 2.5 million disabled people. In the area of education alone, it documents

118 cases affecting 768,205 people in 67 countries. Responding to this documentation and other reports, the United Nations Commission on Human Rights creates the Global Rights campaign to address human rights abuses. Disability rights organizations use this information to insist on a UN convention on the rights of disabled people that would be legally binding on nation-states.

2003 The International Association for the Study of Pain has more than 6,700 members, representing more than 100 countries and 60 disciplinary fields. Chronic pain is one of the leading causes of recurrent and permanent disability in the developed world today, yet less than 1 percent of the U.S. National Institutes of Health's budget supports research into mechanisms and management of pain. The U.S. Congress declares 2000–2010 the Decade of Pain Control and Research.

2004 The *Journal of Gene Medicine* (January) reports that 636 gene therapy clinical trials are completed or ongoing, involving 3,496 patients. The first gene therapy clinical trials begin in the early 1990s.

Today Seventy to eighty percent—approximately 400 million—of the world's disabled people (600 million, or 10 percent of the world's population) live in the developing world, and of the world's poorest of the poor, 20 to 25 percent are disabled. In most countries, 1 out of 10 persons has a disability. Many international efforts are under way to address poverty and disability, such as those of the Action on Disability Development and the Chronic Poverty Research Centre.

Today E-health is the use of emerging interactive telecommunications technologies such as the Internet, interactive TV, kiosks, personal digital assistants, CD-ROMs, and DVD-ROMs to facilitate health improvement and health care services, including those with disabilities. E-health relies on environments that use a variety of technologies that can compensate for the lack of sensory ability. Telerehabilitation is an example of services delivered information technology and telecommunication networks.

Today Celebrating difference is the mantra and visible manifestation of disability culture in all regions of the world.

SEARCHING FOR AND EVALUATING WEBSITES

Anne Armstrong

The Internet, or Web, provides a vast number of channels through which researchers can find information on virtually any subject. The expansiveness of the Web can be daunting to new researchers. On the other hand, researchers often assume that they have mastered the Web in its entirety when indeed they have merely scratched the surface in terms of the numbers of resources they have consulted and searches they have performed.

Because the field of disability studies is continually evolving and inherently multidisciplinary, Web searchers can draw on previously conducted research from disciplines within the humanities, social sciences, and health sciences. This guide aims to expose beginning researchers to a mixture of general and subject-specialized Web-based search tools, as well as strategies for performing sophisticated Web searches and criteria for evaluating websites. In addition to its broad subject coverage, the field of disability studies differs from most fields in that many researchers may themselves have disabilities affecting their ability to perform research on the Web. For this reason, this description concludes with an overview of accessibility issues on the Web and suggestions for further reading.

OVERVIEW OF WEB-BASED RESEARCH TOOLS

When approaching Web searching, researchers should be aware of the multitude of search tools available to them, in addition to the varying purposes of these tools. Many users approach Web searching with the assumption that "everything is in Google," but this is a limiting misconception. No single search engine contains everything on the Web. Furthermore, all search engines function differently and rank results differently. Therefore, sampling various search tools increases the comprehensiveness of results on any topic. This discussion outlines multiple types of search tools available on the Web and offers potential starting points for Internet research on issues related to disability studies, whether from a health sciences, social sciences, or humanities perspective.

The Web-based search tools outlined in this chapter include general search engines, subject-specialized search engines, directories, indexes, catalogs, and Listservs. It is important to note that different types of search tools cover different parts of the Web. The Web is composed of layers. The top layer is detectible by general search engines, while a deeper layer termed "the invisible Web" can be penetrated only by specialized search engines, indexes, and catalogs. Readers should be aware that because the Web is in a constant state of flux, currently available resources may become obsolete over time, and newer, more sophisticated search tools will undoubtedly evolve.

General Search Engines

Most people who have searched the Web are familiar with sites such as Google, HotBot, or Lycos, which allow them to enter a string of keywords into a search box to retrieve a list of relevant websites (see Table 1). These sites, referred to as search engines, search the Web by means of a program called a *spider* (also

Table 1 Selected General Search Engines

Name	URL
AltaVista	www.altavista.com
Excite	www.excite.com
GO	www.go.com
Google	www.google.com
HotBot	www.hotbot.com
Lycos	www.lycos.com
Yahoo!	www.yahoo.com

called a *robot* or *crawler*). Since search engines tend to index millions of websites, they are most useful for entering specific search terms rather than broad concepts such as disability studies.

