



THE BASICS

National Spending for Long-Term Services and Supports (LTSS), 2012

MARCH 27, 2014

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 2012, spending for these services was \$219.9 billion (9.3 percent of all U.S. personal health care spending), almost two-thirds of which was paid by the federal-state Medicaid program.

Concern about the financing and delivery of LTSS is a recurrent issue among policymakers. Many point to the potential effects that the aging of the baby boom population and the increasing longevity of older adults and younger persons with disabilities will have both on the ability of families to assume and/or sustain caregiving roles in the future and on public programs, primarily Medicaid. The most recent congressional action was a provision in the American Taxpayer Relief Act of 2012 (P.L. 112-240), signed by President Obama on January 2, 2013, that included authority for the creation of a “Commission on Long-Term Care.” The Commission issued its report² on September 30, 2013, which contained recommendations in two of three major areas: service delivery and workforce. In the third major area, financing, Commission members did not reach agreement and therefore did not issue any recommendations.³ The already substantial public role in LTSS and potentially catastrophic costs of care to individuals and families will likely lead policymakers to continue to review these issues in coming years. How to improve LTSS financing across multiple populations remains a difficult public policy issue.

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

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a physical, cognitive, or mental disability or condition. A person's need for LTSS is generally measured, irrespective of age and diagnosis, by functional status through measurement of 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.⁴ LTSS 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, or 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 disability, and the setting 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).⁵ 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. But 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. 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 \$100,000.⁶ Other research has shown that the majority of older people receive help from family and other informal caregivers in their own homes and may not incur large out-of-pocket expenses.

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.

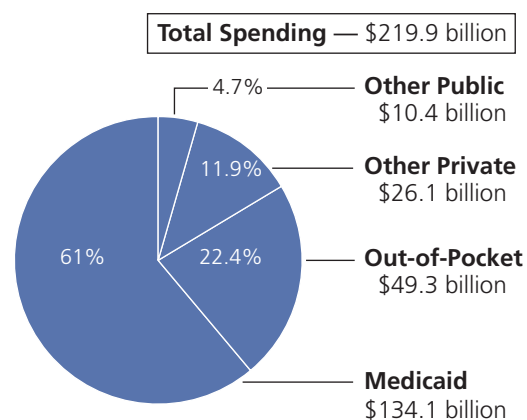
For those requiring assistance at home, especially daily or 24-hour assistance, costs may also be high if family support is limited or unavailable. In 2012, the average national hourly private pay rate for home health aides was \$21 and for homemaker/companions was \$20. The average daily rate for adult 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.⁷

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 \$219.9 billion in 2012, representing 9.3 percent of all personal health care spending (\$2.4 trillion). Medicaid is the dominant source of payment for LTSS, followed by out-of-pocket payments by individuals and families. In 2012, Medicaid paid for 61 percent (\$134.1 billion) of all LTSS spending. Out-of-pocket spending by individuals and families accounted for about 22.4 percent (\$49.3 billion) of spending. Private insurance and other private and public sources paid the balance (Figure 1).⁸ Of all LTSS spending, almost two-thirds (61.3 percent) was for nursing homes and other institutions.⁹ The remainder was for home health care and other HCBS.

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 people 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

FIGURE 1
LTSS Expenditures by Source, 2012



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 the primary line of business—is not captured in the NHEA; for example, homes for the elderly and other residential care. 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 NHEA provided by the Office of the Actuary, Centers for Medicare & Medicaid Services. See Anne B. Martin et al., "National Health Spending In 2012: Rate Of Health Spending Growth Remained Low For The Fourth Consecutive Year," Health Affairs, 33, no. 1, (January 2014): pp. 67–77, <http://content.healthaffairs.org/content/33/1/67.full.pdf+html>.

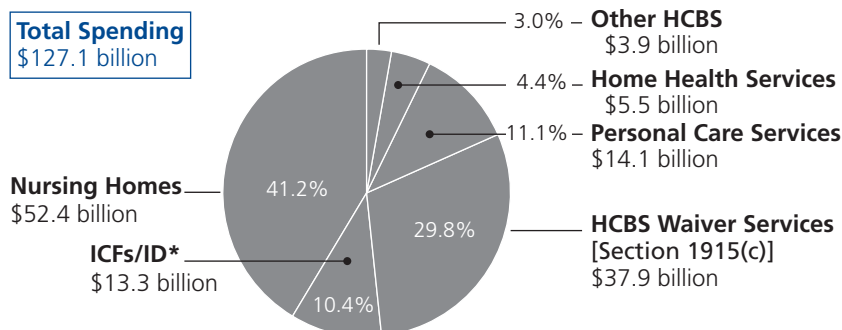
occupational therapy for homebound beneficiaries. It does not cover home care services for those who need sustained assistance over time as a result of frailty or a physical or cognitive impairment. For these reasons, Medicare is not included in the spending amounts presented in this publication.

A substantial portion of Medicaid spending is for LTSS. In fiscal year (FY) 2011, payments for LTSS represented almost one-third of all Medicaid spending (\$127.1 billion out of total Medicaid spending of \$410.9 billion). Of total Medicaid LTSS spending, about 52 percent (\$65.7 billion) was for nursing facility care and care in intermediate care facilities for people with developmental disabilities [known as ICFs/ID or ICFs/MR]), and about 48 percent (\$61.4 billion) was for a wide range of home- and community-based services, primarily section 1915(c) waiver programs,¹⁰ as well as personal care and home health services (Figure 2).¹¹

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 to institutional services. As a result, Medicaid spending for LTSS has gradually shifted toward HCBS over the period FY 1997 to FY 2011 (Figure 3, next page).

