Long-Term Services and Supports: In Brief

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Contents

Introduction 1
What Are Long-Term Services and Supports? 2
Who Needs Long-Term Services and Supports? 2
Who Provides Long-Term Services and Supports? 4
How Much Do Long-Term Services and Supports Cost? 5
Further Reading 6

Tables

Table 1. Population Needing Long-Term Services and Supports (LTSS) in the United States, by Age and Setting 3
Table 2. Estimated Median Costs for Selected Long-Term Services and Supports (LTSS) Providers, 2014 6

Contacts

Author Contact Information 7

Introduction

Spending on long-term services and supports (LTSS)[1] is a significant component of personal health care spending in the United States. Of the $2.4 trillion spent in 2012 on all U.S. personal health care services, $324.2 billion, or 13.7%, was spent on formal, or paid, LTSS. Spending for LTSS includes services in both institutional settings—nursing facilities and intermediate care facilities for individuals with intellectual and developmental disabilities (ICFs/IDD)—and a wide range of home and community-based services such as home health, personal care, and adult day health services. The majority of spending on formal, or paid, LTSS is publicly financed by federal, state, and local governments through programs such as Medicaid, Medicare, the Veterans Health Administration (VHA), and the State Children's Health Insurance Program (CHIP), among others. For 2012, Medicaid (combined federal and state spending) was the single largest payer, at $136.3 billion, or 42.0%, of spending on LTSS. However, LTSS spending may be underestimated as spending data do not include informal, or uncompensated, care provided by family caregivers.

The probability of needing LTSS increases with age. As the older population continues to increase in size, and as individuals continue to live longer post-retirement, the demand for health care services and LTSS is also expected to increase. In 2012, an estimated 43 million individuals were age 65 and older. Over the next 50 years, that number is projected to increase to 92 million in 2060.[2] In addition, advances in medical and supportive care may allow younger persons with disabilities to live longer lives. Given current spending on LTSS and the likely increase in demand for these services, Congress's interest and attention to the role of public and private financing in LTSS may be an important issue going forward.

With respect to public LTSS financing, policy makers are generally concerned with issues of access, cost, and quality of care. For example, federal requirements as well as state decisions concerning eligibility for, or coverage of, certain LTSS determine who receives access to publicly financed LTSS. These requirements and decisions also determine the care settings and the services that may be provided. Costly LTSS may exhaust an individual's financial resources, which may lead to reliance on public support. Federal and state policy makers concerned about overall spending may have an interest in controlling growth in LTSS expenditures or in reducing such expenditures. Moreover, how and where LTSS are delivered may lead to care fragmentation and lack of coordination among service providers and payers.

The following provides an overview of LTSS, including information in response to the following questions: What is LTSS? Who needs LTSS? Who provides LTSS? How much does LTSS cost? The report does not discuss indirect long-term care benefits through federal and/or state tax deductions for LTSS expenditures. Furthermore, this report does not address the economic value of informal caregiving.

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[1] This report uses the term "long-term services and supports (LTSS)" rather than "long-term care (LTC)." LTSS is a term that is more commonly used by researchers and policy makers to better describe the types of assistance that are provided to persons with disability and the frail elderly. Also, the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended) uses LTSS and defines the term to include certain institutionally based and non-institutionally based long-term services and supports [Section 10202(f)(1)]. The term "long-term care" is still used in this report, for example, when referring to private long-term care insurance.

[2] U.S. Census Bureau, *Profile America: Facts for Features, May 2014 Older Americans Month*, Department of Commerce, U.S. Census Bureau News, CB14-FF.07 March 24, 2014, http://www.census.gov/newsroom/releases/pdf/cb14ff-07_older_americans.pdf

What Are Long-Term Services and Supports?

Long-term services and supports (LTSS) refer to a broad range of health and health-related services and supports needed by individuals who lack the capacity for self-care due to a physical, cognitive, or mental disability or condition. Often the individual's disability or condition results in the need for hands-on assistance or supervision over an extended period of time. Moreover, an individual's need for LTSS may change over time as his or her needs or conditions change. Thus, the need for these services and supports is ongoing or "long-term."

LTSS is not medical or acute care services. In general, acute care services are health services provided for the prevention, diagnosis, or treatment of a medical condition. Acute care services are often performed by licensed health care providers (e.g., physicians) in a clinical setting such as a doctor's office or a hospital. While LTSS may be offered in combination with acute care services, LTSS is not intended to treat or cure a medical condition. In contrast, LTSS provides assistance to individuals in maintaining or improving an optimal level of physical functioning and quality of life.

