

Long-Term Care


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What is long-term care?

Long-term care (LTC) is defined as the wide array of medical and social services that are provided over a prolonged period of time to people of all ages with disabilities or chronic illnesses. Such services may include help in performing “activities of daily living” (ADLs)—functions that are related to personal care, such as bathing or showering, dressing, getting in or out of bed or a chair, using the toilet and eating. Long-term care also may include help in performing actions related to independent living, such as preparing meals, managing money, shopping for groceries or personal items, and performing light or heavy housework. LTC services may be needed on a regular or occasional basis, for a few months or a lifetime.

LTC services can be provided in many different settings, such as:

- Institutions—skilled nursing facilities or intermediate care facilities for the mentally retarded;
- Community facilities (assisted living facilities, adult foster homes, residential care facilities, adult day services and senior centers); or
- Private homes. 




Why is long-term care an important issue for state legislators?

The number of older Americans is expected to more than double by 2050, and many elderly people are living into their 80s and 90s. With advancing age comes the likelihood of increased disability, frailty and illness. In addition, medical and scientific advances mean that people born with developmental or other disabilities or who suffer injuries (such as traumatic brain injury) have greatly improved survival rates, but they may need assistance throughout their lives.

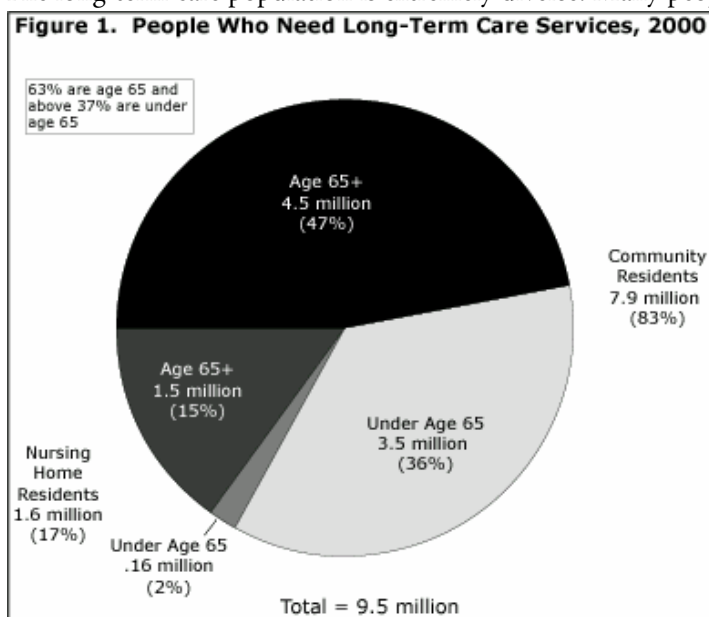
State legislators face two major issues stemming from these demographic pressures: how to ensure that affordable and accessible high-quality LTC services are available to the growing population in need of such services (particularly for low-income people), and how to control their effect on state budgets.

Although it is difficult to contain costs for the growing population of elderly and people with disabilities, state legislators can play a key role in reforming their LTC systems. In particular, many states have been reforming their Medicaid-funded long-term care systems by moving away from costly institutional care, which few people want, toward popular and often less costly home- and community-based services (HCBS). The federal government has been encouraging this trend toward HCBS. It began offering states increased assistance in the form of grant programs (Real Choice Systems Change and System Transformation grants, for example) and flexible LTC funding to stimulate state innovations.

Legislators can foster this process by understanding the available options and learning what has worked in other states. They can ask agency directors to provide information about their state's LTC programs and their costs, populations served, benefits provided, eligibility standards, numbers on waiting lists and available options. 

Who needs long-term care? Who receives long-term care?

The long-term care population is extremely diverse. Many people with developmental or severe physical



disabilities, mental illness and cognitive impairment, as well as the frail elderly, need LTC services—a total of nearly 10 million Americans. Although LTC is typically associated with old age, more than one-third of beneficiaries of LTC services are under age 65. Sixty-three percent of beneficiaries are age 65 and older, and 37 percent are under age 65. More than 400,000 children and 1.1 million adults under age 65 used long-term care services in 2002 (see figure 1).

