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Long-Term Care: Consumers, Providers, Payers, and Programs

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March 15, 2007

Abstract. This report discusses selected characteristics of long-term care consumers and providers. It then describes payers and selected programs that finance long-term care services.

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Long-Term Care: Consumers, Providers, Payers, and Programs

Summary

Long-term care refers to a broad range of health and social services needed by people who are limited in their capacity for self-care due to a physical, cognitive, or mental disability or condition that results in functional impairment and dependence on others for an extended period of time. The need for long-term care affects people of all ages — children born with disabling conditions, working-age adults with inherited or acquired disabling conditions, and the elderly with chronic conditions or illnesses. The need for long-term care services is generally measured, irrespective of age and diagnosis, by a person's inability to perform basic activities necessary to live independently. While the likelihood of needing long-term care assistance occurs more frequently with increasing age, advances in medical care are enabling people of all ages with disabilities to live longer.

About 9.4 million adults, or 5% of the adult population, receive long-term care services in the community or in institutions. About 1.1 million children living in the community have long-term care limitations. While the lifetime risk of individuals using long-term care services varies greatly, a team of researchers has estimated that 69% of people turning age 65 in 2005 with a moderate level of need will use some care before they die; 31% will not need any care.

Regardless of age, people receiving long-term care assistance are more likely to live at home and in community settings rather than in institutions. Adults with long-term care limitations are more likely to live in poverty than people without limitations. Most care received by people with disabilities is provided by informal providers — family and friends — who give care without compensation. Formal care providers range from institutional settings and other residential care facilities to a variety of organizations that provide a wide array of home and community-based services. Accessing and arranging formal care services, delivered through multiple providers, can be complex and confusing for individuals and their families.

National spending on long-term care in 2005 is estimated at $206.6 billion. Medicaid is by far the largest public program that covers long-term care, paying for almost half of the nation's long-term care services, primarily institutional care. Medicare covers post-acute services in skilled nursing facilities and in the home for certain Medicare beneficiaries. In addition, the Older Americans Act (OAA) and the Social Services Block Grant (SSBG) support a wide range of home and community-based long-term care services. Each of these federal programs has differing characteristics, program goals, eligibility requirements, and covered services, which often results in an uncoordinated service delivery system for individuals and families seeking assistance.

In order to assist Congress in future policy deliberations about long-term care services and supports, this report discusses selected characteristics of long-term care consumers and providers. It then describes payers and selected programs that finance long-term care services. This report will be updated occasionally.

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Long-Term Care: Consumers, Providers, Payers, and Programs

Introduction

Long-term care services and support refer to a broad range of health and social services needed by people who are limited in their capacity for self-care due to a physical, cognitive, or mental disability or condition that results in functional impairment and dependence on others for an extended period of time. The need for long-term care affects persons of all ages — children born with disabling conditions, such as mental retardation, or cerebral palsy; working-age adults with inherited or acquired disabling conditions, such as mental illness or traumatic brain injuries; and the elderly with chronic conditions or illnesses, such as severe cardiovascular disease or Alzheimer's disease. While the likelihood of needing long-term care assistance increases with advancing age, advances in medical care are enabling persons of all ages with disabilities to live longer.

Changing the way long-term care services and supports are financed and delivered has drawn congressional attention for more than two decades. Despite significant spending, the nation lacks a comprehensive policy on the financing of long-term care. A number of factors cause concern among federal and state policymakers. Among other things, these include the large personal financial liability many people with disabilities face in paying for long-term care services, sometimes resulting in impoverishment; the high proportion of public long-term care spending devoted to institutional care; predicted increased demand for services as a result of the aging of the population; and a complex delivery system composed of multiple services funded through a myriad of federal programs, often resulting in fragmented and uncoordinated care.

Total U.S. spending on long-term care is a significant component of all health care spending. Of the $1.6 trillion spent on personal health care in 2005, an estimated $206.6 billion, or 12.4%, was spent on long-term care services. Long-term care spending includes payment for services in institutional settings — primarily nursing homes and intermediate care facilities for people with mental retardation — and a wide range of home and community-based services, such as home health care, personal care, and adult day care.

The dominant payer of long-term care expenditures is the Medicaid program. In 2005, Medicaid paid for nearly half of long-term care spending (48.9%, or $101.1 billion). Medicare and out-of-pocket spending by individuals and families accounted for about 20.4% and 18.1%, respectively, of total spending. Private insurance and

other public and private sources paid for the balance of spending (7.2% and 5.3%, respectively).[1]

Despite the large public commitment to financing care, most care received by persons with disabilities is provided by informal sources — family and friends — who provide care without compensation. Many policymakers are concerned about the impact that the aging of the population and increasing longevity of younger persons with disabilities will have on the ability of informal caregivers to continue their caregiving roles in the future.

Although previous Congresses have considered proposals to address issues in long-term care financing and service delivery, consensus has not been reached on what policy directions should be taken to overhaul the system. Congress made a systemic change in federal long-term care policy in 1981 when it created the Medicaid Section 1915(c) home and community-based waiver program for persons with disabilities. The last time that Congress comprehensively reviewed policy options for long-term care reform was in 1990, under the U.S. Bipartisan Commission on Comprehensive Health Care (known as the Pepper Commission).

In 1999, the U.S. Supreme Court ruled on a landmark case for people with disabilities, *Olmstead v. L.C.*[2] The Court held that institutionalization of people who could be cared for in community settings was a violation of Title II of the Americans with Disabilities Act (ADA). This case and subsequent federal and state legislation, as well as activities conducted by the Bush Administration,[3] have encouraged efforts to provide expanded home and community-based services for people with disabilities. More recently, in the Deficit Reduction Act of 2005 (P.L. 109-171), Congress approved a new optional Medicaid benefit that allows states to cover home and community-based long-term care services for people with disabilities. The 109th Congress also approved the Lifespan Respite Care Act of 2006 (P.L. 109-442) to provide grants to states to expand respite care services to family caregivers.

In order to assist Congress in future policy deliberations about long-term care services and supports, this report presents selected characteristics of long-term care consumers and providers. It then discusses federal programs that finance long-term care.

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[1] *National Spending for Long-Term Care*, Fact Sheet, Georgetown University Long-Term Care Financing Project, February 2007 [http://ltc.georgetown.edu/pdfs/natspendfeb07.pdf], visited on Mar. 6, 2007.

[2] 527 U.S. 581 (1999).

[3] On Feb. 1, 2001, President Bush announced the New Freedom Initiative as part of a nationwide effort to remove barriers to community living for people with disabilities. For further information, see [http://www.hhs.gov/newfreedom/init.html], visited on Jan. 9, 2007. This initiative includes a number of activities including a wide range of grants to states for long-term care systems change, and home and community-based services.

Defining Long-Term Care

As stated in the introduction, long-term care services and supports refer to a broad range of health and social services needed by people who lack the capacity for self-care due to a physical, cognitive, or mental disability or condition that results in functional impairment and dependence on others for an extended period of time. Services to assist people with long-term care needs as a result of functional and cognitive impairments can range from helping a frail elderly person bathe, dress, eat, and use the bathroom, to skills training and medication management for a cognitively impaired person, to use of special equipment or devices by a physically impaired person, to nursing care for a ventilator-dependent child. Services may be provided in various settings, including one's home and community, in a residential setting, or in an institution. Long-term care services vary widely in their intensity and cost, depending on an individual's underlying conditions, the severity of his or her disabilities, and the location in which services are provided.

The need for long-term care services is generally measured, irrespective of age and diagnosis, by the presence of limitations in the ability to perform basic personal care, known as activities of daily living (ADLs), or by the need for supervision or guidance with ADLs, because of mental or cognitive impairments. ADLs generally refer to the following activities: eating, bathing and showering, using the toilet, dressing, walking across a small room, and transferring (getting in or out of a bed or chair). An additional set of criteria that assess activities other than basic personal care, known as instrumental activities of daily living (IADLs), measure a person's ability to live independently in the community. IADLs include preparing meals, managing money, shopping for groceries or personal items, performing housework, using a telephone, doing laundry, getting around outside the home, and taking medications. (References to a person's need for long-term care assistance as measured by ADLs and IADLs are used throughout this report.) Some state long-term care programs for people with mental retardation or developmental disabilities define eligibility for services based on a specific diagnosis, sometimes in combination with other factors such as functional limitations.

Federal and state long-term care programs, as well as many legislative proposals and private long-term care insurance, often base eligibility for long-term care assistance on a person's need for assistance with a prescribed number of ADL limitations or a similar level of disability, or the need for supervision in ADLs as a result of cognitive impairment. The number of people potentially eligible for assistance, and therefore program cost, will be affected by whether a program or proposal targets those with, for example, one or more, two or more, or three or more limitations in ADLs. Generally, people who need ADL assistance also need assistance with IADLs. However, eligibility for long-term care assistance through major public programs such as Medicaid or through private long-term care insurance is not generally defined by the need for IADL assistance alone.

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Consumers of Long-Term Care

- About 9.4 million adults — about 5% of the U.S. adult population — receive long-term care services and supports.
- While the likelihood of needing long-term care assistance occurs more frequently in older ages, the need for long-term care affects people of all ages. Of all adults receiving long-term care assistance, 58% are age 65 and older, and 42% are age 18-64.
- Regardless of age, people receiving long-term care assistance are more likely to reside at home and in community settings rather than in institutions. More than three-quarters of adults receiving long-term care assistance reside at home and in community settings, and many have fairly significant limitations.
- Most people who have intensive long-term care limitations (that is, have two or more limitations in ADLs) have lower incomes and are more likely to live in poverty than people without limitations. Among the elderly, people at the oldest ages (i.e., 85 and older) — those most likely to need long-term care assistance — have the lowest incomes.

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Selected Demographic Characteristics of Long-Term Care Consumers

This section presents national survey summary data on the number of adults and children who receive long-term care assistance.[4] The section then presents selected characteristics of adult consumers of long-term care. Identifying the long-term care population is challenging, and estimates of its size and characteristics vary widely. There are many underlying causes for the inconsistent estimates provided through national data. These include varying definitions of receipt of care, how long receipt of care is evident, whether a person receives personal assistance from another person or is simply under supervision with an ADL or IADL, or whether the person uses assistive devices or equipment as a result of a disability. (See **Appendix A** for

[4] Outside the scope of this report are data on those who *need* long-term care but *do not receive* care, or do not receive sufficient care to meet their needs. The data on unmet need for care are limited, but some studies have addressed the issues. For example, see Harriet Komisar et al., *Unmet Long-Term Care Needs: An Analysis of Medicare-Medicaid Dual Eligibles*, Inquiry 42(2) Summer 2005; and Mitchell P. LaPlante et al., *Unmet Need for Personal Assistance Services: Estimating the Shortfall in Hours of Help and Adverse Consequences*, Journal of Gerontology, vol. 59B, no. 2, 2004. Some research has addressed waiting lists for services. For example, see General Accounting Office (now the Government Accountability Office, or GAO), *Long-Term Care; Availability of Medicaid Home and Community Services for Elderly Individuals Varies Considerably*, GAO-02-1121, September 2002 [http://www.gao.gov/new.items/d021121.pdf].

methods of estimating the long-term care population and underlying causes of variation in estimates.)

The Need for Long-Term Care. The need for long-term care affects people of all ages. While the likelihood of receiving long-term care assistance occurs more frequently among people of older ages, the need for long-term care affects individuals of all ages, including children born with disabling conditions and working-age adults.

Children. Few nationally representative surveys to collect information on children with long-term care needs have been conducted. Results from one assessment, the National Health Interview Survey (NHIS), suggested that 2.1% of children age 5-17 years living in the community in 2000 had limitations in their ability to walk, to care for themselves, or perform other activities (not including special education services). This translates to about 1.1 million children in this age range.[5] This calculation likely underestimates the number of children with long-term care needs, as it excludes both children under age 5 and children who reside in facilities. Estimates for children are not discussed in greater detail in this report because the NHIS definition of disability for children differs significantly from the definitions used that used to identify adults with long-term care needs.

Adults. **Table 1** provides broad estimates of the number of adults who receive long-term care services. Because no single nationally representative data set provides estimates in all of the major adult age groups in both home and facility settings, the table combines data from various sources which differ in the time period collected. (Data are for 1999 for the age 65-and-older population and for 1994 for the age 18-64 population; see sources in table notes.) Because of the differing definitions of disability employed and differing time frames, the estimates should be considered indicative rather than absolute. Estimates include all persons who receive long-term care regardless of severity of underlying needs and amount/intensity of the assistance received (but do not include those who need but are not receiving services). Some policy options for the provision of services refer to smaller subsets of this population.

[5] CRS calculations based on (1) Achintya N. Dey, Jeannine S. Schiller, and Diane A. Tai, "Summary Health Statistics for Children: National Health Interview Survey, 2002," Washington, DC, National Center for Health Statistics, *Vital and Health Statistics*, series 10, no. 221, March 2004, and (2) [http://www.childstats.gov/], visited Jan. 22, 2007.

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Table 1. Number of Adults Receiving Long-Term Assistance, by Age

(in thousands of persons)

Age Group	Total U.S. Population	Total	% of Age Group	Total Residing in the Community	% of Age Group	Total Residing in Facilities	% of Age Group
All adults	193,161	9,397	4.9	7,188	3.7	2,208	1.1
18-64 years	158,702	3,918	2.5	3,364	2.1	554	0.3
65 years & older	34,459	5,479	15.9	3,824	11.1	1,654	4.8

Sources: CRS calculations based on data from the National Long-Term Care Survey (1999), the National Health Interview Survey, Disability Supplement (1994), and Spector and colleagues, *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality (AHRQ) Publication No. 00-0049, September 2000.

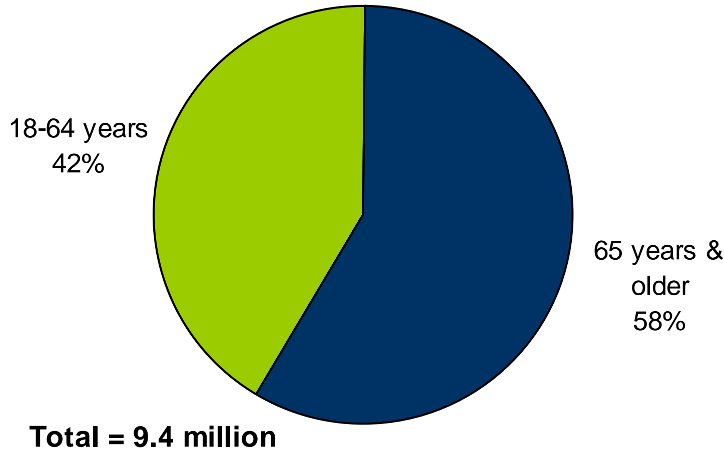
Notes: (1) *In the community* estimates: receipt of human help for at least one IADL or ADL, including reminders or standby help, due to a physical, mental, or emotional problem. Does not include persons who use equipment (assistive technology) to independently manage their disabilities. (2) *In facilities* includes all persons who are in an institutional setting, regardless of status on disability measures. Numbers in facilities are point-in-time estimates of the number of *current* residents in facilities on the day of the survey enumeration. The number of persons with facility usage at any time in the year will be higher due to transitions in-and-out of facilities (discharge of persons with short-term facility usage for an acute event, death, etc.). (3) Estimates for ages 65 and older are for year 1999; for ages 18-64, year 1994. (4) Totals may not add due to rounding.

Number of Recipients. About 9.4 million adults 18 years of age and older — almost 5% of the total U.S. adult population — receive long-term care assistance from other people due to limitations in ADLs or IADLs as a result of physical, mental, or emotional impairments. The likelihood of receiving assistance increases with age — about 15.9% of the total elderly population and 2.5% of the population age 18-64 have long-term care limitations (see **Table 1**[6]).

[6] The primary sources for the data in Table 1 are (1) for population age 18-64 (in the community): National Health Interview Survey (NHIS), Disability Supplement (1994), at [http://www.cdc.gov/nchs/about/major/nhis_dis/nhis_dis.htm]; age 18-64 (in facilities): W.D. Spector, J.A. Fleishman, L.E. Pezzin, and B.C. Spillman. *The Characteristics of Long-Term Care Users*, Rockville, MD: Agency for Healthcare Research and Quality (AHRQ) Publication No. 00-0049, September 2000 (hereafter cited as: Spector and colleagues, *The Characteristics of Long-Term Care Users*). (2) For population age 65 and older: unpublished tabulations of the 1999 National Long-Term Care Survey by Brenda C. Spillman, the Urban Institute, 2003.