Examples of LTSS include a home health aide assisting a frail elderly person with daily personal care activities such as bathing or dressing, a contractor building a wheelchair ramp onto a home, or a senior center providing transportation to a cognitively impaired individual. LTSS includes the use of supports such as special equipment, assistive devices, or technology by a physically impaired person. Services also include more intensive nursing care, such as nursing care provided to a ventilator-dependent child. Residential LTSS settings such as group homes or assisted living facilities (ALFs) may provide LTSS such as meals, laundry and housework, and assistance with medication. Individuals who have severe physical or cognitive impairments may need the 24-hour supervision and nursing or convalescent care-related LTSS that are provided in a nursing facility.

Who Needs Long-Term Services and Supports?

The need for LTSS can affect persons of all ages—children born with disabling conditions, such as mental retardation, or cerebral palsy; certain working-age adults with inherited or acquired disabling conditions, such as mental illness or traumatic brain injury; and the elderly with chronic conditions or diseases, such as severe cardiovascular disease or Alzheimer's disease and related dementia. The need for LTSS is generally measured, irrespective of age and diagnosis, by the presence of functional limitations in the ability to perform basic personal care activities, known as activities of daily living (ADLs), or by the need for supervision or guidance with ADLs because of a mental or cognitive impairment.[3]

ADLs generally refer to activities such as eating, bathing, using the toilet, dressing, walking across a small room, and transferring (i.e., getting in or out of a bed or chair). Instrumental activities of daily living (IADLs) are also used to measure a person's need for LTSS. These activities are necessary for an individual's ability to live independently in the community. IADLs include activities such as 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.

[3] In general, children who need LTSS are those who cannot perform age-appropriate activities, such as walking, or cannot perform other age appropriate self-care activities.

In practice, defining the need for LTSS as the presence of functional limitations measured by the number of limitations in specific ADLs or IADLs has important policy implications. For example, publicly financed programs that cover LTSS, such as Medicaid, often use the number of limitations in ADLs to determine LTSS program eligibility, among other criteria. For those individuals who have a private long-term care insurance policy, the number of limitations in ADLs also forms the basis for triggering benefit eligibility. Thus, defining the need for LTSS through functional limitations and/or the need for supervision with ADLs determines eligibility for public and private financing.

The most recent published data that estimate the number of Americans in need of LTSS indicated 10.9 million individuals of all ages living in the community were in need of LTSS in 2005, or 4.1% of the community-resident population (see **Table 1**). Most individuals prefer to be cared for in their own homes with the assistance of informal providers such as family members or friends, if available. Among the estimated 10.9 million community residents who need LTSS, about half (49.8%) were older adults (ages 65 and older), while slightly less than half (46.6%) were adults ages 18 to 65, and 3.6% were children under age 18 (data not shown). Another 1.8 million individuals needing LTSS were estimated to live in an institutional setting, such as a nursing home, as of 2007. The majority of nursing home residents (86.0%) were adults age 65 and over.

Table 1. Population Needing Long-Term Services and Supports (LTSS) in the United States, by Age and Setting

(data for community residents from 2005; institutional residents from 2007)

	All Ages	Less than Age 18[c]	Ages 18 to 64	Ages 65 and Over
Community Residents[a] (% of community residential population)	10,887,000 (4.1%)	393,000 (0.8%)	5,073,000 (2.8%)	5,421,000 (15.5%)
Institutional Residents[b]	1,788,000	—	250,000	1,538,000

Source: H. S. Kaye, C. Harrington, and M. P. LaPlante, "Long-Term Care: Who Gets It, Who Provides It, Who Pays, And How Much?" *Health Affairs*, vol. 29, no. 1 (January 2010), p. 13.

a. Kaye et al. estimates of community residents comprise households and noninstitutional group quarters such as group homes, dormitories, and homeless shelters. Data are from the 2005 Survey of Income and Program Participation (SIPP) which define a "broadly defined long-term care population" as those persons needing help with one or more Activities of Daily Living (ADL) or Instrumental Activities of Daily Living (IADL).

b. Kaye et al. estimates of institutional residents comprise nursing homes, facilities for persons with intellectual and developmental disabilities, other residential health care facilities, prisons and jails. Institutional residents are based on data from the 2007 American Community Survey (ACS) from table S2601B at http://factfinder.census.gov.

c. For estimates of community residents using SIPP, ADL data were collected for ages 6 and over and IADL data were collected for ages 15 and over; for estimates of institutional residents using ACS, ADL data were collected for those ages 18 and over.

While the need for, use of, and costs associated with LTSS vary across individuals over their lives, the probability of needing LTSS increases with age. Researchers have estimated that over two-thirds of individuals turning age 65 in 2005 will need long-term care before they die; 31%

will not need any care.[4] Thus, as the population ages, the demand for LTSS is expected to increase. In addition, advances in medical care and supportive care are enabling younger persons with disabilities to live longer lives, and requiring the delivery of services and supports for longer periods of time. In particular, increases in the lifespan of individuals with intellectual and developmental disabilities (I/DD) is another factor contributing to the growing demand for community-based residential services as older individuals with I/DD may outlive their family caregivers.[5]

Who Provides Long-Term Services and Supports?