Medicaid is the largest single payer of long-term care services. Medicaid-eligible people who use long-term care services are among the most disabled and chronically ill of the total Medicaid population. Although they accounted for



only 7 percent of the Medicaid population in 2002, these long-term care users consumed more than half (52 percent) of total Medicaid spending that year.

Moreover, the number of people who need LTC services is expected to increase rapidly during the next several decades. People age 85 and older constitute the fastest growing population in the United States; their numbers are expected to increase from about 4 million in 2005 to almost 21 million by 2050, foreshadowing an ever-expanding need for LTC services.

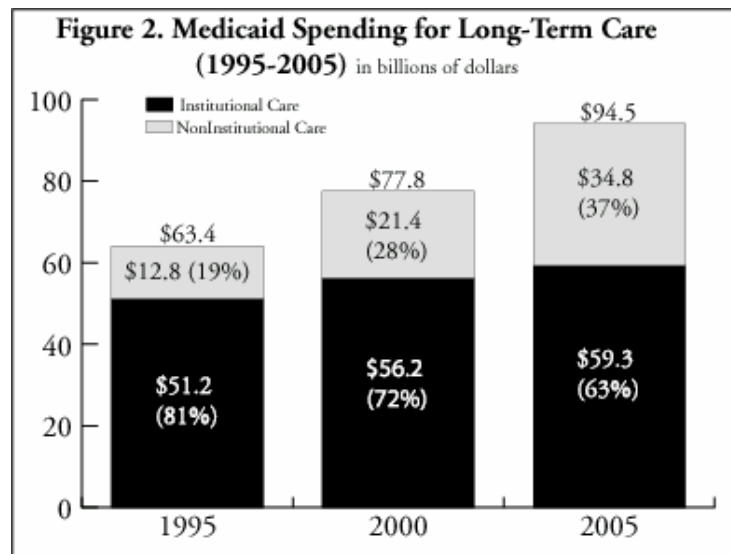
Millions of Americans receive publicly funded LTC services today or are paying for those services themselves while being cared for by family members. However, many other Americans go without needed services because they live alone without family support, lack the financial resources to pay for care, and/or lack information about the community resources that they might use. ¹⁰

How has the demand for long-term care changed in recent years?

A major shift has been occurring in the nation’s long-term care system. In the past, people who needed publicly funded LTC services could look to only two basic sources: the nursing home or intermediate care facilities for the mentally retarded (ICF/MRs). State Medicaid programs are required to pay for nursing home care and home health care for those who qualify under federal and state criteria. However, states may choose the populations and the services they will provide for home- and community-based services funded by Medicaid and/or state general revenues.

With consumers overwhelmingly indicating their preference for home- and community-based care and with evidence that such care is less costly in most cases, state policymakers have been “rebalancing” or redefining their LTC systems. Today, every state has federal waiver programs that allow them to provide a wide range of HCBS services. (The populations eligible for these benefits and the types of services offered vary significantly by state, and waiver programs have capped enrollments.)

As a result, Medicaid spending on institutional care as a proportion of total Medicaid LTC spending had dropped from 90.2 percent in 1987 to 75.8 percent in 1997, and then to 63 percent by 2005. By contrast, home care spending nearly doubled from 10.8 percent in 1987 to 24.0 percent in 1997. By 2005, the proportion of Medicaid spending for home care had risen to 37 percent (see figure 2). (“Home care” under Medicaid consists of home health care, personal care and HCBS waiver programs that give states flexibility in determining the populations covered and services provided.)




Source: Health Policy Institute, Georgetown, July 5, 2006.

If older adults had continued to use nursing homes as they did in 1985, the number of elderly nursing home residents would have totaled almost 2 million in 2004 instead of the actual 1.3 million. Even among

the oldest-old (age 85 and older), use of nursing homes dropped from about 21 percent in 1985 to 13.9 percent in 2004. Experts attribute the decline in nursing home use to the healthier lives of many older Americans today, their continued strong preference to remain in their homes and communities, and the increasing number of alternative services that enable them to live where they choose.

Another major trend has been toward consumer-directed care. In the 1970s, many younger people with disabilities began to challenge the traditional case-managed and agency-operated model of service delivery. The disability rights and independent living movements successfully advocated for a model under which a consumer could hire his or her own aide and direct how and when services were provided.


