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*The mission of the Institute for Medicaid Innovation is to improve the lives of Medicaid enrollees through the development, implementation, and diffusion of innovative and evidence-based models of care that promote quality, value, equity and the engagement of patients, families, and communities.*

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# UNDERSTANDING LONG-TERM SERVICES AND SUPPORTS IN MEDICAID

*Long-Term Services & Supports (LTSS) are utilized by millions of Americans. LTSS includes nursing home services, home health care, intermediate care facility services, and services provided through Home and Community-Based Services (HCBS) waivers.<sup>1</sup> LTSS covers a wide range of medical and non-medical services, often over a prolonged time period. Individuals utilizing these services may have impaired mobility and/or cognitive function, chronic disease or conditions, or physical or mental challenges. The services are delivered by caregivers and support activities of daily living (ADLs) such as eating, dressing, or bathing; medication management; or housekeeping. More complex care is provided by licensed professionals.*

*Many individuals who utilize LTSS are receiving Medicaid, a health care coverage program that is funded jointly by each individual state and the federal government.<sup>2</sup> For a state to provide Medicaid services, it is required by federal law to cover groups of individuals, including low-income families, pregnant women, children, and individuals receiving Social Security Income (SSI). States can choose to provide Medicaid services to other eligible individuals such as seniors or individuals receiving HCBS.<sup>2</sup>*



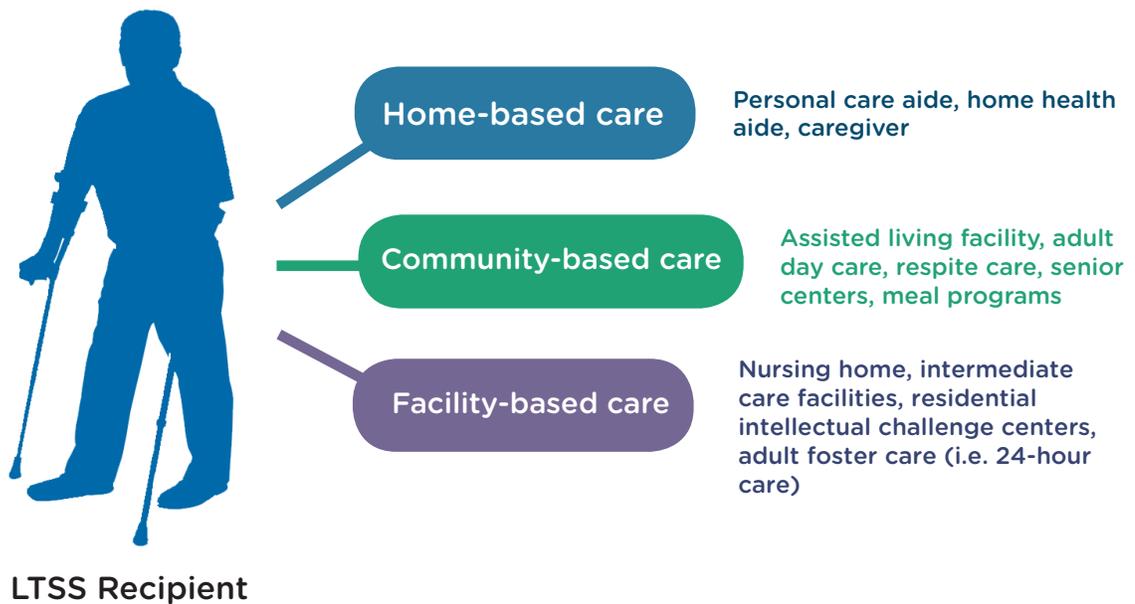
## Background

Before 1935, state-supported poor houses run by the State Board of Charities had become the default location for poor, dependent elderly people.<sup>3</sup> As early as 1935, there was acknowledgment in the U.S. that specific assistance was required for poor seniors and persons with challenges. The Social Security Act of 1935 created the first federally funded Old Age Assistance (OAA) programs, which contributed to the creation of the private nursing home industry.<sup>4</sup> In 1937, the U.S. surgeon general suggested that there be some type of health coverage for those who received Social Security.<sup>3</sup>

LTSS involves a variety of services to help individuals live as independently and safely as possible when they are no longer able to perform all of their daily activities on their own. The assistance can be provided in an individual's home or in an institution such as a nursing home or adult day care center. LTSS includes a wide array of services, ranging from personal care and home health assistance to facilitate independent living at home to services provided in an institutional setting (e.g., nursing homes) to support individuals. These services are often not medical services, but instead, support services that allow individuals to remain independent, often in the community.<sup>5</sup> Figure 1 illustrates settings where LTSS is provided to individuals.



**Figure 1. Settings Where LTSS Is Provided to Individuals**



Source: National Conference of State Legislatures: Long-Term Services and Supports: FAQs: 2013. <http://www.ncsl.org/research/health/long-term-services-and-supports-faqs.aspx>

The Centers for Medicare & Medicaid Services (CMS) and the states work in partnership to create LTSS programs that support maintaining or improving health and quality of life and maintaining independence for eligible individuals.<sup>6</sup> Recipients of LTSS services can be of any age and may have diverse cognitive, mental, and/or physical challenges. Such recipients may include working adults with significant physical challenges, children who are dependent on sophisticated medical technology and are medically fragile, people over age 65 with multiple chronic conditions, individuals on the autism spectrum or with intellectual challenges, or individuals experiencing the advanced stages of dementia.<sup>7</sup>

LTSS is often provided over an extended period of time, and there may be substantial variability in how often a person may need care, ranging from daily to a few times a week, or even more intermittently based on the person's unique needs. The services may be needed for a set time period or for the remainder of the person's life.<sup>5</sup> LTSS services may also be provided by licensed health professionals who provide a variety of medical care for LTSS individuals. These include services such as skilled nursing, medication management, and care coordination services.<sup>6</sup>

In 2011, around 11 million people required some form of paid LTSS.<sup>6</sup> As the U.S. population continues to age, both cost and demand for these services are projected to grow.<sup>6</sup> For example, it is estimated that about half (52%) of Americans who turned age 65 in 2015 will experience an event that will require some level of LTSS assistance during their lifetime.<sup>7</sup>

## Historical Timeline<sup>4</sup>

Long-term care as we know it today has evolved over time. As early as 1935, there was recognition that as people aged, additional state and federal monetary assistance was necessary for seniors living in poverty, which precipitated the development of the Social Security Act (SSA). Federal money was given to the states to provide the services. The funds were prohibited from being used to pay for services or support in public institutions or poor houses, spawning the private nursing home industry and creating a bias toward institutional care for seniors and people with challenges. In 1965, Medicare and Medicaid were added to the SSA but continued the bias toward institutional care, with neither paying for out-of-facility care. With the advent of Medicare and Medicaid, the Older Americans Act (OAA) was created, which formed the Department of Health, Education, and Welfare (HEW) and established the Administration on Aging (AOA). In 1974, final regulations that outlined requirements for nursing homes to be reimbursed for Medicare and Medicaid were created, including staffing levels and qualifications, fire safety provisions, and service provisions. SSA also provided federal grants to states for the development of social service programs, including homemaker services, transportation, adult day care, protective services, nutrition assistance, health support, and training for employment. In 1975, Title XX was formed, which consolidated all financial support to states under one grant, including directing states to reduce use of funds for unnecessary institutional care and instead utilize HCBS. The comprehensive amendments to the OAA in 1978 required states to develop and implement a nursing home ombudsman program and prioritize community alternatives to LTC in institutions. In 1981, an HCBS waiver program was enacted under Section 1915(c) of the SSA, which allowed states to offer HCBS that were not strictly medical through Medicaid as an alternative to institutional care. In 2001, the CMS and the Administration on Aging Real Choice Systems made grants available to states and non-profits to allow for the development of integrated LTSS systems. In 2014, the CMS finalized new rules regarding qualities that HCBS must meet to be considered reimbursable under Medicaid. In 2015, the CMS revised the nursing home Five-Star Quality rating system to reflect the improved performance standards.<sup>8</sup>

Appendix A provides a detailed timeline of the program evolution.

