

2015 WHITE HOUSE CONFERENCE on AGING

Long-Term Services and Supports

Despite efforts to stay healthy and prevent disease, many older adults will eventually develop some degree of limitations and need additional paid or unpaid help with basic daily living activities. Long-term services and supports help older adults and people with disabilities accomplish everyday tasks such as bathing, dressing, preparing a meal, or managing money. These services include health and social services that may be needed to maximize the independence and well-being of an individual.¹ Individuals of all ages may have functional limitations, but these limitations are most prevalent among adults age 65 and older.²

In many cases, assistance with just a few of these tasks can help older adults remain independent in their own home and communities, which a majority of older Americans prefer. Through the Older Americans Act and the Aging Network, social services and personalized information on the services and supports available in each community enhances opportunities for older adults to live independently.³ Overwhelmingly, long term services and supports are provided by family and friends, but may also be provided by professional home care workers, or direct care workers in settings such as assisted living or nursing facilities as well.

Who Uses Long-Term Services and Supports?

Approximately 20 percent (7.7 million) of older Americans receive assistance with their care needs.⁴ Most receive services or supports from family, friends, or professional workers in their homes and communities. An estimated 1.1 million older adults receive services in a nursing home, either as a long-stay resident or for short-stay post-hospital rehabilitation.⁵ The likelihood of needing assistance increases sharply with age: 11 percent of adults aged 65-69 have a functional limitation, compared to 62 percent of the population 90 and older.⁶ Women are more likely than men to need long-term services and supports primarily because they tend to live longer.⁷ Individuals with Alzheimer's disease or other dementia frequently need more of these services and supports than those older adults who have physical disabilities.⁸

Informal Caregivers

Informal caregivers are often called the backbone of long-term services and supports. Family members or friends, who are not paid for their assistance, provide the majority of long-term services and support.

Almost two-thirds of individuals age 65 and older rely exclusively on informal care for their personal care needs. An additional 30 percent use a mix of paid and unpaid care.⁹

Caregivers are more likely to be female (62 percent) and middle-aged (50 percent are 45-64). They are often the older adult's daughter (29.3 percent) or spouse (21.2 percent), although sons (18.3 percent) and other relatives (22.3 percent) also commonly serve as caregivers. Caregivers provide an average of 75 hours of support per month, but there is great variability depending on the number of caregivers in the family and the older person's level of need.¹⁰ As the aging population increases, however, it will be increasingly difficult for family caregivers to meet this demand alone.¹¹

Most caregivers describe substantial positive aspects to caregiving, such as feeling closer to their loved one and reassurance that they are well cared for. However, caregiver strain is of concern as 15 percent of caregivers report significant financial or physical difficulties with caregiving, and more than a quarter experience significant emotional difficulties.¹² Caregiver stress is associated with poorer health for the caregiver and greater likelihood that the care recipient will enter a nursing home. Supporting caregivers decreases caregiver strain and improves the caregiving experience. The Administration for Community Living within the Department of Health and Human Services provides resources for caregivers through the [National Family Caregiver Support Program](#), including information to caregivers about available services, counseling, and respite care. This program provided supports to more than one million caregivers in 2013.¹³ The US Department of Veterans Affairs (VA) also provides resources to caregivers of veterans through its [VA Caregiver Support Program](#). VA offers a variety of training and education programs on-line and in person and connects caregivers to one another through its caregiver peer support programs and caregiver support coordinators.

One of the most promising developments in helping older Americans remain in their homes and communities as they age is the growth of publicly financed consumer-directed services, a model that enables individuals who need long-term services and supports to hire informal caregivers or directly hire home care workers. Evaluations of

"I am a 24-year-old caregiver who spent the last two years caring for my aging mother and grandfather. Shortly after my college graduation, both loved ones encountered major illnesses, which I knew absolutely nothing about."

Megan T., Tennessee

consumer-directed services show that older adults and their caregivers report high levels of satisfaction.¹⁴ This model has the added benefit of easing the financial strain on families. States provide consumer-directed care options through their Medicaid programs. The Affordable Care Act expanded the availability of consumer-directed services by providing states with the option to adopt Community First Choice, in which beneficiaries may choose to self-direct their services.¹⁵ In addition, in some states, the Veterans Health Administration and the Aging Network work together to allow veterans to pay informal caregivers to provide their long-term services and supports.