Today, many publicly funded home care programs allow participants to help draft their care plans, select their personal care assistants (who may be family members), and direct their own services. Most consumers in these programs report greater satisfaction with this model of care and higher quality of life because they have greater control. 

Who provides long-term care? What are the trends in service delivery?

The family has been the backbone of long-term care for decades. About 80 percent of the elderly who need LTC live in their own homes, and about two-thirds of them receive care from families and friends. Less than one-fourth of these individuals supplement that “informal” support with paid help, and only 10 percent receive paid assistance only.

Workers in the LTC system tend to be paraprofessionals, who carry titles such as personal care assistant, home care aide or certified nursing assistant. These “direct care” workers are often paid low wages, receive limited or no benefits, and have high workloads, little training and few opportunities for advancement. These circumstances lead to high turnover in nursing homes, home care agencies and other settings. The result can be inadequate care and poor quality of life for consumers, and high costs and low productivity for providers.

Workforce shortages that already exist in the long-term care system are likely to worsen in coming decades as demand grows, particularly in home and community care. Although the expansion of publicly funded consumer-directed care may ease the situation somewhat, finding answers to LTC workforce issues remains a major concern for state policymakers.

States also are improving consumer access to long-term care services by creating Aging and Disability Resource Centers that coordinate information and assistance. The centers are intended to serve as the entry point to a state’s LTC services and to help people make informed decisions about LTC options. In some states, the centers counsel and refer inquiring residents, regardless of income, to available community services and determine eligibility for publicly funded LTC services. 

Who pays for long-term care?

Although LTC is financed through a combination of public and private resources, the largest public source is the Medicaid program. In 2005, Medicaid paid for almost 49 percent of the total amount spent on

LTC services in the United States. Medicare accounted for more than 20 percent; out-of-pocket spending, 18 percent; and private health and LTC insurance, 7 percent (see table 1).

Table 1. National Spending for Long-Term Care, by Payer, 2005 (in billions)

Payer	Spending for Long-Term Care
Medicaid	\$101.1 (48.9%)
Medicare	42.2 (20.4%)
Out-of-Pocket	37.4 (18.1%)
Private Health and LTC Insurance	14.9 (7.2%)
Other Public and Private	10.9 (5.3%)
Total	\$206.6 (% may not sum due to rounding)

Source: Health Policy Institute, Georgetown University, 2007.

Contrary to popular belief, Medicare and Medicare supplemental insurance will pay only for the cost of some skilled care in approved nursing homes, for a limited period of time and only for expenses

resulting from acute-care episodes rather than for chronic disabilities. Medicare's share of LTC expenditures has increased in recent years, however, as many nursing homes have begun providing more post-hospital rehabilitation services.

Many individuals pay for their own care when they enter a nursing home. However, given the high cost of that care (about \$75,000 annually in 2006), many people deplete their assets and then qualify for Medicaid. More than four-fifths of the elderly who are living in the community and who face a high risk of needing nursing home care do not have enough assets, excluding home equity, to finance a nursing home stay of one year or more. About 63 percent of Medicaid spending on LTC went for institutional services in 2005; a large percentage of this amount went to nursing home care.


Medicaid also pays for HCBS and skilled home health care in all states, and for personal care services in the 35 states that have elected to cover this optional benefit. Assisted living is another key component of state systems. Table 2 illustrates the proportion of various long term care expenditures paid by various funding sources. 

Table 2. National Spending for Nursing Home and Home Care, by Payer, 2005 (in billions)

Payer	Nursing Home Care Spending	Home Care Spending
Medicaid	\$59.0 (45.4%)	\$42.1 (54.8%)
Medicare	21.6 (16.6%)	20.6 (26.9%)
Out-of-Pocket	32.3 (24.9%)	5.1 (6.7%)
Private Insurance	9.1 (7.0%)	5.8 (7.5%)
Other	7.8 (6.0%)	3.1 (4.1%)
Total	\$129.8 billion (% may not sum due to rounding)	\$76.8 billion

Source: Health Policy Institute, Georgetown University, 2007.



What are the most important long-term care financing and service delivery issues that legislators will face during the next five years?