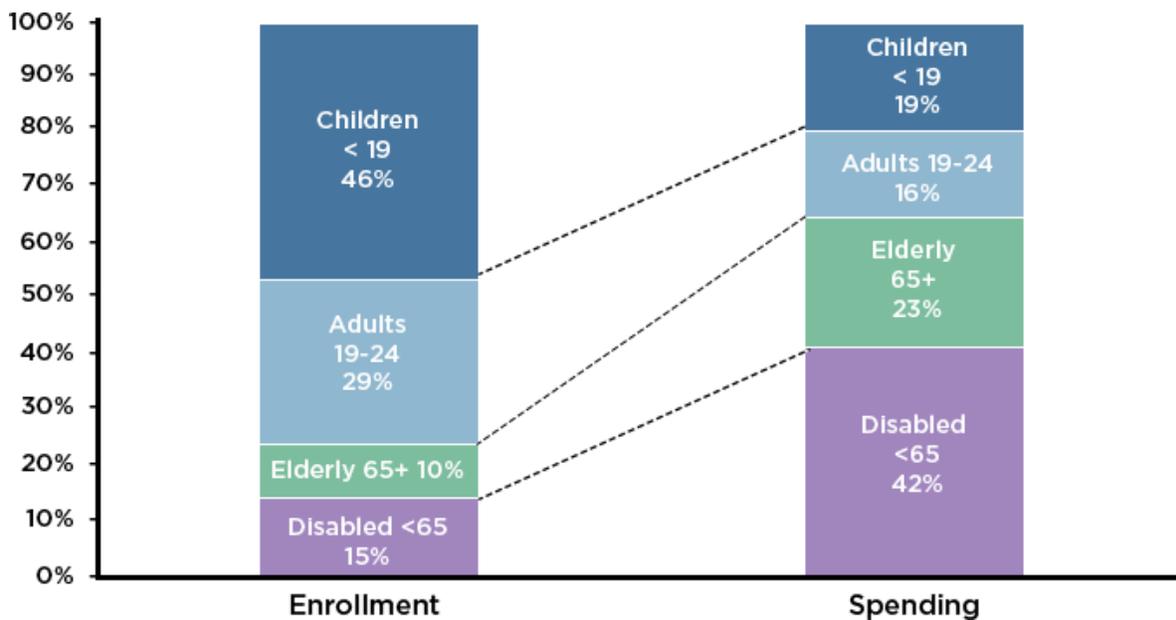
## Medicaid and LTSS

Today, Medicaid is the largest payer of long-term care, or LTSS. Medicaid-eligible individuals who use long-term care services are among the most disabled and chronically ill of the total Medicaid population.<sup>9</sup> Medicaid was enacted in 1965 as a joint federal and state entitlement program providing medical care to low-income individuals. When originally enacted, the primary recipients of long-term care were those in institutions such as nursing homes, with minimal support for individuals with home and community supports.<sup>9</sup>

In 2013, although LTSS enrollees comprised only 6 percent of the Medicaid population, their services comprised 35 percent of total Medicaid spending, illustrating the disproportionate amount of Medicaid spending for these services.<sup>10</sup> Figure 2 compares overall Medicaid enrollment by population and spending for those specific covered populations in 2013:



**Figure 2. Comparison of Medicaid Enrollment and Total Spending by Type of Beneficiary: 2013**



Source: Medicaid and CHIP Payment and Access Commission, MACStats Medicaid and CHIP Databook, December 2016. Compiled by Peter G. Peterson Foundation.  
 Note: Data are from Fiscal Year 2013.

Eligibility for Medicaid-covered LTSS services is based on both functional and financial criteria.<sup>11,12</sup> Under Medicaid, eligibility for LTSS is determined by both state and federal law. There are federal minimum standards, and states can design additional individual criteria, utilizing the federal minimum eligibility as their base. Federal requirements are both by category (e.g., age 65 or above, those with challenges, pregnant individuals, children, certain nonelderly childless adults, or parents) and financial (typically income and resource standards). Non-financial criteria for eligibility may include state and federal residency, immigration status, and documentation of U.S. citizenship.<sup>11,12</sup>

States have the latitude to add additional functional criteria that enhance or clarify the federal criteria.<sup>13 14</sup> Most states employ a functional assessment screening to determine an individual's need to receive services and identify the person's function and health status. The tool may also assist in developing a plan of care for the individual. A specific screening tool is not mandated by the federal government. The tools vary by state, and sometimes within a state, where multiple screening tools may be utilized. There is no one standardized tool, with more than 100 different tools currently in use.<sup>13 14</sup>

Today, the two main LTSS models are Home and Community-Based Services (HCBS) and Facility-based Care.<sup>15</sup> The care is similar in each model; however, the difference is in how the care is delivered and where the individual lives. The similarities and differences are shown in Table 1.



**Table 1. Behavioral Health Financing Models by State, 2019**

	<b>Home and Community-Based Services</b>	<b>Facility-based Care</b>
What LTSS Services can be provided?	Medical and personal services to help with daily living tasks	Medical and personal services to help with daily living tasks
Where does the patient live?	In their own home, or with a family member	In a facility designed to provide LTSS to patients who live there
Where are the services provided?	By caregivers who visit the home, or by going out to visit the providers in the community	Services are provided by caregivers who work onsite at the facility
Who are the paid or reimbursable caregivers?	Family members can sometimes be certified as live-in or visiting caregivers, depending on the state's requirements. Other care can be provided by direct care or medical providers in the community	Caregivers are the professional medical staff who work at or visit the facility

Source: CMS.gov: LTSS Models. 2016. <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/ltss-models.html>

**HCBS services** are designed to assist persons with challenges and the elderly to remain in the community or in their home. These programs assist persons with functional limitations who require assistance with ADLs.

Two programs under HCBS designed to help those needing care stay at home and in their communities are the following:

- Program of All-Inclusive Care for the Elderly (PACE): a long-term program designed by both Medicaid and Medicare. Most individuals in this program receive their LTSS at home.
- Money Follows the Person (MFP) Program: a program designed to assist individuals who are transitioning out of an institution into a home or community setting.<sup>5</sup>
  - o This program has another initiative specifically targeted to tribal individuals to build HCBS specifically for the tribal individuals in Indian country.<sup>15</sup>

Facility-Based Care is provided in a physical facility. The individuals live in these facilities and receive their LTSS from staff employed by the facility. Some examples of facilities available to individuals include:

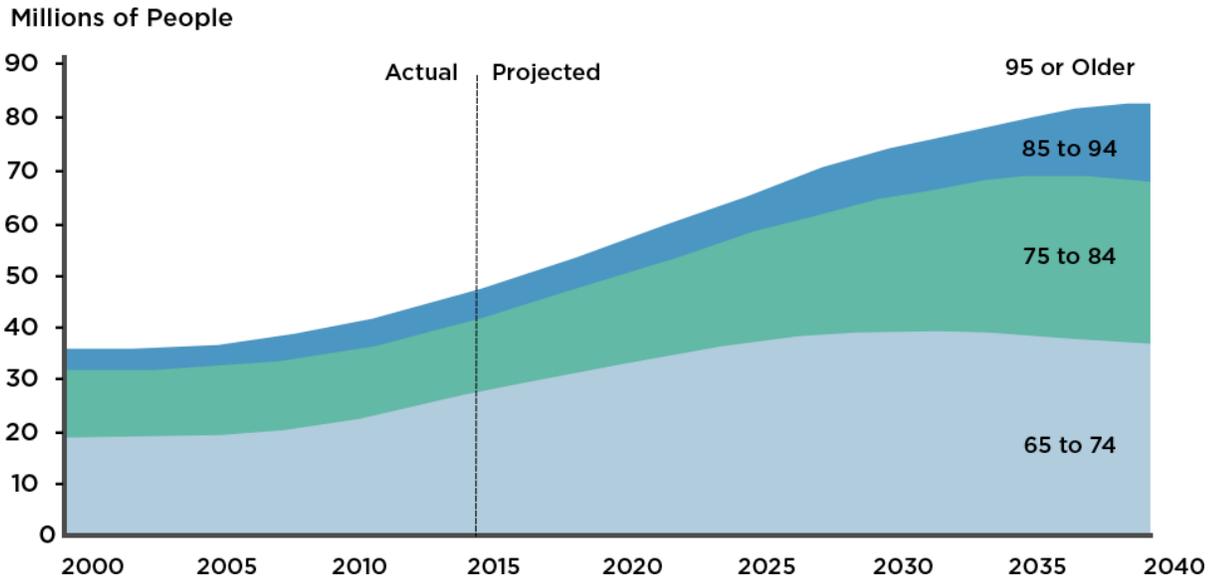
- Assisted Living Centers - Individuals can be independent but receive assistance with ADLs
- Adult Family Homes - home-like environments with a small number of individuals
- Nursing Homes - provide constant medical supervision to individuals
- Intermediate Care Facilities for People with Intellectual Disabilities (ICF/ID)
- Preadmission Screening and Residential Review (PASRR)
- Inpatient Psychiatric Services for individuals under age <sup>21</sup>
- Services for individuals age 65 or older in an institution for mental disease<sup>16</sup>

## Disparities

Research has demonstrated that the U.S. population is aging rapidly, with important implications for LTSS.<sup>17</sup> According to the latest census report, from 2006 to 2016, the number of Americans ages 45-64 (who will reach age 65 over the next two decades) increased by 12 percent, and the number of Americans age 60 and older increased by 36 percent, from 50.7 million to 68.7 million. The number of those over age 85 was projected to increase 350 percent, from 5.5 million in 2010 to 19 million in 2050.<sup>17</sup> Figure 3 represents the projected trajectory of the aging population.