Of the 9.4 million adults receiving long-term care assistance, the majority (58%) are 65 and older, but a substantial proportion (42%) are 18-64 years (see **Figure 1**).

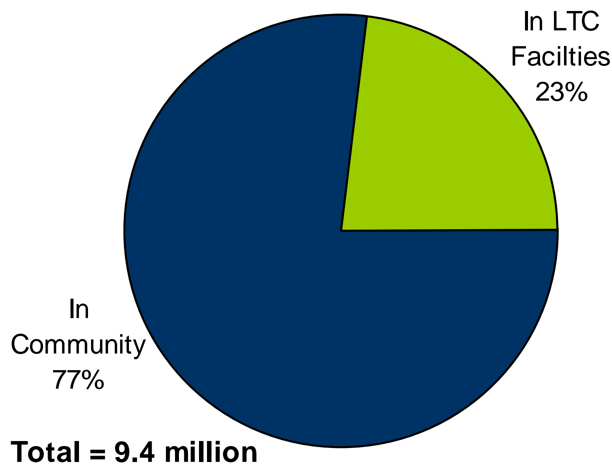
Figure 1. Adults Receiving Long-Term Care Assistance, by Age Group



Sources: CRS calculations based on data from the National Long-Term Care Survey (1999), the National Health Interview Survey, Disability Supplement (1994), and Spector and colleagues, *The Characteristics of Long-Term Care Users*, AHRQ Publication No. 00-0049, Sept. 2000.

Where Recipients Live. The vast majority of adults receiving long-term care assistance live in the community, not in institutions. Of the 9.4 million adults receiving long-term care assistance, more than three-quarters (7.2 million) reside at home or in other community settings (see **Figure 2**). (See notes to Table 1 and Figure 2 for descriptions of data on persons in the community and in facilities.)

Figure 2. Adults Receiving Long-Term Care Assistance, by Type of Residence



Sources: CRS calculations based on data from the National Long-Term Care Survey (1999), the National Health Interview Survey, Disability Supplement (1994), and Spector and colleagues, *The Characteristics of Long-Term Care Users*, AHRQ Publication No. 00-0049, September 2000.

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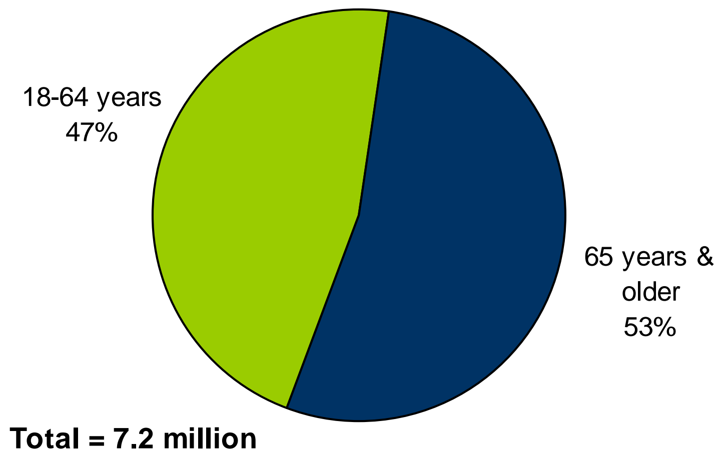
Note: For the population age 18-64 years, the facility estimate includes about 300,000 persons with mental retardation or a related condition living in residential facilities,138,000 persons in nursing homes, 56,000 in mental hospitals, and another 60,000 in other institutional settings. For the elderly population, this includes persons who reside in assisted living facilities and receive substantial nursing care, persons living in nursing, convalescent, and rest homes, mental/long-stay hospitals, and other institutions where three or more unrelated individuals live and where a registered nurse, licensed practical nurse, physician, or other health care professional is on duty daily. Duke University, Center for Demographic Studies, *User's Guide to the NLTCS Questionnaires*, Final Version 1.0. Specific facility or institution types are identified in Duke University, Center for Population Studies, *1999 NLTCS Institutional Survey*.

Of all adults with long-term care limitations living in the community, just over half are age 65 and older, and the remainder (47%) are age 18-64 (see **Figure 3**).

Figure 3. Adults Receiving Long-Term Care Assistance Residing in the Community, by Age Group



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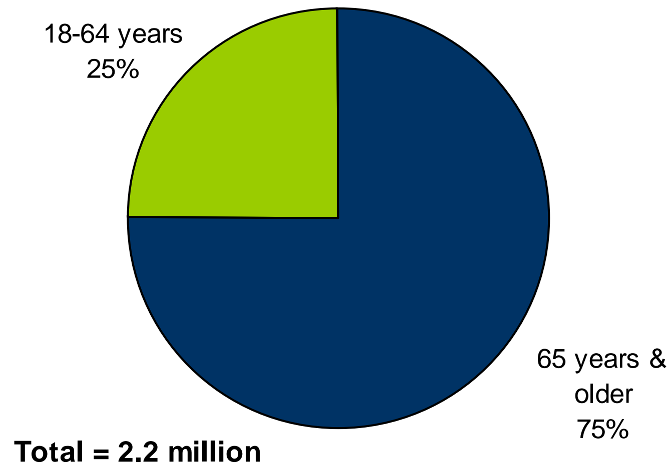
Sources: CRS calculations based on data from the National Long-Term Care Survey (1999), the National Health Interview Survey, Disability Supplement (1994), and Spector and colleagues, *The Characteristics of Long-Term Care Users*, AHRQ Publication No. 00-0049, September 2000.

Ages of Recipients. Of all adults living in nursing homes, the majority are elderly. Just over 2.2 million adults receiving long-term care assistance reside in facilities. The majority (1.7 million, or 75%) are age 65 years and older. Just one-quarter are age 18-64 (see **Figure 4**).

Figure 4. Adults Residing in Long-Term Care Facilities, by Age Group



Source: CRS calculations based on data from the National Long-Term Care Survey (1999), the National Health Interview Survey, Disability Supplement (1994), and Spector and colleagues, *The Characteristics of Long-Term Care Users*, AHRQ Publication No. 00-0049, September 2000. See notes to Figure 2 for definition of facility residents.

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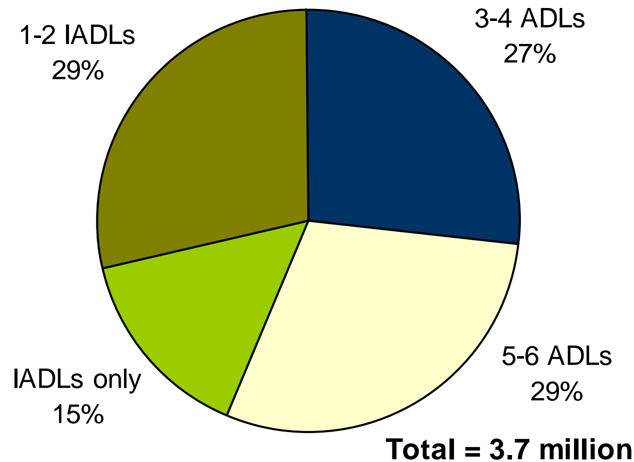
Level of Need. Although people living in long-term care facilities are generally the most impaired, many people with long-term care limitations who live in the community have fairly significant limitations. Typically, people with at least two or more limitations in ADLs or who need supervision with ADLs are considered to be in need of long-term care for purposes of determining eligibility for assistance through publically and privately financed benefits. Those without informal supports from family and friends, or whose needs cannot be met through informal sources, may have to reside in institutions or other residential facilities. But there are many people with significant impairments residing at home who are cared for by family and friends.

Figure 5 shows the level of need by people age 65 and older who live in the community. Of the 3.7 million people age 65 and older who live in the community with long-term care limitations, the majority (56%) have three or more limitations in ADLs. About 29% have limitations in one or two ADLs, and about 15% have less intensive needs, requiring assistance only with IADLs.

Figure 5. Long-Term Care Recipients Age 65 and Older Living in the Community, by Level of Need



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Source: CRS calculations based on data in Federal Interagency Forum on Agency on Aging-Related Statistics, Older Americans, 2004: Key Indicators of Well-Being, November 2004. Indicator 37. Original source of data is the National Long-Term Care Survey, 1999.

A slightly different pattern is evident for younger people age 18-64. A greater proportion of these individuals need assistance with IADLs rather than ADLs. Of the 3.4 million people in this age group living in the community, a majority (56%) need assistance with IADLs only (**Figure 6**). One reason for this is that there is a greater proportion of people in this age group who have developmental disabilities than in the elderly population. Almost 12% of people age 18-64 with long-term care limitations in the community have mental retardation, compared to less than 1% of those 65 and older.[7] People with developmental disabilities may be able to attend to their personal assistance needs, but may need assistance or supervision with independent living tasks such as homemaking, shopping, money management, and taking of medication.

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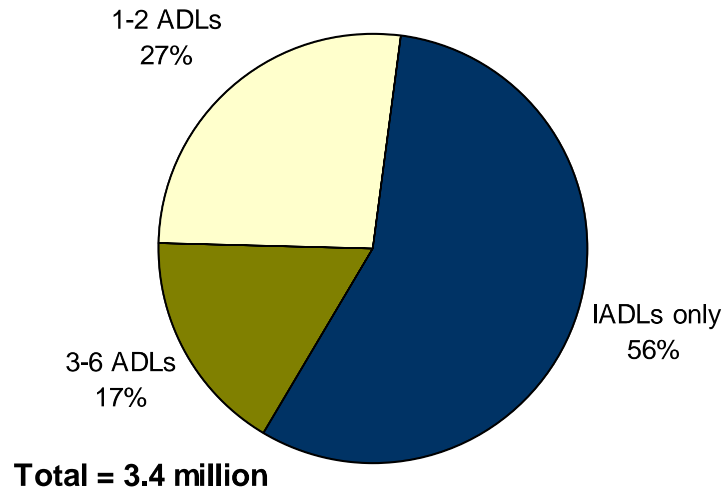
[7] William D. Spector, et. al. *The Characteristics of Long-Term Care Users*, AHRQ Publication No. 00-0049, September 2000. National Health Interview Survey, Disability Supplement (1994).

Figure 6. Long-Term Recipients Age 18-64 Living in the Community, by Level of Need



Source: National Health Interview Survey, Disability Supplement (1994). The Characteristics of Long-Term Care Users. AHRQ Publication No.00-0049, September 2000.

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Income Status of People with Long-Term Care Limitations. People with long-term care limitations are more likely to have low incomes and live in poverty than people without limitations. People with *any* disability, regardless of age, are more likely to have lower incomes and live in poverty than those with no disability. And those with severe disabilities are more financially disadvantaged based on income alone.[8]

Figure 7 compares the income status of people living in the community with ADL limitations with those with no functional limitations (using data from the Lewin Group's HCBS Population Tool).[9] Eligibility requirements for public programs as well as private long-term care insurance coverage often base eligibility for long-term care assistance on a person's need for assistance with a prescribed number of ADL limitations, or a similar level of disability, or the need for supervision with ADLs, as a result of cognitive impairment. Figure 7 shows income status for those with 2 or more ADL limitations. (Income is one measure of total wealth, which also includes assets and home equity not discussed here.)

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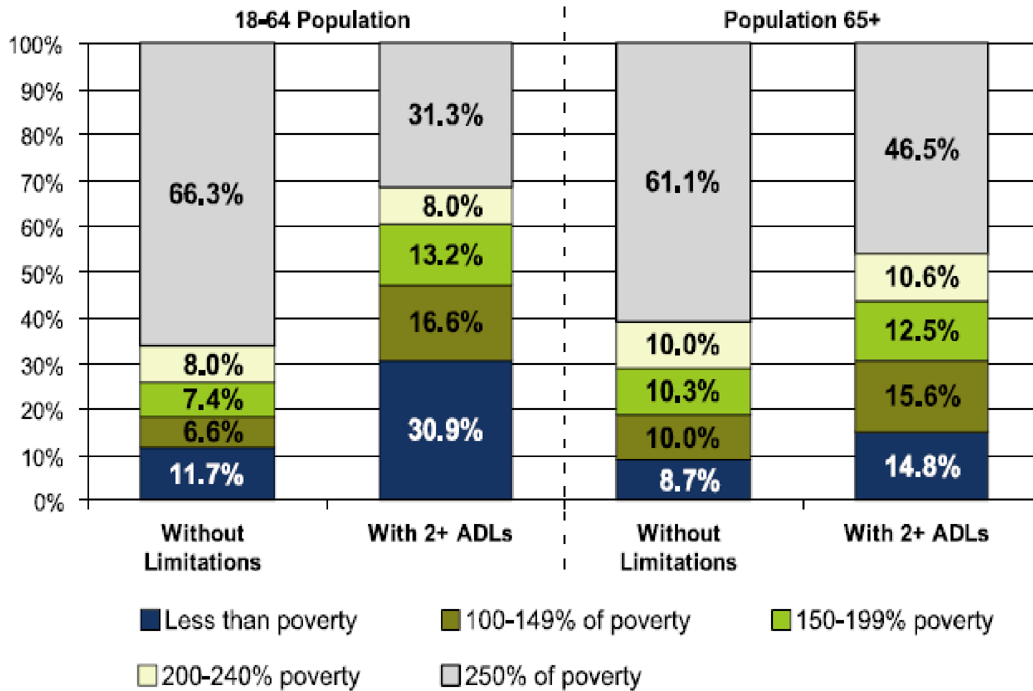
[8] U.S. Census Bureau. *Americans with Disabilities: 2002.* Household Economic Studies. May 2006. See, for example, Table 4 on household income among people with disabilities. [http://www.census.gov/prod/2006pubs/p70-107.pdf].

[9] The Lewin Group Center on Long-Term Care. The HCBS Tool provides national and state estimates of the long-term care population living in the community , using 2000 U.S. Census Bureau Public Use Microdata Sample (PUMS) and the 1996 Survey of Income and Program participation (SIPP), a nationally representative longitudinal survey of the community-dwelling population, at [http://www.lewin.com/NR/rdonlyres/22BE8FA2-6732-41CE-A202-E611B3D8B88F/0/HCBSPopulationToolMethodologyUpdated.pdf].

As shown in **Figure 7**, people age 18-64 with two or more ADL limitations are almost three times as likely to live in poverty than those with no limitations — 30.9% of people with two or more ADL limitations live in poverty compared to only 11.7% of those with no limitations. About 61% of these people with two or more ADL limitations had income below 200% of the poverty level compared to one-quarter of those without limitations.

The correlation between ADL limitations and lower income is also evident among the population age 65 and older. Those age 65 and over with two or more ADL limitations are more than one and a half times as likely to live in poverty than those without limitations — 14.8% of those with two or more ADL limitations live in poverty compared to 8.7% of those with no limitations. Almost 43% of the elderly with two or more ADL limitations had income below 200% of the poverty level compared to almost 30% of those without limitations.

Figure 7. Income Status of People with Two or More ADL Limitations Living in the Community Compared to People with No ADL Limitations, 2005



Source: CRS calculations based on data continued in the Lewin Group, Inc. HCBS Population Tool. [http://www.lewin.com]. The HCBS Tool provides national and state estimates of the long-term care population living in the community , using 2000 U.S. Bureau of the Census Public Use Microdata Sample (PUMS) and the 1996 Survey of Income and Program participation (SIPP), a nationally representative longitudinal survey of the community-dwelling population [http://www.lewin.com/NR/rdonlyres/22BE8FA2-6732-41CE-A202-E611B3D8B88F/0/HCBSPopulationToolMethodologyUpdated.pdf], visited Feb. 12, 2007. Percents may not add due to rounding.

