



THE BASICS

National Spending for Long-Term Services and Supports (LTSS), 2011

FEBRUARY 1, 2013

Long-term services and supports (LTSS)¹ for the elderly and younger populations with disabilities are a significant component of national health care spending. In 2011, spending for these services was \$210.9 billion (9.3 percent of all U.S. personal health care spending), almost two-thirds paid by the federal-state Medicaid program. Concern about the financing and delivery of LTSS is a recurring issue among policymakers. The already substantial public role in LTSS, which presages spending increases as the “baby boom” population ages, along with the potentially catastrophic costs of care to individuals and families, will likely lead policymakers to continue to review these issues in coming years.

The American Taxpayer Relief Act of 2012 (P. L. 112-240), signed by President Obama on January 2, 2013, included a provision to create a “Commission on Long-Term Care.” The Commission is charged with developing a plan to establish, implement, and finance “a comprehensive, coordinated and high quality system that ensures the availability of long-term services and supports” for people who require assistance and for those who want to plan for their future LTSS needs. The law required that the Commission report a plan within 6 months of appointment of its members.

LTSS DEFINED

LTSS refer to a broad range of supportive services needed by people who have limitations in their capacity for self-care because of a physical, cognitive, or mental disability or condition.² A person’s need for LTSS is generally measured, irrespective of age and diagnosis, by functional status, that is, his or her inability to perform basic activities necessary to live independently, and by the need for assistance from another person to carry out these activities.³ LTSS

National Health Policy Forum

2131 K Street, NW
Suite 500
Washington, DC 20037

T 202/872-1390
F 202/862-9837
E nhpf@gwu.edu
www.nhpf.org

exclude medical and nursing services that are needed to manage the underlying health conditions that lead to frailty or disability.

People of all ages may need LTSS: the elderly with physical disabilities or cognitive impairments, such as Alzheimer's disease; working-age adults and children with disabling conditions. Services may be provided in one's home and/or community, for example, through home care and adult day care programs; in residential settings, such as assisted living facilities or board and care homes; or in institutions, such as nursing homes. The intensity and cost of services vary widely, depending on an individual's functional and health status, the severity of his or her disabilities, and the location in which services are provided.

About 11 million adults age 18 and older, almost 5 percent of the total U.S. adult population, receive LTSS. Of those 18 and older, the majority of adults receiving LTSS are 65 years and older (57 percent), but a substantial proportion are adults between the ages of 18 and 64 (43 percent).⁴ The risk of needing LTSS increases with age. One study estimated that, on average, people turning age 65 in 2005 would have needed LTSS for three years. However, it found that the use of services among individuals varied; one-fifth were estimated to have needed care for more than five years and almost one-third to have needed none. Many older people receive help from family and other informal caregivers in their own homes and may not incur large out-of-pocket expenses. However, for a small proportion of people, paying for LTSS can be a significant burden. The study estimated that about 6 percent of people turning age 65 in 2005 were expected to incur out-of-pocket LTSS expenses of \$100,000 or more over their remaining lifetimes, and about 12 percent to incur expenses from \$25,000 to \$100,000.⁵

In 2012, the average annual cost for nursing home care was \$81,030 for a semi-private room and \$90,520 for a private room. The base rate for assisted living communities was almost \$42,600. For those requiring assistance at home, especially daily or 24-hour assistance, costs may also be high if family support is limited or unavailable. In 2012, the average national hourly private pay rate for home health aides was \$21 and for homemaker/companions was \$20. The average daily rate for adult day care services was \$70. Rates for each service vary widely by geographic region and payment source and may be higher when extra services are

provided to individuals with greater care needs, such as those with Alzheimer's disease or other forms of dementia.⁶

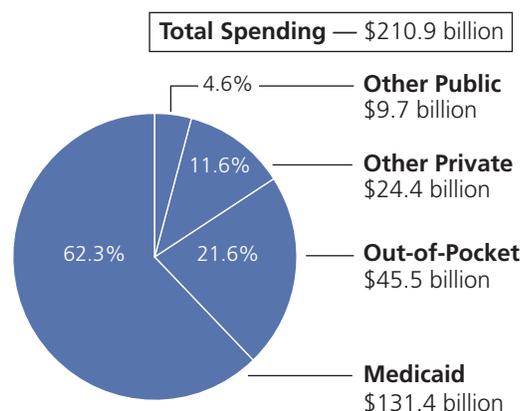
Paying for LTSS can exhaust the resources of people with disabilities and their families and may lead to Medicaid eligibility. But Medicaid coverage for LTSS is limited to people who meet strict income and asset tests and functional need criteria. All states provide Medicaid-financed nursing home care; states vary widely in their coverage of home- and community-based services (HCBS), such as home care, personal care, and adult day care.