While Web searchers tend to pick a favorite search engine and return to it repeatedly, it is important to note that different search engines produce varying results, and that a truly comprehensive Web searcher should compare the results of multiple search engines. The variation between search engines can be attributed to differences between the spiders fueling the search engines as well as differences in the level of indexing and the order in which results are ranked. While some search engines index the full text of documents, others may index only the first page, or merely the *meta-tags*, which are lines of code containing keywords. Web searchers should be aware that developers of websites may intentionally increase their usage of certain words or meta-tags to increase the prominence of their website among search results. This practice has been referred to as *spamdexing* and is most prevalent among the developers of commercial websites advertising products and services. Due to the constant fluctuation of the Web, no search engine is entirely up-to-date; results produced by identical searches can vary greatly from one day to the next, even when one is using the same search engine.

Subject-Specialized Search Engines

Subject-specialized search engines (also referred to as subject portals) developed by educational institutions, associations, government agencies, and corporate entities narrow the broad scope of the Web, providing a focused channel by which researchers can search for information when they have determined the discipline from which their topic stems. Examples of such search engines are listed in Table 2. While subject-specialized search engines index considerably fewer websites and documents than general search engines, the information contained within them has been preselected, ideally by experts within a given field. Many subject-specialized search engines expose searchers to parts of the "invisible Web" not indexed by general search engines. Subject-specialized search engines can ease the research process by whittling down the Web to a more manageable size. However, researchers who use them should take the time to view the criteria for selection of

Table 2 Examples of Subject-Specialized Search Engines

Name	URL	Subject Coverage
Center for International Rehabilitation Research Information and Exchange (CIRRIE)	http://cirrie.buffalo.edu	Rehabilitation research
FamilyDoctor.org	http://familydoctor.org	Health sciences
FirstGov	www.firstgov.gov	Government
Google's Uncle Sam	www.google.com/unclesam	Government
Health*Web*	www.healthweb.org	Health sciences
Mayo Clinic	www.mayoclinic.com	Health sciences
MedlinePlus	http://medlineplus.gov	Health sciences
National Center for the Dissemination of Disability Research (NCDDR)	www.ncddr.org	Disability studies
Social Science Information Gateway (SOSIG)	www.sosig.ac.uk	Social sciences
Thomas	http://thomas.loc.gov/	Legislative information
Voice of the Shuttle	http://vos.ucsb.edu	Humanities
*Web*MD	www.webmd.com	Health Sciences

information contained within them. This information is usually posted within online "help" or "about" pages on the home page.

Table 3 contains search tools that have been developed distinctly for the purpose of locating specialized search engines by subject.

Table 3 Resources for Finding Subject-Specialized Search Engines

Name	*URL*
CompletePlanet	www.completeplanet.com
Direct Search	www.freepint.com/gary/direct.htm
InfoMine	www.infomine.com
Invisible Web Directory	www.invisible-web.net
Librarians' Index to the Internet	www.lii.org
Search Engine Colossus	www.searchenginecolossus.com

Directories

Directories are hierarchically arranged subject guides composed of websites chosen by or recommended to editors of the directory (Table 4). Usually, directories follow a template in which major subject categories such as health, sciences, social sciences, or humanities are posted on the top-level page. Each of these links leads to lists of narrower subcategories. The links on the second level lead to narrower subcategories, and so on. A sample hierarchy from the directory created by Google (available at http://directory.google.com) lists the following subject breakdown: Society → Disabled → Disability studies.

Directories provide Web searchers with the ability to browse recommended resources in various subject areas without having to enter specific search terms. Other useful attributes of directories are that they often contain summaries and evaluations of websites.

Table 4 Selected Directories

Name	*URL*
eBlast	www.eblast.com
Google Directory[a]	http://directory.google.com
Internet Public Library	www.ipl.org
LookSmart	www.looksmart.com
Yahoo! Directory[a]	www.yahoo.com

[a] These sites contain both directories and general search engines.