Figure 3. Elderly Adults as a Share of the U.S. population, 2000-2040



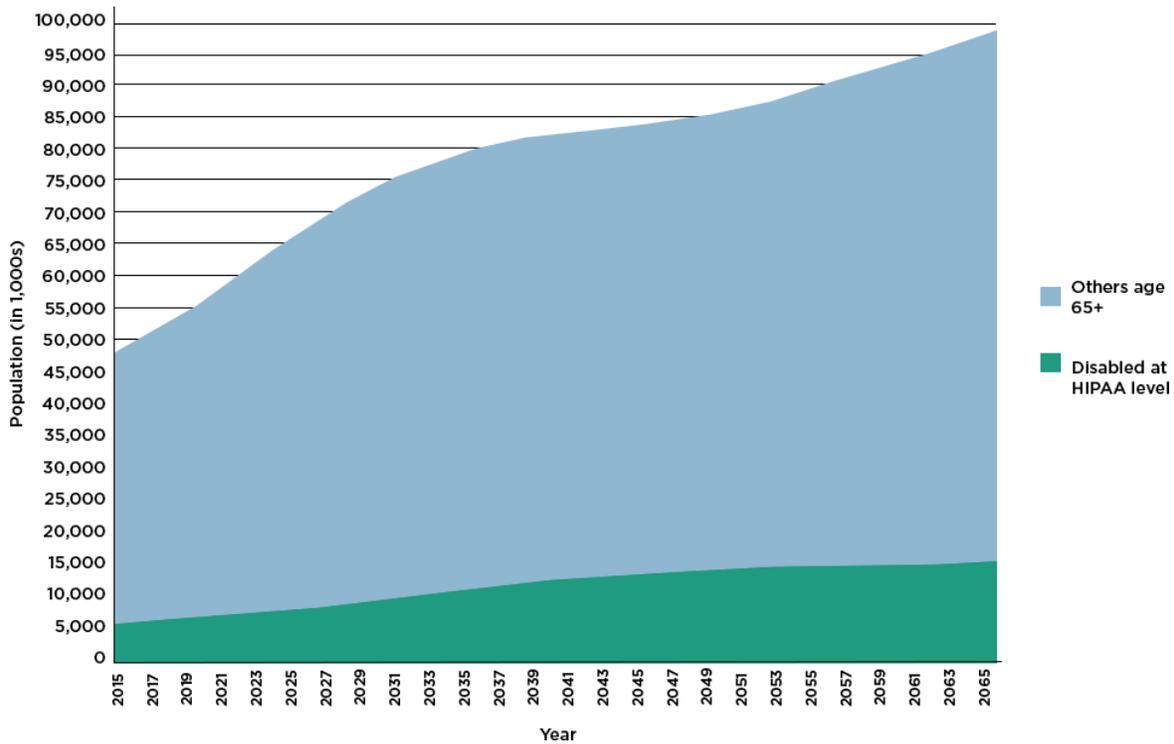
Source: Congressional Budget Office tabulations based on population projections reported in The 2015 Long-Term Budget Outlook. June 2015. Available at: <https://www.cbo.gov/sites/default/files/114th-congress-2015-2016/reports/50250-longtermbudgetoutlook-4.pdf>

As the population ages and functional challenges increase, the need for LTSS also increases.<sup>8</sup> The Urban Institute utilized a microsimulation model, DYNASIM3, which is designed to analyze aging and retirement issues over time. This model included data from a wide range of longitudinal and cross-sectional sources, such as the Medicare Current Beneficiary Study and the National Health and Aging Trends Survey. The model used individuals turning age 65 during 2015-2019, with a future life expectancy of 20.9 years. This model identified the following trends: of individuals age 65 in 2015, 52 percent are estimated to develop a condition or challenge requiring LTSS at some point in their life, with two years being the average duration of care.<sup>8</sup>

As expected, given the aging population, the number of individuals with Health Insurance Portability and Accountability Act (HIPAA)-level challenge, defined as a need for assistance with at least two ADLs that are expected to last at least 90 days or a need for substantial supervision for health and safety threats because of severe cognitive impairment, is expected to grow. The model identified 6.3 million individuals who met these criteria in 2015, with an estimated 15.7 million meeting the HIPAA criteria by 2065.<sup>8</sup> Figure 4 presents projections of the number of persons age 65 and older, including the number meeting HIPAA disability criteria during 2015-2065.



**Figure 4. Total Population Age 65 or Older (in thousands), including Number of People Projected to Meet HIPAA Disability Criteria, 2015-2065**



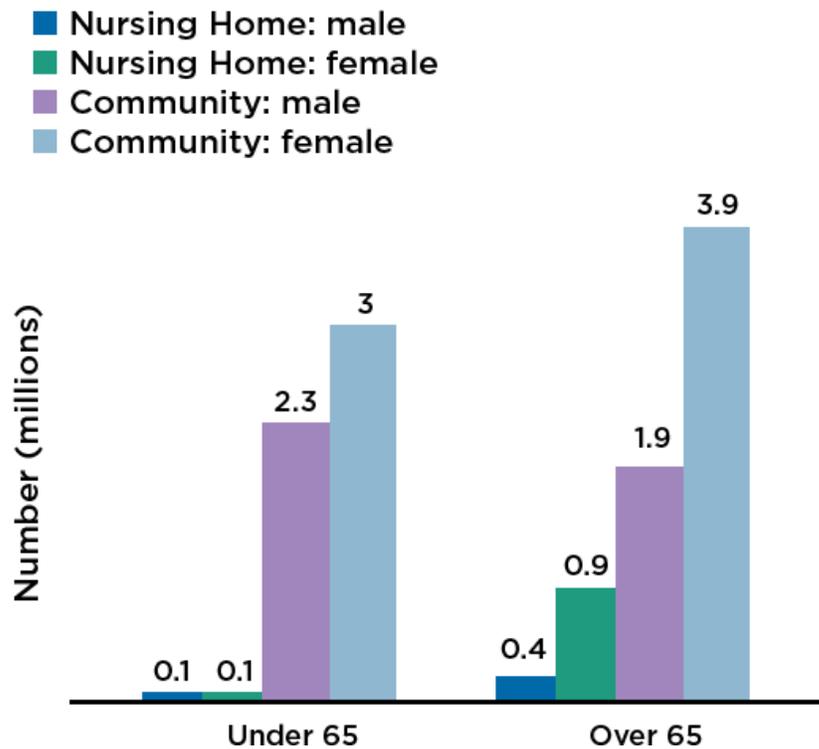
Source: ASPE Issue Brief, HHS Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy, February 2016. <https://aspe.hhs.gov/basic-report/long-term-services-and-supports-older-americans-risks-and-financing-research-brief>

Utilizing this methodology in projecting future LTSS needs, those who may consume LTSS but do not meet the required HIPAA definition (those requiring assistance with only one ADL, for example) are not included in this microsimulation model.<sup>8</sup>

Research has found that women live longer than men and are more likely to develop a challenge, making them more likely than men to require LTSS as they age.<sup>8</sup> In 2016, among the population age 65 and older, there were 27.5 million women and 21.8 million men, or a ratio of 126 women for every 100 men. At age 85 and older, this ratio increased to 187 women for every 100 men.<sup>18</sup> Figure 5 illustrates that women over age 65 disproportionately require more assistance with activities of daily living than men, both in nursing home and community settings.