The President's 2016 Budget continues to emphasize the importance of caregiver supports, with nearly \$50 million in new funding for aging programs that provide critical help and supports to older adults and their caregivers, such as respite and transportation assistance. The President's Budget also provides \$15 million to a new Family Support Initiative focused on assisting family members supporting older adults and/or individuals with disabilities.

Formal Services and Supports

Paid, or formal, assistance may be provided in a number of settings, including:

- At-home
- Adult day support centers allow for the older adult to live at home but receive some assistance such as personal care, social integration, and companionship in a group setting, usually during the work week.
- Residential care communities, such as assisted living and adult foster care, provide 24-hour care and supervision along with assistance with activities of daily living, but generally, not the skilled nursing care found in most nursing homes.
- Nursing homes or nursing facilities provide nursing, medical oversight, personal care, and other services.

Research has shown that delivering formal services and supports in home and community-based programs can improve the quality of care individuals receive as well as reduce health care costs.¹⁶ States are shifting Medicaid spending from institutional long-term services and supports to home- and community-based services, a process known as “rebalancing.”¹⁷ The Affordable Care Act is helping to support this effort through the Balancing Incentives Program which will have invested nearly \$3 billion in 21 states by September 2015. Participating states may use the Balancing Incentive Program funds to increase access to home and community based services.¹⁸ Research indicates that states that have invested in rebalancing have saved money in their long-term services and supports spending compared to the amount that they would have spent had they not invested in rebalancing.¹⁹

Direct Care Workers

Direct care workers include nursing assistants, home health aides, and personal care aides who deliver hands-on long-term services and supports. In 2012, the direct care workforce conservatively totaled more than 4 million workers in the United States. A growing demand for direct care workers is expected, which raises issues of recruiting and retaining the direct care workforce.²⁰

Direct care is a demanding profession with low wages, long hours, and limited benefits. In 2013, the Obama Administration took an important step forward to address this issue for most of the nearly two million direct care workers who provide at-home services. Specifically, the Department of Labor issued a final regulation extending minimum wage and overtime protections to home care workers who, unlike workers who provide services in nursing homes and other residential facilities, lacked such protection. The Department has been committed to assisting employers in implementing the regulation in a manner that affords crucial wage protections to these workers who provide long-term services and supports.²¹ These wage protections and other measures that enhance the labor standards for direct care workers are critical to efforts to recruit and retain a sufficient number into the profession to keep pace with the growing need. Direct care workers, like other low wage workers are likely to benefit from greater access to health insurance through the Affordable Care Act.

While states determine direct care worker training requirements, there are efforts underway by the federal government to identify the core competencies needed by direct care workers.²² Funded by an award from the CMS Center for Medicare and Medicaid Innovations, the California Center for Long-Term Care Education focuses on training personal home care aides in core competencies that will enable them to assume new roles with respect to caring for some of the sickest and most costly Medicare and Medicaid enrollees. These core competencies include being health monitors, coaches, communicators, and navigators. The Personal and Home Care Aide State Training Program, authorized by the Affordable Care Act, supported six states that developed, implemented, and evaluated curricula and certification programs. This program trained qualified direct care workers on core competencies including infection control, safety and emergency training, consumer rights, ethics, and confidentiality, and other important topics.²³ Other innovative models of training include apprenticeship programs and other career pathway approaches.