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Older people with disabilities generally receive social security benefits and other retirement income.[10] Those who are born with a disabling condition may not have work histories that would otherwise entitle them to social security disability benefits; and others may not meet the social security definition of disability that would entitle them to benefits. Younger adults who meet the disability and income requirements for Supplemental Security Income (SSI) may qualify for income benefits under that program which may be their only source of income.[11]

Income declines with advancing age. **Figure 8** shows the income levels for groups of older people ranked by income quintile, without regard to disability. Among the elderly, people at the oldest ages — those most likely to need long-term care assistance — have the lowest income. For example, among married couples with an older member age 65 to 69, the bottom 20% (i.e., bottom quintile), ranked by their incomes, had annual incomes below $23,934, whereas the top 20% (top quintile) had incomes above $89,400. However, for the oldest groups — married-couple households with an older member age 85 or older — the bottom 20% had incomes below $18,376, and the top 20% had incomes above $48,490, much lower than for their younger counterparts.

Moreover, people without spouses tend to have less income than married couples. These people are also less likely to have informal supports (e.g., spouses) to assist them with their long-term care needs. Income levels of single persons are roughly 40% to 50% those of their married counterparts at each age level (and in some age groups, less for lower income groups) (see **Figure 9**). Among single persons age 65 to 69, 40% have incomes below $13,970 (149% of poverty); among those age 80 and over, two-fifths have incomes below $12,410 (132% of poverty) These households would appear to be particularly vulnerable to the often high medical costs associated with chronic illness and many, if not most, are likely to find medigap and long-term care insurance policies beyond their financial means, based on their incomes alone. The cost of formal, paid long-term care services (discussed in the next section of this report) can be quite substantial, especially if care is needed for a sustained period of time. Those with low, or even moderate, income may need to rely on safety net programs, such as Medicaid, when they face long-term care expenses.[12]

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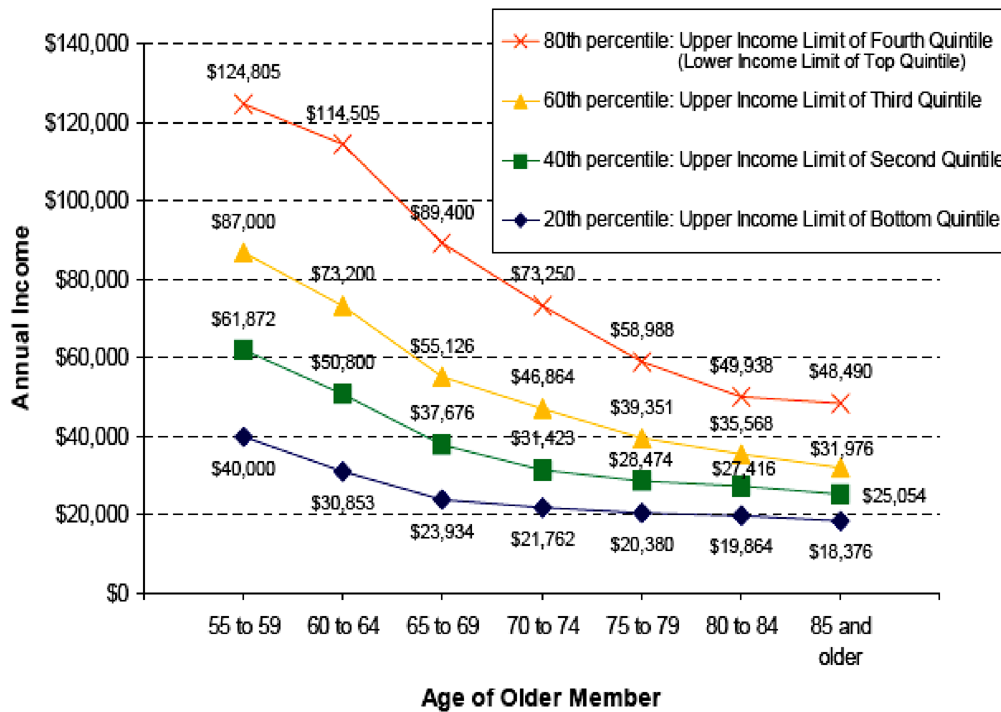
[10] For a discussion of income and income sources of the elderly, see CRS Report RL32697, *Income and Poverty Among Older Americans in 2005*, by Debra B. Whitman and Patrick Purcell.

[11] For more information about SSI, see CRS Report RS20294, *SSI Income and Resource Limits: A Fact Sheet*, by Scott Szymendera.

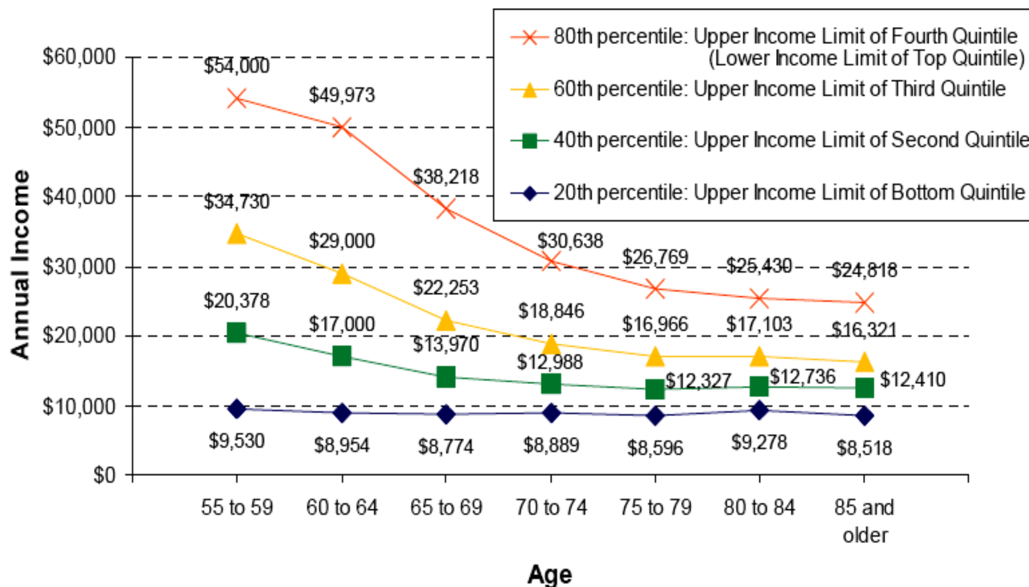
[12] For information about Medicaid eligibility and long-term care, see CRS Report 33593, *Medicaid Coverage for Long-Term Care: Eligibility, Asset Transfers, and Estate Recovery*, by Julie Stone.

Figure 8. Income of Married Couples With a Member Age 55 or Older Living with No Other Household Members, by Income Quintile[a] and Age of Older Member, 2002



Source: Figure prepared by the Congressional Research Service (CRS) based on analysis of U.S. Census Bureau Annual Social and Economic Supplement (ASEC) to the 2006 Current Population Survey (CPS).
a. Income quintiles separately defined for each age group.

Figure 9. Income of Single Persons Age 55 and Older Living with No Other Household Member, By Income Quintile[a] and Age: 2002



Source: Figure prepared by the Congressional Research Service (CRS) based on analysis of U.S. Census Bureau Annual Social and Economic Supplement (ASEC) to the 2006 Current Population Survey (CPS).
a. Income quintiles separately defined for each age group.

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Estimating Risk of Using Long-Term Care Services

The previous discussion presented estimates of the population who receive long-term care based on various national surveys. An understanding of individuals' risk of using long-term care services is important in any discussion of potential changes in long-term care policy in the future. Estimating an individual's lifetime risk of using various types of long-term care services is difficult and is dependent upon many variables. These include an individual's health and/or chronic conditions, availability of family support, and financial means. Nevertheless, using a variety of methodologies and data sets, a number of studies completed in the 1990s attempted to estimate the risk of use of nursing home care.[13]

A 2005 study used a microsimulation model to estimate lifetime risk of long-term care by people turning age 65 in 2005, assuming that current policy and behavior continues.[14] Unlike the previous research, long-term care use was defined to include care in facilities (nursing homes and assisted living facilities) as well as formal home-care services, and informal care provided at home by family members. In this study, those needing long-term care were defined as individuals who had a moderate level of disability as defined by having at least one ADL limitation, and four or more IADL limitations. The study results are presented in **Table 2**.

The study estimated that 69% of people turning age 65 in 2005 would need some long-term care assistance before they died; the other 31% would not need any care. People turning 65 were projected to need care on average for three years, made up of 1.9 years of care at home (either informal or formal care), and 1.1 years in facilities (nursing homes or assisted living facilities). However, these averages conceal the wide variation in individuals' use of long-term care services. For example, as shown in **Table 2**, 35% of people turning age 65 in 2005 will not need any care at home, but 11% will need such care for more than five years. Also, most people turning age 65 will not need care in facilities (63%), but 37% will need care in facilities. More than one-fifth (22%) of all people turning age 65 were estimated to need care for one year or more; and 8% were estimated to need care for more than five years.

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[13] A 1991 study estimated the lifetime risk of entering a nursing home at various ages and the number of years spent there after entry. See Peter Kemper and Christopher M. Murtaugh, *Lifetime Use of Nursing Home Care*. New England Journal of Medicine. Vol. 324, No. 9. February 28, 1991. Another study compared estimates of risk of nursing home use across various studies. Christopher M. Murtaugh, Peter Kemper, Brenda Spillman, and Barbara Lepidus Carlson. *The Amount, Distribution, and Timing of Lifetime Nursing Home Use.* Medical Care. Vol. 35, No. 3. 1997.

[14] Peter Kemper, Harriet L. Komisar, and Lisa Alecxih, *Long-Term Care Over An Uncertain Future: What Can Current Retirees Expect?* Inquiry 42:335-350. Winter 2005-2006. [http://www.inquiryjournal.org].

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Table 2. Remaining Lifetime Use of Long-Term Care By People Turning 65 in 2005

Type of Care	Average Years of Care	% of People Using Type of Care	Distribution By Years Of Care (% of People)				
			None	1 Year or Less	1-2 Years	2-5 Years	More than 5 Years
Any LTC Need	3.0	69	31	17	12	20	20
At Home							
Informal Care Only	1.4	59	41	22	13	17	6
Formal Care Only	.5	42	58	27	8	5	1
Any Care at Home	1.9	65	35	21	14	19	11
In Facilities							
Nursing Facilities	.8	35	65	17	5	8	5
Assisted Living Facilities	.3	13	87	6	3	4	1
Any Care in Facilities	1.1	37	63	15	5	9	8

Source: Peter Kemper, Harriet L. Komisar, and Lisa Alecxih, *Long-Term Care Over An Uncertain Future: What Can Current Retirees Expect?* Inquiry 42:335-350. Winter 2005-2006. [http://www.inquiryjournal.org].

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As pointed out in a later section of this report, informal care by families is the primary source of assistance for those who receive long-term care assistance. This study of risk underlines the importance of informal family caregiving. The 2005 study estimated that 65% of people turning age 65 in 2005 will need care at home (either informal care from families or formal paid care). Assuming current policy and behavior, most (59%) will need informal care; 23% will need such care for two years or longer and 13% will need care for one to two years. Providing care for impaired people for a long duration can place substantial stress on informal caregivers.

As mentioned above, those needing long-term care were defined as those who had a moderate level of disability. Most public programs and private long-term care insurance plans define eligibility for long-term care assistance by a person's need for at least two ADLs. The authors of the 2005 study point out that restricting the definition of long-term care assistance would reduce the estimates of risk of needing long-term care. The study estimates, for example, that 61% of people turning 65 will need help as a result of having three or more ADLs, and need care for an average of 2.2 years over the rest of their lives (as compared to three years for people under the moderate level of disability). People with two or more limitations would need care between 2.2 and three years (in between the severe and moderate levels of disability). While this study used a moderate level of need definition, these estimates do give an

idea of the extent to which people age 65 would be at risk for long-term care and the types of services that may be needed.[15]

Factors Affecting Future Demand for Long-Term Care Services

The previous discussion presented estimates of the population who receive long-term care using national survey data and estimates of risk of using care. Estimating the potential future need for long-term care assistance — either paid formal services or informal care provided by family members — is complex and dependent upon many factors. These include estimates of disability rates among the adult population as well as breakthroughs in medicine that might prevent or treat disabling conditions. Significant medical breakthroughs and more attention to treatment of diseases earlier in life could, of course, also lead to longer age spans and therefore more people surviving to older ages.

Need for long-term care is not an inevitable consequence of aging. Indeed, as shown earlier, almost one-third of people who live past 65 never need long-term care. Evidence accumulated over the past two decades shows people age 65 and older are living longer and healthier lives, with the potential for working longer and postponing medical care needs.[16] A possible decline in disability rates at older ages was first identified in the 1982 to 1989 waves of the National Long-Term Care Survey (NLTCS). More recent evidence from the NLTCS has confirmed this trend and indicates that the rate of decline has continued through the 2004-2005 period.[17] Although the evidence is sometimes conflicting, subsequent well-publicized studies using other data sets[18] have suggested that rates of disability, severe cognitive impairment, and functional limitations have declined substantially in the elderly population. The results of these studies have helped to establish that the disability decline may reflect real improvements in underlying physiological health, as well as better therapies or coping strategies.

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[15] As indicated earlier in this report, various policy approaches to long-term care use different definitions of need. The number of people potentially eligible for assistance under a given policy approach, or estimated to be at risk for long-term care will be affected by how level of need is defined.

[16] (1) Disability Working Group Meeting, Stories of Discovery: the Declining Disability of Older Americans, Washington, DC: Lawton Chiles International House, Nov 30, 2001. (2) Vicki A. Freedman, Linda G. Martin, and Robert F. Schoeni, "Recent trends in disability and functioning among older adults in the United States: A Systematic Review," *Journal of the American Medical Association.* Dec. 2002, pp. 288, 24, Health Module.

[17] Kenneth G. Manton, XiLiang Gu, and Vicki L. Lamb. *Change in Chronic Disability from 1982 to 2004/2005 as Measured by Long-Term Changes in Function and Health in the U.S. Elderly Population*. Proceedings of the National Academy of Sciences. Vol 103. Nov. 28, 2006. [http://www.pnas.org/cgi/content/full/103/48/18374]. Visited Dec. 28, 2006.

[18] For example, the Survey of Income and Program Participation, the Medicare Current Beneficiary Survey, and the National Health Interview Survey.

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Whether such improvements extend to all severity levels and types of disabling conditions remains unclear. Some evidence suggests that larger declines are due to improvements at the lower levels of disability, specifically at the IADL levels. The decline in disability as a result of limitations in IADLs has been attributed, in part, to increased use of assistive technology.[19] These improvements may have decreased individuals' reliance on the need for personal assistance from another person. Recent results analyzing data from the 2004/2005 NLTCS have also shown significant rates of disability decline among those with more severe impairments.[20]

The long-term implications of disability decline among the population age 65 and older depend in large part on whether the trend continues and at what pace. At this time, however, there is no consensus about the likelihood of continued future disability decline among the elderly. Declines in disability may perhaps be affected by expected improvements in the economic status and educational attainment among the elderly. The availability and effectiveness of assistive devices and the treatment or prevention of conditions that lead to disability may also contribute to improvements.

At the same time, disability among the current cohorts of working-age Americans, who will soon be the future elderly, has been increasing over the past few decades. Some research has shown that people under 65 are experiencing fewer disability-free years. This research has pointed to increasing rates of disability in people at age 30 and at age 45 as a result of certain conditions (including respiratory disease, congestive heart disease, and obesity, among others).[21] Lakdawalla and colleagues[22] suggest that today's young cohorts will have higher rates and levels of institutionalization than their older counterparts because of rising disability among the younger cohorts that are beginning to approach old age. They project that the nursing home population will be 10-25% higher than would be suggested by a simple extrapolation of past declines in disability. Of course, rates of institutionalization will also be affected by any changes in policies regarding use of various types of care, specifically, increased incentives for use of home and community-based care.

Despite uncertainty about trends in disability rates, an increase in the demand for long-term care services is expected due to the sheer numbers of people who will be turning 65 in the coming decades. Improvements in the age-specific disability

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[19] Brenda C. Spillman. Changes in Elderly Disability Rates and the Implications for Health Care Utilization and Cost. Prepared for the Office of the Assistant Secretary for Planning and Evaluation, U. S. Department of Health and Human Services Feb. 2, 2003. [http://aspe.hhs.gov/daltcp/reports/hcutlcst.htm]. Visited Dec. 28, 2006.