Article Indexes

Article indexes allow researchers to search by topic for published articles in magazines and scholarly journals. Researchers could certainly locate journal and magazine articles using a freely available search engine such as Google, but they would merely be skimming the surface of what has been published. While the Web provides access to *more* content, it does not provide comprehensive access to research published in journal articles. Article indexes are for the expressed purpose of finding journal articles. With a few exceptions (such as PubMed, an article index of health sciences journals developed and maintained by the National Library of Medicine), article indexes are not freely available on the Web. Libraries purchase subscriptions to multiple article indexes covering a wide spectrum of disciplines. The indexes available through a given library are often dictated by the curriculum of the college or university that the library serves. Thus, large research institutions offer a greater number of specialized article indexes than smaller institutions and public libraries. Due to licensing agreements between article index providers and libraries, off-site access to indexes is usually limited to faculty and students of a college or university. However, there are many libraries that allow members of the public to use their article indexes from within the library. A local public library would be a good starting place for those not connected with academic or commercial organizations.

Since article indexes are proprietary products developed by companies for sale to libraries, they tend to offer specialized search features that are not always available on freely available search engines. These features include subject headings, thesauri, abstracts (summaries of articles), and frequently the full text of articles. Researchers should familiarize themselves with online tutorials, "help" screens, and "about" pages to increase the effectiveness of their searching.

Freely available article indexes relevant to disability studies include the following:

- PubMed: A product of the National Library of Medicine, which includes more than 14 million citations for biomedical articles dating back to the 1950s. URL: http://www.ncbi.nlm.nih.gov/entrez

- CIRRIE: Center for International Rehabilitation Research Information and Exchange, a database containing more than 24,000 citations of international research published from 1990 to the present. URL: http://cirrie.buffalo.edu

Catalogs

While researchers can search indexes to find articles on specific topics, they can search online catalogs to find books. Some catalogs list the books available at individual libraries, while others contain the holdings of multiple libraries and institutions. The individual catalogs of public libraries and universities are usually freely available on the Web. The most comprehensive catalog is called WorldCat, developed by an organization called OCLC (Online Computer Library Center). WorldCat lists books available at public and academic libraries throughout the world. Like most article indexes, WorldCat is not freely available on the Web and must be accessed through a library.

Listservs

Listservs are mailing lists on the Internet that facilitate online discussions on various subjects. They allow researchers within a given field to communicate about scholarly issues via email. People customarily sign up for Listservs by sending an e-mail to the Listserv address stating that they wish to subscribe. Several Listservs related to disability studies are listed in Table 5. In addition, Web searchers can perform a search on a database called tile.net to search for Listservs by topic.

Table 5 Disability Studies Listservs

Name	*URL*
ADA-LAW	http://listserv.nodak.edu/archives/ada-law.html
Disability-Research Discussion List	http://www.leeds.ac.uk/disability-studies/discuss.htm
Disability Studies at Yahoo.com	http://www.groups.yahoo.com/group/disabilitystudies
Disabled Student Services in Higher Education (DSSHE-L)	http://listserv.acsu.buffalo.edu/archives/dsshe-l.html
Women's International Linkage on Disability (D-WILD)	http://groups.yahoo.com/group/d-wild

SEARCH STRATEGIES

Since search capabilities vary from site to site, Web searchers should use online "help" screens and tutorials to learn search tips and strategies for improving their search results. Some search techniques common to several Web-based search tools are summarized below.

Quotation Marks

When entering a search, users should enter phrases in quotation marks to stipulate that they would like the results to contain a specific word combination and order. For instance, multiword concepts such as "disability studies," "adaptive technology," and "section 508" should be entered within quotation marks. Proper names can also be entered within quotation marks.

Truncation

Truncation symbols allow Web searchers to simultaneously search for multiple endings of a given word. For instance, assuming that the asterisk is the designated truncation symbol in a search engine, entering the word "impair*" would produce results including all forms of the word after the root, including "impair," "impaired," "impairment" and "impairments." In addition to adding truncation symbols to the end of words, users may also insert internal truncation symbols if there are potential variations for the spelling of the middle of a word. For instance, entering the word "colo*r" would simultaneously search for the words "color" and "colour." "Help" screens or "search tips" usually list the designated truncation symbol for a given database.