Access to Information and Services

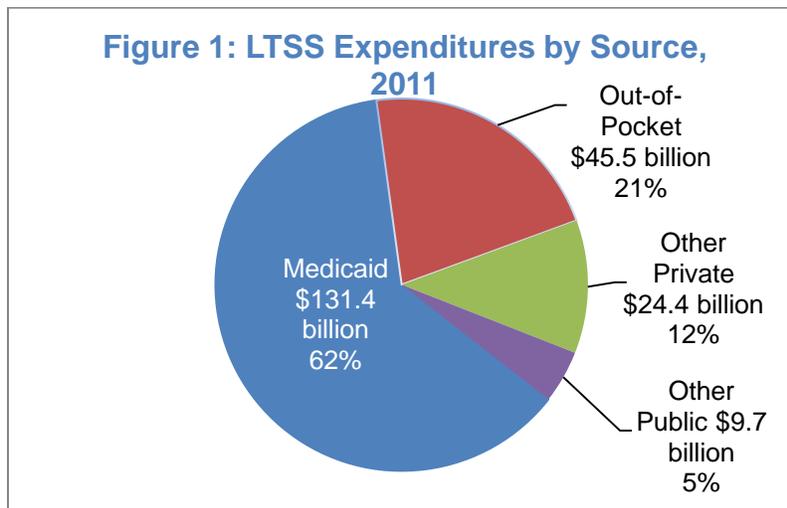
When older adults and their families need additional supports, they may need help understanding their options. Individuals and their families may turn to many places for information, including friends, a geriatric case manager, hospital discharge planners, or providers. With support from the Older Americans Act, area agencies on aging (AAAs), and tribal entities provide personalized information on the services and supports available in each community and assist in decision making (AAA, tribal, and other service information is available through the [Eldercare Locator](#).)²⁴ People selecting a nursing facility or home health care agency can get information on the quality of the services on the Center for Medicare and Medicaid Services' [Nursing Home Compare](#) or [Home Health Compare](#) websites.

To make it easier for consumers to learn about and quickly access services and supports, the Department of Health and Human Services collaborates with the Veterans Health Administration to support states in their development of “No Wrong Door” systems, which serve as a one-stop shop for those seeking long-term services and supports. Through an initiative called [Aging and Disability Resource Centers](#) (ADRCs), states develop a single statewide system of access to long-term services and supports for all populations.

The Department of Health and Human Services is also funding a number of initiatives designed to help older adults with complex care needs better navigate an often complex web of providers and benefits. Programs such as the dual eligible financial alignment initiatives, serve low-income older adults with significant health care needs by streamlining benefits and providing more seamless connections between their providers.²⁵

Financing

The primary source of long-term services and supports is unpaid care provided by friends and family valued at \$234 billion in 2011.²⁶ The largest source of long-term services and supports expenditures is Medicaid, funded at both state and federal levels, and estimated at \$131.4 billion. Other sources of expenditures are out-of pocket spending by individuals receiving services and their families (estimated at \$45.5 billion) and other private sources (\$24.4 billion).²⁷



Source: National Health Policy Forum, 2013

Medicare: More than 90 percent of older Americans have health insurance coverage through Medicare, but one of the common misconceptions is that Medicare will finance long-term services and supports. Medicare covers short-term skilled nursing services following hospitalizations, known as post-acute care. Medicare also covers limited hours of home health services, without requiring a prior hospital stay, under certain conditions.²⁸

Medicaid: Medicaid provides coverage for health care and long-term services and supports for individuals with limited financial resources. Most individuals who are eligible for Medicaid have low income and few assets. States are required to make nursing home care available under their Medicaid programs. However, Medicaid coverage of home- and community-based services is optional, and states may limit the number and type of beneficiaries eligible for these services, as well as the range of services provided. As a result, some states have lengthy waiting times before qualified individuals are able to receive home- and community-based services. The Affordable Care Act took steps to expand access to these services under Medicaid through new options such as the Balancing Incentives Program and Community First Choice, which are described below.

“Local programs such as Meals on Wheels are a godsend. My Dad had this service for a year and a half and it was so comforting to know that there was at least one contact point per day checking in on him.”

Gerianne S., Maryland

Aging Network: With funding support through the Older Americans Act, the Aging Network (a nationwide network of state units on aging, AAAs, tribal entities, and community-based providers) delivers social services to support older Americans, including information and referral on the

services and supports available in each community, home- and community-based services, caregiver supports such as respite and support groups, and congregate and home-delivered nutrition programs.