Figure 5. U.S. Adults Needing Help with Everyday Activities, by Age, Gender, and Setting, 2014



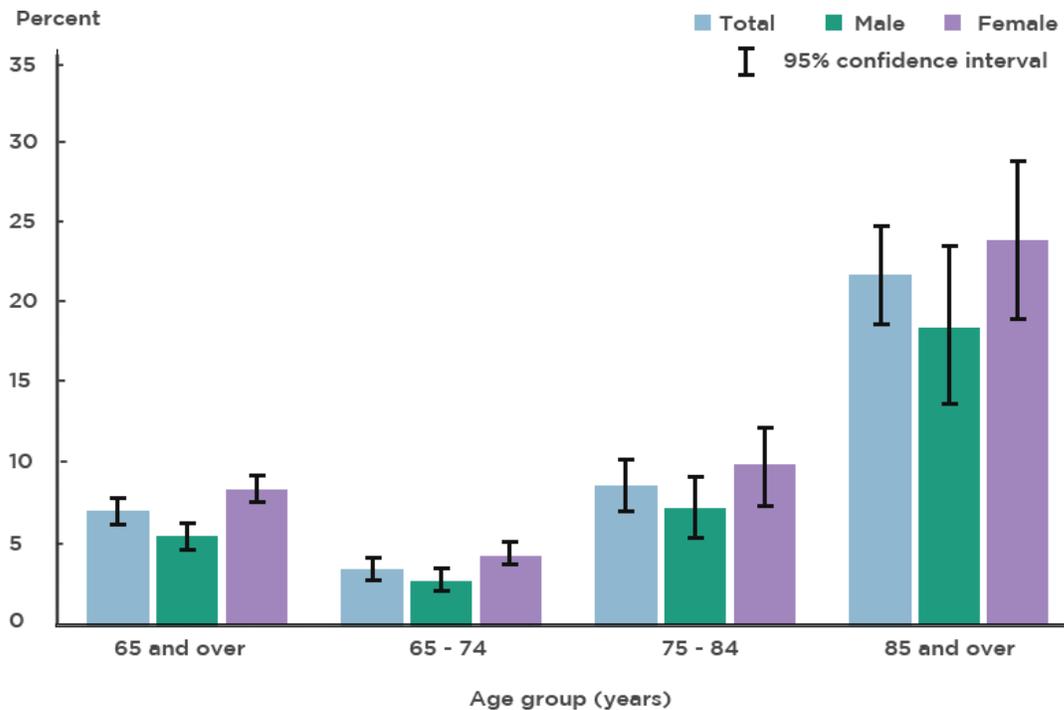
Source: AARP Public Policy Institute Analysis of 2014 National Health Interview Survey and the 2014 American Community Survey, 1-Year Estimates, <https://www.aarp.org/content/dam/aarp/ppi/2017-01/Fact%20Sheet%20Long-Term%20Support%20and%20Services.pdf>

As previously stated, there is projected to be a dramatic increase in those who are age 85 and older, and this age group tends to have higher challenge rates. This age group is also more likely to have experienced the death of a spouse, further limiting their support system to assist with ADLs.<sup>19</sup>

In January-June 2017, the percentage of adults age 85 and older needing help with personal care (22%) was more than twice the percentage for adults ages 75-84 (9%) and more than six times the percentage for adults ages 65-74 (3%).<sup>20</sup> Adults age 85 and older of both sexes are 21.4 percent more likely than adults ages 74-84 at 8.4 percent and five times more likely than those ages 65-74 at 3.6 percent to need help with their personal care. In addition, again comparing adults age 65 and older and adults ages 75-84, women were more likely than men to need help with personal care.<sup>20</sup> Figure 6 highlights the percentage of adults age 65 or older who needed help with personal care, by age group and sex in the United States during January-June 2017.



Figure 6. Percentage of Adults Age 65 or Older Who Needed Help with Personal Care, by Age Group and Sex: United States, January-June 2017



NOTES: Data are based on household interviews of a sample of the civilian noninstitutionalized population. Personal care needs, or activities of daily living, including eating, bathing, dressing, and getting around inside the person's home.

Source: NCHS, National Health Interview Survey, January-June 2017, Family Core component, [https://www.cdc.gov/nchs/data/nhis/earlyrelease/earlyrelease201406\\_12.pdf](https://www.cdc.gov/nchs/data/nhis/earlyrelease/earlyrelease201406_12.pdf)

Of these individuals, 23 percent of persons age 65 and older were members of racial or ethnic minority populations: 9 percent were African-Americans, 8 percent were of Hispanic origin, 4 percent were Asian or Pacific Islander, 0.5 percent were Native American, 0.1 percent were Native Hawaiian/Pacific Islander, and 0.7 percent self-identified as being of two or more races.<sup>20</sup>

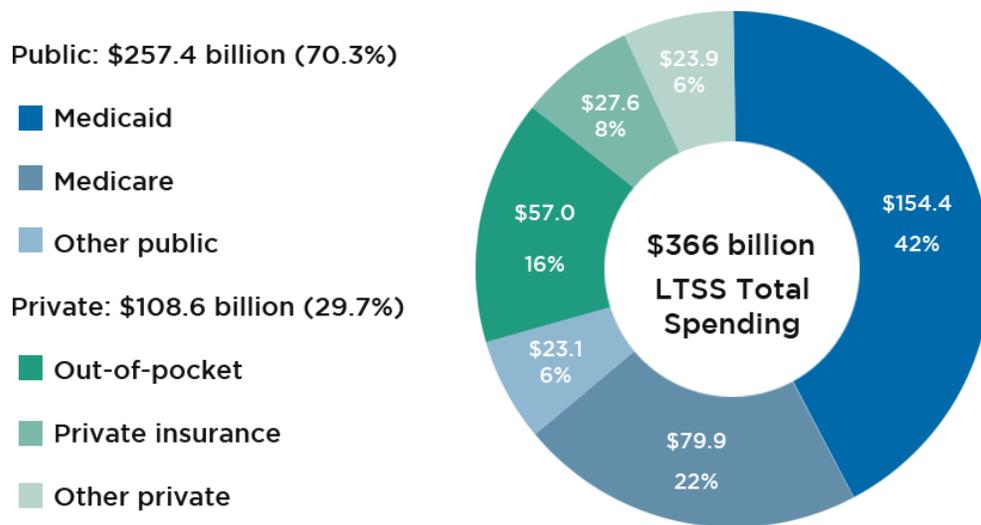
The percentage of adults age 65 and older by race and ethnicity who needed help with personal care was 11.8 percent for Hispanic adults, 5.8 percent for non-Hispanic white adults, and 10.9 percent for non-Hispanic black adults.<sup>20</sup> Based on these data, non-Hispanic white adults age 65 and older are less likely to require help with personal care than Hispanic or non-Hispanic black adults are.<sup>20</sup> It could be anticipated that the ethnic mix will change with the changing ethnic mix of the United States.

## Trends and Costs

About half of all LTSS spending is financed through Medicaid funds, and these costs are expected to increase from \$113 billion annually in 2016 to \$154 billion in 2025.<sup>21</sup> Not all individuals receiving LTSS are covered by Medicaid, as there are a variety of other payers, including Medicare and private insurance; however, these sources total less than half of all reimbursement. Looking at 2016 LTSS spending in total of \$336 billion, Medicaid costs were 42 percent (\$154.4 billion), Medicare was 22 percent (\$79.9 billion), and other public funds were 6 percent (\$23.1 billion). These three public funding sources account for 70.3 percent of all LTSS spending at \$257.4 billion. Private funding categories were a distant 29.7 percent (\$108.6 billion) of total LTSS spending.<sup>6</sup> Figure 7 below includes a breakdown of LTSS spending by payer and cost in 2016:



**Figure 7. LTSS Total Spending by Payer, 2016, \$336.0 Billion**



Source: "Who Pays for Long-Term Services and Supports? A Fact Sheet," Congressional Research Service, August 2018. <https://fas.org/sgp/crs/misc/R43483.pdf>

Institutional settings remain a most common location for recipients of LTSS, with about 59 percent of all services performed in an institutional setting (typically a Medicaid nursing facility) in 2014, at a cost of \$55.1 billion.<sup>8</sup>

Utilization of HCBS continues to increase. In 2014 the total HCBS payments were 41 percent of all LTSS spending nationally, for a cost of \$37.9 billion. This is an increase in reimbursement from 39 percent in 2011.<sup>7,22</sup> In 2016, HCBS services accounted for 57 percent of all LTSS spending. HCBS increased around 10 percent annually in 2016, greater than the average annual increase of 5 percent annually from 2011 to 2015. HCBS comprised the majority of all 2016 LTSS expenditures in 30 states, including the District of Columbia.<sup>25</sup> Excluded from these payments were Medicare costs for eligible short-term facility stays or home health services to support rehabilitation services following an acute care stay.<sup>7</sup>

Costs for LTSS services vary by where the individual receives their LTSS.<sup>23</sup> Institutional care is the costliest option, while utilizing a home health aide and staying in your own home costs approximately two-thirds less; however, this figure does not include the cost of maintaining the home. Table 2 summarizes the annual cost for LTSS care by place of service.