Boolean Logic

Developed by the English mathematician George Boole, Boolean logic is a mathematical framework that Web searchers can apply to broaden or refine their searches. There are three words, or *operators*, that Web searchers can use to combine their keywords to perform more complex searches: AND, OR, and NOT. The three Boolean operators are summarized below, along with potential applications. It is important to read the online "help" section of a database before performing a Boolean search, as Boolean searching does not work in all databases.

Using the Boolean Operator "AND"

Combining words with "AND" narrows a search, as the database retrieves only items that contain *all* the words entered. The second search example below will produce fewer results than the first, since there are three keywords that must appear within the content of each result.

"disability studies" AND theory
"disability studies" AND theory AND history

Using the Boolean Operator "OR"

Entering the term "OR" between keywords stipulates that any, but not all, of the words entered must appear within the search results. Using "OR" is a way of searching for synonyms or related terms when there are multiple words for the same concept. The example below shows how you could broaden your search if you wanted to search for multiple adaptive technology applications in a search engine. The second search example will potentially produce more results than the first, since there is an additional keyword that the results could include.

JAWS OR "Ruby OpenBook"
JAWS OR "Ruby OpenBook" or "window eyes"

Using the Boolean Operator "NOT"

Entering the Boolean operator "NOT" after a word stipulates that the word should not appear within the results. Using "NOT" in a search can be particularly useful if a word is frequently used in multiple contexts and you wish to eliminate results dealing with a particular topic. In the example below, the second search will ideally eliminate items relating to the state of New Mexico, given that the researcher is looking for information on legislation related to disabilities in the country of Mexico. The use of NOT can be too limiting. The second search would eliminate results that discussed both Mexico and New Mexico.

Disabilities AND legislation AND Mexico
Disabilities AND legislation AND Mexico NOT "new mexico"

Nesting

Nesting allows Web searchers to simultaneously search for multiple search terms relating to the same topic. The grouping of synonymous terms within parenthesis is referred to as nesting, as multiple terms relating to the same idea are clustered together as a single concept. When using nesting, the words within the parenthesis are connected by the Boolean operator "OR."

To find information about software for people who are visually impaired, search results are increased by using nesting to group multiple words for each facet of the topic:

(software or "adaptive technology") AND ("visually impaired" or blind)

Plus and Minus Signs

Most general search engines allow users to enter plus or minus signs before a particular word. Entering a plus sign before a word (e.g., +ADA) stipulates that the word must appear within the search results. A minus sign before a word (e.g.,–mobility) stipulates that the word should not appear within the results. Since some search engines also use plus and minus signs as substitutes for Boolean operators, it is important to view online "help" or "search tips."

Search Limits

Most search engines allow users to limit their results by date, language, or document type. Limiting capabilities vary from site to site and are customarily outlined in online "help" screens. In general, article indexes have more sophisticated limiting capabilities than search engines that are freely available on the Web.

EVALUATING WEBSITES

A researcher weighing the quality of a journal article faces a lesser challenge than a researcher considering a website as a potential resource. The publishing industry applies labels to periodicals of varying type: Scholarly journals, popular magazines, trade publications, and newspapers comprise the major categories. Articles submitted to scholarly journals undergo a peer review process by experts in a given field. If in doubt as to the suitability of journal for scholarly purposes, a researcher can consult a directory of periodicals such as *Ulrich's Periodicals Directory,* which indicates whether or not a journal is peer reviewed.

The fact that the Web has no comparable methods of control complicates the task of determining whether a website is appropriate for research purposes. While websites produced by certain types of agencies and organizations certainly undergo a form of *internal*

review, the Web is a free forum; people can post anything they want, and no one has the right to force to take it down if it fails to meet certain standards of quality or accuracy. To complicate the matter, inaccurate or inexpert information can hide like a wolf in the sheep's clothing of sophisticated graphics, layout, and design. The Web has no peer review process to ensure quality. While none of the evaluation criteria outlined below can provide the final word as to the suitability of a website for scholarly use, a researcher who searches the Web with multiple evaluation criteria in mind expedites the process of finding quality information.