[20] Manton, Gu and Lamb. *Change in Chronic Disability from 1982 to 2004/2005 as Measured by Long-Term Changes in Function and Health in the U.S. Elderly Population.*

[21] Jay Bhattacharya, Kavita Choudhry, and Darius Lakdawalla. *Chronic Disease and Trends in Severe Disbility Among Working-Age Populations*. In Workshop in Disability in America, A New Look. Summary and Background Papers. Institute of Medicine. Washington, DC, 2005.

[22] Darius Lakdawalla, Dana P. Goldman, Jay Bhattacharya, Michael Hurd, Geoffrey Joyce, and Constantijn Panis, "Forecasting the Nursing Home Population," *Medical Care*, v. 41, no. 1, 2003.

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rates need to be very large to offset the projected large increase in the number of persons attaining age 65 in the coming years.

The projected demand for long-term care as the baby boom population ages is likely to affect service delivery patterns in the future. These patterns will be affected by many factors, including future availability of family members to provide uncompensated care, the disposable income and assets individuals and families have to pay for services they want, and changes in public policies that might affect what types of services will predominate. While nursing home care has been the principal type of formal care, recent federal and state policy initiatives have emphasized greater use of home and community-based services. These initiatives have been undertaken in response to public preference for home and community-based services as well as to federal and state litigation that has called for expansion of care in such settings.[23] Initiatives have included programs to divert people from using nursing homes as well as to transition people from nursing homes once they have entered. Many believe that an expansion of formal home and community-based services is needed to assist family caregivers who provide the bulk of care.

Some research has also shown that even though the very old (those 85 years and older) have the highest rate of nursing home use, their use of nursing homes is declining. This has been attributed in part to declining rates of disability among this age group as well as improved financial resources to pay for services they want outside of nursing homes (such as home and community-based services and assisted living facilities).[24] If these trends continue, the nature of the service system could change in future years with less reliance on nursing homes and more reliance on care in home and community-based and alternative residential care settings for those people whose needs can be met in these settings.

Others whose needs are more intensive may continue to rely on nursing home care. Indeed, successive national surveys of nursing home residents have shown that, over time, residents have become more impaired and have more limitations in ADLs.[25] Moreover, individuals who cannot afford alternative residential settings

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[23] The Supreme Court's decision in *Olmstead v. L.C.* is a landmark case on the rights of people with disabilities. The Court held that unjustified isolation of persons with disabilities in institutions is regarded as discriminatory under specified circumstances. The Court ruled that "unjustified isolation...is properly regarded as discrimination based on disability." It also noted several limitations: a state treatment professional must determine the appropriateness of the environment; community placement is not opposed by the individual with a disability; and the placement can be easily accommodated. For further information, see *Olmstead vs. L.C. Implications and Subsequent Judicial, Administrative and Legislative Actions*, CRS Report by Melinda De Atley and Nancy Lee Jones. [http://www.congress.gov/erp/rs/pdf/RS20588.pdf]. In addition, a wide range of state litigation has required states to make home and community-based services more widely available.

[24] The Lewin Group. *Nursing Home Use by "Oldest Old" Sharply Declines.* Presented by Lisa Alecxhi at the National Press Club. Nov. 21, 2006.

[25] Frederic H. Decker, *Nursing Homes, 1977-99: What Has Changed, What Has Not?*, National Center for Health Statistics [http://www.cdc.gov/nchs/data/nnhsd/Nursing

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such as assisted living (which are predominantly paid by individual's income) may have to rely on nursing home care paid through Medicaid. Some research has suggested that nursing homes are more likely to serve a lower income population than those in assisted living facilities (which is not generally covered by Medicaid).[26]

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[25] (...continued)
Homes1977_99.pdf], visited Dec. 13, 2006. Hereinafter Frederic H. Decker, *Nursing Homes, 1977-99: What Has Changed, What Has Not?*

[26] Timothy A. Waidmann and Seema Thomas. *Estimates of the Risk of Long-Term Care: Assisted Living and Nursing Home Facilities.* Prepared by the Urban Institute for the U.S. Department of Health and Human Services. July 8, 2003.

Providers of Long-Term Care Services

- Most people with long-term care needs living in the community receive assistance primarily through informal caregivers — families and friends — who provide care without compensation. Most people prefer to be cared for at home with the assistance of informal supports, and many people with significant limitations are cared for by families.

- Some people with severe physical or cognitive impairments who do not have sufficient informal supports or adequate access to formal home and community-based services may need the assistance provided in facilities or other residential settings. Some families may need the assistance of formal home and community-based service providers to supplement family caregiving.

- Formal providers range from institutional settings and other residential care facilties to a variety of agencies and organizations that provide a wide array of home and community-based services. The growth of many types of formal providers has been influenced by the availability of federal financing sources, primarily Medicare and Medicaid.

- Identifying and arranging for long-term care services can be a complex task for individuals and their families. Uneven distribution of services in communities and across states often leads to difficulties in accessing services.

- The aging of society will exacerbate demands on family caregivers who may have to rely increasingly on formal paid care to supplement their caregiving roles. In addition, the increasing longevity of younger persons with disabilities will place stress on older family caregivers.

Informal Care Providers — Family and Friends

A large body of research conducted over the last several decades has documented the enormous support provided by family members to people who need long-term care assistance. The major conclusion of this research is that informal caregivers — family and friends — provide the majority of care to people needing long-term care assistance. Estimates of the number of caregivers to people of all ages receiving long-term care assistance range from 7 million to 10 million persons, depending upon the population served and the amount and intensity of care provided. Some estimates place the number of informal caregivers even higher.[27]

[27] For a range of estimates, see the Administration on Aging (AoA), *National Family Caregiver Resource Guide*, prepared by The Lewin Group, Inc., Washington, DC, August 2002.

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Research from national longitudinal surveys on long-term care has documented the extent of informal caregiving. Using data from the National Long-Term Care Survey and the National Health Interview Survey, **Figures 10 and 11** show that adults with functional impairments receive most of their care from informal sources. Two-thirds of the functionally impaired elderly, and 71% of people age 18-64 receiving care, rely *exclusively* on informal, unpaid assistance.

While adults of all ages provide long-term care assistance, people in middle to late middle age are most likely to be caregivers. In addition, women are more likely than men to serve in the caregiver role, but both men and women provide care. Caregivers often have a number of competing demands — about one-half are employed and one-third have minor children in the home.[28]

The total value (non-economic as well as economic) of caregiving for persons with disabilities can be substantial. Many families make huge sacrifices to care for their frail and ill family members. Gerontologists have documented the strains on family caregivers, particularly the "sandwich generation" (women of middle age caring for both children and older family members) in research dating back decades.[29] Aside from the emotional and physical stress of caring for family members, some caregivers make financial sacrifices by cutting back or sometimes curtailing employment. Some also make financial contributions to family members by paying for caregiving supplies and services.[30]

Some research has attempted to document the economic value (cost) of informal caregiving. Estimates vary widely depending upon the number of caregivers counted and differences in methods to impute the cost of hourly rates for care provided. One study estimated the annual cost of replacing informal caregiving with paid home care at $45 billion to $94 billion.[31] Another study estimated the imputed value of informal caregiving at $166 billion, based on 18.7 billion caregiving hours priced at $9 per hour.[32] Yet another study estimated the economic value of caregiving from $149 billion to $483 billion, depending upon the number of caregivers and imputed hourly

[28] Ibid.

[29] See, for example, Elaine M. Brody, *"Women in the Middle" and Family Help to Older People*, Gerontologist, Vol. 21, No. 5, 1981; Marjorie H. Cantor, *Strain Among Caregivers: A Study of Experience in the United States*, Gerontologist, Vol. 23, No. 6, 1983.

[30] For further discussion, see CRS Report RL31755, *Family Caregiving to the Elderly by Employed Persons: The Effects on Working Caregivers, Employers and Federal Policy*, by Linda Levine.

[31] HHS, Administration on Aging, *Informal Caregiving: Compassion in Action*, [http://aspe.hhs.gov/search/daltcp/reports/Carebro2.pdf].

[32] Mitchell P. LaPlante, Charlene Harrington and Taewoon. Lang, *Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living Provided to Adults Living at Home*, Health Services Research, Vol. 37, No. 2 , April 2002.

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rates.[33] Some research, however, has warned that some estimates may overstate the economic costs of informal caregiving.[34]

The aging of society will exacerbate demands on family caregivers who may have to rely increasingly on formal paid care to supplement their caregiving roles. In addition, the increasing longevity of younger persons with disabilities will place stress on older family caregivers. For example, about 60% of the 4.6 million persons with intellectual and other developmental disabilities receive care from family caregivers and of these people more than one in six were living with caregivers over the age of 60. In addition, persons with developmental disabilities are living longer with medical advances and supportive care. In the 1973, the mean age of death for these persons was 66 years. Some observers indicate that with continued improvement in their health status, people with developmental disabilities could be expected to have a lifespan equal to that of the general population.[35] If so, these people could outlive their family caregivers and may need the assistance of formal providers.

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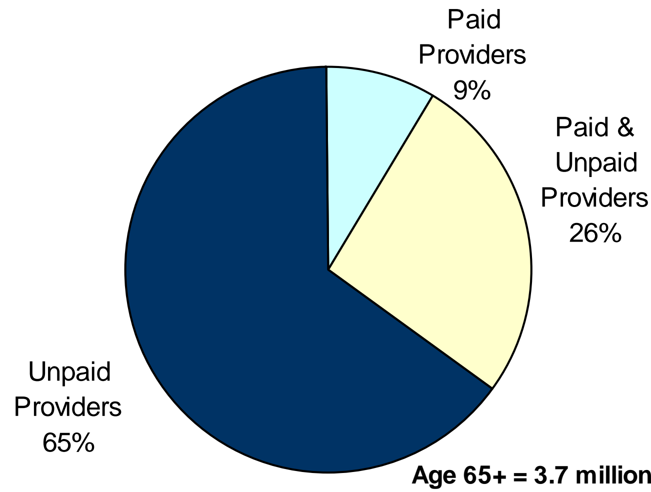
[33] Peter S. Arno, *Economic Value of Informal Caregiving: 2004*, presented at the Care Coordination and the Caregiver Forum, Department of Veterans Affairs, National Institutes of Health, Bethesda, Md. Jan 25-27, 2006. This research is based on previous research by the author and other researchers.

[34] Douglas A. Wolfe, *Valuing Informal Elder Care*, in *Family Time, the Social Organization of Care*. Ed. by Nancy Folbre and Michael Bittman.

[35] David Braddock, Richard Hemp and Mary Rizzolo, et. al. *State of the States in Developmental Disabilities: 2005*. p. 2. Coleman Institute for Cognitive Disabilities, University of Colorado. 2005. Hereafter David Braddock, Richard Hemp and Mary Rizzolo, et. al. *State of the States in Developmental Disabilities: 2005*.

Figure 10. Type of Care Received by People Age 65 and Older Living in the Community



Source: 1999 National Long-Term Care Survey. Estimates prepared by Brenda Spillman, The Urban Institute. cited in *Older Americans 2004, Key Indicators of Well-Being,* Federal Interagency Forum on Aging Related Statistics, 2004.

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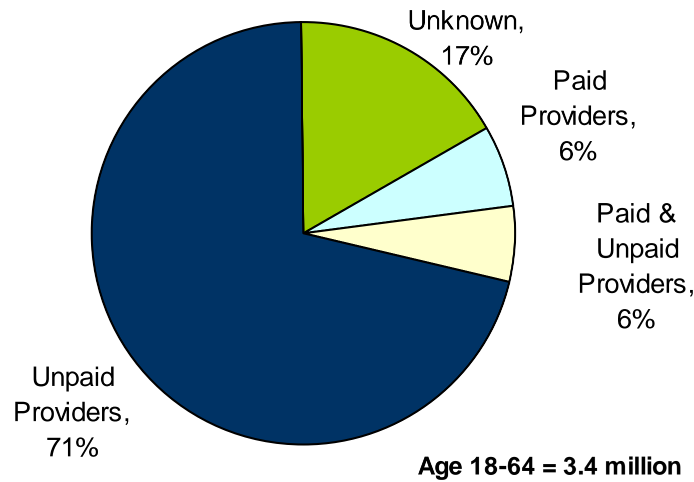
Figure 11. Type of Care Received by People Age 18-64 Living in the Community



Source: National Health Interview Survey, Disability Supplement (1994). William Spector, et al., *Characteristics of Long-Term Care Users*, Prepared for the Institute of Medicine, 1998. AHRQ Publication No. 00-0049. Numbers may not sum to 100% due to rounding.

Various federal and state initiatives have been taken to assist caregivers. For example, the Older Americans Act specifically authorizes family caregiver support services, including respite care for families. Other federal programs, such as Medicaid home and community-based services and the Social Service Block Grant program directly and indirectly provide services that supplement family caregiving assistance (see the next section of this report).

Formal Care Providers

In addition to the enormous amount of care provided by families and friends, the long-term care services system includes thousands of formal care providers that supplement informal caregiving. Most people prefer to be cared for at home with the assistance of family and other informal supports. However, some people with severe physical or cognitive impairments who do not have sufficient informal supports or access to formal home and community-based services may need the assistance provided in facilities or other residential settings. The majority of the long-term care population — those cared for by families — may need the assistance of formal providers to supplement family care.

Identifying and arranging for formal long-term care services can be a complex task for individuals and their families. Understanding the differing eligibility and program coverage requirements for the myriad of home and community-based services paid for by a variety of public payers can be daunting. Moreover, uneven distribution of services in communities and across states often leads to difficulties in accessing services.

Formal providers range from institutional providers, including nursing homes, assisted living facilities, and other residential care facilities to a variety of agencies and organizations that provide a wide array of home and community-based services. The growth of many types of formal providers has been influenced by the availability of federal financing sources, primarily Medicare and Medicaid. Some other federal programs, such as the Older Americans Act, have financed other types of home and community-based services. (The next section of the report and **Appendix D** briefly describe federal programs that finance long-term care services and their eligibility requirements.)

The growth in the nursing home industry during the last 40 years has largely been a result of financing available through the Medicaid program and, to a lesser extent, the Medicare program. Before then, homes for the aged were supported by state funds, private voluntary resources, and individuals' out-of-pocket spending. Similarly, the large state institutions or training schools for people with mental retardation and other developmental disabilities that were established during the latter part of the 19th century and the first part of the 20th century were financed by state and local funds as well as private sources. Changes in the Medicaid program during the 1970s led to federal financing for a specific Medicaid coverage option for intermediate care facilities for people with mental retardation (ICF-MRs).

Home care agencies have a long history of support from charitable and volunteer organizations, dating from the late 19th century. Like nursing homes, growth in the home care industry has been influenced by the availability of federal financing under

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Medicare and Medicaid. The Medicaid home and community-based waiver program has played a major role in influencing the development of many other home and community-based services, such as adult day care programs and small adult residential care homes, that serve the long-term care population.

The following discussion briefly describes the range of formal long-term care services that people with long-term care limitations might use.[36] (The next section of this report briefly discusses the federal programs that finance these services.)

Nursing Homes. While only a small proportion of the long-term care population who use formal care reside in nursing homes, the largest proportion of public long-term care spending is for nursing home care. In 2004, there were about 1.5 million residents in more than 16,100 nursing facilities across the nation (the number of beds totaled 1.7 million).[37]

Services provided in nursing homes include services of nurses, nursing aides and assistants; physical, occupational and speech therapists; social workers and recreational assistants; and room and board. Most care in nursing facilities is provided by certified nursing assistants, not by skilled personnel. In 2004, there were, on average, 40 certified nursing assistants per 100 resident beds. The number of registered nurses and licensed practical nurses were significantly lower at 7 per 100 resident beds and 13 per 100 resident beds, respectively.[38]

Nursing facilities that participate in the Medicare and Medicaid programs are subject to federal requirements regarding staffing and quality of care for residents (42 CFR Part 483). In 2004, 98.5% of the 16,100 nursing facilities nationwide were certified to participate in Medicare, Medicaid, or both.

People may stay in nursing homes for a short duration when they need a period of recuperation after an acute illness or surgery, and for longer periods of time when they can no longer be cared for at home. Long-stay nursing home residents are significantly impaired. Data from the 1999 National Nursing Home Survey (the most recent data available) show that three-quarters of all residents (1.6 million)[39] required assistance with three or more ADLs. Most residents received help with bathing (93.8%) and dressing (86.5%); more than half received help with toileting (56%), and almost half received help with eating (47%).[40]

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[36] This section is not intended to present information on characteristics of the services or the recipients who use them, but is intended to be illustrative of the kinds of formal services that the long-term care population may use.

