



## THE BASICS

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

MARCH 15, 2011

Long-term services and supports (LTSS)<sup>1</sup> for the elderly and younger populations with disabilities are a significant component of national health care spending. In 2009, spending for these services was \$203.2 billion (almost 10 percent of all U.S. personal health care spending), most of it 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 rapid spending increases as the “baby boom” population ages, along with the potentially enormous costs of care to individuals and families, may lead policymakers to revisit these issues in coming years.

#### 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.<sup>2</sup> 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.<sup>3</sup> 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; working-age adults with inherited or acquired disabling conditions; and children born 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;

**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](mailto:nhpf@gwu.edu)  
[www.nhpf.org](http://www.nhpf.org)

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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).<sup>4</sup> The risk of needing LTSS increases with age. One study estimated that, on average, people turning age 65 in 2005 will need LTSS for three years, although the use of services varies widely among individuals. 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. About 6 percent of people turning age 65 in 2005 can be expected to incur out-of-pocket LTSS expenditures of \$100,000 or more over their remaining lifetimes, and about 12 percent will likely have expenditures from \$25,000 to \$100,000.<sup>5</sup>

In 2010, the average annual cost for nursing home care was almost \$75,000; for assisted living facility care, it was over \$39,000. For those requiring assistance at home, especially daily assistance, costs may also be high if family support is limited or unavailable. In 2010, the average national hourly rate for home health aides was \$21 and for homemaker/companions was \$19. The average daily rate for adult day care was \$67. Rates for each service vary widely by geographic region and payment source and may be more when extra services are provided to individuals with greater care needs, such as those with Alzheimer's disease.<sup>6</sup>

Paying for LTSS can exhaust the resources of people with disabilities and may lead to Medicaid eligibility. But Medicaid is limited to people who meet strict income and asset tests and functional need criteria.

## LTSS FINANCING

**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

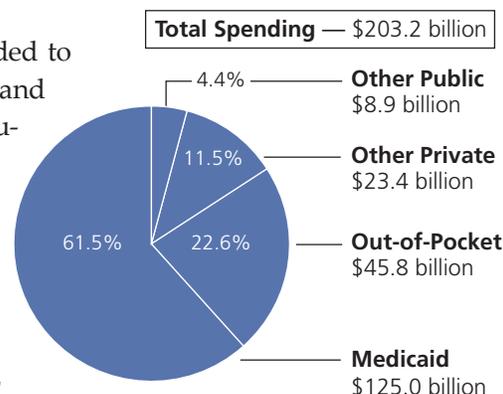
principal payer. In 2009, Medicaid paid for about 62 percent (\$125 billion) of all LTSS spending. Out-of-pocket spending by individuals and families accounted for about 23 percent (\$45.8 billion) of spending. Private insurance and other public sources paid the balance (Figure 1).

**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 meet the Social Security definition 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 because of a physical or cognitive disability or frailty. For these reasons, Medicare's financing of these services is not included in the spending amounts presented in this publication.

**Payments for LTSS represent almost one-third of all Medicaid spending.** In fiscal year (FY) 2009, LTSS (nursing homes, intermediate care facilities for people with mental retardation [ICFs/MR], home health and personal care services, and services provided through home and community-based services waivers)<sup>7</sup> accounted for almost one-third of total Medicaid expenditures.<sup>8</sup>

**Most Medicaid LTSS spending is for institutional care, but in recent years spending for home and community-based care has grown considerably, as has the number of people served.** Federal and state policy initiatives have emphasized greater use of home and community-based services, which most people prefer over institutional services.<sup>9</sup> As a result, Medicaid spending shifts have occurred. In FY 2009, 55 percent of all Medicaid LTSS spending was for institutional care (nursing homes and care in ICFs/MR) compared with 76 percent in FY 1997. In FY 2009, 45 percent of all Medicaid LTSS spending was for home and community-based services compared with 24 percent in FY 1997 (Figure 2, see next page). Medicaid supported home and community-based services for almost 2.8 million people in 2007, an increase of 47 percent since 1999. This growth has been driven primarily by increases

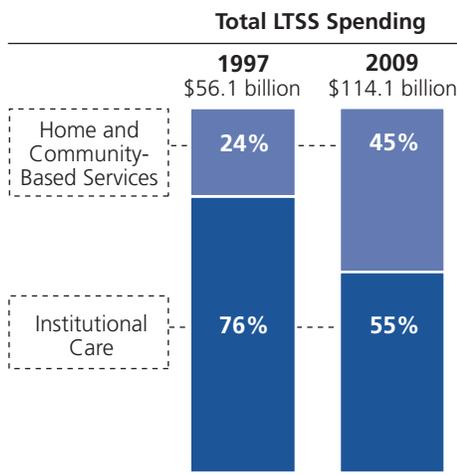
**FIGURE 1**  
**LTSS Expenditures**  
**by Source, 2009**