LTSS can be provided in a private home or community-based setting such as an adult day health center. LTSS are also provided in a facility-based or institutional setting such as a nursing facility. *Formal LTSS* refers to services and supports that are provided by paid individuals who are employed by an organization or agency, such as a nursing home or home health care agency, or can be provided by self-employed individuals. In the United States, about 54,900 paid, regulated long-term care services providers served over 7 million individuals in 2012. These providers include an estimated 22,200 residential care communities, 15,700 nursing facilities, 12,200 home health agencies, and 4,800 adult day health centers.[6] With the exception of adult day health centers, the ownership status of most long-term care providers was for-profit (78.7% of home health agencies, 78.4% of residential care communities, and 68.2% of nursing homes). The majority of adult day health centers were non-profit (54.9%).[7] *Informal LTSS* refers to assistance provided by unpaid individuals, such as family members, friends, and neighbors. The vast majority of LTSS is provided by informal caregivers. A 2009 national survey found that 65.7 million individuals in the United States served as an unpaid family caregiver to an adult or a child in the past 12 months.[8]

Formal LTSS is provided by a range of health care workers employed directly by a provider or hired by an individual or family member. These licensed or skilled health care workers include registered or licensed nurses, physical and occupational therapists, and social workers. However, the majority of LTSS is provided by non-licensed providers such as certified nurse assistants (CNAs), home health aides, and personal care aides.[9] The Department of Labor (DOL), Bureau of Labor Statistics (BLS), estimated that there were just over 2 million home health aides and personal care aides in 2012 (the most recent year for which data are available).[10] However, this

[4] Peter Kemper et al., "Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?" *Inquiry* 42, Winter 2005-2006. The definition of long-term care need is based on a moderate level of disability defined as one or more ADLs or four or more IADLs.

[5] David Braddock, Richard Hemp, Mary Rizzolo, et. al, *State of the States in Developmental Disabilities: 2011*, Coleman Institute for Cognitive Disabilities, University of Colorado, 2011; A. M. W. Coppus, *People with Intellectual Disability: What Do We Know About Adulthood and Life Expectancy?* Developmental Disabilities Research Reviews, v. 18, no. 1, 2013.

[6] L. Harris-Kojetin, M Sengupta, E Park-Lee, and R Valverde. *Long-Term Care Services in the United States: 2013 Overview*. National Center for Health Statistics, 2013. The above estimates exclude data for hospices.

[7] Ibid.

[8] National Alliance for Caregiving and AARP, *Cargiving in the U.S. 2009*, November 2009, http://www.caregiving.org/data/Caregiving_in_the_US_2009_full_report.pdf.

[9] Personal care aides are also referred to as personal care attendants and home care aides. Collectively LTSS workers that provide hands-on assistance to individuals with LTSS needs are referred to as "direct care workers."

[10] Bureau of Labor Statistics, Occupational Employment and Wages, January 2014, Department of Labor, data are for home health aides, personal and home care aides, and nursing assistants and orderlies, http://www.bls.gov/ooh/.

estimate likely underestimates the number of home care workers as it does not include self-employed workers. BLS estimates another 1.5 million nursing assistants in 2012, which is an overestimate of the LTSS nursing assistant workforce as this estimate includes individuals who work in acute care hospitals as well as long-term care settings. Between 2012 and 2022 home health aides and personal care aides are projected to be among the top 20 fastest growing occupations both in terms of rate of growth and numerical growth with a combined increase of 1 million new jobs. Nursing assistants are also projected to be among the top 20 fastest growing occupations in terms of numerical growth with over 300,000 new jobs projected over the same period of time.

How Much Do Long-Term Services and Supports Cost?

LTSS vary widely in their intensity and cost, depending on an individual's underlying conditions, the severity of his or her disabilities, the setting in which services are provided, and the caregiving arrangement (i.e., informal versus formal care). The cost of obtaining paid assistance for these services, especially over a long period of time, may far exceed many individuals' financial resources. Moreover, public programs that finance this care, such as Medicaid or Medicare, may not cover all the services and supports an individual may need. Large personal financial liabilities associated with paid LTSS may leave individuals in need of LTSS and their families at financial risk.