LTSS spending was \$210.9 billion in 2011, representing 9.3 percent of all personal health care spending (\$2.3 trillion) (Figure 1). Spending for nursing homes and other institutions⁷ was the largest share—almost two-thirds (61.4 percent)—of all LTSS spending.⁸ The remainder was for home health and other HCBS.

Medicaid is the dominant source of payment for LTSS, followed by out-of-pocket payments by individuals and families. Of all U.S. spending on LTSS, the federal-state Medicaid program is the principal payer. In 2011, Medicaid paid for 62.3 percent (\$131.4 billion) of all LTSS spending. Out-of-pocket spending by individuals and families accounted for about 21.6 percent (\$45.5 billion) of spending. Private insurance and other private and public sources paid the balance (Figure 1).

Medicare plays no role in financing LTSS. Medicare is intended to cover acute and post-acute medical care for people age 65 and older and for younger populations who qualify for Social Security because of disability. The program was not designed to cover LTSS. Medicare covers skilled nursing facility (SNF) care following a hospital stay of at least three consecutive days for those who require daily skilled nursing and/or rehabilitation services for up to 100 days of care. Medicare also pays for medically necessary home health services; part-time or intermittent skilled nursing care; or physical, speech, or occupational therapy for homebound beneficiaries. It does not cover home care services for those who need sustained assistance over time as a result of a physical or cognitive impairment, or frailty. For these reasons, Medicare is not included in the spending amounts presented in this publication.

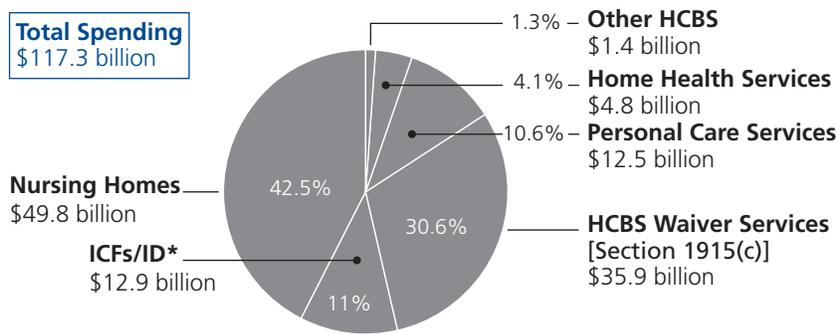
FIGURE 1
LTSS Expenditures by Source, 2011



Note: Totals do not add due to rounding. "Medicaid" includes spending for nursing homes and continuing care retirement communities (including both hospital-based and freestanding facilities), home health care services (including both hospital-based and freestanding facilities), intermediate care facilities for people with intellectual disabilities (ICFs/IDs), home- and community-based services (HCBS) waiver programs, and Children's Health Insurance (CHIP) program spending for nursing homes and home health services. "Other private" includes private long-term care insurance, other health insurance, and other private spending for nursing homes and home health services. "Other public" includes Department of Veterans Affairs, state and local programs and general assistance spending for nursing homes and home health services, and other federal programs for home health services (pre-existing condition insurance plans). "Out-of-pocket" spending includes deductibles, copayments, and any amounts not covered by health insurance for nursing home and home health services. Represents expenditures collected in the National Health Expenditures Accounts (NHEA). Some spending for LTSS—in facilities where social assistance rather than medical care is their primary line of business—is not captured in the NHEA; for example, homes for the elderly and other residential care such as assisted living facility services. Excludes Medicare spending (see text). With the exception of Medicaid coverage of ICFs/ID, excludes other public and private spending for residential intellectual and developmental disability facilities. Excludes the imputed value of family and other non-paid caregiving. Estimates may differ from those published elsewhere due to variation in amounts defined as LTSS.

Source: Prepared by the National Health Policy Forum based on published and unpublished data in the National Health Care Expenditure Accounts provided by the Office of the Actuary, Centers for Medicare & Medicaid Services. See Micah Hartman et al., "National Health Spending in 2011: Overall Growth Remains Low, But Some Payers and Services Show Signs of Acceleration," Health Affairs, 32, no. 1 (January 2013): pp. 87–99, available at <http://content.healthaffairs.org/content/32/1/87.full.pdf+html>.