**Table 2. LTSS Average Costs per Year by Place of Service, 2018**

Place of Service	Cost of Care Per Year
*Private Room-Institution	\$100,000
*Semi-Private Room -Institution	\$90,000
* Assisted Living	\$48,000
Home Health Aide 30 hrs./wk. @\$22/hr.**	\$34,000

\*Depends on Region and Specific Amenities

\*\* Rates may vary by region

Source: Genworth Cost of Care Survey 2018. <https://www.genworth.com/aging-and-you/finances/cost-of-care.html>

## Role of Managed Care in LTSS

In 2009, six states had some form of Managed Long-Term Services and Supports (MLTSS) program; by 2017 that number had risen to 24 states that operated some type of MLTSS program.<sup>24</sup> MLTSS is the delivery system of Long-Term Services & Supports (LTSS) through capitated Medicaid managed care arrangements. Based on the variation in state Medicaid programs, the range of MLTSS services also varies widely. As an example, New York has a partially capitated model-- giving a capitation payment to Medicaid health plans to manage the total member care coordination, even for services not paid for by the Medicaid health plan but paid for by Medicare or Medicaid FFS. States such as Texas, Virginia, and Tennessee are working to integrate LTSS and physical and behavioral health services as an integrated service offering for individuals from their health plans and providers.<sup>24</sup>

Another category of LTSS recipients are eligible for both Medicare and Medicaid. These dually eligible recipients are generally very poor and have complex health needs.<sup>25</sup> This unique population represents a fifth of all Medicare enrollees and accounted for 34 percent of total Medicare spending in 2013, while including 15 percent of Medicaid enrollees, with a cost of 32 percent of all Medicaid spending.<sup>26</sup>

Many of these dually eligible individuals are enrolled in managed care plans known as Dual Eligible Special Needs Plans (D-SNPs).<sup>25</sup> D-SNPs were first offered in 2006. In these plans clinician and hospital services are provided by a Medicare Advantage plan, and Medicaid pays for the Medicare cost sharing, LTSS, and often behavioral health services. These plans enroll individuals who are eligible for both Medical Assistance from a state plan under Title XIX (Medicaid), and Medicare (Title XVIII). These plans offer coordination of both Medicaid and Medicare benefits into a single plan.<sup>25</sup>

These D-SNPs allow states to encourage or require the plans to integrate Medicare and Medicaid benefits for their members. For example, a person may receive hospital and physician services from Medicare Advantage, while Medicaid may pay for that person's Medicare cost-sharing, behavioral health services, or long-term care benefits.

As of January 2018, more than 2.1 million individuals were enrolled in D-SNPs in 41 states, Puerto Rico and the District of Columbia.<sup>25</sup>

## Barriers in Access and Coverage

Medicare and commercial health insurance typically do not cover LTSS costs.<sup>11</sup> Medicare considers most LTSS services as personal care services (e.g., assistance with eating, bathing, and dressing), which Medicare views as custodial care and not medical care. This exclusion qualifies most of the care provided in nursing homes as custodial care.

However, Medicare does cover LTSS hospital care, skilled nursing care provided in a skilled nursing center for a period of time following a qualified inpatient stay, home health services that Medicare deems eligible for coverage, and hospice and respite care services.<sup>8, 11</sup> Private LTSS insurance coverage is available for purchase, but only 8 percent of individuals in the United States who qualify have purchased it.<sup>8</sup>

Medicaid does provide LTSS to individuals, but it is only available to those who meet income and other eligibility criteria.<sup>8</sup> Many Americans who receive formal LTSS pay out-of-pocket initially, as they do not meet the eligibility requirements for Medicaid. For those with longer-term requirements for services, they may pay out-of-pocket in the beginning, but many will ultimately qualify for Medicaid as they spend down their financial resources.<sup>8</sup>

In this model, it was estimated that the majority of adults who were age 65 in 2015 would require LTSS for up to two years sometime in the future, while one in seven adults would require LTSS for five years or more.<sup>8</sup>

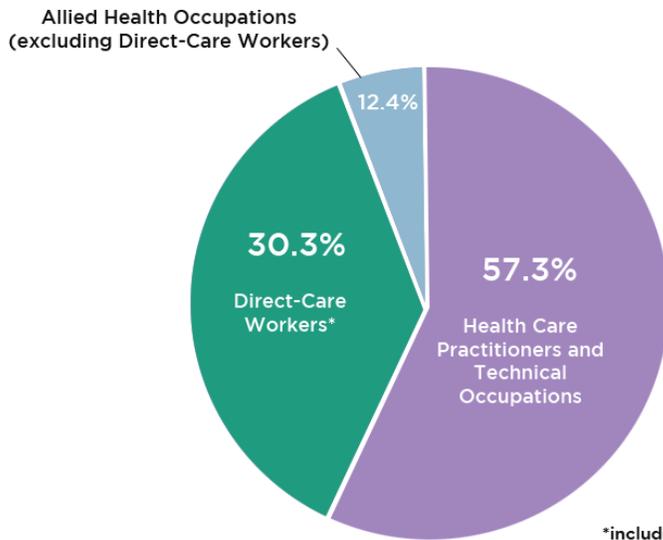
Utilizing the same microsimulation model from the Urban Institute-DYNASIM3, using a base period of individuals turning 65 during 2015-2019, with a future life expectancy of 20.9 years, the average cost incurred to procure these services for an adult turning 65 today is approximately \$138,000.<sup>8</sup> Cost projections use a base 2015 dollar value and utilize the Social Security Trustees ultimate real interest rate of an average of 2.7 percent annual long-term price growth.<sup>8</sup> Based on 2015 dollars, these services can be covered by setting aside \$70,000 in a financial vehicle in 2015.<sup>8</sup> Around half of the cost will be paid by the recipient or their families out of pocket; the remainder will be covered by private insurance or public programs such as Medicaid. The majority of people requiring the care will pay relatively little out of pocket, but about 17 percent (one in six) will spend at least \$100,000 on their LTSS care.<sup>8</sup>

## LTSS Caregiver Composition & Quality Concerns

In 2013, it was estimated that 70-80 percent of LTSS services were provided by direct-care workers, who assisted individuals with bathing, dressing, and other tasks that are required by LTSS recipients.<sup>27</sup> In 2012, this totaled more than four million workers nationally, with more than three million of these workers employed by agencies or institutional facilities. An estimated 800,000 additional workers were employed directly by the individuals requiring the direct care. Of the total U.S. health care workforce in 2012, 30.3 percent were direct-care workers. The remainder of the U.S. health care workforce was divided between health care practitioners and technical occupations (physicians, nurses, and therapists) at 57.3 percent and allied health occupations (medical and dental assistants, and therapy assistants and aides) at 12.4 percent.<sup>27</sup> Figure 8 represents the estimated total U.S. health care workforce in 2012.