Medicaid supported HCBS for 3.2 million people in 2010, an increase of more than 50 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

FIGURE 2
Medicaid LTSS Spending
by Service, FY 2011



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

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 1 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 in 2011,” revised October 2013, Mathematica Policy Research, Inc. and Truven Analytics, for the Centers for Medicare & Medicaid Services, www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Downloads/LTSS-Expenditure-Narr-2011.pdf.

participant growth overall, many states have waiting lists for these programs. In 2012, 39 states reported that there were about 524,000 people on waiting lists for home- and community-based waiver services. 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, and across states.¹²

Even though some states have made progress in shifting service delivery and spending from institutions to home- and community-based settings, spending patterns for HCBS vary widely among the states. For example, in FY 2011, spending on HCBS was 92 percent of all Medicaid LTSS spending in New Mexico 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.¹³

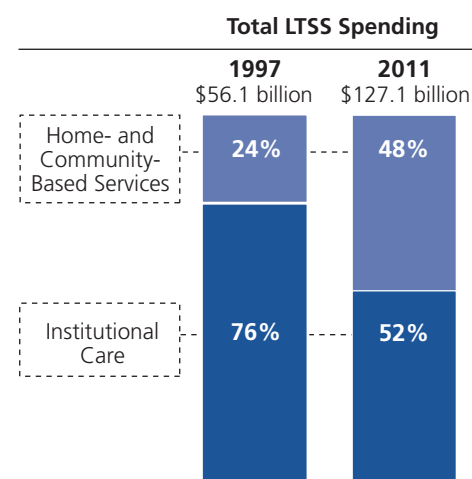
Private long-term care (LTC) insurance plays a small role in financing. (See endnote 1 regarding terminology on long-term care.) Relatively few people have purchased private LTC insurance. About 7.7 million LTC insurance policies were in force as of 2011.¹⁴

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. The Congressional Budget Office estimated that the value of informal care for the elderly in 2011 was about \$234 billion.¹⁵ (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.¹⁶

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

FIGURE 3
Medicaid Expenditures for LTSS, FY 1997 and FY 2011



Note: Data for fiscal years 1997 and 2011 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 home- and community-based services (HCBS) include spending for home health, personal care, and HCBS Section 1915(c) waivers. Data for FY 2011 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, and Money Follows the Person Demonstration. 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, Thompson Reuters, August 17, 2010, available at www.hcbs.org/files/193/9639/2009LTSSExpenditures.pdf, and in Steve Eiken et al., “Medicaid Expenditures for Long-Term Services and Supports in 2011,” revised October 2013, Mathematica Policy Research, Inc., and Truven Analytics, for the Centers for Medicare & Medicaid Services, www.medicare.gov/Medicare-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Downloads/LTSS-Expenditure-Narr-2011.pdf.

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. Commission on Long-Term Care, "Commission on Long-Term Care," December 30, 2013, <http://tcccommission.org/>.
3. For summary information on Long-Term Care Commission, see "The Commission on Long-Term Care, The Basics," National Health Policy Forum, October 17, 2013, www.nhpf.org/library/details.cfm/2938.
4. 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.
5. 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, <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," National Center for Health Statistics, NCHS Data Brief No. 91, April 2012, 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," National Center for Health Statistics, NCHS Data Brief No. 78, December 2011, 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, www.aoa.gov/AoA-Root/AoA_Programs/Elder_Rights/Ombudsman/National_State_Data/2010/Index.aspx.

6. Peter Kemper, Harriet L. Komisar, and Lisa Alecxih, “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 that were estimated at the time of the study.
7. MetLife Mature Market Institute and LifePlans, Inc., “The Market Survey of Long-Term Care Costs,” November 2012, 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 homemakers/companions are national hourly private pay rate averages obtained from licensed agencies that employ these workers (and in some cases for homemakers/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, www.bls.gov/oes/current/oes_nat.htm under “Healthcare Support Occupations.”
8. Based on published and unpublished data in the National Health Expenditures Accounts (NHEA) provided by the Office of the Actuary, Centers for Medicare & Medicaid Services. See Anne B. Martin *et al.*, “National Health Spending In 2012: Rate Of Health Spending Growth Remained Low For The Fourth Consecutive Year,” *Health Affairs*, 33, No. 1, (January 2014): pp. 67–77, <http://content.healthaffairs.org/content/33/1/67.full.pdf+html>.
9. “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). 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.
10. 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.

11. Steve Eiken *et al.*, “Medicaid Expenditures for Long-Term Services and Supports in 2011,” revised October 2013, Mathematica Policy Research, Inc. and Truven Analytics, for the Centers for Medicare & Medicaid Services, www.medicare.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Downloads/LTSS-Expenditure-Narr-2011.pdf.
12. Terence Ng and Charlene Harrington, University of California, San Francisco, and MaryBeth Musumeci and Erica L. Reaves, Kaiser Family Foundation, “Medicaid Home and Community-Based Services Programs: A 2010 Data Update,” March 2014, <http://kff.org/medicaid/report/medicaid-home-and-community-based-service-programs/>.
13. Steve Eiken *et al.*, “Medicaid Expenditures for Long-Term Services and Supports in 2011.”
14. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, “Long-Term Care Insurance,” ASPE Research Brief, June 2012, <http://aspe.hhs.gov/daltcp/reports/2012/ltcinsRB.pdf>. Data compiled November 2, 2011, for ASPE by Eileen Tell at Univita Health, based on LIMRA reports and other Univita data.
15. Congressional Budget Office, “Rising Demand for Long-Term Services and Supports for Elderly People,” June 2013, www.cbo.gov/sites/default/files/cbofiles/attachments/44363-LTC.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, <http://assets.aarp.org/rgcenter/ppi/ltc/i51-caregiving.pdf>.
16. 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, www.nhpf.org/library/details.cfm/2900.