FIGURE 2
Medicaid LTSS Spending by Service, FY 2010 (Preliminary Estimates)



* Intermediate care facilities for people with intellectual disabilities also known as ICFs/MR.

Note: Excludes certain spending for LTSS managed care. Includes upper payment limit programs or provider taxes in some states. Percent does not total due to rounding. Total Medicaid LTSS spending differs from that in Figure 3 due to differences in fiscal and calendar year data, and period covered.

Source: Steve Eiken et al., "Medicaid Expenditures for Long-Term Services and Supports: 2011 Update," table 1, Thomson Reuters, October 31, 2011, available at www.hcbs.org/files/208/1039/2011LTSSExpenditures-final.pdf, which was based on CMS 64 data as reported by states.

Payments for LTSS represented almost one-third of all Medicaid spending; slightly more than half of Medicaid LTSS spending was for institutional care with the balance for a wide range of home and community-based services. In fiscal year (FY) 2010, LTSS (nursing homes, intermediate care facilities for people with developmental disabilities [known as ICFs/ID or ICFs/MR], services provided through the section 1915(c) HCBS waiver program,⁹ home health, personal care services, and other HCBS) accounted for 30.8 percent of total Medicaid expenditures.¹⁰

Of all Medicaid LTSS spending, payments for nursing homes and ICFs/ID represented over 53 percent. Spending for HCBS made up the balance, primarily through Section 1915(c) waiver programs (Figure 2).

In recent years Medicaid spending for HCBS has grown considerably, as has the number of people served. A number of federal and state policy initiatives have emphasized greater use of home and community-based services, which most people prefer over institutional services. As a result, Medicaid spending for LTSS has gradually shifted toward HCBS over the period FY 1997 to FY 2010. In FY 2010, about 47 percent of Medicaid LTSS spending was for HCBS, compared with 24 percent in FY 1997 (Figure 3, next page).

Medicaid supported HCBS for 3.3 million people in 2009, an increase of almost 60 percent since 2000. This growth has been driven primarily by increases in the number of people served by

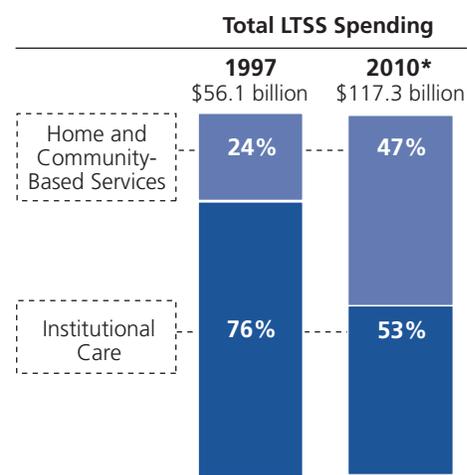
Medicaid's HCBS waiver programs. Despite spending and participant growth overall, many states have waiting lists for these waiver programs. In 2011, 38 states reported almost 512,000 people on waiting lists for home and community-based waiver services, a 19 percent increase over 2010. The average time people spent on waiting lists was more than two years, with wide variations among populations to be served and type of service.¹¹

Even though some states have made strides in promoting HCBS, spending patterns vary widely among states. For example, in FY 2010, spending on HCBS was 76 percent of all Medicaid LTSS spending in Oregon and 24 percent of all Medicaid LTSS spending in Mississippi. Also, spending patterns differ by population group: proportionately less is spent on HCBS for the elderly and younger adults with physical disabilities than for people with intellectual disabilities.¹²

Private long-term care (LTC) insurance plays a small role in financing. (See endnote 1 regarding terminology on long-term care.) Relatively few people have purchased private LTC insurance. About 6 to 7 million LTC insurance policies are in force.¹³

Substantial LTSS assistance is provided informally by family and friends. Despite the significant public commitment to financing LTSS, primarily through Medicaid, most care received by people with disabilities is provided by family and friends who provide care without compensation. As a way to demonstrate the economic value of caregiving, various studies have estimated the imputed "cost" of informal care ranging from tens to hundreds of billions of dollars. For example, the Congressional Budget Office estimated that the value of informal care for the elderly in 2004 exceeded the amount of Medicaid LTSS spending. Others have estimated the imputed value of family caregiving.¹⁴ (The estimated value of informal care is not included in Figure 1.) Regardless of the dollar amount assigned to family caregiving, public programs are unlikely to assume financial or programmatic responsibility for the types, range, and amount of care provided by family caregivers. (For more information, see "Family Caregivers: The Primary Providers of Assistance to People with Functional Limitations and Chronic Impairments," Background Paper No. 84, January 11, 2013, available at www.nhpf.org/library/details.cfm/2900.) Many policymakers are concerned about the impact that the aging of the baby boom population and increasing longevity of older adults

FIGURE 3
Medicaid Expenditures for LTSS, FY 1997 and FY 2010



* Preliminary estimates.