Figure 8. U.S. Health Care Workforce in 2012



Source: Paraprofessional Healthcare Institute, 2013. <https://phinational.org/wp-content/uploads/legacy/phi-facts-3.pdf>

Considerable workforce challenges also exist in providing effective and high-quality LTSS. Some of the concerns are about the quality of both the work environment and the direct-care workers themselves.<sup>27</sup> The federal government provides training for home health aides and nursing assistants who work in Medicare- or Medicaid-certified nursing homes or home health agencies. Some individual agencies or states may require and/or provide training or certification for direct-care workers, but no consistent format exists for training or mandating minimum requirements for these direct-care workers.<sup>27</sup> A direct link exists between a motivated, well-trained, direct-care workforce and the quality of care delivered, so an enhanced focus on supporting this workforce is crucial.<sup>28</sup>

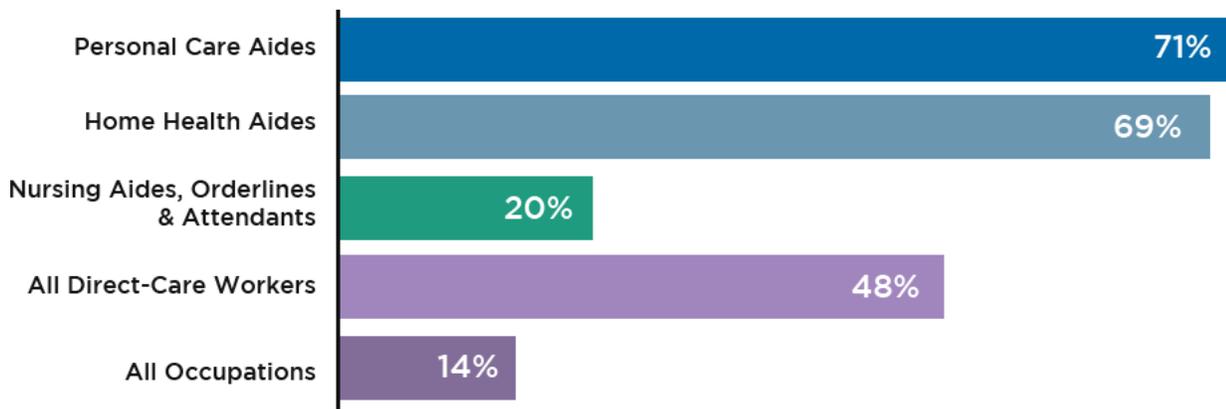
The 2013 Commission on Long-Term Care Report to Congress<sup>29</sup> included a recommendation to the CMS to explore development of national standards for training of the direct-care workforce based on the Personal and Home Care Aide State Training (PHCAST) Demonstration Program.<sup>28</sup> The commission suggested that the CMS encourage states to apply training standards to the Medicaid Direct Care Workforce and support the model competency standards and certification programs being developed by states or the PHCAST Demonstration Program. The program evaluation for the PHCAST program cited improved job satisfaction for the workforce and enhanced career stability.<sup>28</sup>

Also, in the 2013 Commission on Long-Term Care Report to Congress,<sup>29</sup> there was a projected increase in workforce demand for individuals providing LTSS of more than 50 percent over the next decade, an increase of 1.6 million new direct-care workers. At the same time, it was estimated that the current workforce providing LTSS will shrink, as these direct-care workers continue to age out of their working years.<sup>5</sup>

In a different report, with the projected increase in individuals requiring services, a 70 percent increase in the need for workers was projected by 2020, with only a 20 percent growth projected in the actual workforce.<sup>29</sup> The projected demand for sub-categories of direct-care workers include a 70 percent increase in the need for personal care aides; a 69 percent increase in the need for home health aides; a 20 percent increase in nurse aides, orderlies, and attendants; and an overall increased need of 48 percent for all direct-care workers combined.<sup>29</sup> Figure 9 illustrates the projected growing demand for direct-care workers in the U.S. during 2010-2020.



**Figure 9. Growing Demand for Direct-Care Workers in the U.S., 2010-2020**

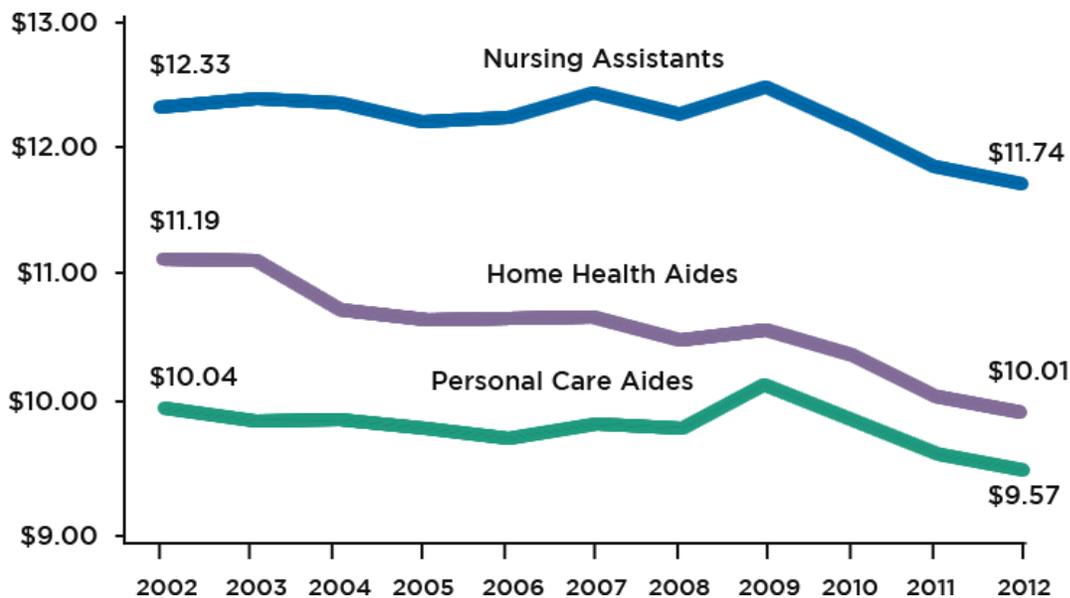


Source: Paraprofessional Healthcare Institute, 2013. <https://phinational.org/wp-content/uploads/legacy/phi-facts-3.pdf>

Direct-care workers account for 30 percent of the total U.S. health care workforce, which far outnumbers other health care practitioner occupations such as physicians, nurses, and therapists.<sup>27</sup> The wages for direct-care workers remain low, and many positions are part time and do not provide employee benefits, which may make these positions unattractive to qualified candidates.<sup>27</sup> About half of all direct-care workers earn below 200 percent of the Federal Poverty Level (FPL), which makes many of them eligible for Medicaid; Supplemental Nutrition Assistance Program (SNAP) benefits; and housing, childcare, and energy assistance benefits.<sup>27</sup> The median wage for direct-care workers for 2002-2012, when adjusted for inflation, actually shows a decrease in compensation in each category. This indicates that actual wages are not keeping pace with inflation, with direct-care workers making less in 2012 than they did in 2002.<sup>27</sup> Figure 10 illustrates the median wage for direct-care workers, adjusted for inflation in 2012 dollars.<sup>5</sup>



Figure 10. Median Wage for Direct-Care Workers, Adjusted for Inflation (2012 Dollars)



Source: Paraprofessional Healthcare Institute, 2013. <https://phinational.org/wp-content/uploads/legacy/phi-facts-3.pdf>

Individuals who remain in the community utilize LTSS services provided by formal caregivers who are compensated by Medicaid, Medicare, private insurance, or directly by the individuals receiving care. However, there are other entities that provide care. In 2004, more than 50 percent of individuals who remained in the community relied completely on unpaid help.<sup>28</sup> There were estimates that 75 percent of individuals who received paid help also relied on unpaid assistance. These unpaid or informal caregivers were typically a spouse, child, other family member, neighbor, or friend.<sup>30</sup> In 2013, the total economic value of unpaid care was estimated at \$470 billion, which outpaced the formal direct-care worker spending of \$339 billion. This nonformal workforce incurs both direct and indirect costs to provide this care (examples include the nonformal workforce reducing their work hours, quitting their job, or taking a less-demanding work role).<sup>8, 30</sup>

## State Variation

Medicaid is authorized by Title XIX of the Social Security Act. It is an optional program for states, but all states, the District of Columbia, and the five U.S. territories currently have some form of a Medicaid program.<sup>1</sup> States have only two mandatory LTSS benefits for their LTSS Medicaid programs: nursing facility services (defined as providing 24-hour care for both medical and skilled nursing needs, rehabilitation services, or health-related services that do not require hospital care) and home health services (nursing, home health aides, and medical equipment and supplies).<sup>11, 13</sup> Additional home health services may be provided by individual states. These include physical, speech, or occupational therapy and audiology services. States can also design the eligibility criteria for utilization of these additional services.<sup>13</sup>

The CMS allows several types of Medicaid plan and waiver programs for HCBS LTSS services.<sup>11, 12, 32</sup> Through the state waiver process, the CMS approves the types of services and populations covered by a state. State Medicaid waivers allow a state to waive certain Medicaid program requirements, allowing for LTSS coverage for individuals not otherwise eligible for Medicaid coverage.<sup>32</sup> Table 3 provides a list of the 1915 HCBS waivers currently available and utilized by states.