[37] *Nursing Home Survey, 2004. 2004 Facility Tables.* National Center for Health Statistics. [http://www.cdc.gov/nchs/about/major/nnhsd/Facilitytables.htm], visited Dec. 22, 2006.

[38] Ibid.

[39] Note that this differs from the number of residents above due to differences in year of estimates.

[40] *National Nursing Home Survey: 1999 Summary*. National Center for Health Statistics. Vital Health Statistics 13(152). 2002. [http://www.cdc.gov/nchs/data/series/sr_13/sr13_

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In 1999, the average length of stay in nursing homes for residents was almost two and half years.[41] Slightly more than 27% of residents had a length of stay of three years or more; about 30% had a stay of one to three years; and 25% had a stay of three months to less than a year. Only 18% of residents has stays of less than three months.[42] The primary diagnosis at admission for 23% of residents was heart disease and other circulatory conditions. Mental and cognitive impairment was the primary admission diagnosis for 16% of residents.[43] The presence of cognitive impairments is a primary reason for residence in nursing homes. About 47% of all nursing home residents have a diagnosis of dementia, including Alzheimer's disease.[44]

The costs of a nursing home stay over an extended period are out of reach for most people unless they receive assistance through private insurance or Medicaid. Annual costs for 24-hour care in nursing homes ranged from about $67,000-$75,000 in 2006. (The average rate for a private room in a nursing home was $75,190 annually, or $206 a day; for a semi-private room, it was $66,795 annually, or $183 per day.)[45]

Alternative Residential Care Settings. Other than nursing homes, there are a host of other residential facilities that serve people with long-term care limitations. Alternative residential care settings provide room and board as well as personal care and other supportive services to people who need some assistance as a result of functional or cognitive impairments, but who do not need sustained nursing care. These facilities may serve the elderly, people with mental retardation and other developmental disabilities, and people with mental illness.

Defining and categorizing "alternative residential facilities" is daunting; terms may number in the dozens and generally differ by state. These settings have been referred to as adult foster care homes, assisted living facilities, group homes, supportive living arrangements, board and care homes, personal care homes, and community residential settings, among many others. Some facilities are considered "community" settings and some are considered "facility" settings.[46] As noted earlier,

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[40] (...continued)
152.pdf], visited Dec. 13, 2006. Hereinafter *National Nursing Home Survey: 1999 Summary*.

[41] *National Nursing Home Survey: 1999 Summary*.

[42] Frederic H. Decker, *Nursing Homes, 1977-99: What Has Changed, What Has Not?* This statistic is for *current* residents.

[43] *National Nursing Home Survey: 1999 Summary*.

[44] American Health Care Association, Oscar Data Reports: Patient Characteristics. [http://www.ahca.org/research/oscar/rpt_MC_mental_status_200606.pdf], visited Dec. 13, 2006.

[45] *The MetLife Market Survey of Nursing Home and Home Care Costs*, Sept. 2006. [http://www.metlife.com/WPSAssets/18756958281159455975V1F2006NHHCMarketSurvey.pdf], visited Dec. 14, 2006.

[46] Brenda C. Spillman and Kirsten Black, *The Size and Characteristics of the Residential Care Population: Evidence from Three National Surveys.* U.S. Department of Health and (continued...)

a specific type of residential setting — intermediate care facilities for people with mental retardation — was created as part of the Medicaid program in 1971. Most other types of settings have been created by states or the private sector. Some receive federal and/or state funding for services and some receive payments from individuals out of their own funds. While nursing homes and intermediate care facilities for people with mental retardation are subject to federal requirements regarding quality of care and types of staffing to be provided to residents, alternative residential facilities are not, but are generally subject to state regulation and/or licensure.

In recent years, the term "assisted living facility" has been given to certain types of facilities that provide room and board, personal care, supportive services, and some health-related care to people with long-term care limitations. The assisted living industry has grown rapidly since the early 1990s. Assisted living facilities generally base their care on a philosophy that values consumer independence, choice, and privacy. Although there is no one definition of assisted living facilities, they are generally referred to as residential group homes that provide personal care and assistance to people with limitations in ADLs and IADLs and have staff that are available 24 hours a day to meet scheduled and unscheduled needs of residents. A survey of assisted living facilities found that a majority of facilities had nurses (either RN's or LPNs) on staff as well as other personnel who provide individuals help with bathing and dressing, and other personal care assistance.[47]

Estimating the number of alternative residential care facilities and residents is complex. Some estimates indicate that more than a million people live in almost 33,000 licensed assisted living residences. (There may be many more facilities that provide room and board and other supportive services, but are not licensed. However, generally, if such residences serve residents under the auspices of a public program, they must be licensed to operate in a state.) One study has estimated that between 2.2-2.3% of the population age 65 and over (about 750,000 people) reside in alternative residential facilities.[48] In addition, there is a sizable population of people with developmental disabilities living in state institutions, intermediate care facilities, and other residential care facilities. In 2004, there were an estimated 462,000 people with developmental disabilities living in these residential care settings.[49]

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[46] (...continued)
Human Services, Assistant Secretary for Planning and Evaluation, January 2006. Hereinafter Brenda C. Spillman and Kirsten Black, *The Size and Characteristics of the Residential Care Population: Evidence from Three National Surveys.*

[47] Catherine Hawes, et al., *A National Study of Assisted Living for the Frail Elderly.* Prepared for the U.S. Department of Health and Human Services. [http://aspe.hhs.gov/daltcp/reports/facres.htm]. Visited Dec. 13, 2006. Hereinafter Catherine Hawes, et al., *A National Study of Assisted Living for the Frail Elderly.*

[48] Brenda C. Spillman and Kirsten Black, *The Size and Characteristics of the Residential Care Population: Evidence from Three National Surveys.*

[49] Ibid., David Braddock, Richard Hemp, and Mary Rizzolo, et. al. *State of the States in Developmental Disabilities: 2005.* This number excludes nursing facilities.

The need for assistance by residents of alternative residential facilities varies widely and differs by type of facility. In general, people who reside in board and care homes, assisted living facilities, and other residential care settings are less impaired than most people residing in nursing homes.[50] However, some residents of these facilities may have the same level of need exhibited by nursing home residents. A survey of 1,175 "assisted living communities" found that residents on average needed assistance with two ADLs (primarily bathing and dressing) and 3.8 IADLs (primarily housekeeping, laundry, managing medications and transportation).[51]

The costs of alternative residential facilities vary significantly. Factors related to cost include size, type and location of the facility, needs and characteristics of the residents, and type of services provided, among others. The costs of care in residential facilities serving people with mental retardation ranged from $52,585 to $134,348 per resident per year in 2002, depending upon the size of the facility, whether the facility is a public or private institution, and whether it is a certified as a Medicaid ICF/MR.[52] In 2005, average annual per resident expenditures in large (those with 16 or more residents) state residential facilities for people with developmental disabilities were almost $149,000.[53]

One study surveyed "assisted living facilities" to determine annual costs. Included in the survey were facilities that were licensed according to each state's licensure standards, provided personal care assistance to residents, and had a private pay rate. In 2006, the national average private pay rate for a private room with a private bath in these facilities was $35,616 annually. Costs are higher if a resident receives more services than covered by the base rate cost. In this survey, almost half (48%) of the facilities provided care for residents with dementia. Some charged additional fees for extra care which ranged from $750-$2,200 monthly.[54]

Adult Day Care Programs. Adult day care programs provide health and social services in a group setting on a part-time basis to frail older persons and other persons with physical, emotional, or mental impairments who require assistance, supervision and rehabilitation to restore or maintain optimal functioning.[55] As federal

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[50] Catherine Hawes, et al., *A National Study of Assisted Living for the Frail Elderly.*

[51] *2006 Overview of Assisted Living*. A Collaborative Research Project of the American Association of Homes and Services for the Aging, American Seniors Housing Association, Assisted Living Federation of America, National Center for Assisted Living, and National Investment Center for the Seniors Housing and Care Industry, 2006.

[52] Rizzolo, Mary C. et. al. *The State of the States in Developmental Disabilities.* The University of Colorado, Colman Institute for Cognitive Disabilities. American Association on Mental Retardation. Washington, DC 2004. p. 5.

[53] David Braddock, Richard Hemp and Mary Rizzolo, et. al. *State of the States in Developmental Disabilities: 2005*. p. 17.

[54] The MetLife Market Survey of Assisted Living Costs, October 2006. Metlife Mature Market Institute, 2006 [http://www.metlife.com/WPSAssets/19759823911162238386V1F2006AssistedLivingStudy.pdf].

[55] For a full discussion of adult day care programs, see CRS Report RL33595, *Long-Term*
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financing for long-term care services has shifted from institutional care to home and community-based care, adult day care services have become an important component in home and community-based services. These services can play a role in preventing or delaying institutionalization for some participants. Adult day care also offers family caregivers the opportunity to continue working and/or to have respite from full-time caregiving responsibilities.

Adult day care programs have grown from a handful of federally supported research and demonstration projects in the late 1960s and early 1970s to more than 3,400 centers in 2002. Services generally provided in adult day care settings include client assessment, nursing services, social services, therapeutic activities, personal care, physical, occupational, and speech therapies, nutrition counseling, transportation to and from the center, and recreational activities. Programs are supported by a variety of federal funding sources, as well as state and local government, private funds, and out-of-pocket participant fees. There are no federal standards for adult day care although national voluntary standards have been developed as a model for care practice.[56]

According to a national survey of adult day care programs, most participants have fairly significant impairments. Almost 60% of participants require assistance with two or more activities of daily living (ADLs); and 41% require assistance with three or more ADLs. Across all centers, the survey found that the two most prevalent conditions among all participants were dementia (52%) and frailty (41%) (i.e., individuals age 60 and older in need of supervision and/or at-risk of social isolation with no dementia). Almost one-fourth (24%) of participants served were diagnosed with mental retardation/developmental disability, while almost another fourth (23%) had physical disabilities but were cognitively intact (e.g., stroke, Parkinson's disease, multiple sclerosis). About one-third (30%) of the population was diagnosed with a chronic mental illness, HIV/AIDS, or a brain injury.[57]

According to the study, in 2002, on average, adult day centers served 25 people per day (with an overall enrollment of 42) at an average cost of $56/day per person and an average daily fee of $46 per person.[58] In general, rates depend on the types and quantity of the services provided, their costs, and availability of public and other private funds.

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[55] (...continued)
Care: Facts on Adult Day Care, by Sarah C. Kaufman and Carol O'Shaughnessy.

[56] The National Adult Day Services Association, in conjunction with the Commission on Accreditation of Rehabilitation Facilities (CARF), has developed and recommended voluntary national standards, referred to as the Standards and Guidelines for Adult Day Care.

[57] Note that participants may have been included in one or more condition/diagnosis categories; and therefore, these proportions do not sum to 100%.

[58] Partners in Caregiving, Wake Forest University School of Medicine, *National Study of Adult Day Services: Key Findings 2001-2002*, at [http://www.rwjf.org/files/newsroom/adultdayPowerPt.ppt#318,1,Slide 1] visited July 27, 2006.

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Home Care Services. Home care services comprise a wide array of services designed to assist people with disabilities and the frail elderly to reside in their own homes with appropriate health and supportive services. "Home care services" is a generic term that may refer to the following types of services: nursing services provided by skilled nursing staff; therapies provided by physical, occupational, or speech therapists; medical social services; personal care services, such as assistance with bathing, dressing, or toileting, provided by home health aide personnel; or homemaker services, including cooking, shopping, or transportation, provided by homemakers or companions.

Home care may be provided by agencies certified to participate in the Medicare and Medicaid programs. Agencies include facility-based organizations, visiting nurse associations and nurse registries. Most home health agencies are freestanding entities and the majority of agencies are relatively small, local or regional providers.[59] In addition to Medicare-certified agencies, home health services are provided by a wide variety of other agencies that provide non-medical home care services, such as homemaker and companion services financed through federal, state, and private voluntary funds as well as through out-of-pocket spending by individuals and families.

According to the latest survey of home health care patients by the National Center on Health Statistics (NCHS), about 1.4 million patients were receiving home health care services from 7,200 agencies in 2000. Medicare was the primary payment source for most home care patients (52%), followed by Medicaid (20%), and private insurance, out-of-pocket funds or family support (17%), with other sources completing the balance.[60]

The vast majority of home health care patients are elderly. According to the NCHS survey, of the 1.4 million patients, 70% were age 65 and older; 30% were under age 65. Of all patients, over one-fifth were age 85 and older. The average length of stay in home health care was 312 days. Most home health care consumers had informal primary caregivers. Over 80% of patients surveyed had a primary caregiver, and almost 76% lived with their primary caregiver.[61]

According to the NCHS survey, of the 1.4 million patients, most (75%) received skilled nursing services, followed by personal care (44%) and therapeutic services (e.g., occupational, physical therapy or dietary therapies) (37%). Almost half of patients received help from home care agency personnel with at least two ADLs,

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[59] Center for Medicare and Medicaid Services (CMS). Health Care Industry Market Update, Home Health, September 22, 2003. [http://www.cms.hhs.gov/CapMarketUpdates/Downloads/hcimu92203.pdf], visited Dec. 19, 2006.

[60] National Center for Health Statistics. *Home Health Care Patients: Data from the 2000 National Home and Hospice Care Survey*. [http://www.cdc.gov/nchs/data/nhhcsd/curhomecare00.pdf]. visited December 18, 2006. This number is lower than data from the Centers for Medicare and Medicaid Services (CMS). According to CMS, more than 2.4 million elderly and people with disabilities receive care from over 8,100 Medicare-certified home health agencies.

[61] Ibid.

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primarily with bathing or dressing. About 43% of patients received assistance with at least one IADL, primarily light housework, preparing meals, and taking medications. The most frequent primary diagnoses upon admission to home health care were diseases of the circulatory system, including heart disease and diabetes.

Home care costs vary widely. One study estimated the average costs of home health aides and homemaker companions from 996 home care agencies nationwide. According to the study, in 2006, the average hourly rate for a home health aide was $19; the average hourly rate for a homemaker/companion was $17.[62] These rates are for agency-based personnel; some home care personnel contract directly with individuals, are not employed by agencies, and would therefore charge different rates.

Care Management Services. Accessing and arranging services — often delivered through multiple providers — can be complex and confusing for individuals and families. Individuals and their families seeking long-term care services often require the assistance of care management personnel who provide consumers advice on care needs and help them gain access to, and coordinate, services. Care management personnel carry out a variety of functions, including assessing an individual's need and eligibility for services; developing a plan of care that charts out the type and amount of services to be provided; authorizing reimbursement for the care if the individual is to receive publicly-financed care; and providing on-going monitoring of the services provided.

Most publicly financed home and community-based long-term care programs administered by states (and financed by either federal and/or state programs) employ care management personnel. In many cases, these personnel use standardized assessment tools to determine an individual's eligibility for services and to identify service needs. Care plans are then developed to match an individual's needs with the services available through the public programs. Case management systems not only assist individuals to receive appropriate care, but often are also used by payers of services to assure that services are targeted on those most in need. Aside from case management systems under the auspices of public programs, some individuals who pay for long-term care services out of their own pockets seek out the services of private care management providers who assist them in finding and arranging services.

While many people needing long-term care services receive assistance through agency-based care management and service providers, recent policy directions have recognized the interests of individuals to manage and direct their own care through "consumer-directed" models of care, rather than by using the services of agency-based case management and service provider personnel. In consumer-directed models of care, consumers with long-term care limitations make their own decisions regarding the types and amounts of care they receive and hire and manage their own caregivers. There are various models of consumer-directed services. In some cases consumers are provided with an individualized budget, and services chosen by the consumer are tracked by a provider organization. In another approach, individuals

[62] The Metlife Market Survey of Nursing Home and Home Care Costs. September 2006. Metlife Mature Market Institute. [http://www.metlife.com/WPSAssets/18756958281159455975V1F2006NHHCMarketSurvey.pdf]. Visited Dec. 20, 2006.

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may receive a cash payment for services, and are responsible for recruiting and managing their direct care providers.[63] Regardless of approach, consumers have the discretion to determine their service arrangement.