Private spending: The main private source used to finance long-term services and support is personal out-of-pocket spending. Depending on the setting and type of care, out-of-pocket spending can be significant. Nursing homes rates average \$90,520 per year for a single occupancy room and \$81,030 per person, double occupancy.²⁹ Assisted living costs average \$42,600 annually, but this may not cover all the direct care service costs. Home care, for 8 hours per day, costs an average of \$58,400 annually.³⁰

Today, long-term care insurance policies are primarily purchased by middle-aged and older adults who are assessed by insurance companies as having less health risk and have higher than average incomes. There are approximately 7.3 million long-term care policies currently in force in the United States³¹ and payments by insurance accounts for 3.3 percent of spending on long-term care annually.³²

Planning for Long-Term Services and Supports

In spite of the large number of people who will need long-term services and supports and the potential threat to retirement security that the high costs represent, most Americans are unaware of how much this care costs or who routinely pays for such services.³³ In 2005, a person turning age 65 had a 69 percent risk of needing long-term services and supports for an average of three years during the remainder of their lifetime.³⁴ Only 58 percent of men turning 65 in 2005 had an expected long-term services and supports need, compared to 79 percent of women. One in ten older Americans will need more than \$100,000 to cover their long-term services and supports costs.³⁵

The role of public programs such as Medicare and Medicaid in financing long-term services and supports is commonly misunderstood. While Medicaid is the largest payer of long-term services and supports, roughly a third of pre-retirees incorrectly assume Medicare pays the most, according to recent survey results.³⁶ Private options (including long-term care insurance, whole life insurance or life insurance riders, reverse equity mortgages, and annuities) are available to help some people plan ahead to pay for their future care. But there is currently no comprehensive long-term care financing program available to all older adults.

Consumer education and outreach on preparing for long-term services and supports is needed. To raise awareness about the prospect of needing long-term services and supports and to encourage baby boomers to begin planning for it, the Department of Health and Human Services (at www.longtermcare.gov) and the Veterans Health

Administration (at www.va.gov/GERIATRICS/Guide/LongTermCare) provide information on planning, decision-making, and long-term services and supports.

Aging services technologies helps address a number of key care issues including falls prevention and detection, chronic disease management, medication management, and cognitive, sensory, and mobility impairments. These technologies hold promise for assisting older adults, individuals with disabilities of all ages living in the community, as well as their informal and formal providers of services and supports.³⁷ However, there are important issues with the development, adoption, and use of aging services technologies and potential lessons that can be learned from other developed nations where these technologies have been implemented more widely.³⁸

Improving Access to Home- and Community-Based Services

In recent years, the Administration has expanded efforts to ensure that older adults and individuals with disabilities have access to person-centered services in community settings.³⁹ For example, the Money Follows the Person Rebalancing demonstration helps states rebalance their Medicaid long-term services and supports systems and provides opportunities for older Americans and people with disabilities to transition back to the community from institutions. The Affordable Care Act extended and expanded this program. As of December 2013, more than 40,500 individuals with disabilities and chronic conditions have transitioned to the community through the program.⁴⁰

The Affordable Care Act also provided additional opportunities to make home- and community-based services options more available. Through the Balancing Incentives Program, for example, 18 states have made structural changes to their home- and community-based services systems and are providing new or expanded services in community settings.⁴¹ Through the Community First Choice Program, an enhanced federal Medicaid match incentivizes states to provide more home- and community-based attendant services.

Under the Obama Administration, the Department of Justice renewed its commitment to enforcement of the Supreme Court's landmark decision in *Olmstead v. L.C.*, which recognized the right of individuals with disabilities to access care for their needs in their own homes and communities instead of in institutional settings.⁴² Through comprehensive *Olmstead* settlement agreements with the Department of Justice, in addition to settlements in private litigation and to voluntary compliance efforts, states have expanded access to home- and community-based services settings throughout the country.

The President's 2016 Budget includes additional legislative proposals to make it easier for states to cover home- and community-based services through Medicaid. These

include proposals for expanding eligibility for home- and community based services and a new pilot program that will simplify Medicaid home- and community based services so that states can more efficiently cover these services. The President's Budget also includes an increase in funding to Centers for Independent Living to help individuals transition from nursing homes to the community or to allow them to remain at home rather than move into facilities.

Discussion Questions

The 2015 White House Conference on Aging aims to foster a national conversation, and the questions listed below are designed to stimulate dialogue on long-term services and supports issues. The White House Conference on Aging will use the feedback received to continue to help shape outcomes of the 2015 White House Conference on Aging. Please provide your thoughts and ideas on our [website](#). All comments will be displayed in the public conversation area of the White House Conference on Aging website.