*Note: Dollars do not total due to rounding. Includes Medicaid spending for nursing homes and continuing care retirement communities (including in hospital-based and freestanding facilities), home health services (including in hospital-based and freestanding facilities), intermediate care facilities for people with intellectual and other developmental disabilities (also known as ICFs/MR), home and community-based services (HCBS) waiver programs, and Children's Health Insurance Program (CHIP) 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. "Out-of-Pocket" includes spending for nursing homes and home health services not covered by insurance, public programs, and other third parties. Excludes Medicare spending and some public and private spending for residential care for those with mental illness, substance abuse disorders, and intellectual disabilities. Estimates may differ from others 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 Expenditure Accounts provided by the Office of the Actuary, Centers for Medicare & Medicaid Services. See Anne Martin et al., "Recession Contributes To Slowest Annual Rate Of Increase In Health Spending In Five Decades," Health Affairs, 30, no. 1 (January 2011): pp. 11–22, available with subscription at <http://content.healthaffairs.org/content/30/1/11.full.pdf+html>.*

**FIGURE 2**  
**Medicaid Expenditures for**  
**LTSS, FY 1997 and FY 2009**



Note: Institutional spending includes spending for nursing facilities and ICFs/MR; home and community-based services (HCBS) spending includes home health, personal care, HCBS waivers, HCBS spending under sections 1115, 1915(j), and 1929 of the Social Security Act, and the Program for All-inclusive Care of the Elderly (PACE).

Source: Based on data from Steve Eiken et al., "Medicaid Long-Term Care Expenditures in FY 2009," Thomson Reuters, August 17, 2010, available at [www.hcbs.org/files/193/9639/2009LTCExpenditures.pdf](http://www.hcbs.org/files/193/9639/2009LTCExpenditures.pdf); data available at [www.hcbs.org/moreInfo.php/nr/topic/205/source/150/doc/3325/Medicaid\\_Long\\_Term\\_Care\\_Expenditures\\_FY\\_2009](http://www.hcbs.org/moreInfo.php/nr/topic/205/source/150/doc/3325/Medicaid_Long_Term_Care_Expenditures_FY_2009).

in the number of people served by Medicaid’s home and community-based waiver programs.<sup>10</sup>

Even though some states have made strides in promoting home and community-based services, spending patterns vary widely among states, ranging from 73.3 percent of all Medicaid LTSS spending in Oregon to 15.1 percent in Mississippi.<sup>11</sup> Also, spending patterns differ by population group: proportionately more is spent on institutional care for the elderly and younger adults with physical disabilities than for people with intellectual and developmental disabilities.<sup>12</sup>

**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, although the market has grown in recent years. About 6 to 7 million LTC insurance policies are in force.<sup>13</sup>

**Substantial LTSS assistance is provided informally by family and friends.** Despite the large public commitment to financing care, most care received by people with disabilities is provided by informal sources, primarily 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.<sup>14</sup> (Expenditures for informal care are not included in Figure 1.) Many policymakers are concerned about the impact that the aging of the baby boom population and increasing longevity of older adults 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 been gaining 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 (PPACA), to refer to a range of supportive services for these populations. We have chosen to use LTSS in this publica-