Other Home and Community-Based Services. In addition to the services discussed above, there are many other home and community-based services that assist people with long-term care limitations to live independently in the community. Among them are: transportation (specialized and non-specialized); congregate and home-delivered meals programs; assistive technology and devices; respite, counseling, and training services for family caregivers; mental health services; emergency response systems; rehabilitation therapies; and home and environmental modification.

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[63] For further information, see CRS Report RL32219, *Long-Term Care: Consumer-Directed Services under Medicaid*, by Karen Tritz.

Payers of Long-Term Care

- About $206.6 billion was spent on long-term care in 2005, representing about 12.4% of all personal health care spending.
- Medicaid is the primary federal program that finances long-term care services, paying about half of all long-term care spending in 2005. It provides institutional and community-based services to people with low income and very limited assets and who meet federally prescribed eligibility categories.
- Medicare plays a limited role in financing long-term care through its coverage of skilled nursing home care and home health services for certain people who need skilled or rehabilitative services of relatively short duration. It accounted for about 20.4% of long-term care spending in 2005.
- Out-of-pocket spending by individuals and families accounted for about 18.1%, and private insurance and other public and private sources paid for the balance of spending (7.2% and 5.3%, respectively)
- Other federal programs, such as the Older Americans Act and the Social Services Block Grant, provide limited support for a range of home and community-based long-term care services.
- Federal programs have differing characteristics, program goals, eligibility requirements, and covered services resulting in a complex and sometimes uncoordinated service delivery system for people with long-term care limitations.

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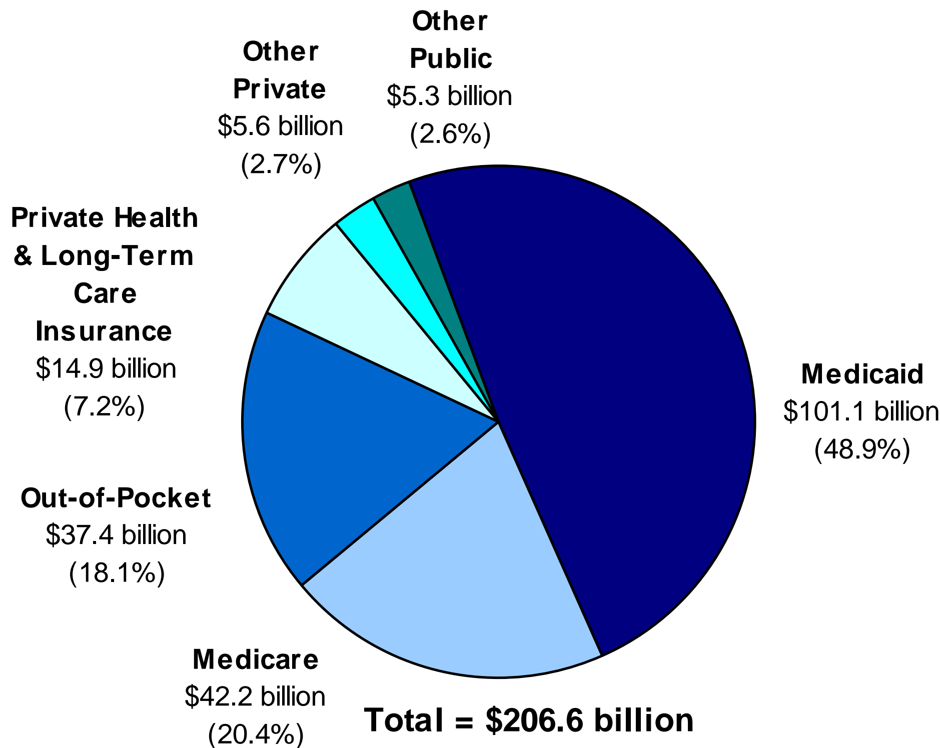
Federal and state governments finance institutional and community-based long-term care services through a variety of programs. The discussion below describes major payers of long-term care services and the federal programs providing long-term care assistance. (See **Appendix D** for further detail on selected programs.)

Total U.S. spending on long-term care is a significant component of all health care spending. Of the $1.6 trillion spent on personal health care in 2005, an estimated $206.6 billion, or 12.4%, was spent on long-term care services. (See **Figure 12**). Long-term care spending includes payment for services in institutional settings — primarily nursing homes and intermediate care facilities for people with mental retardation — and a wide range of home and community-based services, such as home health care, personal care, and adult day care.

The dominant payer of long-term care expenditures is the Medicaid program. In 2005, Medicaid paid for nearly half of long-term care spending (48.9%, or $101.1 billion). Medicare and out-of-pocket spending by individuals and families accounted for about 20.4% and 18.1%, respectively, of total spending. Private insurance and

other public and private sources paid for the balance of spending (7.2%, 2.6%, and 2.7%, respectively).[64]

Figure 12. National Spending for Long-Term Care, 2005



Source: *National Spending for Long-Term Care*, Georgetown University Long-Term Care Financing Project, February 2007[http://ltc.georgetown.edu/pdfs/natspendfeb07.pdf].

Note: Includes data on spending for Medicaid and Medicare nursing home and home health services, and Medicaid home and community-based waivers. Excludes data on spending for services of hospital- based nursing homes and home health agencies paid by sources other than Medicare and Medicaid, and other home care workers not employed by agencies, congregate and home-delivered meals, assisted living facilities without on-site nursing homes, among others. Does not include value of informal care.

For an analysis of trends in national long-term care spending, see CRS Report RL33357, *Long-Term Care: Trends in Public and Private Spending*, by Karen Tritz. The cited report includes a description of spending across all major payers (Medicaid, Medicare, out-of-pocket, private insurance, and others) and across the major categories of spending (nursing home, home health services, and (Medicaid) home and community-based services).

Medicaid is by far the largest of federal public programs that cover long-term care, paying for almost half of the nation's long-term care services, primarily

[64] *National Spending for Long-Term Care*, Fact Sheet, Georgetown University Long-Term Care Financing Project, February 2007[http://ltc.georgetown.edu/pdfs/natspendfeb07.pdf].

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institutional care. *Medicare* covers post-acute services in skilled nursing facilities and in the home for certain Medicare beneficiaries, including dual eligibles (i.e. those eligible for both Medicare and Medicaid). In addition, the *Older Americans Act (OAA)* and the *Social Services Block Grant (SSBG)* support a wide range of home and community-based long-term care services.[65]

Each of these federal programs described below has differing characteristics, program goals, eligibility requirements, and covered services resulting in a complex and sometimes uncoordinated service delivery system for individuals and families seeking assistance. Access to, and availability of, services are dependent upon whether a person meets the program's eligibility requirements and whether services needed are covered. For services that are state-administered (Medicaid, Older Americans Act, and the SSBG), availability varies across and even within states, and in some cases, waiting lists for some home and community-based services exist. (Waiting lists and unmet need for services are outside the scope of this report; see footnote 3 of this report.)

Over the years, federal and state governments have sought to streamline access to services by creating single points of entry to assist individuals to receive the services they need. For example, recently, the Administration on Aging (AoA) and the Centers for Medicare and Medicaid Services (CMS) have devoted funding to create Aging and Disability Resources Centers (ADRCs) to coordinate services and to ease access to services through single points of entry. (See Older Americans Act below). For further information on state efforts, see a series of CRS reports on states efforts to redesign long-term care systems.[66]

Medicaid

The Medicaid program covers nursing home care, intermediate care facilities for people with mental retardation (ICFs/MR), and a broad range of home and community-based services. Medicaid is a means-tested entitlement program covering long-term care services for certain persons who meet the program's categorical, financial, and functional or level-of-care eligibility criteria. The program is state-administered within broad federal guidelines. Medicaid coverage of long-term care

[65] In addition to these programs, a range of long-term care benefits are offered to veterans through the Department of Veterans Affairs. While outside the scope of this report, issues surrounding the financing of long-term care to the veteran population are of concern to the VA due to the increasing number of older veterans. The VA is predicting dramatic increases in utilization of long-term care by older veterans. Over the period 2004-2012, the number of enrolled veterans age 85 and older will increase by 145%, to almost 700,000 persons. For further information, see *An Open discussion: Planning, Providing, and Paying for Veterans' Long-Term Care*, hearing before the U.S. Senate Committee on Veterans Affairs, May 12, 2005.

[66] See CRS reports in this series: *A CRS Review of States: Home and Community-Based Services — States Seek to Change the Face of Long-Term Care*, Arizona (RL32065); Florida (RL32054); Illinois (RL32010); Indiana (RL32295); Maine (RL32166); Oregon (RL32132); Pennsylvania (RL31850); and Texas (RL31968). Hereinafter *A CRS Review of States: Home and Community-Based Services — States Seek to Change the Face of Long-Term Care*.

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is intended to serve as a safety net for persons who cannot afford the cost of institutional care or home and community-based services. Generally, enrollees apply most of their income to the cost of their care to offset Medicaid spending for those individuals.

Financing of institutional care has dominated Medicaid long-term care spending for decades, leading many to describe federal and state long-term care policy as having an institutional bias. In response to consumer preference for home and community-based services, state Medicaid programs have played an increasingly larger role in financing home and community-based services. This has resulted in a shift in Medicaid long-term care spending from institutions to home and community-based services. Yet, because states have flexibility to determine the range and amount of home and community-based services they support, wide variation in the availability of services exists across states.[67]

Medicaid institutional and home and community-based long-term care services include, but are not limited to:

- *Nursing Facility Care.* Nursing facility care is a mandatory service for Medicaid beneficiaries age 21 and over and is available in all states. States have the option to cover nursing home care for persons under age 21.
- *Intermediate Care Facilities for People with Mental Retardation (ICFs/MR).* Institutional care provided to people with mental retardation and developmental disabilities in intermediate care facilities (ICFs/MR) is an optional benefit under state Medicaid plans; however, all states cover this care.[68] Services include room and board and a wide range of specialized therapeutic services to assist those with mental retardation and developmental disabilities to function at optimal levels.[69]
- *Institutions for Mental Disease (IMDs).* IMD coverage for individuals age 65 and older with mental diseases is an optional benefit under state Medicaid plans.
- *Home and Community-Based Services (HCBS) Waiver Program (Section 1915(c) of the Social Security Act).* The HCBS waiver program allows the Secretary of the Department of Health and Human Services (DHHS) to waive certain Medicaid statutory

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[67] For information on state efforts to focus more financing on home and community-based services, see CRS reports in this series: *A CRS Review of States: Home and Community-Based Services — States Seek to Change the Face of Long-Term Care*.

[68] A few states have virtually eliminated coverage of large ICFs/MR due to efforts to provide home and community-based services, or small residential care, for this population.

[69] Medicaid-certified ICFs/MR must offer "active treatment" to residents. *Active treatment* is defined by regulation as aggressive, consistent implementation of a program of specialized and generic training, treatment, health and related services directed toward acquisition of behaviors necessary for the client to function with as much self-determination and independence as possible, and the prevention or deceleration of regression or loss of optional functional status. (45 CFR 483.440)

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requirements to assist states finance care in home and other community-based settings.[70] Examples of services that states may cover are personal care, adult day care, habilitation, case management, respite for caregivers, transportation, among others. (See **Appendix C** for other examples of services that states may opt to cover.) To be eligible for the program, a person must be a member of a specified target group, and meet financial eligibility requirements set by state and federal law and require the level of care provided in a hospital, nursing home, or ICF/MR.

- *Home Health Care Services.* All states are required to provide home health services to persons entitled to nursing facility coverage under a state's Medicaid plan. Home health services must be medically necessary and authorized by a physician as part of a written care plan. Services covered vary by state and may include care by nurses and home health aides, as determined by a person's medical condition.
- *Personal Care Services.* States have the option to cover personal care services for Medicaid beneficiaries who need assistance with ADLs and IADLs. The Medicaid statute defines personal care as services furnished to an individual at home or in another location (excluding institutional settings) that are either authorized by a physician, or at state option, under a plan of care. Services may include assistance with bathing, dressing, eating, toileting, personal hygiene, light housework, laundry, meal preparation, and grocery shopping, among others.
- *Home and Community-based Services State Option (Section 1915(i) of the Social Security Act).* This Medicaid state plan option, authorized by the Deficit Reduction Act of 2005, allows states to cover one or more home and community-based services (specifically those made listed in section 1915(c)) to certain individuals with long-term care needs. States are not required to make services available on a statewide basis. This benefit is limited to individuals whose income does not exceed 150% of the federal poverty level and who meet state-determined level of need criteria. If states cover this option, the needs-based criteria must be less stringent than that used for institutional care eligibility. States may limit the number of individuals served.[71]

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[70] States may waive the following Medicaid requirements: (1) statewideness — states may cover services in only a portion of the state, rather than in all geographic jurisdictions; and (2) comparability of services — states may cover services for waiver participants that are not available to other Medicaid enrollees. In addition to waiving these requirements, states may use more liberal income requirements than would ordinarily apply to persons living in the community. That is, they may use the eligibility standard used to determine financial eligibility for nursing home care — income up to 300% of the SSI level ($1,869 per month in 2007).

[71] For more information, see CRS Report RS22448, *Medicaid's Home and Community-Based Services State Plan Option: Section 6086 of the Deficit Reduction Act of 2005*, by

(continued...)

Medicare

Medicare is a nationwide health insurance program for people age 65 and older and those who meet the social security definition of disability.[72] It is intended to address acute and primary medical care needs, and is not designed to respond to chronic care need of persons with disabilities over a sustained period of time. To the extent that it provides coverage for nursing home and home health services, it does so with the intent of restoring a beneficiary's condition to what it had been before the acute illness or hospitalization. In 2005, Medicare's long-term care spending was $42.2 billion, about 20.4% of all long-term care spending.

The Medicare program covers skilled nursing home and home health care services for persons who need post-acute skilled or rehabilitative services of relatively short duration. The following is a description of these benefits:

- *Skilled Nursing Facility (SNF).* SNF services are covered for persons who require skilled nursing and/or rehabilitation services following a hospitalization of at least three consecutive days. If the beneficiary needs skilled care, Medicare will pay for a portion of the cost for up to 100 days of SNF care per "spell of illness."[73] To qualify for Medicare's home health benefit, a beneficiary must be confined to his or home (that is, be "homebound"). A physician must certify that the beneficiary needs daily skilled nursing care or other skilled rehabilitation services related to the hospitalization, and that these services can only be provided on an inpatient basis. Medicare does not cover SNF care for persons who need care for chronic conditions or disabilities alone.
- *Home Health (HH).* Home health services are covered for beneficiaries who are homebound and need intermittent skilled nursing care, physical therapy or speech therapy. Beneficiaries receiving at least one of these services may also receive home health aide services, medical social work services, and occupational therapy.

[71] (...continued)
Karen Tritz and Carol O'Shaughnessy.

[72] Under Social Security, disability is defined as the inability to engage in substantial gainful activity by reason of a medically determinable physical or mental impairment expected to result in death or last at least one year.

[73] A spell of illness begins when a beneficiary receives inpatient hospital or Part A covered SNF care and ends when the beneficiary has not been an inpatient of a hospital or in a covered SNF stay for 60 consecutive days (§1861(a) of the Social Security Act). A beneficiary may have more than one spell of illness per year.

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Older Americans Act (OAA)[74]

The Older Americans Act is intended to foster the development of a broadly defined, comprehensive and coordinated aging services system. Title III and Title VII of the Older Americans Act authorize grants to states and area agencies on aging to provide a range of services to assist those with long-term care limitations. Services authorized under the act that assist the long-term care population include supportive services (such as homemaker, chore and transportation services), congregate and home-delivered nutrition services, caregiver support services, and the long-term care ombudsman program, among others. The act provides limited funds for home and community-based long-term care services relative to demand. (In FY2007, funding for Title III supportive and nutrition services, family caregiver services, and vulnerable elder rights protection services (which authorizes the long-term care ombudsman program) is about $1.2 billion.)