**Table 3. Current 1915 HCBS Waivers for LTSS Programs**

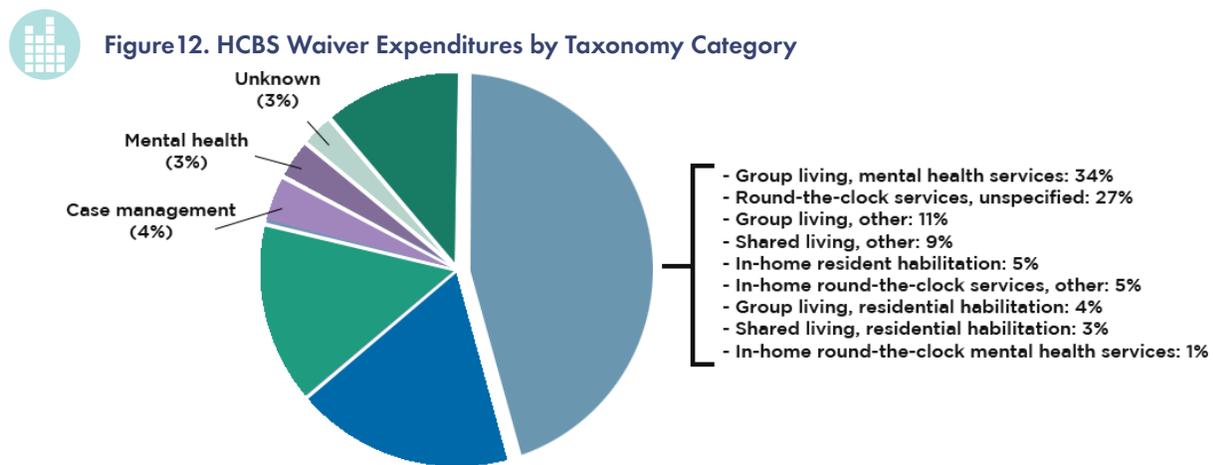
Medicaid Plan and Waiver Program Types	Specific Provisions
HCBS 1915 Waiver Programs	A state-specific vehicle to target services to individuals who need LTSS services. These services, authorized under Section 1915 of the Social Security Administration (SSA), require individuals to meet criteria that are based on the individual's level of need and defined by the state, and are reimbursed through the fee-for-service program.
1915(c) HCBS waivers	A vehicle for states to customize HCBS based on Medicaid beneficiaries who need LTSS. Waivers vary by state, and often more than one type of waiver program may be offered in a single state. These waivers cannot be racially or ethnically limited but can be geographically or diagnosis limited or defined (e.g. Behavioral Health, Intellectual Disability/Developmental Disability).
1915 (i) HCBS waivers	Allow coverage for individuals not in an institution and with incomes of up to 150% of the Federal Poverty Level.
1915 (j) Self-Directed Personal Assistance Services	Allows the individual to direct their care, choose what care is provided, and choose who provides the care. This program can be utilized for individuals already receiving care under a 1915 waiver. States can limit the geographic coverage of these programs and the number of people who participate.
1915 (k) Community First Choice (CFC)	States can provide HCBS under their state plan. This program expands Medicaid opportunities and allows for community integration while states receive enhanced federal matching funds of six additional percentage points for CFC services. The Affordable Care Act of 2010 established this option for states.

Source: (Medicaid.gov, n.d.) <https://www.medicaid.gov/medicaid/hcbs/authorities/1915-c/index.html>

In its 2018 report to Congress, Medicaid and CHIP Payment and Access Commission (MACPAC) recommended several changes to the waiver process to streamline program creation, implementation, and oversight.<sup>32</sup> These changes included:

- Requested Congress to amend Section 1932(a)(2) to allow states to require any or all beneficiaries to enroll in Medicaid managed care. This included individuals who would be dually eligible beneficiaries; children with special health care needs, including children eligible for Medicaid based on challenge or involvement with the child welfare system; or children receiving SSI or who were Alaska Natives or American Indians.
- Recommended extending the approval and renewal periods for all Section 1915(b) waivers from two to five years. MACPAC indicated that this change of extending the renewal timeline to five years would allow both the states and federal government to focus on managing and monitoring the waivers instead of on renewal paperwork. This recommendation would simplify program management for states and the CMS.
- Recommended that Congress revise Section 1915(c) waiver authority to permit Section 1915(c) waivers to waive freedom of choice and selective contracting. The current requirements necessitate that a state complete two waiver applications to utilize the HCBS methodology if the state contracts with a single entity, or if the state wants something less than a statewide program. The current two-waiver requirement necessitates two separate reports--one for each waiver and possibly requiring that the reports be submitted at different times. The recommendation would allow states to operate their HCBS waiver program with one set of reports and to file a single application.<sup>32</sup>

A number of states are utilizing HCBS to transform LTSS in Medicaid.<sup>33</sup> The CMS has created an HCBS taxonomy to gain greater understanding of what HCBS entails and which services are widely used. The taxonomy applies to services covered under Section 1915(c) waivers and State Plan HCBS benefits authorized by Section 1915(i). Utilizing the Taxonomy Category indicators, a recent report analyzing data from 28 states,<sup>33</sup> Figure 12 identifies the utilization breakdown for those states that utilize a 1915(c) waiver to provide their benefit package. As shown, round-the-clock services account for more than 46 percent of all services and cost a total of \$23.6 billion. This equates to more than \$54,000 per user for these services.<sup>33</sup>



Source: The HCBS Taxonomy: A New Language for Classifying Home- and Community-Based Services, Victoria Peebles and Alex Bohl, August 2013. [http://www.cms.gov/mmrr/Downloads/MMRR2014\\_004\\_03\\_b01.pdf](http://www.cms.gov/mmrr/Downloads/MMRR2014_004_03_b01.pdf)

## Looking Ahead: Implications for the Future

The U.S. population is rapidly aging, and the number of older individuals enrolled in the LTSS Medicaid program is increasing. However, as noted throughout this report, there are a number of challenges surrounding the delivery and quality of LTSS in Medicaid. Based on some of these challenges, several clinical, research, and policy opportunities should be pursued to improve LTSS in Medicaid. These opportunities include the following:



### Clinical Opportunities

#### **Utilization of a Common Format for HCBS to Quantify Service Utilization.**

This is especially critical for HCBS, as a wide variety of services are delivered in multiple discreet settings. As mentioned, the CMS has created an HCBS taxonomy to gain greater understanding of what HCBS entails and which services are widely used. Measuring service utilization consistently will better enable the CMS to quantify utilization trends, track the health status of associated individuals, and identify service utilization trends that improve care, quality, and cost.

#### **Standardizing Assessments.**

As mentioned, today there are more than 100 different assessments, sometimes multiple assessments for different populations in the same state. Assessments are the tools used by a program to assess an individual's health conditions and functional needs. These assessments are often used to develop a plan of care specific to the needs of the individual. The potential of utilizing a standardized assessment across states to better understand this population, without the great state variability that exists today, would allow for comparison across a larger population.



### Research Opportunities

#### **Utilization of the HCBS Taxonomy to Compare and Contrast Interventions and Outcomes.**

With implementation of the HCBS taxonomy developed by the CMS, research can begin into the types of services in use and whether their utilization changes quality outcomes and beneficiaries' health and satisfaction.

#### **Value of Direct-Care Workers on Quality Outcomes.**

There are projected direct-care workforce shortfalls in both workforce numbers and the quality of care delivered. These are areas that should be carefully explored to ensure that care is of high quality and is provided in a consistent way. Research on workers and caregivers could focus on workers' availability, improving job quality, imbedding worker training standards, looking at the impact of paying family members to provide LTSS, and researching the private-pay LTSS workforce.



### ***Focus on Workforce and Workforce Development.***

As mentioned earlier, there is a projected shortfall of direct-care workers as the population requiring services increases. A greater focus on workforce development is an integral part of success, as the need for additional direct-care workers who are trained to provide identified and necessary high-quality care increases.<sup>34</sup>

### ***Greater support for the direct-care workforce.***

As mentioned earlier, there is a direct link between direct-care workforce training and engagement. Supporting this workforce through wages and standardized training requirements will provide consistent delivery of care and better ensure quality.