tion. 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), measure 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. An estimated 800,000 to 1 million people reside in such facilities. See Brenda C. Spillman and Kirsten J. Black, "The Size of the Long-Term Care Population in Residential Care: A Review of Estimates and Methodology," prepared for the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, February 28, 2005; available at <http://aspe.hhs.gov/daltcp/reports/ltpopsz.pdf>. Also see Administration on Aging, "2008 National Ombudsman Reporting System Data Tables," table A-1; available at [www.aoa.gov/AoARoot/AoA\\_Programs/Elder\\_Rights/Ombudsman/National\\_State\\_Data/2008/Index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/Elder_Rights/Ombudsman/National_State_Data/2008/Index.aspx). Another study estimated slightly more than 1 million beds: Charlene Harrington *et al.*, "Trends in the Supply of Long-Term Care Facilities and Beds in the United States," *Journal of Applied Gerontology*, 24, no. 4 (August 2005): pp. 265–282; available with subscription at <http://jag.sagepub.com/cgi/content/short/24/4/265>.
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 2010 Market Survey of Long-Term Care Costs,” October 2010, available at [www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-2010-market-survey-long-term-care-costs.pdf](http://www.metlife.com/assets/cao/mmi/publications/studies/2010/mmi-2010-market-survey-long-term-care-costs.pdf). Amount cited for nursing homes is for a semi-private room. The national average annual cost for a private room in 2010 was \$83,585. Amounts cited for home health aides and for homemaker/companions are national hourly rate averages obtained from licensed agencies that employ these workers. Averages are not indicative of what workers earn after agency administrative costs. The U.S. Department of Labor, Bureau of Labor Statistics (DoL/BLS) reports that the average national hourly rate for home health aides was \$10.39 in May 2009. See U.S. Department of Labor, Bureau of Labor Statistics, “May 2009 National Occupational Employment and Wage Estimates,” updated May 14, 2010; available at [www.bls.gov/oes/current/oes\\_nat.htm](http://www.bls.gov/oes/current/oes_nat.htm).
7. 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.
8. Steve Eiken *et al.*, “Medicaid Long-Term Care Expenditures in FY 2009,” Thomson Reuters, August 17, 2010, available at [www.hcbs.org/files/193/9639/2009LTCExpenditures.pdf](http://www.hcbs.org/files/193/9639/2009LTCExpenditures.pdf); data available at [www.hcbs.org/moreInfo.php/nr/topic/205/source/150/doc/3325/Medicaid\\_Long\\_Term\\_Care\\_Expenditures\\_FY\\_2009](http://www.hcbs.org/moreInfo.php/nr/topic/205/source/150/doc/3325/Medicaid_Long_Term_Care_Expenditures_FY_2009).
9. Cynthia Shirk, “Trading Places: Real Choice Systems Change Grants and the Movement to Community-Based Long-Term Care Supports,” National Health Policy Forum, Issue Brief No. 822, May 30, 2007; available at [www.nhpf.org/library/details.cfm/2566](http://www.nhpf.org/library/details.cfm/2566).
10. Terrence Ng, Charlene Harrington, and Jhamirah Howard, “Medicaid Home and Community-Based Service Programs: Data Update,” Kaiser Family Foundation, February 2011, available at [www.kff.org/medicaid/upload/7720-04.pdf](http://www.kff.org/medicaid/upload/7720-04.pdf).
11. Eiken *et al.*, “Medicaid Long-Term Care Expenditures in FY 2009,” table U, “Distribution of Medicaid LTC Expenditures, All Populations,” available at [www.hcbs.org/moreInfo.php/nr/topic/205/source/150/doc/3325/Medicaid\\_Long\\_Term\\_Care\\_Expenditures\\_FY\\_2009](http://www.hcbs.org/moreInfo.php/nr/topic/205/source/150/doc/3325/Medicaid_Long_Term_Care_Expenditures_FY_2009). These rankings are based on data from 40 states.
12. Enid Kassner *et al.*, “A Balancing Act: State Long-Term Care Reform,” AARP Public Policy Institute, 2008; available at [http://assets.aarp.org/rgcenter/il/2008\\_10\\_ltc.pdf](http://assets.aarp.org/rgcenter/il/2008_10_ltc.pdf).
13. Marc A. Cohen, “Long-Term Care Insurance: Are Consumers Protected for the Long-Term?” testimony before the U.S. House Committee on Energy and Commerce, Subcommittee on Oversight and Investigation, July 24, 2008, <http://energycommerce.house.gov/images/stories/Documents/Hearings/PDF/Testimony/OI/110-oi-hrg.072408.Cohen-Testimony.pdf>; and LifePlans, Inc., “Who

Buys Long-Term Care Insurance? A 15-Year Study of Buyers and Non-Buyers, 1990-2005," prepared for America's Health Insurance Plans, April 2007; available at [www.ahipresearch.org/PDFs/LTC\\_Buyers\\_Guide.pdf](http://www.ahipresearch.org/PDFs/LTC_Buyers_Guide.pdf).

14. Congressional Budget Office, "Financing Long-Term Care for the Elderly," April 2004; available at [www.cbo.gov/ftpdocs/54xx/doc5400/04-26-Long-TermCare.pdf](http://www.cbo.gov/ftpdocs/54xx/doc5400/04-26-Long-TermCare.pdf). Estimates for LTSS 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 Ari Houser and Mary Jo Gibson, "Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update," AARP Public Policy Institute, November 2008; available at [http://assets.aarp.org/rgcenter/il/i13\\_caregiving.pdf](http://assets.aarp.org/rgcenter/il/i13_caregiving.pdf).