The following is a description of Older Americans Act programs:

- *Supportive services and centers.* These services are intended to assist older people to reside in their homes and communities and remain as independent as possible. Funds cover personal care, homemaker, chore services, and adult day care, among others;
- *Congregate and home-delivered nutrition services.* These services include meals served to frail older persons and their caregivers at home and in congregate settings, such as senior centers and schools;
- *National Family Caregiver Support program.* This program provides information to caregivers about available services; individual counseling; organization of support groups and caregiver training; respite services to provide families with temporary relief from caregiving responsibilities; and supplemental services (such as adult day care or home care services, for example), on a limited basis, that would complement care provided by family and other informal caregivers; and
- *Long-Term Care Ombudsman Program.* Under this authority, states investigate and resolve complaints related to the health, safety, welfare, and the rights of institutionalized persons; and monitor federal, state and local laws, regulations, and policies with respect to long-term care facilities.

In addition to these programs, in recent years, the Administration on Aging (AoA) has used its Title IV research and demonstration authority to fund Aging and Disability Resource Centers (ADRCs) to assist states create a single, coordinated system of information and access to long-term care services. Recent legislation (P.L. 109-365) expanded AoA's role in promoting home and community-based long-term care services by requiring AoA to conduct research and demonstration projects to

[74] For more information on the Older Americans Act, see CRS Report RL31336, *Older Americans Act: Programs, Funding, and 2006 Reauthorization*, by Carol O'Shaughnessy and Angela Napili.

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identify innovative, cost-effective strategies to modify state systems of long-term care and to assist individuals avoid institutional care.

Despite the Older Americans Act's limited federal funding, many state and area agencies on aging have become the administrative vehicle for other long-term care programs, often including the Medicaid Section 1915(c) home and community-based waiver programs covering older persons. Funding through state and area agencies on aging can fill gaps in services for persons who would not otherwise receive services. The Older Americans Act allows for services to be provided without the restrictions required under other federal programs, such as Medicaid and Medicare, and, in some cases, Title III funds of the Older Americans Act may be used to serve persons who are ineligible for services under these programs.

Social Services Block Grant (SSBG)[75]

The SSBG program, authorized under Title XX of the Social Security Act, is designed largely to assist families and individuals in maintaining self-sufficiency and independence. Its role in long-term care is limited to support for home and community-based services selected and defined by each state. The program authorizes capped formula grants to states for a range of social services that states may elect to provide, within federal guidelines. Federal law establishes broad goals within which states may finance a wide range of services for a variety of population groups.

Services that may be available to people with long-term care limitations include homemaker services, adult day care, transportation, among others. The SSBG is funded at $1.7 billion in FY2007. While it is difficult to determine how much of SSBG funds are used for the long-term care population, in 2004 (latest available), some of its funding was used to provide various services to assist people with long-term care limitations, such as congregate and home-delivered meals, adult day care, and home-based services.

Other Federal Programs

The Department of Veterans Affairs (VA) supports nursing home care and a wide range of non-institutional services to the nation's veteran population. Non-institutional services available to veterans include home-based primary care, home health care, adult day health care, homemaker and home health aide services, home respite care, and community residential care. In addition, veterans with multiple medical, functional or psychosocial problems may receive assessment from an interdisciplinary team of VA professions (Geriatric Evaluation and Management (GEM)) teams.[76]

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[75] For more information, see CRS Report 94-953, *Social Services Block Grant (Title XX of the Social Security Act)*, by Melinda Gish.

[76] For further information, see *Fact Sheet: VA Long-Term Care*, U.S. Department of Veterans Affairs [http://www1.va.gov/OPA/fact/ltcare.asp].

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The Department of Housing and Urban Development (HUD) administers a number of programs that assist adults with long-term care limitations. Three programs base assistance on a person's need for assistance with ADLs. The *Congregate Housing* program provides meals and supportive services, including housekeeping, case management personal care, and transportation, to assist frail elderly remain living independently in HUD-subsidized housing. *Service coordinators* in HUD-subsidized housing developments assist the frail elderly and people with disabilities arrange services such as meal services, housekeeping, medication management, and visits to health care providers. The *Assisted Living Conversion* program allows HUD-subsidized facilities to modify their apartments and common areas to accommodate the frail elderly and provides them with supportive services, including 24-hour staff, supervision of nutrition and medication, and three meals a day.[77]

The Supplemental Security Income (SSI) program provides income assistance for aged, blind, and disabled persons who meet federally defined income and resources tests.[78] Some states provide optional payments to assist people whose needs are not fully covered by the federal payment. In some cases, states provide optional state supplemental payments to those who need assistance with ADLs or IADLs in personal care homes, foster care homes, and other residential care facilities. While states are responsible for the cost of the supplemental payments, they may opt to have the Social Security Administration (SSA) administer the payments.[79]

Other programs such as the Rehabilitation Act of 1973,[80] the Developmental Disabilities Act, and the Assistive Technology Act provide grants to states for certain services and activities that may assist people with long-term care needs.

Private Long-Term Care Insurance

Private long-term care insurance products started developing in the early 1980s. Though the private long-term care insurance market is still limited in size, compared to other payers, it has been growing. Between 1987 (when the Health Insurance Association of America (HIAA) began surveying the industry) and 2001, the market grew by an average of 18% per year. By the end of 2002, 9.2 million policies had been sold. The number of individuals purchasing long-term care insurance has grown over the years, with 900,000 policies sold in 2002, compared to 826,100 policies sold

[77] For further information, see CRS Report RL33508, *Section 202 and Other HUD Rental Housing Programs for the Low-Income Elderly*, by Libby Perl.

[78] For further information, see SSI Income and Resource Limits CRS Report RS20294, by Scott Szymendera.

[79] For further information, see *State Assistance Programs for SSI Recipients*, January 2005 [http://www.ssa.gov/policy/docs/progdesc/ssi_st_asst/2005/ssi_st_asst05.pdf].

[80] For further information, see CRS Report RL33249, *Rehabilitation Act of 1973: 109th Congress Legislation, FY2006 Budget Request, and FY2006 Appropriations*, by Scott Szymendera.

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in 2001, and 752,900 sold in 2000.[81] Although the vast majority of policies (79%) were sold in the individual market, policies have also been sold through employer-sponsored and group association markets (18%), as well as riders of some life insurance policies (3%) that allow for some fraction of the death benefit to be paid in advance to cover long-term care services.[82]

Despite the growth in the number of policies, private long-term care insurance currently covers a very small portion of all long-term care expenditures compared to other payers. The national measure for private insurance spending, the private insurance category of the National Health Accounts Data, includes spending by long-term care insurance products as well as a variety of other insurance products, such as supplemental Medicare coverage (Medigap), traditional health insurance, and certain types of life insurance.[83] The National Health Accounts data indicates that private insurance covered $14.9 billion (7.2%) of the nation's long-term care spending in in 2005 (See **Figure 12**).

Private long-term care insurance products cover certain long-term care services for policyholders who pay premiums, and who meet the functional (e.g., limitations in ADLs) or behavioral eligibility criteria or the need for supervision based on cognitive impairments. Benefit features of these policies vary widely, and care may be covered in a variety of settings such as nursing facilities, assisted living facilities, or the individual's own home. Services that may be covered in home-based settings can include home health, respite for caregivers, homemaker and chore services, and medical equipment, among others.[84] According to a survey of 5,407 individual policies sold in 2000, 77% covered comprehensive benefits, including nursing home and home care, up from 37% in 1990 (based on 14,440 individual policies sold).[85]

Generally speaking, buyers of long-term care insurance tend to be people who have somewhat above average income levels. [86] Long-term care insurance can be

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[81] "America's Health Insurance Plans," *Long-Term Care Insurance in 2002: Research Findings*, Washington, DC, June 2004. (Hereinafter America's Health Plans.)

[82] Ibid.

[83] Certain life insurance policies offer a long-term care rider that pays out a portion of the death benefit in advance if the person demonstrates long-term care needs.

[84] Other features include waiting ("elimination") periods between the onset of qualifying impairments and the commencement of payment; dollar limits for specified benefits, and possible inflation adjustments to those limits; payments that are a flat daily amount paid regardless of whether expenses are incurred, or paid only as reimbursement for services provided by licensed professionals; and a length of time over which benefits may be paid (such as one year, three years, or longer).

[85] Health Insurance Association of America, "Who Buys Long-Term Care Insurance in 2000? A Decade of Study of Buyers and NonBuyers," Prepared by *LifePlans, Inc.*, Washington, DC, October 2002.

[86] At high levels of accumulated wealth, individuals can bear the financial risks without purchasing insurance. At low levels of wealth, insurance is often unaffordable. At middle income levels, persons will likely find insurance more desirable, especially if they are

(continued...)

costly, with premiums depending greatly on the benefit packages purchased and the age of individuals at the time of purchase (generally, the older the individual, the higher the premiums).[87] Price is one of the reasons many people in this demographic group do not buy long-term care insurance. Most people would find this product too expensive if they started considering purchase when already retired; others may not be able to afford it even while still working.

Other reasons for the relatively low purchasing numbers may include a lack of awareness of the risks of needing care; lack of awareness of the costs of care and who pays for these costs; and a belief that there is adequate public coverage through such programs as Medicare, retiree health insurance or other health insurance products.

Conclusion

The need for long-term care affects people of all ages and the risk of needing long-term care at older ages can be substantial. Despite significant spending on long-term care through public sources, primarily Medicaid, most care provided to people with long-term care needs is provided by families who provide care without compensation. The aging of society will exacerbate demands on family caregivers for people with disabilities of all ages, not only for the elderly. In addition, the increasing longevity of younger people with disabilities, as well as evidence of increasing disability among the working-age populations, may lead to more stress on family caregiving. To assist families in their caregiving roles, and to prepare for the aging of the baby boom population, most observers believe that expanded efforts to assist families may be warranted.

The vast majority of adults, regardless of age — over 80% — receive care in home and community settings, *not* in nursing homes or other institutions. Yet, the major payer for long-term care, the Medicaid program, principally has financed institutional care. Recent trends show, however, that this is changing with greater public resources directed at home and community-based care which is preferred by most individuals and families. The ability of the service delivery system to keep up with demand for increased home and community-based services may require continuing monitoring by policymakers. Challenges include uneven availability of home and community-based services across and within states, and an uncoordinated

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[86] (...continued)
concerned about preserving income or assets for a spouse or passing on their wealth to their children. Others may be willing to take the chance of spending down their assets to qualify for Medicaid if necessary.

[87] Once a policy is purchased, premiums must remain fixed throughout the policyholder's lifetime, unless a carrier receives approval from a state insurance commissioner to raise rates for all policyholders in a particular class. Premium increases of policies already sold may also vary by state. Some states may be more likely to approve insurers' requests to increase rates than others states. Approval decisions are based, in large part, on the standards adopted by each state.

service delivery system that is funded by many sources with differing eligibility requirements and service requirements.

Many people believe that planning for long-term care expenses is an essential part of financial planning, but to date most families do not plan and are sometimes faced with a bewildering array of formal care services. Some observers argue that the complexity of long-term care financing for diverse groups of individuals with disabilities — children and working-age persons with disabilities, as well as the elderly, with differing types and severity of impairments — necessitates a multi-pronged strategy of financing and delivery reform. Because of the diverse characteristics of the population in need, one approach to financing may not fit all people. Defining the public and private sector roles in financing and delivery of long-term care for these groups may need to account for their differing needs and financial abilities to pay for the cost of care.

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Appendix A. Background on the National Long-Term Care Survey, National Health Interview Survey, and Medical Expenditure Panel Survey

Data on Persons Age 65 and Older. Estimates of the size and characteristics of the long-term care population age 65 and older are based on the **National Long Term Care Survey (NLTCS)**. The NLTCS is a longitudinal survey designed to study changes in the health and functional status of older Americans. It also tracks health expenditures, Medicare service use, and the availability of personal, family, and community resources for care giving. The survey began in 1982, and follow-up surveys were conducted in 1984, 1989, 1994, 1999, and 2004. The surveys are funded through a Cooperative Agreement between the U.S. National Institute on Aging (NIA) and Duke University's Center for Demographic Studies. The analyses presented in this report are based on unpublished tabulations of 1999 data from the NLTCS team at Duke University.[88] Results from the 2004 susrvey are not yet available.

Users of long-term care are defined as all persons who are institutionalized *plus* persons with chronic disabilities (expected to last 90 days or longer) who reside at home and receive assistance to perform at least one activity of daily living (ADLs) or instrumental activities of daily living (IADLs). Six ADLs are included: bathing, dressing, getting in or out of bed, getting around inside, using the toilet, and eating. Nine IADLs are included: light housework, heavy housework, laundry, meal preparation, grocery shopping, getting around outside the home, managing money, taking medications, and telephoning. Persons are considered to have an ADL disability if they report receiving help or supervision, or report using equipment, to perform the activity or if they do not perform the activity at all because of their health or a disability. Persons have an IADL disability if they report receiving help to perform the activity or report that they are unable to do the activity because of their health or a disability.

Benefits of using the NLTCS data to ascertain the characteristics of the long-term care population include that (1) the sampling frame is broad and includes persons living at home and in other community settings and in facilities; (2) special efforts are made to over-sample populations of particular interest, including the oldest-old and minorities; (3) the data set allows analysis of the characteristics of the long-term care population by disability status, age, gender, race, marital status, and other variables of interest; (4) to the degree possible, survey questions are asked of the person who has long-term care needs — rather than of the head of household or a home health aide; (5) its results are for the population age 65 years and older, which generally has greater long-term care needs than the younger population; and (6) its results are broadly consistent with that of the few other major data sets that collect this information.

[88] Data refer to Medicare enrollees. NLTCS tabulations, 2005.

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A disadvantage of the survey is that, because its sampling frame is drawn from Medicare rolls, it is representative of Medicare beneficiaries only, not of the underlying U.S. population. This is a minor issue because about 95% of older Americans are enrolled in Medicare.[89] A second issue is that some variables of interest are not collected at all and the results are unreliable for a small number of policy-relevant variables. For example, policymakers are interested in the wealth and income profile of persons with long-term care needs because the provision of such services is expensive. The NLTCS collects data on income, but not on wealth.

Data on Working-Age Persons. **The National Health Interview Survey (NHIS)** is a household sample survey conducted annually by interviewers of the U.S. Census Bureau for the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics (NCHS). The most recent year for which these community-level results are available is 2003. However, we utilize the older 1994 data from the NHIS' Disability Supplement. The supplement data are more detailed and were specifically collected to better understand disability in the United States. In addition, there are a number of concerns about the later 2003 data. *First*, the questionnaire is inconsistent with the other sources utilized in this report. It asks about the *need for* (rather than the actual receipt of) help to perform a *subset* of the ADLs: "... need the help of other persons with personal care needs, such as eating, bathing, dressing, or getting around inside the home?" and IADLs: "... such as doing business, shopping, or getting around for other purposes?" *Second*, the questions are asked of the head of the household rather than of the person with the long-term care needs.

The Medical Expenditure Panel Survey (MEPS) is a series of national probability surveys conducted by the Agency for Healthcare Research and Quality (AHRQ) on the financing and utilization of medical care in the United States. See [http://www.meps.ahrq.gov/Data_Pub/Questionnaires/QUESTNHC/Readme.htm], (hereinafter cited as MEPS, 1996). The 1996 Nursing Home Component gathered information from a sample of nursing homes and residents nationwide on the characteristics of the facilities and services offered, expenditures and sources of payment on an individual resident level, and resident characteristics (including functional limitations, cognitive impairment, age, income, and insurance coverage). MEPS, Nursing Home Component, enumerated 138 thousand persons in nursing homes. A more recent survey, the National Nursing Home Survey (NNHS), enumerated 158,700 nursing home residents. We use the 1996 MEPS nursing home results rather than those from the 1999 NNHS because MEPS published tabulations are available for the full range of characteristics provided for community-living users of LTC.

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[89] Brenda C. Spillman, Korbin Liu, and Carey McGilliard, *Trends in Residential Long-Term Care: Use of Nursing Homes and Assisted Living and Characteristics of Facilities and Residents*, Washington, DC: DHHS/ASPE, Nov. 2002.

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Appendix B. Causes of Inconsistency in Estimates of Long-Term Care Population

Identifying the long-term care population is challenging, and estimates of its size and characteristics vary widely. Data from the National Long Term Care Survey (NLTCS), a nationally-representative sample of Medicare enrollees ages 65 years and older, illustrates how widely estimates of the number of older persons with long term care needs could vary depending upon the definition employed. As seen in Table B-1, about 7.1 million older persons had long term care needs in 1999 — if *all* persons with ADL or IADL disabilities plus all persons in institutions are counted. If, however, one excludes persons who receive assistance with only IADLs, the estimate falls to 5.6 million persons. If persons who independently manage their own disabilities through the use of assistive devices or other equipment are also excluded, the estimate falls to 3.8 million older persons. A large number of additional, technically correct, estimates are also possible if one utilizes different combinations of the data available.