Note: Data for fiscal years 1997 and 2010 for institutional care include spending for nursing facilities and ICFs/ID; they do not include spending for care in mental health facilities. Data for FY 1997 for HCBS include spending for home health, personal care, and HCBS Section 1915(c) waivers. Data for FY 2010 for HCBS include spending under Sections 1915(a), 1915(c) waivers, 1915(i), 1915(j), and 1115 of the Social Security Act, and spending for home health, personal care, the Program for All-inclusive Care of the Elderly (PACE), and private duty nursing. Figure excludes certain spending for managed care; includes upper payment limit programs or provider taxes in some states.

Source: Prepared by the National Health Policy Forum based on FY 1997 data in Steve Eiken et al., "Medicaid Long-Term Care Expenditures in FY 2009," figure 1, Thomson Reuters, August 17, 2010, available at www.hcbs.org/files/193/9639/2009LTCExpenditures.pdf, and in Steve Eiken et al., "Medicaid Expenditures for Long-Term Services and Supports: 2011 Update," Thomson Reuters, October 31, 2011, available at www.hcbs.org/files/208/10395/2011LTSSExpenditures-final.pdf.

and younger persons with disabilities will have on the ability of families to assume and/or sustain caregiving roles in the future.

ENDNOTES

1. In recent years, terminology referring to the services and infrastructure to help frail older people and younger people with disabilities remain independent has been changing. Long-term services and supports (LTSS), rather than long-term care (LTC), is a term that has gained wider use and appears to be more descriptive of services people with disabilities need in their daily lives. The term is used in P.L. 111-148, the Patient Protection and Affordable Care Act of 2010 (ACA), to refer to a range of supportive services for these populations. We have chosen to use LTSS in this publication. Long-term care is used when the term applies in a specific case, such as long-term care insurance policies.
2. Some of the narrative for this section was adapted from Carol O'Shaughnessy *et al.*, "Long-Term Care: Consumers, Providers and Payers," Congressional Research Service, Report to Congress, order code RL33919, March 15, 2007, available to congressional staff upon request.
3. The need for LTSS is generally measured by the presence of limitations in a person's ability to perform activities of daily living (ADLs), or 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, called instrumental activities of daily living (IADLs), measures a person's ability to live independently at home. 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. Children who need LTSS are those who cannot perform age-appropriate activities, such as walking, or other age-appropriate self-care activities. Data on the number of children who need or receive LTSS are outside the scope of this report.
4. H. Stephen Kaye, Charlene Harrington, and Mitchell P. LaPlante, "Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?" *Health Affairs*, 29, no. 1 (January 2010): pp. 11–21; available at <http://content.healthaffairs.org/cgi/reprint/29/1/11>. Estimates of the number of people who receive LTSS vary depending on how need is defined, for example, if a person has limitations in a certain number of ADLs and/or IADLs, has difficulty with certain activities, needs the help of another person in performing the activity, or needs the help of assistive technology. The estimate of about 11 million people cited in this publication use the Kaye *et al.* tabulations for the number of adults age 18 and over living in the community who receive ADL/IADL help in the 2007 National Health Interview Survey (NHIS), and the number of nursing home residents in the 2004 National Nursing Home Survey (NNHS). Not included in the estimate are residents in non-nursing home residential care facilities, such as assisted living and board and care homes. The 2010 National Survey of

Residential Care Facilities conducted by the U.S. Department of Health and Human Services found that 733,300 people were residents of residential care facilities for each day in 2010. For estimates of the number of these facilities and residents, see Christine Caffrey *et al.*, “Residents Living in Residential Care Facilities: United States, 2010.” NCHS Data Brief, No. 91, April 2012, available at www.cdc.gov/nchs/data/databriefs/db91.pdf, and Eunice Park-Lee *et al.*, “Residential Care Facilities: A Key Sector in the Spectrum of Long-Term Care Providers in the United States,” NCHS Data Brief, No. 78, December 2011, available at www.cdc.gov/nchs/data/databriefs/db78.pdf. Other references on residential care facilities include: Administration on Aging, “2010 National Ombudsman Reporting System Data Tables,” table A-1, available at www.aoa.gov/AoARoot/AoA_Programs/Elder_Rights/Ombudsman/National_State_Data/2010/Index.aspx.

