Overview of Long-Term Services and Supports

What Are Long-Term Services and Supports?
Long-term services and supports (LTSS) refers 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 an individual’s disability or condition results in the need for hands-on assistance or supervision over an extended period of time. An individual’s need for LTSS may change over time as his or her needs or conditions change.

About 14 million adults in the United States are in need of LTSS, and over half (56%) are older adults aged 65 and over. Most are cared for in their own homes with the assistance of informal providers, such as family members or friends.

LTSS is different from acute care services or post-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. In general, post-acute care services are health services provided over a short term, typically after a hospitalization, to assist an individual with recovery from injury or illness and return to as normal a condition as possible. While LTSS may be offered in combination with acute care or post-acute care services, LTSS is not intended to treat or cure a medical condition. In contrast, LTSS provides assistance in maintaining or improving an optimal level of physical functioning and quality of life.

LTSS includes a variety of services and supports that can be provided in either community-based or institutional settings. Examples of community-based LTSS include a home health aide assisting a frail older adult with daily personal care activities such as bathing or dressing, a contractor building a wheelchair ramp onto a home, or an adult day program providing social and other related support services to a cognitively impaired individual. LTSS can also be provided in a community-based residential care setting, such as a group home or assisted living facility (ALF) that provides housing and services such as meals, laundry and housework, and assistance with medication.

LTSS also includes more intensive nursing care, such as nursing care provided to a ventilator-dependent child in a private home or institutional setting. Individuals who have severe physical and/or cognitive impairments may need the 24-hour supervision and convalescent care provided in an institutional setting, such as a nursing home or institution for individuals with intellectual and developmental disabilities. LTSS also includes the use of supports such as special equipment, assistive devices, or technology.

Who Needs Long-Term Services and Supports?
The need for LTSS can affect persons of all ages—children born with disabling conditions, such as intellectual or developmental disabilities; certain working-age adults with inherited or acquired disabling conditions, such as serious mental illness or traumatic brain injury; and older adults 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 self-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.

ADLs 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) may also be 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, performing housework, using a telephone, doing laundry, getting around outside the home, and taking medications.

While the need for, use of, and costs associated with LTSS vary across individuals over their lifespan, the probability of needing LTSS increases with age. It is estimated that more than half (56%) of Americans who survive to age 65 will develop a disability at some point later in life that is serious enough to need LTSS, 12% will need care for less than a year, and 22% will need care for five or more years. 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, requiring the delivery of services and supports for longer periods of time.

Generally, public and private payers of LTSS determine needs-based eligibility for LTSS. For example, publicly financed programs that cover LTSS, such as Medicaid, often use “functional” eligibility criteria (i.e., limitations in ADLs and/or IADLs), as well as “clinical” criteria that include diagnosis of an illness, injury, disability or other medical condition, treatment and medications, and cognitive status, among other conditions (i.e., autism or intellectual disability, serious mental illness, traumatic brain injury).
Under a private long-term care insurance (LTCI) policy, limitations in a specified number of ADLs are usually the basis for triggering benefit eligibility. Specifically, federal law provides federal tax benefits and minimum consumer protection standards for purchasers of “tax-qualified” LTCI policies, as authorized by the Health Insurance Portability and Accountability Act of 1996 (HIPAA, P.L. 104-191; 26 U.S.C. §7702B). HIPAA tax-qualified LTCI products are required to have defined benefit triggers for when the policy begins to pay long-term care benefits. In general, these triggers require policyholders to be certified by a licensed health care practitioner as unable to perform at least two ADLs for a minimum of 90 days or require substantial supervision due to severe cognitive impairment.

Who Provides Paid Long-Term Services and Supports?
The vast majority of LTSS is provided by caregivers, such as family members, friends, and neighbors, who provide uncompensated LTSS. Some public programs may allow caregivers to be compensated to provide care and/or provide resources to further assist caregivers. A national survey published in 2020 estimated that 53 million adults in the United States served as family caregivers to an adult or a child with special needs in the past 12 months.

Paid LTSS is provided by individuals employed by an organization or agency, such as a nursing home or home health care agency, or by independent providers who are hired by an individual or family member. The National Center for Health Statistics estimated that about 69,000 paid, regulated LTSS and post-acute provider organizations served over 9.5 million individuals in 2018. These providers include an estimated 31,400 residential care communities, 15,600 nursing homes, 11,500 home health agencies, 4,700 hospices, 4,200 adult day health centers, 1,200 inpatient rehabilitation facilities, and 400 long-term care hospitals.

Licensed or skilled health care workers that provide LTSS include registered or licensed nurses, physical and occupational therapists, and social workers. However, most LTSS is provided by nonlicensed providers who are generally referred to as direct care workers and include home health aides, personal care aides, and nursing assistants. PHI, a national policy and advocacy organization on the direct care workforce, estimates about 4.8 million direct care workers in 2022. Among those, about 2.8 million worked in home care; 719,000 in residential care homes; 448,000 in nursing homes; and 871,000 in other industries. However, this likely underestimates the number of direct care workers, as it does not include those privately employed by consumers, the so-called “grey market,” which is difficult to measure. Between 2022 and 2032, the Bureau of Labor Statistics estimates that 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 (a 22% increase) and numerical growth, with an increase of 805,000 new jobs. This is faster than the average rate of growth for all occupations at 3%. Nursing assistants are projected to grow by 4%, with a projected increase of 58,000 new nursing assistants over the same time period.

How Much Do Long-Term Services and Supports Cost?
LTSS varies widely in terms of intensity and cost, depending on individuals’ underlying conditions, the severity of their disabilities, the setting in which services are provided, and the caregiving arrangement (i.e., paid care versus uncompensated 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, may not cover all the services and supports an individual may need. Medicare does not cover most long-term care expenses. Large personal financial liabilities associated with paid LTSS can leave individuals in need of LTSS and their families at financial risk.

For those receiving LTSS at home, the cost varies depending on the amount and duration of care provided (see Table 1). Assuming care is provided for 44 hours per week, per industry guidance, the median annual cost for homemaker services was about $59,500 in 2021, while the median cost of home health aide services was over $61,800. Adult day health centers have a median annual cost of $20,300 per year in 2021. These estimates are national figures and can vary widely by geographic region. For example, across the 50 states and the District of Columbia (DC), median daily rates for home health aide services ranged from $122 to $227, and median daily rates for adult day health centers ranged between $35 and $156.

Residential settings that provide housing and services as well as institutional settings tend to have higher annual costs than home care services, on average. Assisted living facilities had a median annual cost of $54,000, while the median annual cost of nursing home care was about $94,900 for a semi-private room and $108,400 for a private room in 2021. As with estimated costs for home care services, these estimates are national figures and can vary widely by geographic region. For example, across states and DC, the median daily rate for a one-bedroom, single occupancy unit in an assisted living facility ranged from $99 to $229; the median daily rate in a private nursing home room ranged from $195 to $1,036.

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<th>Provider Type</th>
<th>Daily Rate</th>
<th>Monthly Rate</th>
<th>Annual Rate</th>
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<td>Home Health Aide</td>
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<tr>
<td>Assisted Living Facility</td>
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<tr>
<td>Adult Day Health Care</td>
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