- What supports will help caregivers continue to provide care while maintaining their own health and well-being?
- What assistance do older adults and families need when making decisions about long-term service and supports?
- What could be done to ensure sufficient numbers of highly qualified direct care workers for now and the future?
- What could be done to ensure an adequate workforce with the knowledge and skills needed support an increasing population of older Americans with chronic conditions and/or functional limitations?
- Are there current long-term services and supports programs or policies you think are the most or least effective or potentially duplicative?
- How can we better address the costs and increasing need for long-term services and supports?
- How can we harness technology to assist individuals with their long-term service and support needs?

¹ Long-term services and supports (LTSS), sometimes called “long-term care,” may include personal care services, homemaker services, meal assistance, transportation assistance, case management, skilled care, respite care, and many others. Assistance might be needed to perform activities of daily living (ADLs) including: eating, dressing, bathing, toileting, and transferring into or out of bed. Other common LTSS are assistance with everyday tasks, sometimes called instrumental activities of daily living (IADLs) including: housework, managing money, taking medication, preparing and cleaning up after meals, shopping for groceries or clothes, using the telephone or other communication devices, caring for pets, and responding to emergency alerts such as fire alarms.

² Erickson, W., Lee, C., & von Schrader, S. (2014). 2012 Disability Status Report: United States. Ithaca, NY: Cornell University Employment and Disability Institute(EDI).

http://www.disabilitystatistics.org/StatusReports/2012-PDF/2012-StatusReport_US.pdf#cgi.SCRIPT_NAME#

³ The Aging Network is a nationwide network of state units on aging, Area Agencies on Aging, tribal entities, and community-based providers. For more information:

http://www.aoa.gov/AoA_programs/OAA/Aging_Network/Index.aspx

⁴ Erickson, W., Lee, C., & von Schrader, S. (2014). 2012 Disability Status Report: United States. Ithaca, NY: Cornell University Employment and Disability Institute(EDI).

http://www.disabilitystatistics.org/StatusReports/2012-PDF/2012-StatusReport_US.pdf#cgi.SCRIPT_NAME#. Table 1.

⁵ Ibid. Table 3.

⁶ Ibid. Table 2.

⁷ Kemper, P., Komisar, H.L., & Alexih, L. (2005). Long-term care over an uncertain future: What can current retirees expect? *Inquiry*. 42(4): 355-350. Retrieved from

<http://www.ncbi.nlm.nih.gov/pubmed/16568927>.

⁸ Kasper, J.D., Freedman, V.A., Spillman, B.C. (2014). Disability and Care Needs of Older Americans by Dementia Status: Findings from the 2011 National Health and Aging Trends Study. Prepared for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, at Table 9. Retrieved from

<http://aspe.hhs.gov/daltcp/reports/2014/NHATS-DS.cfm>.

⁹ Spillman, B.C., Wolff, J., Freedman, V.A., & Kasper, J.D. (2014). Informal caregiving for older Americans: An Analysis of the 2011 National Study on Caregiving. Prepared for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy. Retrieved from

<http://aspe.hhs.gov/daltcp/reports/2014/NHATS-IC.cfm>.

¹⁰ Ibid.

¹¹ Redfoot, D., Feinberg, L., & Houser, A. (2013). The Aging of the Baby Boom and the Growing Care Gap: A Look at the Future Declines in the Availability of Family Caregivers. AARP Public Policy Institute. Retrieved from <http://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html>.

¹² Ibid. at Table 5.

¹³ For more information, see Administration for Community Living, http://www.acl.gov/About_ACL/Budget/docs/FY_2016_ACL_CJ.pdf.

¹⁴ Wiener, J.M., Anderson, W.L., & Khatutsky, G.,(2007). Are consumer-directed home care beneficiaries satisfied? Evidence from Washington State. *Gerontologist* 47, 763–774.

¹⁵ For more information on self-directed services, see Centers for Medicare and Medicaid Services: <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/community-first-choice-1915-k.html>.

¹⁶ De Jonge, Jamshed, Gilden, Kubisiak, Bruce, & Taler,(2014). Effects of home-based primary care on Medicare costs in high-risk elders. *Journal of the American Geriatrics Society*. 62(10) 1825-31.