Authorship

When determining the credibility of a website, researchers should use multiple techniques to determine the credentials of the author as well as the character of the organization hosting, or sponsoring, the site. If individuals are listed as authors, researchers should take steps to determine their credentials and reputation in the field by performing a search in a general search engine to find biographical information or other documents written about the author. This will also produce references to the author on the sites of other authors within a field. Researchers can also consult a number of biographical sources available at libraries, such as *Who's Who in the America* or sources tailored to particular fields of study, such as *Who's Who in Science and Engineering.*

Website addresses, or URLs (Uniform Resource Locators) can also provide hints as to author affiliations and potential bias. Personal websites are often hosted on commercial ISP (Internet Service Provider) Web servers such as aol.com, or geocites.com. URLs of personal websites often contain first or last names, as well as percent (%) or tilde (~) signs. While personal websites may contain authoritative information, researchers should question why the same content does not appear on a site sponsored by an educational or research organization.. Was the site created as a pastime or to serve as a forum for airing personal views? Or does the site reflect serious scholarship backed up by other credentials and research published in scholarly publications?

Every website URL ends with a *domain name*, usually a series of three letters preceded by a period. The domain name denotes the type of institution that hosts the website and can often provide clues as to the purpose or potential bias of a site. Common domain names include the following:

Educational sites: .edu
Government sites: .gov, .mil, or country codes (e.g., .uk = United Kingdom, .au = Australia, .do = Dominican Republic)
Nonprofit organization sites: .org
Commercial sites: .com

Most URLs contain multiple levels separated by slashes (e.g., http://www.nod.org/stats/). To learn more about the sponsor or publisher of a particular site, you can remove levels of the URL one by one to see where the site is hosted and determine the character of the sponsoring entity. For instance, if a site is hosted on the site of an association, viewing the mission statement on the home page of the association can provide clues as to the bias or purpose of the content. When judging the credentials of the publishing entity, researchers should look for contact information and institutional logos. In general, sites devoid of identifying information or contact numbers and addresses should raise suspicion.

Audience

When evaluating a site, researchers should determine whether the content succeeds in addressing the stated audience through tone and presentation. Sites for adults should not have a childlike appearance or tone. Likewise, sites may be deliberately overrun by technical language or jargon to confuse or mislead a particular audience. High-quality sites clearly define their intended purpose.

Currency

Medical research findings or population statistics may become obsolete at a faster rate than research in the humanities. Web researchers should check sites for copyright dates and the date of the last update. Broken links are a sign of neglect, as they may indicate that URLs have changed or become obsolete since the last update of the site. To verify the currency of information on a site, researchers should check for several sites covering the same subject matter.

Accuracy

Determining accuracy involves further research to ensure that the claims or findings on a site are substantiated by other sources. If a site presents original research, the methods of the research and instruments used should be clearly explained, as well as potential limitations of the research. If authors make claims or conclusions, they should cite their

sources, and these sources should be tracked down to ensure their existence and authenticity. Websites should contain a list of works cited or footnotes on par with any print book or article. Since websites sometimes include fabricated resources, and erroneous or incomplete citations, sources should be verified using library tools such as indexes and catalogs. Lists of works cited with multiple errors reflect irresponsible research. If a website contains links, the links should be checked. Researchers should be wary of websites populated by broken links or links to defunct websites.

Quality

In general, sites that are poorly organized or sloppy should be approached with caution. Shoddy design may point to further weaknesses. Poor grammar and spelling errors are also red flags.

Bias

While bias is not always a negative attribute, Web searchers should be cognizant of bias as the search for information. The bias of a website can be partially discerned by the domain name (as discussed above under "Authorship"). Commercial websites may be motivated by the goal to market a product or service. Nonprofit organizations may promote a political agenda. While bias may be clearly stated in mission statements and "about" pages, many websites deliberately shroud their bias. Thorough research involves consulting additional sources to determine the history and activities of a particular organization. If a site contains links to other sites, those links should be checked to discern the character and activities of the other organizations listed. If a site is sponsored by other organizations, researchers should consider the relationship between the sponsors and the creators of the site.