The 1999 Supreme Court *Olmstead* decision (*L.C. & E.W. v. Olmstead*) increased state responsibility to provide HCBS options to people with disabilities who could be served in the community rather than in institutions. Basing its decision on the Americans with Disabilities Act, the Court suggested that states demonstrate that they have a comprehensive, effective working plan for placing qualified people in less restrictive settings, and that they are making efforts to move people on waiting lists to community programs at a reasonable pace.

The *Olmstead* decision has been a major factor in accelerating state efforts to provide community-based services for people with disabilities. Federal initiatives also have played a significant role. Through the Real Choice Systems Change grant program and the Independence Plus Initiative, the federal government is helping states shift resources to community long-term care systems and to increased consumer choice and control. State policymakers must make significant decisions about how to take advantage of these opportunities within the framework of each state's environment for change and the unique needs of its diverse populations.

State legislators will want to consider how best to control the growth of Medicaid spending on LTC while meeting the needs of low-income people with disabilities. At the same time, policymakers may need to address how best to promote personal responsibility and planning for LTC by people with greater means, such as by encouraging the purchase of private LTC insurance.

Less than 10 percent of people age 50 and older own a long-term care insurance policy. Expansion of the market for these policies can be difficult for several reasons. Many people are reluctant to face their potential need for protection against the high costs of long-term care. Some lack awareness and understanding of this product, at least in part because of the variety of policies available, while others may believe they cannot afford the cost when they also need to save for their children's education and their own retirement.

However, recent federal legislation allows states to create a Long-Term Care Partnership program. These programs operated only in California, Connecticut, Indiana and New York until passage of the Deficit Reduction Act opened the concept to other states. Originally funded by the federal government and The Robert Wood Johnson Foundation, the Partnership program allows a person who purchases and uses a qualified long-term care insurance policy to qualify for Medicaid coverage of LTC while retaining assets in the amount of the insurance benefits they have used. Without this coverage, people must divest themselves of—or “spend down”—their assets before qualifying for Medicaid coverage of LTC. The protected assets also would be exempt from Medicaid estate recovery provisions, which require states to collect from an individual's estate the Medicaid funds spent on their LTC services. ¹⁰

What are promising state practices related to long-term care financing and service delivery?

A number of states are testing creative ways to manage their LTC costs while providing alternatives to institutionalization. In October 2005, Vermont implemented its “Choices for Care” program. This approach gives those with disabilities choice and equal access to either nursing homes or HCBS. Financed by a global budget, the program combines Medicaid funding for HCBS waiver programs and nursing home care. The Vermont program is operating under a Medicaid 1115 Research and Demonstration waiver.

Eligible individuals are divided into three groups: highest need, high need and moderate need. Those in the highest need group are entitled to receive care in either a nursing home or in a home or community setting. The high need group, whose clinical needs are not as severe as the first group’s, have no specific entitlement to LTC services but receive services to the degree that funds are available. Those with moderate needs receive preventive and supportive services to help maintain their well-being and independence.

Another innovative state model for rebalancing LTC is Wisconsin’s “Family Care” program, which operates under a combination of 1915(b) and 1915(c) Medicaid waivers. A managed-care pilot program, Family Care combines funds and services from a variety of existing programs. Services are tailored to each enrollee’s needs and preferences, and participants can remain in their homes in most cases and self-direct their services.

The program was launched in five Wisconsin counties. In February 2006, Governor Jim Doyle announced plans to expand the program statewide. Two additional counties began participating in January 2007. Also under its Family Care system, Wisconsin has created Aging and Disability Resource Centers to handle long-term care inquiries.


Texas provides another example of a state that has taken the lead to expand community care. Under the “Money Follows the Person” program, nursing home residents may move out of an institution to community settings if they request it and if community care is appropriate for them. The funds that would have been used for their nursing home care are channeled instead to community care. More than 10,000 individuals had chosen to leave nursing homes under the program by spring 2006. Encouraged by federal grants and by a new federal demonstration program, the Texas example now is being adopted by other states. ■■■

What new financing and service delivery options are available to states?