For those receiving LTSS at home, the cost for these services can vary depending on the amount and duration of care provided. According to research on the amount of paid LTSS received by adults living at home, those in need of paid personal care services received about 18 hours a week, on average. In 2014, the median cost of homemaker services (e.g., meal preparation, housework) is $19 an hour, whereas the median cost of care provided by a home health aide (e.g., hands-on assistance with personal care needs) is $20 an hour (see **Table 2**). Assuming care is provided 18 hours per week,[11] the median annual cost for homemaker services would be just over $18,000 in 2014, while the median cost of home health aide services would be about $19,000. Those needing more intensive care at home would have higher costs associated with their care. Adult day health centers that provide social and other related support services in a community-based setting for part of the day have a median cost of $65 per day, or almost $17,000 per year in 2014. These estimates are national figures and can vary widely by geographic region. For example, across the United States, hourly rates for home health aide services range between $9 and $39 per hour, and daily rates for adult day health centers range between $12 and $215 per day.

Residential settings that provide housing and services as well as institutional settings that provide room and board tend to have higher annual costs than home care services, on average. Assisted living facilities that provide homemaker services (meals, laundry, or housework) and may provide personal care for those who need assistance with ADLs (but do not yet require constant care provided in a nursing home) have a median cost of over $41,000 annually in 2014. Nursing home care, on the other hand, generally costs more, because it provides assistance 24 hours a day and includes the cost of room and board. In 2014, the median annual cost of nursing home care is

[11] CRS analysis of monthly and annual rates for home health aide and homemaker services assume 18.4 hours of paid personal care per week, on average, based on analysis of national estimates of the number of caregivers and number of hours of care per week based on 2009 data published in L. Feinberg et al., *Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving,* AARP Public Policy Institute, June, 2011.

almost $75,000 for a semi-private room and about $84,000 for a private room.[12] As with estimated costs for home care services, these estimates are national figures and can vary widely by geographic region. For example, across the United States, the monthly rate for a one-bedroom, single occupancy unit in an assisted living facility ranges between $750 and $10,412, while the daily rate in a semi-private room in a nursing home ranges between $104 and $954 per day.

Table 2. Estimated Median Costs for Selected Long-Term Services and Supports (LTSS) Providers, 2014

	Median Hourly Rate	Median Daily Rate	Median Monthly Rate	Median Annual Rate
Nursing Home (Private Room)[a]	—	$240	$7,200	$87,600
Nursing Home (Semi-Private Room)[a]	—	$212	$6,360	$77,380
Assisted Living Facility[b]	—	—	$3,500	$42,000
Home Health Aide (Licensed)[c]	$20	—	$1,472	$19,136
Homemaker Services (Licensed)[d]	$19	—	$1,398	$18,179
Adult Day Health Services[e]	—	$65	$1,300	$16,900

Source: CRS analysis of data from Genworth Financial, *Genworth 2014 Cost of Care Survey: Home Care Providers, Adult Day Health Care Facilities, Assisted Living Facilities and Nursing Homes*, 2014; assumption of 18.4 hours of paid care for Home Health Aide and Homemaker Services based on analysis of national estimates of the number of caregivers and number of hours of care per week based on 2009 data published in L. Feinberg, et al., *Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving,* AARP Public Policy Institute, June, 2011.

a. Nursing Home median monthly and annual rates are based on daily rates, multiplied by 30 and 365 days, respectively.

b. For Assisted Living Facility, this is the median rate for a one-bedroom, single-occupancy unit. Assisted Living Facility median annual rates are based on a monthly rate multiplied by 12 months. These costs exclude entrance fees.

c. For Home Health Aide Services, this is the median rate charged by a non-Medicare certified, licensed agency. Home Health Aide Services median monthly and annual rates are based on 18.4 hours/week multiplied by 4 and 52 weeks, respectively.

d. For Homemaker Services, this is the median rate charged by a non-Medicare certified, licensed agency. Homemaker Services median monthly and annual rates are based on 18.4 hours/week multiplied by 4 and 52 weeks, respectively.

e. Adult Day Health Services median monthly and annual rates are based on 5 days/week multiplied by 4 and 52 weeks, respectively.

Further Reading

For more information about public and private sources of LTSS financing and coverage, see the following CRS reports:

- CRS Report R43483, *Who Pays for Long-Term Services and Supports? A Fact Sheet*, by (name redacted) and (name redacted).

[12] Genworth Financial, *Genworth 2014 Cost of Care Survey: Home Care Providers, Adult Day Health Care Facilities, Assisted Living Facilities and Nursing Homes*, 2014.

- CRS Report R43328, *Medicaid Coverage of Long-Term Services and Supports*, by (name redacted).
- CRS Report R42998, *Medicare Home Health Benefit Primer: Benefit Basics and Issues*, by (name redacted).
- CRS Report R42401, *Medicare Skilled Nursing Facility Primer: Benefit Basics and Issues*, by (name redacted).

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