Special Considerations for Evaluating Health Information on the Web

The American Medical Association (AMA) has published "Guidelines for Medical and Health Information Sites on the Internet" outlining evaluation criteria for websites publishing health information, whether for consumers or health professionals. While these guidelines are technically enforced only on sites sponsored by the AMA or affiliated organizations, they could be applied to all sites containing health information. Many of these guidelines mirror the previously outlined criteria for evaluating all websites, but there are certain factors that are heavily emphasized in the AMA guidelines, including the importance of peer review by experts in the field, the importance of clearly identifying sources of funding, an explanation of the relationship between individual researchers and the institutions sponsoring the research, the importance of clearly stating the purpose and intended audience of a site, and the need to address the stated audience in a consistent and effective tone. Seven criteria for assessing the quality of health information on the Internet have been developed by the Health Summit Working Group (Health Information Technology Institute 1999).

Information on health-related websites should be verified by checking sources such as journal articles, books, and other websites. These measures are needed as health information on the Web frequently includes unsubstantiated claims.

OVERVIEW OF ACCESSIBILITY ISSUES ON THE WEB

Disability studies research is unique in that many scholars in the field have disabilities that may impact their ability to effectively search the Web. While in many ways the Web "evens the playing field" by making a vast number of resources available electronically, inaccessible design frequently places barriers on Web searchers with disabilities.

Principles of Web accessibility have been developed by the World Wide Web Consortium's (W3C) Web Accessibility Initiative (WAI). The WAI establishes guidelines for creating accessible websites, browsers, and authoring tools to increase the ease of use of the Web for users with disabilities. Multiple scenarios outlining potential challenges to Web searchers with disabilities are summarized in a W3C working draft titled "How People with Disabilities Use the Web" (2001). Among other scenarios, the document emphasizes that many Web searchers with cognitive or visual disabilities use OCR (optical character recognition) software, which reads Web page text and transmits the information to a speech synthesizer and/or refreshable Braille display. Many users with visual disabilities use text-based Internet browsers instead of standard graphical browsers. The successful use of these tools requires that images on websites be accompanied by descriptive text and *ALT tags*. ALT tags are textual labels that appear on the computer screen when a mouse moves over an image. Since visually impaired

Web searchers often enlarge Web-based text using screen magnification programs, Web designers must create pages with nonfixed font sizes that can be altered as necessary. These are only a few of the issues facing Web searchers with disabilities. Other population groups with disabilities discussed in the guidelines include individuals with cognitive disabilities, hearing impairment, and mobility-related disabilities. Readers should consult the WAI website for the complete guidelines (http://www.w3.org/WAI/).

To support the goals of WAI, an online tool called Bobby™ helps website developers test the accessibility of their sites and adhere to accessibility guidelines. By entering a URL into the Bobby website, a Web developer can generate a report outlining which features of the site need to be adjusted to make it "Bobby compliant" and adhere to both W3C accessibility guidelines and guidelines established by the U.S. government's Section 508, a 1998 amendment to the Rehabilitation Act requiring that all federal agencies make their electronic and information technology accessible to people with disabilities. Complete information about these guidelines can be found on the Section 508 website (www.section508.gov).

CONCLUSION

While "one-stop shopping" in Google may be tempting, there is no single search engine leading to everything on the Web. Comprehensive and effective research in disability studies involves consulting multiple search tools, including but not limited to general search engines, subject-specialized search engines, directories, and indexes. In addition to using multiple search tools, Web searchers should experiment with multiple search strategies to maximize the effectiveness of their searching. As there are no standards of quality on the Web, researchers should apply multiple evaluation criteria to every website, verifying that research findings posted on sites are supported by other sources. Web accessibility is a crucial component to disability studies, as the Web has the potential to deliver equal content to all users but frequently presents barriers to people with disabilities by failing to adhere to standards of accessible design. Researchers can develop an awareness of accessibility issues on the Web by familiarizing themselves with the standards outlined by W3C's Web Accessibility Initiative and Section 508.

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