The Deficit Reduction Act of 2005 (DRA) provides state policymakers with new opportunities—and new challenges—in long-term care. The DRA allows states to offer home- and community-based services as a state plan optional benefit for qualified individuals with incomes below 150 percent of the federal poverty level (FPL). (Under Medicaid HCBS waiver programs, states have been able to cover individuals with incomes up to 300 percent of Supplemental Security Income—about \$22,438 in 2007, compared to \$14,700 under the 150-percent-of-FPL standard.)

The DRA also eliminated a waiver requirement that eligible individuals must be at risk for institutionalization to be eligible for HCBS. However, states are permitted to cap enrollment for the HCBS option, maintain waiting lists and offer the option without providing services statewide. States also may tighten eligibility for nursing home care. State policymakers may need to decide to what degree they wish to limit the state's financial liability and/or to expand the population served by HCBS under these provisions.

Under the "Money Follows the Person" demonstration project, the DRA also provided for an enhanced Medicaid match rate for each person who is moved from an institution to the community during the 12-month demonstration. The state must, however, continue to provide community services after the demonstration, as long as the person remains in Medicaid and is in need of community services.

Another state administrative innovation that affects the financing of and access to LTC is global budgeting, which involves the development of a single budget appropriation to cover both institutional services and HCBS. Generally, a state legislature will set the budget figure by adopting certain assumptions about the proportion of people who will receive services in various settings; states may cap the caseload in order to control costs. After the long-term care budget is appropriated, the executive branch manages it as one allocation that can be spent at the individual level for either community supports or institutional care. 



Glossary

Activities of daily living (ADLs). Eating, bathing, dressing, transferring to and from a bed or a chair, and using the toilet. People who need LTC services generally have one or more limitations in activities of daily living.

Global budgeting for LTC. A system for consolidating institutional and community service funds in one budget in one state agency, thus allowing the allocation of funds for the most appropriate services for each person with disabilities.

Home- and community-based services (HCBS). Long-term care supports and services—such as skilled nursing, personal care, case management, homemaker service, home modifications, adult day services and respite care—to help people remain in their homes or in community settings, such as assisted living and residential care facilities.

Institutional Care. This term covers skilled nursing facilities (nursing homes) for the frail elderly and others, and intermediate care facilities for the mentally retarded.

Long-term care insurance. These private policies address some of the gaps and limitations found in both Medicare and Medicaid LTC coverage. Such policies pay a set amount over a specified period for each day a policyholder uses a covered service; they typically are purchased by individuals who wish to protect their assets from potentially devastating nursing home or home health costs. Policies vary considerably in terms of coverage, premiums charged, the amount payable per day, length of the benefits, and exclusions of certain injuries or illnesses from coverage.

Rebalancing LTC systems. The concept of shifting a state's long-term care system from an emphasis on institutionalization as the setting for care of most people with disabilities, toward the expansion of home- and community-based services.

Written by independent consultant Barbara Coleman.

NCSL Contact: Donna Folkemer
Group Director, Forum for State Health Policy Leadership
National Conference of State Legislatures
(202) 624-8171
donna.folkemer@ncsl.org

Other Sources

The **Administration on Aging** has an excellent web page that has a wide range of resources on LTC programs, information about the aging network throughout the country (particularly Area Agencies on Aging), and statistics on the elderly, people with disabilities and long-term care at <http://www.aoa.gov>.

The U.S. **Centers for Medicare and Medicaid Services (CMS)** has a wealth of information about HCBS long-term care. Highlights include a collection of links to policies, state profiles and best practices, and data sources on Medicaid LTC services. Go to <http://www.cms.hhs.gov>.

The **Office of Disability, Aging and Long-Term Care Policy** has an extensive collection of reports, research and data sets on its web site: http://aspe.hhs.gov/_office_specific/daltcp.cfm.

The **Community Living Exchange Collaborative and the Home and Community-Based Services Resource Network** has a useful and extensive array of links, which are regularly updated. Research reports, state best practices, HCBS conference materials, federal grant reports and other LTC data are at <http://www.hcbs.org>.

Other good sources of information include **The Robert Wood Johnson Foundation** at <http://www.rwjf.org>; the Paraprofessional Health Care Institute at the **Henry J. Kaiser Family Foundation** at <http://www.kff.org>; and the **Family Caregiver Alliance** at <http://www.caregiver.org>.