Table B-1. Illustration: How Different Definitions of "Disability" Affect Estimates of the Number of Long-Term Care Recipients Age 65 and Over, United States, 1999

(in thousands of persons)

Disability Characteristics		Number of persons
No disabilities		**28,121**
Any disabilities (IADL + ADL + Institutionalized)		**7,106**
IADL disabilities only		1,469
ADL disabilities (with or without IADLs):		4,186
Receives human help with ADL(s)	*220*	
Receives stand-by help with ADL(s)	*309*	
Uses equipment to manage ADL(s)	*1,820*	
Receives both human and standby help with ADL(s)	*72*	
Receives both human help and uses equipment	*1,082*	
Receives both standby help and uses equipment	*175*	
Receives human help, standby help, and uses equipment	*506*	
Institutionalized		1,451

Source: CRS calculations based on unpublished tabulations from Duke University, Center for Demographic Research, received Apr. 29, 2005. Original source of data is the National Long Term Care Survey (NLTCS), 1999.

Notes: (1) Data in this table refer to persons age 65 and older. Estimates of persons with disabilities refer to those persons who report receiving direct help from another person, stand-by help, or use equipment to manage at least one ADL or IADL disability or are institutionalized (regardless of the duration of disability); (2) This table is for illustrative purposes only and its estimates are NOT directly comparable to the estimates of the LTC population provided in the main text for a number of reasons — inclusion of the use of equipment to manage disability, a different time reference for duration of disability, differences in the weighting scheme employed to convert sample survey results to nationally representative results; (3) Estimates may not total due to rounding.

There are many underlying causes for the inconsistent estimates of the long-term care population:

First, most definitions of the need for long-term care are based on a recipient's underlying disability, but there is no generally agreed upon definition of "disability." While frequently measured by the self-reported[90] long-term need for assistance to perform ADLs or IADLs, program and survey definitions appropriately[91] vary widely. Even if an ADL or IADL definition is employed, enumeration of the population with disabilities varies across multiple dimensions including:

- specification of the ADL/IADL tasks included;
- whether the survey question asks if the respondent "has difficulty," "needs help," "receives help," or is "incapable of" performing a task;
- the nature of help received by the person with a disability — whether direct human assistance, stand-by help, or the use of equipment (assistive technology) to perform personal care activities;
- whether the survey question uses the preamble "because of a health or emotional problem ...";
- the frame of reference — does the person have the disability at the present time, had the problem during the past month, or ever?
- whether the disability is chronic, e.g., the respondent had the limitation for at least 90 days;
- who responded to the questionnaire — actual respondent or a proxy (family member, home health aide, etc.).

Second, national efforts to collect statistical information on the long-term care population are fragmentary, resulting in incomplete, and sometimes, inconsistent information. For instance, the Disability Supplement to the National Health Interview Survey (NHIS-D)[92] provides "the most comprehensive information to date about the prevalence of disabilities in the U.S. population living in the community and the health and demographic characteristics of the community population receiving long-term care."[93] However, it collected information only about community-dwelling, non-institutionalized adults. The National Long-Term Care

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[90] As opposed to an individual's measured performance on a set of tasks.

[91] Different policy questions require different types of supporting data. For instance, the data required to project future nursing home usage by persons with three or more ADLs will differ significantly from that required to estimate current at-home service needs by persons who report having difficulty to prepare meals.

[92] See [http://www.cdc.gov/nchs/about/major/nhis_dis/nhis_dis.htm], visited Jan. 27, 2005.

[93] William D. Spector, John A. Fleishman, Liliana E. Pezzin, and Brenda C. Spillman, *The Characteristics of Long-Term Care Users*, Rockville, MD: Dept. Of Health and Human Services/Agency for Healthcare Research and Quality, AHRQ Publication No. 00-0049, Sept. 2000. (Hereinafter Spector and colleagues, 2000).

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Survey (NLTCS)[94] has collected data for both community and institutionalized persons since 1984, but only for the population ages 65 and older. And, the National Nursing Home Survey[95] collects data only about persons who reside in nursing homes.

Third, some surveys are facility-based, but the range of potential long-term care options — for instance, continuing care retirement communities, assisted living, nursing homes, etc. — has expanded greatly over the past decade. Many facility-based data collection efforts fail to capture the full range of long-term care providers or recipients. In addition, they usually do not capture persons with long-term care needs who reside at home.

Fourth, much statistical information has become out-of-date. For instance, while the National Health Interview Survey collects data annually, its supplement on disability was last collected in 1994.

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[94] See [http://nltcs.cds.duke.edu/], visited Jan. 27, 2005.

[95] See [http://www.cdc.gov/nchs/about/major/nnhsd/nnhsd.htm], visited Jan. 27, 2005.

Appendix C. Medicaid Home and Community-Based Waiver Services

Below is a list of the wide array of services that states have opted to cover under the Medicaid home- and community-based waiver program. Each state may determine which services will be covered, and the amount, duration or scope of each particular services.

Some of the services are additional services beyond what is normally available under the Medicaid program (e.g., expanded dental benefits and/or prescription drugs). These types of services are not normally considered within the definition of long-term care services. However, national data do not exist that would disaggregate the Medicaid home- and community-based waiver expenditures into specific sub-types of services. As a result, for purposes of this report, all of these services are considered included in the definition of "long-term care."

- Adult day care
- Services in community-based residential setting
- Assistive technology
- Personal care/Homemaker support services
- Nursing services
- Companion services
- Counseling/Mental health services
- Case management
- Consumer and family skills training
- Dental care
- Home and environmental access and modifications
- Home-delivered meals
- Hospice Interpreter
- Nutrition counseling and supplements
- Prescription drugs
- Medication management
- Emergency response, crisis intervention, and protective services therapies: speech, physical, occupational
- Physician Services
- Respite
- Massage/Acupuncture Transportation

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Appendix D. Selected Federal Programs

Table D-1. Selected Major Public Programs Supporting Long-Term Care Services: Services Covered, Eligibility, and Administering Agency

			Administering agency	
Program	**Services covered**	**Eligibility**	**Federal agency**	**State agency**
Medicaid				
Nursing Homes (NH)	Nursing home care includes room and board, skilled nursing care and related services, rehabilitation, and health-related care. States may also cover therapeutic services, such as physical therapy, occupational therapy, and speech pathology and audiology services.	Persons who are aged, blind and/or who meet the Supplemental Security Income (SSI) definition of disability; AND need the state-defined level of care provided in a nursing home; AND meet the income and asset criteria of at least one of the state's financial eligibility pathways. Major pathways include SSI and/or State supplemental payment (SSP)` recipients, persons whose income is at or below 100% of the federal	Centers for Medicare and Medicaid Services (CMS)/ HHS	State Medicaid agency and sometimes another state agency

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Program	Services covered	Eligibility	Administering agency	
			Federal agency	State agency
		poverty level (FPL), persons who are defined by the state to be medically needy, and persons whose income does not exceed about 221% of the federal poverty level, or 300% of the (SSI) level. These criteria vary by state.		
Intermediate Care Facilities for persons with Mental Retardation (ICF/MR)	Services include room and board and a wide range of specialized therapeutic services to assist persons in functioning at optimal levels. Must offer "active treatment." "*Active treatment*" is defined by regulation as aggressive, consistent implementation of a program of specialized and generic training, treatment, health and related services directed toward acquisition of behaviors necessary for the client to function with as much self-determination and independence as possible, and the prevention or deceleration of regression or loss of optional functional status. (45 CFR 483.440)	Persons with mental retardation or developmental disabilities; AND need the state-defined level of care provided in an ICF/MR; AND meet the income and asset criteria of at least one of the state's financial eligibility pathways (described above)	CMS/HHS	State Medicaid agency and sometimes another state agency

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Program	Services covered	Eligibility	Administering agency	
			Federal agency	**State agency**
Institutions for Mental Disease (IMD)	Diagnosis and treatment or care of persons with mental diseases, including medical attention, nursing care and related services	States may cover individuals age 65 and older and individuals who are in hospitals or nursing facilities that are institutions for mental diseases. Individuals must meet the state-defined level of care provided in an IMD; AND meet the income and asset criteria of at least one of the state's financial eligibility pathways (described above).	CMS/HHS	State Medicaid agency and sometimes another state agency
Psychiatric facilities for people under age 21	States may provide Medicaid coverage for individuals under age 21 in psychiatric facilities with accreditation of Joint Commission on Accreditation of Healthcare Organizations (JCAHO), the Commission on Accreditation of Rehabilitation Facilities, the Council on Accreditation of Services for Families and Children, or by any other accrediting organization with comparable standards that is recognized by the state. Persons	Individuals under age 21 who meet the state-defined level of care criteria for psychiatric facilities AND meet the income and asset criteria of at least one of the state's financial eligibility pathways (described above).	CMS/HHS	State Medicaid Agency and sometimes another state agency

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Program	Services covered	Eligibility	Administering agency	
			Federal agency	**State agency**
	age 21-64 are not covered under this benefit.			
Home and Community-Based 1915(c) Waiver (HCBS waiver)	Wide range of home and community-based services, such as case management, homemaker/home health aide, personal care, adult day health, habilitation, respite, rehabilitation, day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic illness, as well as other services that the Secretary may approve. States have flexibility to offer additional services if approved by the Secretary of HHS. Excludes room and board**.**	Persons who are aged, blind and/or disabled, or are in one of the other eligibility categories defined by the state, such as those with AIDs, mental illness, traumatic brain injuries, and others, AND need the state-defined level of care provided in a nursing home, ICF/MR, or hospital; AND meet the income and asset criteria of at least one of the state's financial eligibility pathways (described above). States may limit the number of individuals who can receive these services.	CMS/HHS	State Medicaid Agency and sometimes another state agency
Home Health (HH)	Nursing, home health aides, medical supplies, medical equipment, and certain appliances delivered to Medicaid beneficiaries in their homes. States may	Persons who are enrolled in Medicaid AND meet the state's definition of need for home health services.	CMS/ HHS	State Medicaid Agency and sometimes another state agency

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Program	Services covered	Eligibility	Administering agency	
			Federal agency	**State agency**
	also cover therapeutic services, such as physical therapy, occupational therapy, and speech pathology and audiology services.	All home health services must be medically necessary and authorized on a physician's orders as part of a written care plan.		
Personal Care (PC)	Services furnished to an individual at home or in another location (excluding hospital, nursing facility or ICF/MR, or institution for mental diseases) that are authorized by a physician, or at state option, otherwise authorized under a plan of care. Services offered under the personal care option may include assistance with ADLs and IADLs, and may include personal hygiene, light housework, laundry, meal preparation, grocery shopping, using the telephone, medication management, and money management. For persons with cognitive impairments, such services may include cuing along with supervision.	Persons enrolled in Medicaid AND who meet the state's definition of need for personal care services.	CMS/ HHS	State Medicaid Agency and sometimes another state agency
Targeted case management	Case management services that are not necessarily delivered as part of some other service (i.e., the 1915(c) waiver). Examples include service/support planning, monitoring of services, and assistance to persons on obtaining	Persons enrolled in Medicaid AND eligibility criteria for the benefit as defined by the state.	CMS/ HHS	State Medicaid agency and sometimes another state agency

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Program	Services covered	Eligibility	Administering agency	
			Federal agency	**State agency**
	benefits, such as food stamps, energy assistance, and emergency housing. TCM may not be available statewide.			
Home and Community-Based State Plan Option	Same services as those included under the Medicaid Section 1915(c) HCBS waiver. States may not offer services other than those listed in the statute (case management, homemaker/home health aide, personal care, adult day health, habilitation, respite, rehabilitation, day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic illness). States may provide services on a less than statewide basis.	Those who are Medicaid-eligible AND have income below 150% of FPL. Individuals must meet the state-established needs-based criteria which must be less stringent than the level of care required for an institution. States may limit the number of individuals who can receive these services.	CMS/HHS	Medicaid agency and sometimes another state agency
Other Services	A wide range of optional services, such as rehabilitation services, private duty nursing, physical and occupational therapy and transportation services.	Individuals must meet the state's financial and categorical requirements for Medicaid state plan services AND meet other eligibility criteria as defined by the state. These criteria vary by state and service.	CMS/ HHS	State Medicaid Agency and sometimes another state agency

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Program	Services covered	Eligibility	Administering agency	
			Federal agency	**State agency**
Medicare				
Skilled Nursing Facility (SNF)	Comprehensive nursing home services, including skilled care, rehabilitation and other related services for up to 100 days.	Beneficiaries who require skilled Nursing care and/or rehabilitations services following a hospitalization of at least three consecutive days. A physician must certify that the beneficiary needs daily skilled nursing care or other skilled rehabilitation services that are related to hospitalization, and that these services can be provided only on an inpatient basis.	CMS/ HHS	NA
Home Health (HH)	In-home skilled nursing or therapy (physical, speech/language, occupational) services, part-time intermittent services of a home health aide, medical supplies and durable medical equipment, medical services provided by an intern or resident in training, and certain other outpatient services involving the use of certain equipment available in the beneficiary's home. Services must be delivered under the care	Medicare beneficiaries must meet Medicare's definition of "homebound," be under the care of a physician, and need skilled nursing care on an intermittent basis or skilled therapy care.	CMS/ HHS	NA

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Program	Services covered	Eligibility	Administering agency	
			Federal agency	State agency
	of a physician and in accordance with a plan of care periodically reviewed by a physician.			
Older Americans Act				
Supportive services and centers	Senior services and social services, such as transportation, personal care, homemaker, chore services, and adult day care.	Persons age 60 and over. No means test, but services are to be targeted to those with greatest social or economic need, with particular attention to those with low income, minority older people, those residing in rural areas, those at risk of institutionalization, and those with limited English-speaking proficiency.	Administration on Aging/HHS	State agencies on aging
Nutrition services	Meals served to frail older persons and their caregivers at home and in congregate settings, such as senior centers and schools.	Persons age 60 or older and their spouses of any age; persons under age 60 with disabilities who reside in housing facilities occupied primarily by the elderly where congregate meals are served; persons with disabilities who reside at home with, and accompany, older persons to meals; and nutrition service	Administration on Aging/HHS	State agencies on aging

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Program	Services covered	Eligibility	Administering agency	
			Federal agency	**State agency**
		volunteers. Services must be targeted toward persons with the greatest social and Economic need, with particular attention paid to those with low income, minority older people, those residing in rural areas, those at risk of institutionalization, and those with limited English-speaking proficiency.		
Ombudsman program	States and local ombudsmen investigate and resolve complaints related to the health, safety, welfare, and rights of institutionalized persons; monitor federal, state and local laws, regulations, and policies with respect to long-term care facilities; provide information to public agencies regarding problems of older persons in long-term care facilities; and establish procedures for access to facilities' and patients' records, including protection of the confidentiality of such records.	Persons age 60 and over. No means test, but services are to be targeted to those with greatest social or economic need, with particular attention to those with low income, minority older people, those residing in rural areas, those at risk of institutionalization, and those with limited English-speaking proficiency.	Administration on Aging/HHS	State agencies on aging

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Program	Services covered	Eligibility	Administering agency	
			Federal agency	**State agency**
National Caregiver Support Program	Support groups and caregiver training; respite services; and limited supplemental services (such as adult day care or home care services, for example)	Generally, people age 60 and over. No means test, but services are to be targeted to those with greatest social or economic need, with particular attention to low-income individuals, and to older persons who provide care o people with severe disabilities (including children with severe disabilities). Under certain circumstances, grandparents and certain other caregivers of children may receive services.	AdminisGtration on Aging/HHS	State agencies on aging
Social Services Block Grant (SSBG)				
SSBG	Various social services as defined by the state, including some long-term care services, such as homemaker, home health aide, personal care, and home-delivered meals	No federal eligibility criteria; states have discretion to set their own criteria.	HHS	State social services/ human resources agency. In some cases, other state agencies may administer a portion of Title XX funds for certain groups, e.g., state agency on aging

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