### ***Congress amending Section 1932(a)(2) to allow states to require any or all enrollees to enroll in Medicaid managed care.***

Include dual-eligible individuals, children with special health care needs, children in foster care, and other historically excluded populations in MLTSS programs.

### ***Congress extending the approval and renewal periods for all Section 1915(b) waivers from two to five years.***

This would allow more time for the CMS and the states to focus on program delivery, and not paperwork, at frequent intervals.

### ***Congress revising Section 1915(c) waiver authority to permit Section 1915(c) waivers to waive freedom of choice and selective contracting.***

This would compress required waivers from two to one and align reporting timelines for the various programs.

### ***Standardizing Assessments.***

As mentioned, today there are more than 100 different assessments, and on occasion, multiple assessments for different populations are utilized in the same state. The potential of standardized assessments across states to better understand this population without the great state variability that exists today would allow for comparison across larger populations.

## Appendix A. Timeline of LTSS Program

1935	The Social Security Act (SSA) enacted, known as the Old Age Assistance program. Federal money given to states to provide financial assistance to seniors living in poverty. It specifically precluded payments to public institutions, or poor houses. This spawned the private nursing home industry, creating a bias toward institutional care for persons with challenges and seniors.
1950	The Old Age Assistance (OAA) Program was modified to make payments directly to nursing homes and not to individual recipients. States were also required to license participating nursing homes.
1965	Amendments to the SSA included Medicare and Medicaid. Medicare did not provide long-term care (LTC) and focused only on acute care. Medicaid covered care in institutions but not homes, continuing the bias toward institutions to provide LTC. This made states and the federal government as the largest payers for LTC. Government expenditures and nursing home utilization increased dramatically.
1967	Provisions for states to govern the licensing of nursing home administrators included in Amendments to the SSA, responding to public outcry regarding perceived fraud and abuse in nursing homes.
1968	HEW was authorized under the “Moss Amendments” to develop standardized regulations for Medicare and Medicaid, including withholding of funds for nursing homes performing below the standard of comprehensive regulations designed to improve nursing home care.
1974	Final regulations created and enforced for skilled nursing facilities. Medicare and Medicaid participation required facilities to maintain staffing levels, develop fire safety plans, and outline staff qualifications and service delivery methods  SSA provided federal grants for social service programs to states. The programs included homemaker services, transportation, adult day care, protective services, nutrition assistance, health support, and training for employment.
1975	Title XX was created, consolidating all federal assistance to states under a single grant. Required states to reduce or prevent unnecessary institutional care by providing home and community-based services (HCBS).
1978	All states were required to develop and implement a nursing home ombudsman program and prioritize community alternatives to LTC under the comprehensive OOA amendments of 1978.
1980	The National Long-Term Care Channeling Demonstration was created by the U.S. Department of Health and Human Services (HHS). The demonstration focused on frail seniors, testing cost-effectiveness and quality. This demonstration concluded in 1986.

1981	States were allowed to offer HCBS that were not strictly medical through Medicaid as an alternative to institutional care. This HCBS waiver program was enacted under Section 1915(c) of the SSA.
1982	The Katie Beckett Medicaid state plan option established under the Tax Equity and Fiscal Responsibility Act permitted states to cover children with challenges living in the community, not just in institutions.
1984	OAA is reauthorized, continuing the role of State Area Agencies on Aging in coordination with HCBS.
1987	<p>The Robert Wood Johnson Foundation (RWJF) supported public/private partnership programs for long-term care in four states. This was to encourage purchase of LTC insurance to offset individuals' need for care financed by Medicaid.</p> <p>OAA was reauthorized, adding six additional distinct authorizations of appropriations including in-home services for frail seniors, an LTC ombudsman, and prevention of neglect, abuse, and exploitation.</p> <p>The Nursing Home Reform Act, under OBRA- 87, based on documented quality issues seniors were facing in nursing homes, developed quality standards for Medicare and Medicaid-certified nursing homes.</p>
1988	<p>The U.S. Bipartisan Commission on Comprehensive Health Care was created by Congress, to recommend legislative action on health and long-term care. Later renamed the Pepper Commission to honor its creator and inaugural chair, Rep. Claude Pepper (D-FL).</p> <p>The Medicare Catastrophic Act of 1988 expanded skilled nursing benefits (SNF), removed time limits on most hospital service coverage, and added protections against spousal impoverishment because of nursing home costs. Long-term custodial care in a nursing home remained exempt from coverage. Medicaid was also required to cover Medicare premiums and cost-sharing for beneficiaries below 100% FPL and with limited assets: Qualified Medicare Beneficiaries (QMBs).</p>
1989	The Medicare Catastrophic Act was repealed; QMBs and provisions regarding spousal impoverishment were retained.
1990	<p>State Medicaid programs were required to pay premiums for Medicare beneficiaries with incomes of 100-120% FPL under OBRA-90. Partial hospitalization services in community mental health centers were added to Medicare coverage.</p> <p>Americans with Disabilities Act (ADA) was enacted to end exclusion and segregation by integrating people with challenges into the community.</p> <p>A report of proposed LTSS financing was released by the Pepper Commission, including recommendations to establish social or government insurance to maintain resources for those with severe challenges to stay at home or return home after a short stay in a nursing home, establishment of a floor against impoverishment for all nursing home users regardless of the length of their stay in nursing home, a proposal for the initial 3 month nursing home stay to be covered with a 20% copayment, and Medicare coverage for individuals with impairments in 3+ ADLs. These recommendations were never enacted.</p>

1993	As part of the Clinton Health Care Plan, improved Medicaid coverage for institutional care, expansion of HCBS, and development of minimum standards for LTC insurance and associated tax incentives were proposed. This plan was never enacted.
1994	Final rules for the Nursing Home Reform Act, OBRA-87, were published.
1995	RWJF and HHS spearheaded an initiative known as the Medicaid Cash and Counseling Demonstration, which allowed beneficiaries to self-direct their HCBS instead of only utilizing traditional services provided by agencies. Based on data from consumer advocates demonstrating positive effects, The Nursing Home Reform act narrowly escaped repeal.
1999	Based on the ADA's community integration mandate, the Supreme Court issued the Olmstead decision, which promoted expanded coverage for people with challenges.
2000	The Americans Act Caregiver Program authorized grants to states to fund supports that provided assistance to family and other informal caregivers to provide care at home.
2001	The Centers for Medicare & Medicaid Services (CMS) and the Administration on Aging's Real Choice Systems made grants available to states and non-profits to allow for development of integrated LTSS systems.  The New Freedom Initiative removed barriers to community living for people with challenges.
2005	The Deficit Reduction Act, the Medicaid Follows the Person (MFP) rebalancing program, provided states with federal funding to expand community-based care, add optional HCBS plans, and offer self-direction of personal care services. The transfer of assets for nursing home Medicaid applications look-back period was expanded from 36 to 60 months. Individuals are encouraged to purchase LTC insurance by allowing qualification for Medicaid if the individuals need extends beyond the coverage period in their policy.
2006	Under the OAA Amendments of 2006, principles of consumer education for long-term care planning, self-directed community-based services for older individuals at institutionalization risk, and evidence-based prevention programs are signed into law.
2010	Under the Affordable Care Act (ACA) The Community Living Assistance Services and Supports (CLASS) Act is enacted with the goal of a national voluntary LTSS insurance program financed by individual premiums.  The Community First Choice state plan option, an MFP extension, and the Balancing Incentive Program provide options to states under their Medicaid program to expand HCBS and support improvement in the LTC infrastructure. States are also required to apply spousal impoverishment standards when Medicaid applicants receive HCBS for the 5-year period beginning January 1, 2014. This is expanded from nursing home residents only.

2011	First Baby Boomers turn 65.
2013	The Commission on Long-Term Care, a bi-partisan group formed under the American Taxpayer Relief Act of 2012, issues a report that reviews the LTSS program and policy issues to Congress. Included in the report are recommendations for workforce and service delivery; the report highlights financing approaches suggested by members; no agreement on financing is ever reached. The CLASS Act is also repealed.
2014	CMS finalizes new rules regarding HCBS qualities that settings must meet to be considered Medicaid services.
2015	CMS revises the nursing home Five-Star Quality rating system, reflecting improved performance standards.

Source: Long-Term Care in the United States: A Timeline (The Henry J. Kaiser Family Foundation, 2015). <https://www.kff.org/medicaid/timeline/long-term-care-in-the-united-states-a-timeline/>

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