5. Peter Kemper, Harriet L. Komisar, and Lisa Alexih, “Long-Term Care Over an Uncertain Future: What Can Current Retirees Expect?” *Inquiry*, 42, no. 4 (Winter 2005–2006): pp. 335–350. Authors cited dollars in present value amounts.
6. MetLife Mature Market Institute and LifePlans, Inc., “The Market Survey of Long-Term Care Costs,” November 2012, available at www.metlife.com/assets/cao/mmi/publications/studies/2012/studies/mmi-2012-market-survey-long-term-care-costs.pdf. The base rate for assisted living facilities refers to an average of assisted living facility costs for a package of services that typically include room and board, at least two meals a day, housekeeping, and some personal assistance. Base rates may be higher or lower depending on the number and types of services offered. Amounts cited for home health aides and homemaker/companions are national hourly private pay rate averages obtained from licensed agencies that employ these workers (and in some cases for homemaker/companions from unlicensed agencies). Averages do not indicate what workers actually earn after agency administration costs. The U.S. Department of Labor, Bureau of Labor Statistics (DoL/BLS) reports that the average national employee compensation per hour for home health aides was \$10.49 in May 2011. See U.S. Department of Labor, Bureau of Labor Statistics, “May 2011 National Occupational Employment and Wage Estimates,” updated March 29, 2012, available at www.bls.gov/oes/current/oes_nat.htm under “Healthcare Support Occupations.”
7. “Other institutions” refers to spending for care in intermediate care facilities for people with intellectual disabilities paid by Medicaid and spending for care in continuing care retirement communities (CCRCs).
8. This calculation includes nursing home and CCRC spending paid by Medicaid, the Children’s Health Insurance Program (CHIP) other public sources, out-of-pocket, other private sources, and intermediate care facilities for people with intellectual disabilities, known as ICFs/ID, paid by Medicaid. See notes for Figure 1.
9. Under Section 1915(c) of the Social Security Act, known as the Medicaid home and community-based services waiver authority, states may provide a wide range of home and community-based services, including case management, home care, personal care, adult day care, habilitation, assistive technologies, and respite care for caregivers, among others. States

may limit the number of people to be served, the type of services to be offered, and the geographic area where services are to be provided. To be eligible for Section 1915(c) services, people must meet the state's level-of-care criteria for institutional care in addition to income and assets eligibility requirements.

10. Steve Eiken *et al.*, "Medicaid Expenditures for Long-Term Services and Supports: 2011 Update," Thomson Reuters, October 31, 2011, available at www.hcbs.org/files/208/10395/2011LTSSExpenditures-final.pdf. For the list of home and community-based services included in this calculation, see the footnote in Figure 3.
11. Terence Ng *et al.*, "Medicaid Home and Community-Based Services Programs: 2009 Data Update," Kaiser Commission on Medicaid and the Uninsured, December 2012, available at www.kff.org/medicaid/upload/7720-06.pdf.
12. Steve Eiken *et al.*, "Medicaid Expenditures for Long-Term Services and Supports: 2011 Update."
13. Marc A. Cohen, "Long-Term Care Insurance: Are Consumers Protected for the Long-Term?" testimony before the Committee on Energy and Commerce, U.S. House of Representatives, Subcommittee on Oversight and Investigation, July 24, 2008, available at www.gpo.gov/fdsys/pkg/CHRG-110hhrg58423/html/CHRG-110hhrg58423.htm. See also the National Health Policy Forum's April 15, 2011 Forum Session, "Private Long-Term Care Insurance: Where Is the Market Heading?" available at www.nhpf.org/library/details.cfm/2855.
14. Congressional Budget Office, "Financing Long-Term Care for the Elderly," April 2004; available at www.cbo.gov/sites/default/files/cbofiles/ftpdocs/54xx/doc5400/04-26-longtermcare.pdf. Estimates for the number of informal caregivers and the economic value of their contributions vary widely, depending on the number of caregivers counted, the ages and characteristics of the population being cared for, and the differences in methods used to impute the hourly rates for care provided. For another analysis, see Lynn Feinberg *et al.*, "Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving," AARP Public Policy Institute, July 2011, available at <http://assets.aarp.org/rgcenter/ppi/lc/i51-caregiving.pdf>.