¹⁷ Kaye. (2012). Gradual Rebalancing of Medicaid Long Term Services and Supports Saves Money and Serves More People, Statistical Model Shows. *Health Affairs*. 31 (6) 1195-1203.

¹⁸ <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/balancing-incentive-program.html>.

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- ¹⁹ Kaye, LaPlante, M., & Harrington, C. (2009). Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending? *Health Affairs*. 28 (1) 262-272.
- ²⁰ U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation. (2011). Understanding Direct Care Workers: A Snapshot of Two of America's Most Important Jobs (Certified Nursing Assistants and Home Health Aides). Retrieved from <http://aspe.hhs.gov/daltcp/reports/2011/CNAchart.html>.
- ²¹ Application of the Fair Labor Standards Act to Domestic Service (29 C.F.R. Part 552). A federal district court judge has issued orders in *Home Care Association of America v. Weil*, Civil Action No. 14-967 (D.D.C.), vacating parts of the Rule. The Department of Labor has appealed to the U.S. Court of Appeals, and a decision is pending.
- ²² Centers for Medicare and Medicaid Services. (2014). *Roadmap for the Direct Service Workforce Core Competencies*. Available at: <http://www.medicare.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/workforce/downloads/dsw-core-competencies-phase-iii-december-2014.pdf>.
- ²³ For more information: <http://bhw.hrsa.gov/nursing/grants/phcast.html>
- ²⁴ For contact information for AAAs and other helpful resources, go to: www.eldercare.gov or call 1-800-677-1116.
- ²⁵ For more information, see Center for Medicare and Medicaid Services: <http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/FinancialModelstoSupportStatesEffortsinCareCoordination.html>
- ²⁶ Congressional Budget Office. (2013). Rising Demand for Long-Term Services and Supports for Elderly People.. Retrieved from <http://www.cbo.gov/sites/default/files/cbofiles/attachments/44363-LTC.pdf>.
- ²⁷ National Health Policy Forum. (2013). National Spending for Long-Term Services and Supports (LTSS), 2011. Retrieved from www.nhpf.org/uploads/announcements/Basics_LTSS_02-01-13.pdf.
- ²⁸ For more information, see Centers for Medicare and Medicaid Services: <http://www.medicare.gov/coverage/home-health-services.html>.
- ²⁹ MetLife Mature Market Institute. (2012). Market Survey of Long-Term Care Costs. Retrieved from <https://www.metlife.com/assets/cao/mmi/publications/studies/2012/studies/mmi-2012-market-survey-long-term-care-costs.pdf>.
- ³⁰ Ibid.
- ³¹ Cohen, M., Kaur, R., Darnell, B. (2013). Exiting the Market: Understanding the Factors Behind Carriers' Decision to Leave the Long-Term Care Insurance Market. Retrieved from <http://aspe.hhs.gov/daltcp/reports/2013/MrktExit.shtml>.
- ³² Congressional Budget Office. (2013).
- ³³ AARP. (2006). *The Costs of Long-Term Care: Public Perceptions Versus Reality in 2006*. Retrieved from http://www.aarp.org/relationships/caregiving/info-2006/ltc_costs_2006.html.
- ³⁴ Kemper et al. (2005).
- ³⁵ Ibid.
- ³⁶ U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation. (2015). What do people know about long-term services and supports? *Forthcoming*.
- ³⁷ For more information, see: www.abledata.com and www.techforltc.org.
- ³⁸ ASPE Report to Congress: Aging Services Technology Study. (2012). Retrieved from <http://aspe.hhs.gov/daltcp/reports/2012/astsrptcong.cfm>.
- ³⁹ Health and Human Services. (2014). Guidance for Implementing Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs. Retrieved from www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf.
- ⁴⁰ For more information, see Centers for Medicare and Medicaid Services: <http://www.medicare.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Money-Follows-the-Person.html>.
- ⁴¹ For more information, see Centers for Medicare and Medicaid Services: <http://www.medicare.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Balancing-Incentive-Program.html>.
- ⁴² For more information regarding the Supreme Court's decision in *Olmstead v. L.C.*, see Department of Justice: <http://www.ada.gov/olmstead/index.htm>.